

## THE SHIFTING SANDS OF BEREAVEMENT CARE IN PALLIATIVE CARE



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### Today's journey

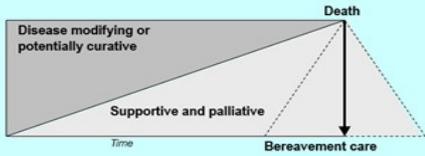
- What do we mean when we say bereavement care?
- Where does bereavement care fit in palliative care?
- What do we know about bereavement and bereavement services?
- What happens in St. Francis Hospice Dublin?
  
- What about the future?

### Dame Cicely Saunders



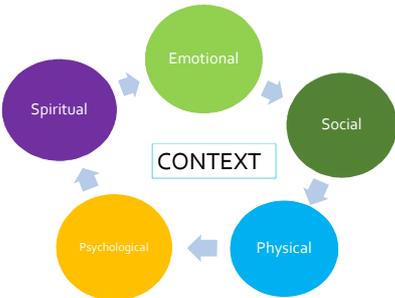
- Founder of the modern hospice movement
- Vision for palliative care - care of the dying; research and education
- Care of family and friends – not just the patient
- Care in bereavement, not just during the illness

### Palliative care Current model



Murray, S. A et al. BMJ 2005;330:1007-1011

### Impact of bereavement



### Bereavement Needs Assessment

Assessment requires engagement with the family and discussions throughout the patient journey and should not be left to the last days of patients' lives. Bereavement services also need to be in place, as assessment is not a standalone activity but part of a process aiming to match support to need.

(Relf et al; 2010: 5)



### Palliative Care Bereavement Services

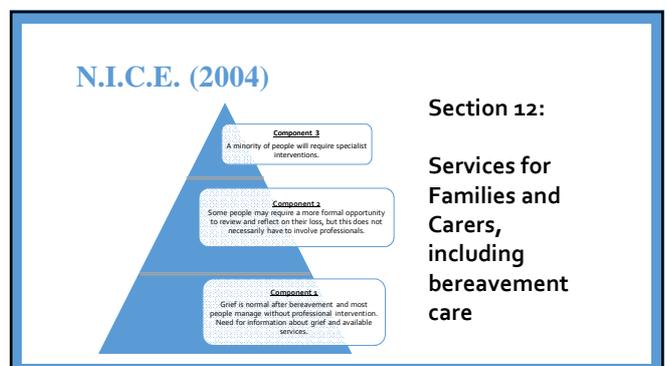
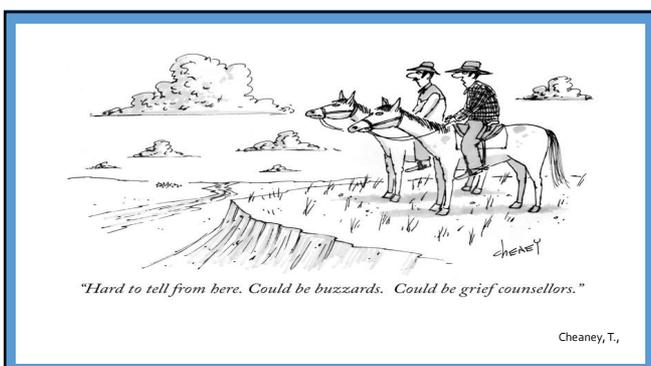
What model of service should be provided?  
How do we identify those at most vulnerable or "at risk"?

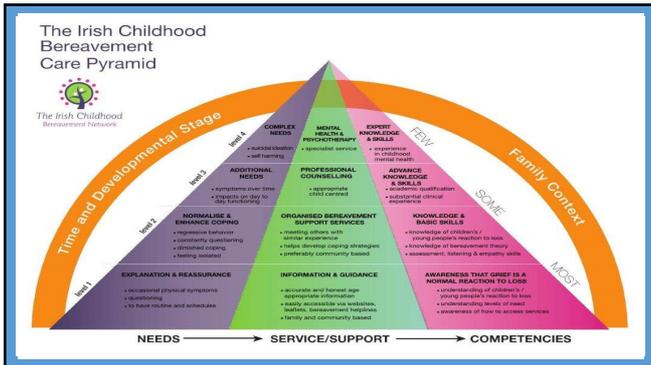
- Family as the unit of care – includes children, adults, groups, vulnerable adults
- Increasing family complexity – blended families
- More people working
- Increased migration

What is the evidence?

### Convergences from the research

- ✓ Of some of the theories
- ✓ Value of social support
- ✓ Need for information
- ✓ Risk BUT also resilience
- ✓ Context, role including caregiving
- ✓ Social variables including socioeconomic
- ✓ Not everyone needs counselling





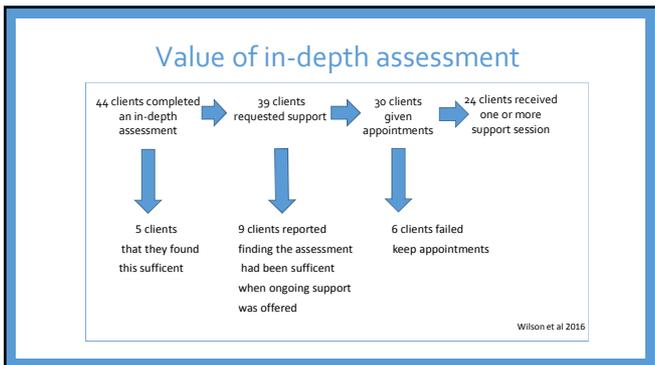
“Whilst there have been some significant developments in bereavement care, the impact of these is as yet largely unknown and there is no tool to enable the quality of services offered to be checked or assessed with any degree of objectivity”

(Cruse Bereavement Care & Bereavement Services Association, 2014:4)

### Value of in-depth assessment

- Assessment can clarify concerns and in itself be helpful to those being assessed, as it offers them opportunities to discuss their situation.
- Assessment facilitates objective decision making about the type and level of bereavement service that may be needed.

(Wilson et al, 2016: 6-7)



Go around and see what is being done and then see how your own circumstances can produce another version

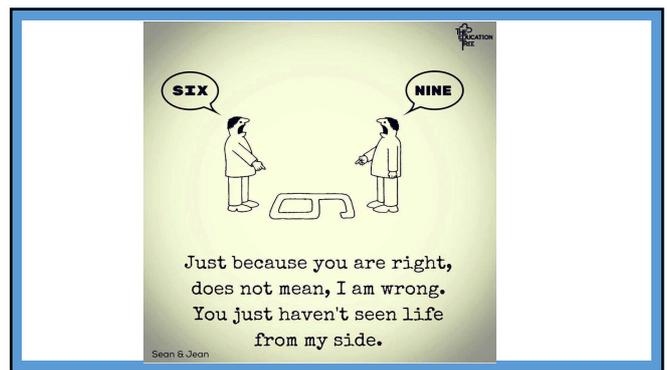
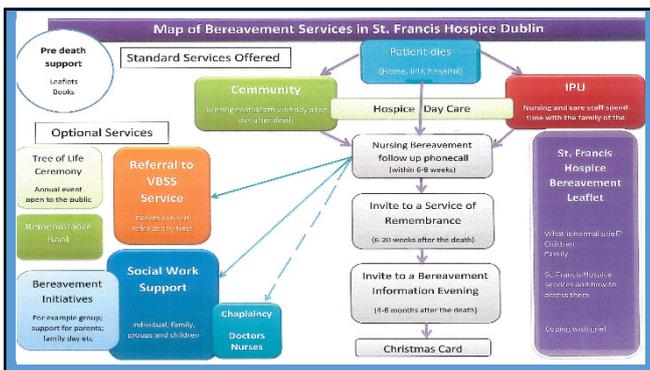
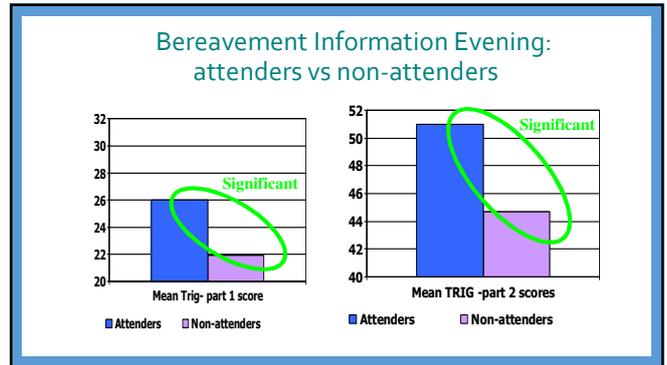
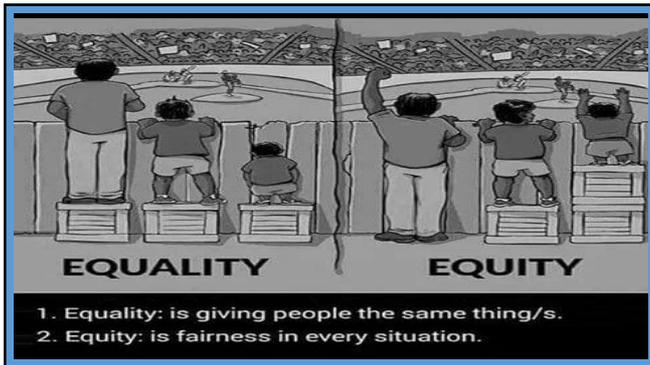
The **vision** has to stay the same  
The **delivery** needs to change

ECHO project on twitter April 2017

### St. Francis Hospice Dublin

**Raheny**  
In-patient unit: 19 beds  
Community Palliative Care Team  
Hospice Day Care

**Blanchardstown**  
In-patient unit: 24 beds  
Community Palliative Care Team  
Hospice Day Care



## A case for change in Hospice

- Population increase - Rising level of need
- Increasing vulnerability and complexity
- Increasing need for proactive rather than reactive care
- A role in the much needed integration of health and social care
- The requirement to do more with less
- Constrained and uncertain funding

“As the environment of care again threatens to fail too many and too often, hospices will need to unite in their thinking and develop a strong voice individually and collectively.”

Dame Clare Tickell

*"People who have been bereaved can experience social isolation because people don't know what to say or how to act towards them, and it is therefore important to develop community capacity to support people who have been bereaved."*

To Absent Friends...a people's festival of story telling and remembrance 2015;6

### Public health approach to palliative care

*"...it is important to look not only at data from clinical encounters, but at bereavement as it is lived out in everyday life."*

Rumbold and Aoun in Absent Friends 2015;12

- Links with community
- Networks, not just provider
- Rituals of remembrance and memorialisation build solidarity

### Public health approach to palliative care

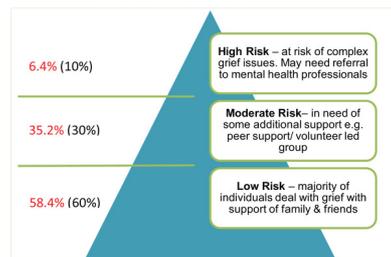
*"Need to think about populations as well as individuals. That is what professional responsibility is"*

Dame Barbara Monroe

Perspective for Planning	Palliative care services	Palliative care approach everywhere
	Specialist services	Actions in all settings of health care
	Institutional approach	Community approach
	Services approach	Population approach
	Individual service	Systems approach

Gómez-Batiste et al, 2017: 49

### Public Health Model



Aoun, S, Breen, L, Howling, D, Rumbold, B, McNamara, B and Hegney, D, (2015) Who Needs Bereavement Support? A Population Based Survey of Bereavement Risk and Support Need, PLOS accessed 22/05/15 @ 15:07

*"Dying is not a technical glitch of the human operating system; it's a feature. It's the only prediction we can make at birth that we can bank on. Everyone will die, and it's very likely somebody we love will die before we do. And yet the bereaved are often treated like those to whom something unnatural or disgraceful has happened. People avoid them, don't invite them out, fall silent when they enter the room. The grieving are often isolated when they most need community."*

Luscombe 2017

### What is our vision?

- Sustainability
- Evidence based
- Range of responses to need
- Develop partnerships and networks networks

*"When illness, death and grief strike people want to feel that they are part of a kind and compassionate nation"*

Taoiseach Enda Kenny



## Concluding points

- Bereavement care in palliative care involves support before, during and after death
- We need to value the role of bereavement support in palliative care
- Each palliative care service should have a range of responses to bereavement care
- We need to develop standards based on evidence
- We must develop networks and links with the communities we are based in - integration

**To all the staff and volunteers in St. Francis Hospice Dublin**

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