Presentation by Pauline Smith, Clinical Lead, End of Life Care, West Midlands Strategic Health Authority, made to the Bereavement Pathways Project Stakeholder Event, Birmingham Children's Hospital, February 12 2008.

(This presentation was made in conjunction with slides)

Good morning,

I am very pleased to be speaking here today and to be both part of and supporting how the BSA and CRUSE working together, will move forward with work on the pathway.

I guess even apart from own our work roles, that our life experiences can resonate with this pathway work. Mine certainly can!

The tension I hold here is to ensure that the impact of loss and significant losses are life events and part of being human and living in communities and society and yet some will/may require a 'more specialised even professional' input. How do we maintain this balance and keep us as the public with core life and living know how?

In this session, I'll speak and then provide time for some discussion about the context I'm about to share, so as to clarify any areas prior to your workshops this afternoon and the future work required.

So , I would like to situate the Bereavement pathway in the context of the pathway and work currently taking place in Health and social care on and for End of Life care.

I'll talk about what we mean by the term End of Life and care and what is currently happening at national, SHA West Midlands and in Primary Care Trusts (PCTs); then from my perspective suggest where and how the Bereavement pathway could fit/work.

Then I'll finish with some ways forward, briefly introduce/suggest issues that will need to be addressed, and then summarise what I have outlined here

In using this term I am talking about End of Life (EoL) for all those with long term conditions, frailty and old age. It is used as an alternative to the term Palliative Care which has become very equated with being of value to those with advanced cancer and then Hospice care which, depending on the audience, is also equated mostly with cancer and maybe dying itself – the last few days or symptom management. These Terms are all problematic: End of Life care, Palliative Care, Hospice care, MacMillan, Marie Curie. How does anyone make sense of these for the first time?

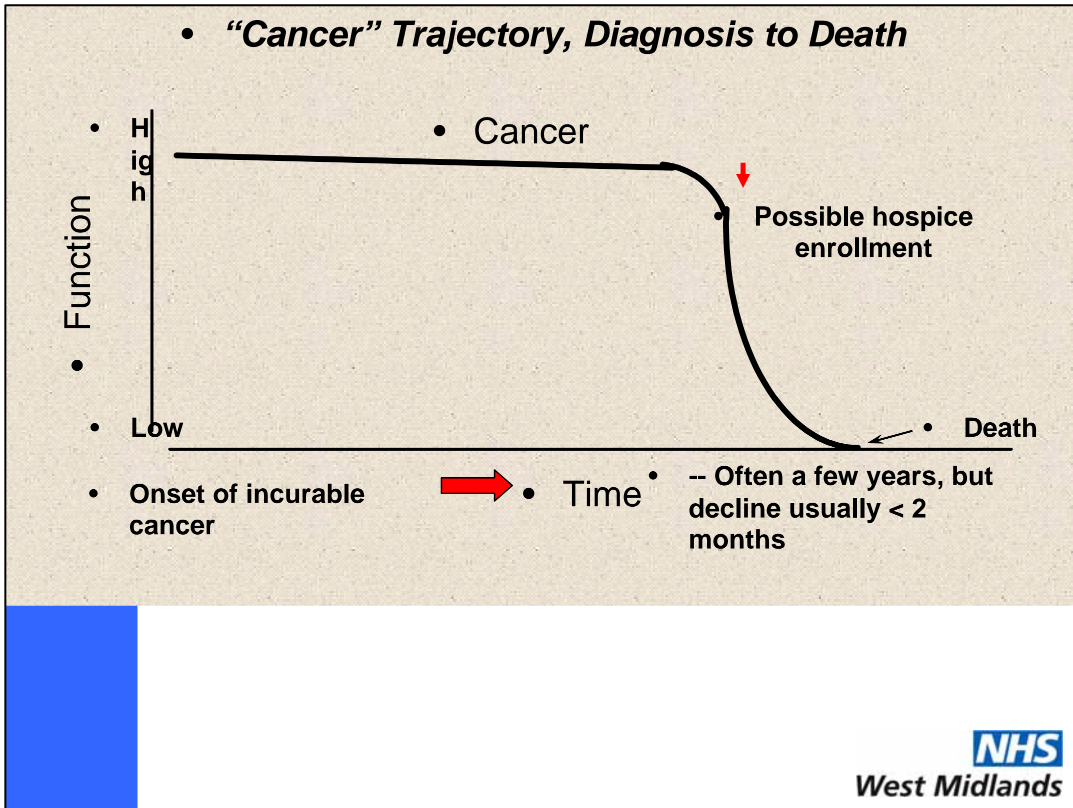
Dying and death in the 21st century is a very different experience to that 50 or 100 years ago and I'll say something about why in a moment.

Just think about this for yourself – what do you imagine a 'natural death to be', how long will dying take? For yourself or those close to you – what do you expect and how do these expectations affect our bereavement and need for 'structured input' after the event?

The reasons for these changes are numerous and include massive technological and pharmacological advances, so that the switch between life and death can be very fragile. For a number of long term conditions (LTC), the disease journey while marked by functional deterioration is also marked by acute on chronic episodes where these episodes can be managed or not. People can live with a LTC for many years because while there are not curative interventions, there are disease management interventions even during very advanced stages of diseases. Dying also takes a much longer time these days

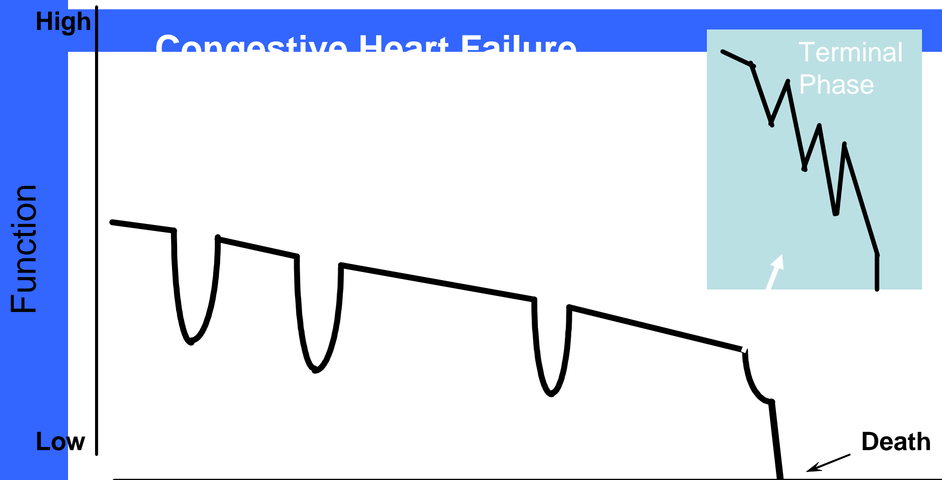
So when does EoL care start? That is a difficult question and while we are talking about the last year of life, of course situations are not as black and white as this – but supportive quality of life care is needed alongside the acute management.

This is important for you to know because the experience of dying is now very different. This EoL term is not used to address sudden unexpected deaths, but this is also your territory – so that your work and mine intersect and each is covering more than the other.



- Some illustration of dying time – though this is incorrect for cancer now which is as much a long term condition as others – with palliative chemo and DXT for example

Organ failure



Begin to use hospital often, self-care becomes difficult

Time

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

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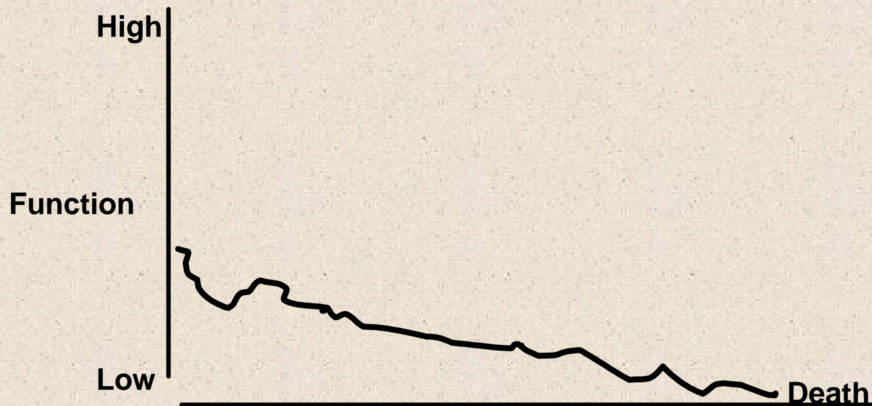
- At any of these acute on chronic periods, death could be the outcome; what we are not good at doing presently is having such discussions about what to expect in and over time at much earlier points

Dementia/Frailty Trajectory



Onset could be deficits in ADL, speech, ambulation

Time

Quite variable - up to 6-8 years

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- 5 – 10 years here from diagnosis to death, but again recognising this we are not yet having conversations while those with dementia have capacity

For health care we know we have much to get right in places for the care at and immediately after death for the person (respecting religious and cultural and ritual beliefs), and all those significant others – made more complex now in 21st century when we have more marriages within a life time with children, so what family means could be different.

Then there is the need of staff – those with short term intense relationships such as in the acute hospital and those with longer and deeper relationships over time in the community/care home sectors

What you may have thoughts about is when bereavement care could and should begin for these people dying and I'll return to this later; and how to separate, or not, psychological care from bereavement care, or is it the same type – addressing losses.
My husband had cancer in his early30s and has since died, but the loss of normality, a future, a working role and all sorts are issues to address.

Do we need to consider the 'demand' for bereavement care – probably not given that the majority is contained as a natural part of life and lived as such. Yet our population is increasing, mostly because we are all living much longer and this means two things:

1. Many old people may be living alone and die with little or no family or friends around – what does this mean for the needs of the family and significant others?
2. Many of the population, especially those up to 50 are unlikely to have experienced a significant loss or death, and so be unfamiliar with both he process of what to do and the emotional responses in and over time

I know I am unusual –as many of you here may be – having my first very major loss beyond grandparents at 18, throughout my 20s and then again 30s and continuing – just unusual, and not an expert. I will return to this as rationale for pathway and steps required.

Nevertheless taking account of data we know that 1% of the population dies every year.

So in Health Care what do we access. Though mindful not to medicalise loss and bereavement, we may need more immediate support interventions and those who steer us to manage the processes, though some of these are accessed for those defined with pathological grief.

IIt is iteresting that Colin Murray Parkes is updating and revising his very core text, which was one I certainly drew on well over 25 years ago - Bereavement Studies - and of course many others since have been 'researching' the bereavement experience. Who are your favourites here; what do we resonate with?

It is interesting, for example, that for Western people funerals can take at least two weeks to arrange and happen now - quite a different closure and ritual response.

What services and care do we have now?

- Priests, Religious/faith leaders
- Funeral Directors
- Cultural rituals
- Community support
- Carers support groups
- Family and friends

These are of course not listed in any order. I am struck by comments made by some Clergy friends and colleagues that funerals are more emotionally 'difficult'/complex and I haven't got to the bottom of this, but I do think they take a heavy load on behalf of society at these times, increasingly unnoticed. The important point here is the variety of support and care available and drawn on.

What about the length of time for interventions and when - and differences?

In terms of the pathway I think it is important we look at how resources are depicted and the entry points and the referral points and criteria, and how we/the public even know what exists

I have deliberately chosen a mosaic metaphor here, so that we see the foundation and how other bits are then configured larger but all in pieces – they make a picture but need not be complete and are not like a jigsaw where pieces fit together and have an edge.

What is a normal or abnormal bereavement? Is this the same as previously depicted?

So back to context. There is a National EoL strategy expected after June this year. Starting over 18 months ago, just the developing work has thrown lots into relief about our current experiences of death.

I mention Dementia because at the moment many of those with Dementia and their carers are not given the opportunity to be partners at this time because decision making process are started too late in the disease process and after 'capacity' has been lost. In NHS West Midlands our dementia pathway proposes that EoL care commences after diagnosis - the opportunity - and is reviewed. We all have a vested interest in this because as we all live longer we have a one in four chance of developing dementia if over 85 and one in three of experiencing impact of dementia – either self or those close to us.

Lord Darzi's NHS review reports in June 2008, for the 60 year anniversary of NHS. There are eight pathway groups, of which one is End of Life care

In NHS West Midlands we have a strategy for the next five years, Investing for Health. We know that 60% of deaths are taking place in the acute hospital setting – and that we are failing to:

1. have any dialogue and discussions with patients at times when they have an opportunity to be involved in how they want their last years or so to be lived and disease 'managed'
2. To do any advanced care planning and work with the wishes and decisions of patients

So there is a section on EoL in the chapter 'Care closer to home' As a way of addressing this agenda there are now formal EoL leads in every PCT and accompanying network to address the local EoL issues. For example, NICE guidance and bereavement services for those with cancer - joining up and equitable, but know they are not!

The strategy raises seven challenges, regardless of which service or which disease or which pathway. As part of the work for developing the strategy I undertook an International Literature Review to find out how other countries were managing to facilitate and increase numbers of deaths in the home. What emerged was a number of factors that collectively need to be in place - a composite', that is all of these if deaths at home are to be a consistent happening.

In the range of services required to be needs responsive for dying at home, you will note that bereavement care or services are not part of this, though psychological services are.

So what of the EoL pathway and where could/should the Bereavement care pathway fit? Lord Darzi's groups were charged with developing pathways or principles.

It may seem strange to say that the Bereavement pathway also needs to start at Public Health, and given all the reasons I have stated for re-empowering society/the public and because of increasing lack of familiarity with dying and death and loss, this is where we need to start

There are lots of exciting ideas about how messages can be portrayed – media, TV, drama, Education Curriculums - the life journey that includes losses and death. Then planning may increase at times of diagnosis of advanced condition, with disease state, and increasingly as dying advances and happens.

There is a range of issues that are seemingly common for my EoL work and your bereavement pathway and areas/aspects we will need to pay attention to. This is not according to a script or stereotype, but how are we functioning with cultural competence and how we listen to those who are different in context, values and lifestyles to ourselves. You may have some expertise or ideas for how we contribute to managing these to support healthy living.

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

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