

Step Three

Understand Our Healthcare Choices



Big Word for This Session: COURAGE

Don't be afraid, for I am with you. Don't be discouraged,
for I am your God. I will strengthen you and help you.
I will hold you up with my victorious right hand.

— ISAIAH 41:10, (NLT)

It put us on the do-whatever-it-takes path.



First 911 call was made on February 16, 1968.

This started the shift in end-of-life care from a process managed by a family doctor to a high-speed, high-tech, multi-doctor, multi-machine impersonal series of events that

can leave us vulnerable and voiceless and makes it nearly impossible to die.

This almost happened to my mom.

Prolonged suffering before death emerged as a public health crisis in the mid-20th century.

...direct result of modern medicine's original sin: believing that we can vanquish death.

Given doctors' success at saving lives threatened by severe injuries and infections, they presumed they could overmaster death.

...we have yet to make a single person immortal. Instead, we have condemned countless incurably ill patients to needless anguish.

- Ira Byock, MD January 31, 2018



2. What did Dr. Murray's physician friend do when he heard his own difficult diagnosis?

Went home and stayed home.

3. Do doctors tell us the unvarnished truth?

No.

How can we decide what to do if we don't have the truth about our condition?

Ask hard questions. Take the lead in your care.

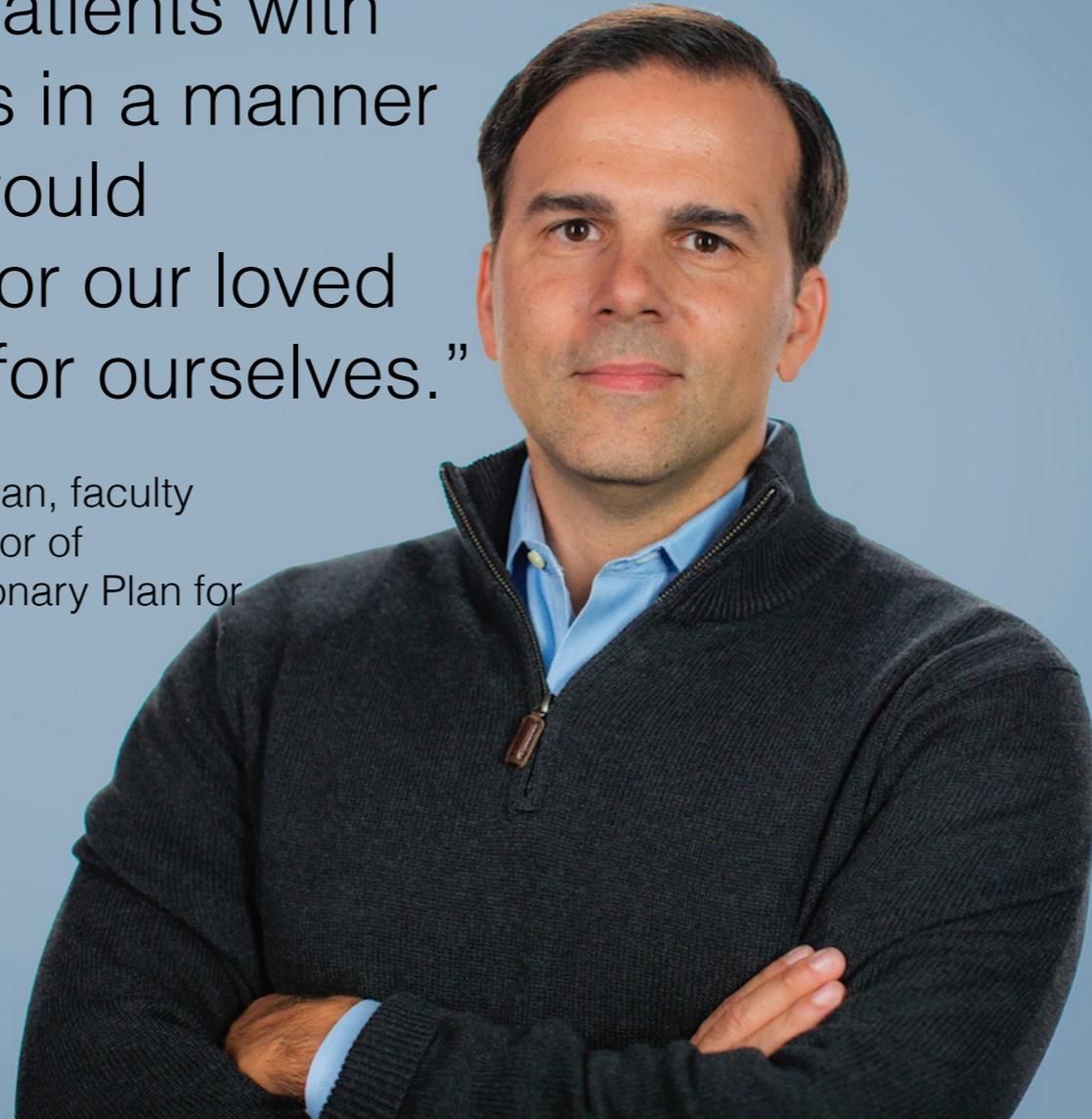
Don't settle for the default, standard care, until you have struggled with the choices.



Doctors rarely tell us about the gentle path.
Most don't even learn about this option until they are dying in the ICU.
The doctors spin a diagnosis in such a positive way
we actually think we're going to get well.

“...the overwhelming majority
of us treat patients with
serious illness in a manner
we would
never want for our loved
ones, or even for ourselves.”

–Dr. Angelo Volandes, physician, faculty
Harvard Medical School, author of
The Conversation: A Revolutionary Plan for
End-of-Life Care



It's obvious, physicians know more about
treatments than we do.

4. Why do you think it's more acceptable to say say "I'm fighting this disease than "I'm dying?"

Seen others cured?

We're pro-life so we have to be pro-medicine?

We paid for care might as well cash in?

Giving God time to do a miracle?

Fear?

Like being the center of attention?

Like being the victim?

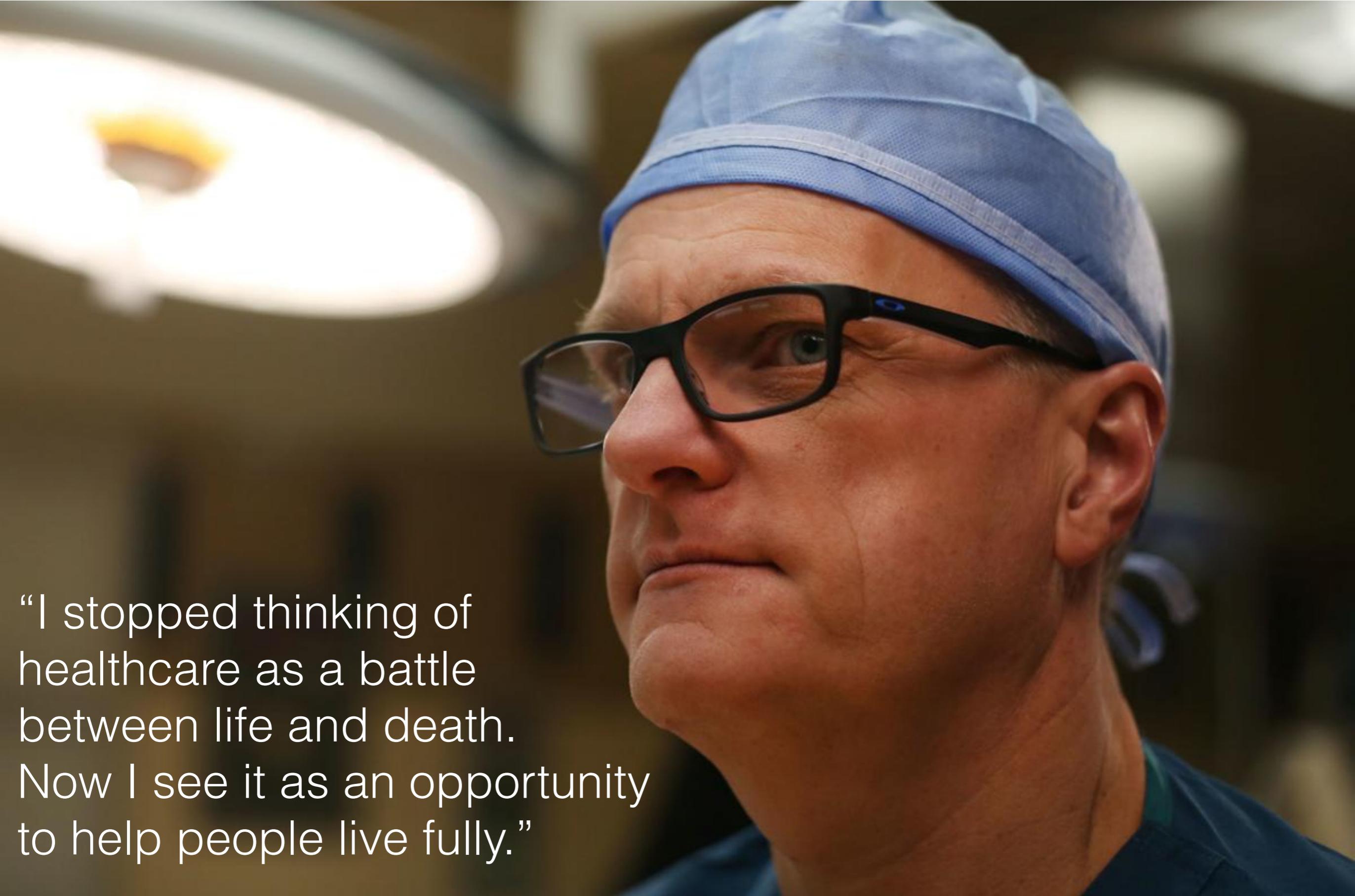
We're rich?

Does fighting help us make our death a worship experience?

I don't want to die fighting disease,
I want to die loving God and loving people.



Most Americans don't want to sort out healthcare choices so they simply do what doctors tell them to do. This is the reason as many as 80 percent are dying in institutions. Fear is underlying the sequence of events that brings so many to the kind of death they never wanted for themselves. Thinking about our soul is a waste of time for modern medicine so as we defer to modern medicine we break the first two commandments.



“I stopped thinking of healthcare as a battle between life and death. Now I see it as an opportunity to help people live fully.”

Neurosurgeon W. Lee Warren in *I've Seen the End of You*

We can choose Romans 8:5-6

“Those who live according to the flesh have their minds set on what the flesh desires; but those who live in accord with the Spirit have their minds set on what the Spirit desires. The mind governed by the flesh is death, but the mind governed by the Spirit is life and peace.”



Dietrich Bonhoeffer 1906-1945

Pastor, Theologian, Spy, Martyr

We will die as we
have lived.

5. Discuss the story
of Bonhoeffer on page 67.
What did the Nazi doctor
say when he witnessed
the execution?

The Nazi physician in
attendance at the
hanging wrote,
“I have never seen a man
die so entirely submissive
to the will of God.”

“Death is not bitter, if we have not become bitter.
Death is grace, the greatest gift that God
gives to people who believe in him.
Death is mild, death is sweet and gentle;
it beckons to us with heavenly power,
if only we realize that it is the gateway to our homeland,
the tabernacle of joy, the everlasting kingdom of peace.”
-Bonhoeffer

6. What would it take for you to get to where Bonhoeffer was when he wrote this?
How can you make your death a worship experience for all who are present as he did?
Not just the last five minutes but the last few years, months, weeks, and days?

How do we know that Bonhoeffer worshipped in his death?

Our post-modern, post-Christian, hyper-medicalized culture puts pressure on us so we must prepare in advance or we can be swept up in the whirlwind.

To worship all the way to heaven will require “tough love” communication with physicians and family.

Page 82-83 Words Don't Mean The Same Thing

They Say: Treatment

You think: Cure.

They think: process—procedure—protocol—usual intervention.

They say: Perhaps

You think: Of course.

They think: maybe but more likely not.

They say: Your cancer has responded to the chemotherapy

You think: I am going to be cured.

They think: There has been some effect on the tumor.

They say: We can try

You think: It will work.

They think: It is technically possible to do this but there is no suggestion of success.

They say: We can enroll you in a study.

You Think: Great. I'm going to get cutting-edge treatment.

They Think: You fit the criteria we are seeking for the research.

You want to participate in order to add to medical knowledge.

7. Does anyone have personal experience with friends or family who were too optimistic about physician reports?

Does this help to explain why lay people may be confused as they enter into treatment for a serious illness?

In the hospital we have to take the lead to manage our own care. The hospitalist is in charge of you and doesn't know you.





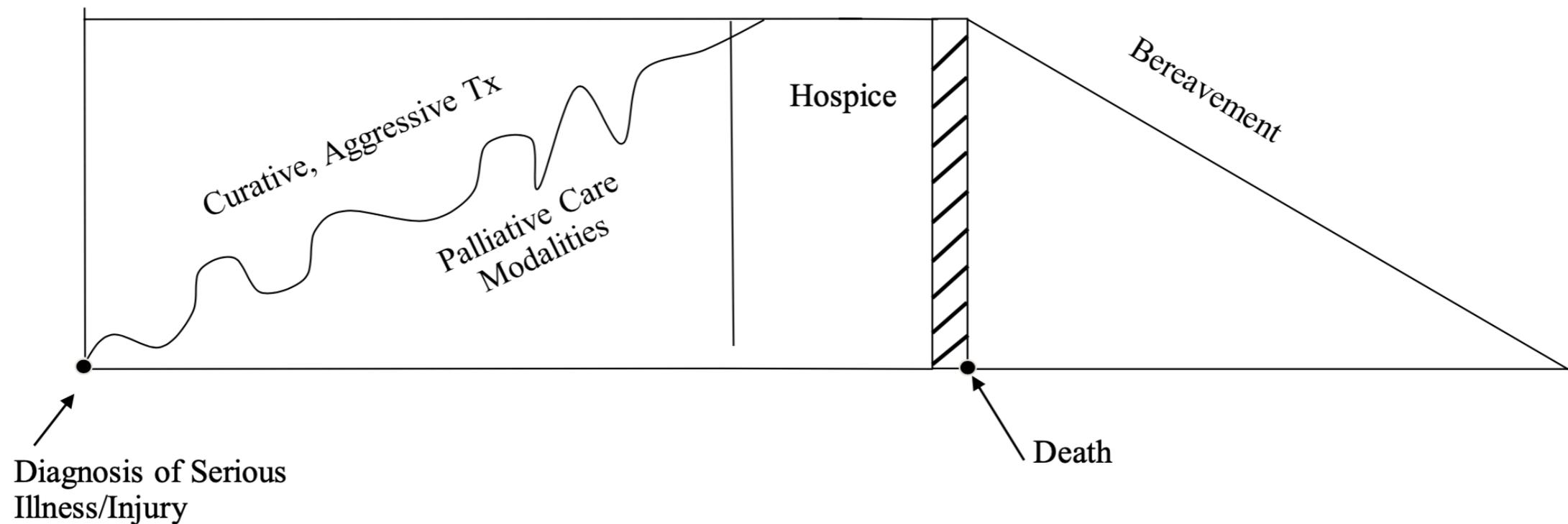
“Despite my training and experience, I am almost completely incapable of practicing as both a thoracic medical oncologist and a palliative care physician simultaneously.”
-Toby Campbell, MD



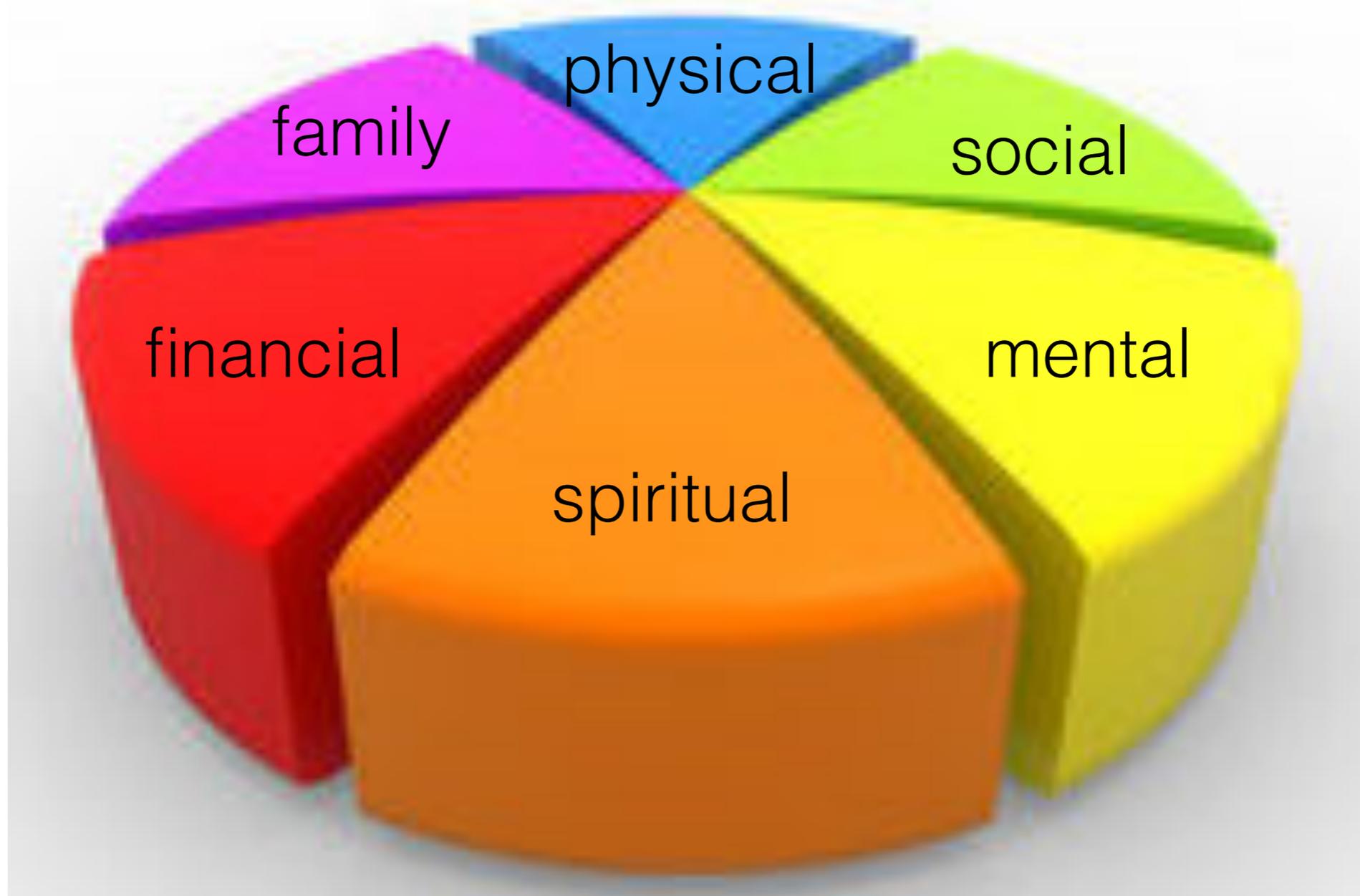
Too bad we treat diseases and organs
not the whole person.
-Louise Aronson, MD

The best care includes palliative the minute you hear a difficult diagnosis. You can go back to your primary care doctor for this.

Current Model for Pal Care



Hospitals are only good for 1/6 of the whole you unless you demand a palliative care consultation.



The big sub-specialities (I call them the part docs)
who tend to hold on to us are:

cardiologists
pulmonologists
nephrologists
neurologists
oncologists

Research released May 2019 shows that **cardiologists
are waiting too long to *refer patients to comfort care.**

-JAMA (Journal of American Medical Association)

*We do not have to wait for referral. We are the customer.

We can demand comfort (Palliative Medicine) the minute we hear a difficult diagnosis.

One veteran
nurse said,
“We treat
until we kill.”

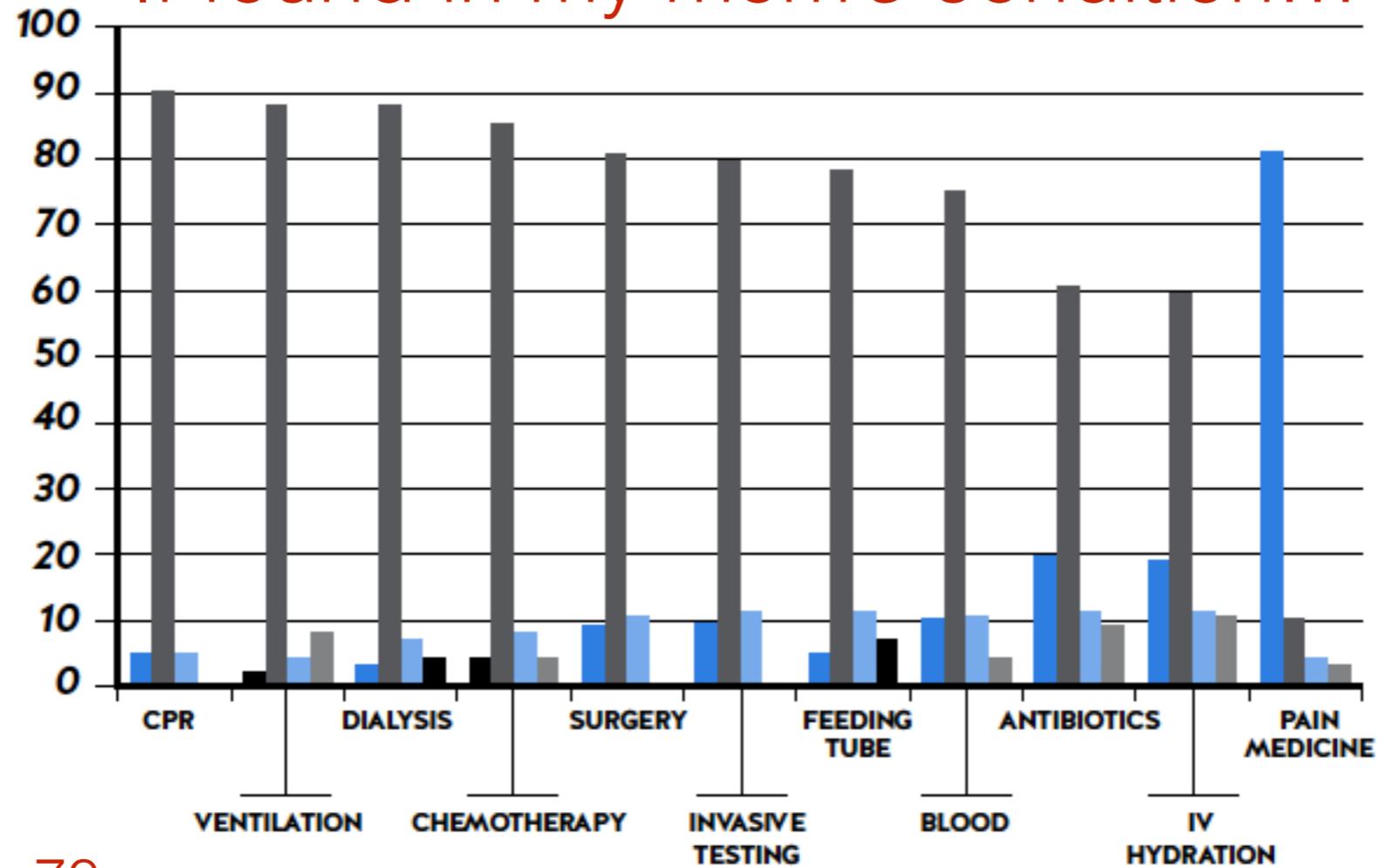
-Westberg
Symposium
4.14.2021



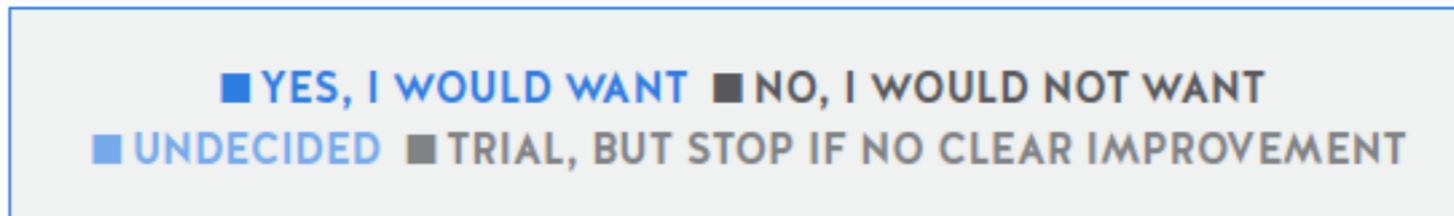
Look back at the essay on pages 69-70.
What can we learn from physicians?

Like my dad, doctors avoid much of what they do to us.
They understand the burden vs. the benefit of treatments.
They know that medicine has limitations and an end.

If found in my mom's condition...



Reading 3 page 70



Dr. Greene was happy to take my call. He explained that he was diagnosed on August 4, 2022 with hepatocellular carcinoma that has metastasized to both lungs and his pelvis. For me this is one of those life-is-not-fair moments. Just like when a person who has never smoked a cigarette dies of lung cancer, Dr. Greene has never consumed alcohol that can lead to cirrhosis of the liver that can lead to this cancer. He has never used intravenous drugs which can lead to Hepatitis B which can lead to this cancer.

“My only symptom was fatigue for about a year before my wife insisted that I get to the ER,” he said. Dr. Greene came home from his last day of work on August 4 and his wife took him to the ER as she was tired of him being tired.

From the ER he was admitted to the hospital where tests were done, and the carcinoma discovered. While Dr. Greene noticed loss of appetite and fatigue, he caulked it up to natural aging as he is now 62.

At the time of the discovery, the cancer had spread and the typical approaches to cancer would not be productive. He was told with no treatment he has six months to live this life and with monoclonal antibiotics he could extend that another 6 months. He is now taking monoclonal antibodies in his doctor’s office every three weeks. This has improved his appetite and he is in no pain.

“I never planned to take treatments, yet I can see that my family needs this extended time,” he told me. This fits the research I have seen about how physicians deal with serious illness. They understand the trajectory of their case, they know what treatments can and can’t do and typically opt out of aggressive care and choose the palliative path.

He said, “I’m a laid-back guy. My hope is in my salvation. I do not dread what is before me.” Let us all pray that our Father God work his will and that deep abiding peace settles over Dr. Greene and all of those who love him—including me.

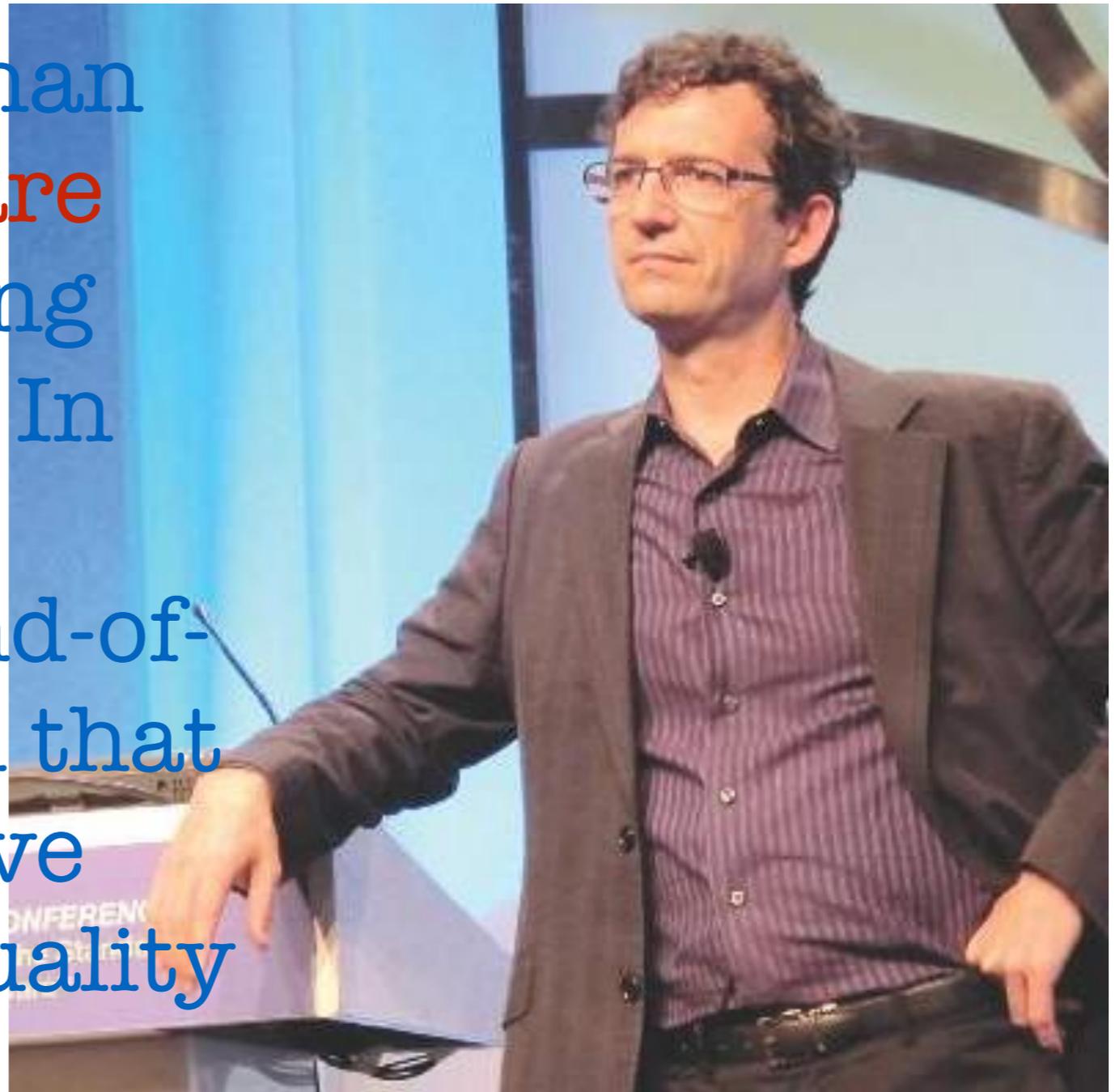


Dr. Jeffrey Greene

“1% of patients account for more than 20% of US healthcare spending much being done at end-of-life. In short, we spend lots of money on end-of-life care even when that care doesn't improve the length or the quality of people's lives.”

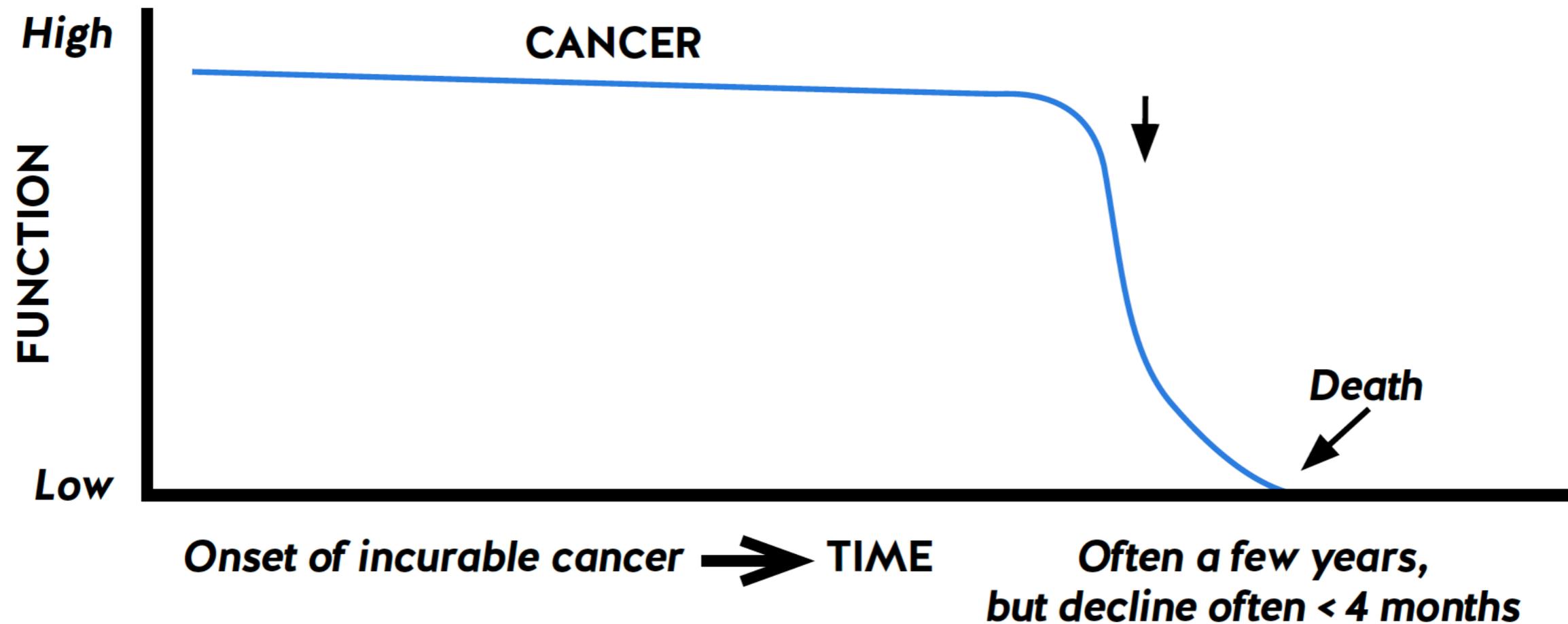
-Peter Ubel, MD

Forbes 2.25.2020



My dad knew when he had arrived at the place you see the graph turn down.

INCURABLE CANCER TRAJECTORY DIAGNOSIS TO DEATH



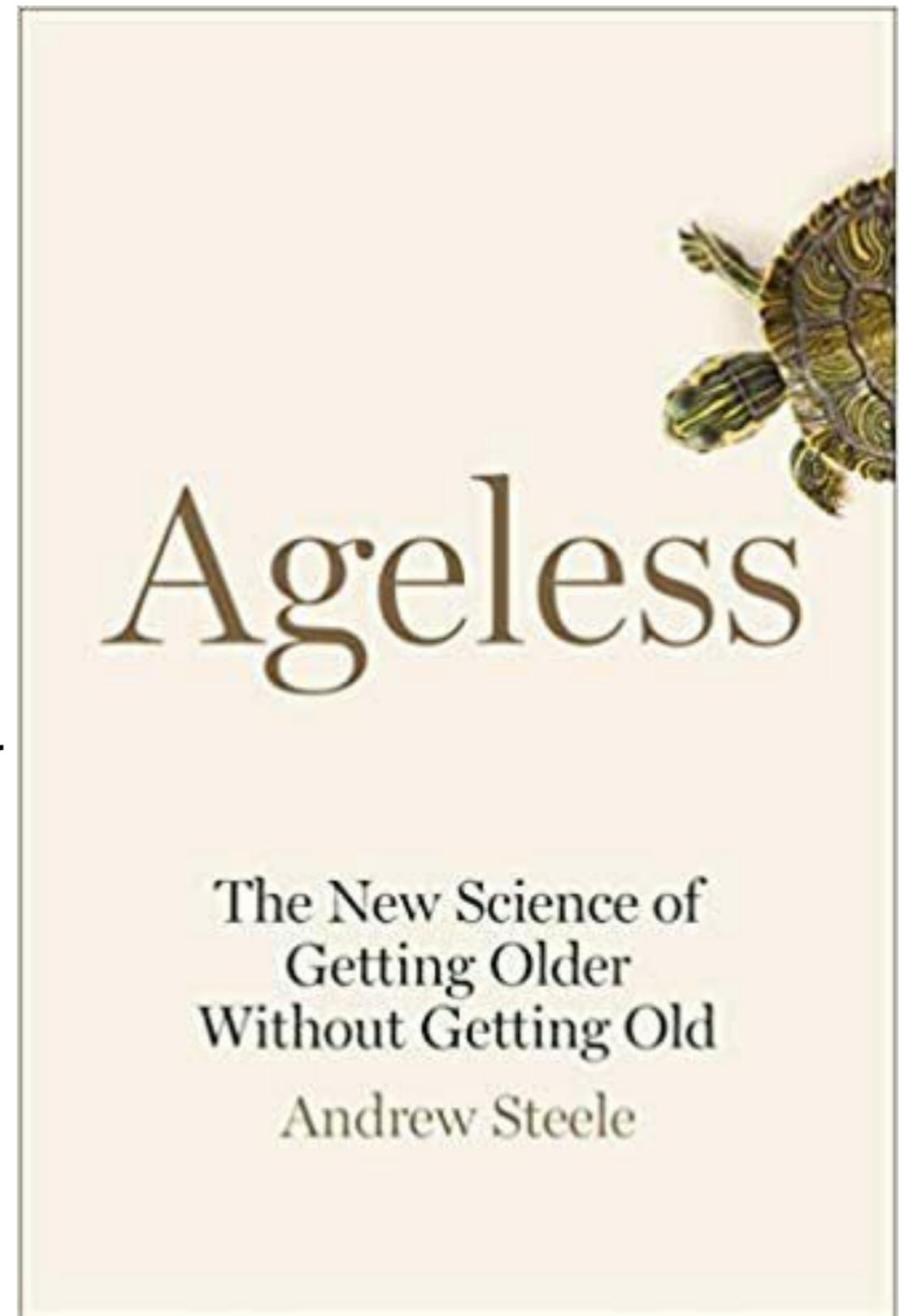
Generally predictable course, short decline
Relatively well resourced hospice care fits well

He announced, "Save the healthcare for the grandchildren!"

The average 80-year-old is suffering from five different diagnoses and taking similar number of medications to treat them. Surviving cancer just tees you up for the next age-related disease on the list.

Wall Street Journal April 10, 2021

Reminds me of my interview
with Dr. Joanne Lynn



Doctors get on the gentle path sooner than we do.



“I want to die like my father died. He was not big on medicine. He died at home surrounded by family.”

-Dr. Joseph Gallo



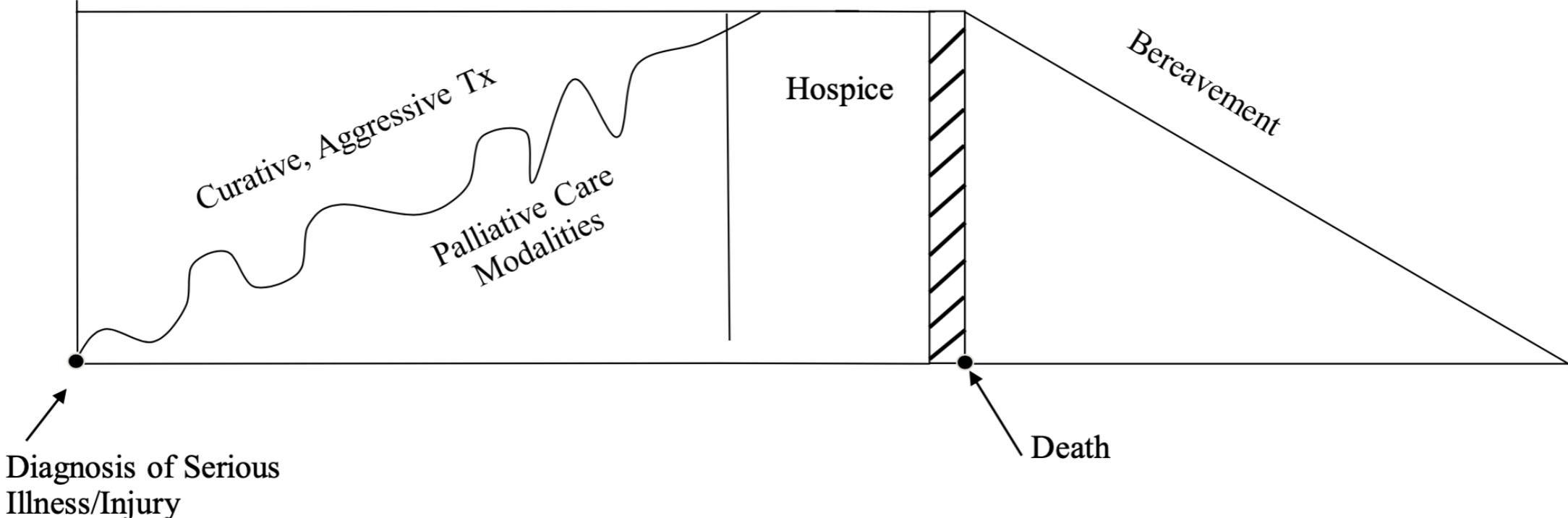
“My physician patient made me promise I would never admit him to the hospital. He had practiced medicine in the ICU for 22 years and was only 58 when he died.”

-Dr. Mohana Karlekar
Chief of Palliative Medicine

Was he more eager to go to Jesus than spend time as a patient in the ICU?

This is the type of care that physician received.

Current Model for Pal Care



JOKE: Why are there nails in a coffin?
So the oncologist can't deliver another dose of chemo.

“Functional status is a
real-world marker for
physiological fitness.”

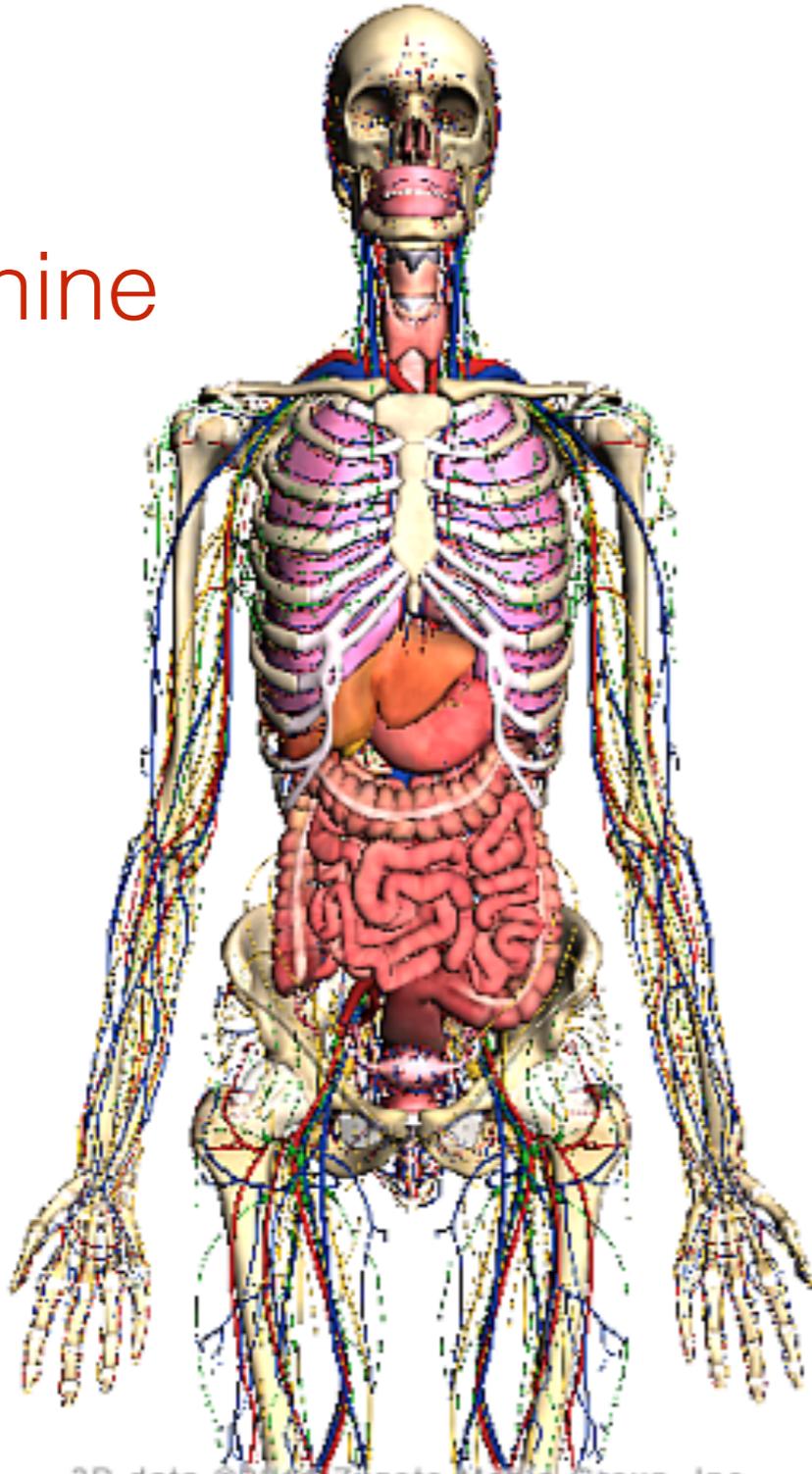
–Louise Aronson, MD in *Elderhood*

Hint: If you can't walk across a
room you are probably not
strong enough to benefit from
chemotherapy.

“Health care today is doled out in installments that do not add up to a human story. Bodily organs get treated one part at a time, while the patient’s humanity is often ignored.”

-Christopher Kerr, MD

Machine



More than a Machine



“It has
become
easier to live
longer but
harder
to die well.”

Christopher Kerr, MD, PhD
Death Is But A Dream

Wife and nurse stopped the aggressive care.

I turned to the same nurse who was by my side and asked her to verify that they had been 45 minutes into this code. She agreed with me that it had indeed been 45 minutes. It was then I said enough was enough and go tell the rescue team I am calling this code.

I could not in good conscience have them continue this assault on Steve's body. ENOUGH! The nurse obediently got someone as they all trotted out to me to talk to me.

Steve's doctor was crying. I looked straight into her eyes and said "*Why are you crying? Don't you know there is life after this life?*" She blinked several times and said "*I am the doctor and I should be comforting you.*" I shook my head no. I told her "*My faith tells me he is in a much better place than here and he is in the presence of God.*" I told her "*Thank you for trying to help him and I am at peace with his death.*" She then hugged me and walked away.

It was then that the chaplain said to me "*I have worked here many years and you are the very first person who said they were a Christian that ever acted like one.*"

Paulette
Meeks
Faith
Community
Nurse



“Our effort to extend life leaves
no space for accepting
death.”

Sunita Puri, MD

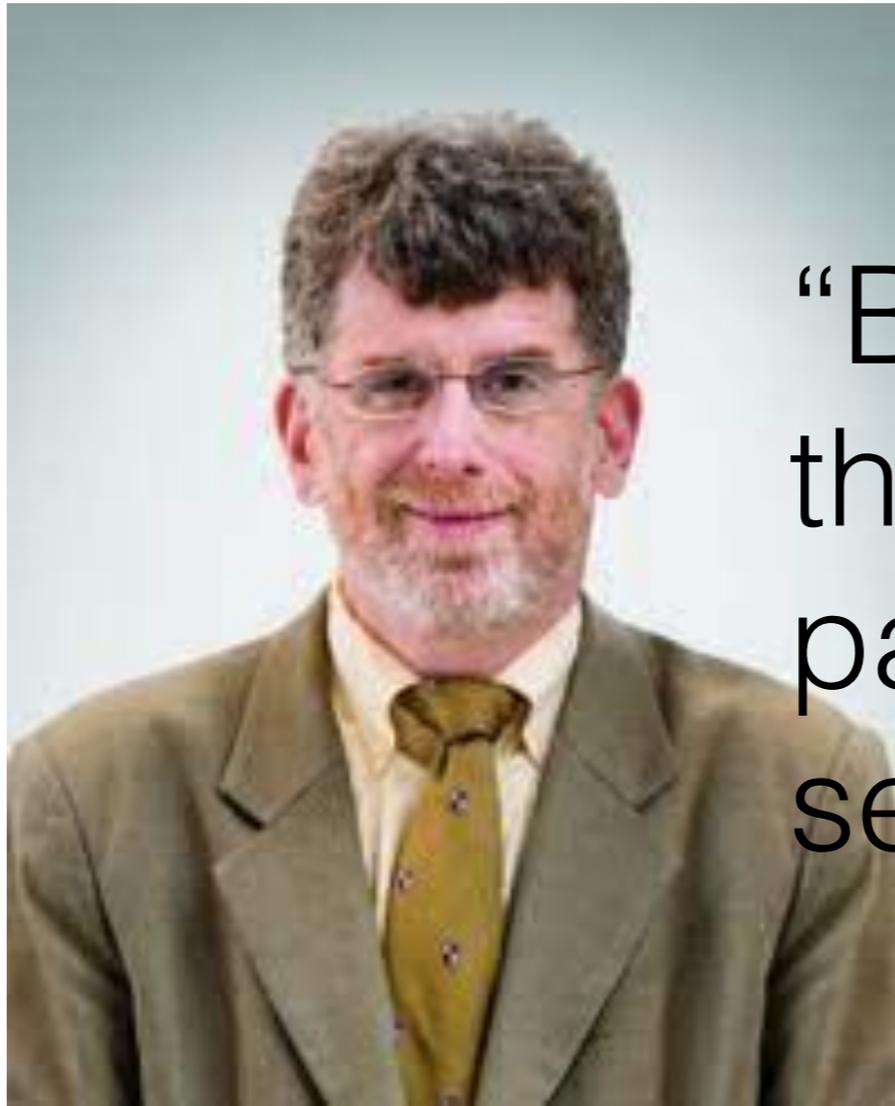
8. What are we to do as Christians when we or loved ones are presented with a difficult diagnosis?

Ask hard questions
Turn back to pages 73-75

When you hear a difficult diagnosis, ask:

- Will you be surprised if I am alive a year from now?
Two years from now?
- Should I sell my furniture this month? This year? Do I need to make changes in my home?
- Please describe this diagnosis in detail so I can understand what this means to me and my family.
- What is the typical trajectory of this disease?
- What are the treatment choices?
- Can I speak with others who have made these various choices?
- Can I speak with the families of some who have died from this disease?
- Can you tell me the story of a patient who is thriving after your recommended treatments?
- I want a palliative care consultation before I make any treatment decisions.
(They will tell you no but you must override this.)

Getting a peaceful death takes courage and effort.



“Bad news is something that disrupts the patient’s and family’s sense of the future.”

-Robert Arnold, MD

Founder of Vital Talk

University of Pittsburgh School of Medicine
Director of Palliative Medicine and Medical Ethics



“Five Key Questions at the End of Life”

1. What is your understanding of your current health or condition?
2. If your current condition worsens, what are your goals?
3. What are your fears?
4. Are there any tradeoffs you are willing to make?
5. And perhaps later...

What would a good day be like?

Atul Gawande, MD writes in *Being Mortal*

If science can't be questioned it's not science anymore. It's propaganda.

-Aaron Rodgers
12.30.2021



Wallet Card • In Case of a Medical Emergency

Please know that I want to live this life fully all the way to the end. I or my proxy will want a Palliative Care consultation upon my arrival to a hospital or other medical treatment facility.



Signature

Date

See page 154.



Palliative care is delivered by a team that typically includes a physician, a nurse, a social worker and a chaplain.

Palliative care is for anyone with any serious illness at any stage of the illness.

This team works on mind, body and soul pain and discomfort.

palliative care is also called supportive care, comfort care, compassionate care

Palliative medicine addresses Total Pain. This is a concept formulated in the body of work of Cicely Saunders, 1958-1967.

The 2020 pandemic brings TOTAL PAIN into a new focus.

Pain can be physical, psychological, social, emotional, spiritual or a combination.

What kind of pain is created by social distancing?

What kind of pain is created by media coverage of the pandemic?

What kind of pain is created by the anxiety of the unknown?

9. What do you imagine will be your greatest fear if presented with a difficult diagnosis?

Pain? Dying before you finish your to-do or want-to list?

Being alone? Losing your mind? Going into debt?

(Can look back at page 17.)

10. What are we to do with our fears?

Give them to Jesus.

Nail them to the cross.

Hang around fearless friends.

Share with your Circle of Care your detailed plans made on pages 157-164.

Fix your heart on heaven each and every day.

Fill your mind with scripture.

Think on the good, the noble, the true—not what the

hyper-medicalized culture dumps on us all day everyday.

To take the lead when you hear a difficult diagnosis will take courage?
Would you be afraid to question a physician? If yes, why?

No because I now have a list of questions (page 73) and I now know that physicians don't want to bring up the subject of my death. I must do it myself.

11. What did we learn from Betsy?

a. Who did Betsy fire and why?

An arrogant doctor.

b. What did she tell her new doctor?

That she wants a partner not a boss.

c. Did her new doctor believe in prayer?

Yes.

d. What did Betsy do over every pill and every treatment?

She prayed.

e. When Betsy prayed for help, what did God give her?

Peace.

f. What did Betsy do three times a day for years?

She read Psalm 103 outloud.

Memorize this:
Doctors do not have to live with
what they do to you.

Before our next session.

Let's look at page 88.
Flip over to page 109 and 113.

Father, help us see what you want us to see.

Dispel any fears or anxieties we have
about our own death and the
deaths of those we love.

Set us free!

In Christ's name we ask. Amen