OVERVIEW of HOSPICE AND PALLIATIVE CARE

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Objectives

Pharmacists

1. Compare and contrast hospice and palliative care.
2. Discuss the role of the pharmacist within the interdisciplinary team.
3. Identify strategies to improve the quality of life for patients living with serious and/or terminal illness.

Pharmacy Technicians

1. Compare and contrast hospice and palliative care.
2. Discuss ways to provide primary palliative care.
3. Recognize the role of medication management in the hospice and palliative care settings.

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Disclosure

I have nothing to disclose

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Patient Case

CZ is a 70 yo female who was diagnosed with metastatic NSCLC 3 years ago and has been treated with 2 different types of chemotherapy and an immunotherapy. She was admitted to the hospital with new onset seizures at home and unfortunately, now found to have brain metastases. The oncologist offers her a new chemotherapy that was approved 2 months ago. She expresses interest in trying the treatment but has many unmanaged symptoms including n/v, fatigue and headaches. Her ECOG performance status is a 2. Her spouse is overwhelmed at the thought of the care she will need at home due to her declining condition.

What is the best type of care for her at this time?

A. Home hospice care
B. Inpatient hospice care
C. Palliative care
D. Home health

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C. ***Palliative care***
D. Home health

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What is Palliative Care?

Palliative care – specialized, supportive medical care for people with serious illness that focuses on providing relief from the pain, symptoms and distress of serious illness

Other supportive care

- Time devoted to intensive family meetings and patient/family counseling
- Resolves questions and conflicts between families/patients and physicians on achievable goals of care
- Spiritual support

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So It's Like Hospice, Right?!

Hospice - type of care and a philosophy of care that focuses on the treatment of a terminally ill patient's symptoms, and support for for their family, toward the end-of-life

ALL hospice care is palliative but NOT all palliative care is hospice

BOTH are team-based approaches with focus on improving quality of life including spiritual and psychosocial support

Unlike hospice, palliative care can be provided **at the same time** as curative treatments

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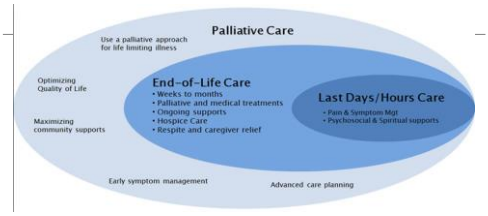

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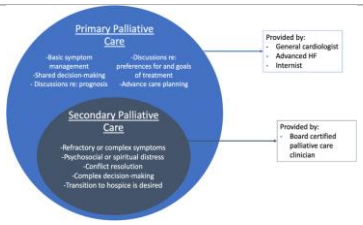
Primary vs. Specialty Palliative Care



Role of Palliative Care in the Outpatient Management of the Chronic Heart Failure Patient - Scientific Figure on ResearchGate. Available from: https://www.researchgate.net/figure/Primary-vs-specialty-secondary-palliative-care_fig1_337713366 [accessed 7 Apr, 2022]

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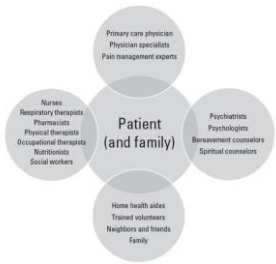
Palliative Care Team



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Who is an Appropriate Referral?

Anyone with a serious illness experiencing uncontrolled symptoms, such as
- Pain
- Dyspnea
- Anxiety
- Nausea/vomiting
- GI symptoms

Anyone with a serious or chronic illness needing
- Spiritual support
- Emotional support
- Goals of care clarification
- Care coordination

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Who is an Appropriate Referral?

Cancer	CHF	COPD	Chronic Kidney Disease
Cirrhosis	ALS	Parkinson's Disease	Dementia

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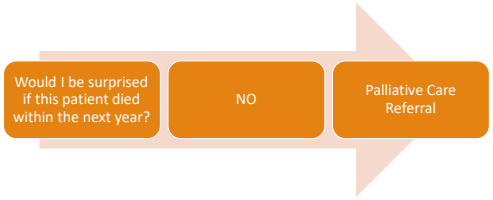
The Surprise Question



BMC Med. 2017; 15(1):139.

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ECOG Performance Status

Grade	ECOG performance status
0	Fully active; able to carry on all predisease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any self-care; totally confined to bed or chair
5	Dead

Abbreviation: ECOG, Eastern Cooperative Oncology Group.

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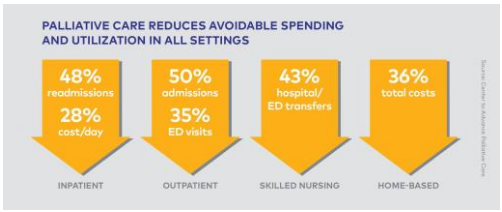
Benefits of Palliative Care



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Palliative Care and Oncology

Temel et al – NEJM 2010;363:733-42

- 151 patients with newly-diagnosed metastatic non-small cell lung cancer randomized to standard treatment or standard treatment + PC
- Primary Outcome: QOL
- Secondary outcomes: mood, aggressive treatment at EOL

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Palliative Care and Oncology

Results in intervention arm

- Better understanding of the disease, prognosis, and options
- Significantly higher QOL scores (p=0.03)
- Fewer depressive symptoms (p=0.01)
- Less aggressive end of life care (p=0.05)
- Less use of chemotherapy near end of life
- Less hospitalization and intubation
- More and longer use of hospice
- **Survival 2.7 months longer (p=0.02)**

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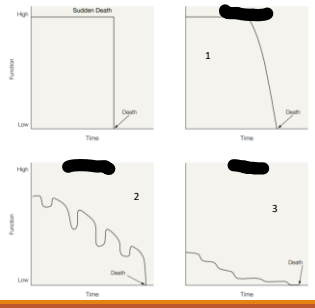
PATTERNS OF DECLINE

A. CHF
B. Dementia
C. Cancer



JAMA. 2003;289(18):2387-2392.

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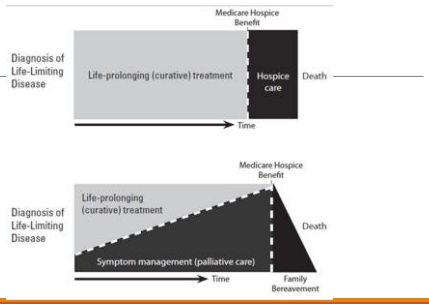

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Hospice Myths

Which of the following is NOT a common myth about hospice care?

A. Hospice is a place to die, like an inpatient facility or hospital
B. Choosing comfort care means giving up hope
C. Hospice care includes spiritual support
D. Hospice care is only for patients with a few days or weeks to live

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Hospice

Hospice is intended for patients with a life expectancy of 6 months or less

Disease specific prognostic indicators and tools are used to determine life expectancy

Like palliative care, it is team based care through the work of an IDT

The hospice benefit is covered 100%

Is it billed per diem, so hospice covers medications, equipment, and personnel

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Levels of Hospice Care

- Routine Home Care
- General Inpatient Care
- Inpatient Respite Care
- Continuous Home Care

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Role of the Pharmacist

Direct patient care
- Optimal symptom management
- Anticipate transitions of care related to pharmacotherapy plan

Medication order review and reconciliation
- Medication-use process

Education
- Medication counseling
- Provider and nursing in-services

Administrative
- Ensure safe use of medications
- Policy and procedure development
- Algorithms and protocols for best practices

Am J Health-Syst Pharm 2016;73:1351-67

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Top Ten Tips from PC Pharmacists

1. Fentanyl is tricky due to variable PKs
2. Drug-induced QT prolongation is dose and route related; uncommon at doses typically used in PC
3. Corticosteroids are amazing (my favorite drug is dexamethasone ☺)
4. Opioid selection should depend on PK with particular caution using methadone
5. Remember the "odd ball" side effects with PC medications
6. Management of refractory constipation
7. Immunotherapy targeted oral oncolytics – adverse effects and management
8. Uses and adverse effects of olanzapine
9. Consider the good, bad, and ugly of NSAID use
10. Benzodiazepines may be useful for anxiety, dyspnea, and insomnia

J Palliat Med 2018;21(7):1017-1023

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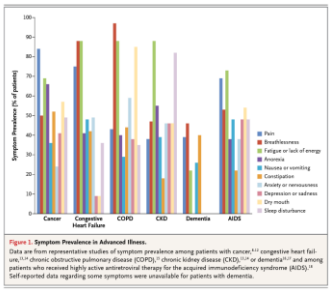

Figure 1. Symptom Prevalence in Advanced Illness.
Data are from representative studies of symptom prevalence among patients with cancer,[4,5] congestive heart failure,[6,7] chronic obstructive pulmonary disease (COPD),[8] chronic kidney disease (CKD),[9,10] or dementia[8,11] and among patients who received highly active antiretroviral therapy for the acquired immunodeficiency syndrome (AIDS).[12] Self-reported data regarding some symptoms were unavailable for patients with dementia.

NEJM 2015;373:747-55

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Principles of Symptom Management

Use frequent, standard assessment

Oral medications when possible, altering the route as needed

Assess for medication side effects; anticipate and treat as necessary

Discontinue medications no longer contributing to symptom control

Address possible reversible contributing causes

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Deprescribing

- The practice of discontinuing potentially inappropriate prescription and nonprescription medications in patients when the possible risks outweigh the benefits

Management of polypharmacy
- ↓drug-drug interactions
- ↓drug-disease interaction
- identify inappropriate dosing

Decrease pill burden for patients and in turn improve adherence to medications

Encourage and improve patient engagement in medication management

Resolution of adverse drug reactions

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Pain Assessment

P = palliating/provoking

Q = quality

R = region/radiation

S = severity

T = timing (onset, duration, frequency)

U = YOU (goals, activity level, QOL)

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Dose Adjustments

Educate for good record keeping of PRN doses

"How many tablets per day do you need to stay comfortable?"

Make the dosage increases count!
- Increase the total daily dose of opioid by 25-50% for mild to moderate pain
- Increase the total daily dose of opioid by 50-100% for moderate to severe pain

Long-acting, sustained-release opioids can be increased every 24 hours (with the exception of transdermal fentanyl and methadone)

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Opioid-Induced Constipation

First-line options
- Stimulant laxatives
  - Senna 2 tabs PO at bedtime, titrate up to 4 tabs PO BID if needed
  - Bisacodyl 10-30 mg PO at bedtime
- Osmotic laxatives
  - Polyethylene glycol 17 grams in 8 oz of water daily
  - Lactulose – 10-20 grams (15-30 mL) PO daily or BID

Add additional agents if needed
- Bisacodyl suppository
- Magnesium
- Evaluate for ileus
- Low or high impaction

Hospice prayer:
Happy is the patient in the PM,
who has a BM in the AM

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Fatigue in Advanced Cancer

Potential contributors
- Anemia
- Autonomic dysfunction
- Cancer-related symptoms
  - Pain, anxiety, depression, dyspnea, anorexia/cachexia, insomnia
- Treatment related
- Comorbidities
- Deconditioning
- Dehydration
- Hypoxia
- Infection
- Neuroendocrine alterations
- Polypharmacy
- Tumor byproducts – inflammatory cytokines

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Fatigue Management

Non-pharmacologic
- Education, exercise, acupuncture

Pharmacologic
- Psychostimulants
  - Methylphenidate – initial dose of 2.5-5 mg PO daily, increase to 15-30 mg PO daily
  - Modafanil – initial dose of 50 mg PO daily, increase to 200-400 mg PO daily
- Corticosteroids
  - Dexamethasone 1-4 mg PO daily – BID
- Megestrol acetate 160 mg PO TID
- Antidepressants
  - Bupropion 150 mg PO daily
  - Paroxetine 20 mg PO daily

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Dyspnea - Treatment

Non-pharmacologic
- Re-positioning (avoid lying flat), maintain cool room temps, relaxation exercises, acupuncture, minimal exertion

Pharmacologic
- Oxygen therapy for documented hypoxia esp. COPD
- Opioids – first-line treatment
  - No optimal agent or dose although nebulized route not shown to be superior; consider opioid naïve vs. opioid-tolerant patient
    - Morphine most commonly used (typical starting dose 2.5-5mg PO/SL q4h PRN)
    - Rescue doses at 30-50% of scheduled dose typically effective
- Anxiolytics
  - Benzodiazepines reserved for breakthrough or refractory dyspnea compounded by anxiety or when ADRs limit titration of opioids to efficacy

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Terminal Restlessness

Falls in the spectrum of delirium

Signs may include:
- Skin mottling and cool extremities
- Mouth breathing with hyperextended neck
- Calling out for dead family members or friends
- Talking about packing bags, taking a trip, going for a care ride
- Periods of deepening somnolence
- Agitation

Assess for other contributing factors
- Medication withdrawal, kidney/liver failure, fecal impaction, urinary retention, uncontrolled pain, psychosocial or spiritual problems

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Terminal Restlessness - Treatment

Treat underlying cause

Non-pharmacologic interventions

Pharmacologic
- Benzodiazepines
  - Lorazepam 0.5-2 mg PO/SL every 4 hours PRN
  - May need to schedule
  - May worsen if delirium
- Can consider addition of antipsychotic if agitation component
  - Haloperidol 1-2 mg PO/SL every 4 hours PRN

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Secretions

Respiratory secretions common in the last days of life
- Most frequent with pulmonary malignancies and brain tumors
- ~76% of patients die within 48 hours of onset
- "Death rattle" disturbing for caregivers, painless to patient
- May often be corrected by re-positioning

Contributing factors
- IV hydration or tube feedings
- Diminished cough reflex or dysphagia
- Prolonged dying phase

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Secretions – Treatment

If secretions are thick and patient is not close to death
- Consider optimizing hydration
- Nebulized NS and/or guaifenesin SR 600-1200mg PO q 12 hrs.
- If secretions thinner, can use gentle suctioning and anticholinergics

In patient near death, suctioning not recommended
- Anticholinergics
  - Atropine eye drops 1%
    - 1-2 drops SL every 30 minutes PRN
  - Scopolamine/Scopolamine patch
    - Initial dose: 0.2mg SQ/IV every 4 hrs PRN; may titrate to 0.4mg PRN (continuous infusion may also be used 0.1-1mg/hr)
    - 1 patch to back of ear every 72 hrs; may increase to 2 patches if needed (**NOTE**: slow onset of action 6-8 hrs)
  - Hyoscyamine
    - 0.125-0.25mg PO every 30 minutes PRN
  - Glycopyrrolate
    - Initial dose: 0.2mg SQ/IV every 4 hrs PRN; may titrate to 0.8mg every 4 hrs, continuous infusion may also be used (0.4-1.2mg daily)

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Patient Case

CZ received 4 cycles (once every 21 days) of single agent chemotherapy but continues to become weaker with each infusion. For the last 2 treatments, she required a wheelchair to get into the clinic and shares with the chemo nurse that her quality of life is dismal. She requires assistance with ADLs, is sleeping ~14 hrs per day and drinks a few Ensures each day as she has no appetite. During her palliative care clinic visit last week, the team discussed her goals of care in which she expressed to her family that she no longer wishes to receive any more treatment as it's just too much on her body.

What is the next appropriate type of care at this time?

A. Respite care
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The Conversation

"Just as no doctor is born knowing how to handle a scalpel, the same is true for how to communicate effectively with seriously ill patients and their families about end of life topics."

-Diane Meier, MD

Palliative Care Pioneer

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Goals of Care Conversation

Prepare ahead of time for discussion

Private setting, minimize interruptions

Establish rapport

Use good communication skills

Employ shared making decision making

Take the patient's health literacy into account

Use plain language

Allow for and manage emotions before moving forward with conversation

Thank them for speaking with you

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Assess knowledge and understanding of illness and prognosis

- Tell me what you understand about your (your loved one's) illness?
- Has anyone ever spoken to you about what to expect from your disease?
- What conversations have you had with other doctors about the care you wish to receive?
- What is your understanding of what lies ahead with your illness?
- What is your perception of your overall health?
- Do you think you can manage your health care needs at home?

FINEOUT-OVERHOLT E, MELNYK BM, STILLWELL SB, WILLIAMSON KM. EVIDENCE-BASED PRACTICE, STEP BY STEP: CRITICAL APPRAISAL OF THE EVIDENCE: PART III. AM J NURS. 2010 NOV;110(11):43-51.

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Patient-centered goals of care

- Tell me what most worries you about your illness and what is important to you?
- As you look to your future what is most important?
- Tell me more about what no giving up, fighting, and miracles might look like for you
- Does the treatment you are receiving feel right to you?
- If it turned out that time was limited, what is most important to you right now?
- What comes to your mind when you think of hope?
- Is there any that would be worse than death for you?

FINEOUT-OVERHOLT E, MELNYK BM, STILLWELL SB, WILLIAMSON KM. EVIDENCE-BASED PRACTICE, STEP BY STEP: CRITICAL APPRAISAL OF THE EVIDENCE: PART III. AM J NURS. 2010 NOV;110(11):43-51.

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NURSE statements for articulating empathy

	Example	Notes
Naming	"It sounds like you are frustrated"	In general, turn down the intensity a notch when you name the emotion
Understanding	"This helps me understand what you are thinking"	Think of this as another kind of acknowledgment but stop short of suggesting you understand everything (you don't)
Respecting	"I can see you have really been trying to follow our instructions"	Remember that praise also fits in here eg "I think you have done a great job with this"
Supporting	"I will do my best to make sure you have what you need"	Making this kind of commitment is a powerful statement
Exploring	"Could you say more about what you mean when you say that…"	Asking a focused question prevents this from seeming too obvious

https://www.vitaltalk.org/guides/responding-to-emotion-respecting/

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Three fundamental skills

	Example	Notes
Tell me more	"Tell me more about…"	Use when you are not sure what someone is talking about (rather than jump to an assumption).
Ask-tell-ask	"What do you think about…" "Here's what the tests show" "Does that make sense…?"	Related to Assess-Knowledge-Respond in SPIKES. Think of this as one unit of information transfer
"I wish" statements	"I wish I could say that the chemo always works"	Enables you to align with the patient while acknowledging the reality of the situation

https://www.vitaltalk.org/guides/responding-to-emotion-respecting/

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When to Discuss CPR

Timing
- Hospital Admission
- Serious irreversible illness
- Change in condition
- When care becomes futile

Framing the discussion
- Explore values
- Perception of illness
- Hopes for future

Distinguish between choices
- CPR vs Life Sustaining Treatments
- Mechanical Ventilation
- Pressors
- Dialysis
- Artificial Nutrition
- Antibiotics

Describe terms
- Cardiac Arrest
- CPR

DOWNAR J, HAWRYLUCK L. WHAT SHOULD WE SAY WHEN DISCUSSING "CODE STATUS" AND LIFE SUPPORT WITH A PATIENT? A DELPHI ANALYSIS. J PALLIAT MED. 2015 FEB;18(2):185-91.

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Tailored Approach

NO discussion is the same

Sensitive to cultural beliefs

Appropriate to clinical status

Tailored to education, knowledge, level of understanding

Allow time to process information presented

DOWNAR J, HAWRYLUCK L. WHAT SHOULD WE SAY WHEN DISCUSSING "CODE STATUS" AND LIFE SUPPORT WITH A PATIENT? A DELPHI ANALYSIS. J PALLIAT MED. 2015 FEB;18(2):185-91.

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Conclusions

- Palliative care is a type of team-based care to improve QOL is patients with serious illness and can be given with curative treatments.
- Hospice care is a type of team-based care to reduce suffering in patients with terminal illness.
- Patients with any serious chronic condition may be appropriate for palliative care referral.
- Patients thought to be in the last 6 months of their life may be appropriate for hospice referral.
- Effective treatment strategies exist for common symptoms encountered in hospice and palliative care.
- Structured communication techniques are available and recommended to guide discussions of patient and family goals and preferences

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Selected Resources

Provider education

- Center to Advance Palliative Care
  - www.capc.org
- American Academy of Hospice and Palliative Medicine
  - www.aahpm.org
- Education in Palliative and End-of-Life Care
  - www.epec.net
- Palliative Care Fast Facts
  - www.mypcnow.org
- Vital Talk
  - www.vitaltalk.org

Patient education

- www.getpalliativecare.org
- www.theconversationproject.org

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