

# A Closer Look at Surrogate Decision Making

Ellis Medicine Grand Rounds

June 2, 2023

George J. Giokas, MD

Palliative Care Partners

Palliative Medicine Consult Service at Ellis Medicine

# Learning Objectives

AFTER ATTENDING THIS ACTIVITY, PARTICIPANTS SHOULD BE ABLE TO:

1. IDENTIFY THE ELEMENTS DETERMINING CAPACITY FOR MAKING MEDICAL DECISIONS
2. INCORPORATE COMMUNICATION TECHNIQUES TO ASSESS THE PATIENT'S PREFERRED LEVEL OF FAMILY INVOLVEMENT
3. DESCRIBE HOW TO INCREASE THE INVOLVEMENT OF COGNITIVELY IMPAIRED INDIVIDUALS WITH THEIR CARE GOALS.

*THE PRESENTER HAS NO RELEVANT FINANCIAL DISCLOSURES*

# Take Home Points

- Decisional Capacity is not all or none
- Surrogate decides WITH the patient, not for the patient
- Involve family early

# Karen Quinlan

1975 persistent vegetative state following  
ingestion of substances 21 y.o.

Parents sought to disconnect ventilator

MDs objected – liability concerns

NJ Supreme Court - 1976

*Competent persons have the right to refuse  
life-sustaining treatment and that this right  
should not be lost when the patient becomes  
incompetent*



Procedure established ... After a prognosis, confirmed by a hospital ethics committee, that there is “no reasonable possibility of a patient returning to a cognitive, sapient state” treatment could be discontinued

Ethics committees were established to help resolve issues without going to court

Other states enacted living will legislation

Karen survived extubation, parents did not seek to remove feeding tube, she died 9 years later

# Nancy Cruzan



1983 TBI from MVA 25 y.o.

persistent vegetative state, dependent on tube feedings but not on a ventilator.

Family requested removal of TF (Nancy resided at facility operated by State of Missouri)

Missouri Supreme Court – tube feeding could be stopped (right of self-determination) but only Nancy could make that determination ...or others with “clear and convincing evidence” of Nancy’s wishes

1990 Appealed to US Supreme Court (5-4 dcsn)

State of Missouri can adopt standards of evidence.

Justice Sandra Day O'Connor ...statements delegating medical decision-making should be constitutionally protected

Spurred the development of HC Proxy

TF stopped, Nancy died 9 days later

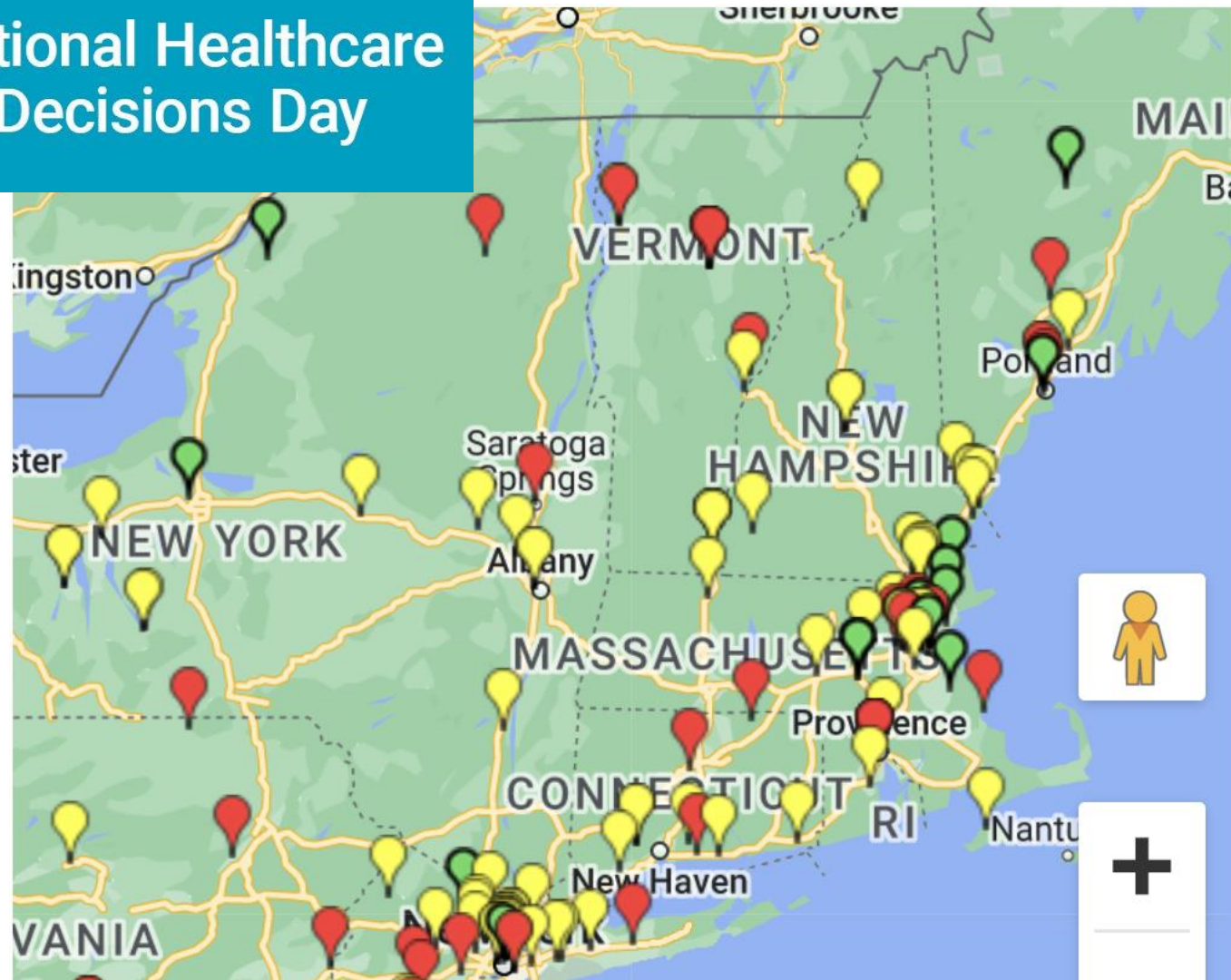


# Named Your Health Care Agent?

1. Thinking About It
2. Completed
3. Completed and revisited



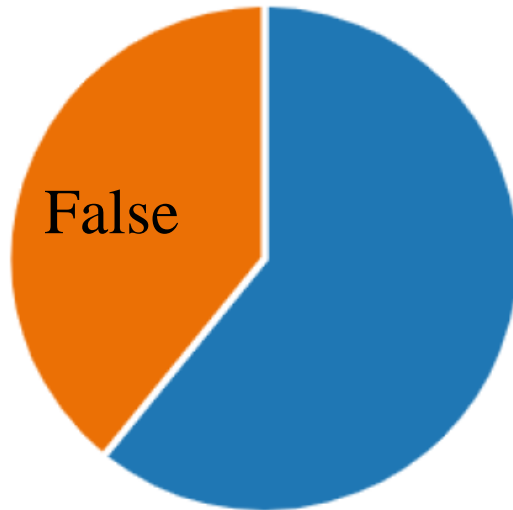
# National Healthcare Decisions Day



Thank you Barbara Petrillo, Tony Green  
Kelly Leonard, Allison Murphy, & Emily Spinner

# Ellis Medicine National HealthCare Decisions Day Quiz

April 2023 1769 responses \*



~~A Living Will is an active medical order that must be followed similar to a MOLST~~

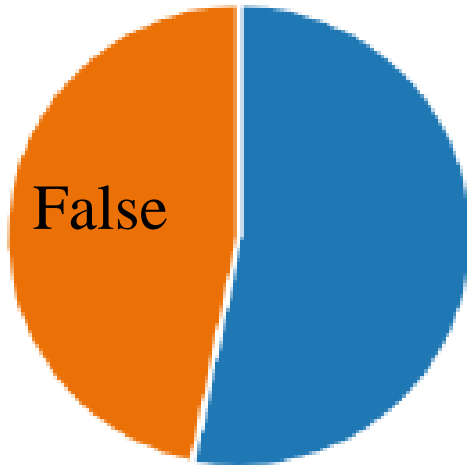
National Healthcare  
Decisions Day

\* Data courtesy of Emily Spinner

# Ellis Medicine National HealthCare Decisions Day Quiz

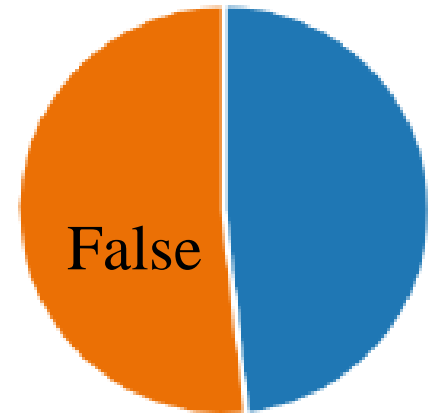
April 2023 1769 responses \*

National Healthcare  
Decisions Day



~~A NYS Power of Attorney can  
make health-care decisions~~

~~Need to be legally married to  
make health-care decisions  
for your partner~~



\* Data courtesy of Emily Spinner

# NYS Family HealthCare Decisions Act

In order of highest priority:

- Court appointed guardian
- Spouse, if not legally separated from the patient, or the domestic partner
- Son or daughter, age 18 or older
- Parent
- Brother or sister, age 18 or older
- Actively involved close friend, age 18 or older

“who is reasonably available, willing, and competent to serve as a surrogate decision-maker”

# What is a “domestic partner”?

has entered into a formal domestic partnership recognized by a local, state or national gov’t or is covered as a domestic partner under the same employment benefits or health insurance;

Shares a mutual intent to be a domestic partner with the patient, considering all the facts and circumstances, such as:

They live together.

They depend on each other for support.

They share ownership (or a lease) of their home or other property.

They share income or expenses.

They are raising children together.

They plan on getting married or becoming formal domestic partners.

They have been together for a long time.

# Who qualifies as a “close friend”?

A “close friend” is any person, 18 or older, who is a friend or relative of the patient. This person must have maintained regular contact with the patient; be familiar with the patient’s activities, health, and religious or moral beliefs; and present a signed statement to that effect to the attending doctor.

# Substituted Judgment

The treatment decision that the patient would have made if he or she could

# Best Interests

The treatment decision that is in the patient's best interests

# How Accurate are Surrogates regarding Patient Preferences?

***68% of the time*** surrogates accurately predicted patients' preferences

*2006 Literature review*

Surrogates more accurate than others, such as MDs.

Surrogate predictions may mirror their own preferences



# How Stable Are Patient Preferences?

Patients change their minds over time but not in a predictable way

Some older patients wanted less aggressive care w/in 2 weeks of being hospitalized but ...often reverted to prehospitalization preferences for more aggressive care several months later.

Older patients were more accepting of receiving medical treatments in future states of mild to severe disability after they developed some disability

# What Do Patients Think Should Be Done When the Living Will and Surrogate Decisions Differ?

*Families and physicians make decisions:*

*70% of older inpatients and 78% of seriously ill  
adults*

Strictly follow own stated preferences:

30% of older inpatients and 22% of seriously ill  
older adults

**Concern for loved ones** expressed by dialysis and  
cancer patients.

“Patients may prefer that their loved ones make decisions that they can live with, even if some of these go against the decisions those patients would have made for themselves”

# “Relational Autonomy”

Childress &  
Arnold, JPSM 2021

“Interdependence is not an incidental feature of the human experience; it is central to it.

Individuals progressively negotiate and renegotiate their roles with trusted others throughout life. “

Largent Hastings Center 2022



# Neither are Either / Or

Patient  
Has  
Capacity for  
All Decisions

**Capacity For  
Decision Making**

Patient  
Lacks  
Capacity for ALL  
Decisions

The  
Patient Alone  
Makes  
the Decision

**Decision Maker**

Surrogates  
Makes  
Decisions  
*for the Patient*



Mount Williamson Sierra Nevada Ansel Adams 1944

## Elements of Medical Decision Making

Receive, evaluate, and mentally manipulate information and  
Communicate a treatment preference

## Demonstrate Understanding

*Tell me in your own words what we are asking you to choose*

*Can you why you feel that way?*

*What happens if we don't do ...*

**Demonstrate Logical Thought process** Is the process by which the patient arrives at the decision rational?

**Consistent?** Day to day & consistent with the patient's values

# Decision making capacity is

## Task specific

More complex decisions require a higher level of decision-making ...

Designating a health care agent (less complex)

Life & death decisions (CPR, dialysis)

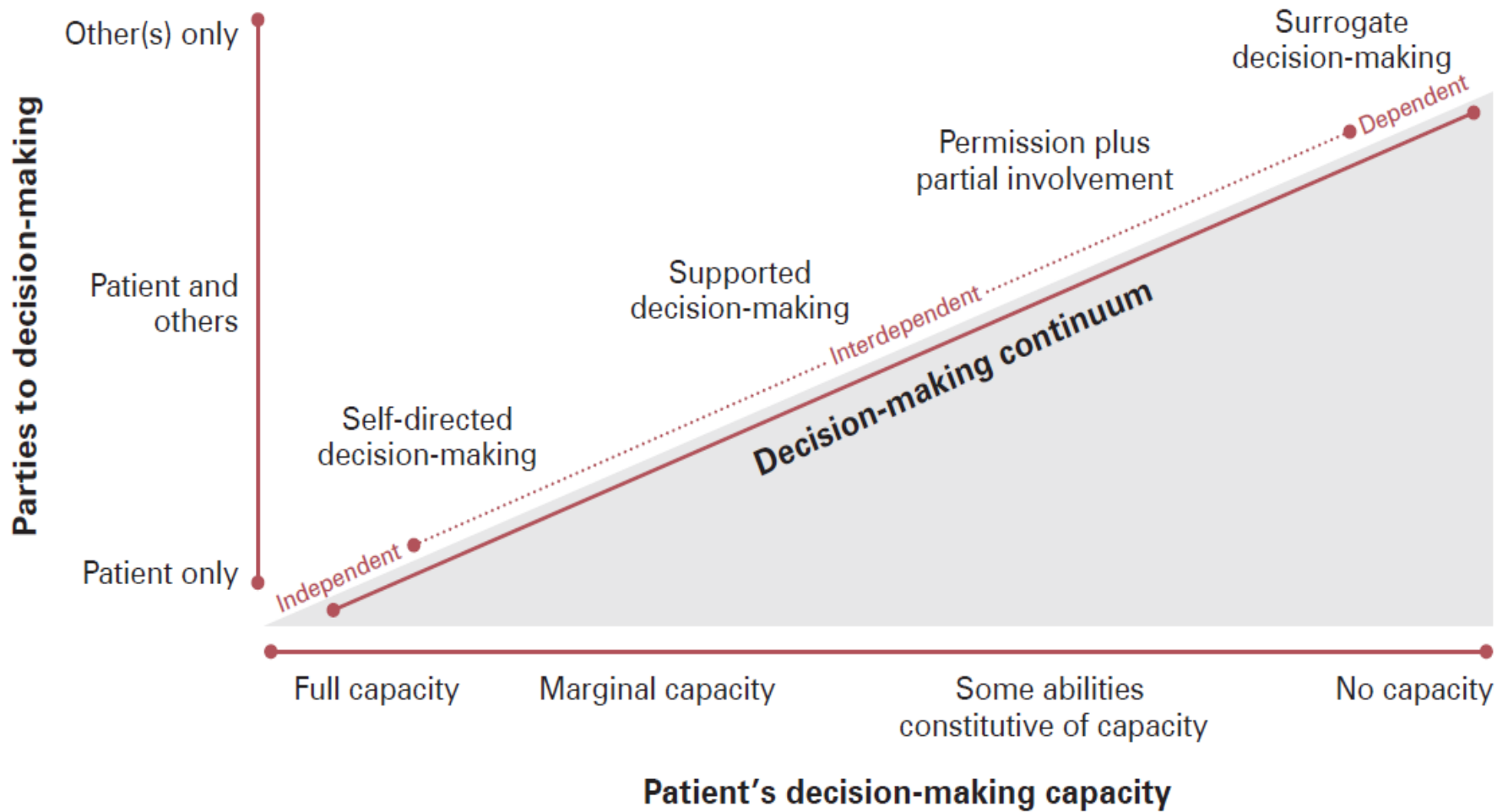
**“This sliding scale view of decisionality holds that it is proper to require a higher level of certainty when the decision poses great harm.”**

## Time specific

Metabolic encephalopathy, sundowning



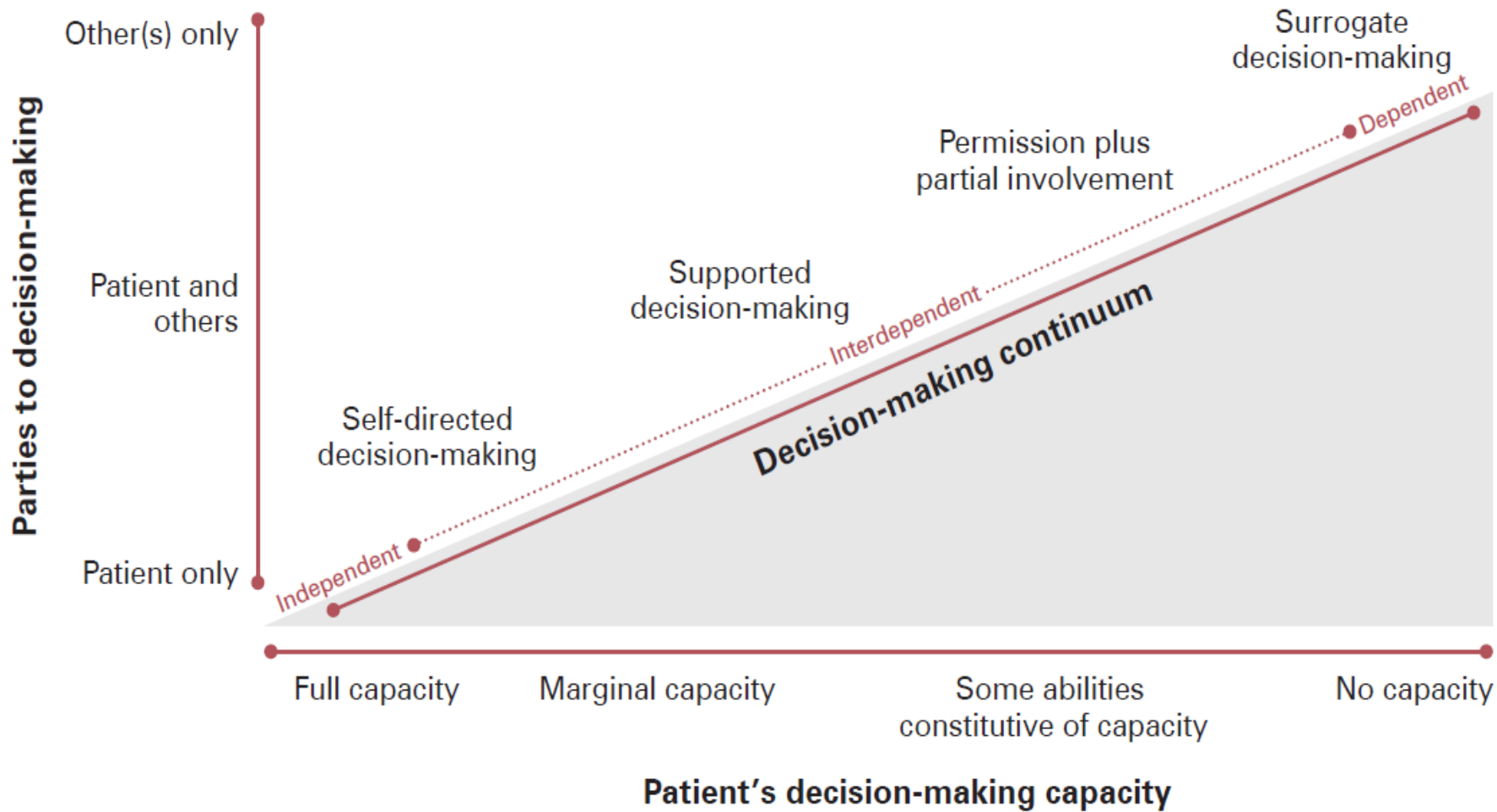
**Figure 1.**  
**A Continuum of Medical Decision-Making**



“Because even if someone doesn’t have capacity, they still may be able to express important values and interests and should be involved in conversations rather than being cutout.”

Emily Largent. GeriPal PodCast Feb 2023

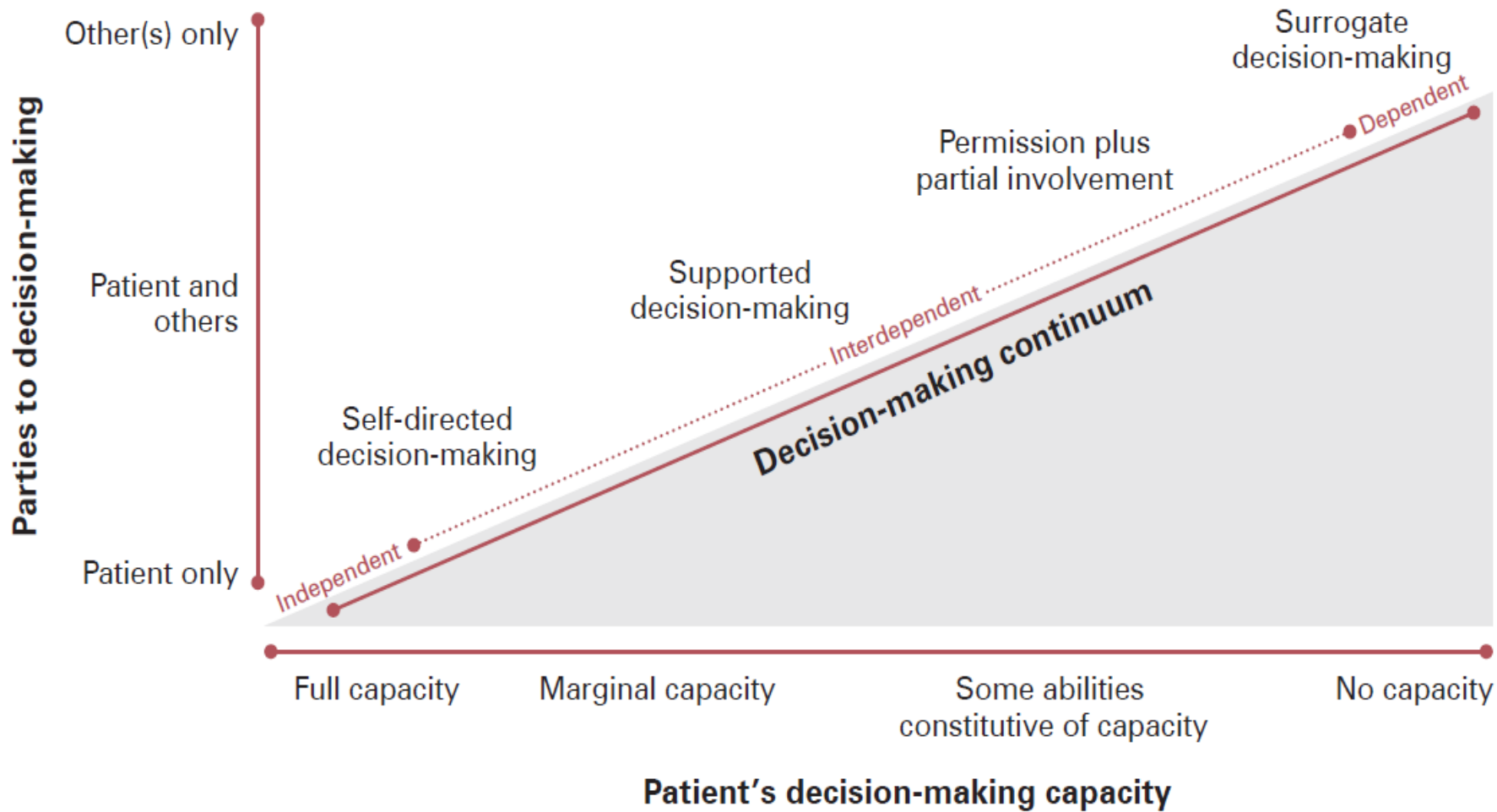
**Figure 1.**  
**A Continuum of Medical Decision-Making**




# The 3 Stages of Man



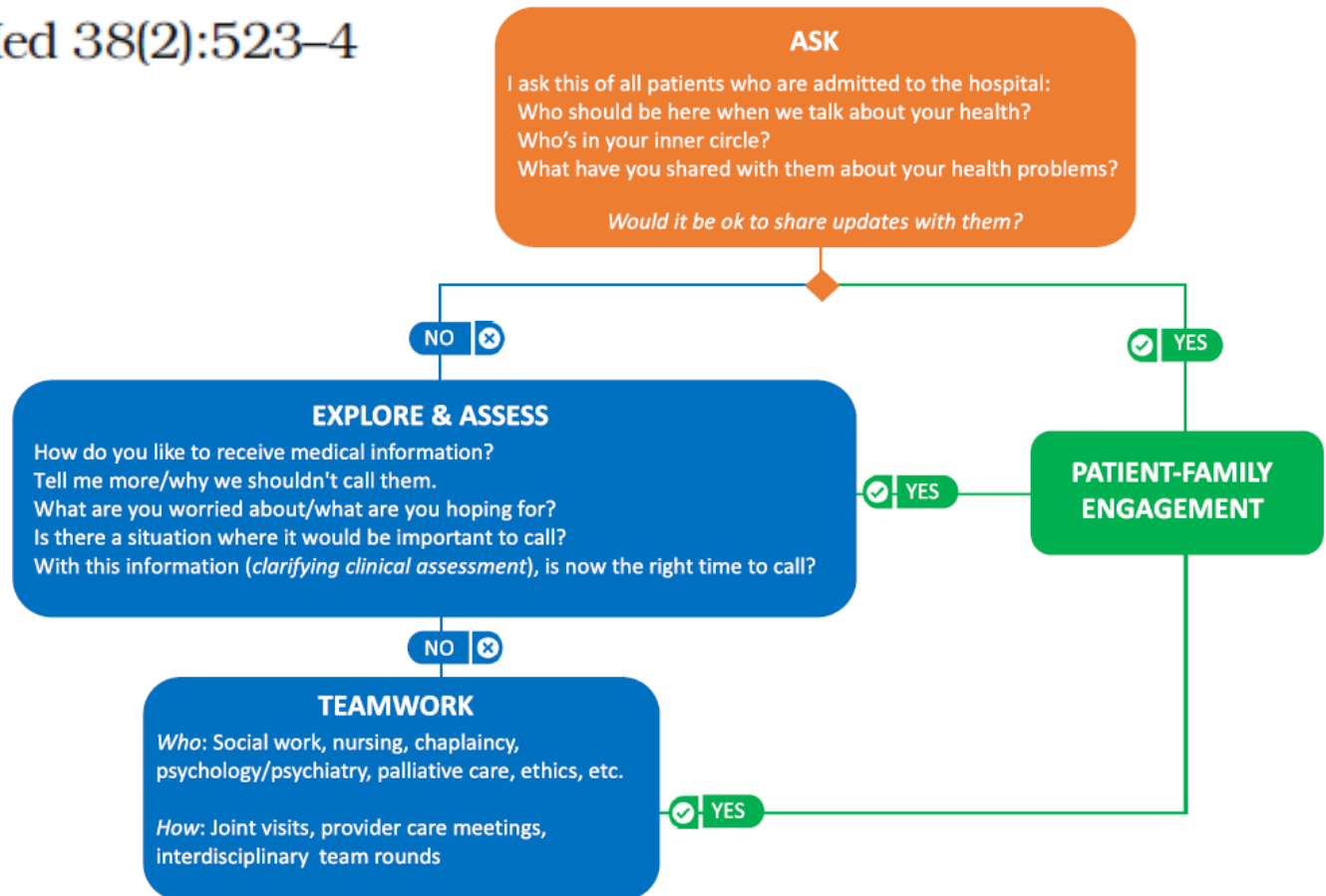
**Figure 1.**  
**A Continuum of Medical Decision-Making**



# Make the Call: Engaging Family as a Critical Intervention

Anne B. Rohlfing, MD<sup>1,2</sup> , Anne E. Kelly, LCSW<sup>3</sup>, and Lynn A. Flint, MD<sup>3,4</sup>

J Gen Intern Med 38(2):523–4



## **Ask:**

I ask this of all patients who are admitted to the hospital:  
Who should be here when we talk about your health?  
Who's in your inner circle?  
What have you shared with them about your health problems?

## **If you get pushback ...Explore**

Tell me more/why we shouldn't call them  
How do you like to receive information?  
What are you worried about/ What are you hoping for?  
Is there a situation where it would be important to call?  
(After clarifying clinical situation) ....is now the right time to call?

# Areas of Moral Distress

1. Patient and/or Family in Denial
2. Surrogate making decisions seemingly against the patient's prior directives or not in the best interests of patient
3. Unreasonable Hopes



# *“They’re in DENIAL”*

**Too overwhelmed, exhausted** to understand

**Lack of trust**

**Protecting family – cultural norms**

**Undertreated anxiety or depression    delirium**

Patients **may not understand** the information,  
Language or cultural barriers, Encephalopathy

**Ask-Tell-Ask**

Patients are given **mixed messages**

**Clinician back-pedals** when we’re uncomfortable

Denial may be **healthy coping**

When there is  
*conflict*, think  
*emotion*

David Weissman, MD

# Families' Difficult ICU Decisions

Schenker, et al. J Gen Int Med 2012

## **Tensions**

Responsibility for the loved one's death

A chance of recovery

Family well-being

## **Coping Mechanisms**

Recalling prior discussions

Sharing decisions with family

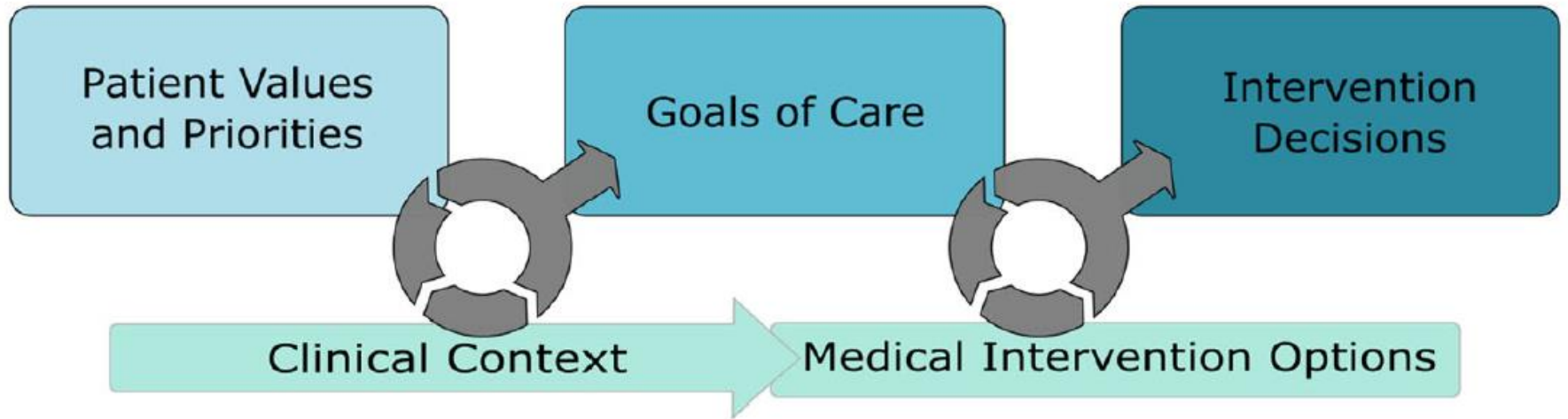
Delay/defer decisions

Spiritual/religious practices

Story-telling

# Helping surrogates

- Is there a shared understanding of the patient's condition and prognosis.
- Bring the patient's "voice" into the room
- Expect emotions
- Frame the decision around the goals ...The details of the medical plan should flow from the overall goals
- Once you have a sense of the patient's goals offer to make a recommendation that reflects those goals.



Shared  
Decision Making

Paternalistic  
Decision Making

Consumerism  
Decision Making

# Helping Surrogates

- Don't argue over the facts; repeating the facts over and over again is not likely to be effective.
- Use the "I wish" statements ... I wish our medicines were more effective; I wish we had more medical treatment to offer than we do
- "Tincture of Time"
  - For surrogates to do their necessary grief-work.
  - For clinical picture to crystalize
  - "More will be revealed" ...backstory to emerge

### *Table 3. Harm-Reduction Strategy When Patients Request Treatments That Do More Harm Than Good*

Acknowledge and adhere to the patient's treatment philosophy so that patient and family feel heard and respected.

Stop regularly discussing limitations on invasive treatments unless this issue is raised by the patient or family.

Address the medical team's discomfort and disapproval by:

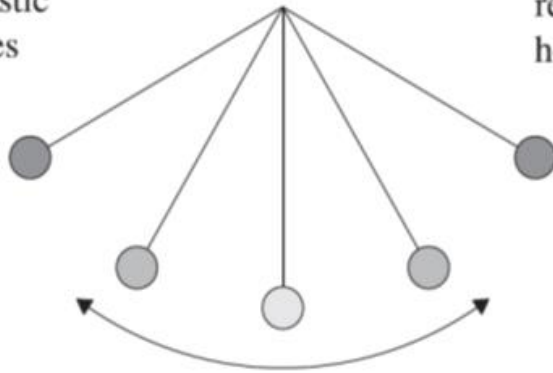
- Communicating the reasoning behind the treatment decision.

- Finding other patient-centered goals to work toward (symptom management, support, disease treatment).

Use clinical judgment to limit treatment that does not advance patient-defined goals.



more  
realistic  
hopes



less  
realistic  
hopes



Hope for cure



Hope for  
other things

“Hope means different things to different people, and different things to the same person as he/she moves through stages of illness”

# Take Home Points

- Decisional Capacity is not all or none
- Surrogate decides WITH the patient, not for the patient
- Involve family early

# Selected References

Emily Largent, et. al. **Deciding With Others: Interdependent Decision-Making.** Hastings Center Report. 52 (6); 2022: 22-32

Anne B. Rohlfing, et. al. **Make the Call: Engaging Family as a Critical Intervention.** Journal of General Internal Medicine. 38(2); 2022: 523–4

Emily Largent, et. al. **Involving the inner circle.** GeriPal Podcast. Feb 23, 2023  
<https://geripal.org/involving-the-inner-circle-emily-largent-anne-rohlfing-lynn-flint-anne-kelly/>

Timothy Quill, et.al. **Discussing Treatment Preferences with Patients Who Want “Everything.”** Annals of Internal Medicine. 151; 2009:345-349.

Schenker Y, et al. **I Don’t Want to Be the One Saying ‘We Should Just Let Him Die’: Intrapersonal Tensions Experienced by Surrogate Decision Makers in the ICU.** J Gen Intern Med. 2012.

Vig,E, et. al. **Responding to Surrogate Requests That Seem Inconsistent With a Patient’s Living Will.** Journal of Pain and Symptom Management. November 2011.

David Weissman, et al. **Helping Surrogates Make Decisions.** Fast Facts & Concepts. Palliative Care Network of Wisconsin. 2015