

End-of-life care for persons living with dementia- Applying Palliative Care Principles

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Learning Objective

By the end of the session, learners will be able to:

- integrate palliative care principles into care of patients with dementia
- incorporate goals of care discussions throughout the trajectory of illness
- list resources to help with care and education

Back in 1983

“Dr. Hilfiker was called in the middle of the night for a patient with advanced dementia who had developed a fever. On examination, he diagnosed pneumonia, and then had a sobering dilemma. Having known the patient for many years, even before the onset of dementia, Hilfiker's “human sympathies” told him that the patient had a “desire to die.” His bleary-eyed choice was to either send her to a hospital for aggressive treatments, “toxic antibiotics,” intravenous hydration, and more “heroics” that would potentially cure her pneumonia but cause discomfort, or treat her in the nursing home with its limited resources.

How do you define palliative care?

pal - lee - uh - tiv

PALLIATIVE CARE ?

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? ? ?

WHY HAVE I BEEN OFFERED THIS?

Palliative Care is a gentle & distinct approach to caring for people with illnesses that can't be cured (like advanced heart lung, kidney and neurological diseases, and advanced cancer.)

It doesn't mean that you have days to live! The earlier you have contact the easier it is for you to access a range of services, equipment & expertise to make life more COMFORTABLE.

#@?! **I'M NOT READY TO DIE JUST YET!**

BUT I'M STILL HAVING TREATMENT!

Palliative Care works **ALONGSIDE** your specialists to make sure all aspects of your illness are managed to best suit you.

If you have ANY CONCERNS, talk to your DOCTOR and/or PALLIATIVE CARE TEAM

Is palliative care a death sentence?

BETTER OUTCOMES WITH EARLY PALLIATIVE CARE:

Fewer days in hospital in the last two weeks of life:



More likelihood of a non-hospital death:



PEOPLE DYING FROM NON-CANCER CAUSES WERE MUCH LESS LIKELY TO GET EARLY PALLIATIVE CARE:



Qureshi D. et al. *Palliat Med.* 2018.

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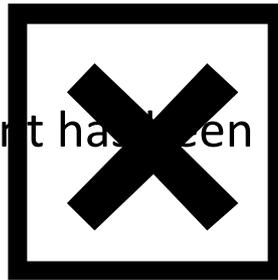


LESS LIKELY TO GET EARLY PALLIATIVE CARE: PEOPLE DYING FROM NON-CANCER CAUSES WERE MUCH

W h a t i s
P C ?

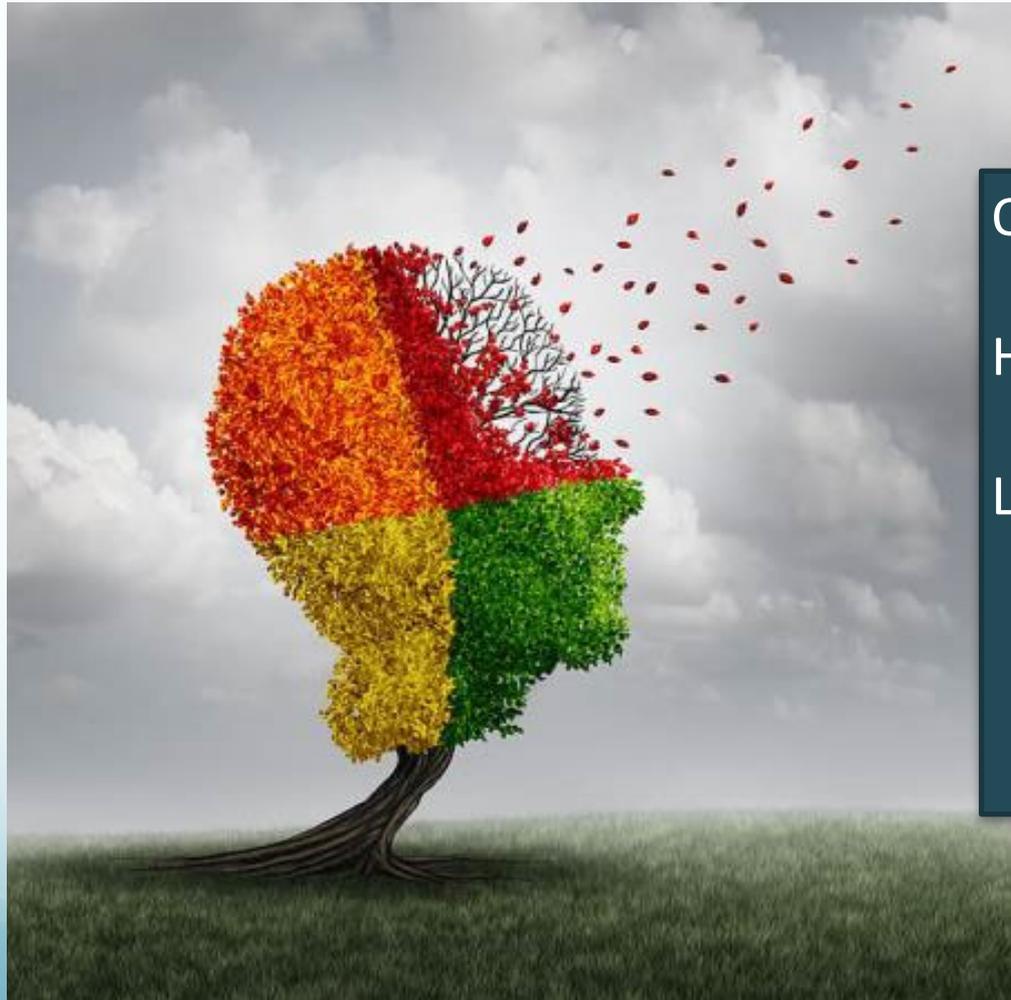


An approach to care. It is
NOT: a time, a place, a
state of being



“This patient has been made palliative”

Palliative care in dementia: Is there an issue?



Often not considered terminal

High hospitalization rates

Less pain control, palliative measures

Palliative Care in Dementia

2013 EAPC'–

Dementia is
a terminal
illness



Knowing
this= greater
comfort in
the dying
process

- [White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care - PubMed \(nih.gov\)](#)
- “Improving quality of life, maintaining function and maximizing comfort...throughout the disease trajectory.”

“Dignity- conserving therapy”



illness-related concerns that impinge on
the patient's sense of dignity goals



dignity-conserving repertoire pertaining to
the patient's psychological make-up and
spiritual beliefs



social dignity inventory

How can we help (earlier?)

- Reframe dementia as a chronic *AND* life limiting illness
- Assess willingness to talk about the disease trajectory
- Consider practical examples of choices, rather than abstractions
- Elicit patient preferences and values early in the course
- The family is part of the ‘unit of care’



Nathan Stall 🇨🇦 @NathanStall · Mar 26

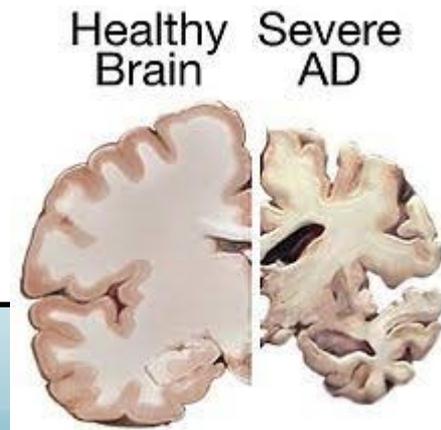
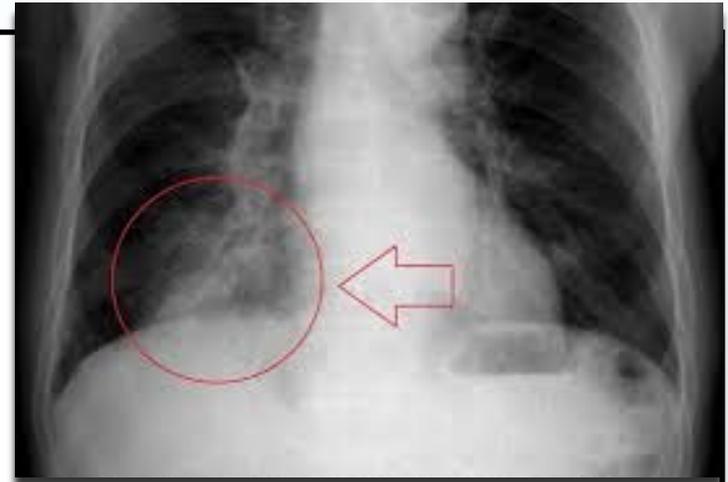
Dying With Dementia: Underrecognized and Stigmatized

"Despite the high prevalence of dementia at the end-of-life, discussions about dementia rarely acknowledge its terminal nature".

Important editorial in @AGSJJournal: onlinelibrary.wiley.com/doi/10.1111/jg...

[@kieranleung](#) [@GerPalBlog](#) [@EMWiders](#)

Hard reality



How we can help

- Focus on maintaining or improving QOL
 - PC principles for treating reversible illnesses
- Normalize decrease in PO intake early
- Not ‘if’ they will aspirate again, it’s ‘when’,
 - “what will we do next time?”
- "Sitting with their suffering"

The Code Status



Goals of Care are more important!

Discussing Goals of Care

- The surprise question

Guiding data:

- pneumonia = 47% 6 mo. mortality rate;
- febrile episode = 45% 6 mo. mortality rate;
- eating problems = 39% 6 mo. mortality rate

G Tubes



- Early vs Late dilemma
- [Feeding Tubes for People with Alzheimer's Disease: When you need them – and when you don't - Choosing Wisely Canada](#)



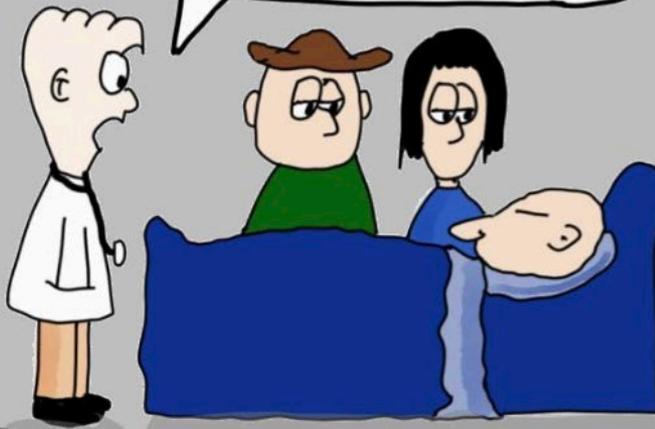
‘Unfortunately, your loved one is not eating because they are dying. They are not dying because they are not eating’

- Your role: **start early, be honest about experiences with tubes (bad and good?)**

STOMACH FEEDING TUBES IN ADVANCED ENDSTAGE DEMENTIA

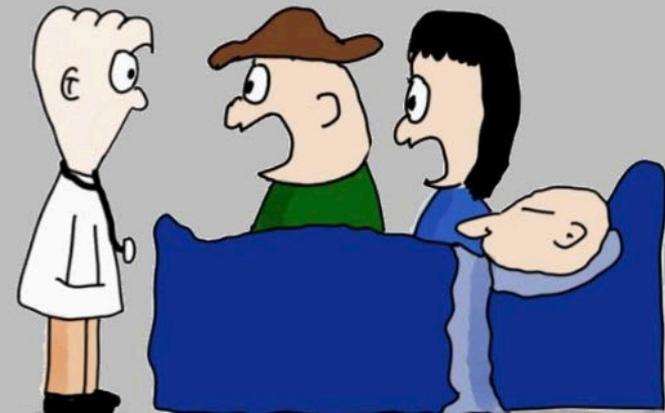
Clinicians

- He has a limited life span.
- A feeding tube will not change that.
- He could die under anesthesia.
- He could get an aspiration pneumonia.
- Tubes can become infected.
- They can be uncomfortable.
- He could pull it out which is very painful.
- They do not actually improve nutrition.
- They do not improve quality of life .
- We don't recommend it.



The public

DO IT!!!!



PC approach: LTC/Frailty/Dementia

- Hospital admissions prevention
- “Palliative care content” in order sets
- No effect on survival (QOL??)

What is the PATH

When you are participating in health care decisions, it is important to ask the following questions:

- [FACT form](#)

	Yes	No
Could treatment worsen quality of life?		
Could the treatment worsen function or memory?		
Is it possible that the person will not be able to return home and will need to move to a nursing home after treatment?		
Are there options for minimizing symptoms including pain?		

“The last 24 hours”- what to expect



Confusion

Manage based on goals



Congestion

Often worse for family than patient



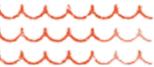
Skin changes

Mottling may be indicative



Breathing changes

Apnea and agonal breathing



Grief comes
from loss

Alzheimer Society



AMBIGUOUS LOSS AND GRIEF IN DEMENTIA

A resource for individuals and families

A resource for individuals and families



I c a n ' t g o
o n , I ' l l g o o n



The Old English word for
grief, heartsarnes, literally
means soreness of the heart;



You are gone.

Three words. And not one
of them
exists now in any

other context.



I measure every Grief I meet
With narrow, probing, eyes –
I wonder if It weighs like Mine –
Or has an Easier size.



W h a t d o y o u
t h i n k a b o u t
M A I D

What about palliative sedation?

MAiD and frailty- MAiD and dementia

- the average age around 75 years
- Dementia diagnoses 4% of cases
- “Multiple comorbidities” 7.8% (2023)
 - frailty (no definition given), osteoporosis, osteoarthritis, or fractures
 - Netherlands Annual Report, “multiple geriatric syndromes” was approximately 2%

Track 1 versus 2

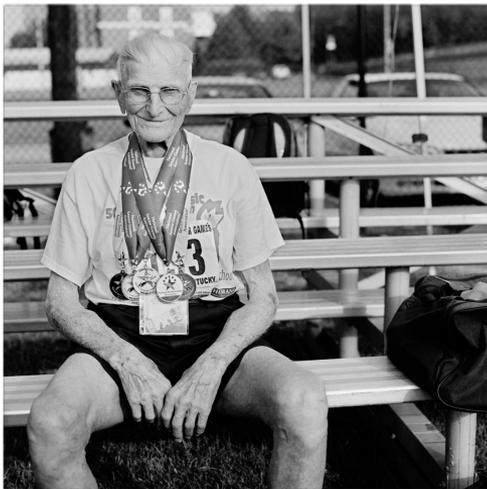
- [2.+MAID.pdf \(squarespace.com\)](#)

Issues:

- RFSD versus Not...
- Capacity
- Consent and “10 minutes to midnight approach”

Final Thoughts...

- **Atul Gawande – “...it’s not about a good death, but a good life, lived right to the very end.”**



Haikus about Frailty & Dementia

Old Man in Office

Trying to get out of our chair

We need some new ones

Old folks home
how are you today mum?
who are you dear?





I know what you want. I know what Daddy wants. I know what my sister wants. But I know what I want, and I want to

STAY RIGHT WHERE I AM.

IS THAT CLEAR?!