TALKING ABOUT DEATH WON'T KILL YOU

Kevin Bezanson & Kathy Kortes-Miller

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Potential Conflicts of Interest

Speaker: Dr. Kevin Bezanson

Relationships with commercial interests:

- Grants/Research Support: Research for Health In Humanitarian Crises (Non-Profit)
- Speakers Bureau/Honoraria: Pallium Canada LEAP Facilitator (Non-Profit)
- Consulting Fees: None to declare
- Other: None to declare

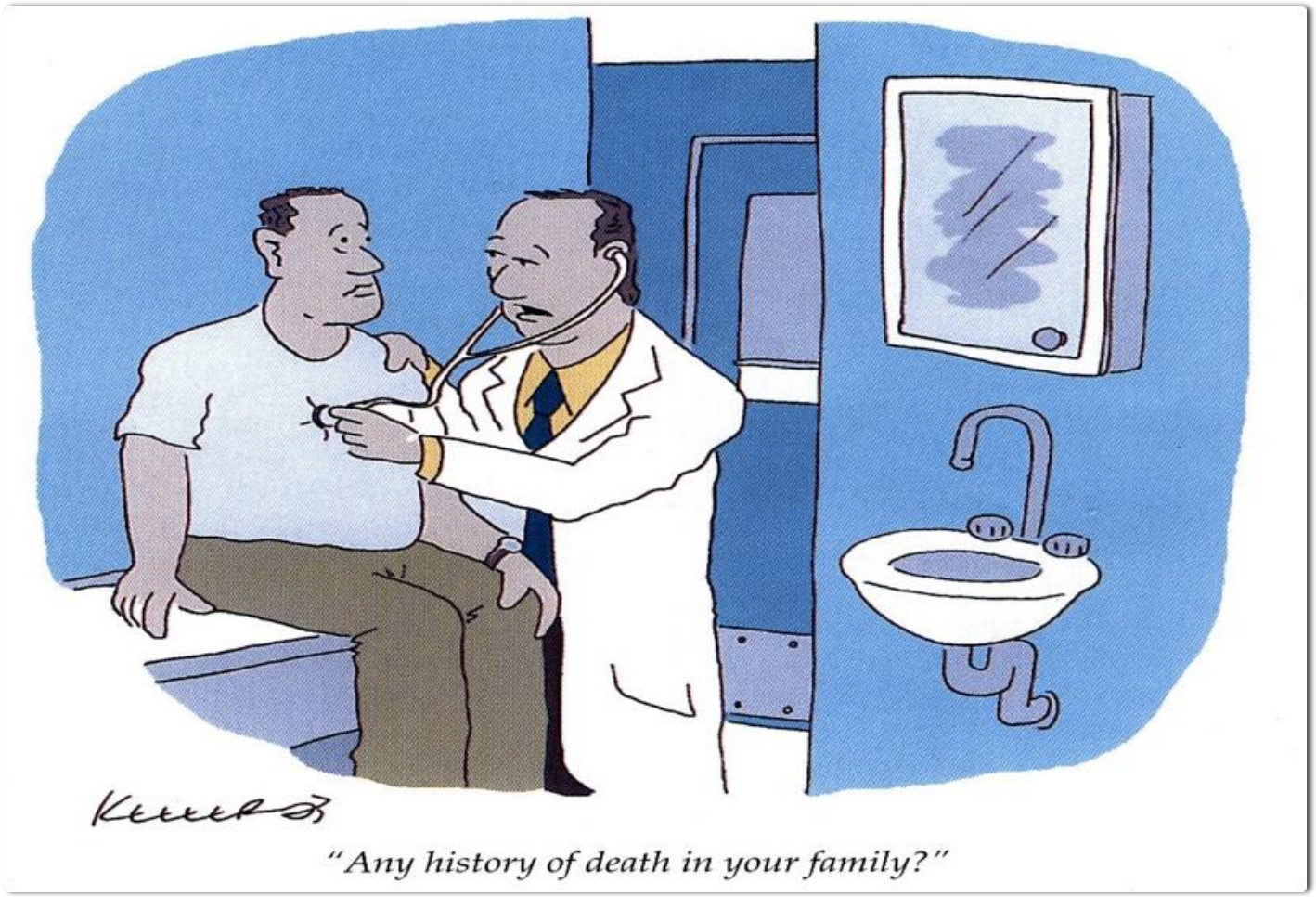
Potential Conflicts of Interest

Speaker: Dr. Kathy Kortes Miller

Relationships with commercial interests:

- Grants/Research Support:
- Speakers Bureau/Honoraria: Pallium Canada LEAP Facilitator (Non-Profit)
- Consulting Fees: None to declare
- Other: Wrote and published a book (ECW Press) with the same name as this presentation in March 2018

The Why



The prevalence of human mortality is stable

We know who dies, when and where…

RESEARCH

What matters most in end-of-life care: perceptions of seriously ill patients and their family members

Daren K. Heyland, Peter Dodek, Graeme Rocker, Dianne Groll, Amiram Gafni, Deb Pichora, Sam Shortt, Joan Tranmer, Neil Lazar, Jim Kutsogiannis, Miu Lam, for the Canadian Researchers, End-of-Life Network (CARENET)

An abridged version of this article is available in the Feb. 28, 2006, issue of *CMAJ*.

- 5 hospitals across Canada
- face-to-face questionnaire to older patients with advanced cancer and chronic end-stage medical disease and their family members
- n = 440 patients 55+ yrs with 50% likelihood of dying in next 6 mo.
- 160 relations

Perspective of Families: Top 5 Important Issues

1. To have trust and confidence in the doctor looking after the patient
2. To not have your family member be kept alive on life support when there is little hope for a meaningful recovery
3. **That information about your family member's disease be communicated to you by the doctor in an honest manner**
4. To have an adequate plan of care and health services available to look after him or her at home, after discharge from hospital
5. That your family member has relief of physical symptoms such as pain, shortness of breath, nausea

Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., ... & Lam, M. (2006). What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal*, *174*(5), 627-633.

Do conversations about EOL harm families?

NO!

If physicians discussed EOL options/the future with patients, bereaved families reported:

- Higher satisfaction with communication from physician, comfort of patient
- Better understanding of “what to expect” as family member died
- Significantly associated with fewer aggressive medical interventions
- Twice as likely to rate their care as “the best imaginable”

Teno J et al. JAGS 2007. Engel SE et al. JAGS 2006.

Brighton, L. J., & Bristowe, K. (2016). Communication in palliative care: talking about the end of life, before the end of life. Postgraduate medical journal, postgradmedj-2015.

Outcomes of EOL discussions

Patients who have EOL discussions with their doctors *More* likely to:

- Have an advance directive
- Understand illness terminal
- Die at home
- Have EOL choices followed (i.e. DNR order)
- Choose hospice
- Improved QOL for EOL patients (Sx relief, MD communication, emotional support, being tx with respect)
- Decreased Major Depression in Bereaved Caregivers

Less likely to:

- Have a feeding tube

Wright et al. JAMA 2008

“You generally don’t die well
if you don’t know you are dying”

Who's Job Is It?...After You

- Patients demonstrated varying degrees of reticence, evasion or reluctance to initiate any conversations about end of life care preferences.
- Most assumed that staff would initiate such conversations, while staff were often hesitant to do so.
- Staff-identified barriers: taking away hope and issues of timing.
- Staff were often guided by cues from the patient or by intuition about when to initiate these discussions.

Almack, K., Cox, K., Moghaddam, N., Pollock, K., & Seymour, J. (2012). After you: conversations between patients and healthcare professionals in planning for end of life care. *BMC palliative care*, *11*(1), 15.

After You means…

- Fewer than 40% of patients with Cancer
- Only 15% of people with COPD
- 10% of people with chronic kidney disease

Brighton, L. J., & Bristowe, K. (2016). Communication in palliative care: talking about the end of life, before the end of life. *Postgraduate medical journal*, postgradmedj-2015.

Fire Fighting

- https://www.youtube.com/watch?v=BbNi_-wYXJE&feature=share&fbclid=IwAR1WlF_z7nr2JJsGhknUuQ8FjtBfw9r91AllzvQzonCmHnj8OmGNWBFFKSs

Do we do a good job of discussing the future?

As a profession – no. Why not?

- Perceived Lack of Training
- Stress
- Take away hope
- No time to address emotional needs
- Harm patients (they'll give up and die sooner)
- Hurt our relationship with the patient
- What if we're wrong? Uncertainty about prognosis
- It's emotionally difficult for us
- Explicit requests by patient/family not to discuss

This is despite strong evidence patients benefit from this and consistent evidence they want to talk about it!

Hancock Palliat Med 2007.

Components of Health Care Decision Making

Components of person-centred decision-making

ACP= if in the future a patient loses capacity to make a decision, prepares SDM(s) for decision-making with guidance from expressed wishes and values

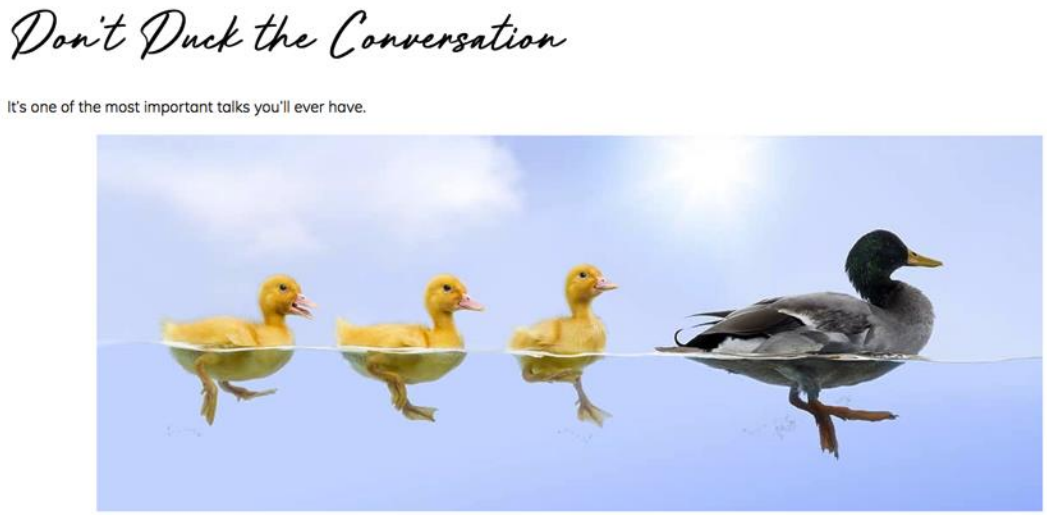
GOC=prepare for decision-making by learning patient's views on their clinical picture, his or her goals for their care, how values & goals align(or not) with approach being considered

Why is ACP important?

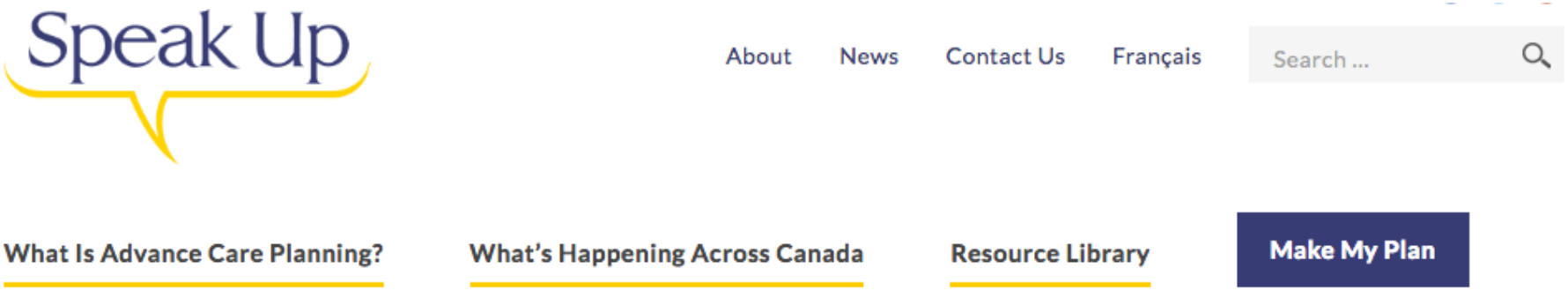
Individuals who engage in advance care planning and/or appointed a substitute decision maker:

- Much more likely to have their end-of-life wishes known and followed
- Family members had significantly less stress and depression
- More satisfied, as were their families and substitute decision makers
- Fewer life-sustaining procedures and lower rates of intensive care unit (ICU) admissions
- Better quality of life and death
- Less costly care in last weeks of life

https://www.speakupontario.ca



https://www.hospicenorthwest.ca/resources/dont-duck-the-conversation/



https://www.speakupontario.ca

“No news is not good news, it is an invitation to fear.”

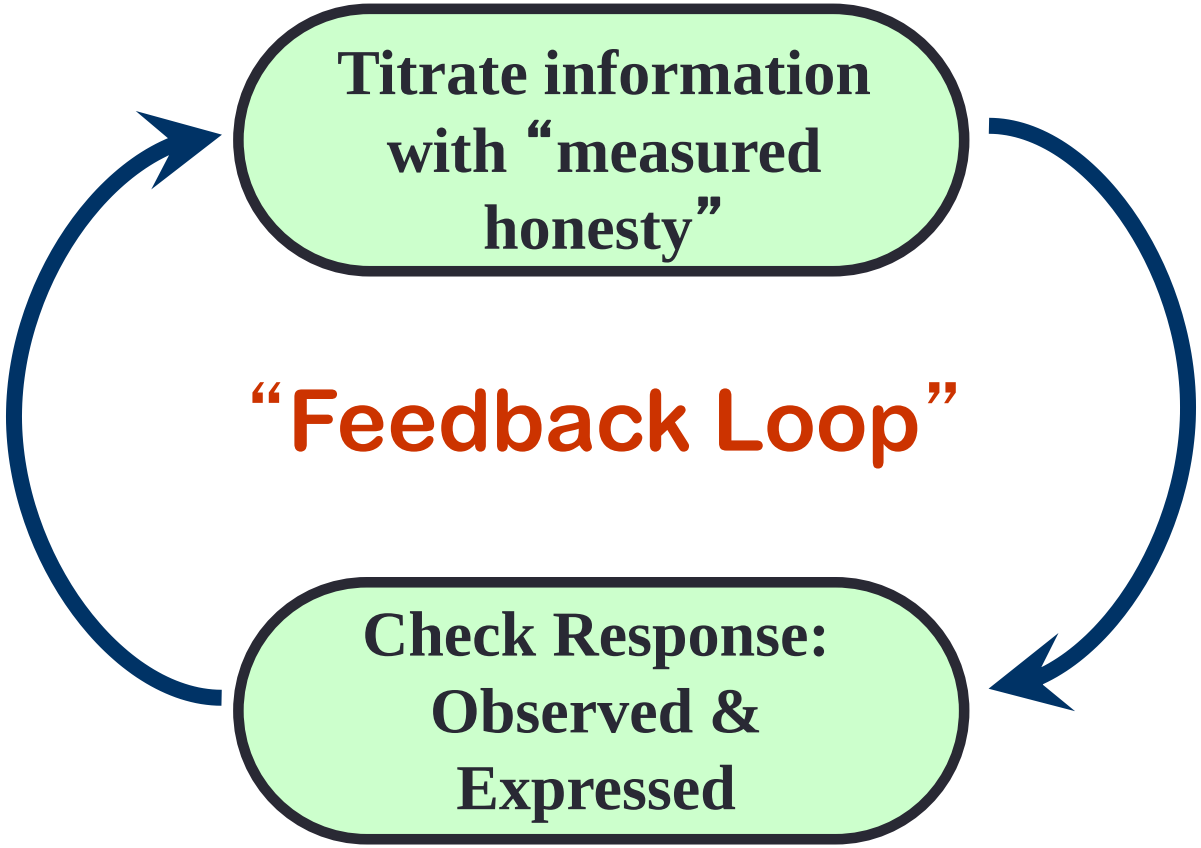
- CM Fletcher


See, Bernard? Julia's approach was just that tad more sensitive. OK- so who wants another crack at breaking the bad news?
Millard

SPIKES: Robert Buckman

- STEP 1: SETTING UP the Interview
- STEP 2: Assessing the Patient's PERCEPTION
- STEP 3: Obtaining the Patient's INVITATION
- STEP 4: Giving KNOWLEDGE and Information to the Patient
- STEP 5: Addressing the Patient's EMOTIONS with empathic responses
- STEP 6:SUMMARY and STRATEGY

doi: 10.1634/theoncologist.5-4-302
The Oncologist August 2000 vol. 5 no. 4 302-311



The response of the patient determines the nature & pace of the sharing of information

The Dr. Mike Harlos Feedback Loop

"*An expert in breaking bad news is not someone who gets it right every time – he or she is merely someone who gets it wrong less often, and who is less flustered when things do not go smoothly.*"

Robert Buckman

“The real question is not ‘what do you tell your patients?’ but rather ‘what do you let your patients tell you?’”

Dame Cecily Saunders

Key Communication Techniques

- Ask open-ended questions
- Use nonverbal cues (nods, “uh-huh”)
- Provide empathic responses
- Use repetition
  - Repeats back to the patient what they said. Used to prove listening.
- Use paraphrase
  - Your summary of what the patient said. Used to ensure understanding.
- Confront emotions…yes, even difficult ones (anger)
- Summarize

“The best way to talk about dying is to talk about living”

ATUL GAWANDE
FROM THE BOOK “BEING MORTAL”

Starting off Question

What do I need to know about you to provide you with the best care possible?

Dignity Therapy

Chochinov, H. M. (2008). Dignity. Dignity? Dignity!. *Journal of palliative medicine*, *11*(5), 674-675.

Communication

- Patients are entitled to expect that those who care for them, will be able to listen, to explain and to communicate with them.

- Patients are also entitled to expect that healthcare professionals will be able to communicate effectively with each other.

- Whatever the circumstances, the need for good communication is constant and is integral to good **care**.

Communication

- Patients look to us for knowledge, guidance, reassurance, hope, meaning, and compassion.

- Patients know we have been through similar situations with other patients and look to us for guidance and what is“normal”.

The single biggest problem in communication is the illusion that it has taken place

-George Bernard Shaw

Fears about communication for the healthcare provider:

- Fear of being blamed (blame the messenger)
- Fear of the untaught
- Fear of eliciting a reaction (tears, anger)
- Fear of saying “I don’t know”
- Fear of expressing emotion (crying)
- Fear of medical hierarchy
- Fears and anxieties about their own death

Hope ≠ Lying

- Focus on hope and what CAN be done.
- Explore other goals besides cure.

  "Knowing what you now know…

  What would be most important for you at this time OR

  How can you make the time you have the best possible?"

Initiating Conversations

1. **Normalize**

   "Often people in circumstances similar to this have concerns about _____"

2. **Explore**

   "I'm wondering if that is something you had been thinking about?"

3. **Seek Permission**

   Would you like to talk about that?

Words Make A Difference

MAID vs. Palliative Care

“Do Not Resuscitate” vs. “Allowing a Natural Death”

“Want us to do Everything” vs. “Focus on Comfort”

Improving our cultural competence

- Recognize family and community members in decision making wherever they are located (not just POA)
- Sit down
- Introduce everyone in the room before beginning a conversation
- Use Indigenous Navigators wherever possible
- Create spaces for listening

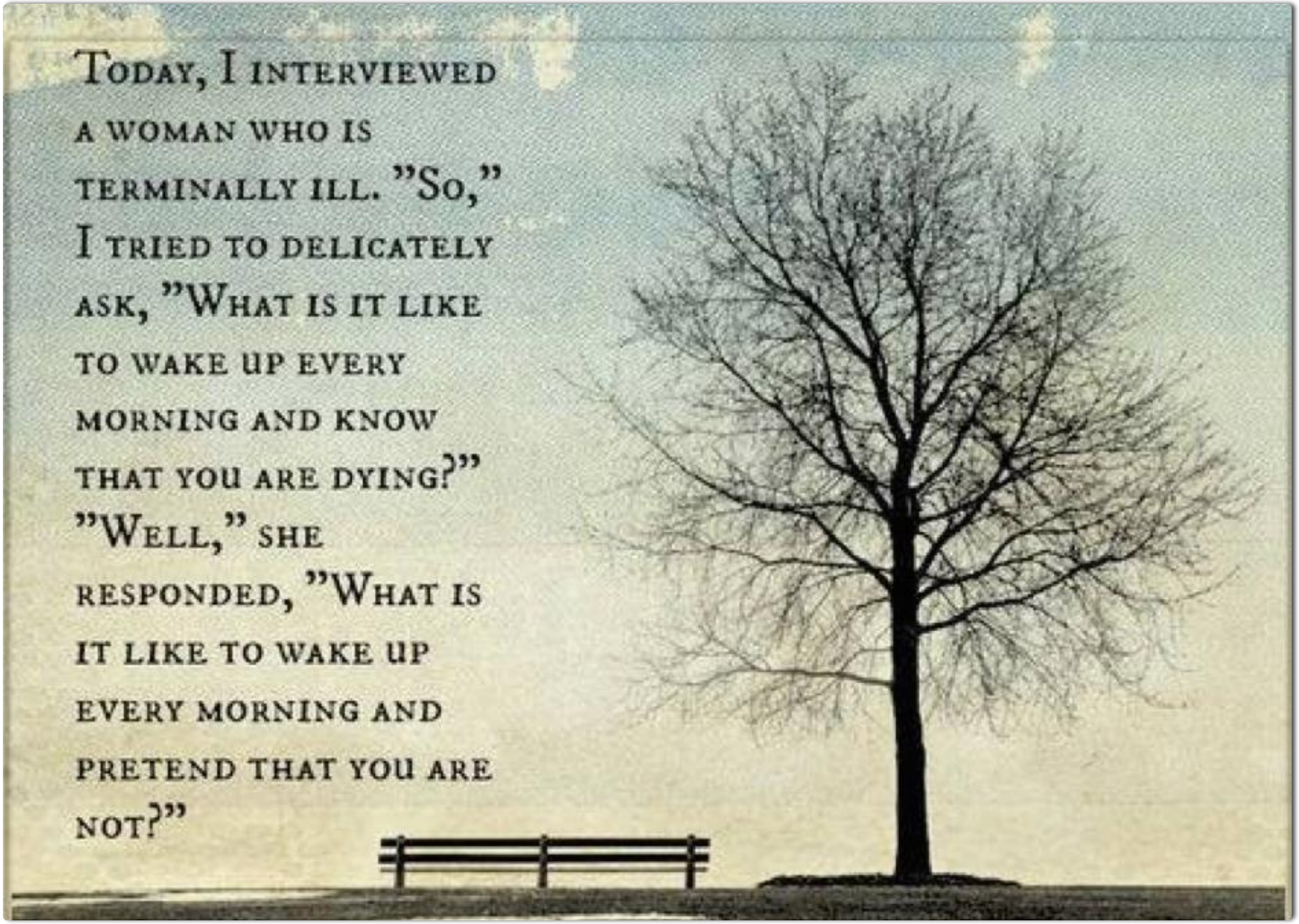
Request for Hastened Death

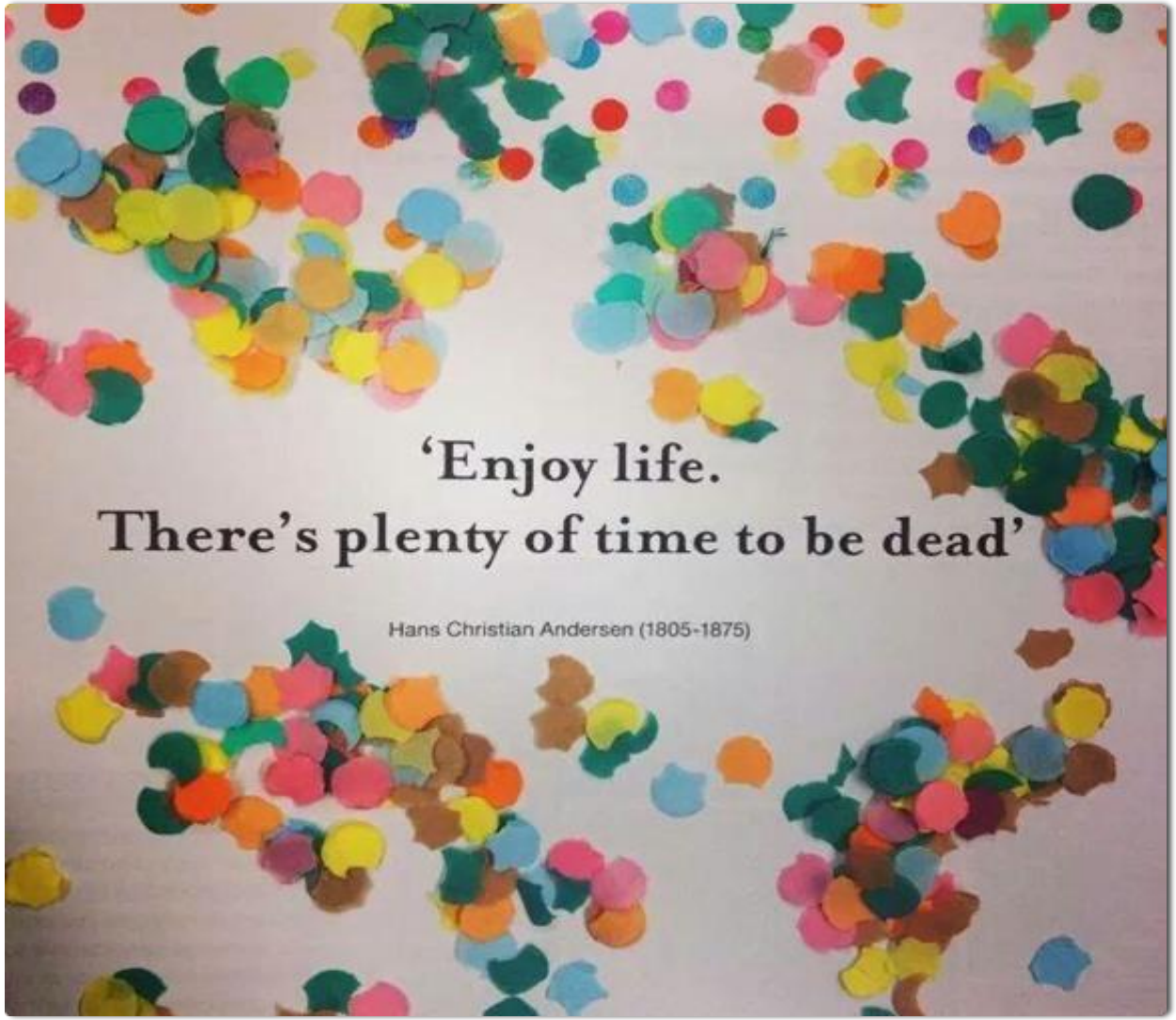
Not an automatic and immediate referral for MAID!

Not an automatic and immediate referral for Palliative Care!

AN INVITATION & OPPORTUNITY TO EXPLORE SUFFERING/NEEDS AND

UNDERSTANDING/ GOALS OF CARE…


TODAY, I INTERVIEWED A WOMAN WHO IS TERMINALLY ILL. "SO," I TRIED TO DELICATELY ASK, "WHAT IS IT LIKE TO WAKE UP EVERY MORNING AND KNOW THAT YOU ARE DYING?" "WELL," SHE RESPONDED, "WHAT IS IT LIKE TO WAKE UP EVERY MORNING AND PRETEND THAT YOU ARE NOT?"


'Enjoy life.
There's plenty of time to be dead'
Hans Christian Andersen (1805-1875)

Who Dies – James Keelaghan

Who Dies?

Everyone Dies.

Oh Everyone Dies!

Who Dies – James Keelaghan

My nephew once asked me when he was quite young

Who dies? Everyone dies.

No use denying it, one day you're gone…

Oh everyone dies

Princes and paupers, there's no one immune

and no one who'll escape their demise

So you'd better make use of each day that you're given…

Oh everyone dies

Who Dies – James Keelaghan

Now people have pondered this time and again

Who dies? Everyone dies

We suspect that we're more than mere mortal remains…

Oh everyone dies

Wise men and prophets they've all had their say

on the nature of our afterlives

But in case there's no beer there we'll have one more round…

Oh everyone dies

Who Dies – James Keelaghan

Your time may be short or your time may be long

Who dies? Everyone dies

But its going to happen as sure as you're born…

Oh everyone dies

Friends and relations and all we hold dear

will one day pass to the other side

So we'd better embrace them as long as they're here…

Oh everyone dies