Improving End of Life Care for Older People

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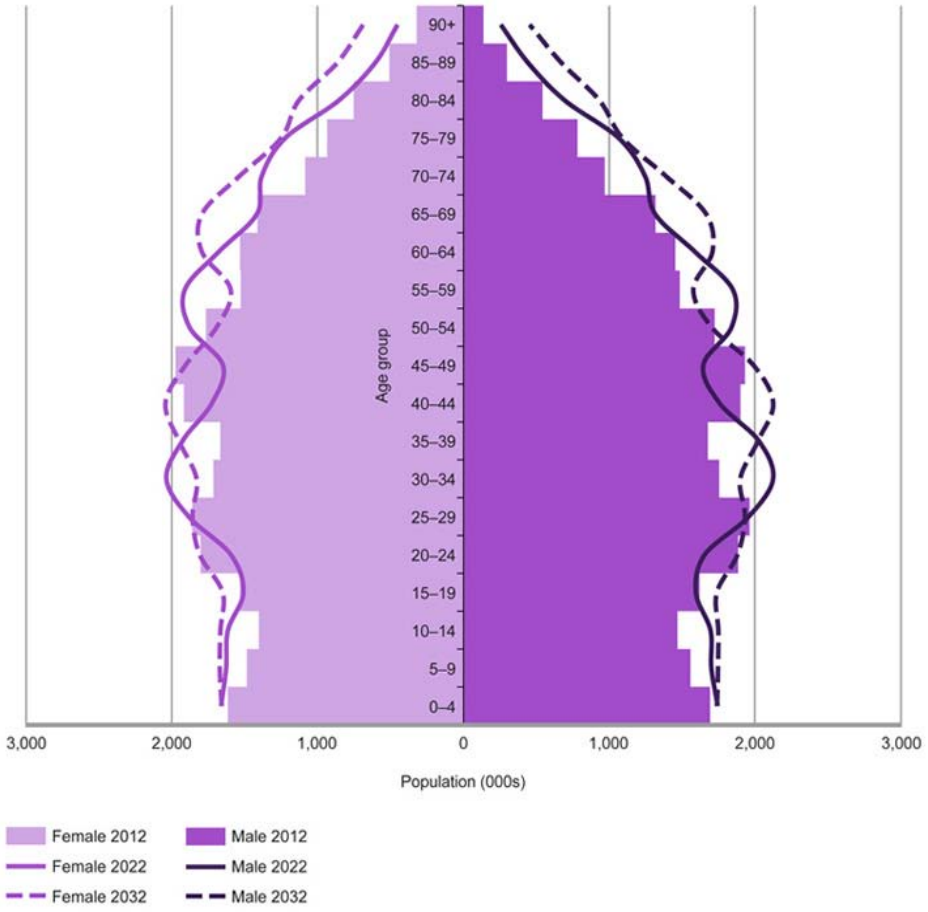
...Last scene of all,
That ends this strange eventful history,
Is second childishness and mere oblivion,
Sans teeth, sans eyes, sans taste, sans everything.

William Shakespeare, *As You like it.*

Key Issues

- Successful ageing
- Place of Care
- Quality, safety and choice: Francis & Neuberger
- Uncertainty
- **Right place, right approach, adequate resource**

Successful Ageing



Next 20 years number of people:

>85 in England will double
>100 will quadruple

Largest single group of NHS users

2/3 acute hospital beds used by +65

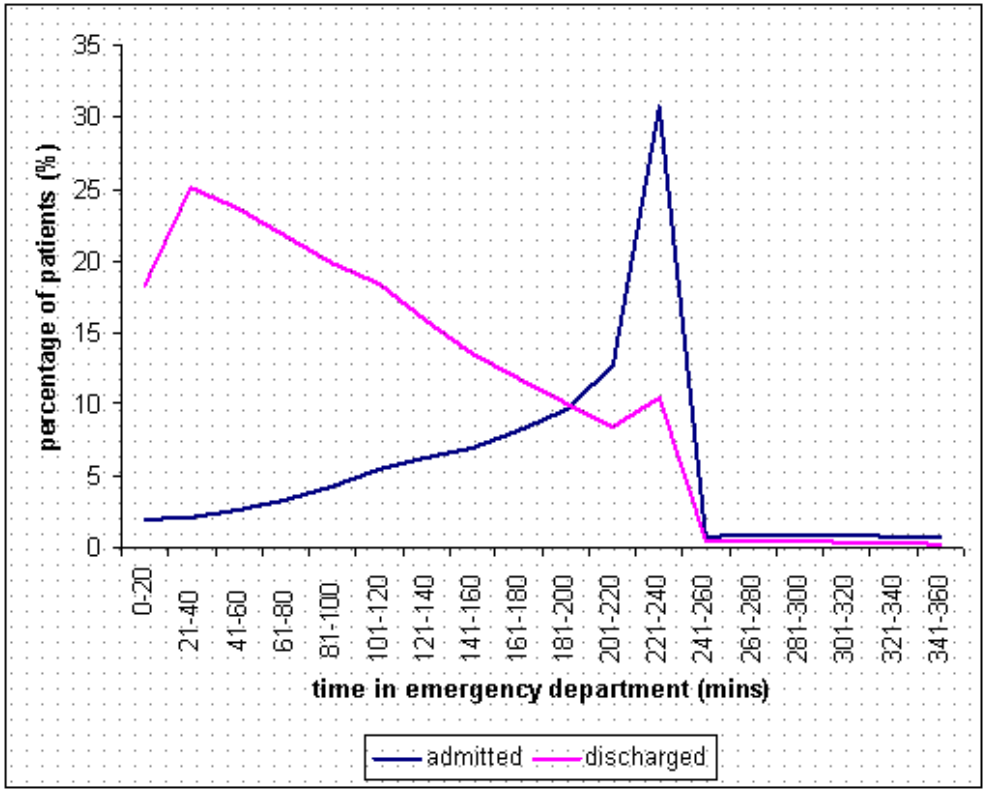
+65 used 40% of all hospital bed days

43% NHS spend on those aged +65

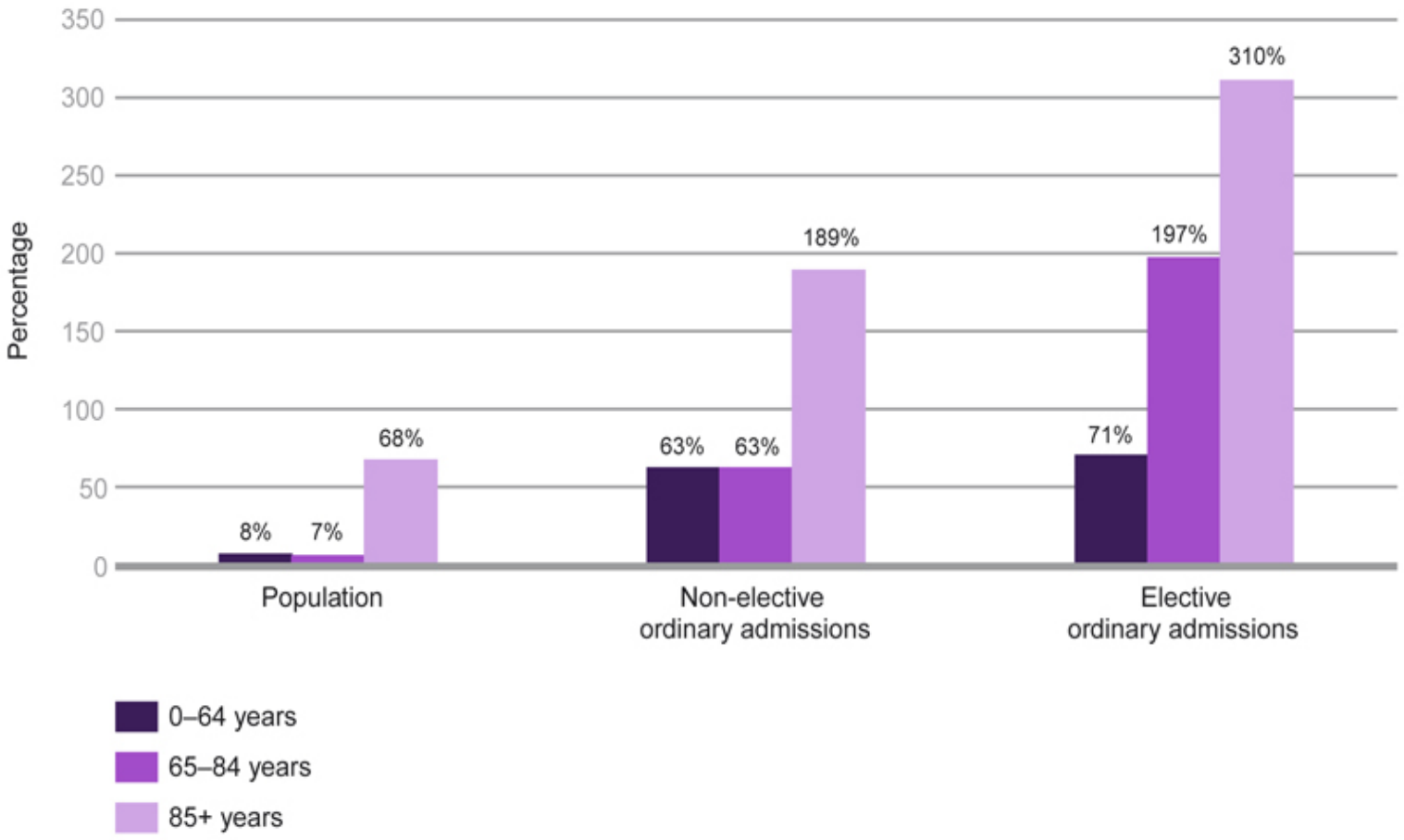
Kings Fund 2013

Compression of Morbidity

- 685K people >65 in UK with dementia
- 2025: 1M in UK will have dementia
- Dementia in UK costs £17Bn pa
- 130K people have a stroke in E&W pa
- 1/3 will be left with disability
- 250K in UK living with long term disability following stroke

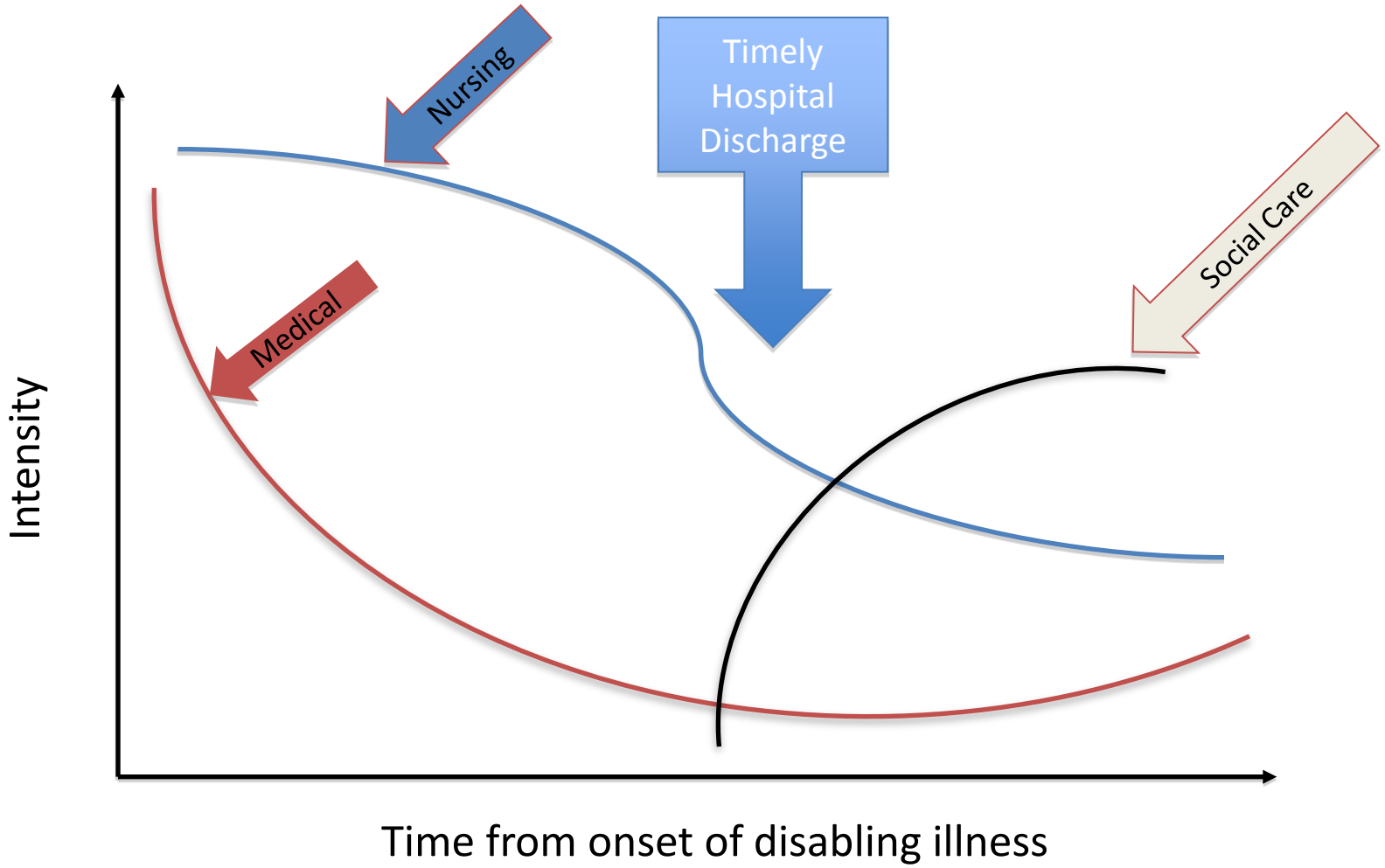


Rise in Health Demand (England)*



*Kings Fund 2013

Illness Recovery *



*Adapted from HAS Thematic Review 1997

Multi-morbidity & Frailty

- 1 in 4 adults has 2 or more long term conditions
- 50% of older people have 3 or more LTC
- *Comorbidity* independent risk factor for adverse outcomes
  - QoL, mortality, healthcare demand, disability, treatment complication
- *Multi-morbidity:* co existent, not necessarily co-dependent conditions
- *Frailty*: biological, psychological, social and/or economic failure
- 11% of community dwelling 65+; more common in women*

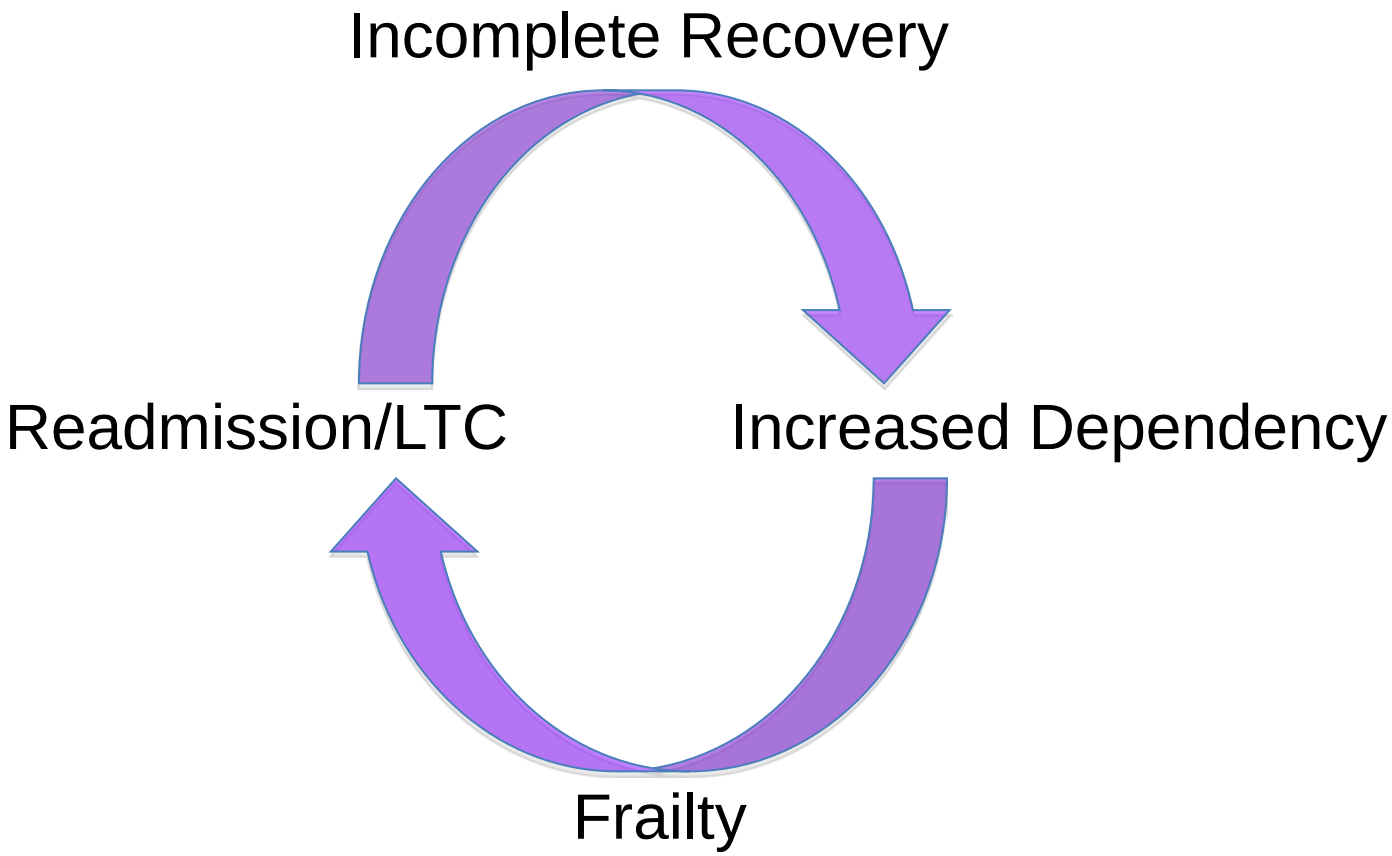
*Collard et al. JAGS 2012: 60(8);1487-1492

Frailty

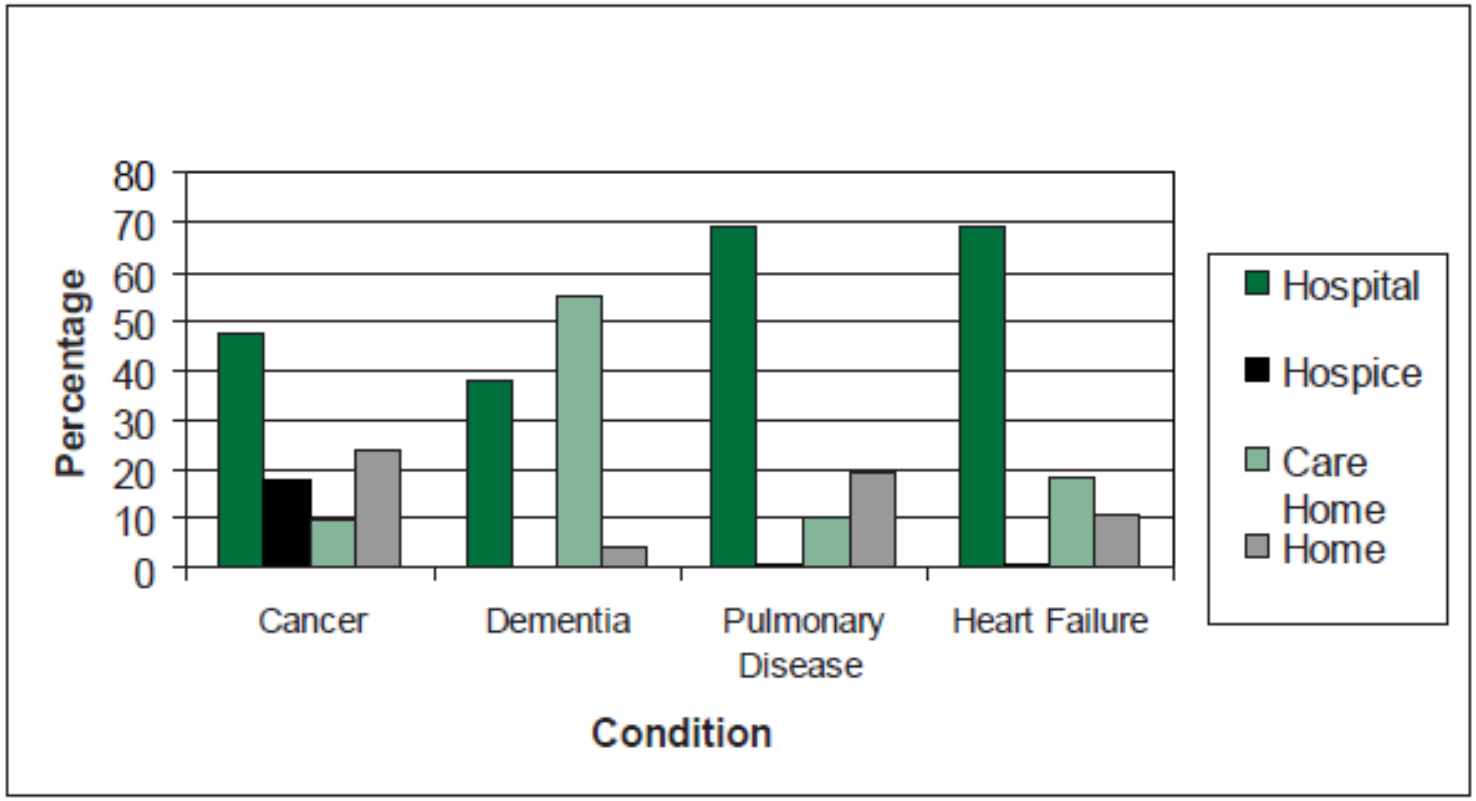
- Frailty index: ratio of actual to possible health deficits
- Death rate for healthiest at baseline (FI=0) 0.18 at 2 years, 0.69 at 7 years
- Baseline FI>0.45 associated with 100% 7 year mortality
- There is a limit to frailty of FI=0.7
- There is a limit to the number of health conditions people can tolerate

Age Ageing. 2013 May;42(3):372-7

Uncertain outcomes



Medicalised Death



Source: National Audit Office analysis of 2006 Mortality Statistics for England

Hospital Regulation (CQC)

- 2011 CQC: dignity and nutrition in English hospitals
- Outcome 1: respecting and involving people
- Outcome 5: meeting nutritional needs
- 100 hospitals inspected
- 20% non-compliant (one or both standards not met)
- 35% needed to improve one or both standards
- 45% fully compliant

Clinical Evidence

- Very little in relation to **sustaining** life in final days and hours…
- Mostly negative
- Hospitals are geared to sustaining life
- Are they equipped for end of life care?

End of life nutrition

- Reduced oral intake is common near to death
- Only a small number of studies published on this issue
- Cochrane (2011)*
  - 4 prospective non-controlled trials
  - one systematic review (MND)
  - No RCTs or prospective controlled trials
- Unknown whether assisted nutrition enhances QoL or survival

*Good P et al (2011) Cochrane

Feeding & dementia

Eating among last activities impaired*

Feeding tubes common in terminal stage: 34%**

Large number of patients receiving this intervention

No evidence of benefit from PEG/NGT in advanced dementia***

* Gillick (2000) NEJM
** Mitchell et al (2003) JAMA
***Cochrane 2009

DNACPR: Uncertainty

Octagenerians (mean 86 years):

- Hospital survival 1 in 9 (1 in 4 <80 years)
- Of survivors, 38% go home; 62% require long term care
- Death predicted by age and disease
- Treat 12 to save one life
- Treat 29 for one long term (21 months) survivor

Right approach?

- Focus on cure not care
- But not everyone can be cured
- 1900 85% people died at home, by 1950s: this had declined to 50%
- Medicalisation has led to loss of social focus on dying
- Misalignment of health and social care impedes end of life care

Life sustaining treatment

Important as the sanctity of life is, it may.. take second place to human dignity

Where a patient is dying, the goal may properly be to ease suffering

To ease the passing…rather than to achieve a short prolongation of life*

* Burke v GMC [2005]

Communication and Planning

Advance care planning is part of good practice

Person's informed views paramount if benefit outweighs burdens

If person lacks capacity, decide on basis of best interests

Advance refusals should be respected

General Medical Council

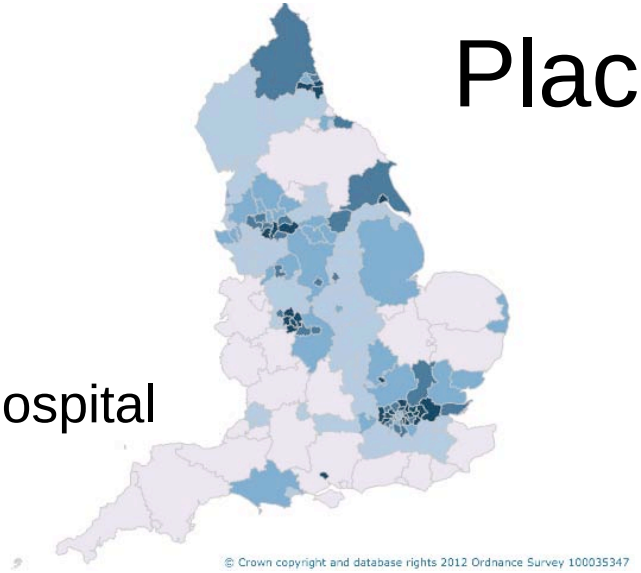
- Work closely with the patient, or their representative(s)
- Provide information clearly (prognosis, options, benefits, burdens)
- **Must consider palliative care options early**
- **Must seek other opinions (doubt, dispute, withdrawal)**
- Advance care planning: **must respect *valid* refusals**

General Medical Council

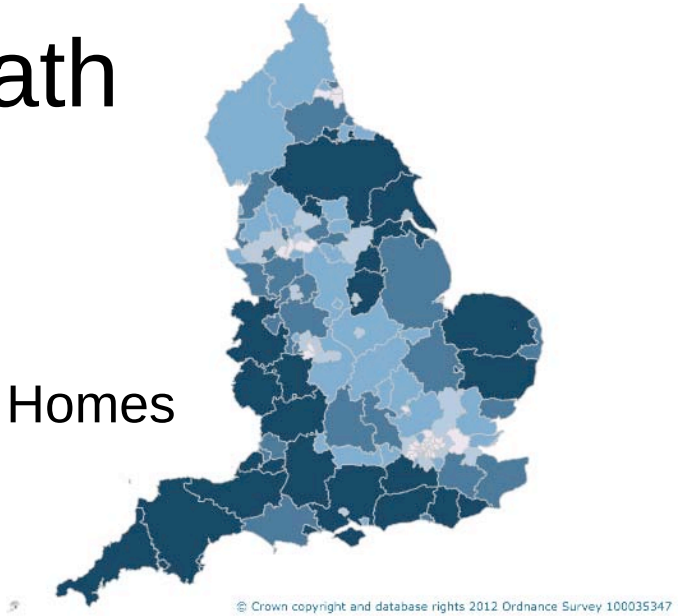
- Death imminent: **may** withdraw or stop **if** burdens>benefits
- **Must** give weight to prior patient request to continue until death
- **Must** keep patient under review and reassess burdens/benefits

Place of Death

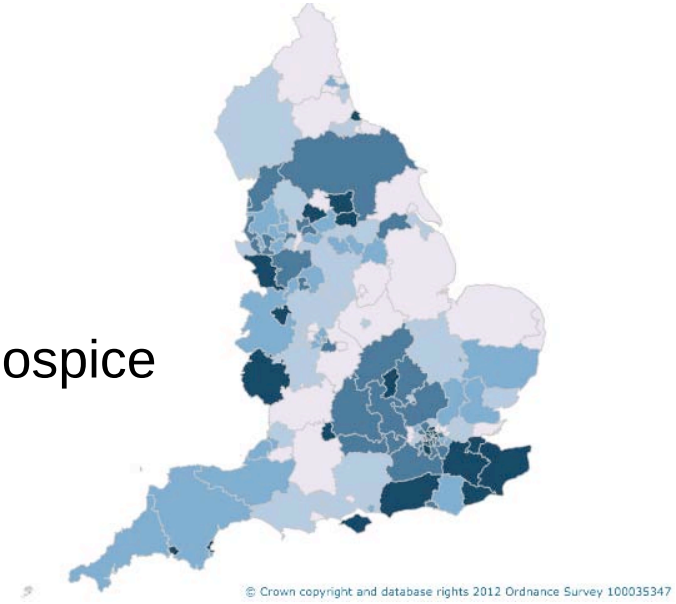
Hospital



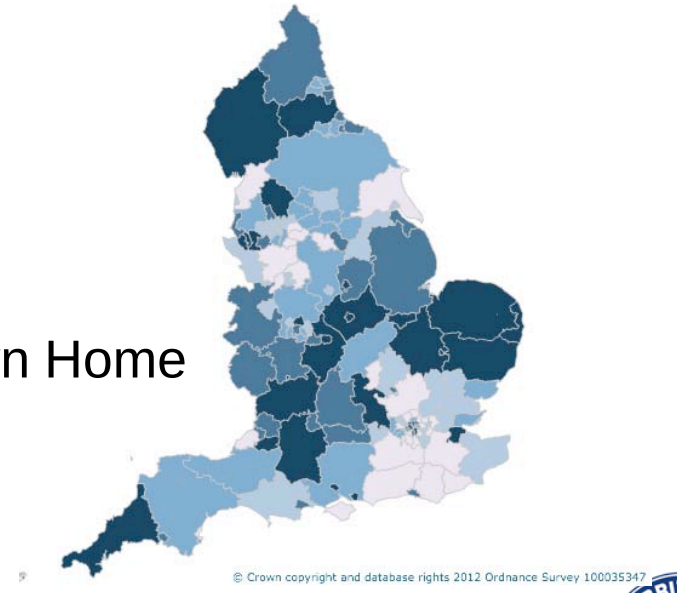
Care Homes



Hospice



Own Home



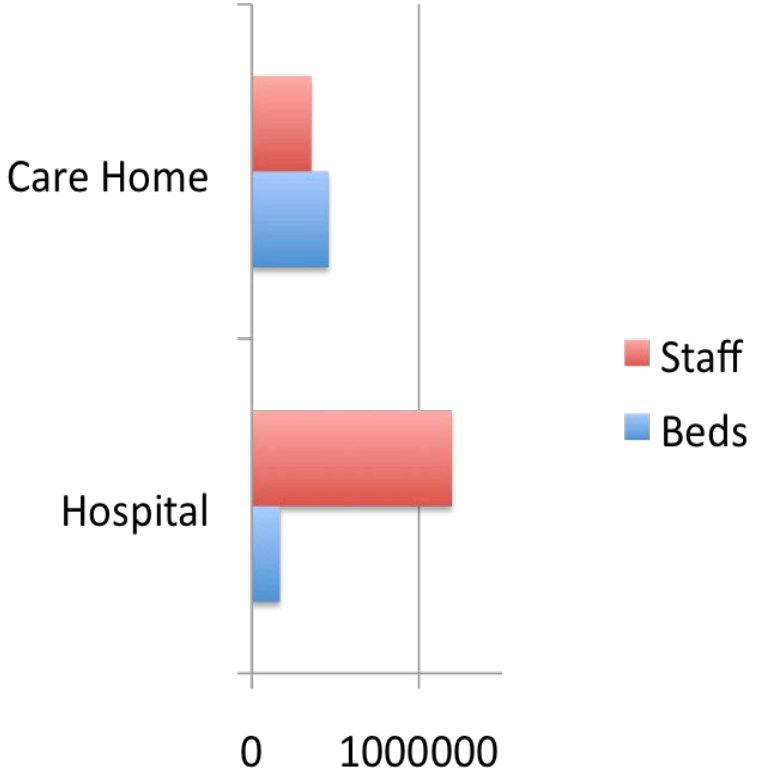
National End of Life Intelligence Network: deaths Data 2008-10

Place of Care: Care Homes

- Shift of ‘geriatric long stay’ from 1981 onwards
- Independent sector predominance in last 20 years
  - 1970: 20,300 independent NH places
  - 2010: 200,000 independent NH places
- Contraction of NHS in patient resource:
  - 1970 75,000 long stay NHS beds
  - 2010 15,000
- England market value: £22Bn
  - massive public funding to private sector (£16Bn)

NHS v Care Home Beds

- 167,000 NHS hospital beds
- 18,255 care homes 459,448 beds
- Care needs overlap between types of home
- 355,000 care workers & senior care workers
- Unknown number of nurses in care homes



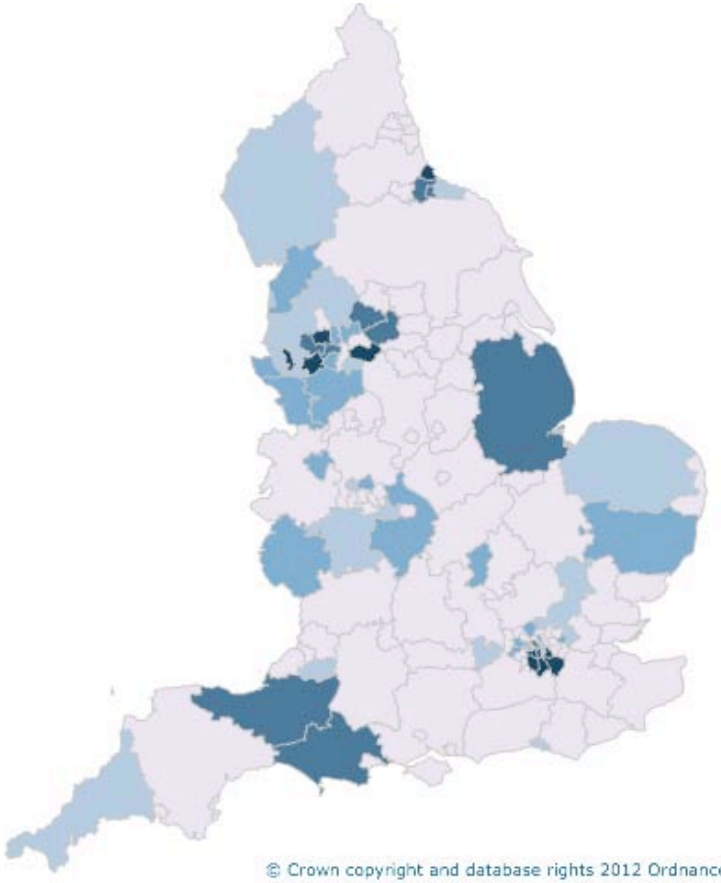
Care Home Mortality

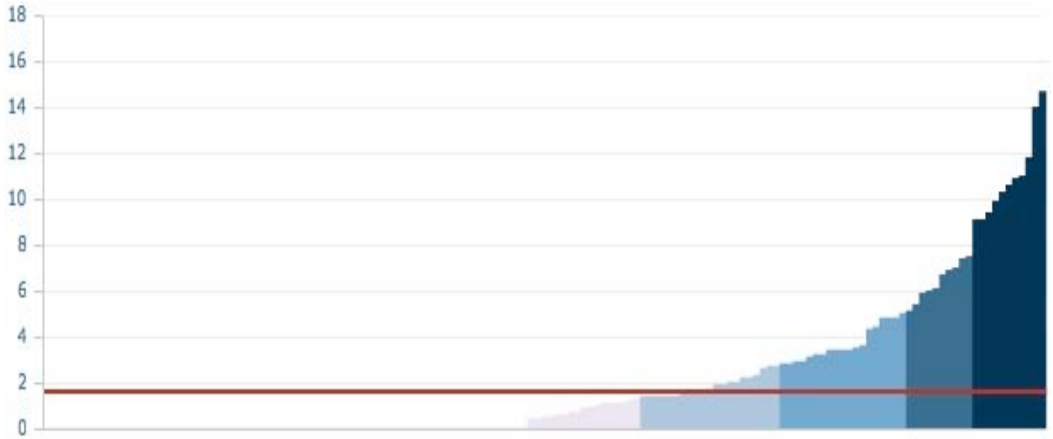
- 26% +65 residents die within one year (3.3% community)
- SMR (nursing)=419 (95% CI 396-442)
- SMR (residential)=284 (95% CI 266-302)
- Age, diagnosis weaker mortality predictors in care homes v community
- Drug classes and primary care utilisation strongest mortality predictors
- Primary care utilisation: proxy for frailty to prompt EoL decisions

Age Ageing (2013) 42 (2): 209-215.

Are care homes equipped?

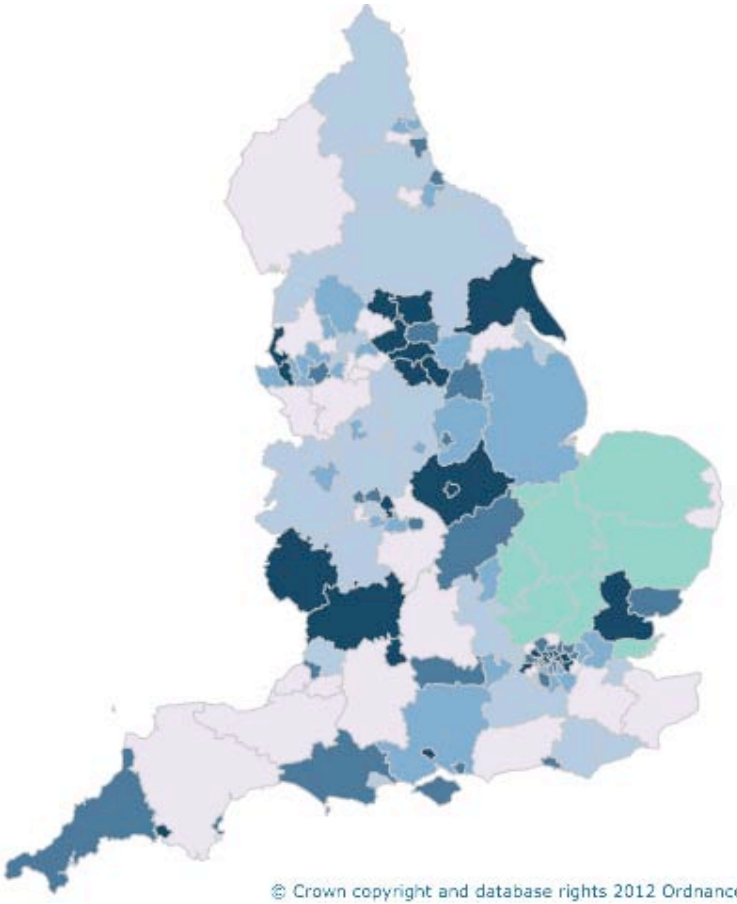
Homes Achieving GSF 2012 (%)

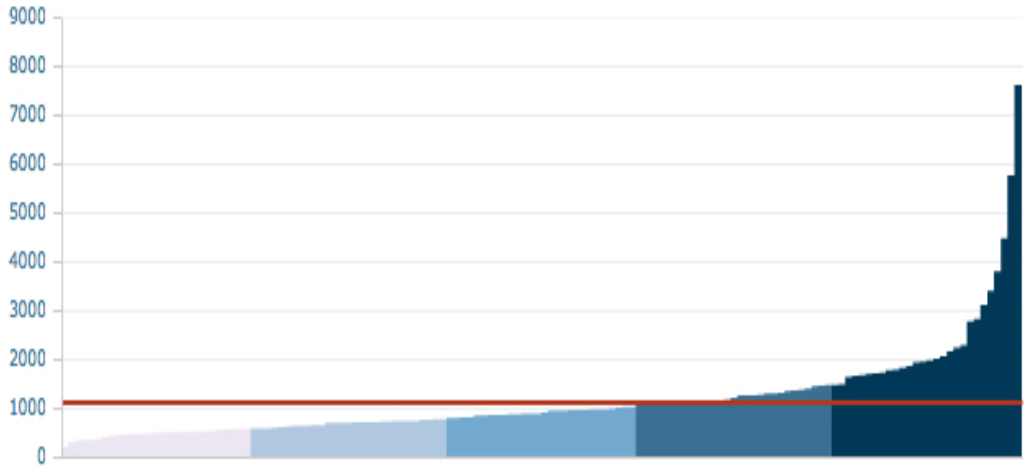




End of Life Care Spend

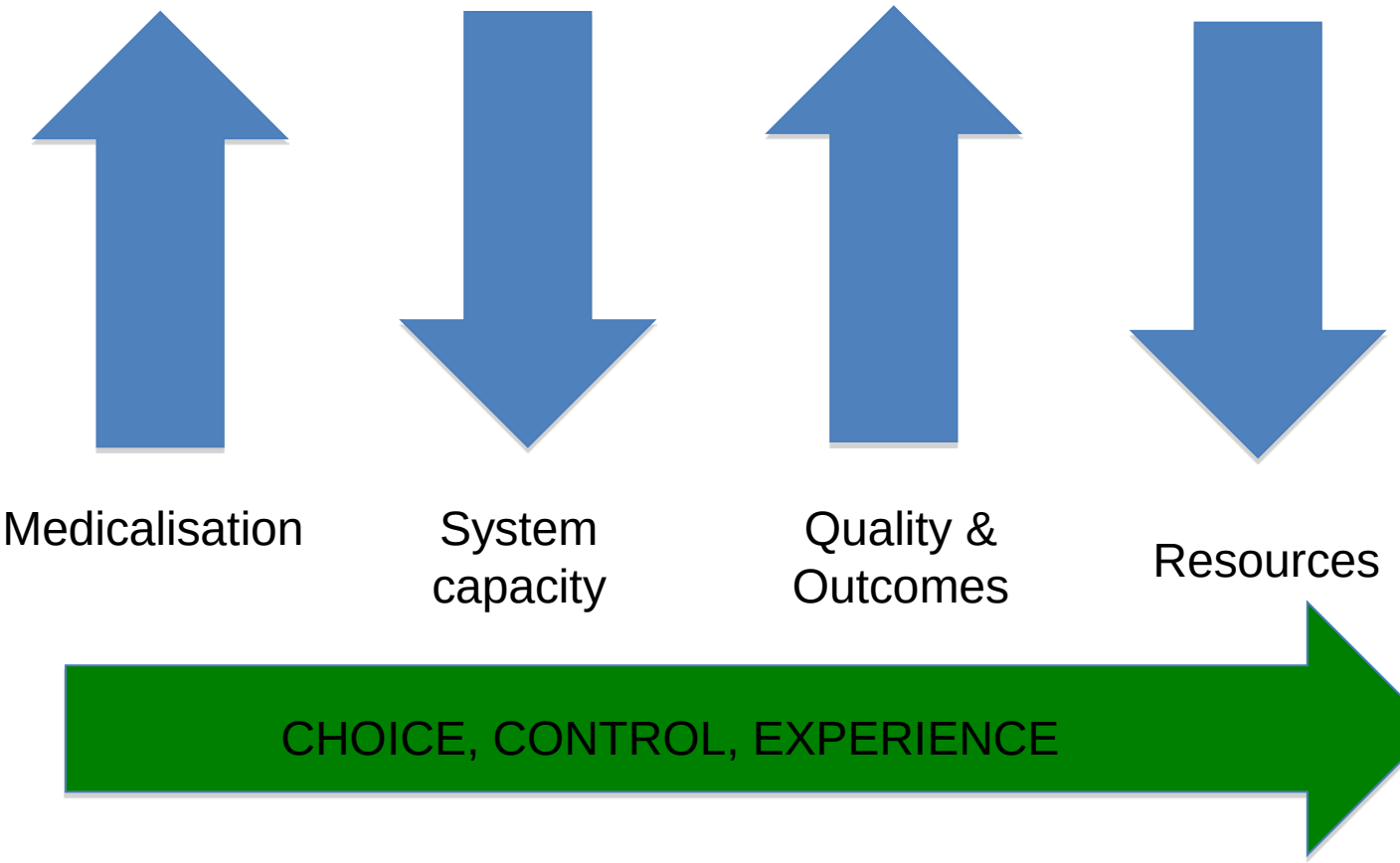
Total spend per death on End of Life Care 2011 (£s)





National End of Life Intelligence Network

The challenge…



Hospital Regulation (CQC)

- Lack of respect for privacy and dignity: curtains not closed
- Call bells out of reach or not responded to
- Staff condescending or dismissive
- Inadequate staff numbers and training
- No help given with meals, interruptions during mealtimes
- Inadequate dietary assessment, monitoring, hand hygiene

Francis: Themes

Corporate focus on process at expense of outcomes

Failure to listen properly to complaints: lack of transparency

Staff disengagement with management: weak voice

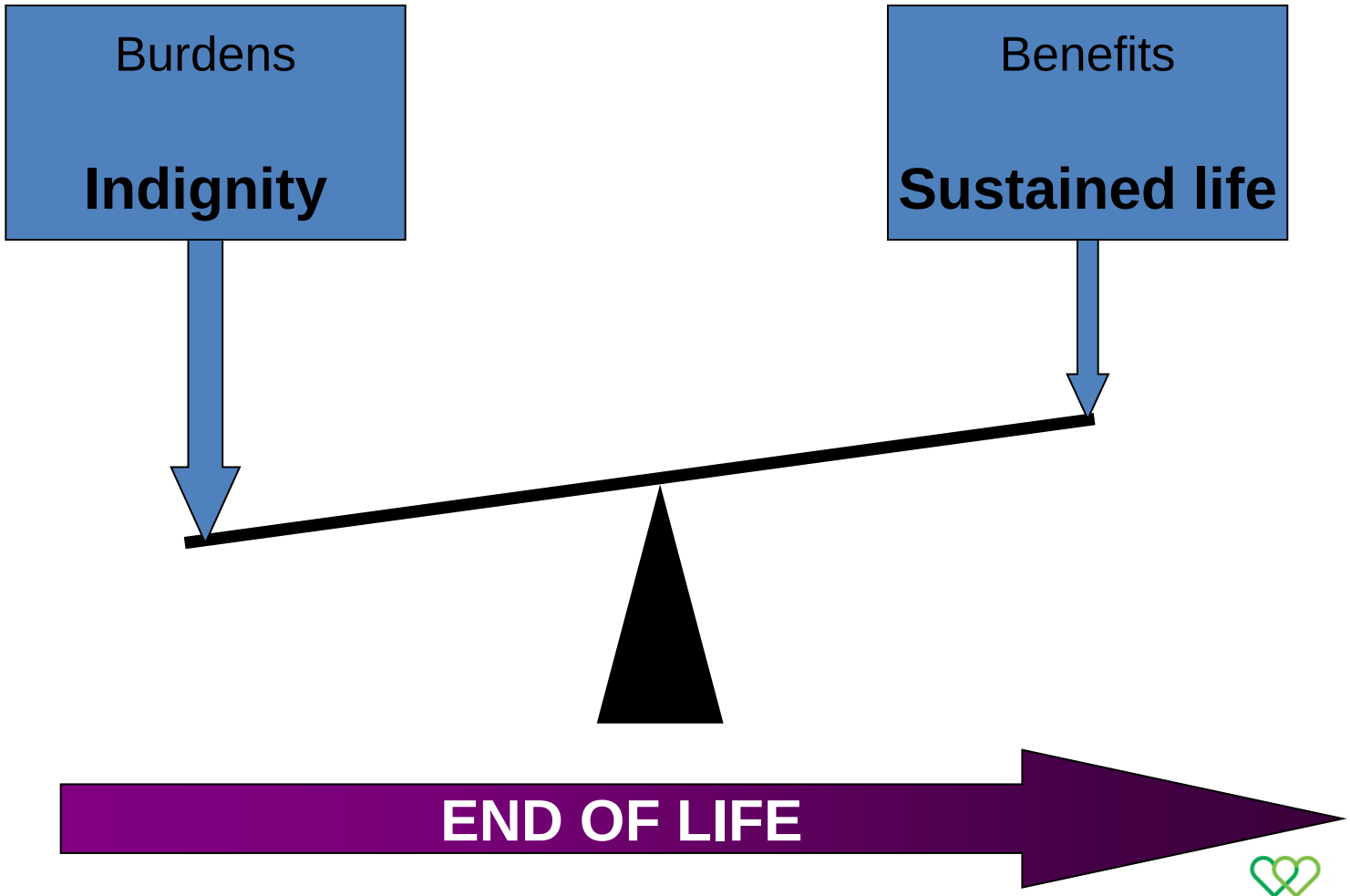
Insufficient maintenance of professional standards

Lack of staff support: appraisal, supervision, professional development

Inadequate resourcing of elderly care: *‘abuse of vulnerable persons’*

Quality and Outcomes

Interests: *overall benefit*



Simple Messages

DIGNITY AND RESPECT

- Treat the person as an individual
- Ask the person how they would like to be addressed
- Involve the person, and their next of kin when appropriate, in all discussions and decisions

EATING AND DRINKING

Check if the person:

- Is in the most comfortable position prior to eating
- Has had the opportunity to wash their hands before and after eating and check fingernails for cleanliness and length
- Has had their mouth and dental hygiene assessed

USE OF THE TOILET

Ensure the person has:

- Privacy and dignity
- Timely and prompt assistance if required
- The opportunity for hand washing

COMMUNICATION

- Check the person has been assessed for hearing, sight and language difficulties
- Use plain language and simple explanations
- Make sure you have understood the person and that the person has understood you

MOBILITY

- Encourage the person to maintain their NORMAL mobility and routine as much as possible
- Check the person's foot hygiene and toenail length
- Ensure the person's footwear is clean, well fitting and within reach

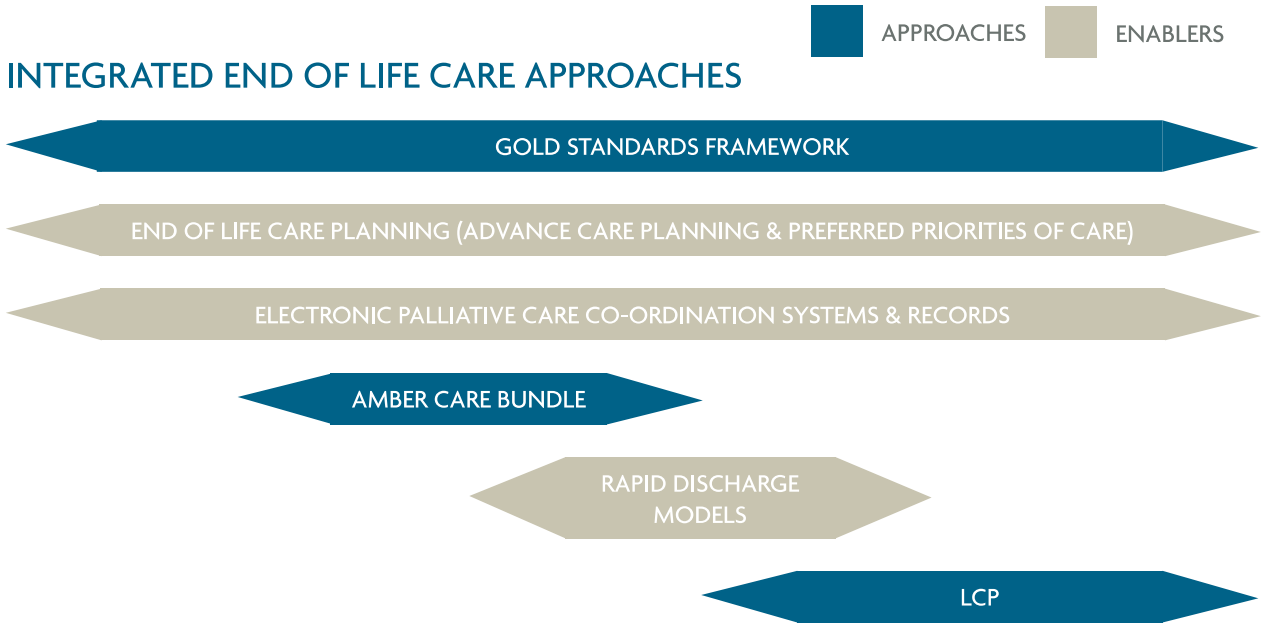
UHSM Green Your Hospital

BRITISH GERIATRICS SOCIETY

LCP Independent Review 2013

- System-wide strategic approach to improve care of the dying
- Abandon terms ‘LCP’: use ‘end of life care plan’
- Improved diagnosis, prognostication and communication of ‘dying’
- Shared decision making and accountable responsibility
- Review guidance on nutrition, hydration, DNACPR
- Better support, training and regulation of end of life care
- Cease financial incentives to use the LCP or equivalent approach
- Link care of the dying to the Vulnerable Older People’s Plan

End of Life*



tting down
The person is
letting go

*More Care, Less Pathway: a review of the Liverpool Care Pathway. Neuberger 2013

Improved End of Life Care for Older People

- Well timed and documented person centered advance care planning
- A personalised and contemporaneous care plan for end of life
- Care which responds to change in circumstances and choices
- Open, honest communication with patients, families and carers
- Clearly identified accountable professionals who are supported
- An adequately resourced integrated health and social care system

Case Example 1

- Mrs A, 83: history of COPD, IHD, osteoathrosis
- Fall: fractured neck of femur treated surgically
- Prolonged surgical recovery, delirium, depression
- Declined most care and interventions over 2 months
- No mental capacity for most decisions: engaged, supportive family
- Best Interests gradually moved from sustained life to end of life care
- Died peacefully in hospital with family in attendance

Case Example 2

- Mrs B, 92: Alzheimer's disease, living with son
- Repeated admission with delirium, urinary infection, increasing disability
- Not able to eat and drink, losing weight: did not tolerate nasogastric feeding
- No mental capacity for any welfare decisions
- Family strongly supportive of maintained life: subcutaneous hydration
- Moved into long term NHS care: detailed, personalised care planning
- Remains alive, more interactive and comfortable with uncertain prognosis

End of Life

- **End of life is inevitable…**
- …but sometimes attenuated by medical intervention
- **Offer treatment, if feasible, for comfort & dignity…**
- ….until no longer wanted or needed
- **Basic care must always be provided…**
- **Right place, right approach, adequate resource**

Key Points

- More people are living longer, better lives
- Compression of morbidity into later life is a success story
- Inequity in some areas poor is leading to poor outcomes
- Poorly configured EoLC creates unmanageable system pressures
- Better balanced medical and social care and investment is needed
- Care delivery must refocus on personalised, flexible choice
- Integrated care must aim to deliver these improvements