

“Ethical Dilemmas at End of Life”



Karen J. Nichols, DO, MA, MACOI, MACP, CS-F

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Disclosures

- None

Background

- President – ACOI (2000-2001)
- President – AOA (2010-2011)
- Dean - Midwestern University/Chicago College of Osteopathic Medicine
 - (2002-2018)
- Professor – Internal Medicine - retired
- ACGME Board of Directors (2015 -2022)
 - Chair – Board of Directors (2020-2022)
- Private Practice – (1985-2002)
- End of Life Care Committee (Council on Palliative Care Issues) – AOA
 - Chair – (1999-2009)

@karenjnichols

karenj.nichols_do

kjn@kjnichols.com



Karen J. Nichols, DO


Leadership Consultant and Speaker on
End-of-Life Care Issues





Objectives

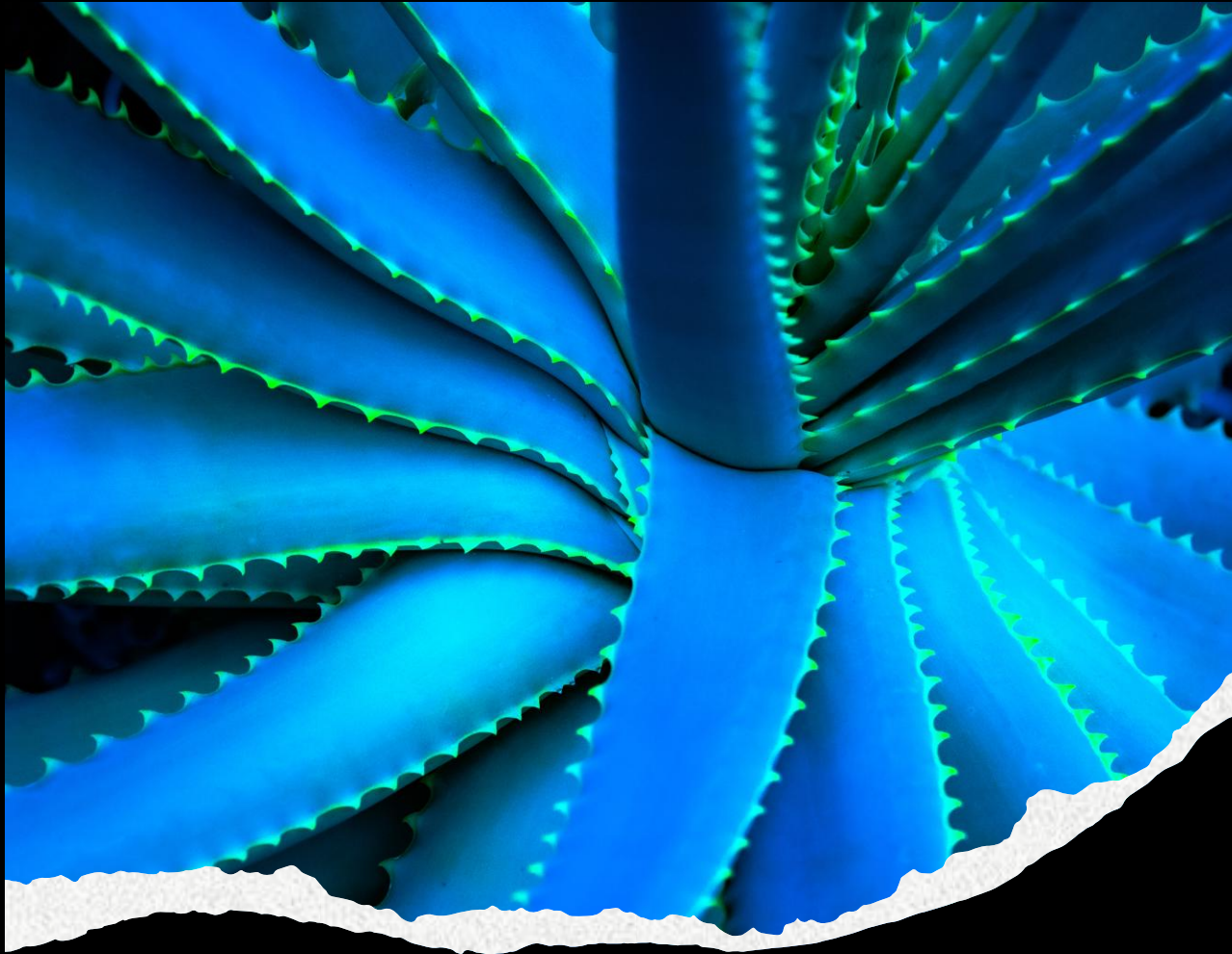
- Understand that the basis for all decision-making is the patient's goals of care
- Understand the difference between withholding and withdrawing ventilator support
- Recognize and manage medical futility
- Describe the different types of advance directives

A scenic landscape photograph of a river flowing through a canyon. In the background, there are prominent red rock mountains, some of which are illuminated by a warm, golden light, possibly from the setting or rising sun. The foreground shows a river with a rocky bank on the left and a large, dark tree on the right. The text "So let me tell you about....." is overlaid in a white, cursive font on the right side of the image.

So let me
tell you
about.....

*The
Osteopathic
Profession's
Finest Hour*





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

- Uncertainty about prognosis
- Decision to shift goals often irrevocable
- Insufficient technical training
- Medical culture regards death as failure
- Suffering is difficult

2/1/20XX



... How Americans died in the past

- Prior to antibiotics, people died quickly
 - infectious disease
 - accidents
- Medicine focused on caring, comfort
- Sick cared for at home
 - with cultural variations

Medicine's shift in focus . . .

- Potential of medical therapies
 - “fight aggressively” against illness, death
 - prolong life at all cost
- Improved sanitation, public health, antibiotics, new therapies
 - increasing life expectancy (until COVID)

End of life in America today

- Modern health care
 - only a few cures
 - live much longer with chronic illness
 - dying process also prolonged

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Sudden death, unexpected cause

- ◆ <10%
- ◆ MI,
accident



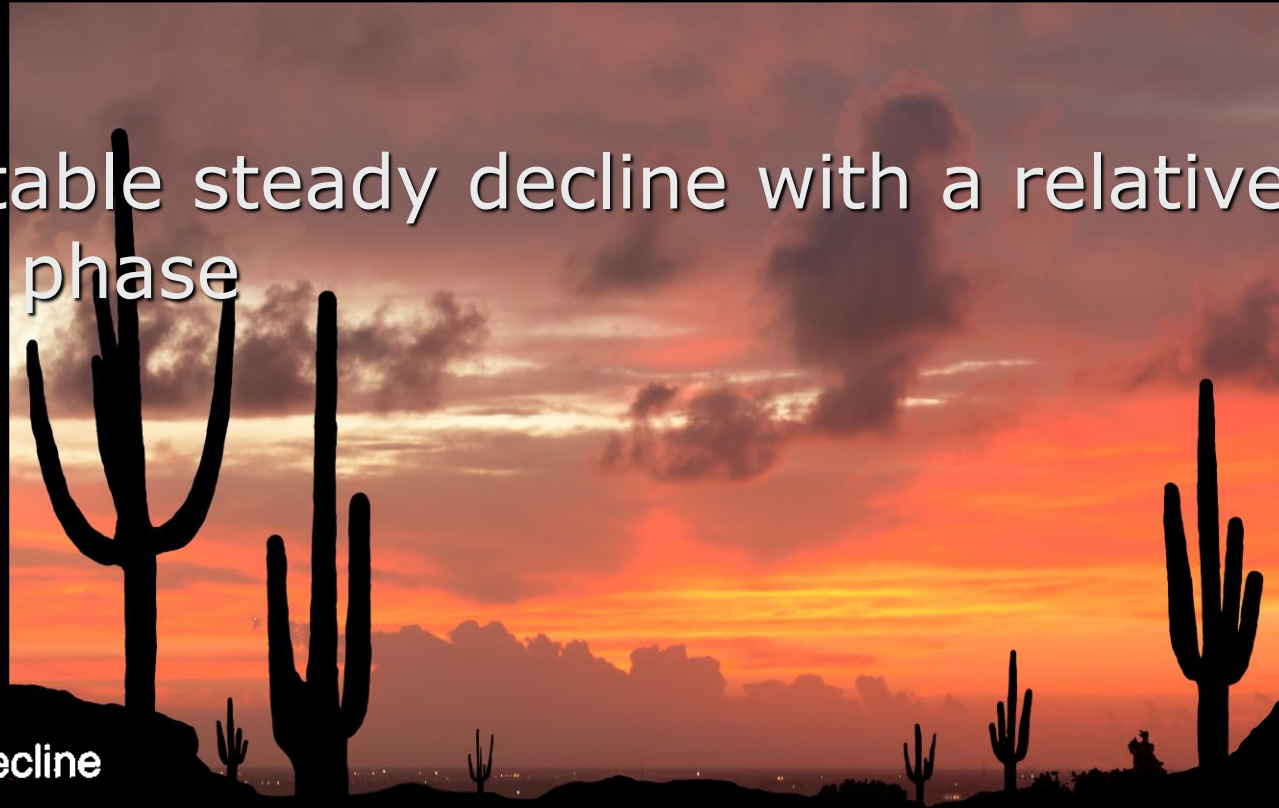
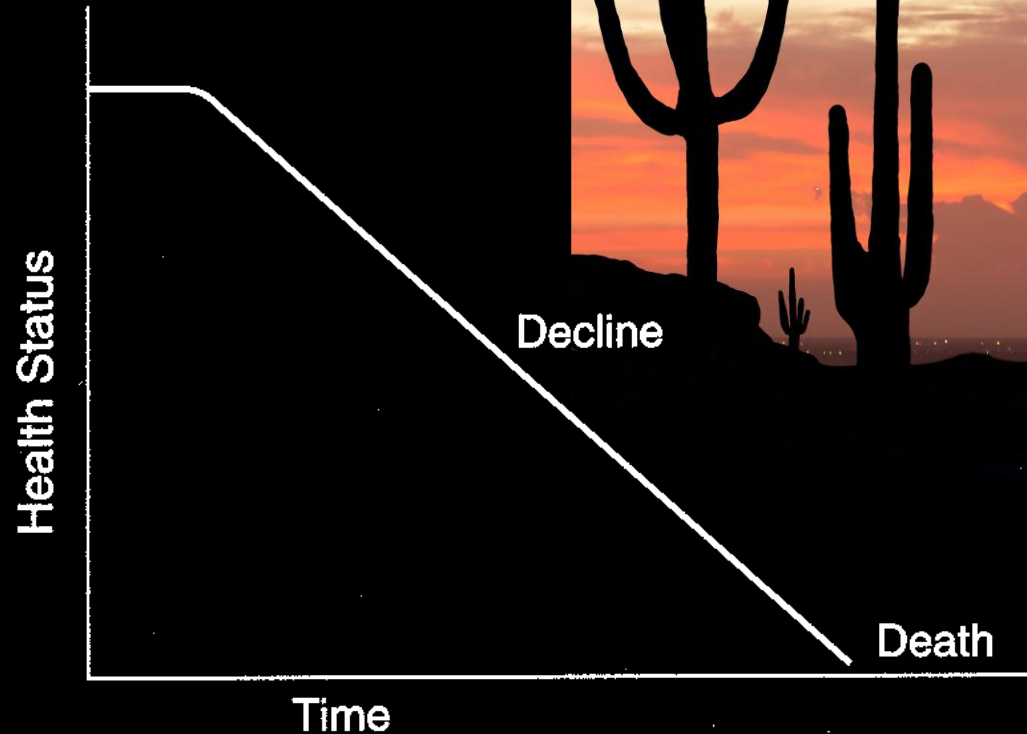
Protracted life-threatening illness

14

◆ > 90%

– A - predictable steady decline with a relatively short “terminal” phase

◆ Cancer



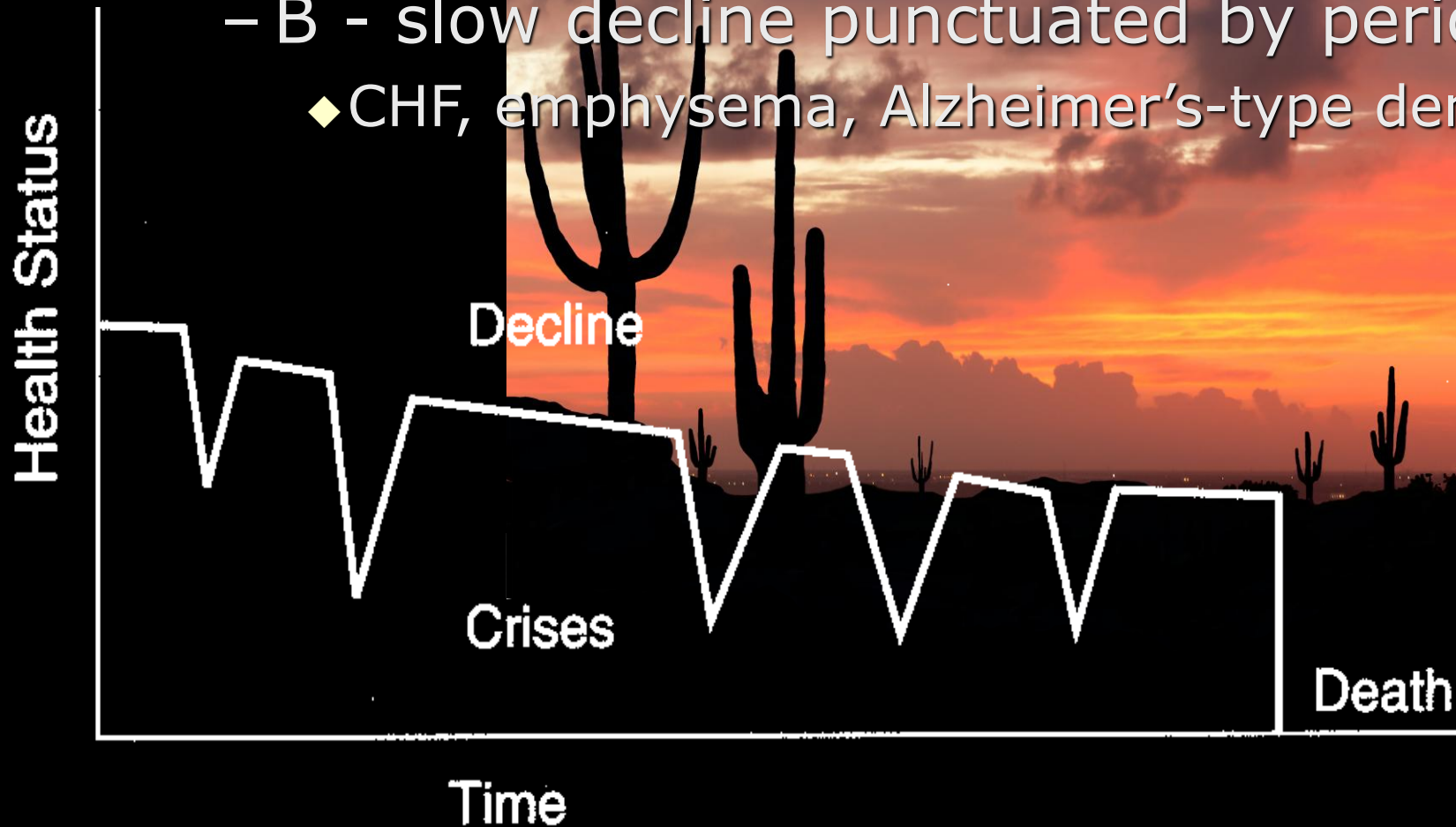
Protracted life-threatening illness

15

◆ > 90%

– B - slow decline punctuated by periodic crises

◆ CHF, emphysema, Alzheimer's-type dementia



What shall we talk about??

- Goals of Care
- Withhold vs. Withdraw
- Medical Futility
- Saying “I’m Sorry”
- Secondary Effect
- Advance Directives

Goals of Care

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- ◆ The most important starting point for any conversation about end of life!



What are the¹⁸ choices available?

- “What do YOU (your patient) want?”
- “Does anyone else KNOW what you want?”

◆ Everyone has a personal sense of

- who we are
- what we like to do
- control we like to have
- goals for our lives
- things we hope for



- ◆ Hope, goals, expectations change with illness
- ◆ Physician's role to clarify goals, treatment plan



Potential goals of care

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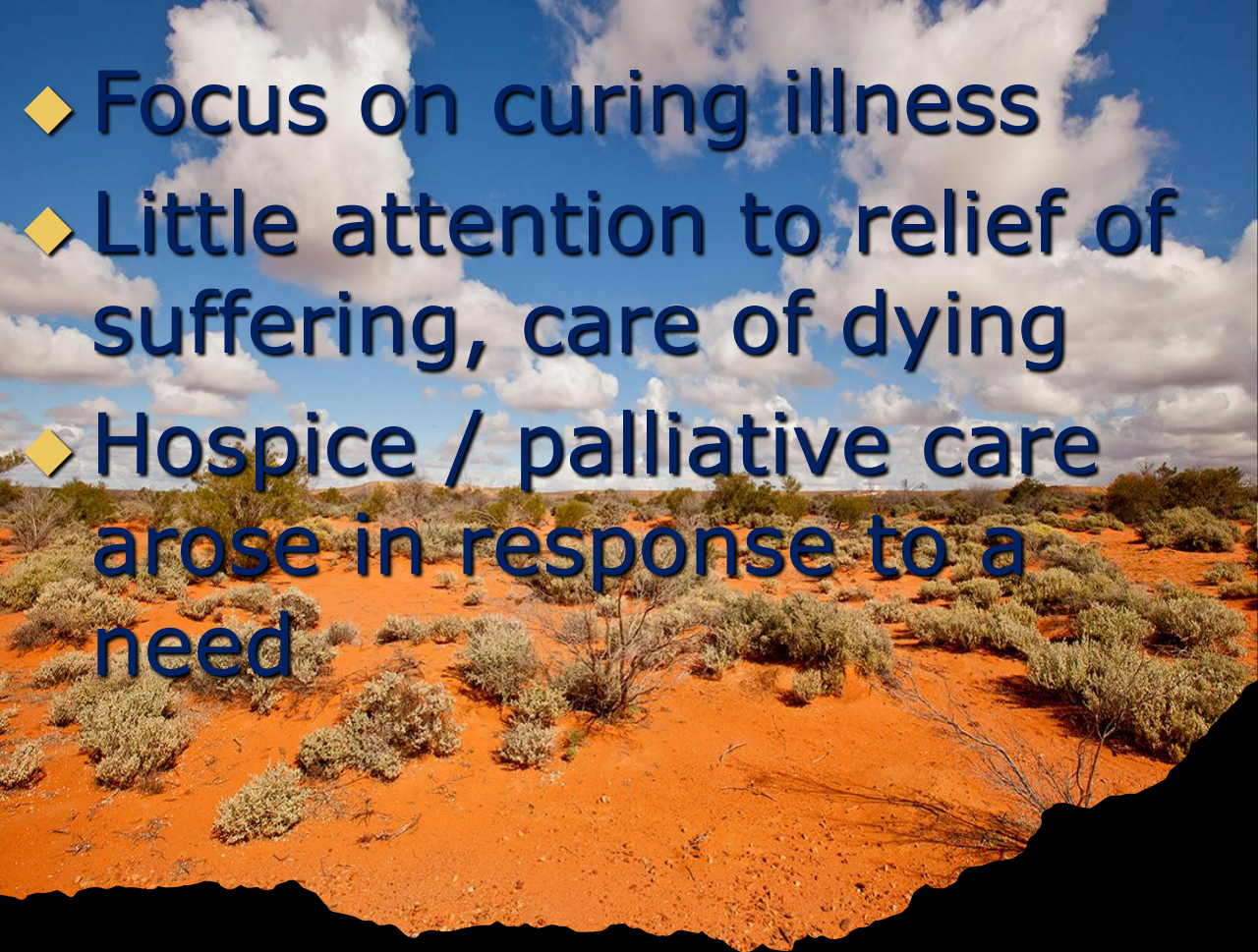
- ◆ Cure of disease
- ◆ Avoidance of premature death
- ◆ Maintenance or improvement in function
- ◆ Prolongation of life



- ◆ Relief of suffering
- ◆ Quality of life
- ◆ Staying in control
- ◆ A good dying
- ◆ Support for families and loved ones

Historically, a dichotomous division of goals of care

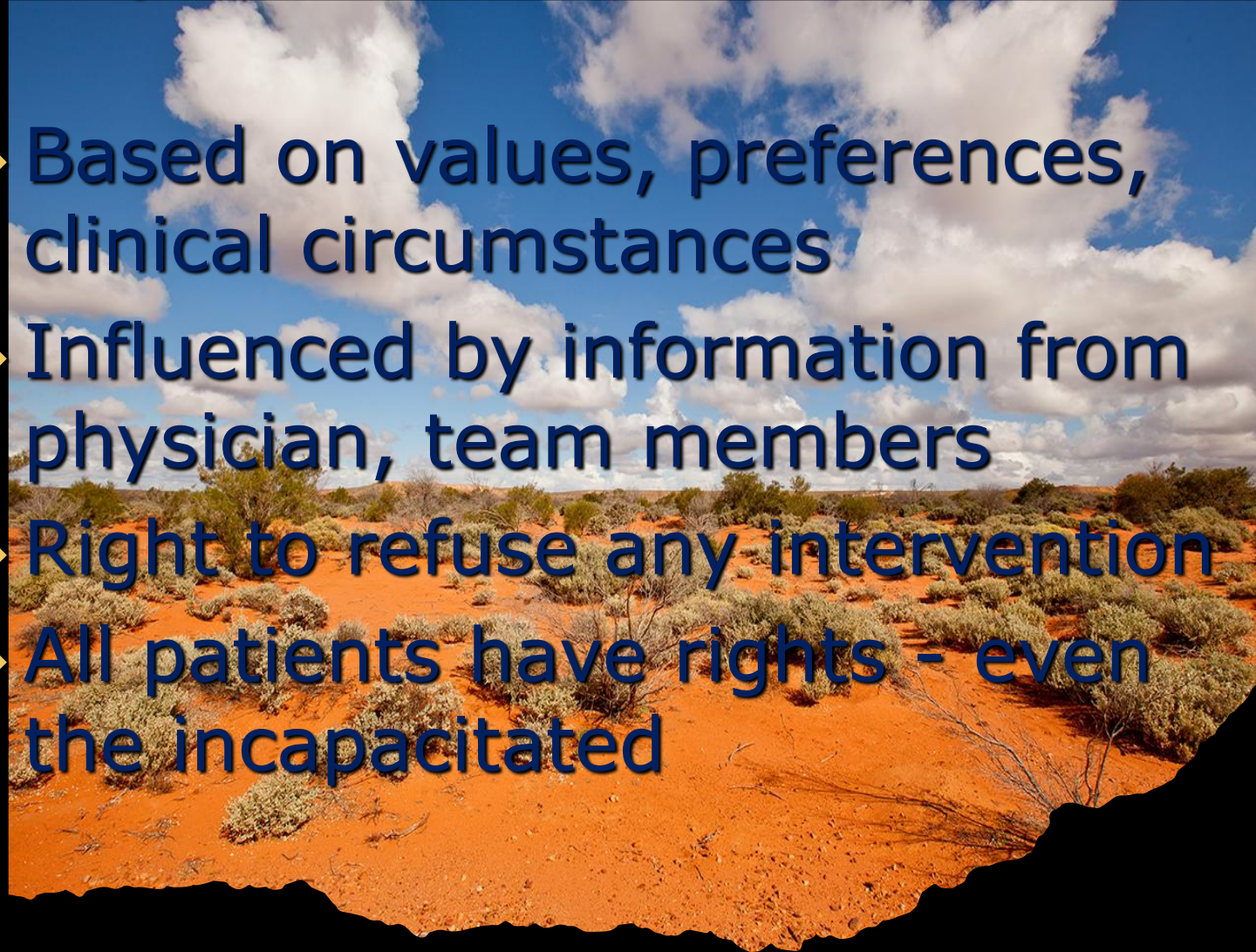
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- 
- ◆ Focus on curing illness
 - ◆ Little attention to relief of suffering, care of dying
 - ◆ Hospice / palliative care arose in response to a need

Determine specific priorities

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- ◆ Based on values, preferences, clinical circumstances
- ◆ Influenced by information from physician, team members
- ◆ Right to refuse any intervention
- ◆ All patients have rights - even the incapacitated



Case #1

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- ◆ A 35 year old severely debilitated AIDS patient with lymphoma develops acute short of breath and has a positive V/Q scan. He has a living will which states he wishes no heroic measures if terminal. The nurse calls you to intubate the patient, since he is not terminal.



You should intubate this patient.

25

- ◆ A. Agree
- ◆ B. Disagree



It feels harder to withdraw than to withhold therapy.

26

- ◆ A. Agree
- ◆ B. Disagree



There is no ethical difference between withholding and withdrawing therapy.

27

- ◆ A. Agree
- ◆ B. Disagree



◆ Withholding treatment vs. withdrawing treatment

28



Case #2

29

- ◆ An 82 year old Caucasian female with breast cancer develops an acute bowel obstruction requiring emergency surgery for decompression. She suffers a massive CVA in surgery and can't be extubated. Brain CT shows massive cerebral edema and she quickly herniates. EEG shows that she meets...



...criteria for brain death. You recommend disconnecting the ventilator. Her husband says, "No, she is still breathing and still has a heart beat."



You are required to follow his
direction.

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- ◆ A. Agree
- ◆ B. Disagree

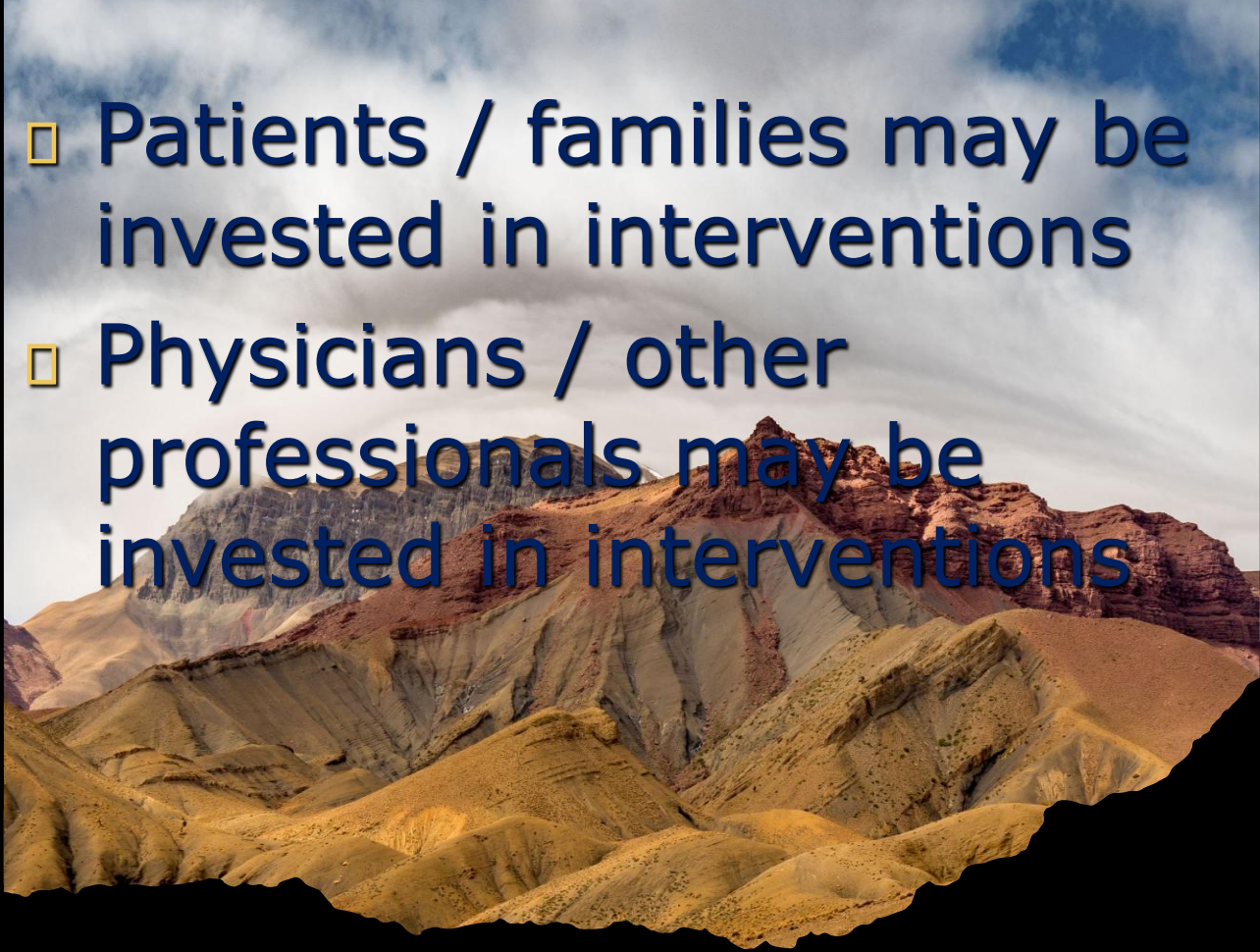


◆ Medical Futility



Physicians and futility

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- 
- Patients / families may be invested in interventions
 - Physicians / other professionals may be invested in interventions

Definitions of medical futility


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- Won't achieve the patient's goal
- Serves no legitimate goal of medical practice
- Ineffective more than 99% of the time
- Does not conform to accepted community standards



Is this really a futility case?

35

- 
- Unequivocal cases of medical futility are rare
 - Miscommunication, value differences are more common
 - Case resolution more important than definitions

Differential diagnosis of futility situations

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- A. Inappropriate surrogate
- B. Personal factors
- C. Values conflict
- D. Misunderstanding



A. Inappropriate Surrogate

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B. Personal factors

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- Distrust
- Guilt
- Grief
- Intra-family issues
- Secondary gain



C. Difference in values

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- Religious
- Miracles
- Spiritual
- Value of life



D. Misunderstanding: underlying causes . . .

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- ❑ Doesn't know the diagnosis
- ❑ Too much jargon
- ❑ Different or conflicting information
- ❑ Previous overoptimistic prognosis
- ❑ Stressful environment



D. Misunderstanding: underlying causes . . .

41

- ❑ Sleep deprivation
- ❑ Emotional distress
- ❑ Psychologically unprepared
- ❑ Inadequate cognitive ability



Misunderstanding: how to respond . . .

42

- Choose a primary communicator
- Give information in
 - small pieces
- Use understandable language
- Do not hedge to “provide hope”
- Involve other health care professionals (ethics committee)



Case #3

43

- ◆ A 39 year old white female is scheduled for revision of a scar from an excisional breast biopsy. She has 3 young children and is recently widowed. The cosmetic result was sub-optimal. You see the patient pre-op. You say "I'm sorry" and the patient pulls back in surprise.



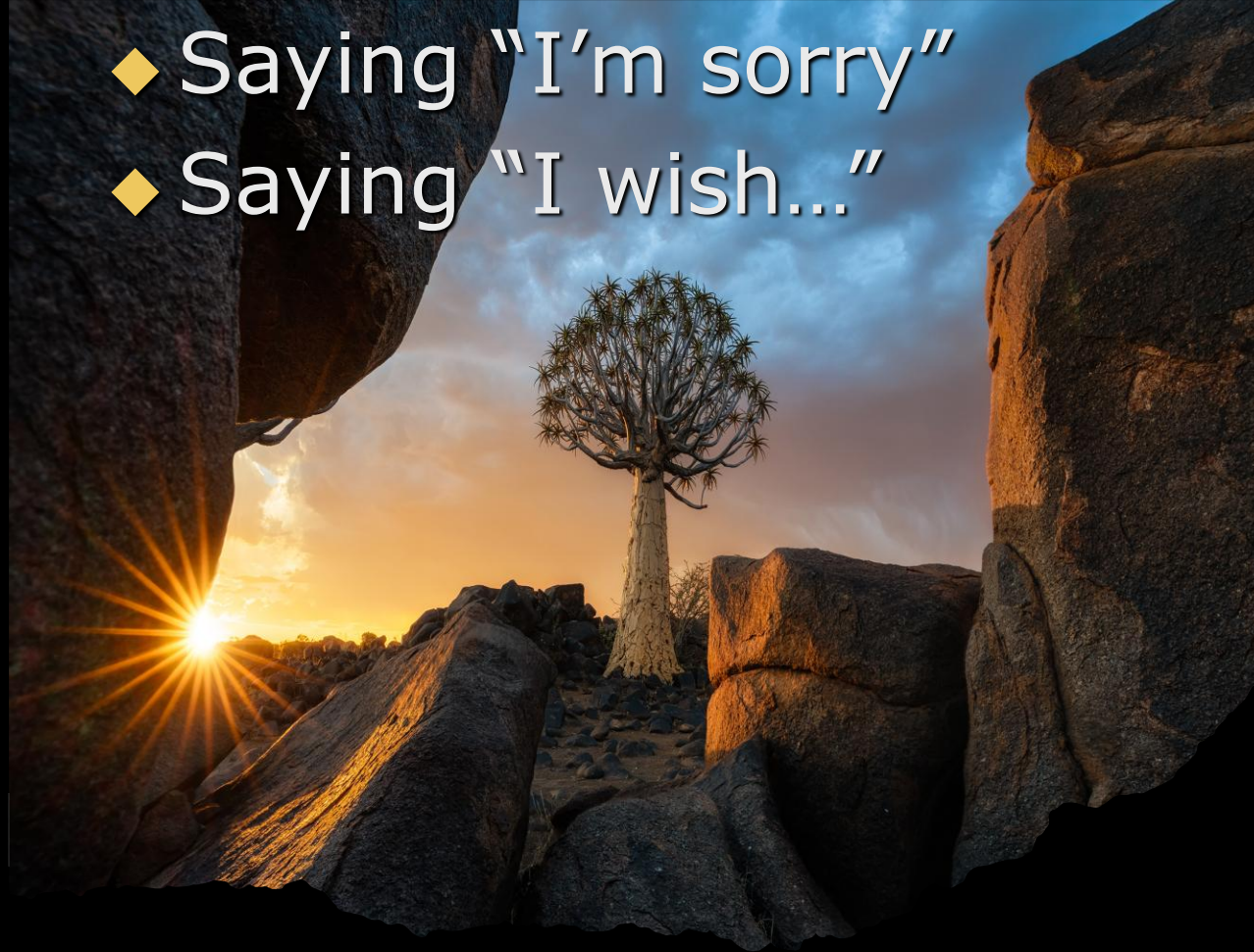
Saying “I’m sorry” means:

44

- ◆ A. It’s my fault
- ◆ B. I did something wrong
- ◆ C. I should have evaluated you sooner
- ◆ D. I wish this problem wasn’t happening to you



- ◆ Saying "I'm sorry"
- ◆ Saying "I wish..."



Case #4

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- ◆ A 79 year old white female post-op from a bowel obstruction. She has breast and colon cancer with mets to the bones. You have been consulted for pain management and have been increasing the dosing of her pain meds, but she requires dosing 2-3 times the recommended dosage and still indicates she is in pain.



That's all you can do.

47

- ◆ A. Agree
- ◆ B. Disagree



The dose doesn't matter, just relieve the pain

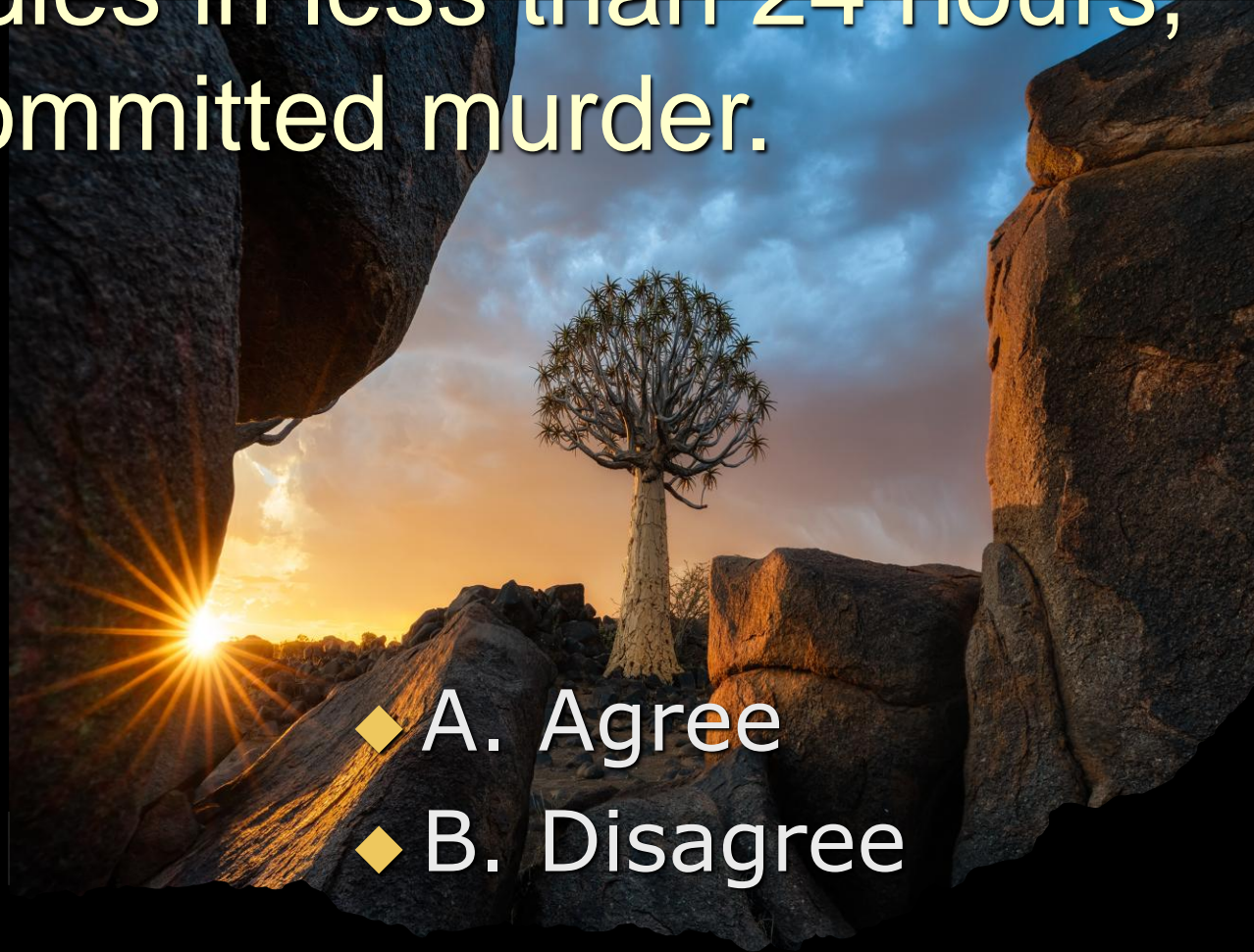
48

- ◆ A. Agree
- ◆ B. Disagree



If you prescribe an increased dose, and the patient dies in less than 24 hours, you have committed murder.

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- ◆ A. Agree
- ◆ B. Disagree

What killed the patient?

50



◆ Secondary Effect

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The Physician's Role

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The dying patient's perspective

- ◆ "What tormented Ivan Illych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result."

The Death of Ivan Illych

Leo Tolstoy 1886



Physician's Role


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- ◆ Latent function: lending strength
- ◆ Pulls "strings"
- ◆ Affects the physiological processes
- ◆ The longer you care for a patient, the more responsible you are for the patient's welfare.



Physician's Role

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- ◆ Physician/patient relationship exists even if the physician is nasty, uncaring, unkind
 - ◆ Physician/patient relationship can make pain/suffering better or worse
 - ◆ Enduring the pain/suffering is more tolerable if the cause is known and is not just the result of random chance
- 

Physician's Role

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- ◆ Suffering can often be relieved in the presence of continued pain, by:
- ◆ -making the source of the pain known,
- ◆ -changing its meaning,
- ◆ -demonstrating that it can be controlled,
- ◆ -that an end (to the pain) is in sight.



There is never a time that nothing can be done.

57

- ◆ Not useless things
- ◆ Not lies and false promises
- ◆ Patient may die, but can be in control
- ◆ Sometimes talking with the patient is the only tx

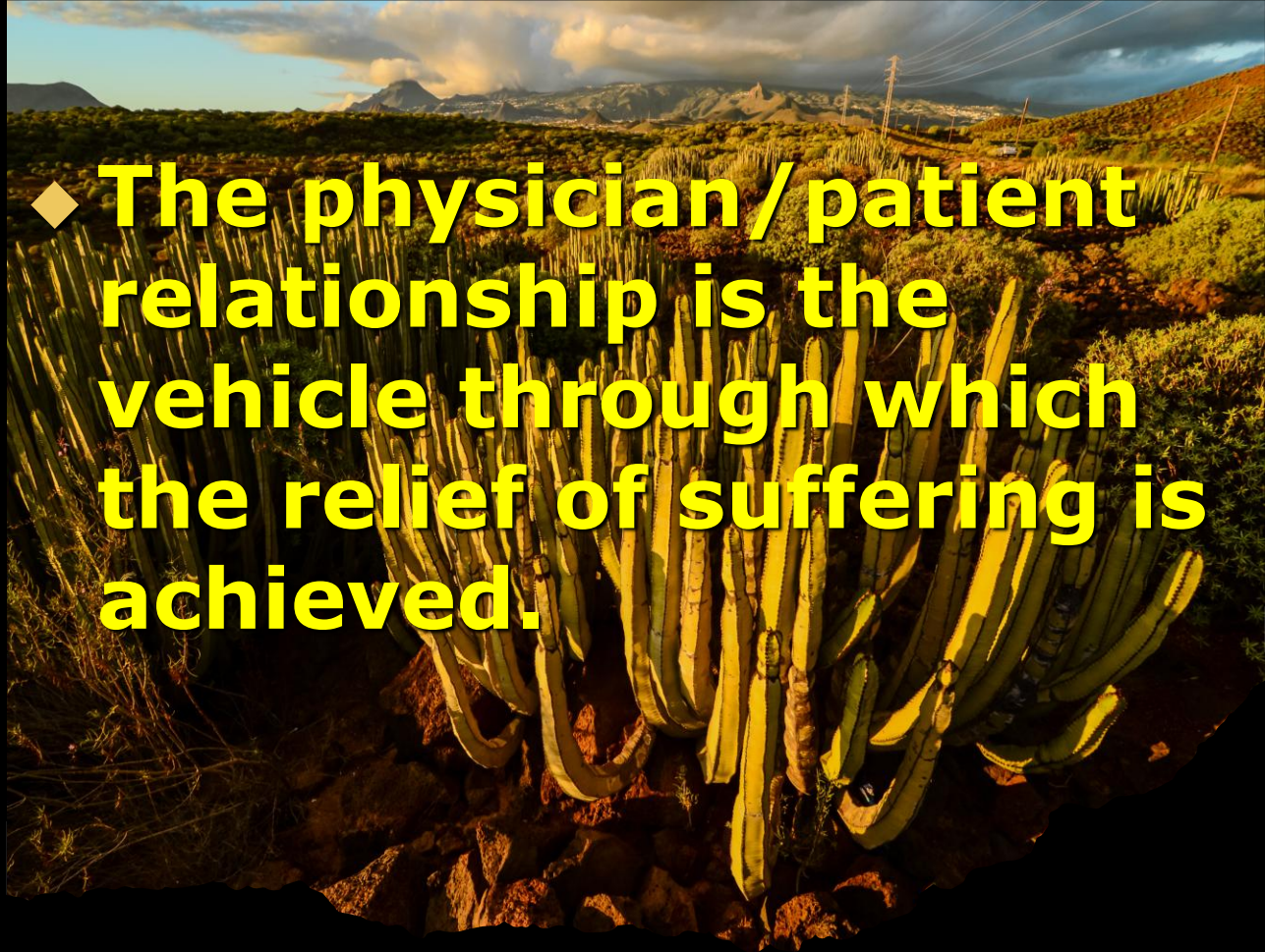


There is never a time that nothing can be done.

58

- ◆ Not useless things
- ◆ Not lies and false promises
- ◆ Patient may die, but can be in control
- ◆ Sometimes talking with the patient is the only tx
Sometimes talking with the patient is the **BEST** tx

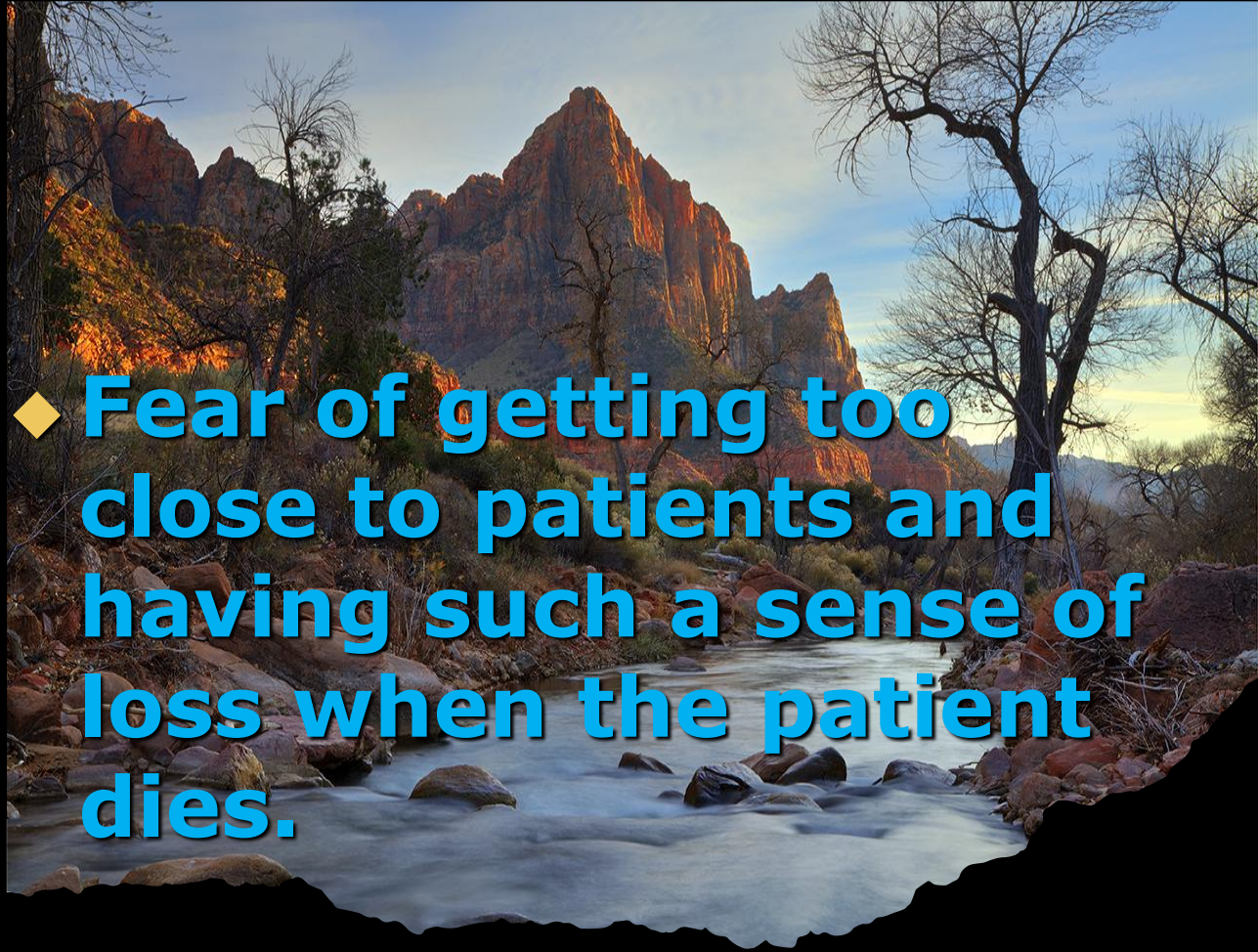


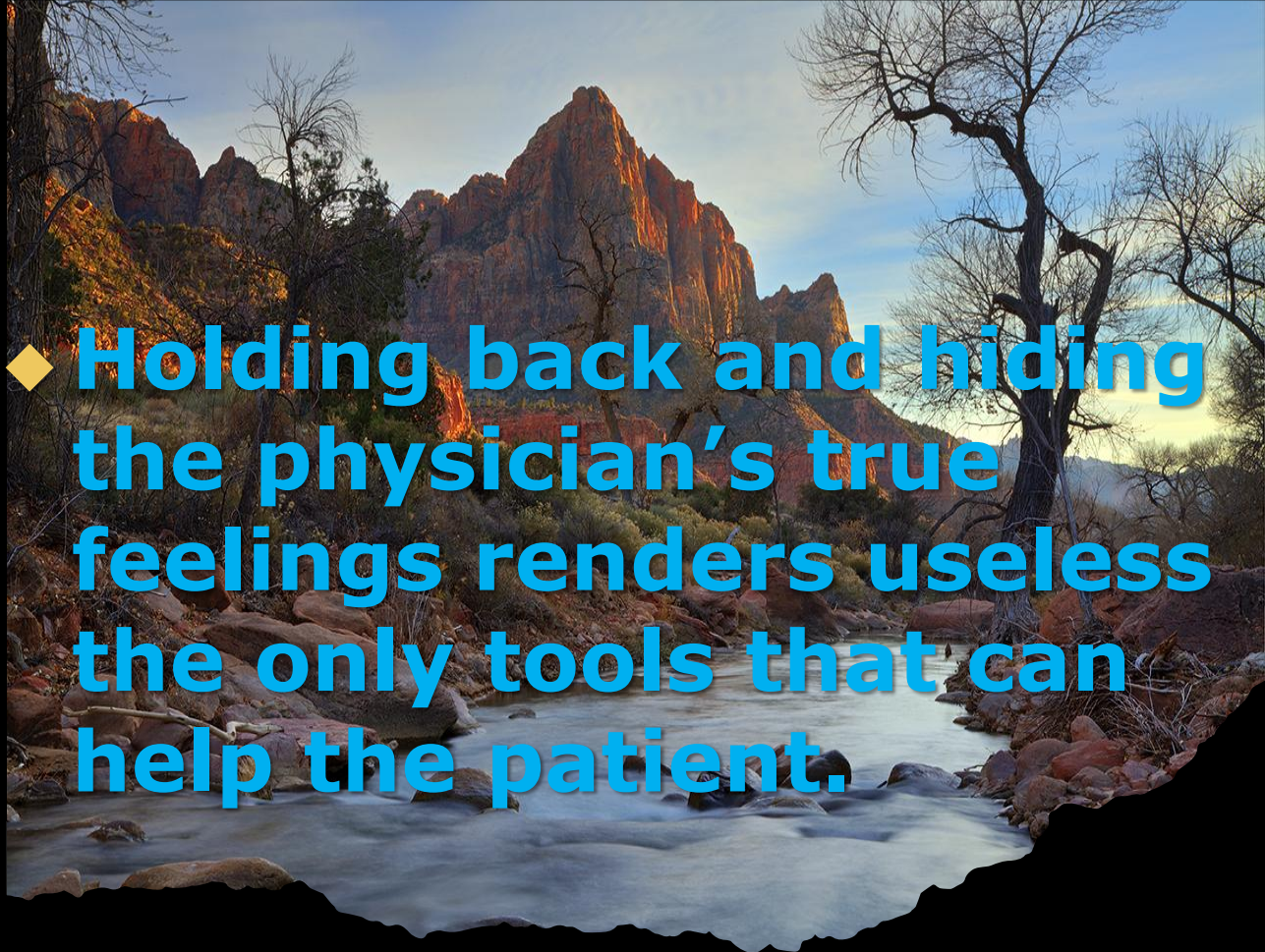


◆ **The physician/patient relationship is the vehicle through which the relief of suffering is achieved.**

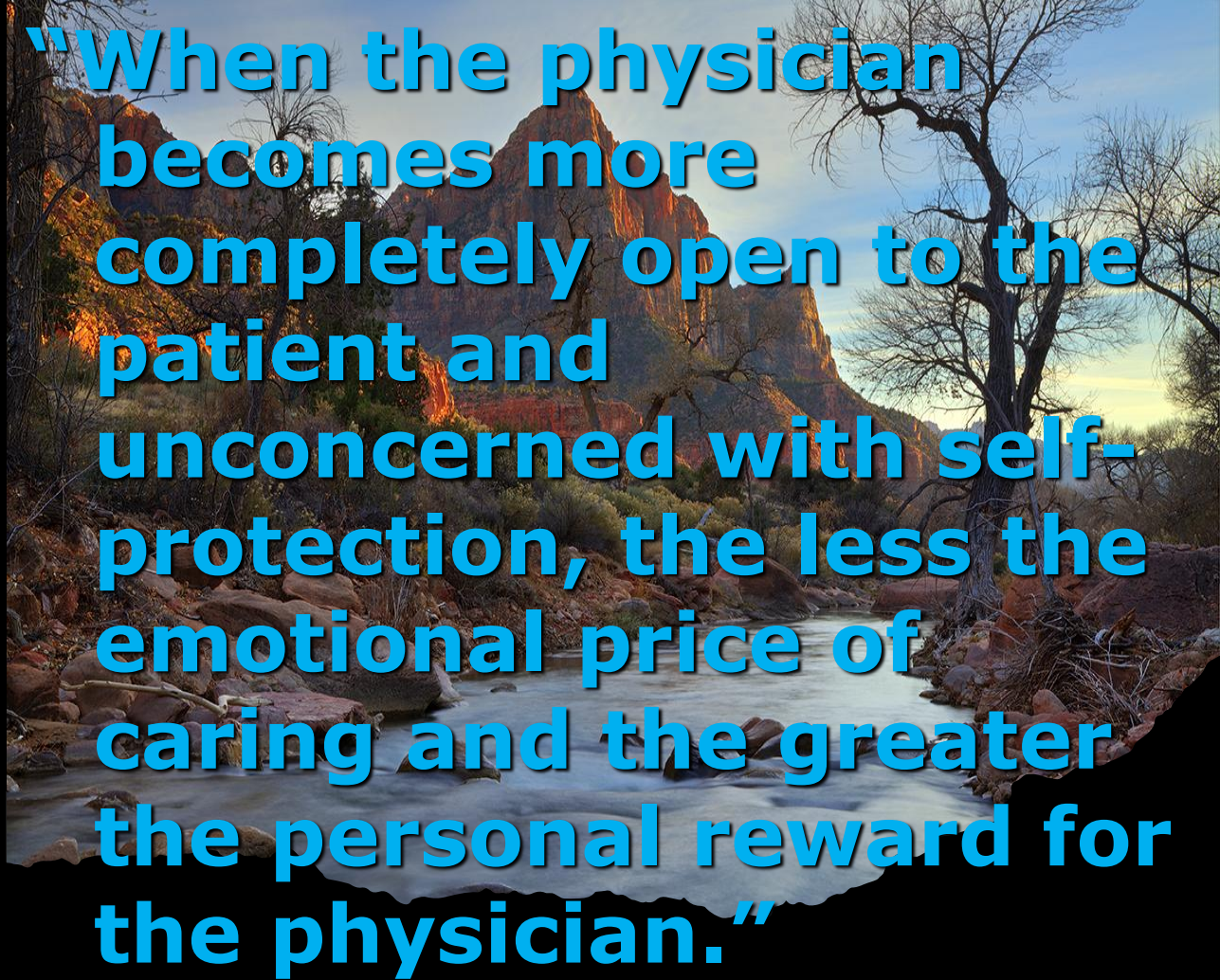
Physician's concern:

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- 
- ◆ **Fear of getting too close to patients and having such a sense of loss when the patient dies.**



◆ **Holding back and hiding the physician's true feelings renders useless the only tools that can help the patient.**



"When the physician becomes more completely open to the patient and unconcerned with self-protection, the less the emotional price of caring and the greater the personal reward for the physician."

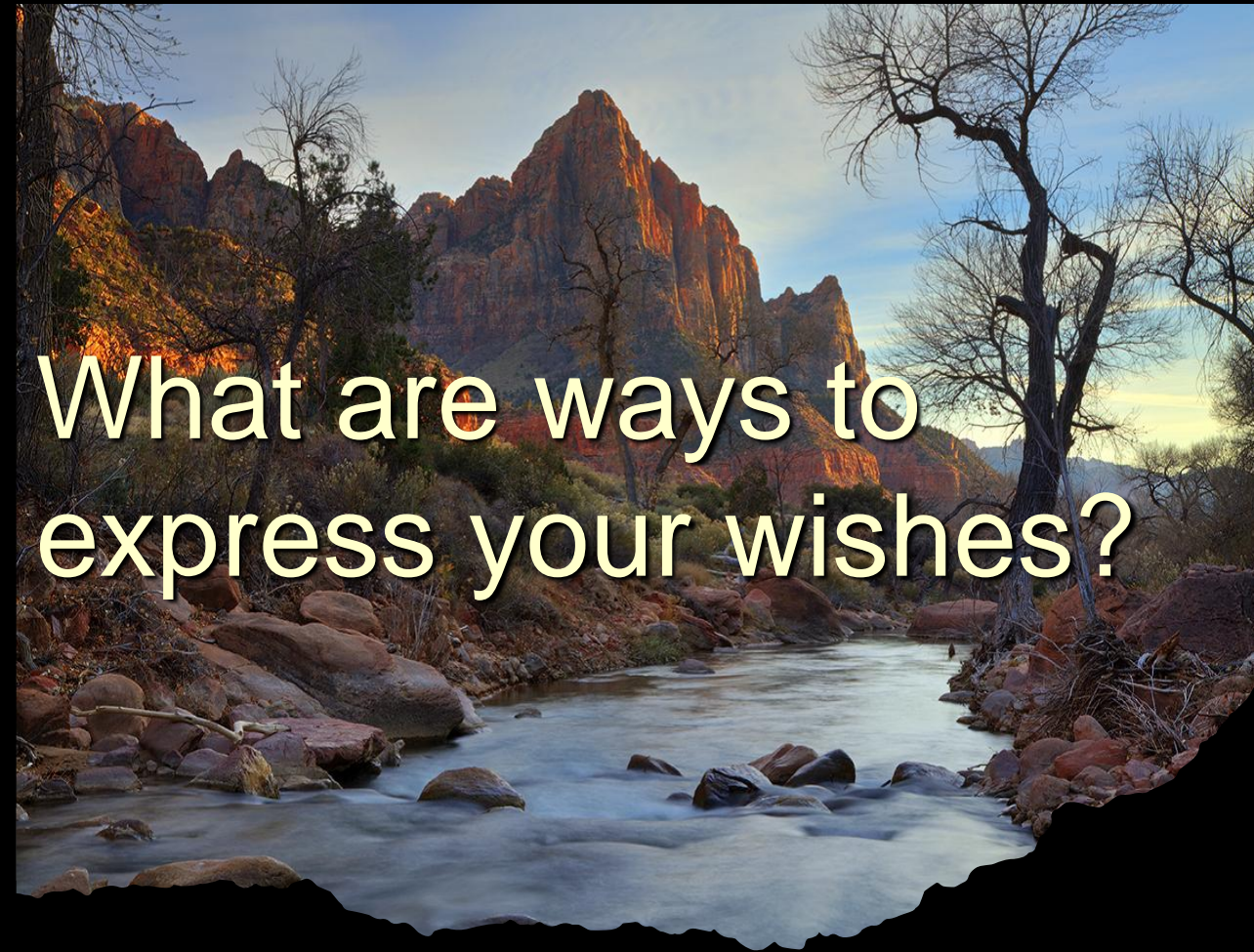
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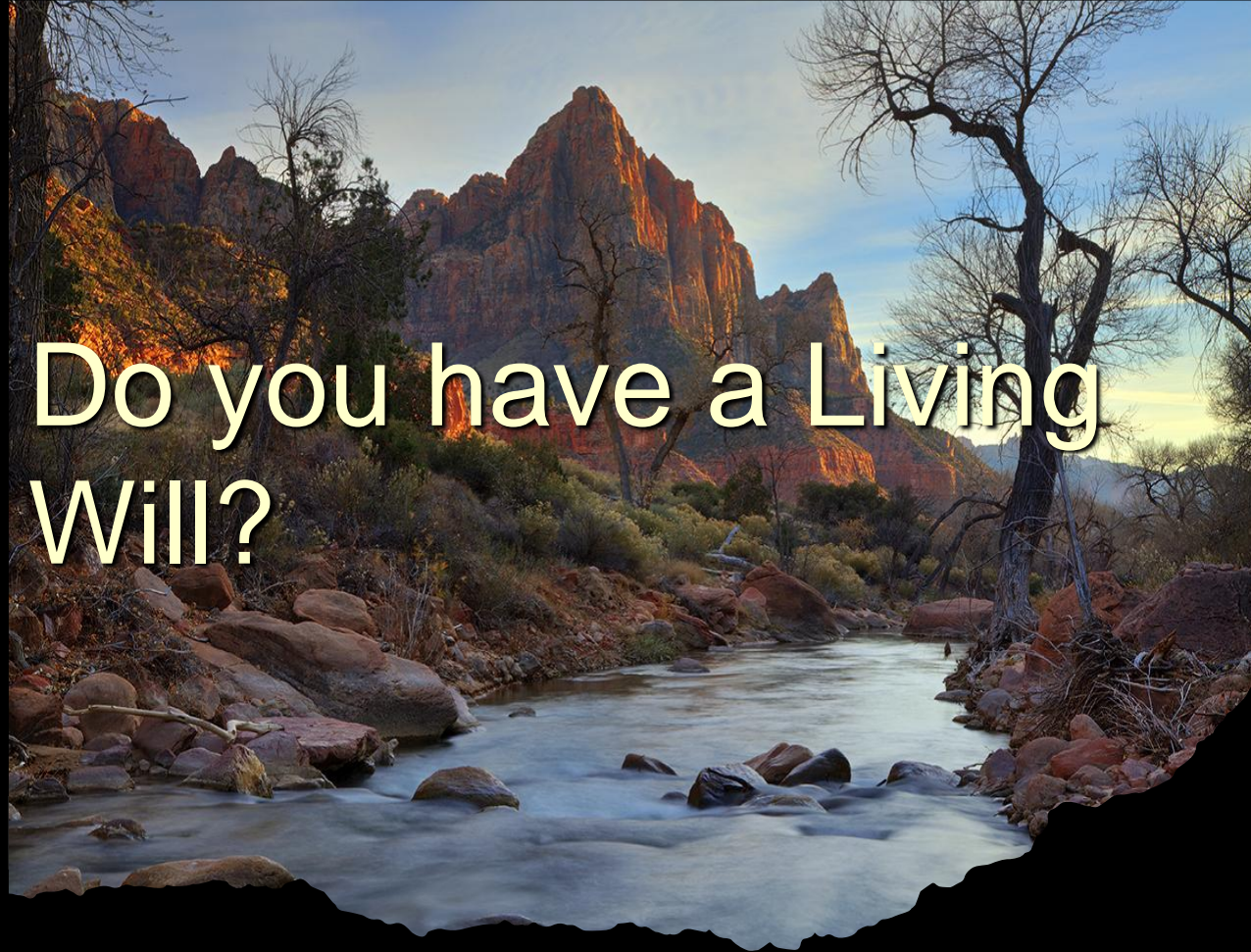
Case #5

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- ◆ A 55 year old severely debilitated patient with lymphoma develops acute short of breath and has a positive V/Q scan. He has never wanted to talk about what to do in case to worsening prognosis.





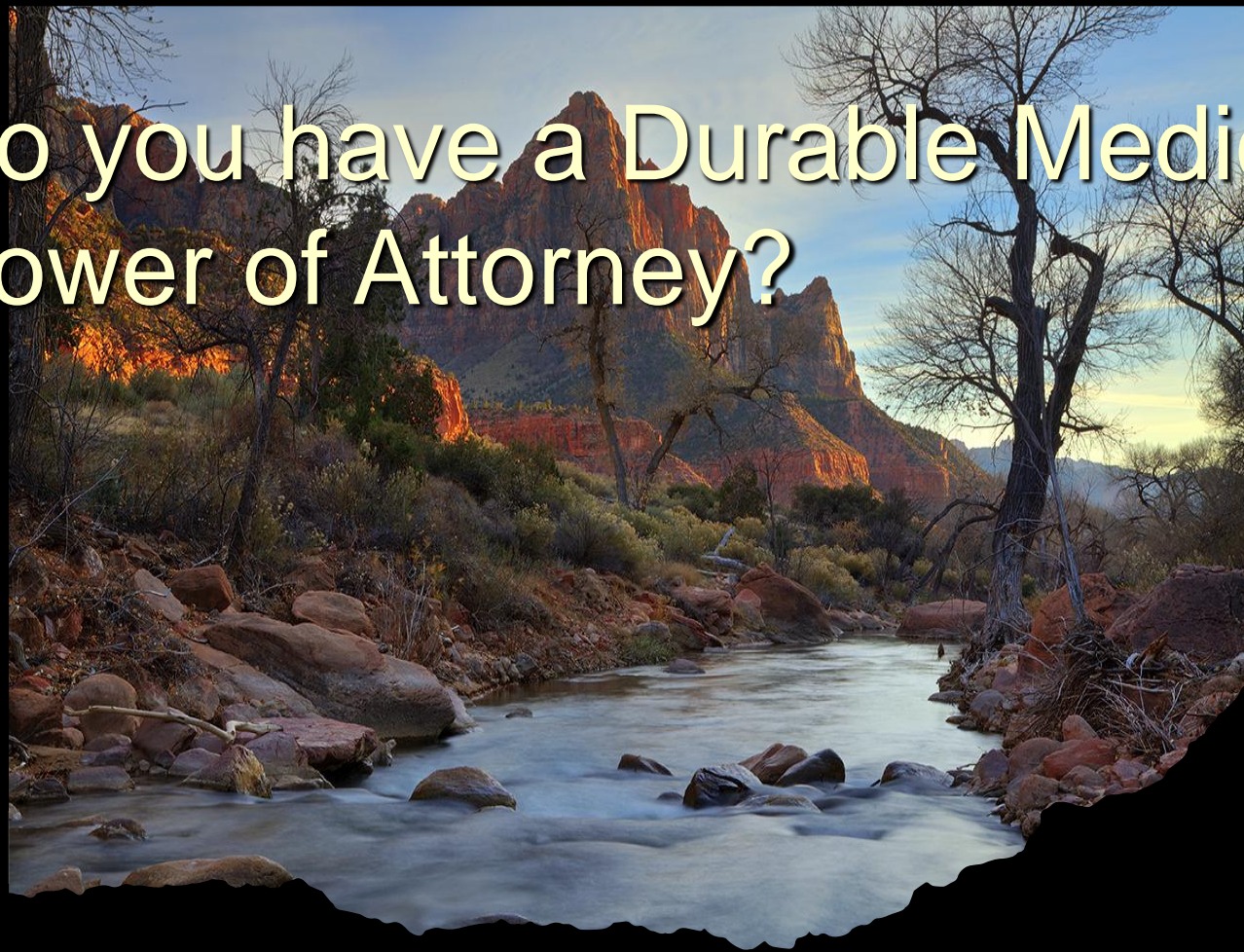


Do you have a Living Will?

- ◆ A. Yes
- ◆ B. No

Do you have a Durable Medical
Power of Attorney?

- ◆ A. Yes
- ◆ B. No



A Living Will is preferable over a Durable Medical Power of Attorney

- ◆ A. Agree
- ◆ B. Disagree



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Living Will Durable Medical Power of Attorney (for Health Affairs)

Sample Footer Text

Summary: Quality of care at the end of life

- Adherence to patient values/preferences/GOALS!!
- Symptom management
- Coordination of care
- Family support
- Care for the whole person, including emotional and spiritual well-being



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*...the REST
of the
Story!*

Sample Footer Text

"...cure sometimes,
comfort often,
care always"

The Osteopathic Profession's Finest Hour

Karnik, S. Kanekar, A.
“Ethical Issues
Surrounding End-of-Life
Care: A Narrative Review”
ncbi.nlm.nih.gov



Thank you

Karen J. Nichols, DO
kjn@kjohnichols.com



“Ethical Dilemmas at End of Life”



Karen J. Nichols, DO, MA, MACOI, MACP, CS-F

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