

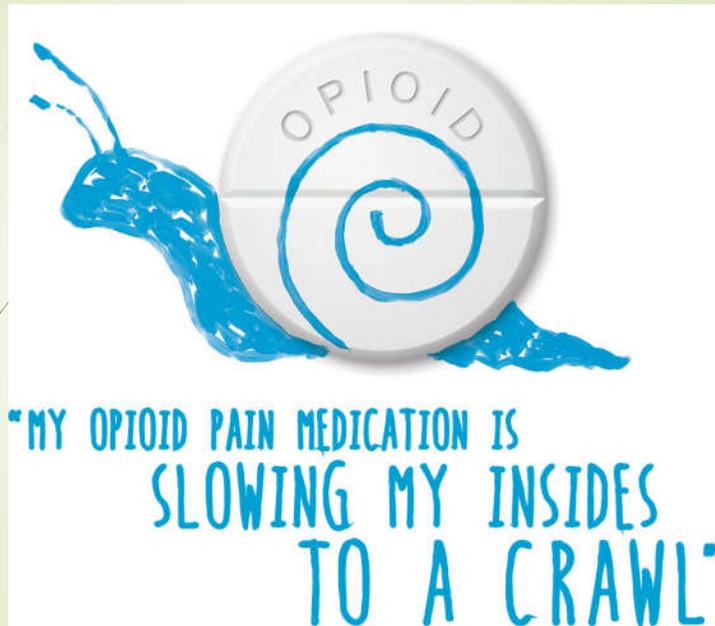
Innovations in Palliative Care

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Objectives

At the end of the talk, participants should be able to:

- ◀ Distinguish between palliative care and hospice care
- ◀ Implement one new language skill to communicate difficult information to patients/families
- ◀ Identify opportunities and strategies for initiating palliative care in your practice and reasons for doing so



Case 1

- ◀ Patient with bladder cancer, losing weight, in pain, recent ICU stay. Wife is hesitant to come to palliative care clinic

- ◀ Where do we begin?

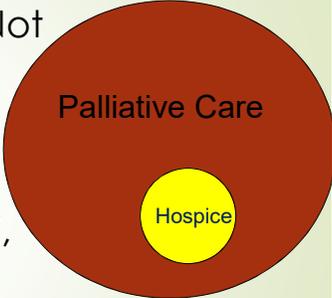
Palliative Care – what it is.

Palliative care is about living; Not death and dying

Patient centered

Interdisciplinary: MD, RN, LCSW, chaplain, PharmD

Appropriate at any stage in a serious illness



Integrating Palliative Care¹



Model to understand the place of palliative care proposed by Ferris, Balfour and colleagues (2002)



Palliative Care = Supportive Care

Google: "Palliative care and bridge"

<https://www.youtube.com/watch?v=IDHhg76tMHc>

Why does this matter?

The good cells are as important as the bad cells. If we focus on the good, patient's can handle a lot more treatment for the bad.

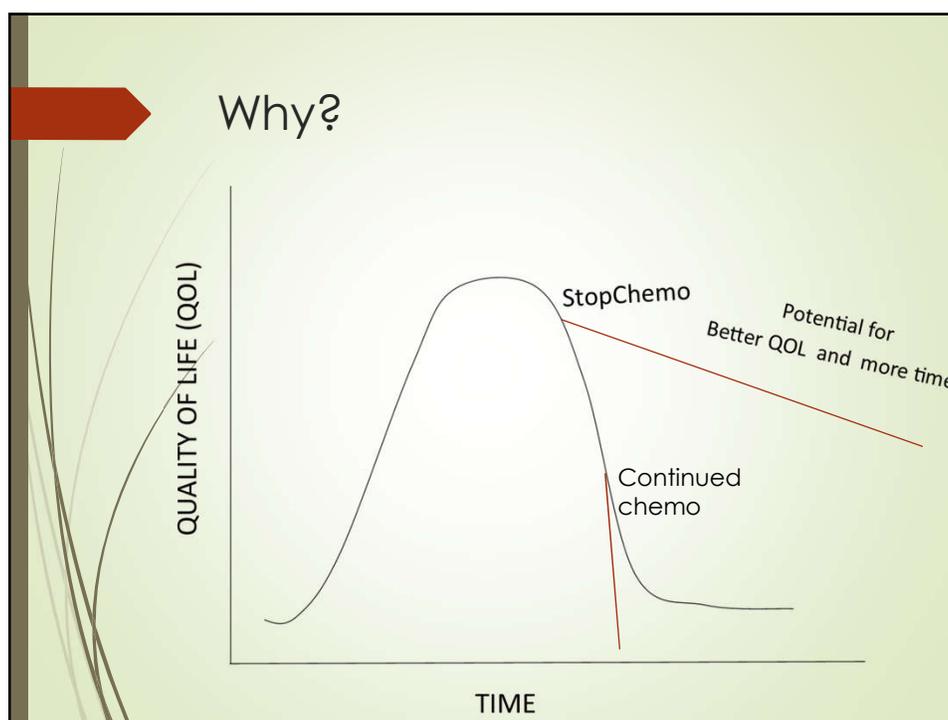


QOL versus Time

In reality, better QOL can lead to more time.

-Temel et al (2010): "Despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care (33% vs. 54%, $P = 0.05$), median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, $P = 0.02$)."²

-Other studies have shown that patients with various diagnoses live, on average, 1-2 months longer with earlier hospice referral versus usual care.³



Case 1

- ◀ Physician – started methadone for pain, mirtazapine for appetite and sleep. Patient went back to eating, gained 20 pounds. Called to see how he was doing and he was out fishing.
- ◀ LCSW – spouse received free counseling sessions through the Advanced Illness Care Coordination (AICC)⁴ program.
- ◀ Nurse – direct line to nurse for symptom mgmt and questions.
- ◀ Chaplain – spiritual support and advocacy with patient's church.
- ◀ PharmD – med rec with hospital meds and de-escalation of medications not needed (statins, BP meds).



What happened?

- ◀ Patient got better, returned to chemo for 9 more months and did well. Palliative care continued to treat symptoms and help with goal setting plus support for him and his wife.
- ◀ He taught all of his grandkids how to fish (goal #1 at first consult).
- ◀ When he started to decline the second time, the discussions had already been done and he enrolled in home hospice.
- ◀ He lived many more months with hospice care and continued to fish and enjoy time with his family. He died on hospice services after a short significant down turn in his health status related to the cancer. His wife and daughters were at the bedside. Family at peace – “it was as good a death as someone could ask for”.



Case 2

- ◀ Patient with end stage heart failure, awaiting heart transplant.
- ◀ Where do we go from here?

Case 2⁵

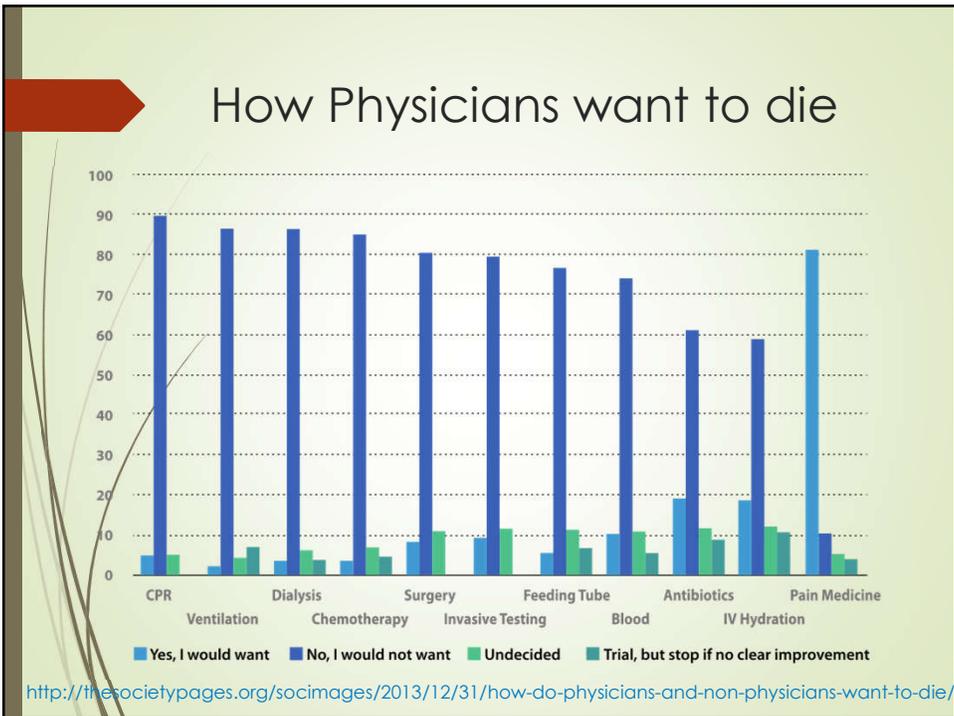
- ◀ Liquid morphine 0.25mL (5mg) for dyspnea
- ◀ Miralax for constipation
- ◀ Planning and goals of care discussions leads to a Physician Order for Life Sustaining Treatment (POLST)
 - ◀ “functional or a memory”
 - ◀ “either the glory of God or the glory of transplant”
 - ◀ Agreed with milrinone but decided against LVAD over the course of multiple discussions

POLST⁶

DPH <small>Georgia Department of Public Health</small>	POLST <small>GEORGIA</small>
PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)	
Patient's Name: _____	
Date of Birth: _____	Gender: Male <input type="checkbox"/> Female <input type="checkbox"/>
A CODE <input type="checkbox"/> Allow Resuscitation (CPR) <input type="checkbox"/> Allow Natural Death (DNOR) - Do Not Attempt Resuscitation. <small>** Signature of a state survey physician is needed for this section to be valid if this form is signed by an Authorized Person who is not the Health Care Agent. See additional guidance under D1 on back of form.</small> When not in cardiopulmonary arrest, follow orders in B, C and D.	B Check One <input type="checkbox"/> Comfort Measures: Use medication by any route, positioning, wound care, and other measures to relieve pain and suffering. Use oxygen, suction, and manual treatment of airway obstruction as needed for comfort. Do not transport to hospital for life-sustaining treatment. <input type="checkbox"/> Limited Additional Interventions: In addition to treatment and care described above, provide medical treatment, as indicated, DO NOT USE intubation or mechanical ventilation. Transfer to hospital if indicated. Generally avoid aggressive care only. <input type="checkbox"/> Full Treatment: In addition to treatment and care described above, use intubation, mechanical ventilation, and performance as indicated. Transfer to hospital and/or intensive care unit if indicated. Additional Orders (e.g. dialysis): _____
C Check One <input type="checkbox"/> No antibiotics: Use other measures to relieve symptoms. <input type="checkbox"/> Determine use or limitation of antibiotics when infection occurs. <input type="checkbox"/> Use antibiotics if life can be prolonged. Additional Orders: _____	D Check One <input type="checkbox"/> No artificial nutrition by tube. <input type="checkbox"/> Trial period of artificial nutrition by tube. <input type="checkbox"/> Long-term artificial nutrition by tube. Additional Orders: _____
ARTIFICIALLY ADMINISTERED NUTRIENT-FLUIDS Where indicated, always offer food or fluids by mouth if feasible.	
DISCUSSION AND SIGNATURES The basis for these orders should be documented in the medical record. To the best of my knowledge these orders are consistent with the patient's current medical condition and preferences and comply with the requirements of applicable Georgia law.	
Physician Name: _____	Physician Signature: _____
License No.: _____ State: _____	Phone: _____
Consenting Physician Name (if needed - see D1, or A&A of Form): _____	Consenting Physician Signature (if needed): _____
License No.: _____ State: _____	Date: _____
Phone: _____	Phone: _____
Patient or Authorized Person Name: _____ <small>**Authorized person must meet age of patient and decision-making capacity.</small>	Patient or Authorized Person Signature: _____
Date: _____	Phone: _____
Relationship to Patient (check all that apply): <input type="checkbox"/> Self <input type="checkbox"/> Health Care Agent <input type="checkbox"/> Spouse <input type="checkbox"/> Court-Appointed Guardian <input type="checkbox"/> Son or Daughter <input type="checkbox"/> Parent <input type="checkbox"/> Brother or Sister	

Why is POLST a better way to discuss End of Life Wishes?

- ◀ Most patients believe CPR is used when a patient is still alive. It is not. You must be without pulse/without breathing for CPR to be started.
- ◀ "If I'm DNR, then what happens if I faint in the parking lot?" Answer: we make sure you are ok and figure out if your dehydrated or with low blood sugar, etc.
- ◀ Most patients believe CPR works most of the time. TV has taught our patients that you not only survive CPR but wake up, ask for a hamburger and walk out of the ER. This is not true.





Informed consent

- ◀ Definition: permission granted in the knowledge of the possible consequences, typically that which is given by a patient to a doctor for treatment with full knowledge of the possible risks and benefits.



Case 2

- ◀ Patient did die at home, likely from PEA arrest, after having dinner with his family. His wife went to do dishes, he continued to talk to her and then “just stopped” slumped forward in his chair.
- ◀ 911 was called but the POLST protected his wishes to be “functional or a memory” and “glory of transplant or glory of God”.



Case 3

- ◀ Patient with progressive neurologic disease. Catholic faith. Questioning how God will perceive his choices.
- ◀ Spiritual and emotional health.



Chaplaincy at EOL⁷

- ◀ Flannelly et al (2012): American Hospital Association's Annual Survey and outcome data from The Dartmouth Atlas of Health Care in a cross-sectional study of 3,585 hospitals.
- ◀ The analyses found significantly lower rates of hospital deaths ($\beta = .04, p < .05$) and higher rates of hospice enrollment ($\beta = .06, p < .001$) for patients cared for in hospitals that provided chaplaincy services compared to hospitals that did not.



Case 3

- ◀ Regular chaplain visits with patient and wife focusing on depression and spiritual distress of the patient. If he went on hospice, was he giving up? If he stopped BiPap, would this go against God's plan for him?
- ◀ Regular chaplain visits with children, especially young son, for coping strategies and support.
- ◀ Multiple extended conversations with patient and wife around End of Life and hospice services. Planning of funeral.
- ◀ Physician symptom management for "air hunger", discussions about feeding tube, anxiety, pain.



What happened

- ◀ Patient ended up on our outpatient palliative care services and later, home hospice services. He had 4 very good years after he was no longer able to walk or eat by mouth. He went to Disney twice with his family while on home hospice services.



Case 4

- ◀ 88 yo female with end stage renal disease
- ◀ Multiple medical issues but enjoys her life at her ALF – has many friends, crafts, plays piano, sings
- ◀ Primary care taker of her husband who has dementia
- ◀ Two adult daughters
- ◀ Patient answers ambiguously regarding dialysis depending on which daughter attends nephrology appointment



Match goals with care.



Case 4

- ◀ Clear goals of care discussion over the course of two visits with daughters present. Patient's Charlson Co-morbidity index is high and evidence points to her not receiving great benefit from dialysis- patient becomes clear on what is important to her and decides against future dialysis. ⁸⁻⁹
- ◀ Simplifying medicines, lab draws, doctor's visits, Procrit injections - helping with pill box and organization
- ◀ Coping strategies when frustrated with husband with dementia; planning for his care
- ◀ POLST and plan of care of what is and is not acceptable in medical care



What happened?

- ◀ Her lower leg edema improved with lymphedema clinic. She required fewer diuretics and she became more mobile at the ALF.
- ◀ We minimized her medicines to the very necessary and improved pain and constipation management.
- ◀ Her kidneys are still end stage but have been stable without the need for too much diuretic.
- ◀ She is still living at the ALF, she celebrated 90 recently. If you stop by to visit, you might hear her singing and playing the piano.

Case 5

- ◀ 45 yo female with Stage IV Ovarian Cancer on 6th line chemotherapy now with 2nd malignant bowel obstruction complaining of acute pain crisis.
- ◀ Home regimen includes 150 mcg/hr fentanyl patch with appropriate breakthrough pain medication.
- ◀ She is placed on a morphine PCA inpatient with 2mg IV morphine Q15 minute bolus/demand. Patient is writhing in pain and asking for more pain medicine.
- ◀ Attending states this is "outside [his] parameters" and nurses are in moral distress over patient in pain but also "causing death" with increased opioids.

There is an app for that

- ◀ Fentanyl 150mcg/H patch = 300mg oral morphine = 100mg IV morphine in a 24 hour period.
- ◀ PRN should be 10% of daily basal dose.
- ◀ Breakthrough dose would be 30 mg oral morphine or 10 mg IV morphine. If someone were in excruciating pain, you increase by 50-100% of current dose = 15 to 20 mg IV morphine would be appropriate in this woman. 15 mg IV morphine = 2 mg IV hydromorphone (8-10 po hydromorphone).¹⁰

Shewmon D, Marcellino C. Opioids Dosage Conversion. Oct 08, 2014



What can we say at the bedside...

- ◀ Opioids do not hasten death at EOL ¹¹⁻¹⁴
- ◀ The Principle of Double Effect does not exist (at least when it comes to opioids and end of life) - stop using it!!!
- ◀ Instead, consider saying something like this:
 - ◀ The [opioid] will help with pain and shortness of breath. When dosed correctly, as the doctor is doing, pain and shortness of breath will improve. It will not take time away, instead, it will allow [loved one] to use their energy for other things instead of using energy to fight pain or to struggle to breathe. It takes a lot of energy to fight pain or struggle to breathe.
 - ◀ They may get more sleepy. This is more likely the fact that they have tired themselves out significantly due to pain/dyspnea and now they can actually get some rest. Sometimes opioids can add to confusion or make people less alert but we find at EOL, it is more likely the disease process itself that does this.

Case 5

- ◀ Started solumedrol IV
- ◀ Patient given 2 mg IV hydromorphone Q15minute boluses
- ◀ Basal fentanyl restarted while PCA boluses given
- ◀ Converted fentanyl and hydromorphone PCA to methadone inpatient while venting PEG placed
 - ◀ Total 650 mg oral morphine equivalent = 45 mg methadone – started methadone 15mg po Q8H while in hospital and then pt went home on methadone 20mg po Q12H to simplify
- ◀ Once tolerating po, converted solumedrol to po decadron
- ◀ Went home with hospice; lived at home with husband and did fairly well for 6 more weeks

Case 6

- ◀ Patient comes to clinic angry with all of her doctors and "the whole medical system". We sit and listen. It turns out, she is mad because everyone is talking "at her" and not "to her". We find out she has a strong support network, she is incredibly insightful but has some medical literacy issues. Faith is very important to her. She did not want to hear prognosis yet she was told anyway so she could "make her decision based on facts". What might we do differently?

Language matters

- ◀ Ask permission for everything. Just like asking permission to examine a patient, asking permission to give difficult news is a way not to "assault" someone's senses.
 - ◀ You have given a warning shot that it is difficult news so they can prepare themselves. Also, most patients will give you permission and when they do, they have taken ownership that they wanted that bad news. It also gives them a chance to decide if they are ready for the news or if they need support around them or someone on the phone.
- ◀ Ask permission to give prognosis. Many patients will say yes but quite a few will say no. Many will say, "not right now". Respect that and find other ways to make sure they are educated about the decisions they will have to make.
 - ◀ When giving prognosis say things like:
 - ◀ Use ranges – "weeks to months, months to years"
 - ◀ Explain trajectory: "when you see changes month by month, prognosis is months; when you see changes week by week, then prognosis is weeks..."
 - ◀ Many faith-based patients appreciate when a providers says "humans cannot cure this disease". Using the term "human" allows for hope in the divine but still lets patients know the truth of what medicine can actually accomplish.



Case 7

- ◀ 70 yo male patient with dementia comes to clinic with his wife. Patient has moderate dementia and is able to communicate but has difficulty with complex decision-making. He and wife want to discuss advance care planning. Patient states, "I don't want to starve to death like my mother did." You ask more questions about what the patient saw in his mother's end of life care.



Advance care planning in dementia

- ◀ Healthcare Directive in Dementia
 - ◀ www.dementia-directive.org
 - ◀ A specific advance directive for what type of care a patient wants as dementia progresses
 - ◀ Desire for more aggressive care is common in mild dementia; comfort care alone is often desired in advanced stage dementia – this document helps separate out what a person wants at different stages

Interventions and Dementia

- ◀ Feeding tubes do not prolong survival or prevent bed sores in patients with end stage dementia.
 - ◀ Meier DE, et al. High short-term mortality in hospitalized patients with advanced dementia: Lack of benefit of tube feeding. Arch Intern Med, Vol 161, Feb 26, 2001. pp 594-599.
- ◀ Data shows that antibiotics may prolong life by a few months, but decreases quality of life significantly in patients with end stage dementia; some patients may agree with oral antibiotics but do not want hospitalization or PICC line for IV antibiotics
 - ◀ Heerema, E, (2013). Antibiotic Use in Advanced Dementia. About.com Alzheimer's/Dementia
- ◀ Normalize how we stop eating and drinking before death. We are not starving our loved ones.

Other cases

- ◀ Our clinic often sees patients who will go forward with curative intent therapy but the road will be difficult. It may be difficult due to decisions, support, symptoms, resources or all the above. Those patients do better with palliative care support and have a better chance of getting through treatment. Who graduates from clinic?
 - ◀ Cancer patients that receive cure or long term remission
 - ◀ Transplant patients who receive transplants
 - ◀ Patients who stabilize because it was all the other stuff interfering with their care (illiteracy, lack of resources, lack of support, financial barriers). Once those issues were resolved, they did well.

Summary

- ← Innovative Language & Techniques
 - ← Integrate palliative care early
 - ← Explain how neither palliative/hospice care nor opioids at end of life hasten death (use evidence)
 - ← Use the UTube video about "Palliative care: You are a bridge"
 - ← Drawing charts to visualize when chemo hurts instead of helps
 - ← Ask permission to give difficult information (it softens the blow and then the patient takes ownership of wanting the knowledge; it completely changes how a patient accepts new "bad" information).
- ← Innovative people and programs – AICC (Swr) and Chaplain support
- ← Innovative tools - opioid calculation (there is an app for that), POLST
- ← Anything else?

Resources

1. Ferris FD, Balfour HM, et al. A Model to Guide Patient and Family Care; Based on Nationally Accepted Principles and Norms of Practice. *Journal of Pain and Symptom Management*. 2002; 24(2): 106-123
2. Temel JS, et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. *N Engl J Med* 2010; 363:733-742.
3. Connor SR, et al. Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window. *J Pain Symptom Manage*. 2007; 33: 238-246.
4. Engelhardt JB, et al. Effects of a Program for Coordinated Care of Advanced Illness on Patients, Surrogates, and Healthcare Costs: A Randomized Trial. *Am J Manag Care*. 2006;12:93-100
5. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier. Palliative Care in the Treatment of Advanced Heart Failure. *Circulation* 2009; 120: 2597-2606
6. <http://www.gapolst.org/>
7. Flannely K, Emanuel L, Handzo G, Galek K, Sifton N, Carlson M. A National Study of Chaplaincy Services and End-of-Life Outcomes. *BMC Palliative Care* 2012;11:10
8. De Biase, O Tobaldini, C Boaretti. Prolonged conservative treatment for frail elderly patients with end-stage renal disease: the Verona experience. *Nephrol Dial Transplant* 2008;23:1313-7.
9. Jassal SV, Kelman EE, Watson D. Non-dialysis care: an important component of care for elderly individuals with advanced stages of chronic kidney disease. *Nephron Clin Pract* 2011;119:c5-9.
10. Shewmon D, Marcellino C. Opioids Dosage Conversion. Oct 08, 2014
11. Chan JD, Treece PD, Engelberg RA, et al. Narcotic and benzodiazepine use after withdrawal of life support: association with time to death? *Chest*. 2004;126:286–293.
12. Mazer MA, Allgood CM, Wu Q. The infusion of opioids during terminal withdrawal of mechanical ventilation in the medical intensive care unit. *J Pain Symptom Manage*. 2011 Jul; 42(1):44-51.
13. Wilson WC, et al. Ordering and administration of sedatives and analgesics during the withholding and withdrawal of life support from critically ill patients. *JAMA*. 1992 Feb 19;267(7):949-53.
14. Maltoni M, Scarpi E, Rosati M, et al. Palliative sedation in end-of-life care and survival: a systematic review. *J Clin Oncol*. 2012;30(12):1378-1383.
15. Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991; 7:6-9.
16. Underwood LG, Teresi J. The Daily Spiritual Experience Scale: Development, theoretical description, reliability, exploratory factor analysis, and preliminary construct validity using health related data. *Annals of Behavioral Medicine* 2002; 24, 22-33.
17. <https://agingwithdignity.org/five-wishes/about-five-wishes>

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If we don't have time for questions, please contact me at:

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