

Facilitating Effective End of Life Communications

Beyond DRN/DNI



Thinking about death

01

Death Café

[Death](#)

02

Death

[Death 2](#)

03

Machines that go
ping

[More death](#)

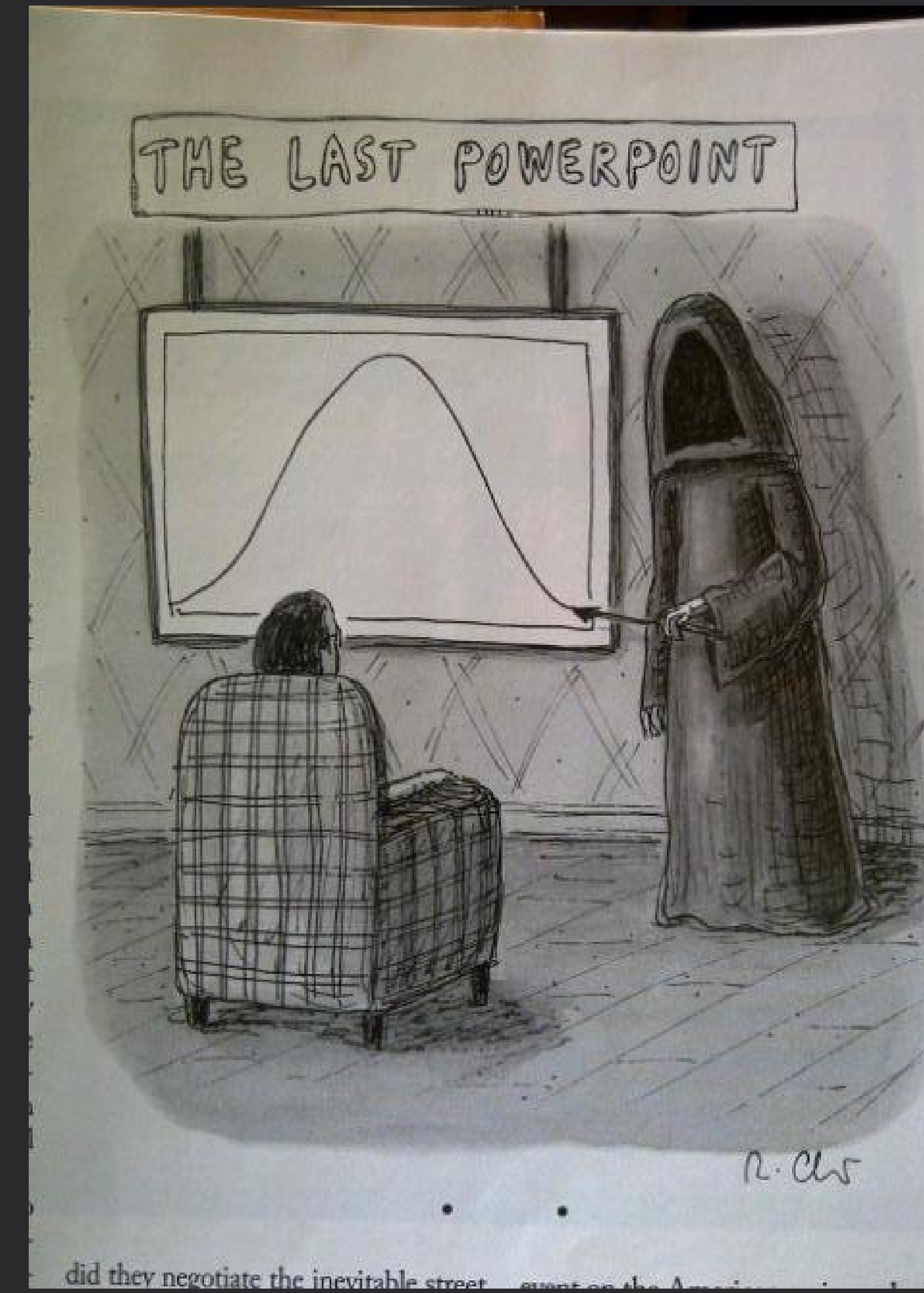
Ask Yourself

In many clinical encounters



ASK YOURSELF:

- Did I ask my patient about preferences for end-of-life care?
- Do I know who to contact if the patient cannot communicate their wishes?
- Did I include the family?
- Do I feel confident that I know my patient's wishes for care?
- Did I accurately document the nature of the conversation and decisions made?



What is your answer?

QUESTION 11

In order to provide you with the best care possible, what three non-medical facts should your doctor know about you?

QUESTION 15

What do you fear more: experiencing the worst pain of your life or not getting a chance to say goodbye to your family?

QUESTION 23

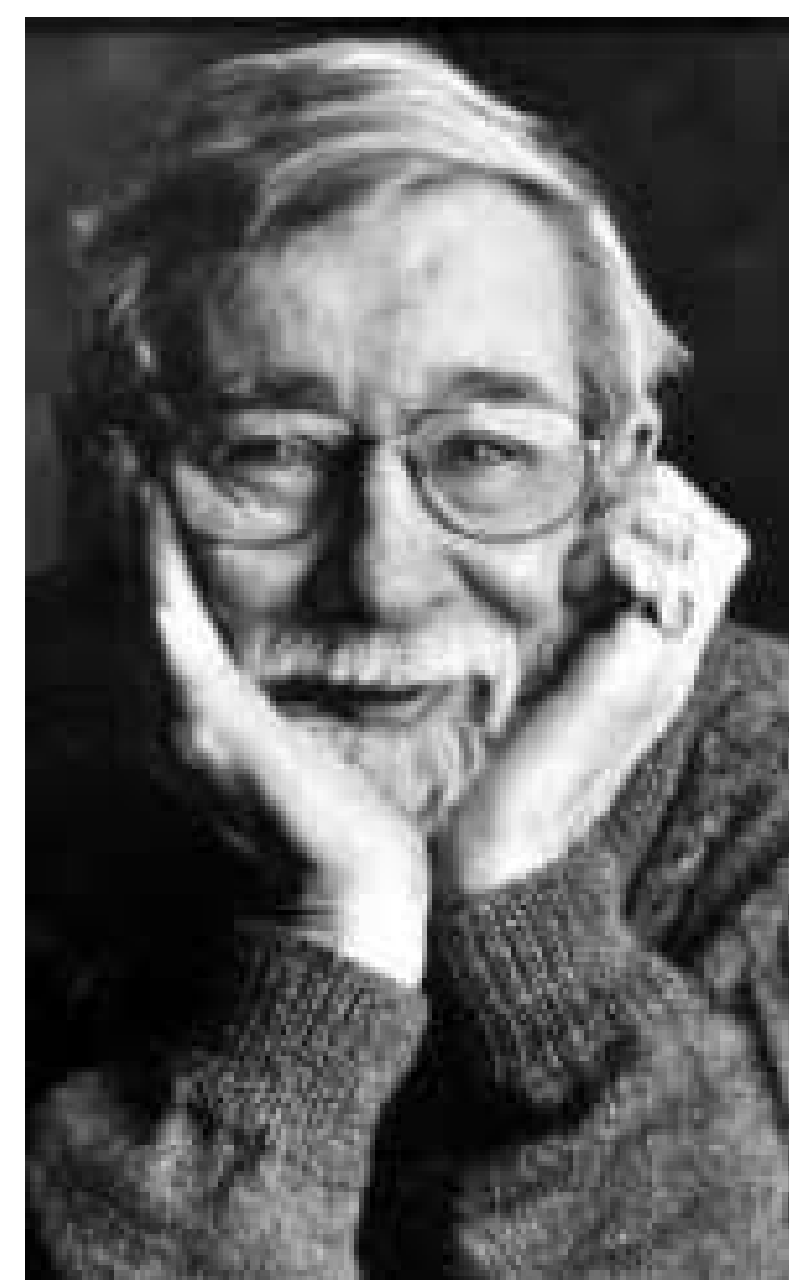
If you could control only one thing about the place that you spend your last hours of life, what would it be?

QUESTION 22

Imagine you were lost at sea and your family had to pay for the search to find you. Who should make the decision about how long to search for you?

Define palliative care

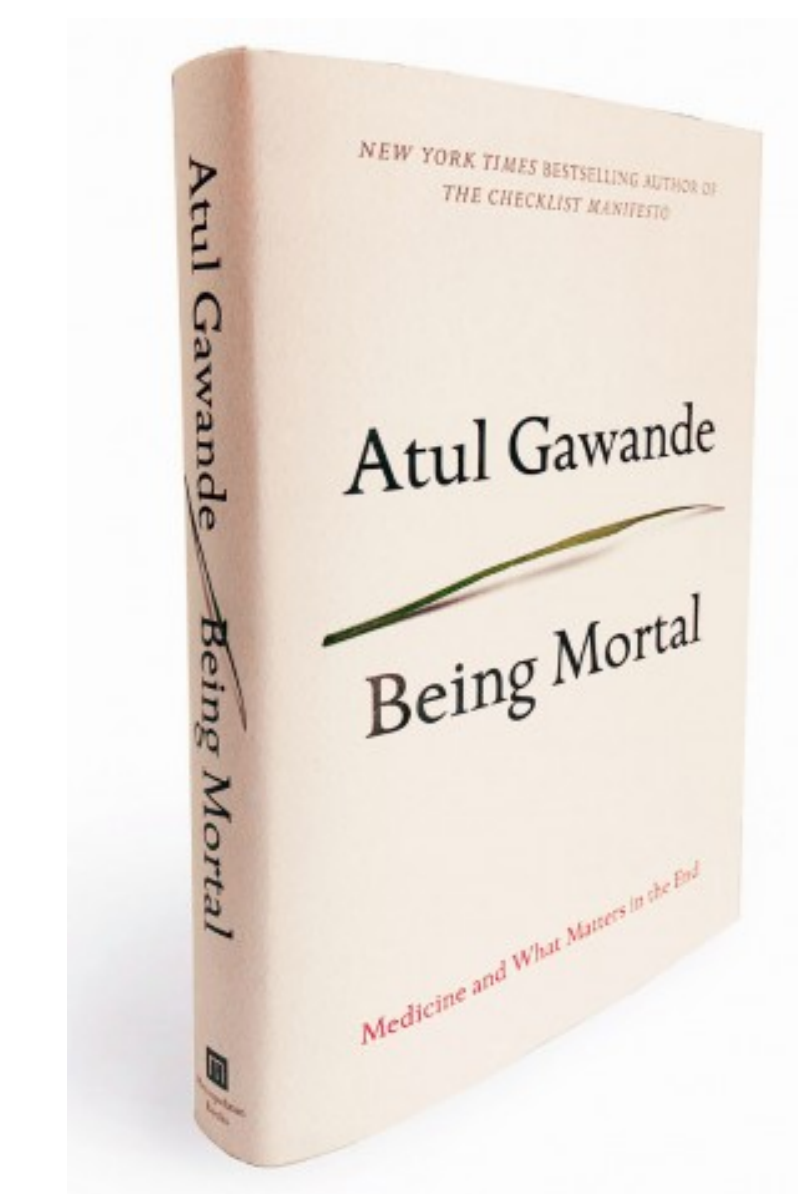
01
Who



02
When



03
Why



Early enrollment in palliative care can lower risk of hospitalization in the last two weeks of life



Study shows that early palliative care is less available to people dying of non-cancer causes, suggesting that these populations could benefit most from improved early identification.

The researchers examined administrative health records from the last two weeks of life for nearly a quarter of a million Ontarians (2010-2012).

They looked to see if starting palliative care early is associated with less hospitalization in the last two weeks of life.

They grouped the population by those who started palliative care early before death (60 days or more), late (15 - 59 days), very late (1-14 days or less), or never.



BETTER OUTCOMES WITH EARLY PALLIATIVE CARE:

Fewer days in hospital in the last two weeks of life:

9.2 days > Early start 11.7 days > Late start

More likelihood of a non-hospital death:

40% > Early start 27% > Late start

PEOPLE DYING FROM NON-CANCER CAUSES WERE MUCH LESS LIKELY TO GET EARLY PALLIATIVE CARE:

56% people with cancer / 12% people with frailty / 16% people with organ failure

Qureshi D. et al. *Palliat Med.* 2018.

ICES Data. Discovery. Better Health.
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HEALTH SCIENCES



Define Goals of Care Etc.

01
ACP

02
GOC

03
Advance
Directive



- Advance Care Planning (ACP) is a **process** of reflection and communication.
- It is a time when you **reflect on your values and wishes** regarding your future health and personal care in the event that you become incapable of consenting to treatment or other care.

Speak Up

Goals of care conversations consist of putting prior ACP conversations about wishes into the current clinical context, resulting in medical orders for the use or non-use of life-sustaining treatments.



Code status strategies

Beyond DRN/DNI

Limited



Code status strategies

Beyond DRN/DNI

Oh the horror

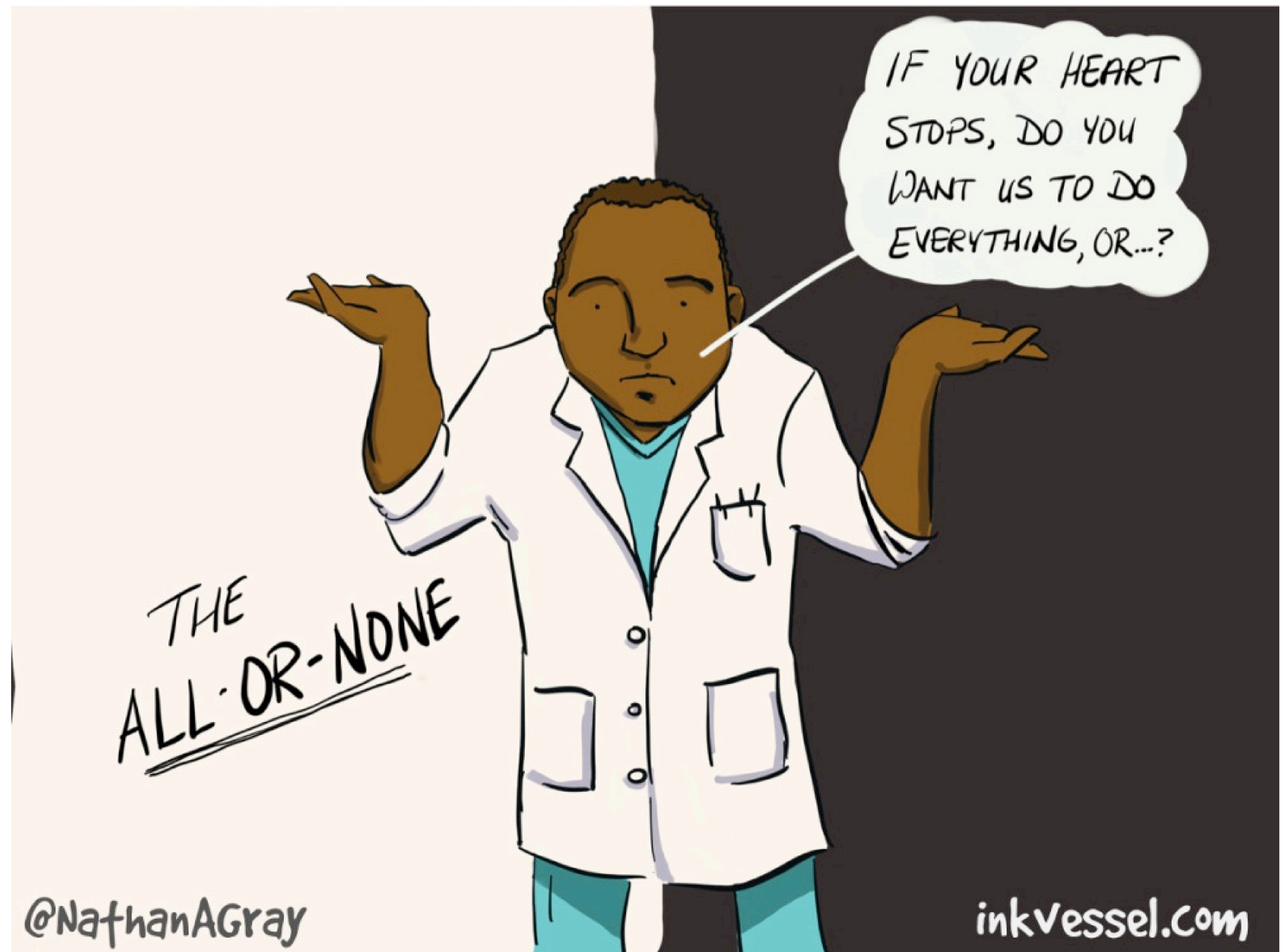


Code status strategies



Code status strategies

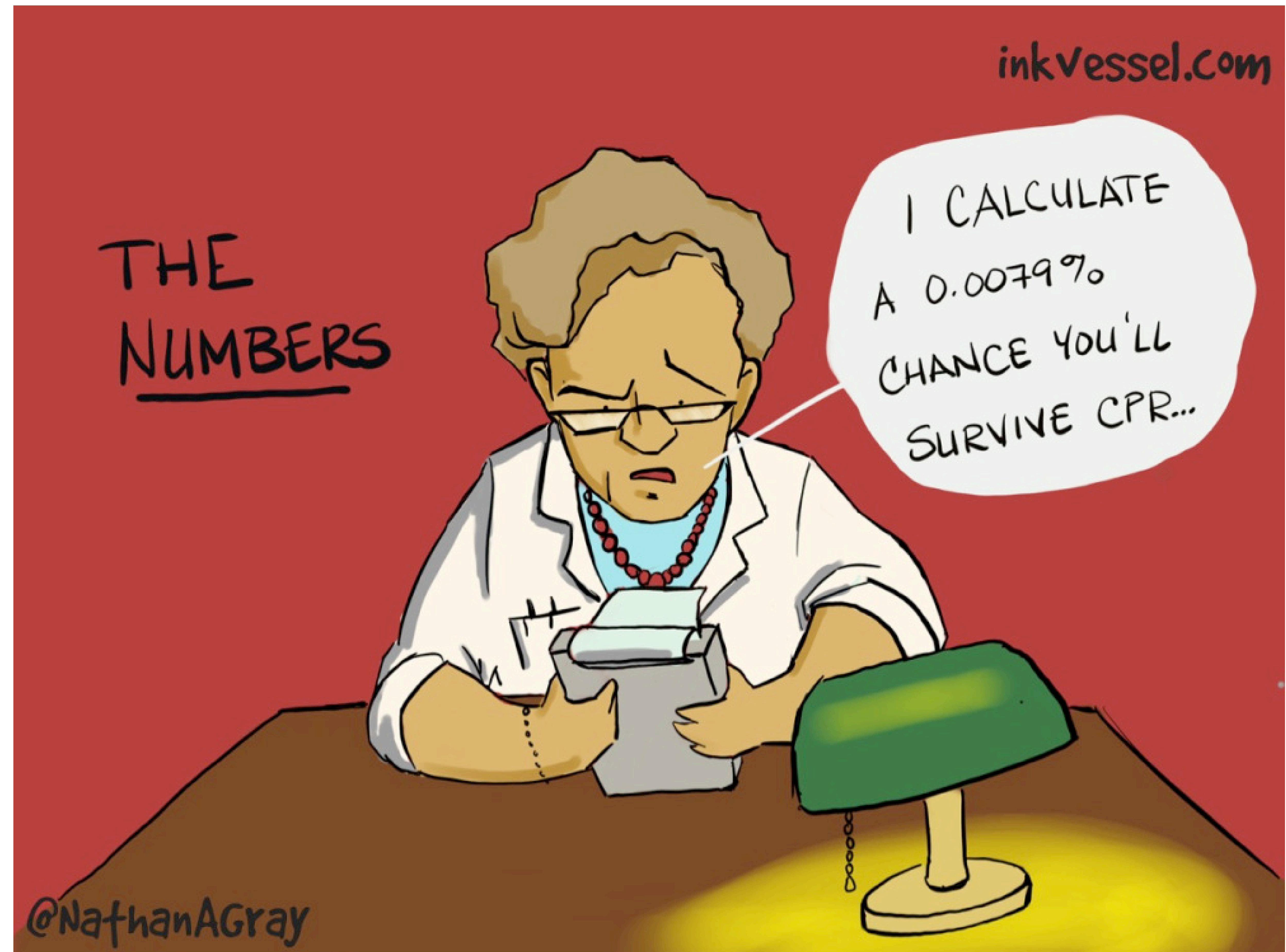
BeyondDRNI



Code status strategies

Beyond DRN/DNI

Stats



Is it really
consent?



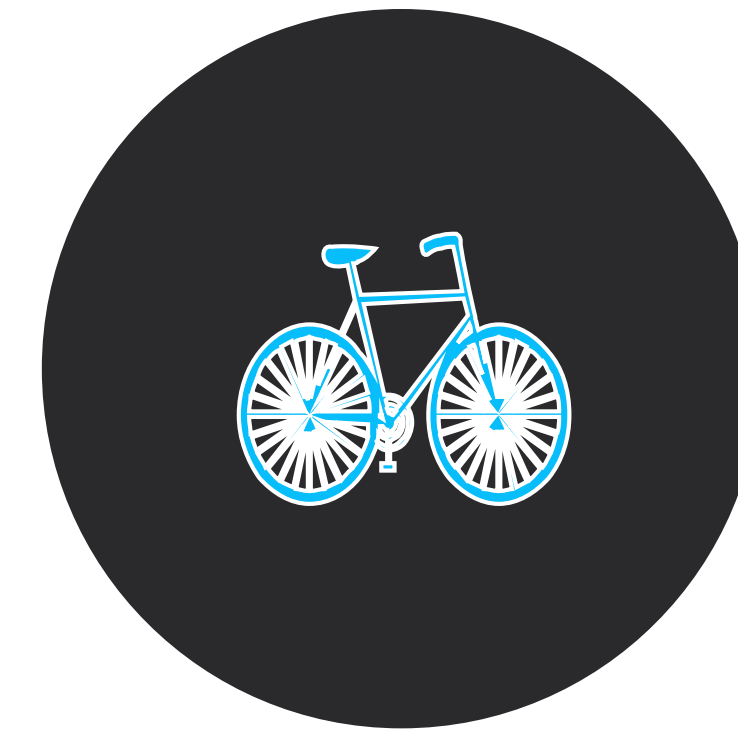
Are they capable??

A black smartphone with a grey screen. The screen displays the text "4 Questions" in blue, underlined. A thin black line extends from the top of the phone, connecting to a large rectangular box on the right side of the slide.

4 Questions



Do they know their prognosis



What are their goals for the time they have left



What are their biggest fears



What are they willing to sacrifice for the sake of more time

Serious Illness Conversation Guide

CLINICIAN STEPS

- ☐ **Set up**
 - Thinking in advance
 - Is this okay?
 - Combined approach
 - Benefit for patient/family
 - No decisions today
- ☐ **Guide** (right column)
- ☐ **Summarize and confirm**
- ☐ **Act**
 - Affirm commitment
 - Make recommendations to patient
 - Document conversation
 - Provide patient with Family Communication Guide

CONVERSATION GUIDE

Understanding	What is your understanding now of where you are with your illness?
Information preferences	How much information about what is likely to be ahead with your illness would you like from me? <small>FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.</small>
Prognosis	<i>Share prognosis, tailored to information preferences</i>
Goals	If your health situation worsens, what are your most important goals?
Fears / Worries	What are your biggest fears and worries about the future with your health?
Function	What abilities are so critical to your life that you can't imagine living without them?
Trade-offs	If you become sicker, how much are you willing to go through for the possibility of gaining more time?
Family	How much does your family know about your priorities and wishes? <small>(Suggest bringing family and/or health care agent to next visit to discuss together)</small>

Serious Illness Conversation Guide

CONVERSATION FLOW

PATIENT-TESTED LANGUAGE

1. *Set up the conversation*
Introduce the idea and benefits
Ask permission
2. *Assess illness understanding and information preferences*
3. *Share prognosis*
Tailor information to patient preference
Allow silence, explore emotion
4. *Explore key topics*
Goals
Fears and worries
Sources of strength
Critical abilities
Tradeoffs
Family
5. *Close the conversation*
Summarize what you've heard
Make a recommendation
Affirm your commitment to the patient
6. *Document your conversation*

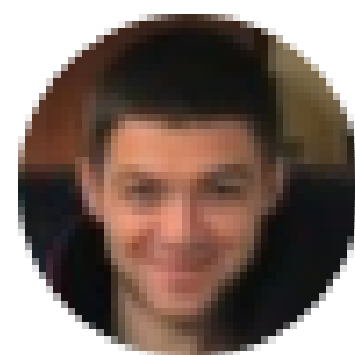
- SET UP
"I'm hoping we can talk about where things are with your illness and where they might be going — **is this okay?**"
- ASSESS
"What is your **understanding** now of where you are with your illness?"
"How much **information** about what is likely to be ahead with your illness would you like from me?"
- SHARE
Prognosis: "I'm worried that time may be short."
or "This may be as strong as you feel."
- EXPLORE
"What are your most important **goals** if your health situation worsens?"
"What are your biggest **fears and worries** about the future with your health?"
"What gives you **strength** as you think about the future with your illness?"
"What **abilities** are so critical to your life that you can't imagine living without them?"
"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?"
"How much does your **family** know about your priorities and wishes?"
- CLOSE
"It sounds like _____ is very important to you."
"Given your goals and priorities and what we know about your illness at this stage, I **recommend...**"
"We're in this together."



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CPR is useful if the heart is “the first organ to stop”, not “the last organ to stop”!



Dan Thomas
@dan26wales

Follow

I do often come across the term “prognostic uncertainty” being used when people are clearly dying

Sometimes it is being used as a euphemism for dying by doctors who can’t bring themselves to tell the truth to the person or their family

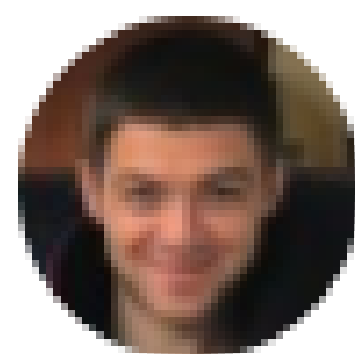
Prognostic uncertainty in complex patients was frequently cited by registrars and consultants as a reason to avoid these conversations.^{36–38} Nevertheless, we would encourage clinicians to share this uncertainty in honest discussions with patients.

11:58 PM - 6 Nov 2018

23 Retweets 54 Likes



8 23 54



Dan Thomas @dan26wales · 6 Nov 2018
(The above screen shot is from the @RCPFuture “talking about dying”

If doctors can't prevent your heart from stopping when you are alive, then it's extremely unlikely that they can restart it when you are dead

Using the frailty lens



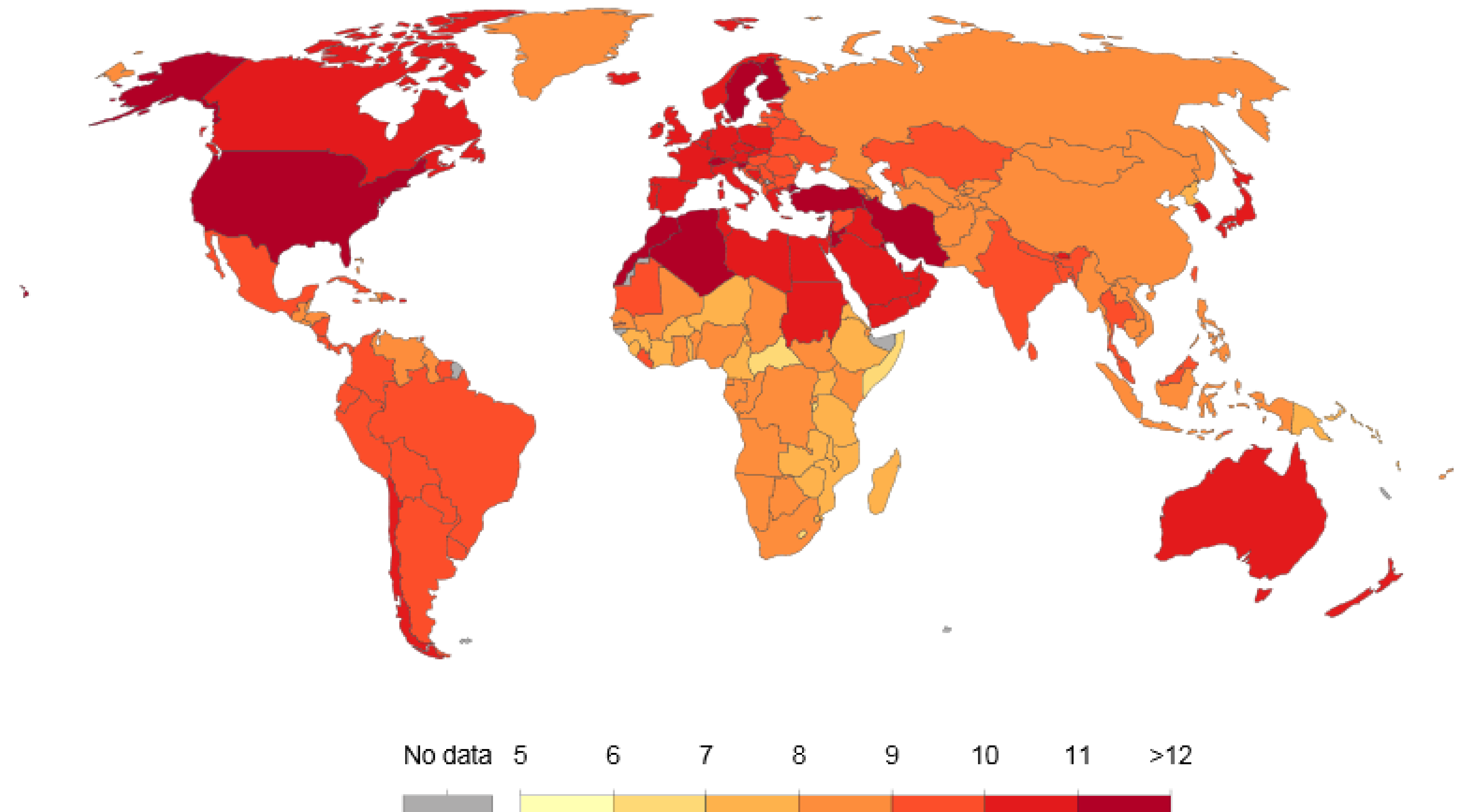
"Give it to me nuanced, Doc."

“...for
what
lies
ahead”

Expected years of living with disability or disease burden, 2016

Average number of years with disability an individual born in the respective year can expect to experience. This is calculated as the difference between total and healthy life expectancy.

Our World
in Data



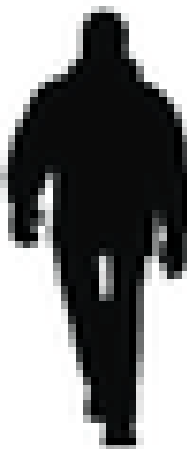
Source: IHME, Global Burden of Disease

OurWorldInData.org • CC BY-SA

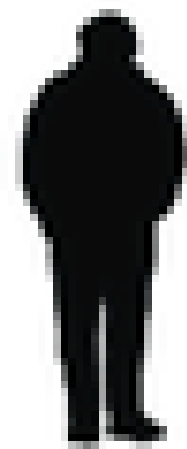
Clinical Frailty Scale*



1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.



3 Managing Well – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.



4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being “slowed up”, and/or being tired during the day.



5 Mildly Frail – These people often have **more evident slowing**, and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



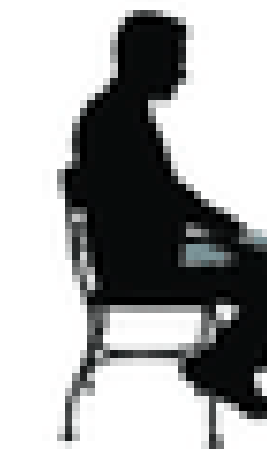
6 Moderately Frail – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.



7 Severely Frail – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



9 Terminally Ill - Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail**.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

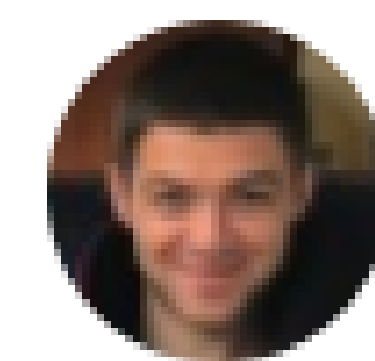
In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.

2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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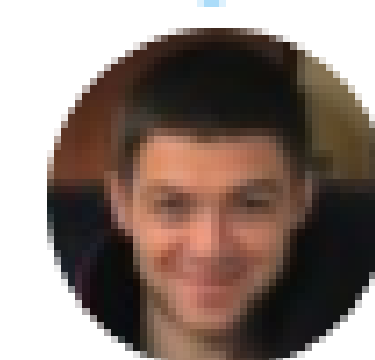
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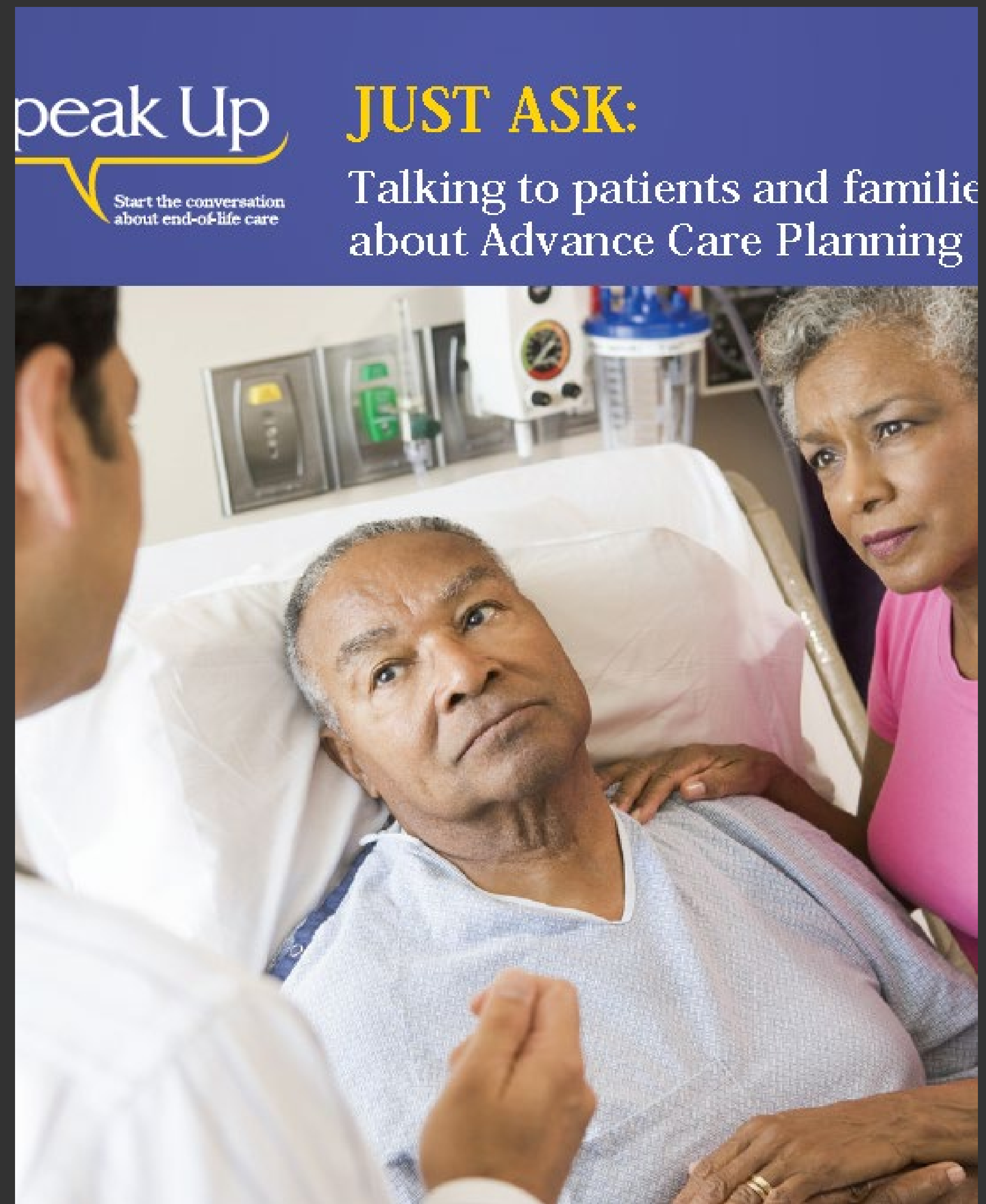
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Fill this in triplicate

[Speak Up!](#)



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