PALLIATIVE & END OF LIFE CARE

FAITHS , HEALTH AND WELLBEING SEMINAR
MAY 2017

Dr John Speakman

OVERVIEW

- A short history of palliative medicine and hospices
- Palliative medicine now and in the future
- End of Life Care in the UK - where are we now after the Liverpool Care Pathway ?

Palliative care – a definition

- **Palliative Care Defined**

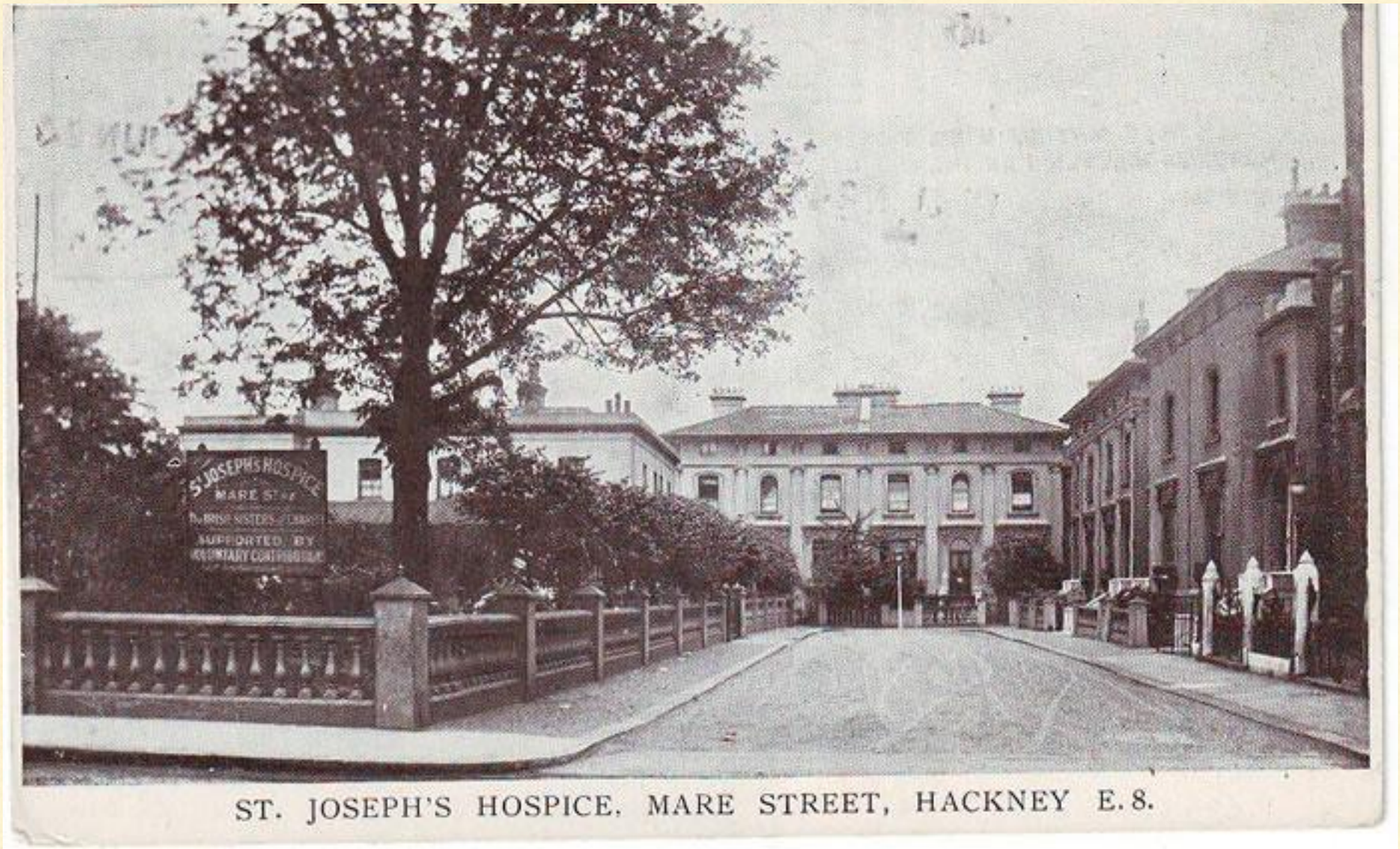
- Palliative care is part of *supportive care*. It embraces many elements of supportive care. It has been defined by NICE as follows:
- Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

- WHO 1990
- NICE 2004

Science and Charity

Doctors for the dying - Picasso and Munk

EARLY HOSPICES
UK 1900



ST. JOSEPH'S HOSPICE, MARE STREET, HACKNEY E. 8.


MISSIONARIES OF CHARITY
HOME FOR SICK AND DYING
DESTITUTES

A brief history

WE ARE MACMILLAN. CANCER SUPPORT

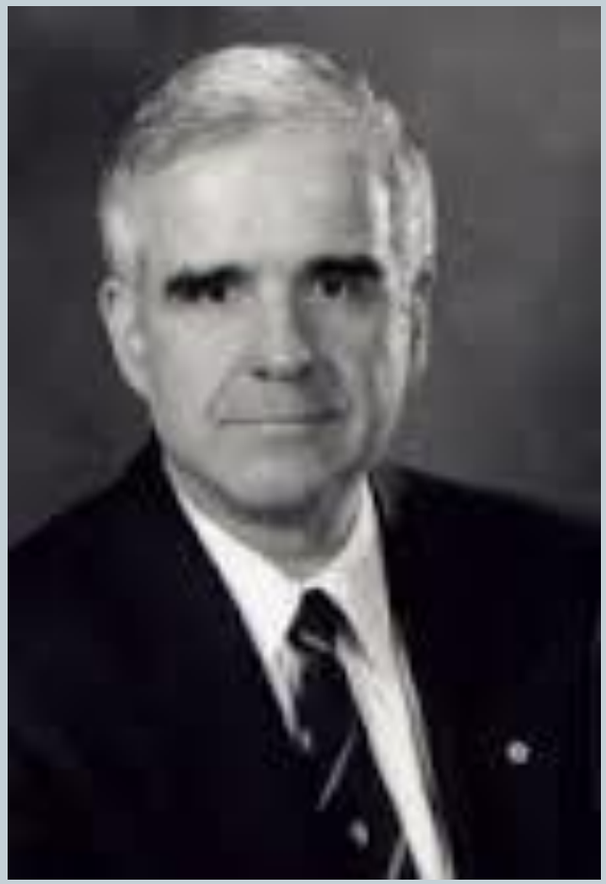
Marie Curie Cancer Care

St Giles hospice

St. Richard's Hospice CARING FOR LIFE

life changing. Birmingham St Mary's Hospice

Dr Balfour Mount



To ‘palliate’

- Make (a disease or its symptoms) less severe or unpleasant without removing the cause
- Allay or moderate (fears or suspicions)

Palliative chemotherapy / SACT

- Palliative Chemotherapy: No Longer a Contradiction in Terms : The Oncologist **December 1999** Vol 4 No 6 470-477
- V.R. Archer, L.J. Billingham and M.H. Cullen

What do we mean by ‘palliative patients’?

- ‘Palliative’ is now used interchangeably
- Palliative chemotherapy
- Palliative radiotherapy
- Palliative surgical procedures
- Many aspects of medical care are ‘palliative’ (dialysis ?)
- *‘they're palliative’*
- **Does this matter ?**

Who needs specialist palliative care ?

- Complex pain or other symptom control (this might be at any stage of illness)
- Complex psychological , psychosocial or spiritual support required for patient / family
- Complex issues regarding future care - this might include ethical dilemmas or e.g. care at home

3 DOMAINS

- Hospices (>200 in UK , average funding from NHS is only 30%)Growth has been unplanned and locally driven. Services can be variable. Terminology can be confusing.Limited beds. Short stay. Symptom control , ‘respite’ , care of the dying .

- Home (patient under care of GP)

- Hospital (some charitable contribution to hospital posts)

HOSPITAL PALLIATIVE CARE AT UHB

- 1800 referrals a year (v 700 in 2006)
- 70 % are cancer patients (v 92 % in 2006)
- Consultant x1
- Specialist nursing team
- Advisory and supportive role

THE FUTURE OF PALLIATIVE CARE ?

- More non cancer patients
- More supportive care / more proactive rather than reactive
- Enhanced links outside of hospital
- What is our role in the STP ?

END OF LIFE CARE

- Are we speaking the same language ?
- Hours / days ?
- Months ?
- Who decides ?

EOL CARE

- 500,000 deaths per year in UK
- Over 50% in hospital
- Most hospital deaths are expected
- Most people (80%) indicate they would prefer to die ‘at home’- however this is not necessarily their most pressing concern
- Good symptom control (pain) , being treated with respect and dignity and care for family members are often of more concern

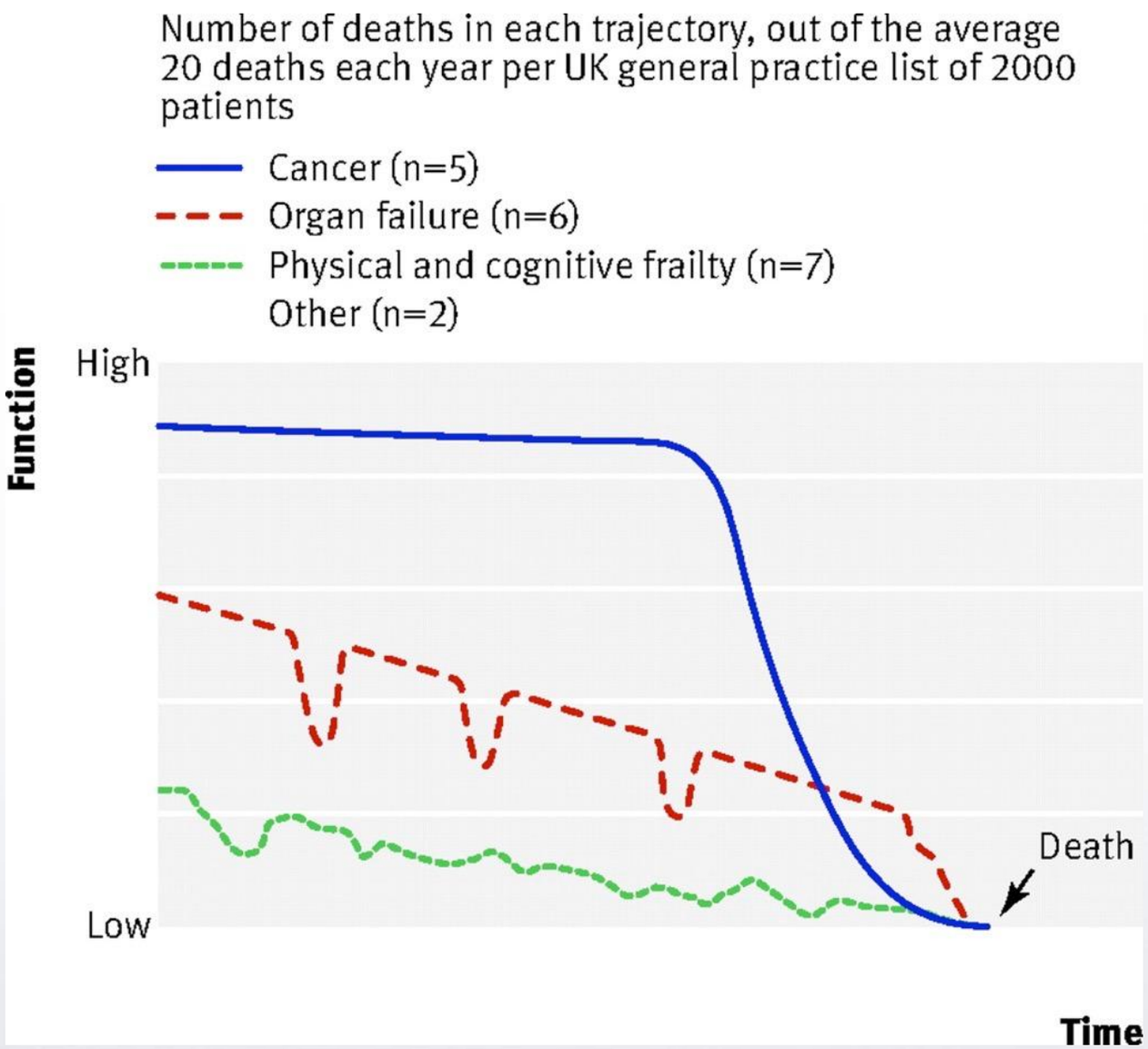
How sick are your patients ?

Imminence of death among hospital inpatients: Prevalent cohort study
Clark et al
Palliative Med **June 2014** vol. 28 no. 6 **474-479**

10,700 patients in 25 hospitals across Scotland on a given census date
Follow up over the next 12 months
29% died during follow up
32% of those who did not survive died during the index admission

At UHB when we repeated this study 32 % of patients died over a 12 month follow up period .

Cancer and non cancer



Death in the late 20th Century

- Most of us are dying in hospital rather than ‘home’
- Growing concern around the quality of care of the dying in hospital
- Evolution of the Liverpool Care Pathway

LIVERPOOL Care Pathway
Promoting best practice for care of the dying

- Widely used and recommended across the UK
- Nationally audited

LCP

- National End of Life Care strategy
- Quality marker and measure for end of life care
- GMC guidance on end of life care
- NICE quality standard

- Widespread use in NHS (and hospices …?) versions updated x12
- Support and training variable and locally led

What could go wrong ?

Cash incentive for NHS trusts that meet targets on Liverpool Care Pathway

HOSPITALS BRIBED TO PUT PATIENTS ON PATHWAY TO DEATH

Page 20 Mail 8/11/12 S1

'We weren't told dad was on death pathway'

Family's fury over controversial end-of-life plan

By **Will Lyon**

A PENSIONER died in horrific circumstances after he was put on the controversial Liverpool Care Pathway by doctors without his family's permission, it was claimed yesterday.

Diabetic Arthur Oszek, 86, was admitted to Ayr General Hospital hospital after a fall.

His stepdaughter Ann Murdoch, 65, was told he had been put on the Liverpool Care Pathway – a withdrawal of food and fluids – in a bid to let his body focus on medication to make his final days as comfortable as possible.

But Mrs Murdoch was furious that doctors had not asked for permission to put him on the Pathway and demanded he be allowed to fight for his life and taken off the plan.

After 20 hours of discussions, doctors agreed to restore Mr Oszek's food and drink – but by then it was

Distraught: Ann Murdoch

Suffered: Pensioner Arthur Oszek

manageress said: 'It was dreadful. He was taken into the hospital because he had a couple of falls and he was put on the drip.

'But then, after a number of days, he was suddenly taken off it and he was just begging for a drink.'

We demanded he be put back on his medication and eventually they agreed.'

Mr Oszek, a former miner from Ayr, died within 24 hours as his body was unable to recover.

Although the great-great-grand-

dying for 17 hours until the inevitable happened. No one should have to see their loved one needlessly die like that in front of them.

'You wouldn't even make a dog die like that. None of the doctors came in to check on his condition. In the end, we were dabbing a damp cloth over his cracked lips.'

She added that it was only when she heard of similar cases where people were put on the Pathway without consent that she felt she couldn't hold back her anger.

She said: 'We don't want anyone else to suffer what we suffered.'

Mandy Yule, director of integrated care and partner services at NHS Ayrshire and Arran, said it could not comment on Mr Oszek's case until an official complaint had been received from his family. She insisted it always consulted families before proceeding with the Liverpool Care Pathway.

She added: 'The Liverpool Care Pathway is an end-of-life care plan to ensure that patients in the last few days of life receive the quality of care needed.

'Communication with patients

LCP concerns

- Poor communication
- Nutrition and hydration at the end of life

Review findings and themes

- Terminology (end of life / dying / pathway or plan of care ?)
- Evidence base (diagnosing dying , drugs at end of life)
- Communication (relaying the ‘diagnosis’ and the uncertainties)

- Accountability (shared decision making and evidence to show this)
- Nutrition and hydration (support for oral intake to be normal practice, GMC /NMC guidance)
- Improving documentation (of communication between seniors and patients/ families)
- Training and education (from professional bodies , ugrad and pgrad)

NOW

- No more ‘pathways’ for end of life care
- Personalised care plans

- EOL care is part of the core business of hospital CQC inspections

Priorities for Care of the Dying Person

The Priorities for Care when it is thought that a person may die within the next few days or hours..

1. this possibility is recognised and *communicated* clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

2. Sensitive *communication* takes place between staff and the dying person, and those identified as important to them.

3. the dying person, and those identified as important to them, are *involved* in decisions about treatment and care to the extent that the dying person wants.

4. the needs of families and others identified as important to the dying person are *actively explored*, respected and met as far as possible.

5. an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion

EOL CARE - THE FUTURE

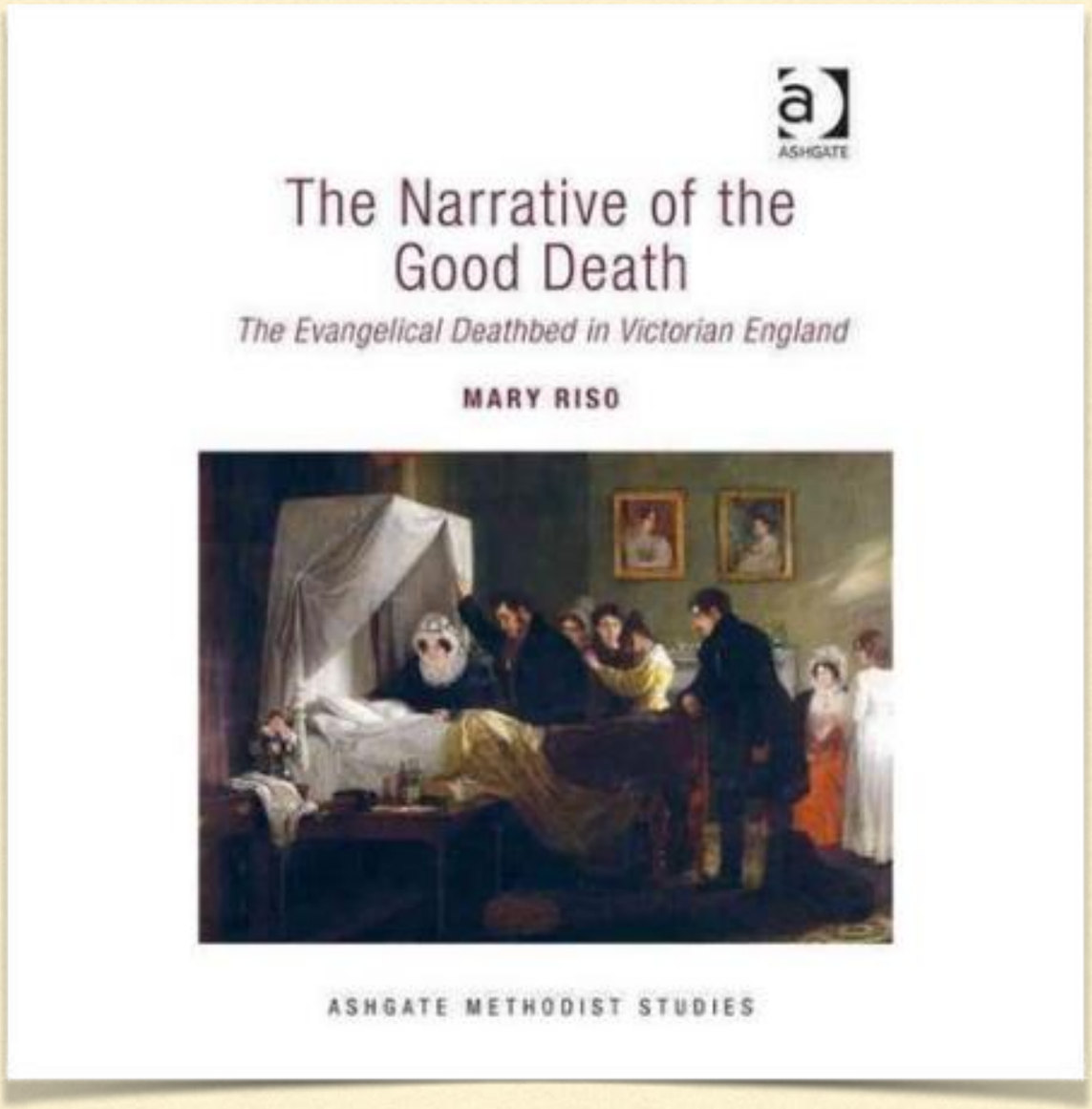
- More people to die at home rather than hospital (Is this a good thing ? Is this a better use of NHS resources ?)

- Better joined up communication / IT systems

EOL CARE -THE FUTURE

- Societal change
- Death cafes
- Dying matters / YODO
- Advance care planning (rather than advance care PLAN)
- ADRTs / LPA

EOL CARE - THE FUTURE



- Is a good death always possible?
- Or should we be happy with good enough ?

Bereavement survey at UHB

- Postal questionnaire 2-3 weeks after death- returns per year 600 (46% response)
- Ongoing concerns – 20 % report not being told ‘they may die’
- 20% felt they would have wished for more support from doctors
- Use of euphemism around death / dying
- 80 % of those who replied said they thought UHB was best or most appropriate place for their relative to die
- Leaflet and comfort care packs for relatives

THANK YOU

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