

Bereavement pathway

End of Life Care work – where
does the Bereavement pathway fit
and how?

Overall themes

- Where now for End of Life Care and what is happening
- Where the bereavement pathway should and could fit
- Issues to consider
- Some ways forward

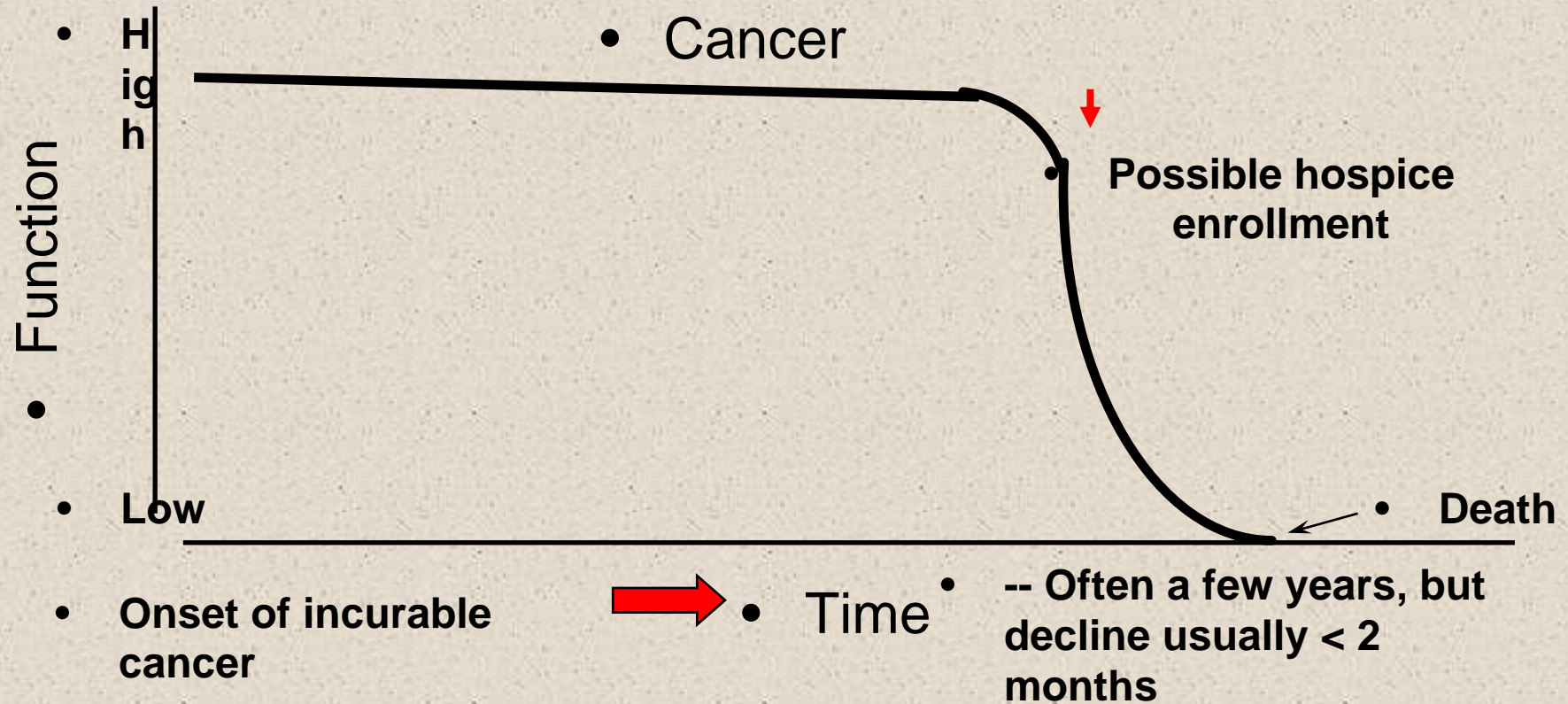
Starting point 1: End of Life care for all

End of Life Care in this context is taken to mean for:

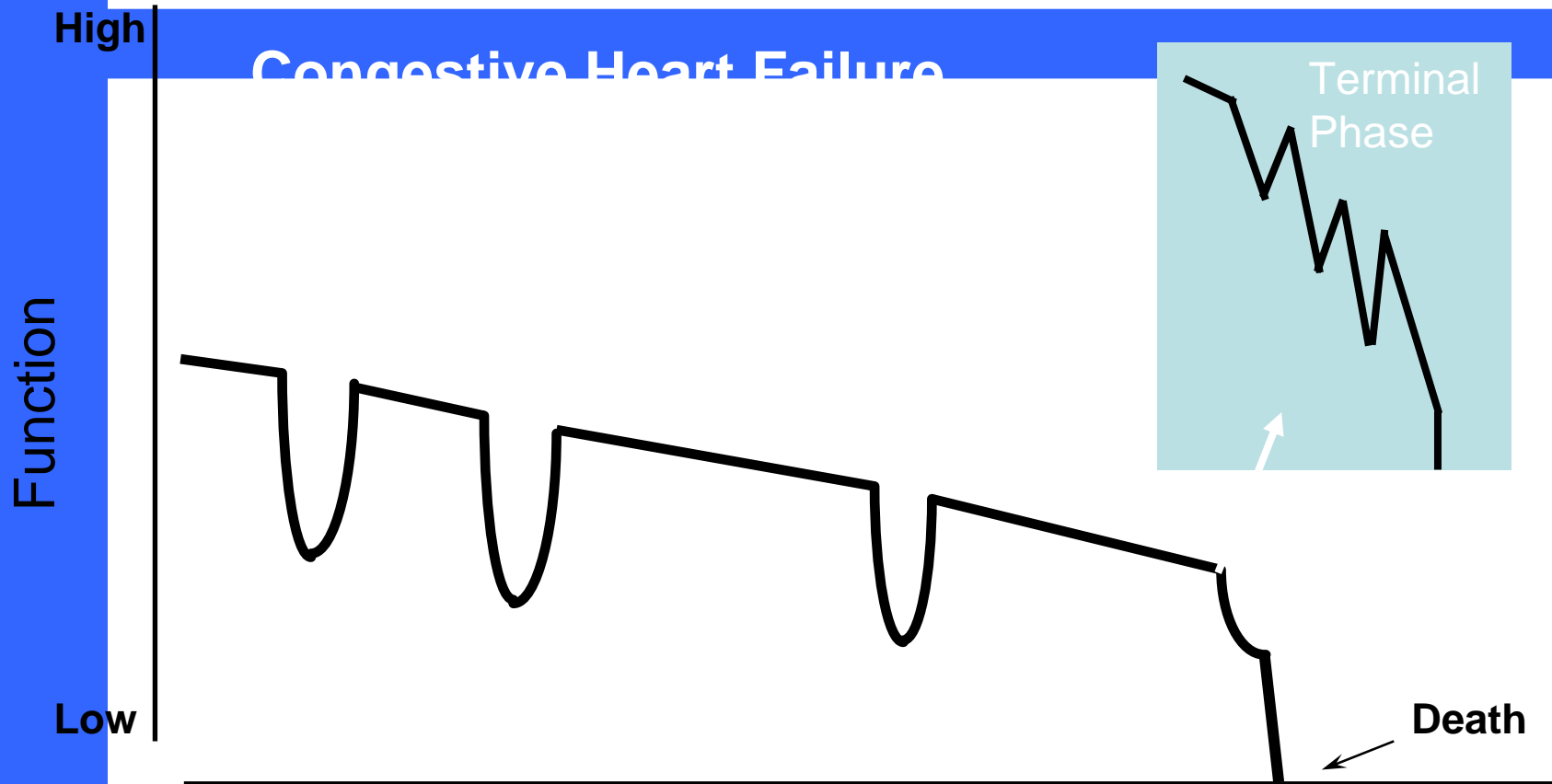
- All those with a long term condition or frailty

It does not address sudden unexpected deaths through trauma, accidents, suicide

- **“Cancer” Trajectory, Diagnosis to Death**



Organ failure

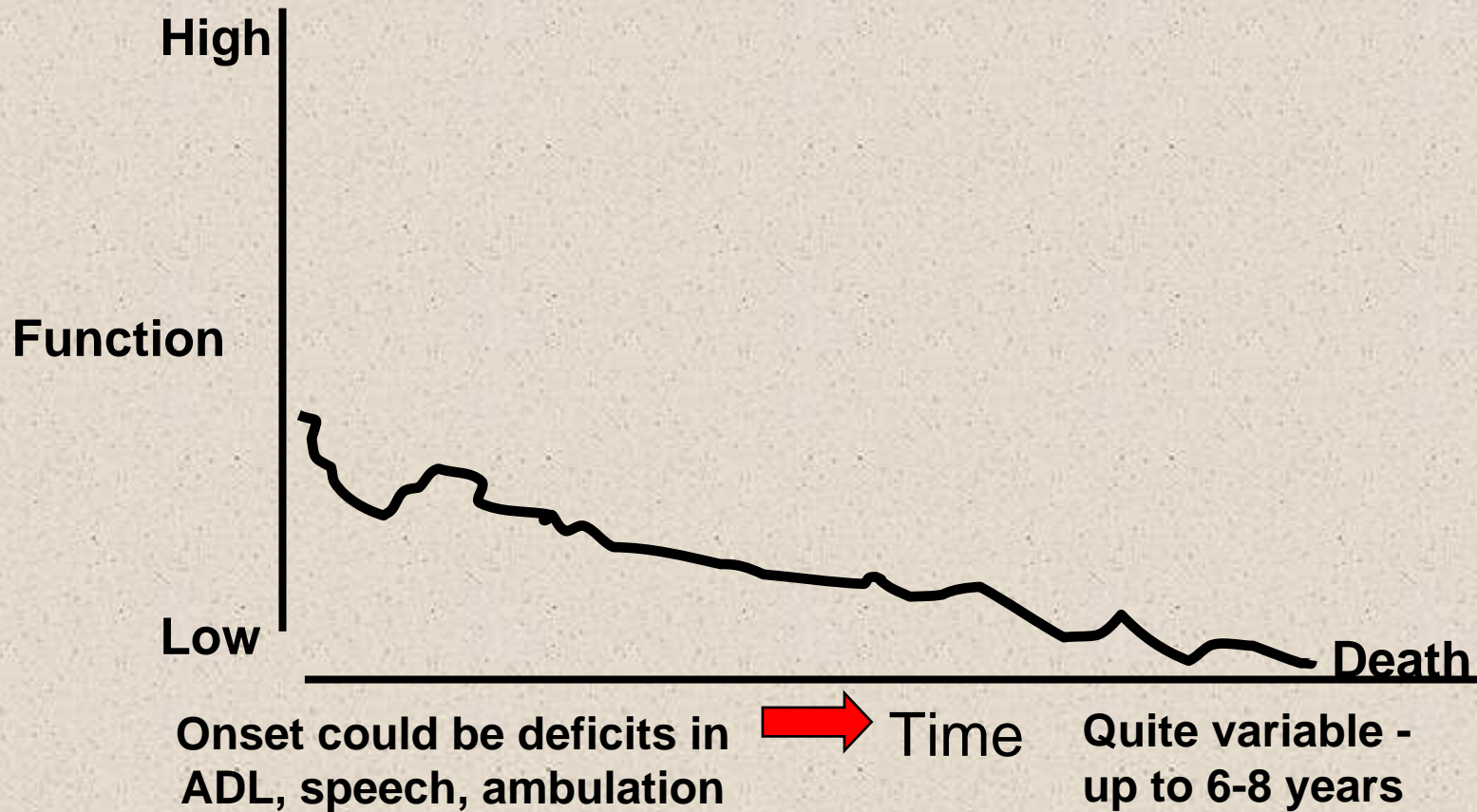


Begin to use hospital
often, self-care
becomes difficult

→ Time

~ 2-5 years, but death
usually seems "sudden"

Dementia/Frailty Trajectory



Starting point 2: End of Life care after death

Includes care

- Immediately after death for those family members or significant others (what is the time span of immediately?)
- And staff?
- And should/could include addressing significant losses during living with dying/advancing diseases or states

'demand' for bereavement care services?

- 1% of the population dies every year
(so over 543,000 deaths and increasing)
- 2% of the 1% will be sudden/unexpected deaths
(so approx 12,000)
- In every GP practice = 1% of patient list

What services and care do we have now?

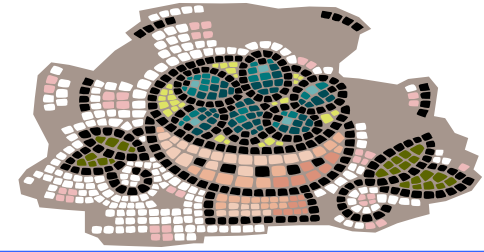
Varied

- Hospital Bereavement service
- Psychologist
- Occupational health
- Psychiatrists and Psychologists
- GP based Counsellor
- Hospices (for those affected by cancer)
- All voluntary organisations: Cruse, Samaritans, Crossroads, Therapists, Counsellors -----

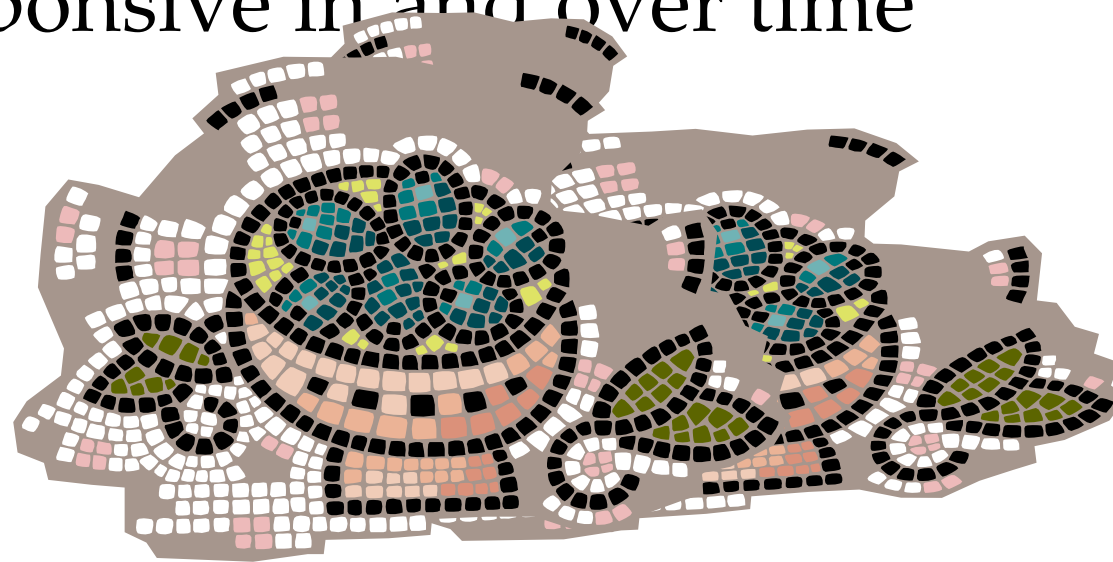
What services and care do we have now?

- Priests, Religious/faith leaders
- Funeral Directors
- Cultural rituals
- Community support
- Carers support groups
- Family and friends
- Help lines – e.g. after television programmes

What we need?



A mosaic of services that is needs responsive in and over time



But

which is depicted somewhere? And access easy and known by ??

Strategic direction in NHS re End of Life care

- National End of Life Care strategy expected after June 2008
- National dementia strategy expected 2008
- NHS Darzi review 'Our NHS our future'

- NICE Guidance – Supportive and Palliative Care (cancer)
- Children's Palliative Care
- Long Term conditions NSF

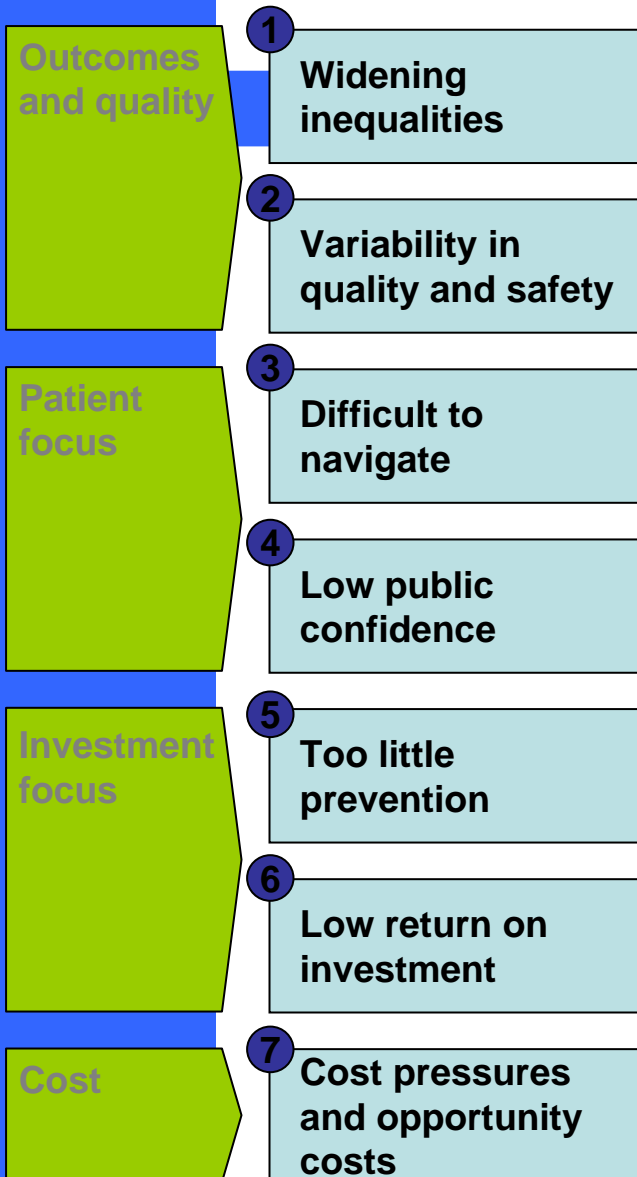
Strategic direction in NHS re End of Life care

NHS West Midlands

- Investing for Health -
 - Staying Healthy
 - Care Closer to home --- End of life care
- PCTs End of Life Care networks

www.ifh.westmidlands.nhs.uk

The 7 challenges



- Despite improvements in overall health status, inequalities in health have widened
- There remains an unjustifiable variability in the quality and safety of services and individual care
- We do not always help patients to navigate the system
- The public, our 'customers' have little confidence that their local NHS will get better
- We are not achieving enough in prevention
- We spend substantial amounts of resources on clinical activities where there is little return on investment in terms of improved health, or where there are more cost-effective alternatives
- The rate of cost pressures arising from doing "more of the same" outstrips any conceivable rate of increased funding

Range of services required to be needs responsive for dying at home

Composite Factors supporting dying in a community setting:

1. Patient thoroughly informed about the illness	7. Hospital/other settings beds available
2. Preference for place of care known	8. Technology such as hospital beds at home, infusion devices and spinal catheters when needed
3. 24 hour, 7 day a week access to a range of generalist and specialist services <ul style="list-style-type: none">• Immediate access to both planned and emergency visits• Regular visit by a physician/community health care team member	9. Support offered to both patient and carer <ul style="list-style-type: none">○ Psychological, spiritual, cultural and social needs

Range of services required to be needs responsive

<p>4. Care based on wishes of the patient and family</p>	<p>10. Availability of housekeeping, transportation or meal at home services</p>
<p>5. Community Care is not a complement to but replaces institutional care</p>	<p>11. Availability of day care</p>
<p>6. Multiprofessional approach to include speech therapy, nutrition/dietician, physiotherapy, occupational therapy,</p>	<p>12. Support for Carer needs are broken down further to reveal</p> <ul style="list-style-type: none"> •Employer support for time for caring •Access to community home based services •Carer respite facilities •Multiple care givers

Darzi review – End of Life group pathway

- Public Health
- Identification of patient
- Assessment and planning – advanced care planning
- Co-ordination of care
- Ongoing care
- Last few days of life
- After death and Bereavement care

Public Health agenda component 1

- Development of 'Compassionate community networks'

Because of

- Reduction/loss of community networks, neighbours etc
- Cultures in transition and intergenerational issues
- Dispersal of families, changed lifestyles

Public Health agenda component 2

- Generating awareness of dying, death and loss in the 21st century

To the public, patients and carers

Because

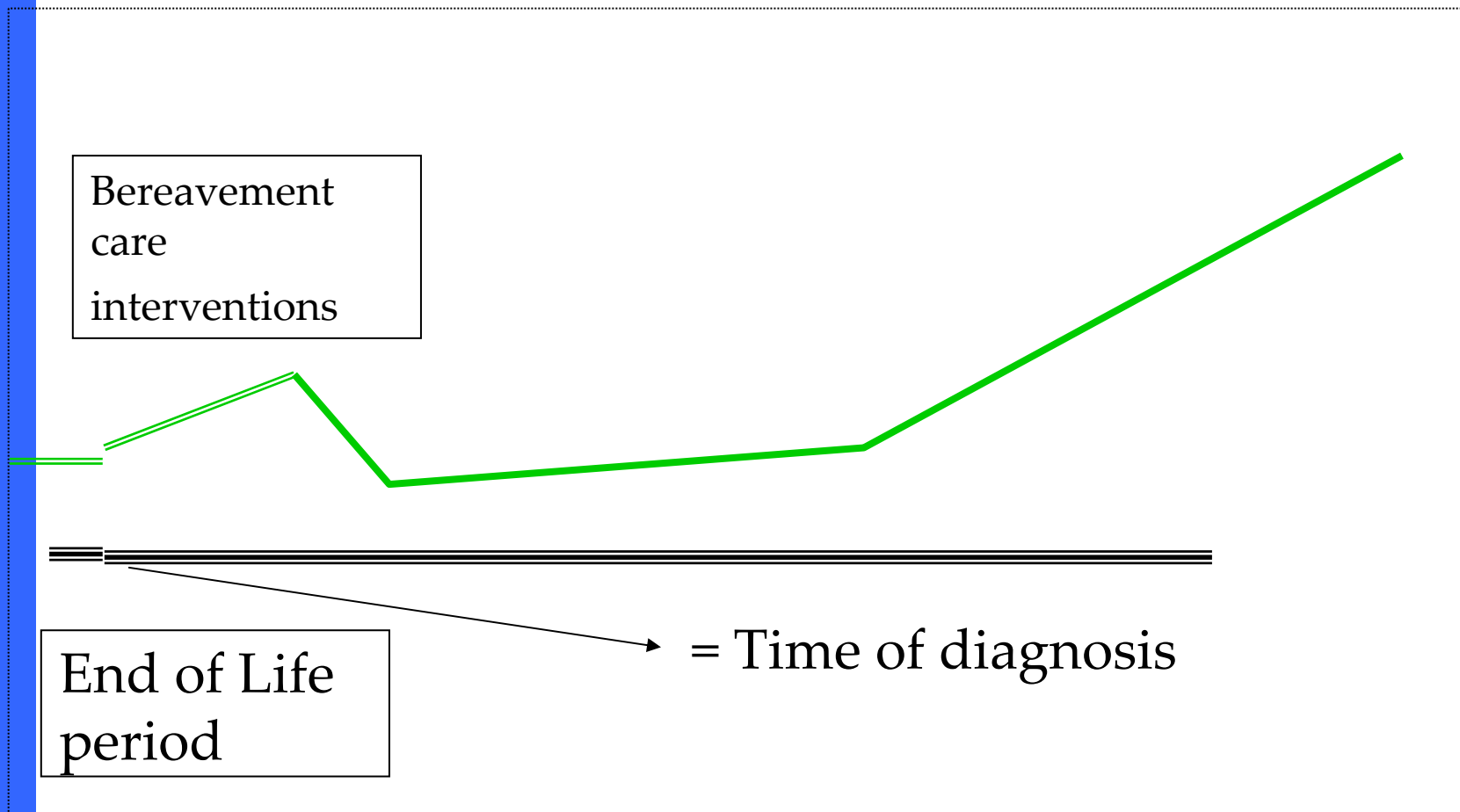
- Medicalisation has led to disempowerment of us all and we need to rebalance this to be partners in care

Examples of 2 in progress

- Pan Birmingham Palliative Care Network Campaign 'Living well until the end of life'
- SHA, Arts Council and Voluntary organisation piece of work developing stories in and for end of life period

www.birminghampalliativecare.nhs.uk

Where does bereavement care fit?



Other issues – where to

- Addressing the needs of the variety of ethnic, religious and cultural groups/communities in a variety of places – transitional, generational and location
- Relationships with other ‘caring’ input or?
- Some parts, a commissioned service or?
- Those with Dementia and their carers
- Increase in loneliness?
- Organ donation - when is death?

summary

- End of Life period needs to pay attention to 'losses'
- Bereavement care will be composed of a mosaic of services, people and resources
- We could all benefit from knowing more 'about and how to' at times of loss
- Now timely to influence and lead on 'getting this right' for us all