Alzheimer's Disease and Other Related Dementias: Palliative Care for the Alzheimer's Patient

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Objectives

- Define palliative care
- Differentiate palliative care from hospice?
- Describe the benefits of palliative care
- Review initiatives TN has taken to advance palliative care
- List palliative care resources

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Mrs. D

- Dx with Alzheimer's in early 90s
- Husband had died 4 years prior
- Lived alone
- 2 daughters lived locally
- Always lived a vibrant life

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Would Mrs. D benefit from Palliative Care?

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2016 Alzheimer's Disease Facts and Figures

Alzheimer's Dementia 2016

- 5.4 million Americans are diagnosed with dementia or dementia like illness
  - By 2050, this number will grow to 13.8 million
- Every 66 seconds in the US, one individual will develop Alzheimer's disease
  - In 2050, once case will develop every 33 seconds
  - Resulting in ~1 million new cases annually

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2016 Alzheimer's Disease Facts and Figures
Alzheimer's Dementia 2016

- In 2015, more than 15 million family members and their unpaid caregivers provided an estimated 18.1 billion hours of care to people with dementia which is about $221 billion
- Average per person Medicare payment for services to beneficiaries age > 65 are greater than 2.5 times that for those beneficiaries without these conditions
- Medicaid payments are 19 times as great
- Total payments in 2016 estimated to be $236 billion for those > 65 with dementia

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Now what do you think? Would Mrs. D benefit from Palliative Care?

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Palliative Care Definition www.capc.org

Palliative care(PC) is specialized medical care for people living with a serious illness.

PC provides relief from the symptoms and stress of the illness.

The goal is to improve QOL for both the patient and the family

It is provided by a specially-trained team of clinicians who work together with a patient's other doctors to provide an extra layer of support.

PC is based on the needs of the patient, not on the patient's prognosis.

It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

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Older Model of Palliative care

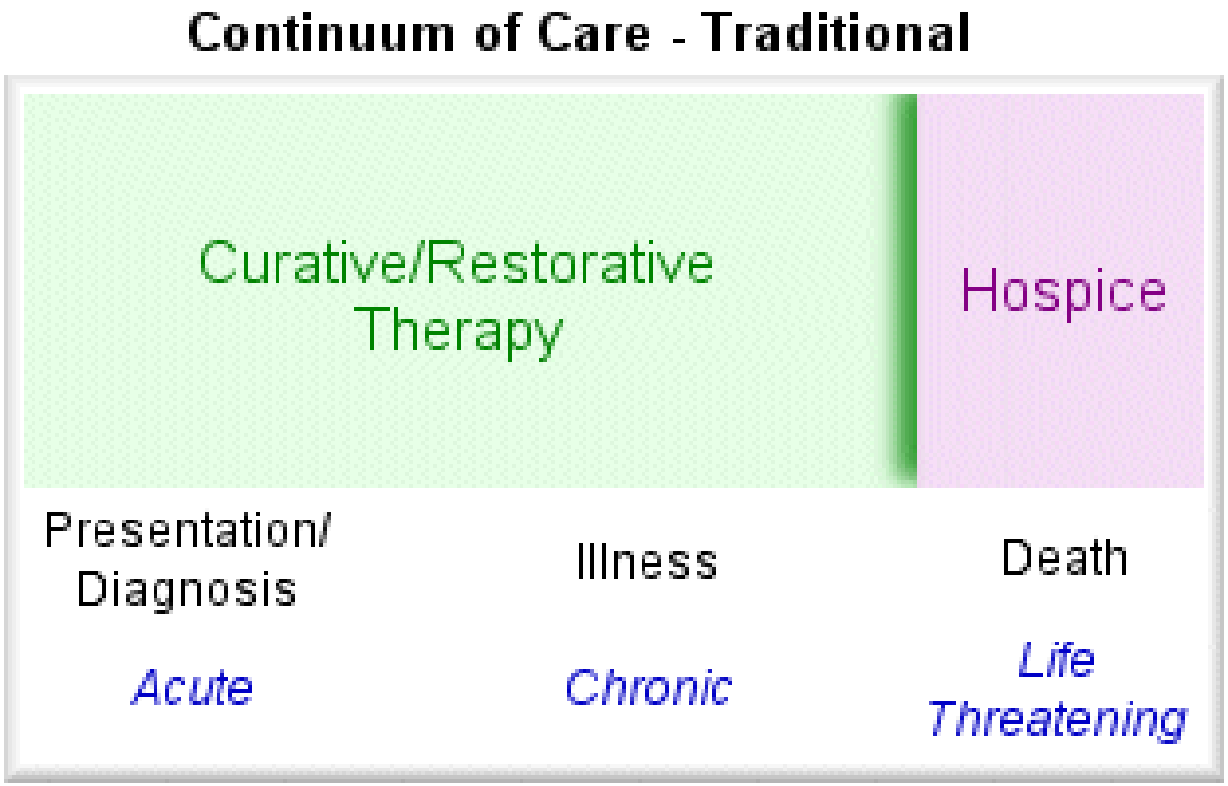

Figure 1. Adapted from Frank D. Ferris, 2000.

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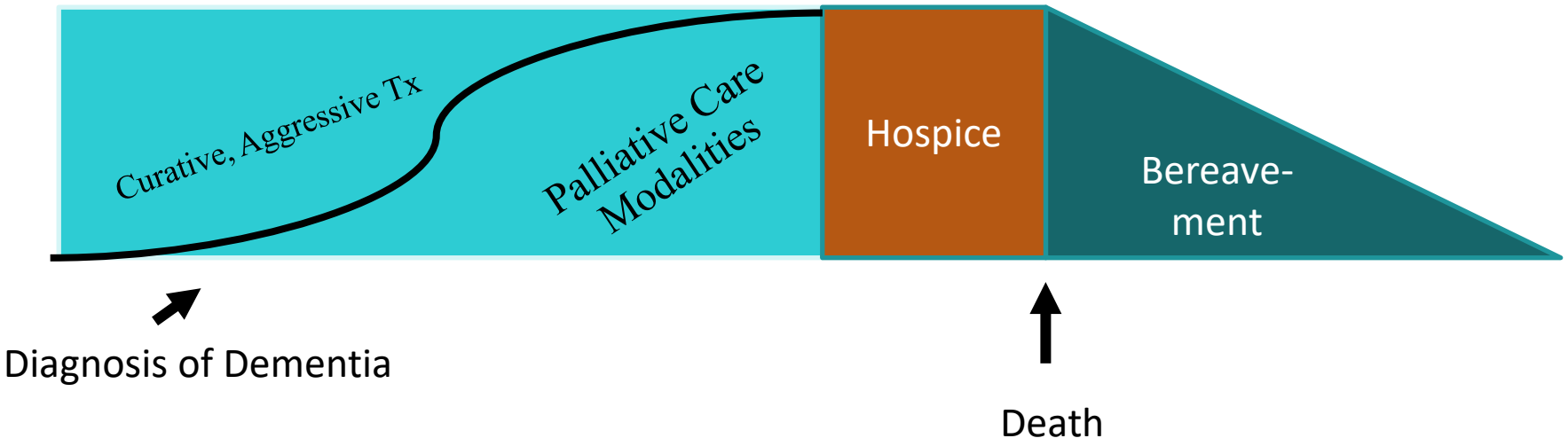
Current Palliative Care Model



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Differentiating Palliative Care from Hospice

Palliative Care

- Medical Specialty
- Focuses on those that are seriously ill
- No defined life expectancy
- Ideally integrated while pursuing curative cure
- Interdisciplinary care
- Patient and Family Centered

Hospice

- Insurance Benefit
- Requires a terminal illness/incurable condition
- Life expectancy <6 mos.
- Treatments are for palliation only
- Interdisciplinary care
- Patient and Family Centered

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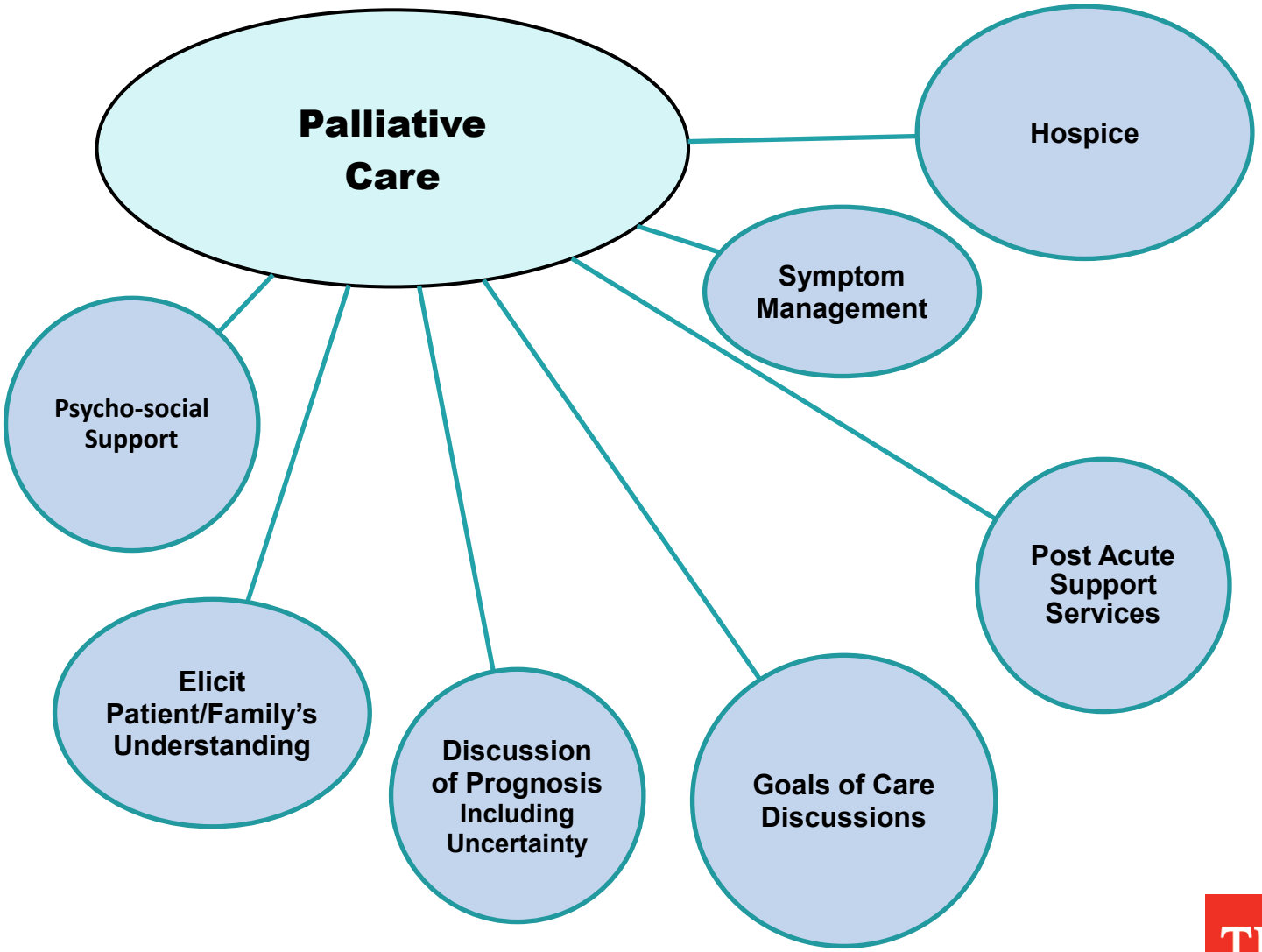

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Palliative Care Interdisciplinary Team

- Physician
- Advanced practice provider
- Social worker
- Chaplain
- Pharmacist
- Child life specialist
- Music therapist, speech pathologist…

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Mrs. D

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Palliative Care Interventions

How can palliative care as a specialty support patients with dementia and their families?

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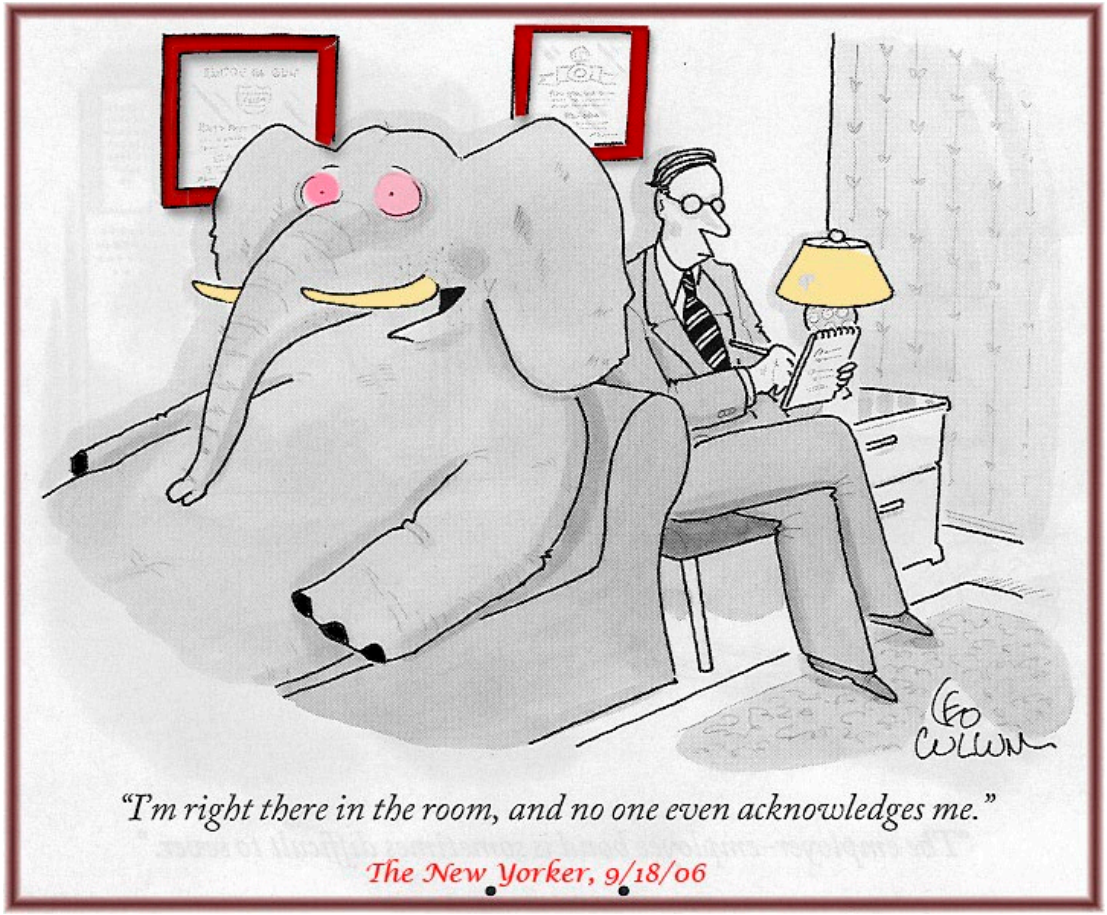

"I'm right there in the room, and no one even acknowledges me."

The New Yorker, 9/18/06

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Educate and Plan for Future

Educate	Discuss	Review	Identify
Educate patient and family on dementia	Discuss what this means for patient and their caregivers/family	Review periodically where you think the patient is (in trajectory) AND where you think they will be headed in the next several months	Identify complications specific to that patient

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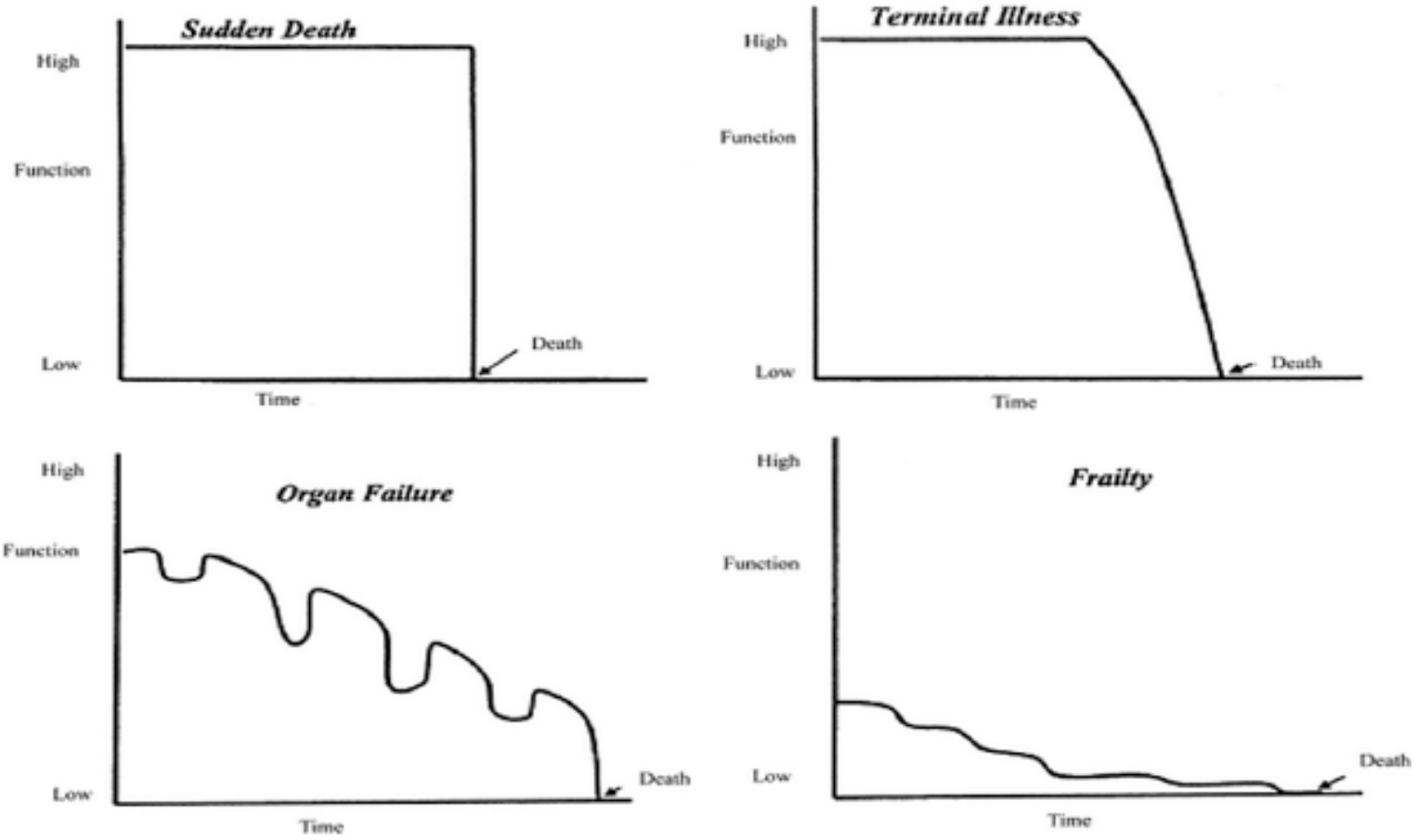
Proposed Trajectories of Dying



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Check in with the Caregiver

Palliative care focuses on the whole person-this includes family

Acknowledge the concept of caregiver burn out

Ensure the caregiver has time to care for themselves

Review available resources

- Day programs
- Support programs
- Caregiver programs such as Choices

Encourage caregiver to engage other family members for help

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Goal Concordant Care

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Most people fear this image

when they hear the words

“Dementia”

AND

Many may have clear wishes

on what “kind of care”

they would want at the EOL

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Concordance of Care and Treatment Decision for Persons with Dementia

Ernecoff.et al. JPM 2018

- Data used from a GOC cluster RCT testing video aide to enhance GOC for NH residents in North Carolina
- Participants: 302 dyads (resident and family member) in 22 LTC facilities
- Dyads were followed for 9 months
- Eligible residents: Global deterioration scale 5, 6 or 7
- Mean age 86
- 81.5% women
- 85% white
- Mortality at 9 months → 60%

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Concordance of Care and Treatment Decisions for Persons with Dementia

Ernecoff.et al. JPM 2018

- Most families prioritized comfort even when “Death was not imminent”
- Families chose comfort as goal for 66% residents at baseline
- Concordance with what family decision maker wanted with what LTC plan reflected was 49%
- At follow up, concordance increased to 69%
- In multivariate analysis, choice of comfort was associated with half as many hospital transfers
  - No changes as it relates to hospice admissions or treatment plans for symptoms

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Barriers to Achieving

“Goal Concordant Care”

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Multiple Barriers Exist

- *Health Care Providers*
- Health Care System
- Families
- Patients

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Prognostication… We Are Just Not That Good At It

BMJ. 2000 Feb 19;320(7233):469-473

U. Chicago Medical Center Study: extent and determinants of error in prognostication

Study participants:

- *343 physicians*
- *468 terminally ill patients*

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Christakis et al.

BMJ. 2000 Feb 19;320(7233):469-473

- *Median survival for patients 24 days*
- *20% predictions were accurate (within 33% estimated survival time)*
- *63% predictions were over optimistic*
- *17% predictions were overly pessimistic*

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Christakis et al.

BMJ. 2000 Feb 19;320(7233):469-473

- *Physicians overestimate prognosis by factor of 5*
- *As duration of physician patient relationship increases, and time from last contact decreases, prognostic accuracy decreases*

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Discomfort with the truth
if we had it…

Christakis et al

Annals of Internal Medicine. Jun 2001. Vol134(12);1096-1105.

- Study:
  - 326 patients
  - 258 physicians
- Physicians stated:
  - 37% of time they would provide frank estimates
  - 63% of time, would provide no estimate or either a conscious over/underestimate

Multiple Barriers Exist

- Health Care Providers
- *Health Care System*
- Families
- Patients

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Barriers to Palliative Care

Midtbust et. Al. 2018 BMC Health Serv Res

Qualitative study done in Norway at 4 LTC facilities

Interviewed RNs and LPNs from each facility interviewed (N=20)

Results

- Lack of continuity as a “major threat”
- Lack of resources-working culture focused on business aspect of care
  - Sicker patients require more resources which may not be available
- End of life transitions paradoxically worked against optimal EOL care
  - As patients became sicker, and complicated, they had to be moved to a different care setting

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Health Care Systems

- *Is Complicated*
- *Lots of transitions where important information can be lost*
- *Insufficient Resources*
- *Focus is on acute issues, and less often on big picture*

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Multiple Barriers Exist

- Health Care Providers
- Health Care System
- *Families*
- Patients

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Families are…

- *Actively trying to advocate for loved ones*
- *Also conflicted*
  - *Hoping to extend life*
  - *Do not want their loved one to suffer*
- *Afraid*

Multiple Barriers Exist

- Health Care Providers
- Health Care System
- Families
- *Patients*

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Patients Are…

http://www.apa.org/pi/aging/programs/eol/end-of-life-factsheet.aspx

- *Afraid*
  - *That they will die alone*
  - *They will die in misery*
  - *They will burden their family*
- *Uncertain*
  - *What to expect..*

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Advance Care Planning

Engage in Advance Care Planning

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Surrogate Decision Makers need Better Preparation for Their Role: Advice from Experience Surrogates

Bakke et al JPM 2022

- 40 participants reported making decisions for others
- 5 Themes identified
- 1-Lack of surrogate's preparation and guidance
- 2-Needing guidance to initiate ACP
- 3-Needing guidance to learn patient's values and preferences
- 4-Needing guidance to communicate with physicians and advocate
- patient's choices
- 5-Needing guidance to make informed surrogate decisions

* Many surrogates in this study supplemented/substituted patients wishes with their own wishes when making decisions

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Advance Care Planning

- At minimum, identify a surrogate
- Engage patient in what is and is not an acceptable quality of life
- How important is it to be…
  - Cognitively intact
  - Physically able (do ADLs)
  - Live at home
- Ideally complete and advance care directive
  - POST
  - TN Advance Care Directive for Health Care

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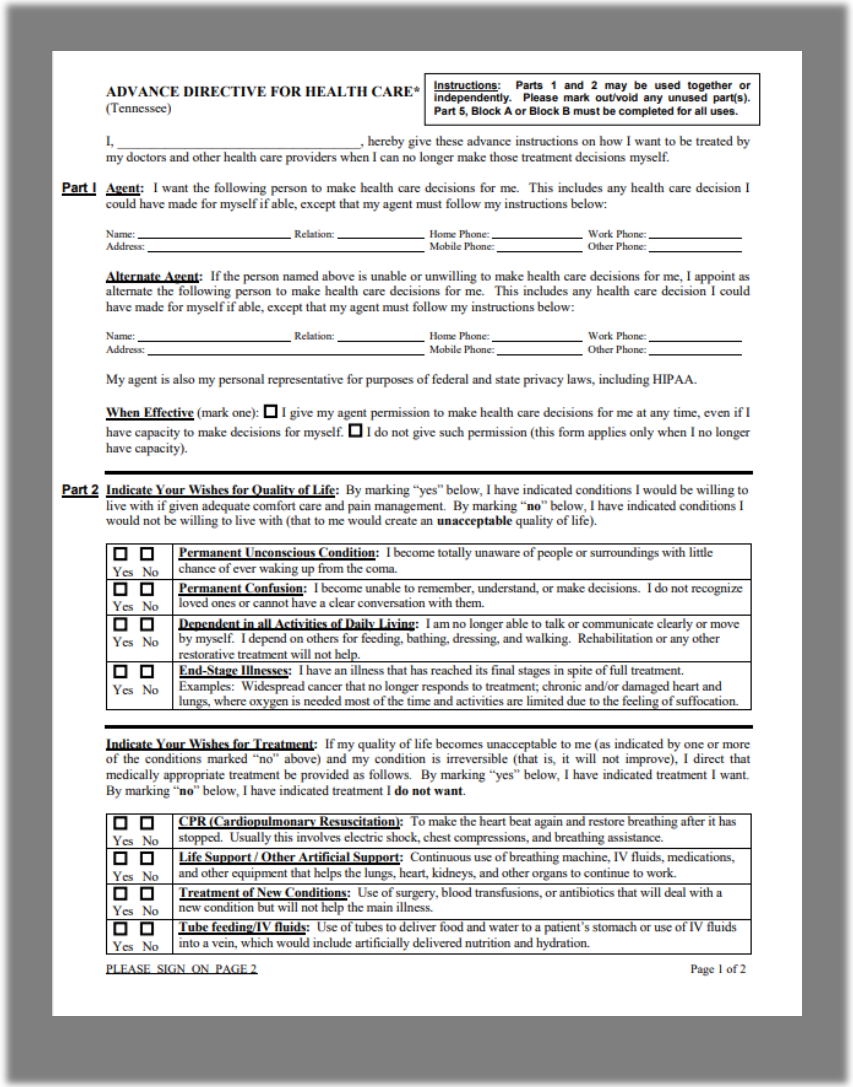

ADVANCE DIRECTIVE FOR HEALTH CARE
(Tennessee)

Instructions: Parts 1 and 2 may be used together or independently. Please mark out/void any unused part(s). Part 5, Block A or Block B must be completed for all uses.

I, _____, hereby give these advance instructions on how I want to be treated by my doctors and other health care providers when I can no longer make those treatment decisions myself.

Part 1 **Agent:** I want the following person to make health care decisions for me. This includes any health care decision I could have made for myself if able, except that my agent must follow my instructions below:

Name: _____ Relation: _____ Home Phone: _____ Work Phone: _____
Address: _____ Mobile Phone: _____ Other Phone: _____

Alternate Agent: If the person named above is unable or unwilling to make health care decisions for me, I appoint as alternate the following person to make health care decisions for me. This includes any health care decision I could have made for myself if able, except that my agent must follow my instructions below:

Name: _____ Relation: _____ Home Phone: _____ Work Phone: _____
Address: _____ Mobile Phone: _____ Other Phone: _____

My agent is also my personal representative for purposes of federal and state privacy laws, including HIPAA.

When Effective (mark one): ☐ I give my agent permission to make health care decisions for me at any time, even if I have capacity to make decisions for myself. ☐ I do not give such permission (this form applies only when I no longer have capacity).

Part 2 **Indicate Your Wishes for Quality of Life:** By marking "yes" below, I have indicated conditions I would be willing to live with if given adequate comfort care and pain management. By marking "**no**" below, I have indicated conditions I would not be willing to live with (that to me would create an **unacceptable** quality of life).

☐ Yes ☐ No	**Permanent Unconscious Condition:** I become totally unaware of people or surroundings with little chance of ever waking up from the coma.
☐ Yes ☐ No	**Permanent Confusion:** I become unable to remember, understand, or make decisions. I do not recognize loved ones or cannot have a clear conversation with them.
☐ Yes ☐ No	**Dependent in all Activities of Daily Living:** I am no longer able to talk or communicate clearly or move by myself. I depend on others for feeding, bathing, dressing, and walking. Rehabilitation or any other restorative treatment will not help.
☐ Yes ☐ No	**End-Stage Illnesses:** I have an illness that has reached its final stages in spite of full treatment. Examples: Widespread cancer that no longer responds to treatment; chronic and/or damaged heart and lungs, where oxygen is needed most of the time and activities are limited due to the feeling of suffocation.

Indicate Your Wishes for Treatment: If my quality of life becomes unacceptable to me (as indicated by one or more of the conditions marked "no" above) and my condition is irreversible (that is, it will not improve), I direct that medically appropriate treatment be provided as follows. By marking "yes" below, I have indicated treatment I want. By marking "**no**" below, I have indicated treatment I **do not want**.

☐ Yes ☐ No	**CPR (Cardiopulmonary Resuscitation):** To make the heart beat again and restore breathing after it has stopped. Usually this involves electric shock, chest compressions, and breathing assistance.
☐ Yes ☐ No	**Life Support / Other Artificial Support:** Continuous use of breathing machine, IV fluids, medications, and other equipment that helps the lungs, heart, kidneys, and other organs to continue to work.
☐ Yes ☐ No	**Treatment of New Conditions:** Use of surgery, blood transfusions, or antibiotics that will deal with a new condition but will not help the main illness.
☐ Yes ☐ No	**Tube feeding/IV fluids:** Use of tubes to deliver food and water to a patient's stomach or use of IV fluids into a vein, which would include artificially delivered nutrition and hydration.

PLEASE SIGN ON PAGE 2

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Part 3 **Other instructions, such as hospice care, burial arrangements, etc.:** _____

_____

_____

_____

_____

(Attach additional pages if necessary)

Part 4 Organ donation: Upon my death, I wish to make the following anatomical gift for purposes of transplantation, research, and/or education (mark one):

☐ Any organ/tissue ☐ My entire body ☐ Only the following organs/tissues: _____

_____

☐ No organ/tissue donation

SIGNATURE

Part 5 Your signature must **either** be witnessed by two competent adults ("Block A") **or** by a notary public ("Block B").

Signature: _____ Date: _____
(Patient)

Block A Neither witness may be the person you appointed as your agent or alternate, and at least one of the witnesses must be someone who is not related to you or entitled to any part of your estate.

Witnesses:

1. I am a competent adult who is not named as the agent. I witnessed the patient's signature on this form. _____
Signature of witness number 1

2. I am a competent adult who is not named as the agent. I am not related to the patient by blood, marriage, or adoption and I would not be entitled to any portion of the patient's estate upon his or her death under any existing will or codicil or by operation of law. I witnessed the patient's signature on this form. _____
Signature of witness number 2

Block B You may choose to have your signature witnessed by a notary public instead of the witnesses described in Block A.

STATE OF TENNESSEE
COUNTY OF _____

I am a Notary Public in and for the State and County named above. The person who signed this instrument is personally known to me (or proved to me on the basis of satisfactory evidence) to be the person who signed as the "patient." The patient personally appeared before me and signed above or acknowledged the signature above as his or her own. I declare under penalty of perjury that the patient appears to be of sound mind and under no duress, fraud, or undue influence.

My commission expires: _____ _____
Signature of Notary Public

WHAT TO DO WITH THIS ADVANCE DIRECTIVE: (1) provide a copy to your physician(s); (2) keep a copy in your personal files where it is accessible to others; (3) tell your closest relatives and friends what is in the document; (4) provide a copy to the person(s) you named as your health care agent.

* This form replaces the old forms for durable power of attorney for health care, living will, appointment of agent, and advance care plan, and eliminates the need for any of those documents.

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A COPY OF THIS FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED

Tennessee Physician Orders for Scope of Treatment (POST, sometime called "POLST")

This is a Physician Order Sheet based on the medical conditions and wishes of the person identified at right ("patient"). Any section not completed indicates full treatment for that section. When need occurs, first follow these orders, then contact physician.

Patient's Last Name

First Name/Middle Initial

Date of Birth

Section A *Check One Box Only*

CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and is not breathing.

☐ **R**esuscitate (CPR) ☐ **D**o **N**ot Attempt **R**esuscitation (DNR / no CPR) (**A**llow **N**atural **D**eath)

When not in cardiopulmonary arrest, follow orders in **B, C,** and **D.**

Section B *Check One Box Only*

MEDICAL INTERVENTIONS. Patient has pulse and/or is breathing.

☐ **Comfort Measures.** Relieve pain and suffering through the use of medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location. Treatment Plan: Maximize comfort through symptom management.**

☐ **Limited Additional Interventions.** In addition to care described in Comfort Measures Only above, use medical treatment, antibiotics, IV fluids and cardiac monitoring as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). **Transfer** to hospital if indicated. Generally avoid the intensive care unit. **Treatment Plan: basic medical treatment.**

☐ **Full Treatment.** In addition to care described in Comfort Measures Only and Limited Additional Interventions above, use intubation, advanced airway interventions mechanical ventilation as indicated. **Transfer** to hospital and/or intensive care unit if indicated. **Treatment Plan: Full treatment including in the intensive care unit.**

*Other Instructions:*_____

Section C *Check One*

ARTIFICIALLY ADMINISTERED NUTRITION. Oral fluids & nutrition must be offered if feasible.

☐ No artificial nutrition by tube.
☐ Defined trial period of artificial nutrition by tube.
☐ Long-term artificial nutrition by tube.

*Other Instructions:*_____

Section D *Must be Completed*

Discussed with:
☐ Patient/Resident
☐ Health care agent
☐ Court-appointed guardian
☐ Health care surrogate
☐ Parent of minor
☐ Other: _____(Specify)

The Basis for These Orders Is: (Must be completed)
☐ Patient's preferences
☐ Patient's best interest (patient lacks capacity or preferences unknown)
☐ Medical indications
☐ (Other) _____

Physician/NP/CNS/PA Name (Print)	Physician/NP/CNS/PA Signature Date NP/CNS/PA (Signature at Discharge)	MD/NP/CNS/PA Phone Number: ( )

Signature of Patient, Parent of Minor, or Guardian/Health Care Representative

Preferences have been expressed to a physician and /or health care professional. It can be reviewed and updated at any time if your preferences change. If you are unable to make your own health care decisions, the orders should reflect your preferences as best understood by your surrogate.

Name (Print)	Signature	Relationship (write "self" if patient)

Agent/Surrogate	Relationship	Phone Number ( )

Health Care Professional Preparing Form	Preparer Title	Phone Number ( )	Date Prepared

TDH, Division of Health Licensure and Regulation, Office of Health Care Facilities, 665 Mainstream Drive, Second Floor, Nashville, TN 37243

PH-4193 (Rev 7/15) RDA-10137

Made Fillable by eForms

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Palliative Care in Tennessee

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Palliative Care Initiatives in Tennessee

- Palliative Care Task Force Created in 2017 as a result of Chapter 420 of the Public Acts of 2017
- TN State Palliative Care and Quality of Life Council in 2018 enacted as Public Chapter 955
- Council is comprised of clinicians across the state
- Meets quarterly
- Meetings are open to the public

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TN Palliative Care State Council Achievements

- *Definition of palliative care adopted by TN assembly*
  - *Resulted in exception for palliative care patients in language for opioid prescribing*
- *Palliative Care State Conferences*
  - *May 20st 2019*
  - *April 1st 2022*
- *Palliative Care Summit April 15th and 16th 2021*
  - *Resulted in dedicated pediatric palliative care forum*

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TN Mentor Program

February to June 2021: Partnership with THA and DOH

- *11 mentors & 24 mentees completed program*
- *All participants given tool kit*
- *All learning virtual*
- *Topics covered:*
  - *Consult Etiquette and Team Dynamics*
  - *Communication*
  - *Advance Care Directives*
  - *Telehealth*
  - *Making the Case*

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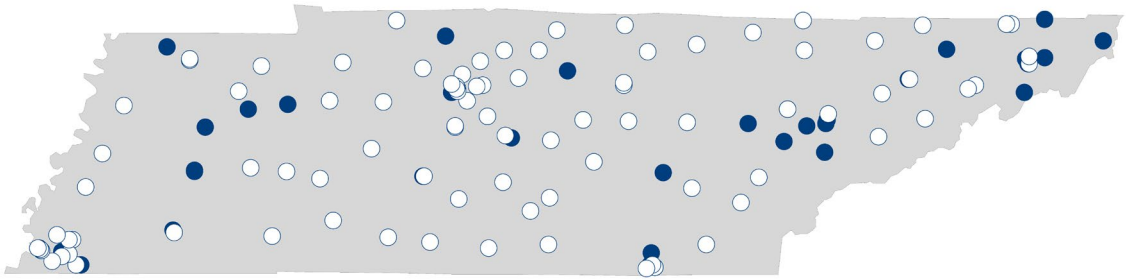
Hospital Palliative Care Availability in Tennessee

www.capc.org

- *Includes hospitals of all sizes.*
- *Solid dots indicate hospitals that report palliative care programs*
- *Empty dots indicate hospitals that do not currently offer palliative care*



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Hospital Based Palliative Care Programs in TN

- *East South-Central Region = AL, KY, MS, TN*
- **The 2019 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals grade excludes hospitals that have fewer than 50 beds.*
- *Report Card grades are as follows:*
  - *A (80% or more) of hospitals with 50+ beds have palliative care*
  - *B (60-79%)*
  - *C (40-59%)*
  - *D (20-39%)*
  - *F (less than 20%)*

Location	2019 Grade*	< 50 beds	50-150 beds	151-299 beds	300+ beds
State	61.7% B	47.8% (11/23)	47.1% (8/17)	42.9% (6/14)	93.8% (15/16)
Region	48.2% C	31.3% (40/128)	23.6% (21/89)	52.0% (26/50)	86.5% (45/52)
National	71.5% B	36.3% (557/1535)	51.1% (474/928)	75.6% (578/765)	93.7% (671/716)

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Accessing Palliative Care in TN

Inpatient Acute Care Hospitals

- Hospital based palliative care teams
- Partnerships with hospices & community palliative care organizations

Outpatient/Community

- Home based palliative care via
  - Hospice agencies
  - Palliative care entities
    - Aspire
- Outpatient clinics
  - Independent Practices
  - Linked to a larger health care institution

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Palliative Care Resources

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Advance Care Planning

Health Care Decision Making (tn.gov)

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Additional Resources

- Palliative Care Advisory Council (tn.gov)
- www.capc.org
- www.aahpm.org
- www.vitaltalks.org
- Home of Fast Facts and Fast Fact CME - Palliative Care Network of Wisconsin (mypcnow.org)
- The Conversation Project - Have You Had The Conversation?

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Mrs. D

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To Summarize

- The burden that dementia poses to patients, families, and the health care system is only going to grow
- Palliative care aims to maximize QOL for patients with serious illness at any time in their illness AND
- Palliative care is well suited to support patients and families with dementia
- Tennessee as a state has embarked on many initiatives to advance palliative care

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Thank you!

Questions????

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