

UW ECHO in Geriatrics

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Talking about Death Won't Kill You

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Objectives:

- Identify the difficulties in talking about death
- Define hospice care
- Identify the benefits and limitations of hospice
- Recognize the tensions of choosing hospice
- Suggestions for addressing patient and family expectations
- Provide ideas for starting the conversation

Why is talking about death so hard?

- We must face our own mortality
- We don't feel prepared
- We have thoughts that talking about something will make it happen (to “jinx” it or magical thinking)
- We don't want to upset our loved ones

Hospice Background

Dame Cicely Saunders, founder of the first modern hospice England, 1967

“You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.”

Focused on the patient, not the disease

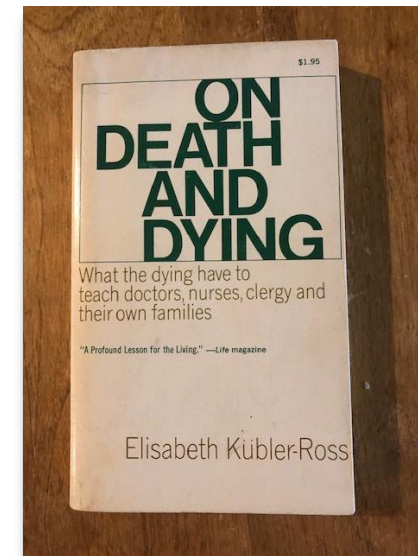
Introduced the idea of “total pain” which included psychological, spiritual and physical discomfort



Elisabeth Kübler-Ross

- Psychiatrist and pioneer of the death-and-dying movement.

In her groundbreaking bestseller *On Death and Dying*, (1969) Elisabeth Kübler-Ross overturned how physicians and medical professional treat dying patients.



Benefits of Hospice care

Medicare Hospice Benefit (and most other insurance)

- The hospice team: RNs, SW, Aide, Chaplain, Medical Director
- Provides medications for pain and symptom management
- Provides durable medical equipment and oxygen
- Service is provided in the patient's home, long-term care, assisted living or a group home
- The patient is not required to be homebound
- Bereavement support for the patient's family

Limitations of Hospice Benefit (and other insurance)

- Hospice does not provide 24-hour care, nurses are available “on-call” for consultation or a home visit
- Families or friends are expected to provide the day-to-day care
- Hospice facilities are often expensive for the daily rate
- The patient’s PCP or the oncologist is no longer consulted
- Hospice care varies from place to place, town to town

Janie: A case study

Clinical information

- 74 yr old female with no chronic conditions
- Diagnosed with stage 3 pancreatic cancer 6 months after the death of her husband (April 2021)
- Worked part-time at the local hospice providing harp music to patients
- Under the care of Oncology at Mass General in Boston
- Elected to have aggressive chemotherapy and surgery

At the beach on Cape Cod



Why is it so hard to accept hospice care?

I don't want to give up. I want to say I fought the cancer to the end!

I don't want to disappoint my family

I don't want to give up hope for a miracle.

I'm not dying - yet!

I don't want to leave my loved ones

What are other reasons for
avoiding hospice?

Type your answers in the chat box!

What matters in end-of-life care?

- How comfortable do you want to be?
- What are your fears or worries for the future?
- What are your goals or priorities?
- What would a good day look like?
- How do you want to be treated?



How do you start the
conversation?

(Zoom Poll)

Janie: the rest of the story

From a text message on August 25, 2021

“I long for a stretch of days—5? 6?—with no hassle, no doctors, nothing hurting.

Need to tell you that I called Boston and canceled the Whipple surgery. I’m working on getting hooked up with hospice, my coterie of buddies over there in Chatham. I’m not scared of death and dying, but I am scared of the Whipple. I’ve spoken with some nurses who confirm my fear that it’s not easy for some patients. And recovery can be lengthy with setbacks.”

- Janie died October 13, 2021, at her home on Cape Cod surrounded by friends.



Resources:

- Byock, Ira. *Dying Well: Peace and Possibilities at the End of Life*. Riverhead Books, New York NY 1997
- Gawande, Atul. *Being Mortal (Medicine and what Matters in the End)*. Metropolitan Books, New York NY 2014
- Kübler-Ross, Elisabeth. *On Death and Dying (What the dying have to teach doctors, nurses, clergy and their own families)*. The MacMillan Company, New York, NY 1969
- Morris, Virginia. *Talking About Death Won't Kill You*, Algonquin Books of Chapel Hill NC 2001
- [Why We Don't Talk About Death \(But Should\) - Legacy.com](#)
- **Article: Goals of Care.** [Julie W. Childers, MD¹](#) . JAMA. 2022;327(15):1449-1450. doi:10.1001/jama.2022.4619





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