Advance Care Planning

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Objectives

- Describe the modern healthcare environment and its effects decision making
- Define advance care planning (ACP)
- List 5 steps to successful ACP
- List two resources for ACP

Disclosures

No Relevant Financial Relationships
with Commercial Interests

No Conflicts of Interest

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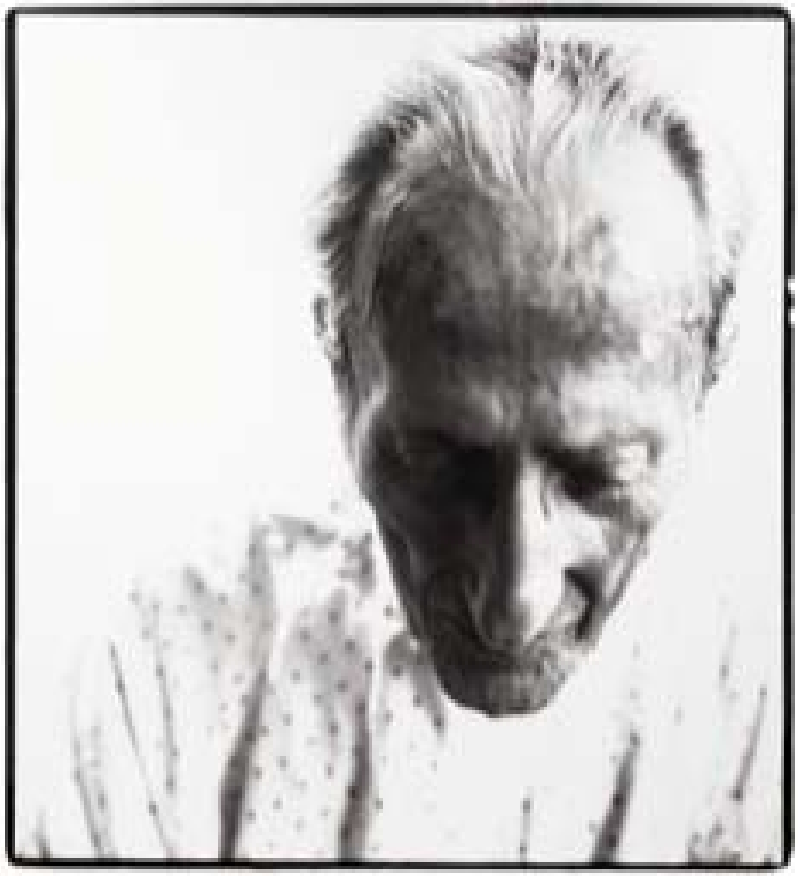
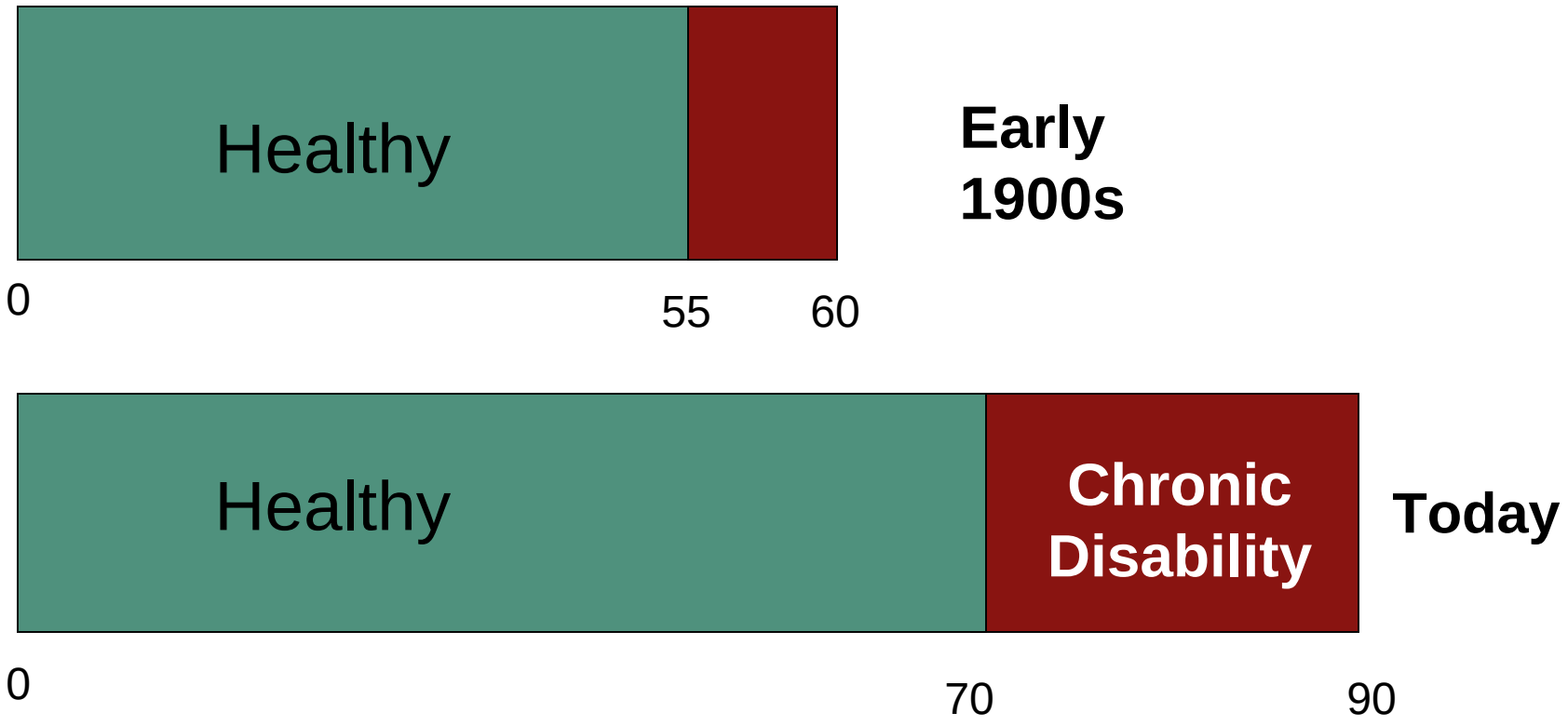
Societal Demographics

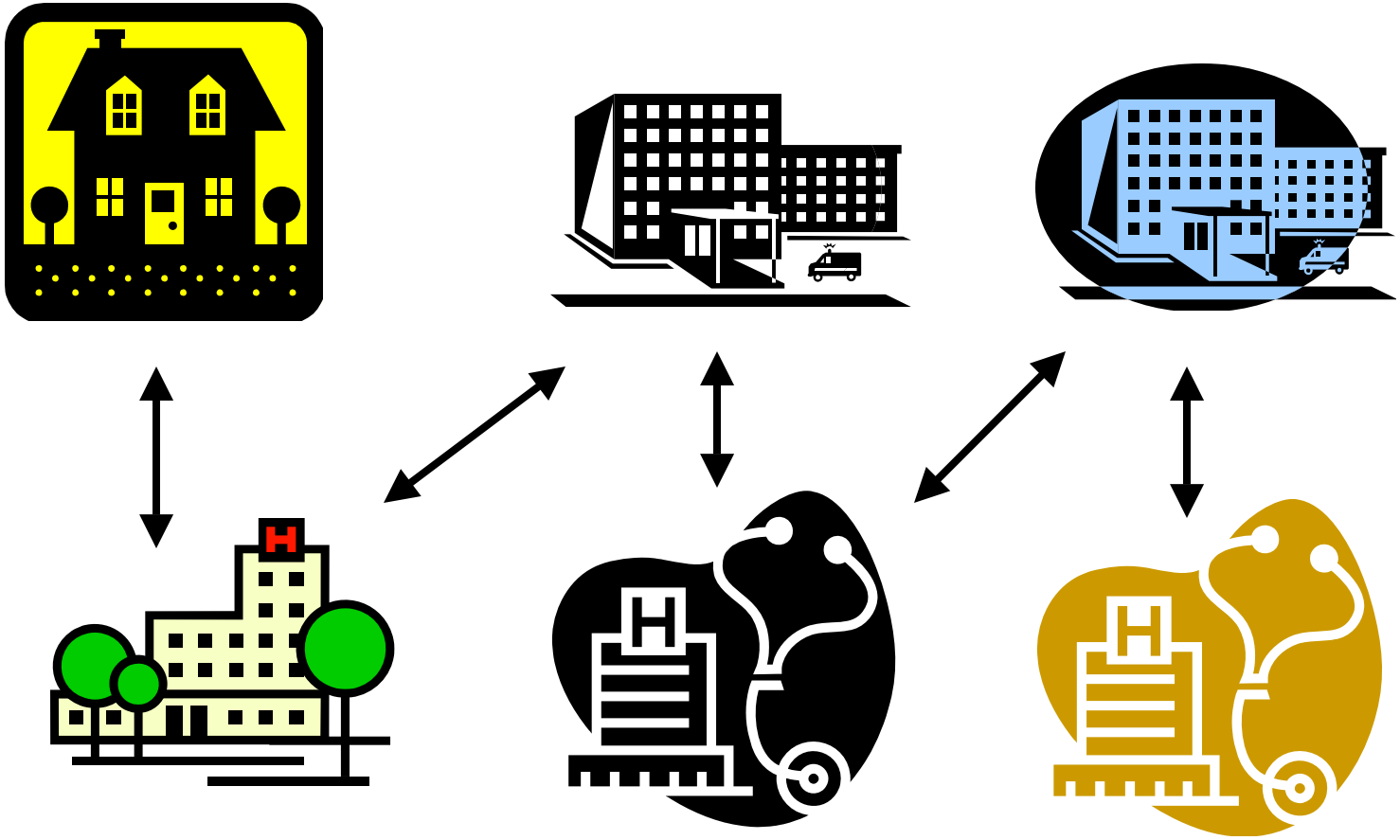
- Society is aging
- Life span has increased
- Patients live longer with chronic diseases
- Health care costs are increasing



Effects of Health Advancements: Patients are Older and Sicker



Healthcare Today



Healthcare Today:

Quality Improvements:

- Hospitalist movement
- Intensivist movement
- Resident work hour restrictions
- Sub-specialization of medicine

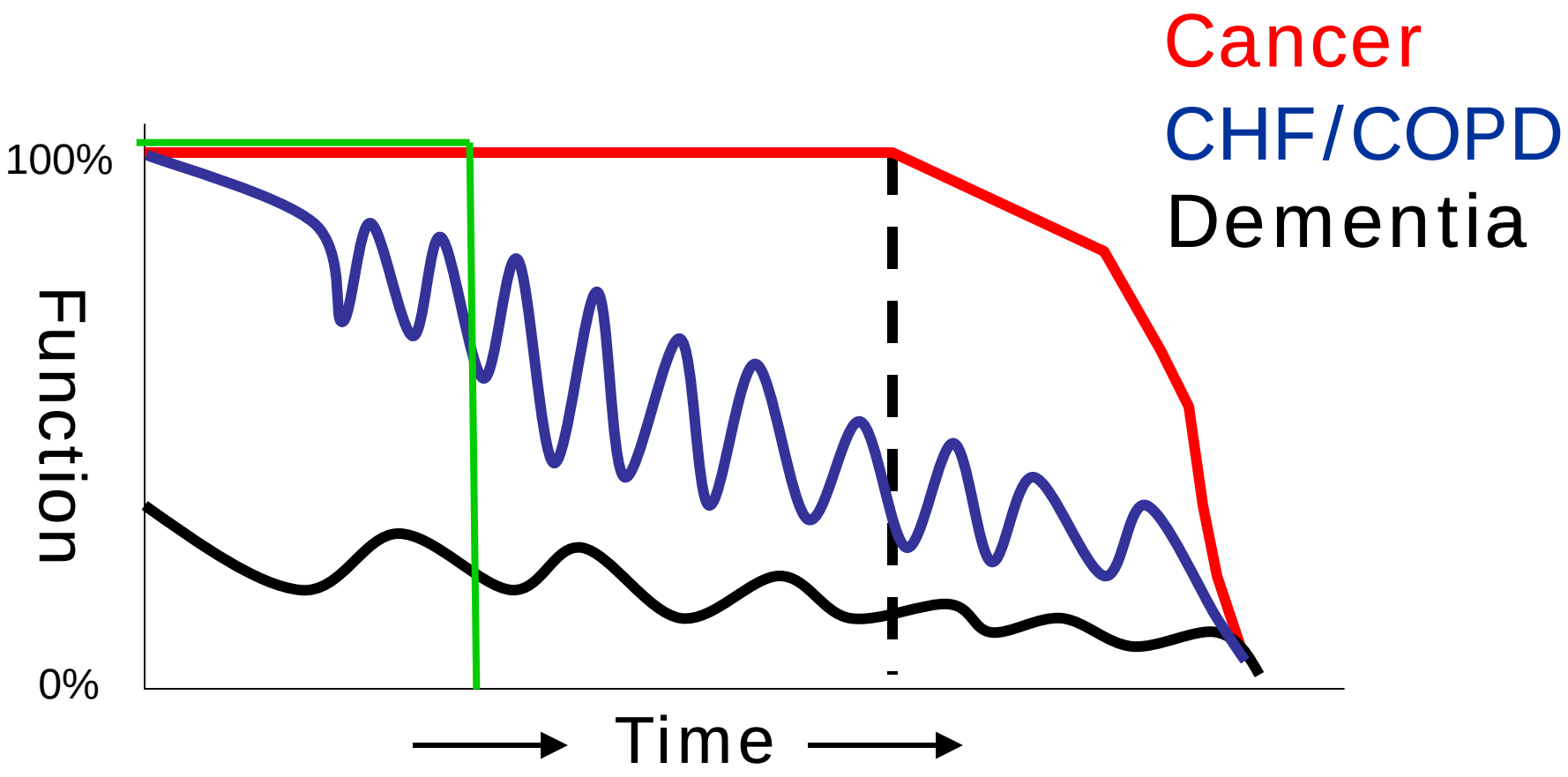
Consequence:

Fractured Patient Care

Healthcare Today: Patient Perspective

- *"Who is my doctor?"*
- *"Why doesn't my regular doctor ever come?"*
  - *"Has anyone called their office?"*
  - *"Do they know I am here?"*
  - JAMA "My Turn"
- *"Mom hasn't been good for a while…"*
  - Take the long view
  - When do debility & chronic decline become dying?

Trajectories of Illness



JAMA. 2003;289:2387-2392.

Healthcare Today:

- Forrest or tree?
- Paid more to do than to avoid

Medical Care for the Older Adult

Anticipatory Guidance & Advance Care Planning are Key!

- Educate on usual disease course
- Describe possible complications
- Normalize weight loss
- Discuss artificial feeding/hydration early
- Assess social/financial needs of pt/family
- Empower patient and family to be advocates in a complex medical system
- Define quality of life

Advance Care Planning (ACP)

- At its core, ACP is about values
- Each one of us has a sense of:
  - who we are
  - what we like to do
  - control we like to have
  - goals for our lives
  - things we hope for
- Goal of ACP is to elicit health care values,
  Aka "Goals of Care"

Goals of Advance Care Planning:

- Goal is to understand patient and their values
- #1 Establish Healthcare proxy
  - This is key goal in outpatient setting, where many non-geriatric patients will be full code
- Promote patient autonomy and control
- Create trust between clinician and patient
- Avoid future confusion and conflict
- NOTE: Goal is NOT to get the DNR!

What is meant by Goals of Care?
Goals of Care = Patient Values

- Cure disease
- Avoid premature death
- Maintain or improve function
- Prolong life
- Avoid pain
- Avoid dependence
- Improve life quality
- Stay in control
- Support for families & loved ones support

Goals may change as illness evolves

Instruments Used in ACP

1) Instructions for Medical Care
   - Verbal statements
   - Personal letter or value statement stating preferences
   - Physician notes
   - **Living will**

2) Designation of decision maker
   - Health Care Proxy or Agent
   - Surrogate
   - **Durable Power of Attorney for Health Care**

"Advance Directives"

Decision Making & Dementia: More Challenging?

- Is dementia a terminal illness?
- Can the patient speak for themselves?
  - Capacity?
  - Communication difficulties? (Aphasia?)
  - Advanced Directives?
- Does their surrogate understand the disease evolution? The patient's wishes?
- How can we prognosticate accurately?

Decision Making

- Straight-forward (?)
  - End-stage dementia
  - Advanced dementia with other terminal illness
  - Early dementia with early stages of other chronic illness
- Challenging
  - Moderate dementia with other chronic illnesses
  - Mild – moderate dementia with other terminal illness
  - Dementia, infection and delirium +/- terminal illness

Tube feed or not tube feed? That's the question

- The facts:
  - Effect on life span?
  - Increases suffering? Morbidity?
- Need for better pt/family education
  - Discussing benefits and burdens of therapy
  - Use neutral language
  - Separate facts from your opinion
    - Please offer your opinion

Tube Feeds: The Evidence

- No evidence for
  - Decreasing aspiration risk
  - Improving nutritional status
  - Decreasing risk of pressure sores
  - Prolonging survival
    - 60% mortality at 6 months
  - Improving quality of life
- Lower rates of PEG placement with prior advance care planning

Effective Advance Care Planning: 5 Steps

1. Introduce the topic

- Be straightforward, calm, routine, positive

- *"Do you smoke or drink alcohol? What do you do for a living? Do you have a living will?"*
- *"We know what our Plan A is, I would like to talk about a Plan B."*
- *"I want to help you achieve what you want out of your health care. I want you to achieve your goals."*

Effective Advance Care Planning: 5 Steps

2. Structure discussion
   - Determine proxy first, elicit values, describe scenarios and options for care; consider worksheets
3. Document patient preferences
4. Review, update
5. Apply directives when need arises

Goals of Care Family Meeting

- Convey to patient/family:
  - Scope of illness
  - Usual disease course
  - Prognosis
    - Know the facts
- Define “acceptable” and “unacceptable” quality of life from pts view

Goals of Care Family Meeting

Define choices to be made, benefits and burdens of each choice

- Limits of technology
- Not everything is a choice

Anticipatory guidance

- ***"My kidney doctor told me I wouldn't survive a code blue."***

OK to give an opinion!

CPR on TV: Where Pts get their data

- **97 TV** episodes reviewed
- **60 CPR** occurrences
- CPR usually caused by trauma, only 28% caused by cardiac etiology
- 75% of patients survived the immediate arrest
- 67% of patients appeared to survive to hospital discharge

Diem SJ et al. NEJM 1996; 334:1578-82

Prognosis Key to Informed Decisions

371 adults 60+ y/o asked about DNR

- 41% wanted CPR at baseline
- Only 22% wanted it after learning true probability of CPR
- Hypothetical life expectancy <1 yr: only 5% wanted CPR.

Murphy DJ, et al. NEJM. 1994;330:545-49.

CPR and Hospital Discharge:

- **Factors predicting survival:**
  - Myocardial infarction
  - Coronary heart disease
  - Hypertension
- **Factors predicting <u>failure</u> to survive to d/c:**
  - Sepsis the day prior to the CPR event
  - Serum creatinine >1.5 mg/dl
  - Metastatic cancer
  - Dementia
  - Dependent status

Phrases to Avoid:

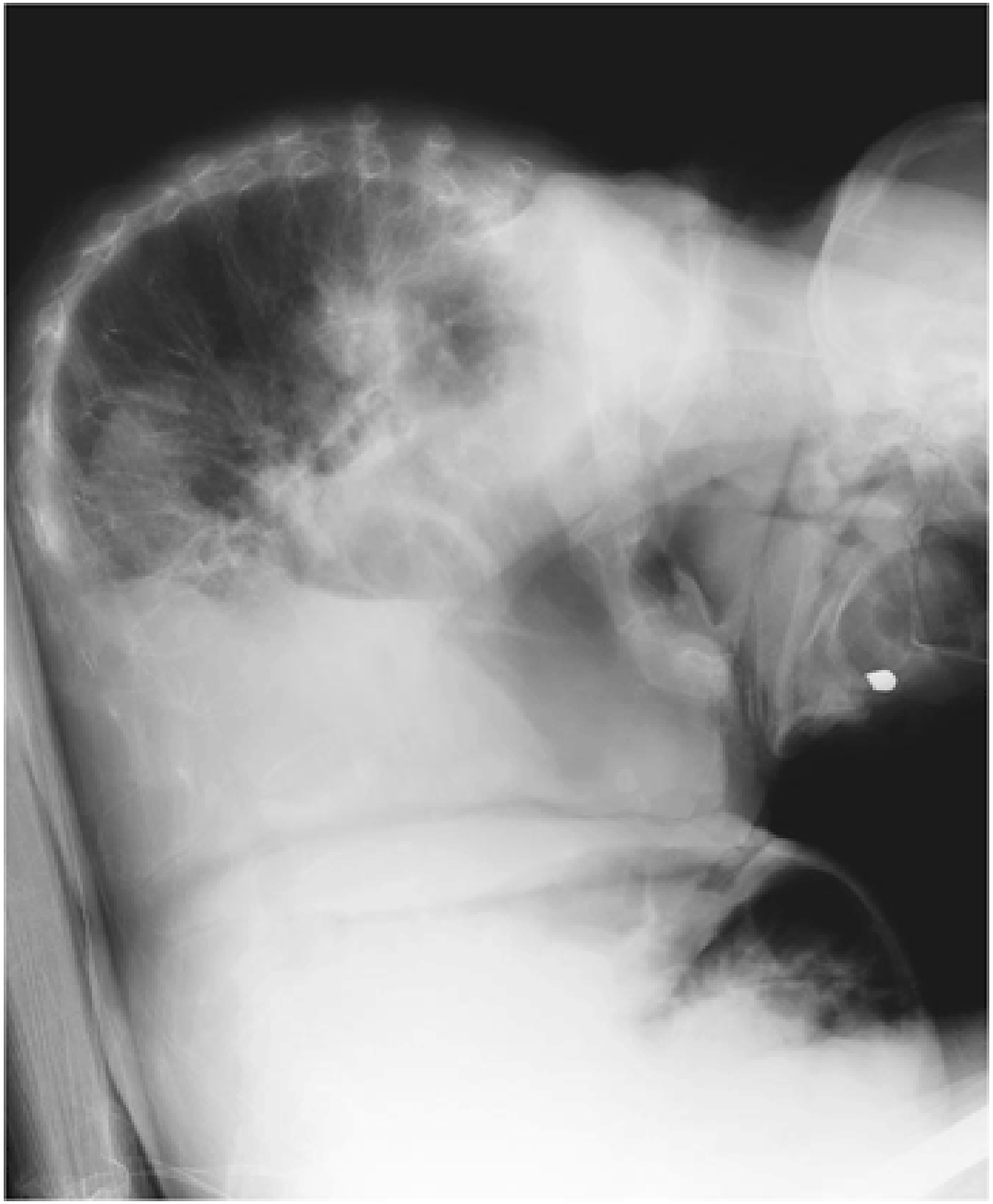
- *“Do you want us to do everything?”*
- *“Do you want us to start your heart if it stops?”*
- *“If we do CPR we will break your ribs and you will need to be on a breathing machine – you don’t want us to do that – do you?”*
- *“Will you agree to discontinuing care?”*
- *“There is nothing more we can do…”*

Statements to Consider:

- *“What makes life worth living? What if you could no longer do these things?”*
- *“Has anyone close to you ever died? What are your feelings about that experience?”*
- *“If you were to die despite our best efforts, would you want us to use heroic measures to try and bring you back?”*
- *“If you were called to heaven today, do you have unfinished business in this world, or would you want to go in peace?”*

Consider Saying:

- Validate & reassure the pt/family
- Reduce guilt
- Give permission to change direction
  - *"You are making good decisions"*
  - *"If this was my mother, I would do the same thing"*
  - *"If I only knew ….!" "You made the best decision with the information you had at that time."*
  - *"Many people stop radiation when it causes this much discomfort. No one will be upset if you stop"*
    - *"The chemo has failed us."*



89 y/o Female

- Osteoporosis
- Dysphagia
- Weight loss
- Dyspnea →
- Respiratory Failure →
- Death

Blechacz B, Gajic O. NEJM. 2008 Jun 12;358(24):e28.

Case Examples

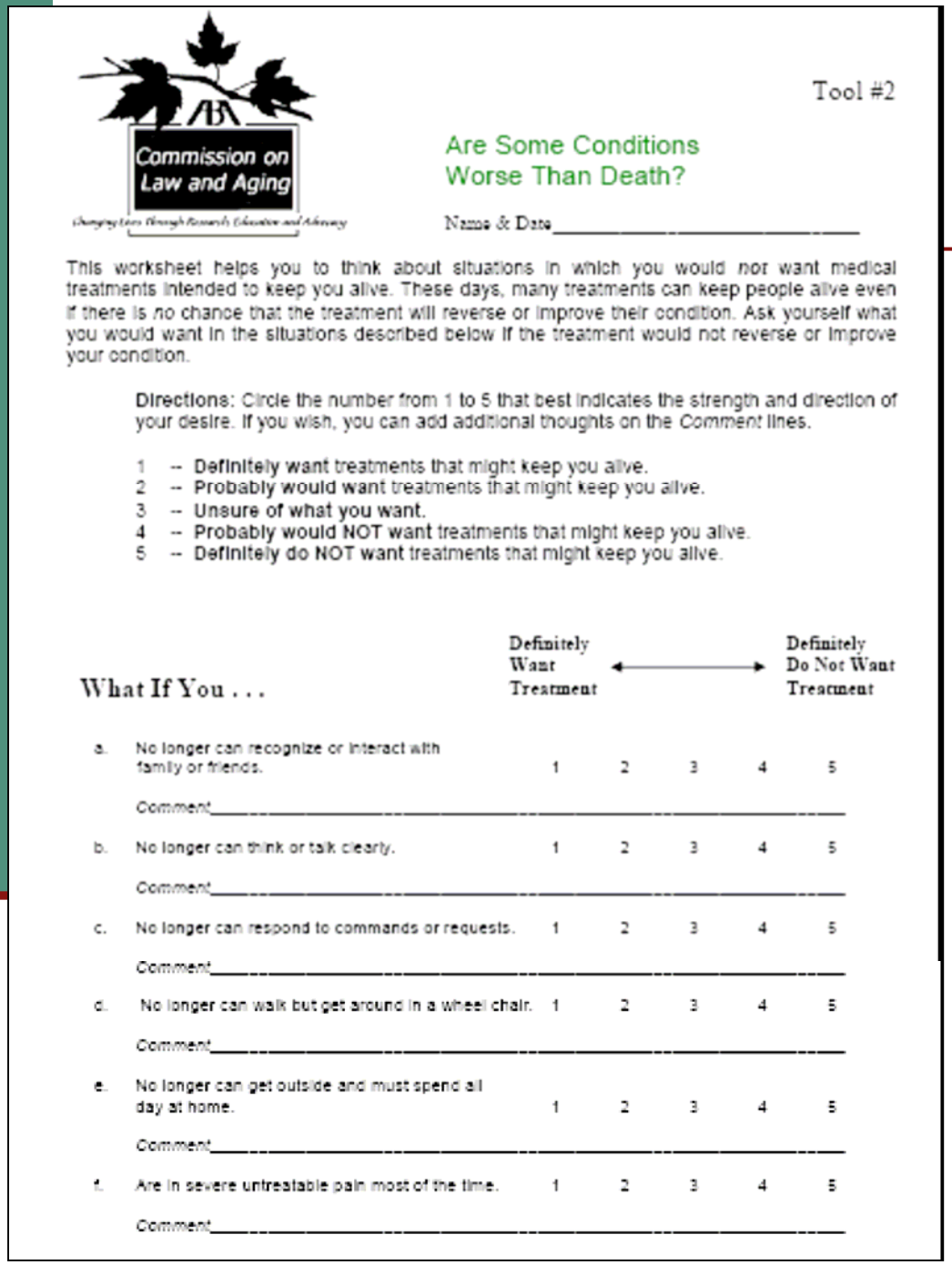
- Millie is a 94 y/o NH pt with dementia, CHF, CRI and recurrent infections.
- She is spoon fed, and minimally verbal, yet she still wanders about the NH.
- She has had 4 admissions in 6 months, all for aspiration pneumonia.
- She now presents to the ED in respiratory distress.

Resources

Consumer's Tool Kit for
Health Care
Advance Planning

Second Edition

American Bar Association's Commission on Law & Aging, Consumer's Tool Kit for Health Care Advance Planning: http://www.abanet.org/aging/toolkit/



Commission on Law and Aging

Changing Lives Through Research, Education and Advocacy

Tool #2

Are Some Conditions Worse Than Death?

Name & Date_____

This worksheet helps you to think about situations in which you would *not* want medical treatments intended to keep you alive. These days, many treatments can keep people alive even if there is *no* chance that the treatment will reverse or improve their condition. Ask yourself what you would want in the situations described below if the treatment would not reverse or improve your condition.

Directions: Circle the number from 1 to 5 that best indicates the strength and direction of your desire. If you wish, you can add additional thoughts on the *Comment* lines.

1 -- **Definitely want** treatments that might keep you alive.
2 -- **Probably would want** treatments that might keep you alive.
3 -- **Unsure of what you want.**
4 -- **Probably would NOT want** treatments that might keep you alive.
5 -- **Definitely do NOT want** treatments that might keep you alive.

What If You . . .	Definitely Want Treatment ← → Definitely Do Not Want Treatment				
a. No longer can recognize or interact with family or friends.	1	2	3	4	5
Comment_____					
b. No longer can think or talk clearly.	1	2	3	4	5
Comment_____					
c. No longer can respond to commands or requests.	1	2	3	4	5
Comment_____					
d. No longer can walk but get around in a wheel chair.	1	2	3	4	5
Comment_____					
e. No longer can get outside and must spend all day at home.	1	2	3	4	5
Comment_____					
f. Are in severe untreatable pain most of the time.	1	2	3	4	5
Comment_____					

Are Some Conditions Worse Than Death?

What is QOL?

What is suffering?

http://www.abanet.org/aging/toolkit/

What treatment would you want if:

- You could no longer talk or think clearly?
- You could no longer recognize or interact with your family?
- You couldn’t swallow safely and a feeding tube was suggested?
- You couldn’t breathe and needed a breathing machine indefinitely to keep you alive?
- You could no longer control your bowel or bladder?
- You lived in a nursing home?
- You had pain most of the time?

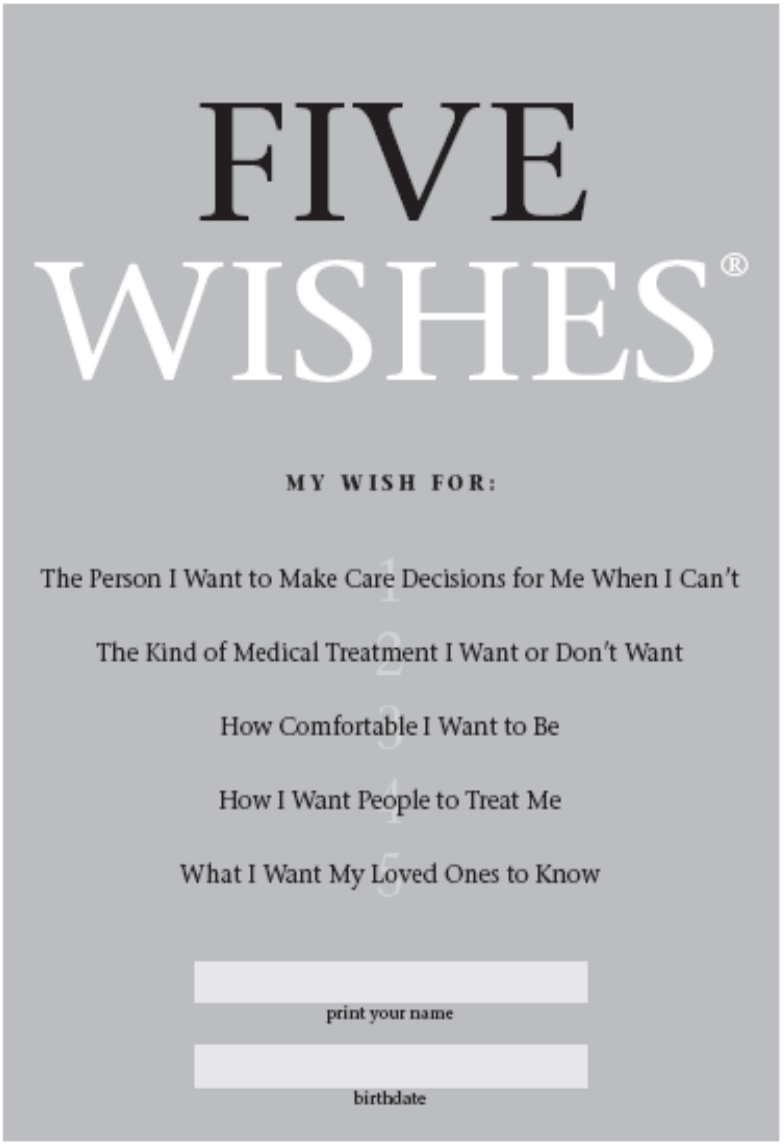
http://www.abanet.org/aging/toolkit/

Resources

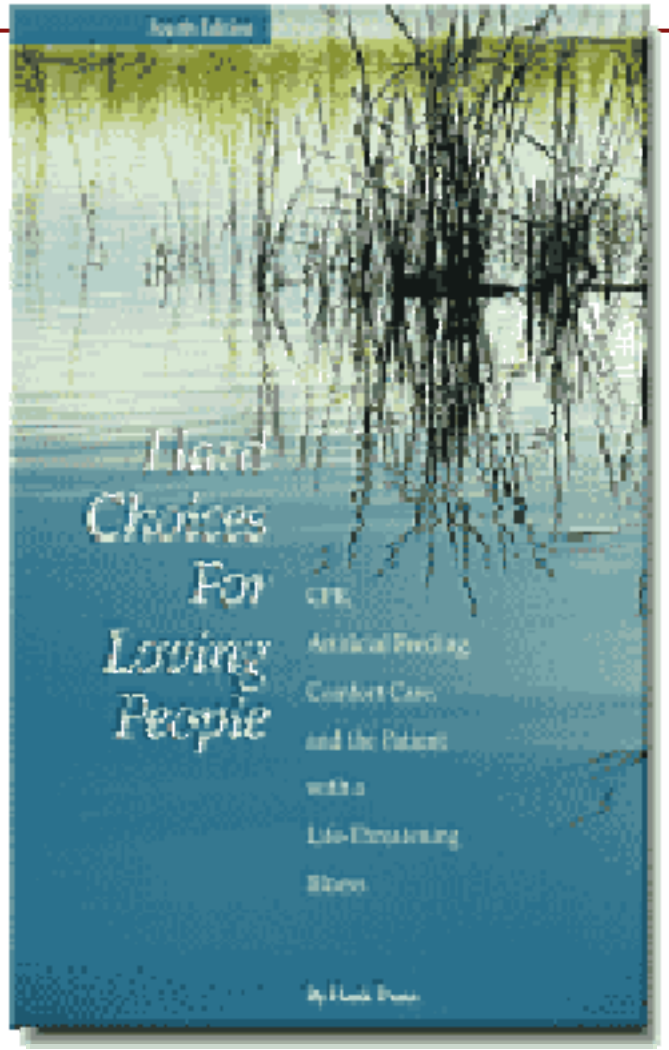
Example of a living will that explores a patient's values & goals

5 Wishes is valid in many states; does not require a lawyer. Easy to read 1888-5-WISHES

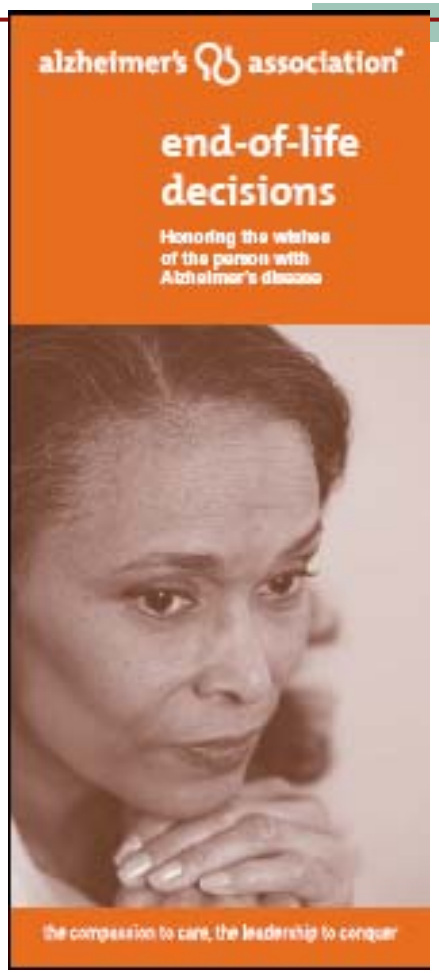
www.agingwithdignity.org



Resources for Family



http://www.hardchoices.com/



http://www.alz.org/alzheimers_disease_publications.asp

The Essence of Compassion

"You matter because you are you, and you matter to the end of your life.
We will do all we can not only to help you die peacefully,
but also to live until you die."

- Dame Cicely Saunders

Thank you for listening!

Questions?

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