HOW TO TALK TO YOUR PATIENTS ABOUT PALLIATIVE CARE

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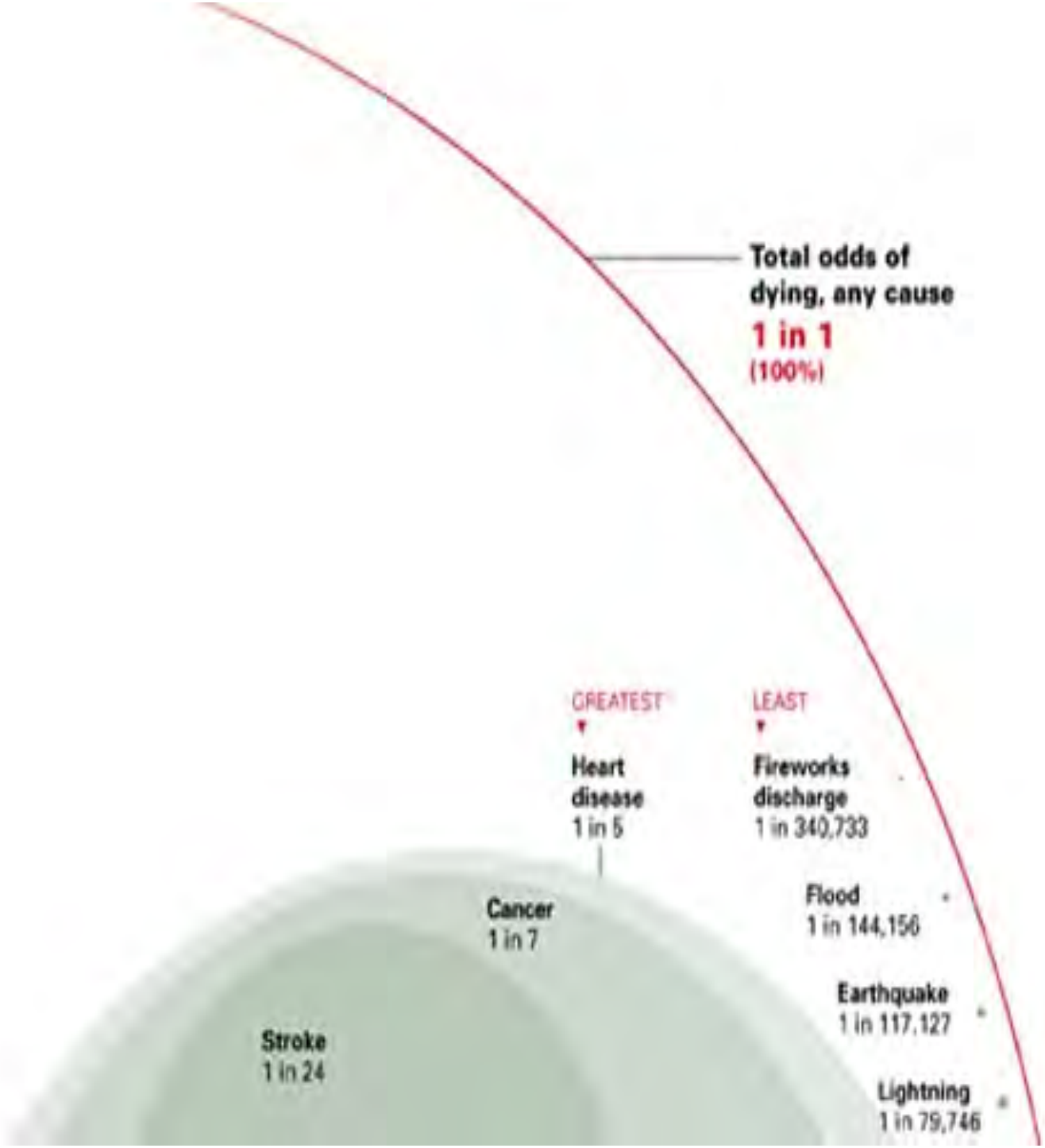
LEARNING OBJECTIVES

- Understand and define palliative care and hospice
- Perform a comprehensive assessment for prognostication
- Apply effective approach and strategies in communicating palliative care with patients, families, and other healthcare professionals

HUMAN CYCLE: From Birth To Death


Total odds of dying, any cause
1 in 1
(100%)
GREATEST
LEAST
Heart disease
1 in 5
Fireworks discharge
1 in 340,733
Cancer
1 in 7
Flood
1 in 144,156
Earthquake
1 in 117,127
Stroke
1 in 24
Lightning
1 in 79,746

A CENTURY OF CHANGE

RAND Health, 2003

	1900	2000
Life expectancy	47 years	75 years
Usual place of death	Home	Hospital
Most medical expenses	Paid by family	Paid by Medicare
Disability before death	Usually not much	Average 2 years

HEALTHCARE EXPENSE OVER A LIFE SPAN

RAND Health, 2003

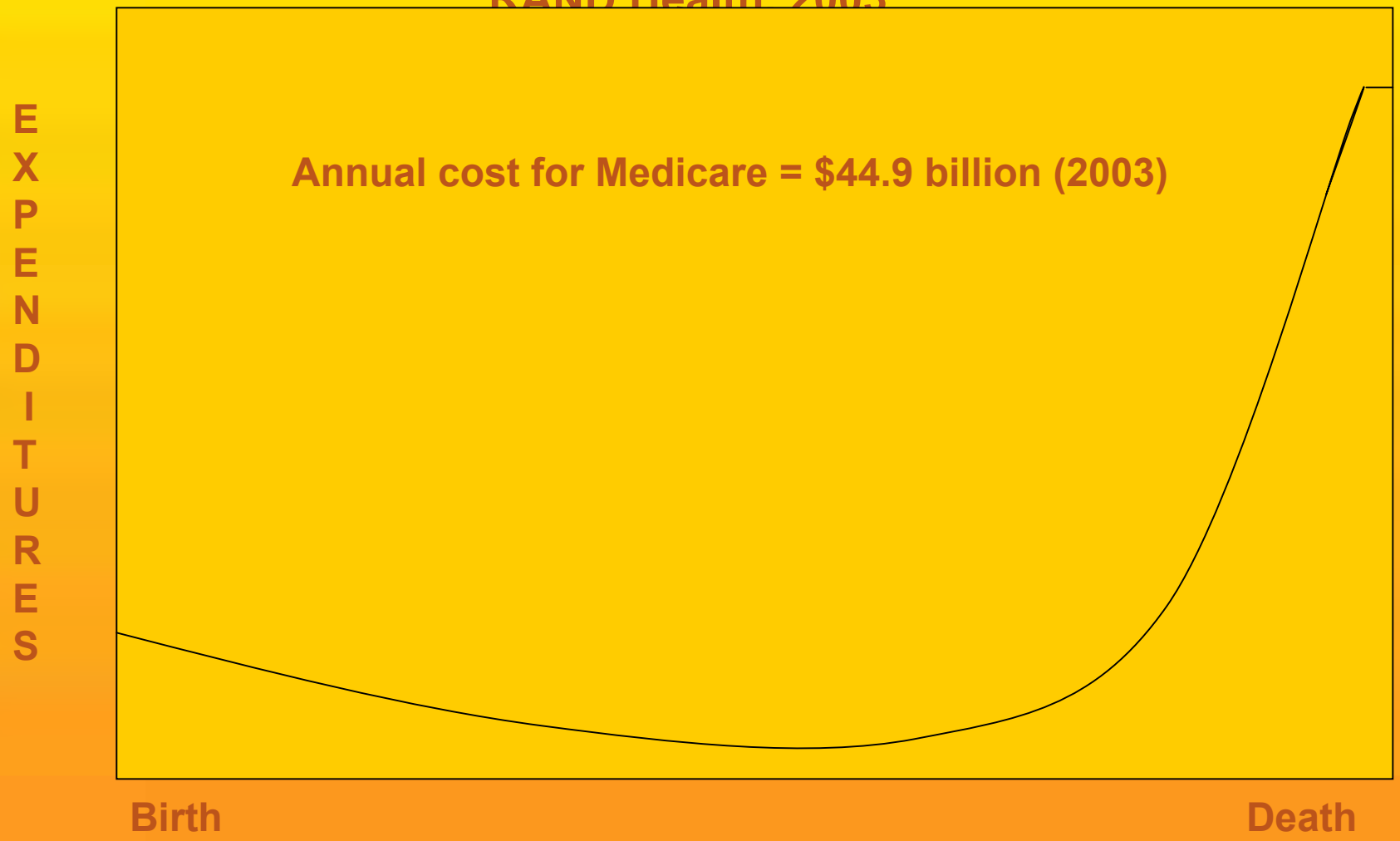


Figure 1: A dichotomous intent

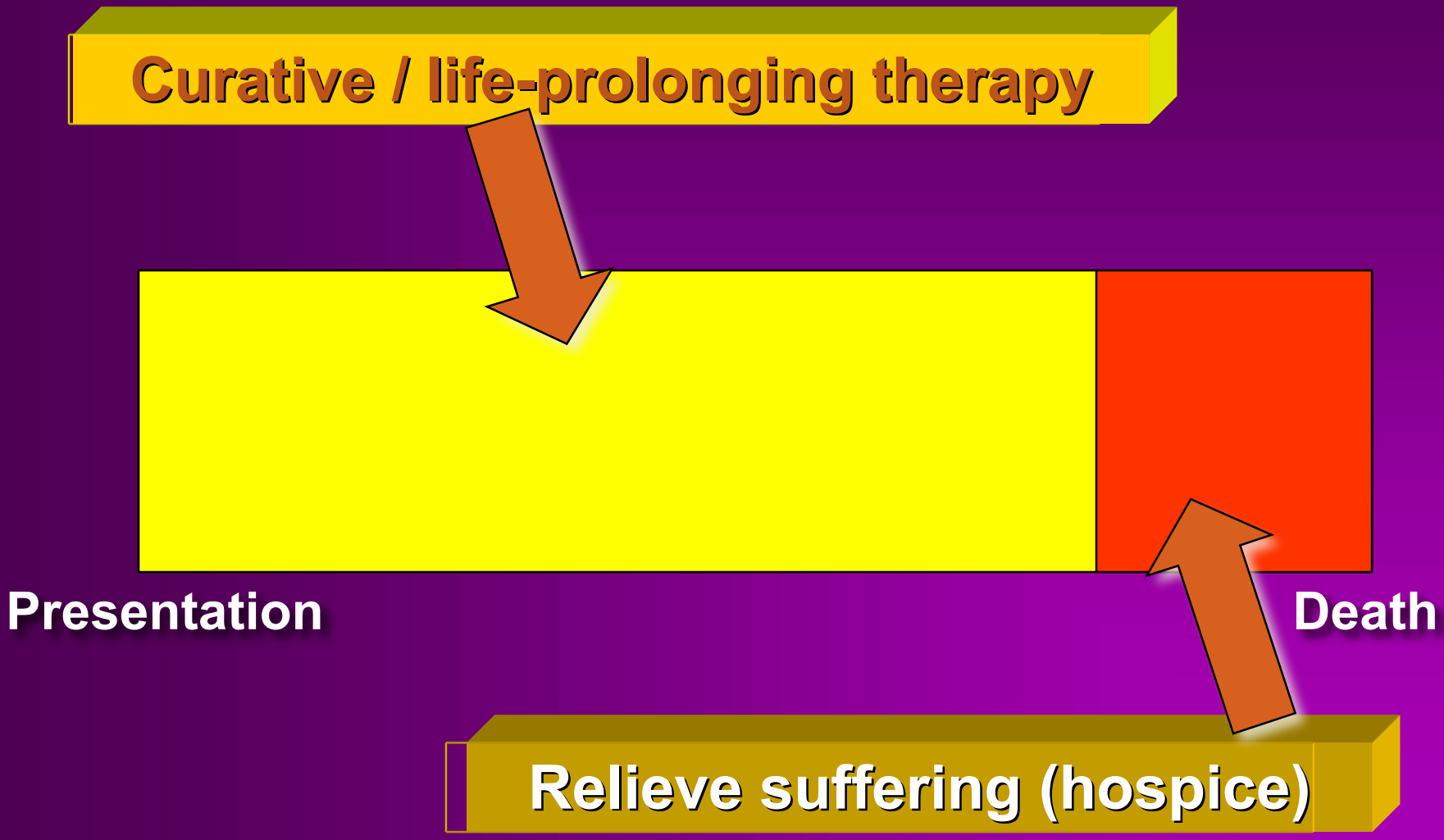
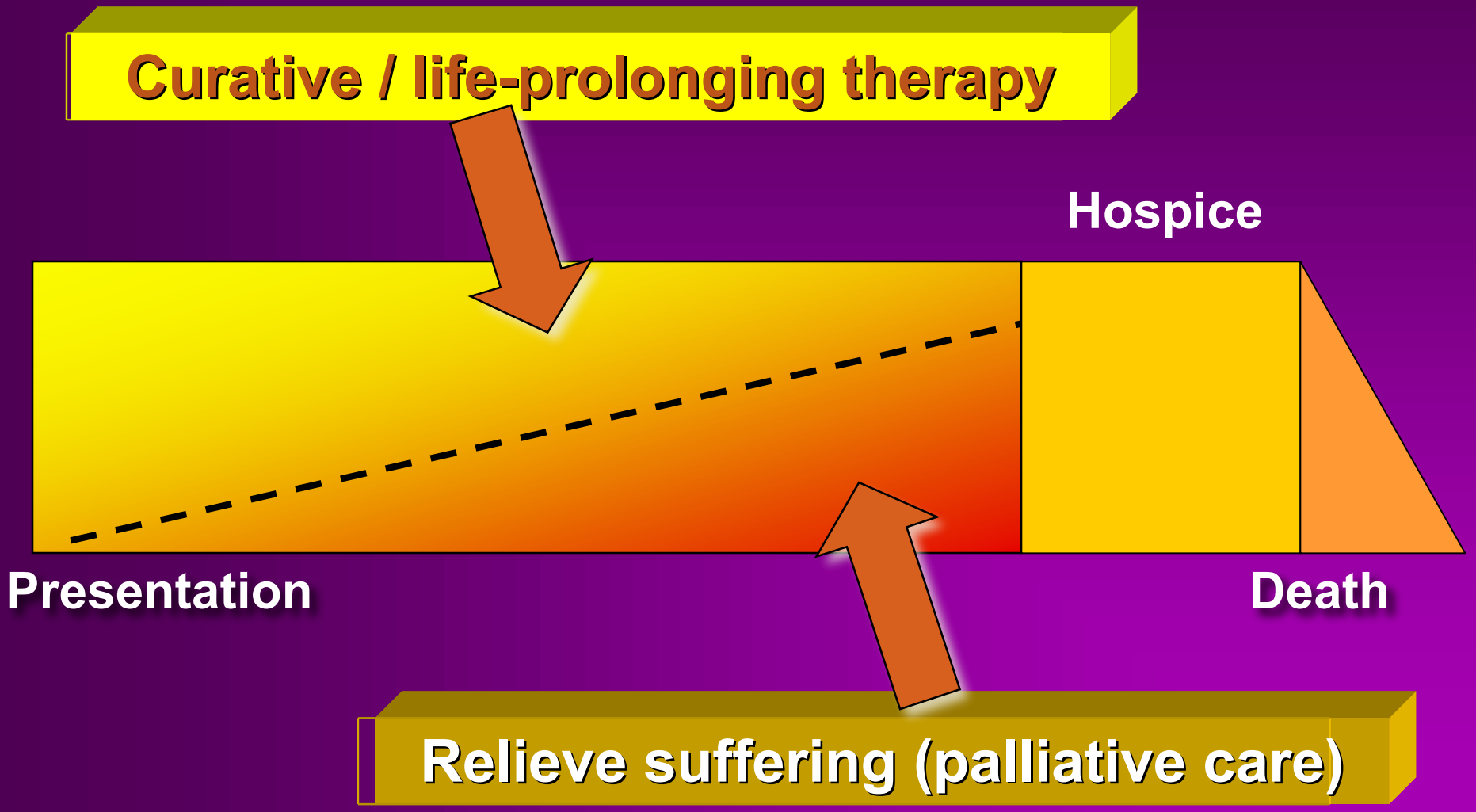


Figure 2: The interrelationship of therapies with curative and palliative intent



PALLIATIVE CARE DEFINITION under NYS LAW

- Palliative care: “health care treatment, including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient’s quality of life, including hospice care.”

PHL

2997-c

PALLIATIVE CARE DEFINITION: WHO 1990

- The active total care of patients whose disease is not responsive to curative treatment.
- Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount.
- Achievement of the best quality of life for patients and their families.

PALLIATIVE MODEL of MEDICAL CARE

- Goals of palliative medicine
  - Prevent and relieve suffering
  - Support for the best quality of life
- Whole-person care
- A philosophy of care and an organized, structured system of care delivery
- Interdisciplinary team

HOSPICE CARE in the U.S. HEALTHCARE SYSTEM

- Medicare benefit
- Application of palliative care near the end-of-life
- Requirements:
  - Prognosis of less than 6 months
  - 2 certifying physicians
  - Patient consent

	CURATIVE CARE	PALLIATIVE CARE
Goal of care	Cure	Relief of suffering
Object of analysis & treatment	Disease process, collection of parts	Patient & family, psychosocial, spiritual, physical
Symptoms	As clues to diagnosis	As entities in themselves
Information value	Objective, measurable, verifiable data	Objective & subjective data + patient's illness experience
Therapy indication	Cure or delay progression	Control symptoms, relieve suffering
Outcome value	**Death is the ultimate failure!**	**Patient living fully, comfortably till death is a success!**

PROGNOSTICATION

- Only 20% accurate
- FUNCTIONAL ABILITY: single most important predictive factor

FUNCTIONAL ASSESSMENT

Activities of Daily Living (ADLs)	Instrumental Activities of Daily Living (IADLs)
D – Dressing	S – Shopping
E – Eating	H – Housekeeping
A – Ambulating	A – Accounting
T – Toileting	F – Food Preparation
H – Hygiene	T – Telephone/ Transport

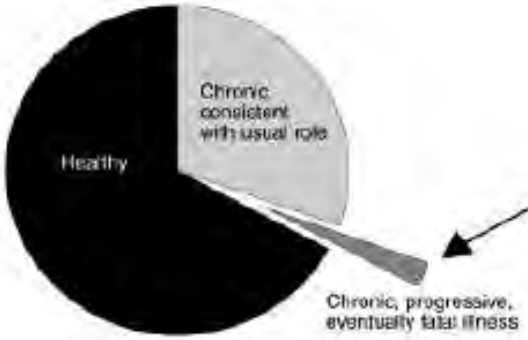
FUNCTIONAL PERFORMANCE SCALE

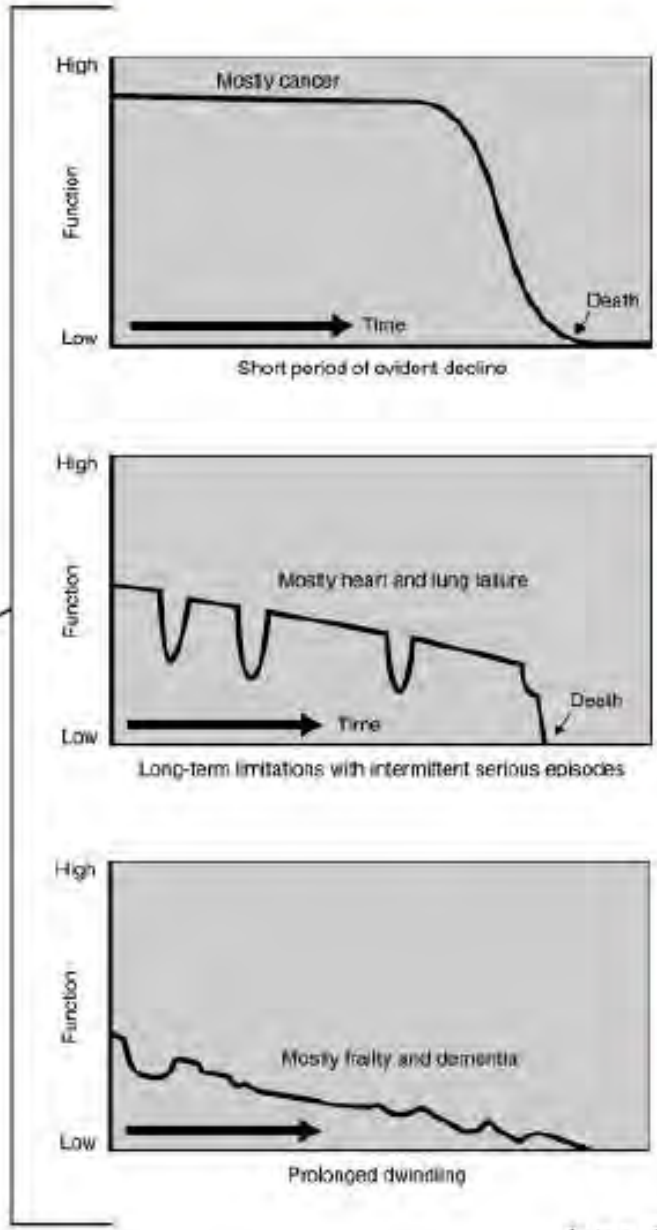
ECOG	Description	KARNOFSKY
0	Normal, no symptoms	100
1	(+) symptoms, self-care	70 – 90
2	In bed < 50% waking hrs	50 – 60
3	In bed > 50% waking hrs	30 – 40
4	In bed 100% waking hrs	10 – 20
5	Moribund, death	0

DYING TRAJECTORY:
Accidental, Catastrophic Death

Typical Patterns of Decline over Time in Different Chronic Conditions

Herz-Kreislaufzentrum Würzburg





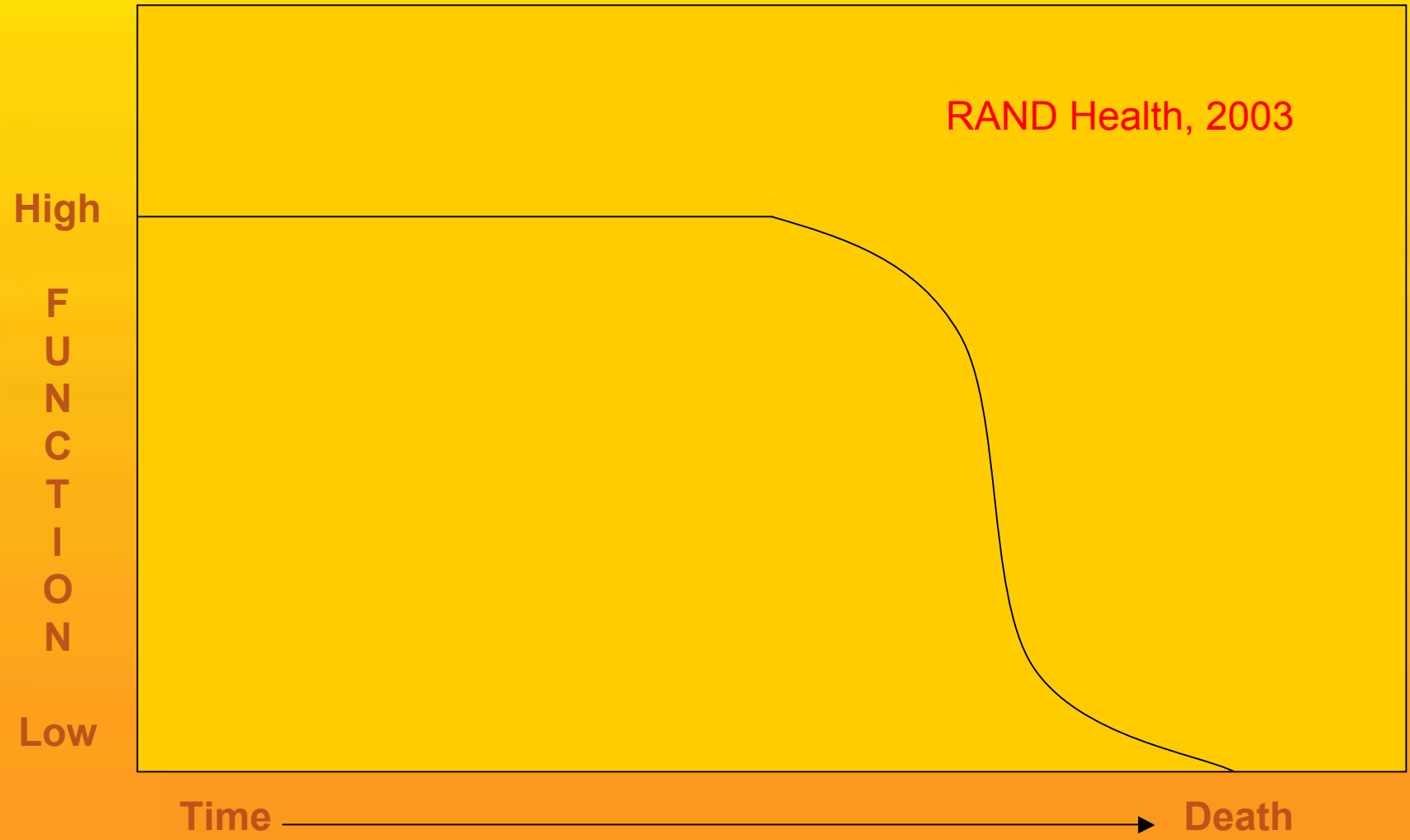
Short period of evident decline - typical of cancer

Long-term limitations with intermittent exacerbations and sudden dying - typical of organ system failure like CHF

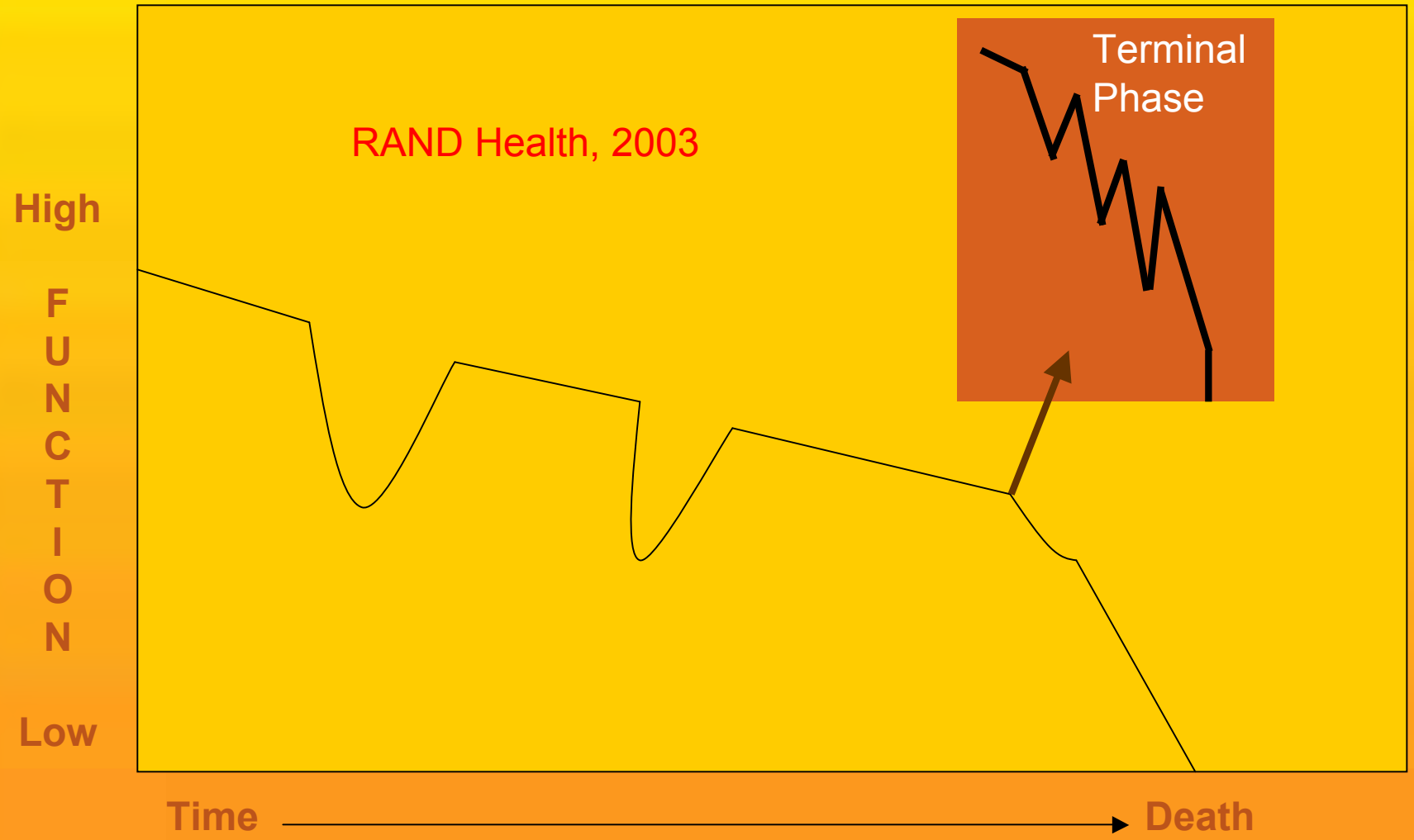
Prolonged dwindling – typical of dementia, disabling stroke, and frailty.

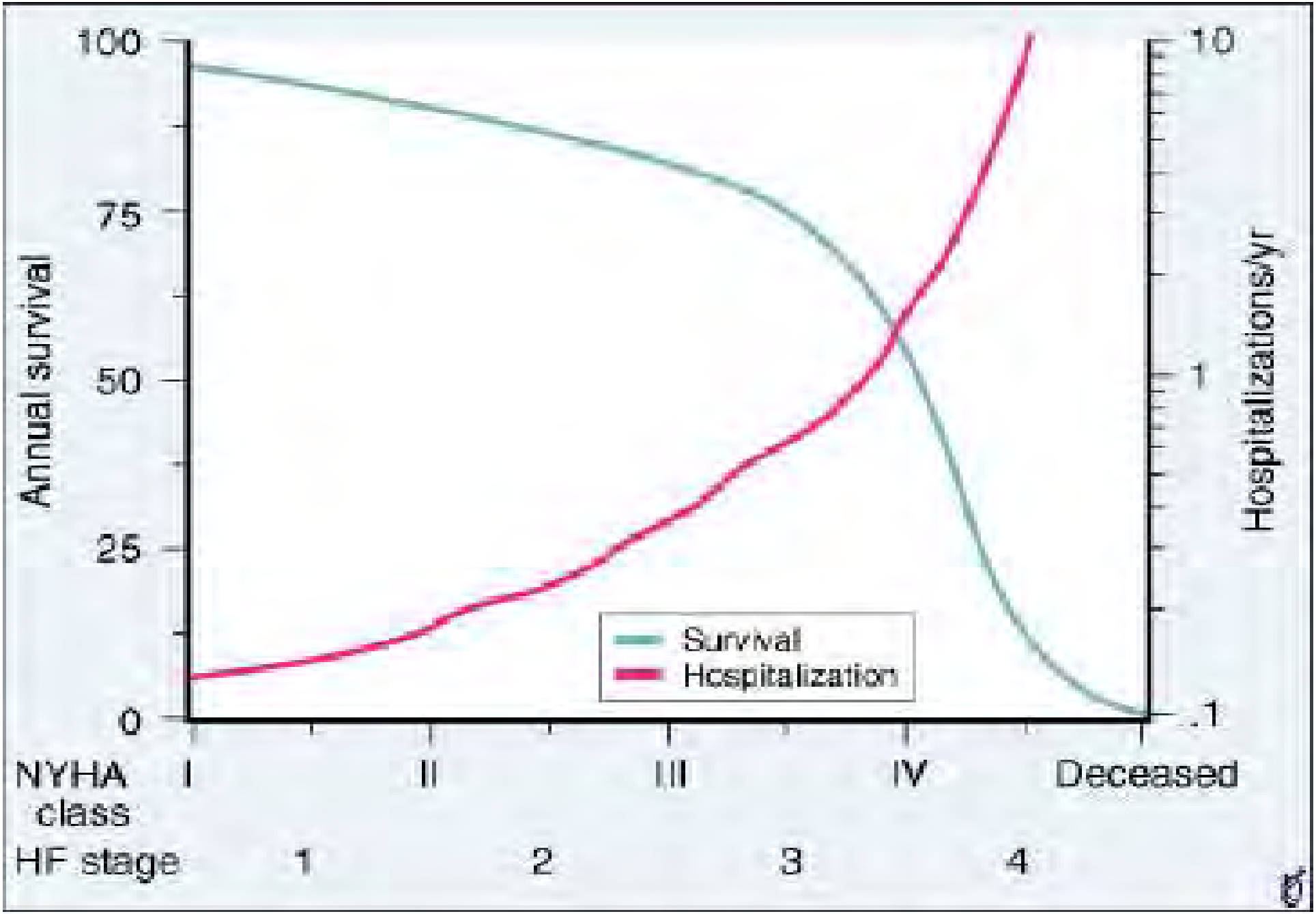
Lynn J. et al; White Paper 2003: WP-137

DYING TRAJECTORY: Cancer Death

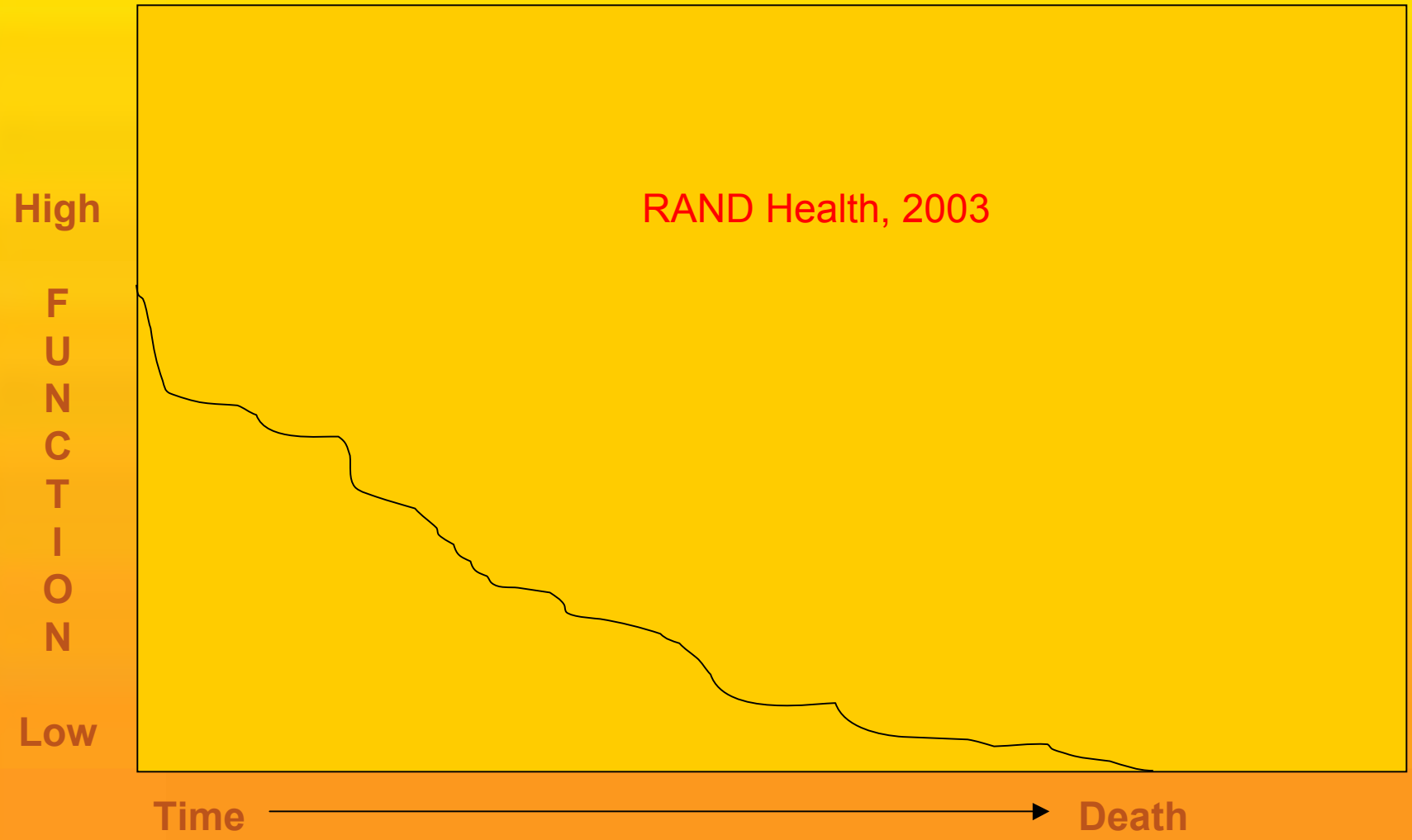


DYING TRAJECTORY: Organ Failure





DYING TRAJECTORY: Neurological, Dementia



PROCESS & DEVELOPMENT of PROGNOSIS & PLAN of CARE

- **P** – Perform a thorough review of the patient's history and life story
- **L** – Look at objective data
- **A** – Assess information
- **N** – Negotiate the treatment goal

COMMUNICATION

"Things went from bad to worse, but we're hopeful now that things are going badly again."

3 MOST COMMON ELEMENTS

- Transmitting medical information
  - Sharing good and bad news
- Engaging in therapeutic dialogue
  - Exploring patient's and family's dealings and deepest concerns
- Making decisions with patients and their families

ROLE OF PHYSICIANS

- *"Appropriate treatment for a patient need not include every effort to prolong life regardless of its quality, and what could be done for a patient with an acute remediable condition may be burdensome for one who is terminally ill."*

ROLE OF PATIENTS

- Develop renewed sense of personhood and meaning
- Bring closure to relationships
- Bring closure to worldly affairs
- Accept the finality of life and surrender to the transcendent

ROLE OF THE FAMILY

- Help dying person be as independent as possible
- Help steward financial & human resources
- Allow to die in place of choice whenever feasible
- Work with Palliative/ Hospice Care team
- Call for help
- Express as much love, caring, forgiveness

STRATEGIES FOR EFFECTIVE COMMUNICATION

- Understand nonverbal communication
- Encourage patients to talk and listen to what they say
- Respond with empathy
- *Use appropriate humor*

DISCUSSING PALLIATIVE CARE

1. Establish Proper Setting
   - Private
   - Comfortable
   - Everyone seated
   - Turn off/ forward pager/ phone
   - Encourage patient to bring family
   - Have tissues available
   - Encourage staff members to participate

DISCUSSING PALLIATIVE CARE

2. Introductions
   - Allow everyone to state name and relationship to patient
   - Build relationship/ rapport

"Can you tell me something about your father? What kind of person is he?"

DISCUSSING PALLIATIVE CARE

3. Assess Patient/ Family Understanding
   - Encourage all present to respond
   - Ask for a description of changes in function over course of illness

"What is your understanding of your current medical situation?"

DISCUSSING PALLIATIVE CARE

4. Medical Review/ Summary
   - Summarize “big picture” in few sentences
   - Use “dying” if appropriate
   - Avoid organ-by-organ medical review
   - Avoid medical jargon
   - Answer questions

DISCUSSING PALLIATIVE CARE

- *"I'm afraid I have some bad news and I wish things were different. Based on your over-all condition and what I see, there is a high likelihood of dying."*

DISCUSSING PALLIATIVE CARE

5. Silence/ Reactions
   - Respond to emotional reactions
   - Prepare for common reactions: acceptance, conflict/ denial, grief/ despair, anger
   - Respond empathetically

"This must be very hard. I can imagine how scary/ difficult/ overwhelming this must be."

"You appear angry; can you tell me what upsets you most?"

DISCUSSING PALLIATIVE CARE

6. Discuss Prognosis
   - Assess how much patient and family want to know
   - Provide prognostic data using a range
   - Respond to emotions

"Some people like to know every detail about their illness, others prefer a more general outline or would defer to the family for decisions. What kind of person are you?"

"Although I can't give you an exact time, given your illness and condition, I believe you have (hours to days) (weeks to months). This is an average, some live longer and some live shorter."

DISCUSSING PALLIATIVE CARE

7. Assess Patient/ Family Goals
   - Prolong life
   - See a family milestone
   - Improve function
   - Relief of suffering
   - Staying in control
   - Return home

"Knowing that time is short, how do you see yourself spend that time?"

"Are there any important goals or tasks left undone?"

DISCUSSING PALLIATIVE CARE

8. Present Broad Care Options
   - Stress priority of comfort, no matter the goal
   - Make a recommendation based on knowledge/ experience

"Given what you have told me, I would recommend…"

"How will the decision affect you and other family members?"

DISCUSSING PALLIATIVE CARE

9. Translate Goals Into Care Plan
   - Review current and planned interventions
   - Make recommendations to continue or stop based on goals
   - Discuss DNR, Hospice/ Home Care, Artificial Nutrition/ Hydration, Future Hospitalizations
   - Summarize all decisions made

CONFIRM YOUR CONTINUED AVAILABILITY REGARDLESS OF DECISIONS

DISCUSSING PALLIATIVE CARE

10. Document and Discuss
    - Write a note: who was present, what decisions were made, follow-up plan
    - Discuss with staff members, including consultants
    - Check your emotions
    - Ask staff members

"How do you think the meeting went? What will you do differently in the future?"

MANAGING CONFLICT

Listen and make empathic statements

- Determine source of conflict: guilt, grief, culture, family dysfunction, lack of trust, etc.
- Clarify misconceptions
- Explore values behind decisions

MANAGING CONFLICT

- Set time-limited goals with specific outcomes
  - Improved cognition
  - Mobility
  - Oxygenation
- Decisions on goals of care and code status is a process

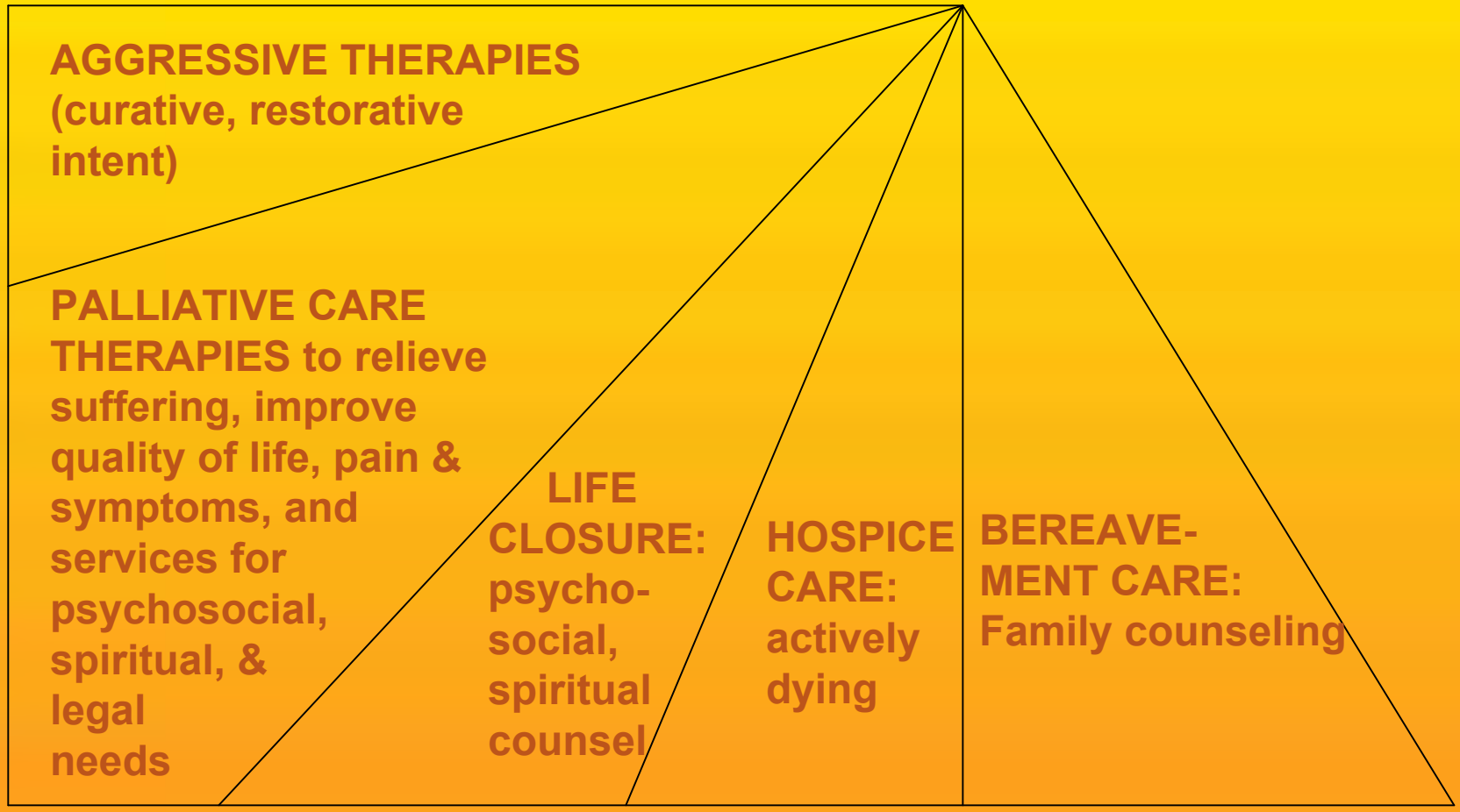
STRATEGIES TO IMPROVE SKILLS

- Know your personal strengths and weaknesses
- Use appropriate language
- Appropriate use of silence and empathic response
- Develop a script
- Develop confidence

TAKE HOME POINTS

- Recognize opportunities for discussion and integration of palliative care in clinical practice
- Use of a mental protocol will assist in discussing palliative care
- Effective communication with patients and families is therapeutic and often resolves conflict
- Consider Palliative Care Consult if you need additional assistance
- **Practice, Practice, Practice!**

CONTINUUM OF CARE



Daniel Callahan, *adapted from*
The Troubled Dream of Life

- *A medicine that embodies an acceptance of death would represent a great change in the common conception, and might set the stage for viewing the care of dying people not as an afterthought when all else failed but as one of the ends of medicine.*
- *The goal of a peaceful death should be as much a part of the purpose of medicine as the promotion of good health. That means medicine must abandon the modern cultic myth that in the cure of disease lies the cure of death…*