

# Challenges in Providing Palliative Care

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# Objectives

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- Define palliative care
- Differentiate palliative care from hospice
- Describe processes to help support palliative care outcomes
- Discuss effective communication approaches for health care providers

# How Americans Die: A Century of Change

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	<u>1900</u>	<u>2000</u>
■ Age at death	46 years	78 years
■ Causes	Infection Accident Childbirth	Cancer Organ failure Stroke/Dementia
■ Disability	Not much	2-4 yrs
■ Financing	Modest	Substantial

# Why Palliative Care?



# Definition

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Palliative care is both a philosophy of care and a highly organized system for delivering care

Goal is to assure that each person experiences the best quality of life throughout the illness trajectory

# PALLIATIVE CARE

## What Is It?

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- Prevention and relief of symptoms including pain.
- Attention to emotional and spiritual needs
- Care for the patient and family as a unit
- Sensitive communication, goal setting and advance planning
- Interdisciplinary care

# WHAT DO WE DO?

- Pain management
  - physical
  - spiritual
  - psychosocial

Communication

Goal Setting

Bereavement

Psychosocial Support



# Where to provide palliative care?

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- Inpatient setting
- Outpatient setting
- Home
- Nursing home
- Hospice

# Hospice

## What is it?

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- A program designed to provide palliative care when life expectancy is six months or less
- Covered by Medicare and Medicaid
- Covered by private insurance plans with enhanced home care benefits
- Interdisciplinary team

# What does the hospice benefit cover?

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- Visits by team- usually not daily
- Medications related to hospice diagnosis
- Durable medical equipment
- Respite Care
- Emergency/continuous care in the home or nursing home
- Hospitalization for acute symptom management
- One year of bereavement support for family
- Does not cover custodial care

# Caring for patients near the end of life – why is it so hard?

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- Uncertainty about prognosis
- “Do no harm” -- truth telling vs. hope
- Insufficient training – symptom management, communication
- Suffering is emotionally difficult
- Medical culture – death as a failure

# Barriers to Palliative Care: Related to Providers

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Uninformed about prognostic factors

Uninformed about pain treatment

- e.g. how to assess pain, use opioids

Poor or no training in end-of-life care

Communication skills

Cultural insensitivity

Fear of ethical, legal, or religious impropriety

Fear of accelerating death

Fear of litigation

- Not “doing everything”
- Fear of going against family wishes

Personality deficiencies

- ego, arrogance, abuse of power

# Barriers to Palliative Care: Related to Patients

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- Difficulty accepting impending death
  - Expectation of miracles
  - Inability to “give up hope”
  - Fear of talking about death
  - Fear that “giving up” = personal weakness
  
- Fear of the impact of a death at home
  
- Failure to discuss advance care plans

# Barriers to Palliative Care: Related to Health Care System

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- Increased number of hospital beds correlates to increased hospital deaths.
  - *“if you build it, they will come!”*
- Lack of organizational structure to support excellent end of life care in all care settings.
- Financial disincentives exist that force care toward aggressive orientation.
- Resource allocation in outpatient setting

# Process to Support Palliative Care

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All center around communication

# Process Example

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Elicit goals of care

- Can change over time
- Describe decisions that need to be made now and the future

# Goal Setting—Key Principles

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- All end of life clinical decisions flow from an open discussion with the patient/surrogate about their illness, their prognosis and their future goals. Conversely, without such a discussion, appropriate decisions concerning end of life care cannot be made.
- The provider must be knowledgeable regarding the illness prior to the discussion:
  - Prognosis, Treatment options: Risks and Benefits, Achievable Outcomes

# Goals of Care

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- Solicit information
  - Condition and prognosis -- “What have the doctor’s told you about the situation?”
- Provide information
- Solicit values
  - Hopes, fears
  - Values towards end of life tradeoffs
  - “States worse than death”
- Deal with emotions

# Goals of Care

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*Language has unintended consequences!*

- “Do you want us to do everything possible?”
- “We can choose to do nothing.”
- “There’s really no hope.”
- “Will you agree to withdraw care?”
- “He’s failed all of the chemotherapy we’ve tried.”

# Process Example: Goals of Care

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- Set stage:

“Our common objective, yours as the family and ours as the professional care giving team, is to discover which of the options in front of us is most likely to help the patient (your father). We can share with you based on our medical experience what we believe is most likely to do this, but you have to help us understand what you think your dad would want based on who he is, what he values, and what his goals are at this point.”

# Process Example: Goals of Care

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***TEAM SHOULD FEEL  
COMFORTABLE MAKING  
TREATMENT  
RECOMMENDATIONS!!!!***

# Goals of Care

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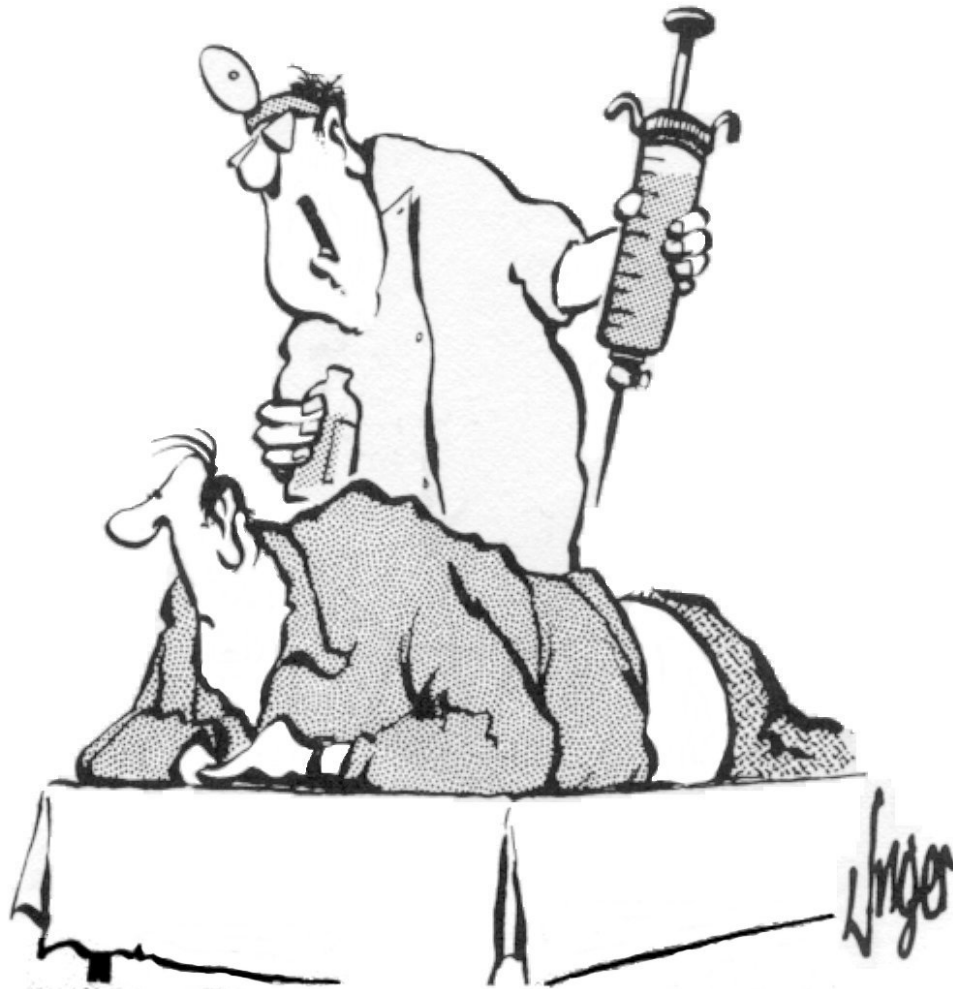
## *Leveling the decision making field*

- “We can shift the focus of our efforts towards maximizing his quality of life “
- “We are going to aggressively treat his symptoms so that he can remain comfortable.”
- “His comfort and dignity will be our top priority.”
- “Is there anything else we can do to help meet her or your needs?”

# Process Example

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- Improve pain management



**"I'll give you something to ease the pain."**

# Barriers to Effective Pain Management

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- Confusion of physical dependence with psychosocial dependence (addiction)
- Fear of tolerance- ‘taking strong medication early- it won’t work when I really need it’
- Fear of opioid toxicity
- The “Good Patient”
- Significance of pain

# Barriers to Effective Pain Management

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- “Tell me exactly how you are taking your medication?”
- “It must be so hard to take all these pills, in the last week how many times have you forgotten to take one or two?”
- Normalize the concern- “Some people fear they might become addicted if they take this medication, is that something you worry about?”
- Ask specifically about prior experience or family experience with opioids to clear misconceptions.
- Ask about side effects and educate about what to expect.

# Process Example

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- Develop criteria for care/family conferences (on admission, status change)

# Process Example

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- Determine if patient has decision making capacity
- Capacity a medical determination whereas competence a LEGAL term.

# Process Example

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- Identify and record surrogate decision maker and alternates.
- Ensure that decision maker is **AWARE** of their status and that they are **FAMILIAR** with patient wishes if at all possible.

# Process Example

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- Do not re-hospitalize
- Ensure all family involved in formulating plan of care aware of decision as well as members of health care team.
- Discuss hospice if not already discussed.

# Process Example

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- Identify professional point person responsible for coordinating care, talking with family
- Designate family member as point person for dissemination of information.

# Palliative Home Care

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- Why
- Staff education
- Conversation approaches

# FairCare Model

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- Builds knowledge and communication skills to discuss specifics in end-of-life situations
- Step by step guide to help people find dignity, choice and inner peace as advanced illness progresses
- Respects and supports individual while forming a comprehensive guide to end-of-life situations
- Created to meet needs and unrealized opportunities in the lives of the dying

# FairCare Model con't.

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## 1. Individuality

- Tell me the story of your medical history!
- What has your doctor told you about your illness?
- What has happened since the?
- Tell me where you grew up and where you have lived?
- What is/was family like?
- Where did you go to school?
- Marriage? Children?
- How are you coping with all this?
- What do you understand as your treatment options, prognosis?
- Does spirituality play some role in your life?

# FairCare Model con't

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## 2. Fears

- What if anything, are you worried about or afraid of?
- Do you have any fears about your illness getting worse?
- If you've lost family members or other loved ones, how did they die?
- What was that like for you?
- What are your loved ones' fears about your illness?
- How can we help you to take more control of your situation?

# FairCare Model con't.

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## 3. Practical Issues

- Are you comfortable talking to your doctor about your options?
- Can we schedule a family meeting with everyone in your family to discuss what is going on?
- How are you dealing with recent changes in your health?
- Tell me about the practical problems your illness is creating for you.
- Have you thought about setting up a Living Will and Health Care Proxy?
- Have you considered any legal, financial or other practical issues that need to be resolved?

# FairCare Model con't.

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## 4. The Turning Point

- This must be a tough time. I'd like to know how it is for you?
- Have you and your family thought about not continuing aggressive care in the future?
- Whatever you decide is right for you. There are options that allow a person to ask for comfort care when the time is right. Hospice or home care directed towards comfort may be something to consider.
- How are you doing with this? Do you think you are depressed?
- How are things going for you and your family with this illness?
- There is a great deal we can do to help you be comfortable.

# FairCare Model con't.

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## 5. Finding Peace

- Let's be certain your family and your doctor are with you on your decision to get comfortable.
- I am so glad that you (the family or significant others) are able to come to this meeting.
- Have you thought about where you want to be when you slow down?
- Can someone care for you at home?
- What is your pain level (1-10)?
- Let's discuss what dying might be like.
- Is anything weighing on your mind:
- Are there things you want to do before you are too weak?
- There are many ways to find peace of mind in this dying process. Do you want to look at some of them?

# Resources

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- Growthhouse [www.growthhouse.org](http://www.growthhouse.org)
- [www.getpalliativecare.org](http://www.getpalliativecare.org)
- End of Life/Palliative Education Resource Center (EPERC) [www.eperc.mcw.edu](http://www.eperc.mcw.edu)
- Center to Advance Palliative Care  
[www.capc.org](http://www.capc.org)
- Hospice [www.nhpco.org](http://www.nhpco.org)

# Summary

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- **Goal:** Relief of suffering  
Maximize quality of life

**Challenge:** How can we achieve these goals  
for our patients

# Contact Information

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# Questions?

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