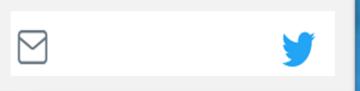
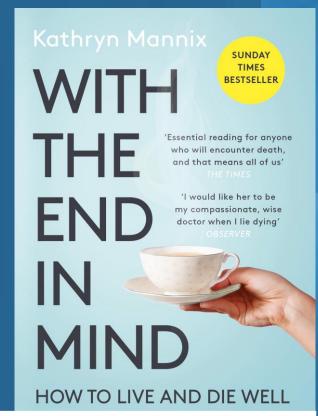
Recognising Dying: Why does it matter and how should we talk about it?

So here's a thing...



















So many messages...



Why didn't anybody tell us?

- What happens?
- That s/he was sick enough to die?
- That he wasn't suffering?
- That it was OK to bring the children?
- What the noises she made were caused by?
- That we had choices about the place of care?
- That death was very close?





Reclaiming the Forgotten Wisdom

- What happens?
- Is it painful?
- Will it frighten my family?
- Will I suffer?
- Who will support me?
- Who will protect my interests?
- Will I have any choices?



What does our end of life care workforce need?

Knowledge

Normal dying process

Phases and progression

Symptom management (or how to access)

When to get help

How to access and contribute to local ACP process

Skills

Communication

Tender conversations

Ability to sit with distress without seeking to solve, distract or reassure

Leadership

Attitude

Death is a normal event

Preparation is both possible and helpful

Sharing info enables calm

Sharing understanding brings families together



Normal dying

- A biological process with sequential changes that are fairly consistent from person to person (like birth)
- Associated with loss of energy, increased need for sleep, reduced appetite and thirst
- Sleep as an 'energy aid'
- Gradual, unnoticed onset of intermittent unconsciousness
- Continuing unconsciousness with periodic (brain-stem) breathing
- Gradual reduction in blood pressure and peripheral perfusion (cold hands, dusky nails, cold nose)
- Cessation of breathing
- Heart stops last. This is NOT a 'cardiac arrest' situation.

Dealing with uncertainty in Acute Medicine

- What's the diagnosis?
- What's making him/her so sick?
- What's reversible?
- How reversible?
- Is there an outcome worse than death?

- What does he/she know?
- What are his/her wishes?
- How much disability is s/he prepared to tolerate?
- What's more important to him/her, quality of life or length of survival?



Useful concepts

Is death a possible outcome?

What would 'dying well' look like?

Parallel planning: restorative & EoL care at the same time

Pre-sedation pause for communication

Helpful phrases

"Sick enough to die..."

"In case we can't reverse this..."

"If s/he's sicker by tomorrow, what might we wish we had done today?"

"What do you know about dying?"



Dying safely

• Familiarity - people more than place

Autonomy – a sense of still mattering, being a person, being valued

Good symptom control

 Covid lessons: how to enable a sense of continuity in the person's story



How do we enable change?

- This is a public health issue
- It requires a change of public understanding
- It requires leadership and political will, more than funding or strategic change

- It needs to capture the public imagination...
- ... and that means stories more than data.



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THE LANGUAGE OF-**KINDNESS**

> A Nurse's Story

CHRISTIE WATSON

It made me cry. It made me think. It made me laugh." ADAM KAY author of This is Going to Hurt

> Marie Curie



SHERWIN B. NULAND

With a New Foreword by Paul Kalanithi

Reflections on Life's Final Chapter



'As powerful and sensitive as anything I have ever read' Oliver Sacks

We need true stories, told well, in accessible formats, from a variety of sources, until the truth of 'Normal Dying' is re-established, and nobody remembers how they know. They just know.







It's time to reclaim the Forgotten Wisdom

How will you lead the way?

What can you do tomorrow, next week, next month that will change the way we think and talk about dying?



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