

A Brief History of Death

Elizabeth Gundersen, MD, FHM, FAAHPM

BRRH *Virtual* Grand Rounds

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Disclosure Statement

I have no professional or financial conflicts to disclose.

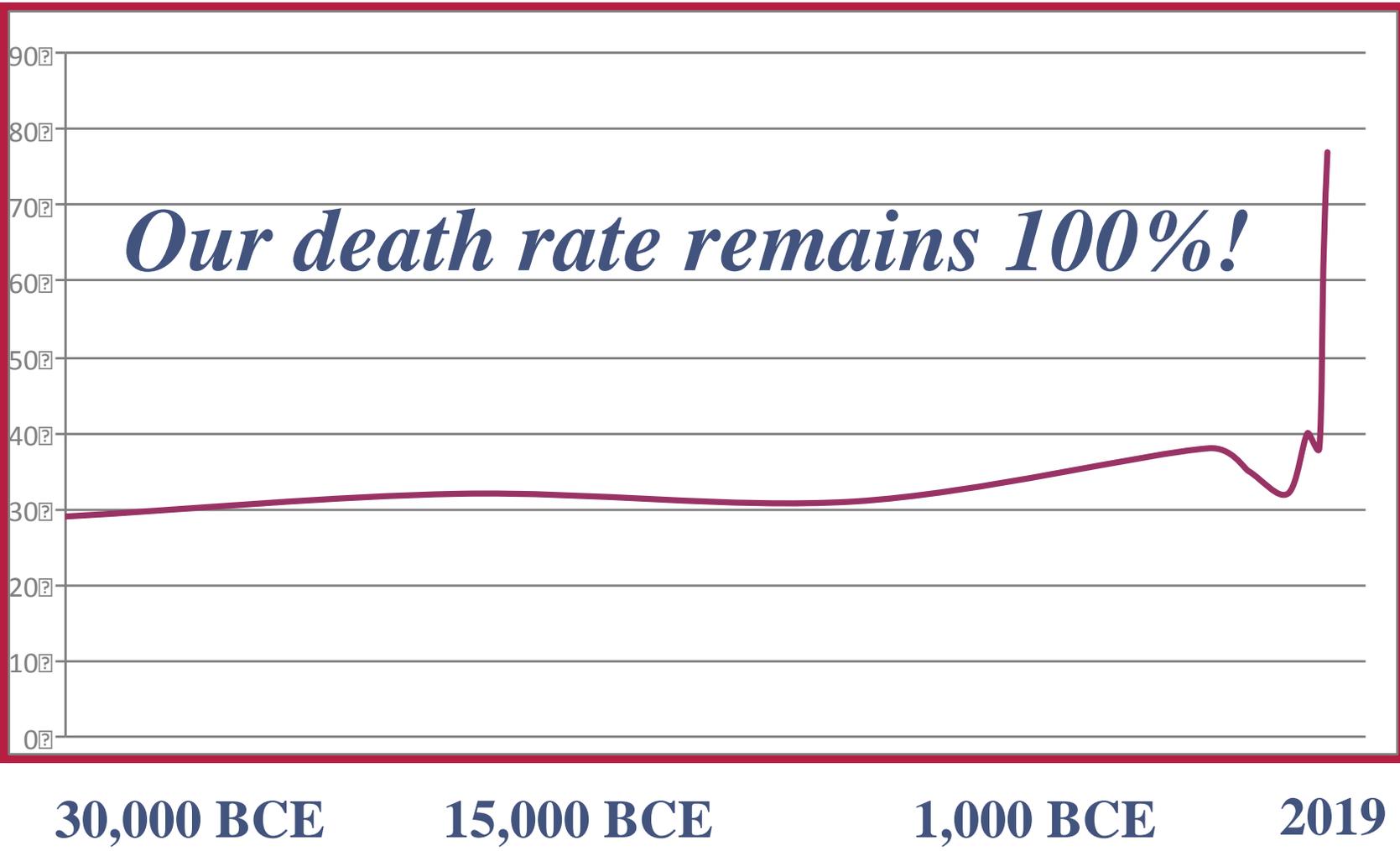
Objectives

- Describe the current state of end-of-life care in the United States
- Discuss the origins of societal attitudes towards death and dying and how these affect the care of seriously ill patients
- Explore effective approaches to the care of seriously ill and dying patients



Everyone has a story...

Life Expectancy (Years)



End-of-Life Landmarks

- 1967: Dame Cicely Saunders opens the 1st hospice in London
 - Relief from physical pain and suffering
 - Preservation of dignity
 - Help with spiritual and psychosocial pain of death
- 1982: Medicare Hospice Benefit established
- 1983-1990: Nancy Cruzan case
- 1991: Patient Self Determination Act (PSDA)
 - Written information about the right to make decisions about care

End-of-Life Care, Then & Now

Then

SUPPORT study – 1995

Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment

“Substantial shortcomings in care for seriously ill hospitalized patients”

Now

Institute of Medicine (IOM) published *Dying in America* – 2014

Seriously ill patients continue to receive care that is poor quality & high cost

Patients are not informed of likely treatment outcomes that would allow for decision-making based on their values



Disconnect

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care

18% report having had an end-of-life conversation with their doctor



92% of people say that talking with their loved ones about end-of-life care is important.

32% have actually done so



60% of people say that making sure their family is not burdened by tough decisions is extremely important.

56% have not communicated their end-of-life wishes.





30% die in acute care hospitals

70% of Americans would prefer to die at home



12% die in other places



20% die in nursing homes



8% die in a hospice facility



30% die at home



“If you come into our hospital,
we’re not going to let you die.”

UCLA Medical Center CEO David T. Feinberg, 2009

How Did We Get Here?

- **Medicine**
- **Movement**
- **Media**
- **(hu)Manity**
- **Metaphor**



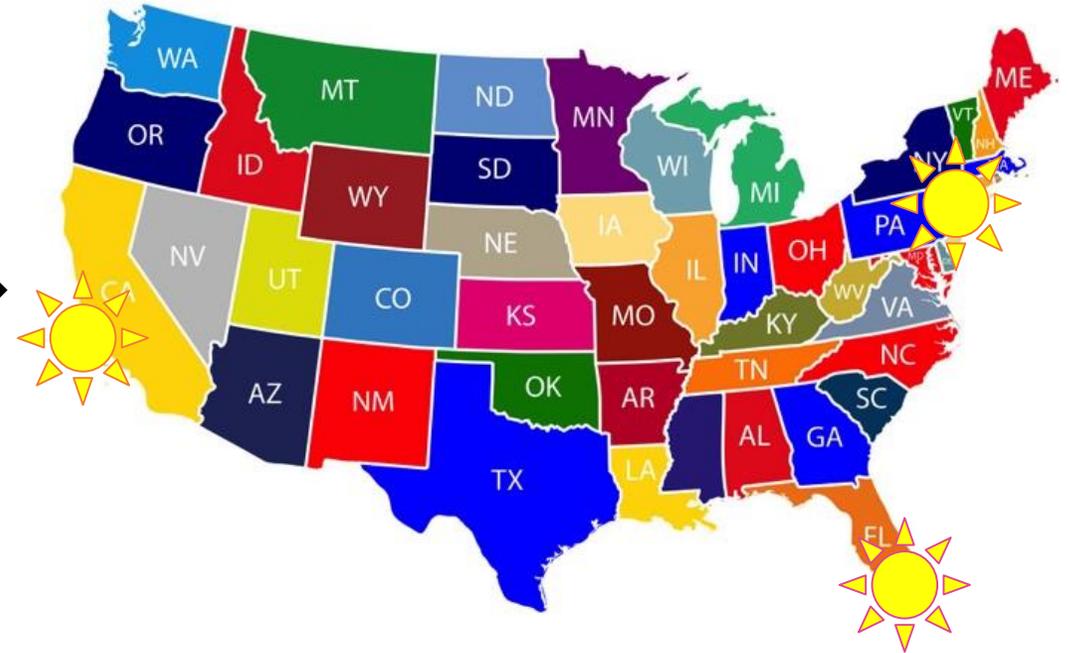
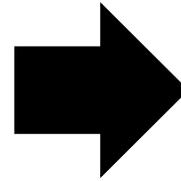
Medicine: Milestones

- 1928: The Iron Lung
- 1931: Minimally Invasive Surgery
- 1936: The Pacemaker
- 1943: Dialysis
- 1947: Cardiac Defibrillation
- 1953: Heart-Lung Bypass Machine
- 1954: First Successful Organ Transplant (kidney)
- 1971: CT Scanner
- 1982: Successful Implantation of an Artificial Heart
- 2011: First immunotherapy approved

Movement: Changing Households



In 1850, 70% of white elderly parents lived with their children

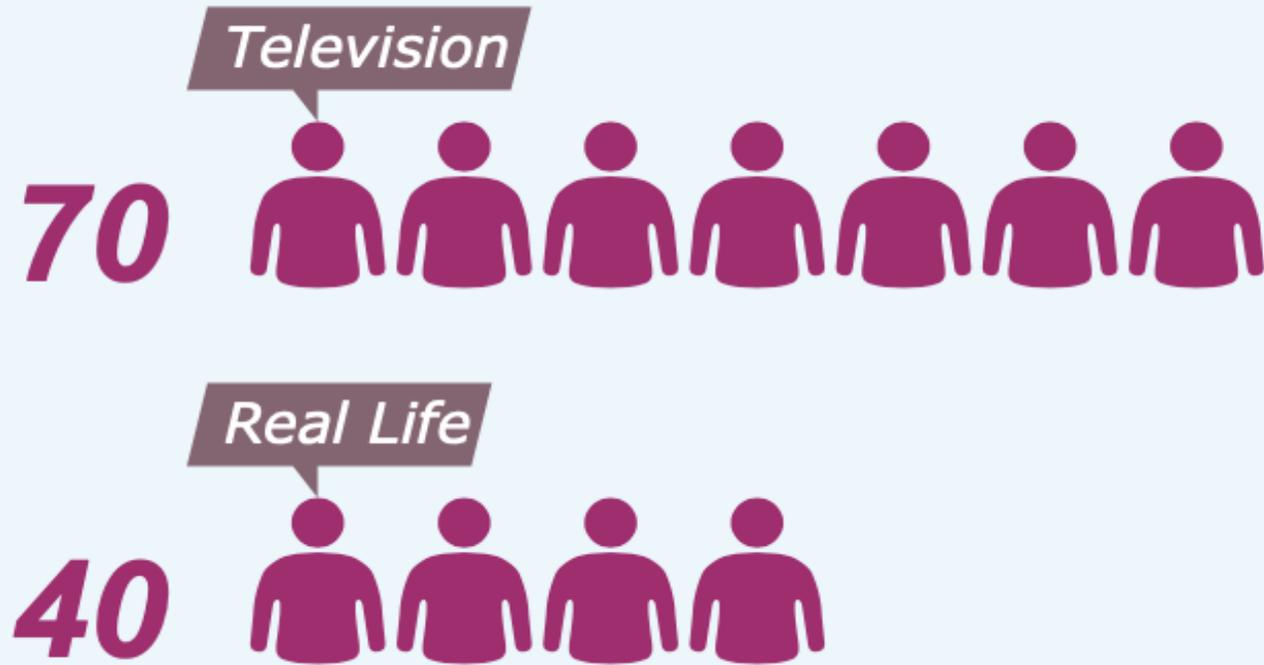


In 2016, 20% of the population lived in multigenerational homes

Media



In What Percent of Cases is CPR Successful?



(Hu)manity

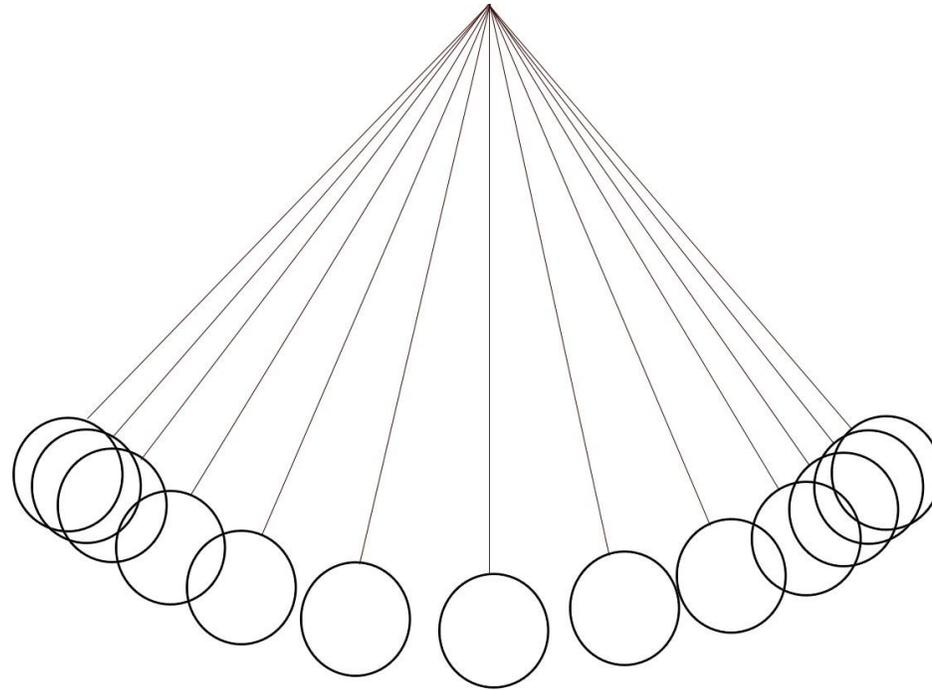
- Lack of training
- Time
- Compensation
- Discomfort
- Role confusion



The Doctor Patient Relationship



Paternalism



Shared Decision Making



The “buffet option”

“Arriving at an acceptance of one’s mortality is a process, not an epiphany.”

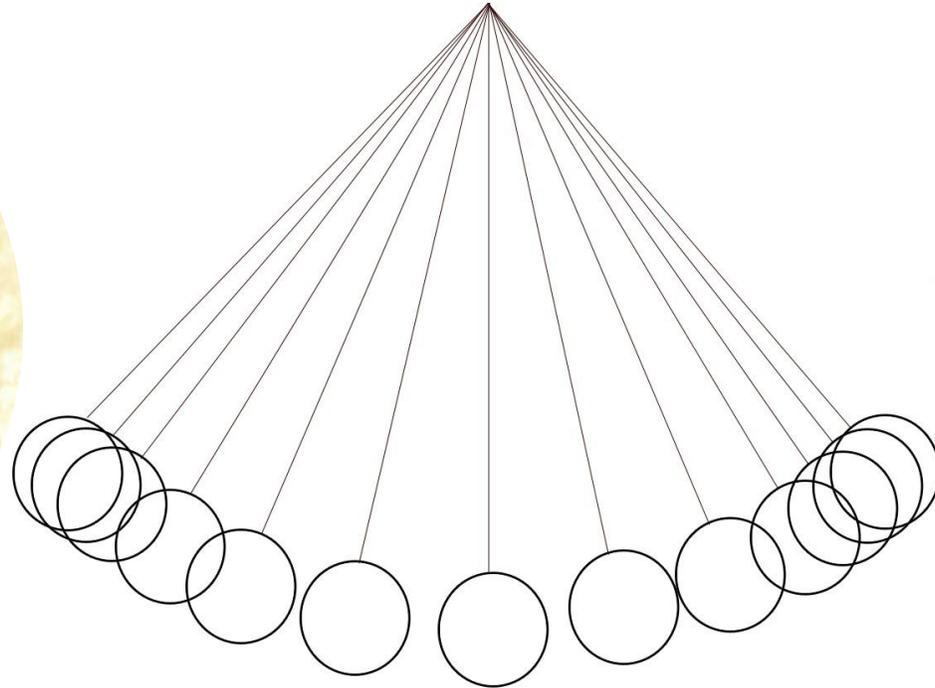
-Atul Gawande



Prognostic Awareness



Less realistic hopes



More realistic hopes

Metaphor: How Do We Talk About Illness?





Barack Obama 

@BarackObama

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John McCain is an American hero & one of the bravest fighters I've ever known. Cancer doesn't know what it's up against. Give it hell, John.

5:49 PM - 19 Jul 2017

15,719 Retweets **45,098** Likes



 1.1K

 16K

 45K



By **Melissa Bailey, Kaiser Health News** and **JoNel Aleccia, Kaiser Health News**

April 16, 2018 at 1:00 p.m. EDT

As she nears death at age 92, former first lady Barbara Bush’s announcement that she is seeking “comfort care” is shining a light — and stirring debate — on what it means to stop trying to fight terminal illness.

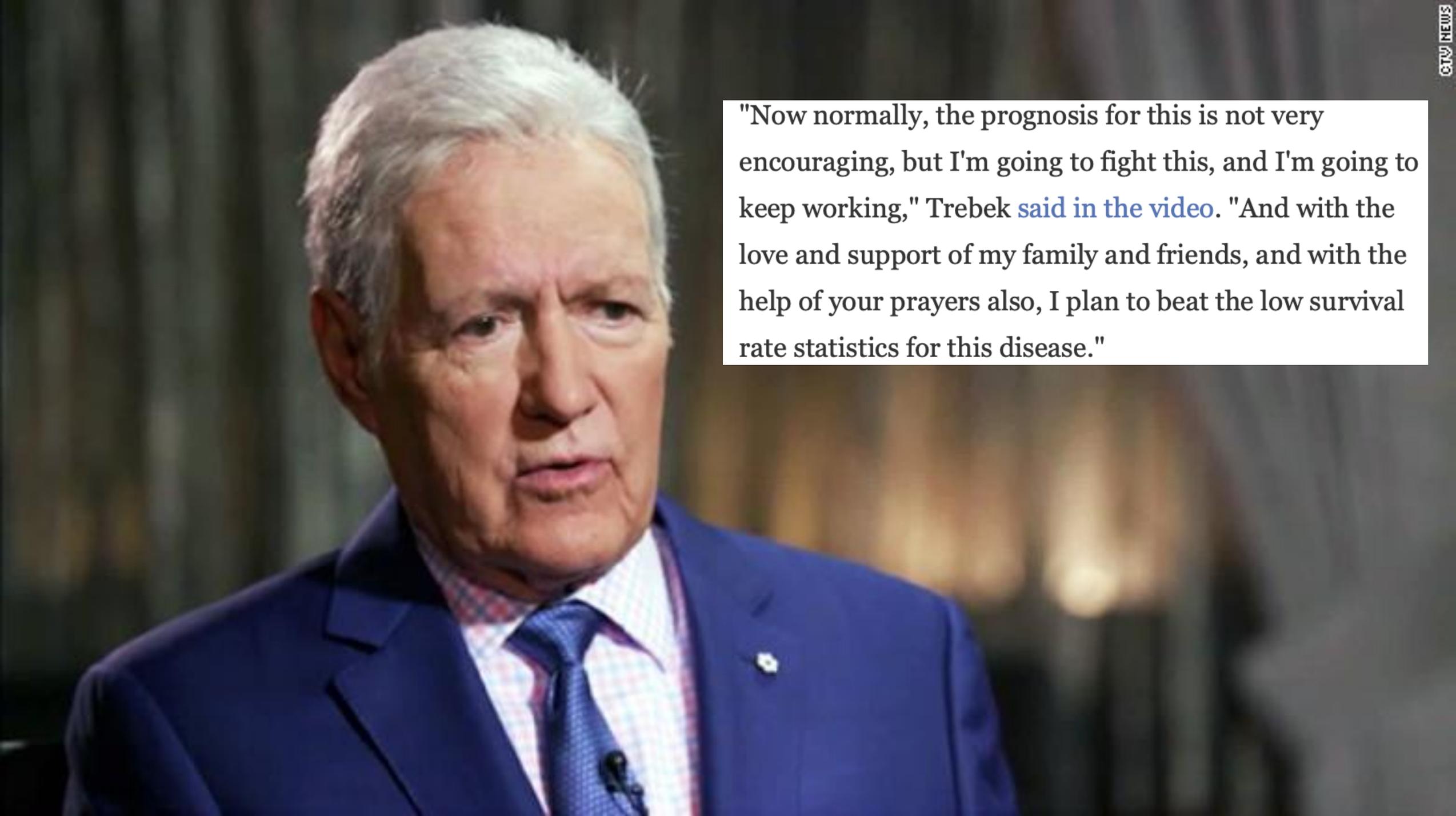
Bush, the wife of former President George H.W. Bush, has been suffering from congestive heart failure and chronic obstructive pulmonary disease, according to family spokesman Jim McGrath.

In a public statement Sunday, the family [announced](#) she has decided “not to seek additional medical treatment and will focus on comfort care.”



A source close to Aretha Franklin's family told CBS News the **legendary singer is seriously ill**. Franklin, who is 76, has battled health problems for several years.

A source close to the family told CBS News Monday that Franklin is at home in hospice care. Celebrities and politicians reacted to the word of her poor health Monday. "Praying for the Queen of Soul," singer Mariah Carey tweeted. "Hillary and I are thinking about Aretha Franklin tonight," former President Bill Clinton wrote.



"Now normally, the prognosis for this is not very encouraging, but I'm going to fight this, and I'm going to keep working," Trebek [said in the video](#). "And with the love and support of my family and friends, and with the help of your prayers also, I plan to beat the low survival rate statistics for this disease."

Added Lewis: “I have a fighting chance.”

He declined to say where he would receive cancer treatment or what that would entail. But he said he may not always be around the halls of Congress in the coming weeks.

“I may miss a few votes during this period, but with God’s grace I will be back on the front lines soon,” he said in asking for prayers.

Lewis also said he was “clear-eyed about the prognosis” even as doctors have told him that recent medical advances have made this type of cancer treatable in many cases. He added that “treatment options are no longer as debilitating as they once were.”

The American Cancer Society estimates 3% of patients with stage 4 pancreatic cancer are alive five years after being diagnosed.



Where Does This Leave Us?



Emotion Overwhelms Cognition

Emotion



Cognition

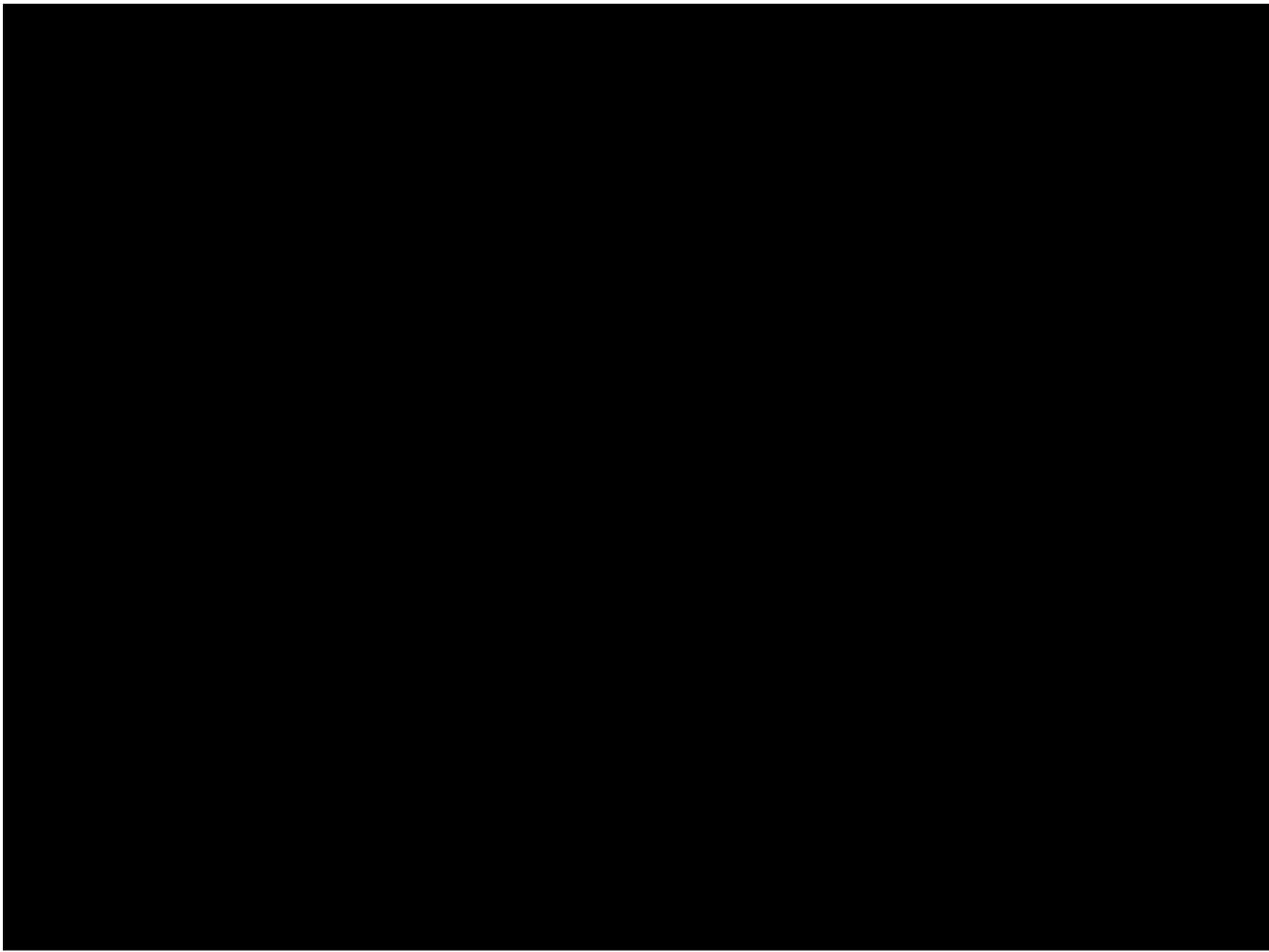
Empathy

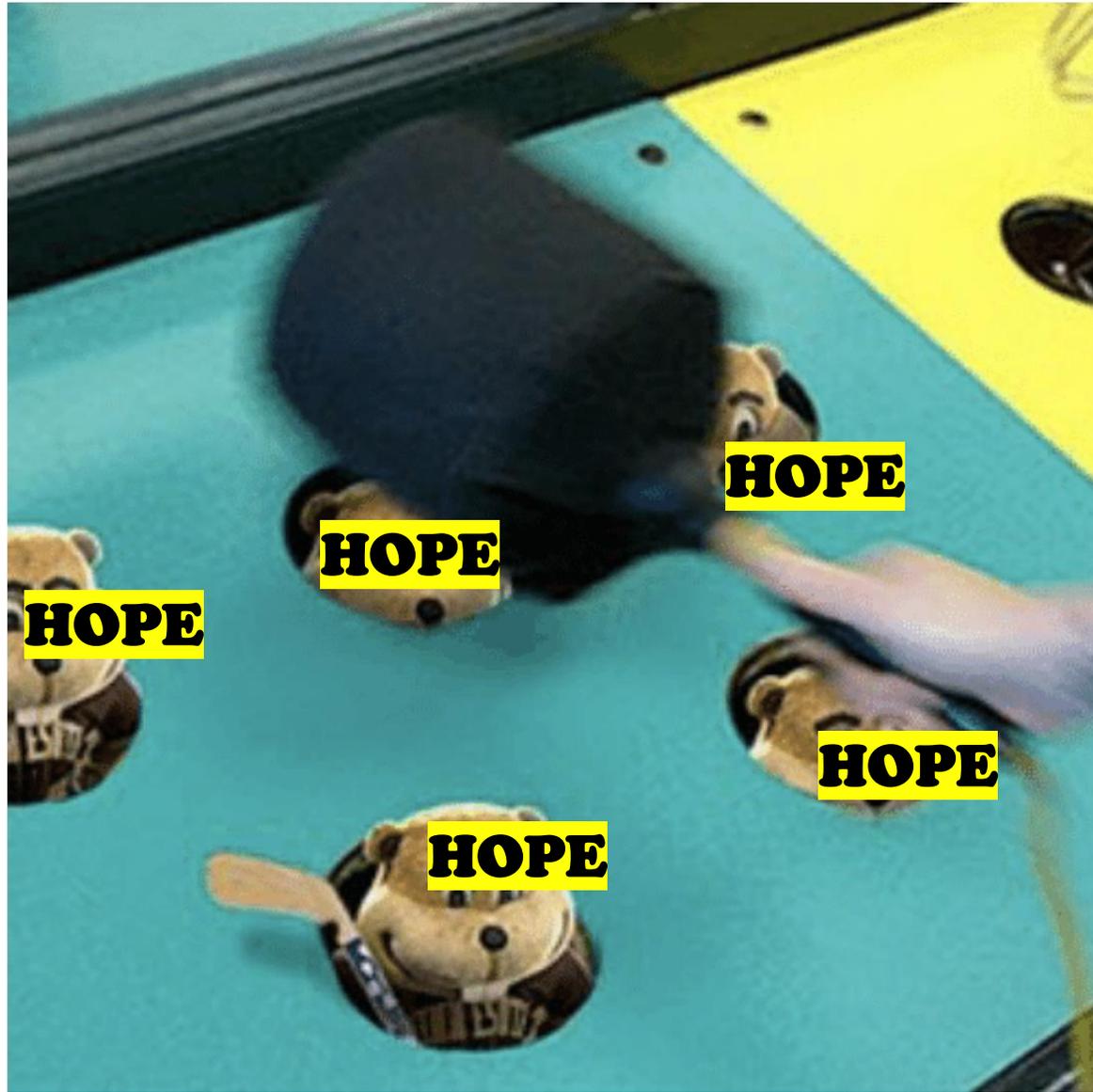
- Words matter
 - So does silence
- Sit with patient hopes *AND* worries
 - Plan for the worst, hope for the best
- Magic phrases



Words Matter







Sit with Hopes and Worries

- Deepening
- Broadening
- I hope...I fear
- I hear you're hoping for x,y,x **AND** I worry the decline we have seen is going to continue/something serious is going to happen in the next few (days/weeks/months/years)
- I wish...

NURSE: Responding to Emotion with Empathy	WHAT YOU SAY OR DO	COMMENTS
N - Name	“You sound frustrated.”	Acknowledges the emotion. Be careful to suggest only. In general, turn down the intensity (scared -> concerned)
U - Understand	“I can’t imagine what you are going through.” “I could imagine many people in your situation might feel...”	Acknowledges or normalizes the emotion or situation. Avoid suggesting you understand or relate to their experience, because we often can’t.
R - Respect	“I can see you really care about your mother.”	Expression of praise or gratitude about the things they are doing. This can be especially helpful when there is conflict.
S - Support	“We will do everything we can to support you through this process.”	Expression of what you can do for them and a good way to express non-abandonment. Making this kind of commitment can be a powerful statement.
E - Explore	“Can you tell me more about...”	Emotion cues can be expressions of underlying concerns or meaning. Combining this with another NURSE statement can be very effective and help you understand their reasoning or actions. Make sure to avoid judgment and come from a place of curiosity.

©Adapted with permission from VitalTalk by Caroline J. Hurd churd@uw.edu

COVID-19: Admitting

Is my grandfather going to make it?

I imagine you are scared. Here's what I can say: because he is 90, and is already dealing with other illnesses, **it is quite possible that he will not make it out of the hospital.** Honestly, it is too soon to say for certain.

Are you saying that no one can visit me?

I know it is hard to not have visitors. The risk of spreading the virus is so high that I am sorry to say we cannot allow visitors. **They will be in more danger if they come into the hospital.** I wish things were different. You can use your phone, although I realize that is not quite the same.

COVID-19: Notifying

What they say	What you say
Yes I'm his daughter. I am 5 hours away.	I have something serious to talk about with you. Are you in a place where you can talk?
What is going on? Has something happened?	I am calling about your father. He died a short time ago. The cause was COVID19.
[Crying]	I am so sorry for your loss. [Silence][If you feel you must say something: Take your time. I am here.]
I knew this was coming, but I didn't realize it would happen this fast.	I can only imagine how shocking this must be. It is sad. [Silence] [Wait for them to restart]

COVID-19 (& other times...) : Anticipating

What you fear	What you can do
That patient's son is going to be very angry.	Before you go in the room, take a moment for one deep breath. What's the anger about? Love, responsibility, fear?
I don't know how to tell this adorable grandmother that I can't put her in the ICU and that she is going to die.	Remember what you can do: you can hear what she's concerned about, you can explain what's happening, you can help her prepare, you can be present. These are gifts.
I have been working all day with infected people and I am worried I could be passing this on to the people who matter most.	Talk to them about what you are worried about. You can decide together about what is best. There are no simple answers. But worries are easier to bear when you share them.

Racism

What the patient does or says	What the clinician does and says
Patient describes frustration or lack of engagement with health care, e.g., “I went to the emergency room, but they didn’t really do anything.”	“I have heard from other black patients that they have had negative experiences with health care that make it hard to trust the medical system. I realize that racism exists in medical care. How much has it affected you?”
Patient describes frustration with a clinician, e.g., “That doctor did not seem to listen to me.”	“That sounds frustrating. I acknowledge that we clinicians don’t always listen well, and sometimes racism is involved. I want to do what I can to help you get the care you need.”

A Final Word

- You must refill your own empathy tank
- Have compassion for yourself and your team
- Find those moments that bring you connection and joy



Resources

- CAPC.org
- VitalTalk.org
(see VitalTips app)

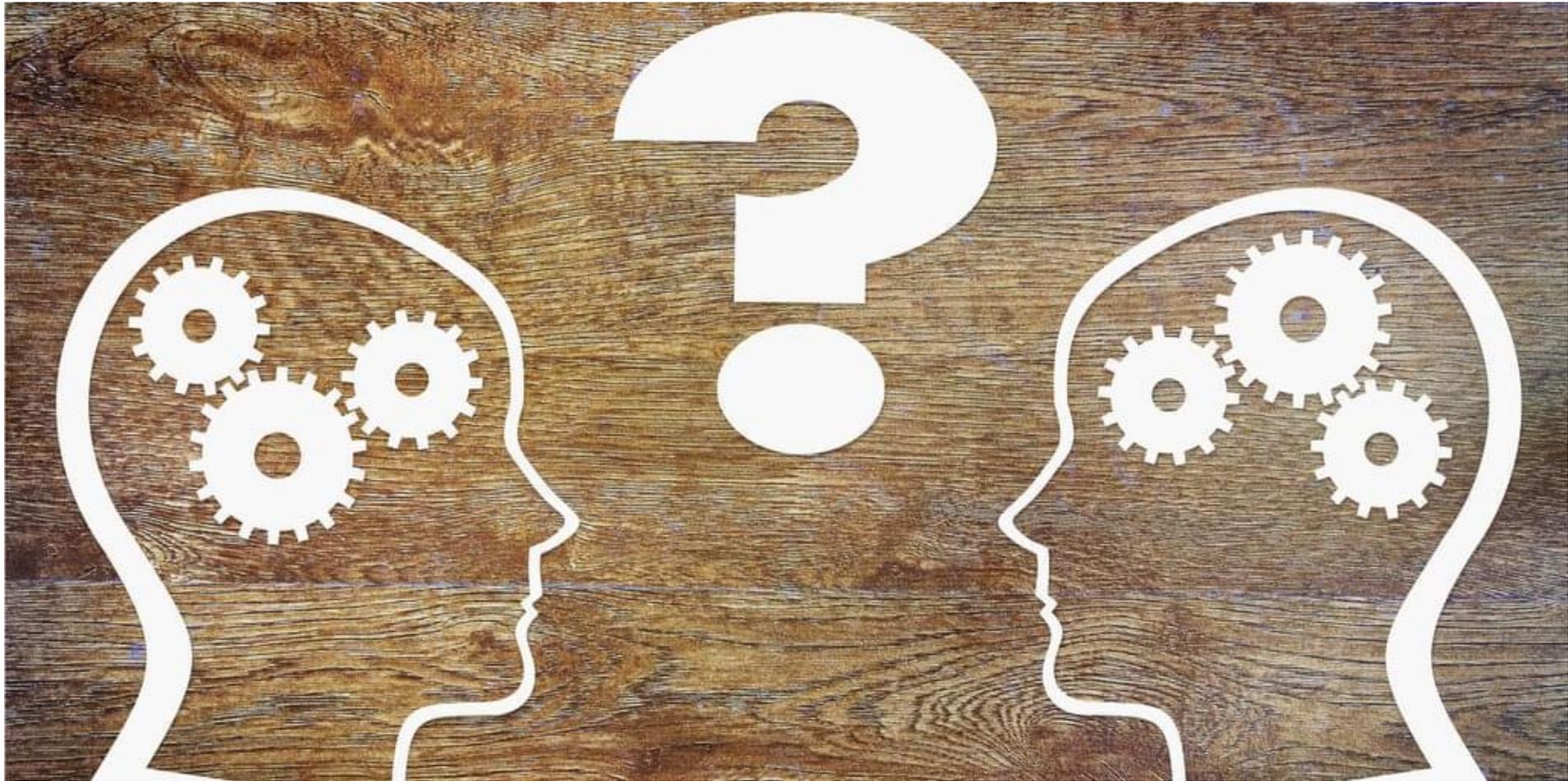
TOOLKIT

CAPC COVID-19 Response
Resources



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egundersen@health.fau.edu

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