What Matters Most in Goals of Care Discussion

Ellis Medicine

DOIM Medical Grand Rounds Webinar

April 29, 2022

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PROGRAM LEARNING OBJECTIVES

After attending activity, participants should be able to:

1. Describe a Format for leading goals of care discussions with patients and families

2. Identify Available Resources

3. Describe key elements of hospice and Community Based Palliative Care Programs currently available in our community.

The presenters do not have any relevant financial disclosures

Presentation outline

1. What is Goals of Care
2. Key Elements of Goals of Care Discussions
3. Hospice and Community Based Palliative Care Programs
4. Coping & Hoping with Serious Illness

Palliative Care

Philosophy of Care

Skill Set

Clinical Service

A. Sanders, PhD

Goals of Care

Clinician / HealthCare System Perspective

"We're Stuck"
No Discharge Plan

Reduce LOS

Reduce Readmissions
They need to be on hospice

Get the DNR !

Do No Harm

Protect Patient from Burdensome Interventions
Goal Concordant Care

HealthCare Costs

"They're in in Denial"

Patient / Clinician Conflict

Conflict within Clinical Team

Patient Perspective

Time at Home

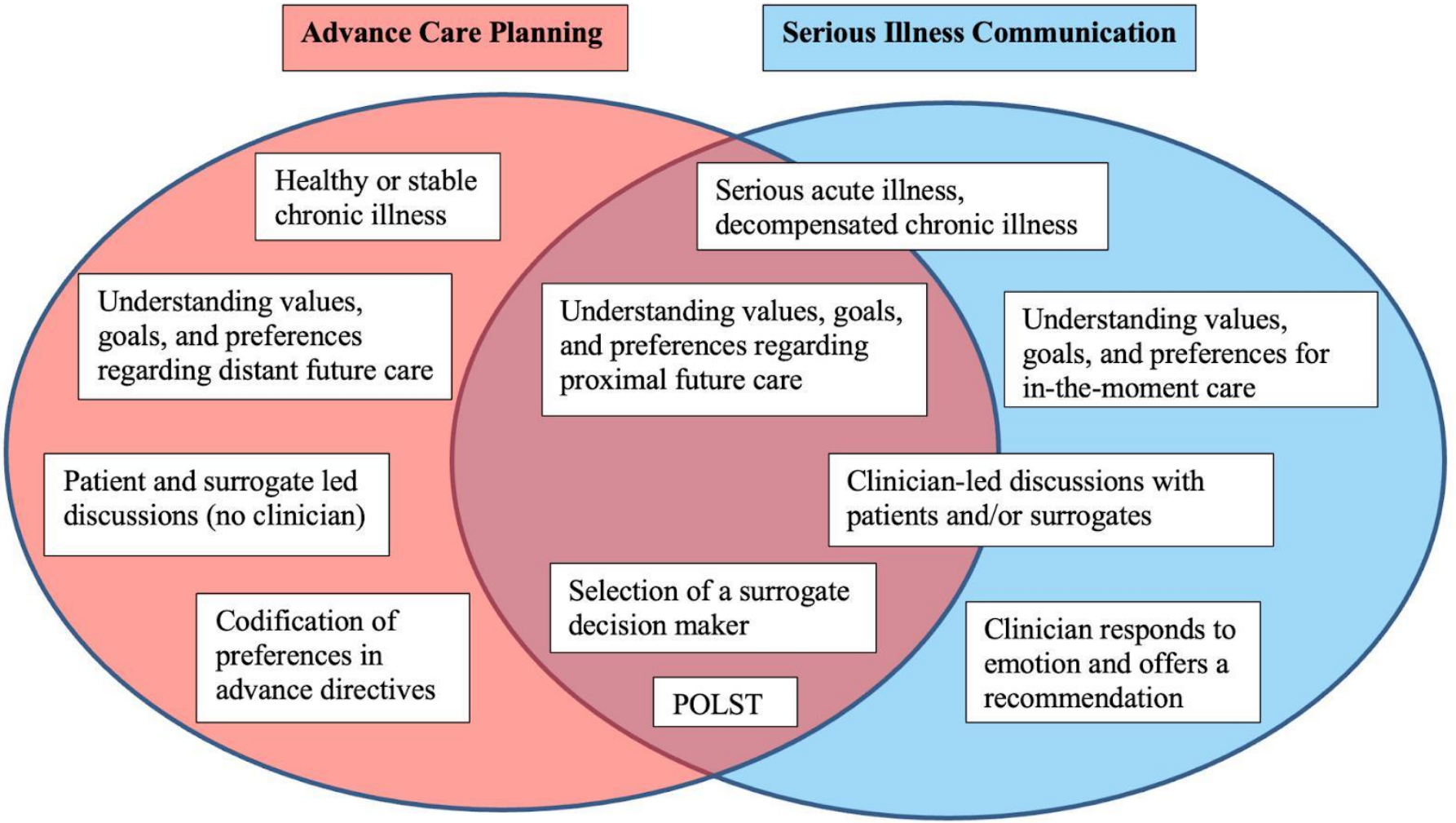
"What Matters Most"

Coping with Serious Illness

Opportunity for Closure at End of Life

Family to be at Peace

Figure: Areas of Distinction and Overlap between Advance Care Planning and Serious Illness Communication



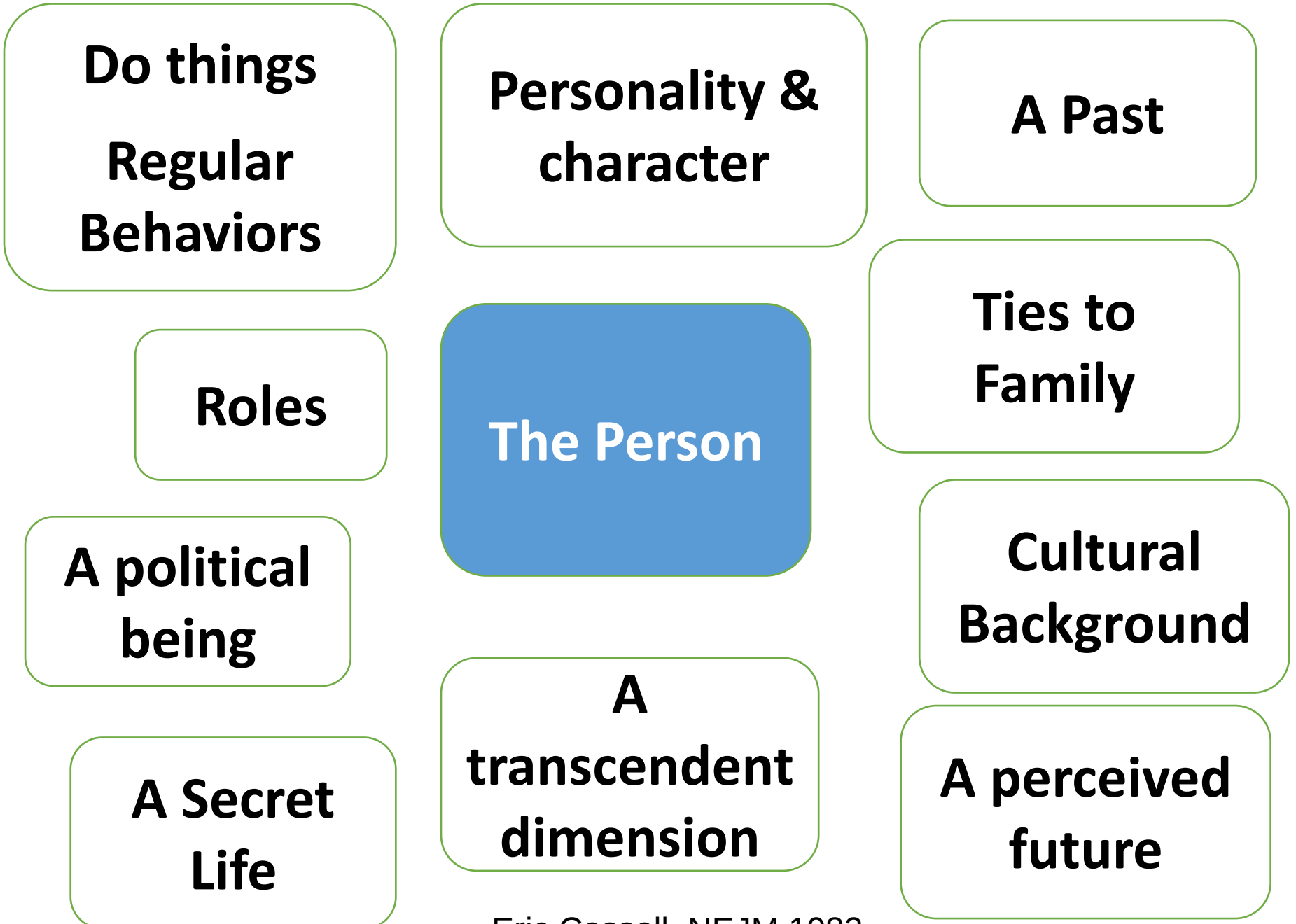
Alex Smith, MD GeriPal Podcast Feb 2022

Serious Illness … a health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life, or excessively strains their caregivers

Kelly and Bollens, Journal of Palliative Medicine 2018

“The fundamental nature of illness is not medical; it is personal.”

Ira Byock, M.D.



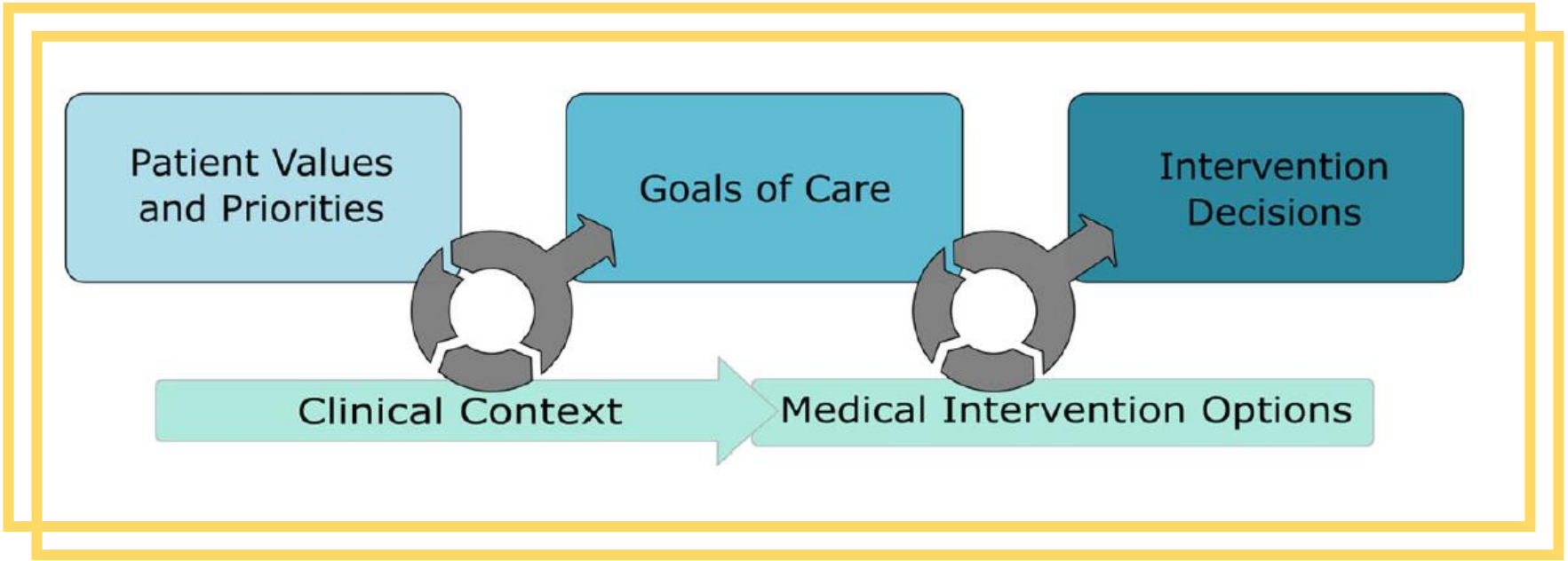
Eric Cassell, NEJM 1982

"A person has a past. The experiences gathered during one's life are a part of today as well as yesterday. Memory exists in the nostrils and the hands, not only in the mind. A fragrance drifts by, and a memory is evoked. My feet have not forgotten how to roller-skate, and my hands remember skills that I was hardly aware I had learned. When these past experiences involve sickness and medical care, they can influence present illness and medical care. They stimulate fear, confidence, physical symptoms, and anguish. It damages people to rob them of their past and deny their memories, or to mock their fears and worries. A person without a past is incomplete."

Eric Cassell, NEJM, 1982

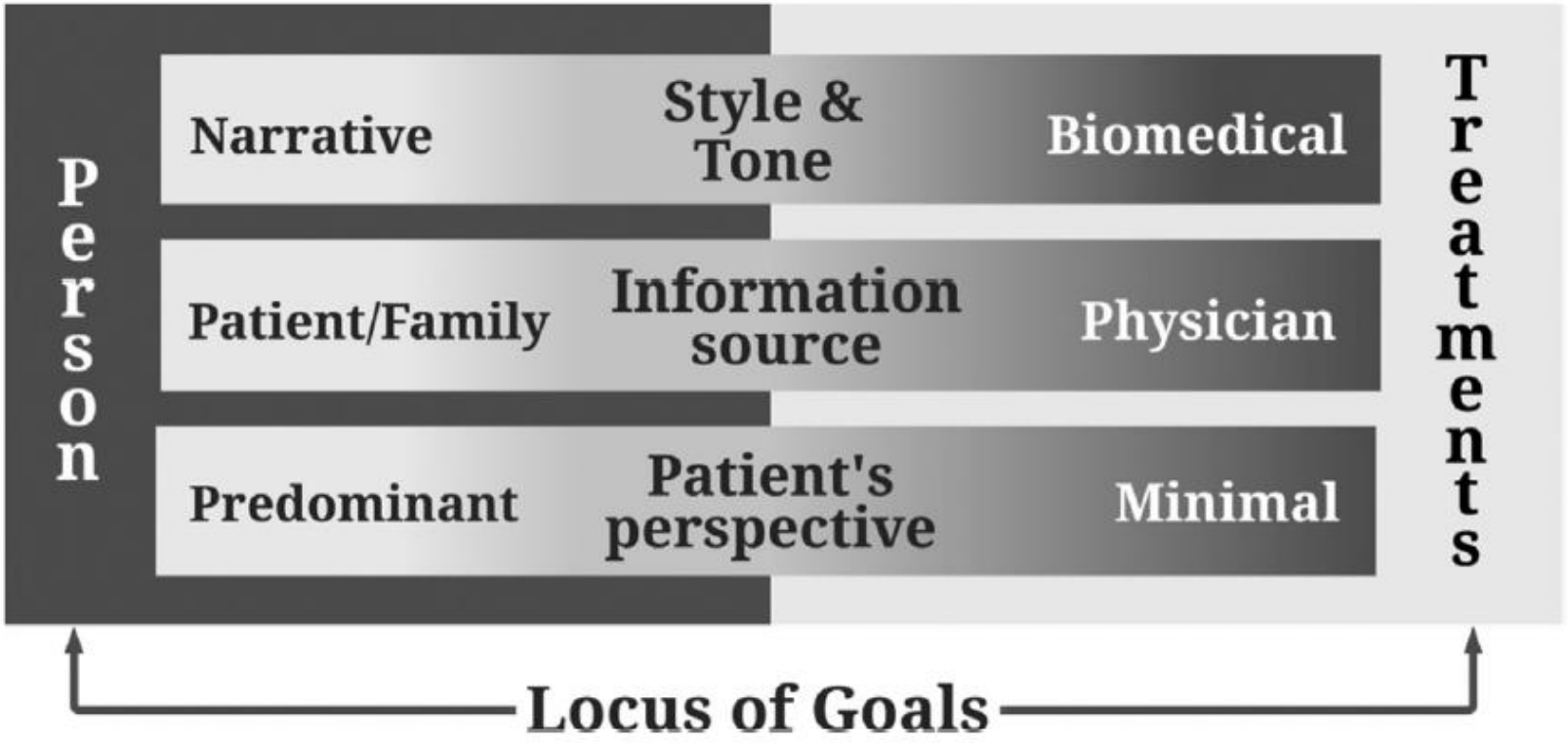
“We are stardust
We are golden
We are billion year old carbon
And we’ve got to get ourselves
Back to the garden”

Joni Mitchell, Woodstock, 1969



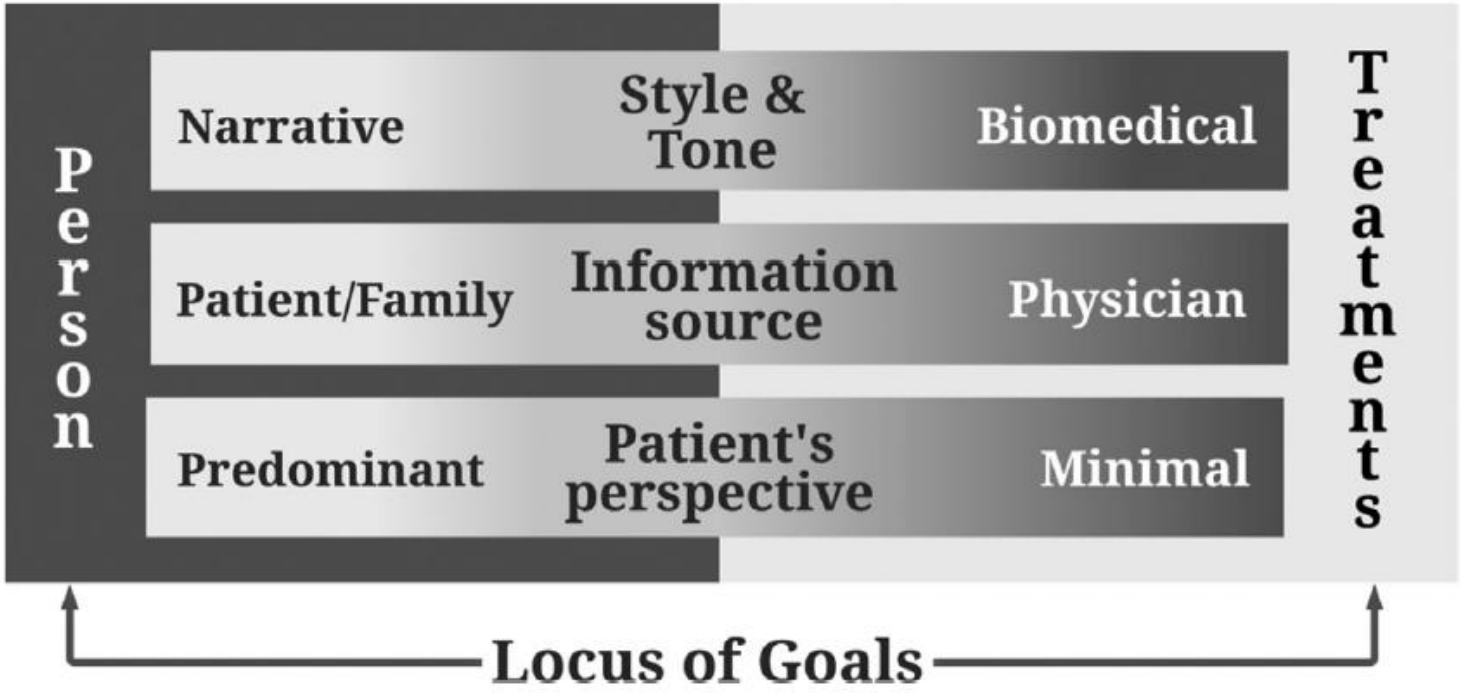
K Secunda, Journal of General Internal Medicine, 2019

Approach the meeting as
a *learning opportunity for the clinician*



J Myers, Journal of Pain and Symptom Management 2022

Renal function continued to deteriorate.
No significant uremic symptoms, not interested in dialysis despite lengthy conversation.
Palliative evaluation as per primary team requested yesterday.
Will continue to monitor. Waiting for the labs today.
Potassium was improving yesterday.
Based on the labs from yesterday probably no emergency indication for dialysis however with very poor renal function I think the safest approach is to proceed with elective dialysis



Goals of Care – Stepwise Process

1. Assess how much the patient knows and wants to know about their illness and prognosis
2. Share information according to the patient's preferences and respond empathically to emotion.
3. Explore values, priorities and goals … open ended questions
4. Make a medical recommendation (ask permission)

It is a procedure … *Don't skip steps*

Don't focus on a decision … its a process not an epiphany

Jacobsen, Bernacki, & Palladino JAMA 2022

Don’t skip steps, like crossing the street

Stop

Don’t jump to fix and make better

Look

Nonverbal communication cues

(Active) Listening

Serious Illness Conversation Guide

Clinician Steps

- **Set Up**
  - Thinking in advance
  - Is this okay?
  - Combined approach
  - Benefits 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

Source: Ariadne Labs

https://www.ariadnelabs.org/serious-illness-care/for-clinicians/

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?*
For example: *Some people like to know about time, some like to know what to expect and others like to know both.*

Prognosis: Share prognosis, tailored to information preferences

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 central 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?*

What Matters to Me

A Workbook for People with Serious Illness

NAME

DATE

ARIADNE LABS

the conversation project

My Health

What is your understanding of your current health situation?

How much information about what might be ahead with your illness would you like from your health care team?

About Me

MY GOOD DAYS • What does a good day look like for you?

Here are some things I like to do on a good day:

EXAMPLES

Get up and dressed • Play with my cat • Make a phone call • Watch TV • Have coffee with a friend

MY HARD DAYS • What does a hard day look like for you?

These are the toughest things for me to deal with on a hard day:

EXAMPLES

Can't get out of bed • In a lot of discomfort • No appetite • Don't feel like talking to anyone

MY GOALS • What are your most important goals if your health situation worsens?

These are some things I would like to be able to do in the future:

EXAMPLES

Take my dog for a walk • Attend my child's wedding • Feel well enough to go to church • Talk to my grandchildren when they come to visit

https://www.ariadnelabs.org/2021/11/16/what-matters-to-me-workbook/

My Care

Everyone has their own preferences about the kind of care they do and don't want to receive. Use the scales below to think about what you want at this time.
Note: These scales represent a range of feelings; there are no right or wrong answers.

- **Answer where you are right now.** For each scale below, think about what you want now. Revisit your answers in the future, as they may change over time.
- **Use your answers as conversation starters.** Your answers can be a good starting point to talk with others about why you answered the way you did.

As a patient, I'd like to know...

Only the basics about my condition and my treatment — All the details about my condition and my treatment

When there is a medical decision to be made, I would like...

My health care team to make all the decisions — To have a say in decisions whenever possible

What are your concerns about medical treatments?

I worry that I won't get enough care — I worry that I'll get too much care

How much medical treatment are you willing to go through for the possibility of gaining more time?

Nothing: I don't want any more medical treatments — Everything: I want to try any medical treatments possible

If your health situation worsens, where do you want to be?

I strongly prefer to be in a health care facility — I strongly prefer to be at home, if possible

When it comes to sharing information about my illness with others...

I don't want those close to me to know all the details — I do want those close to me to know all the details

MY FEARS AND WORRIES • What are your biggest fears and worries about the future with your health?

These are the main things I worry about:

EXAMPLES

I don't want to be in pain • I'm worried that I won't be able to get the care I want • I don't want to feel stuck someplace where no one will visit me • I worry about the cost of my care • What if I need more care than my caregivers can provide?

MY STRENGTHS • As you think about the future with your illness, what gives you strength?

These are my main sources of strength in difficult times:

EXAMPLES

My friends • My family • My faith • My garden • Myself ("I just do it")

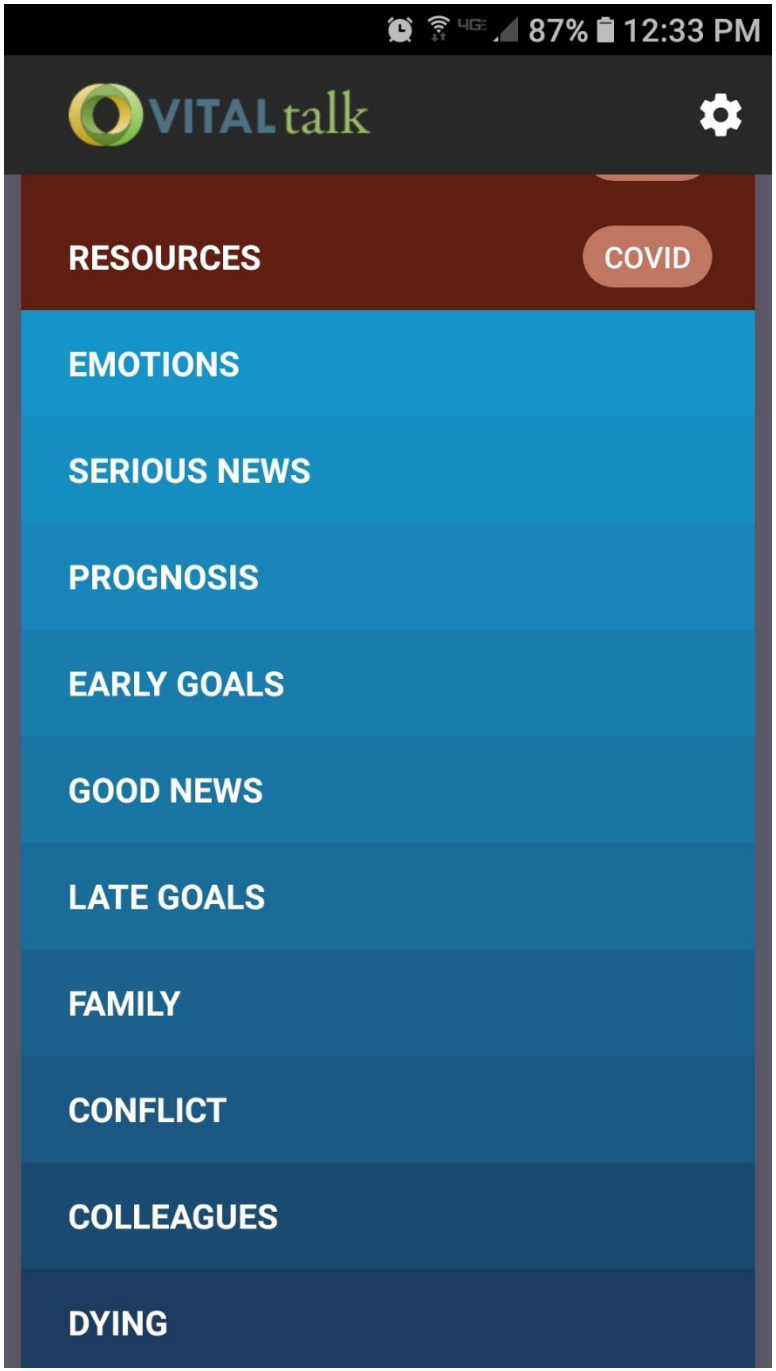
MY ABILITIES • What abilities are so critical to your life that you can't imagine living without them?

I want to keep going as long as I can...

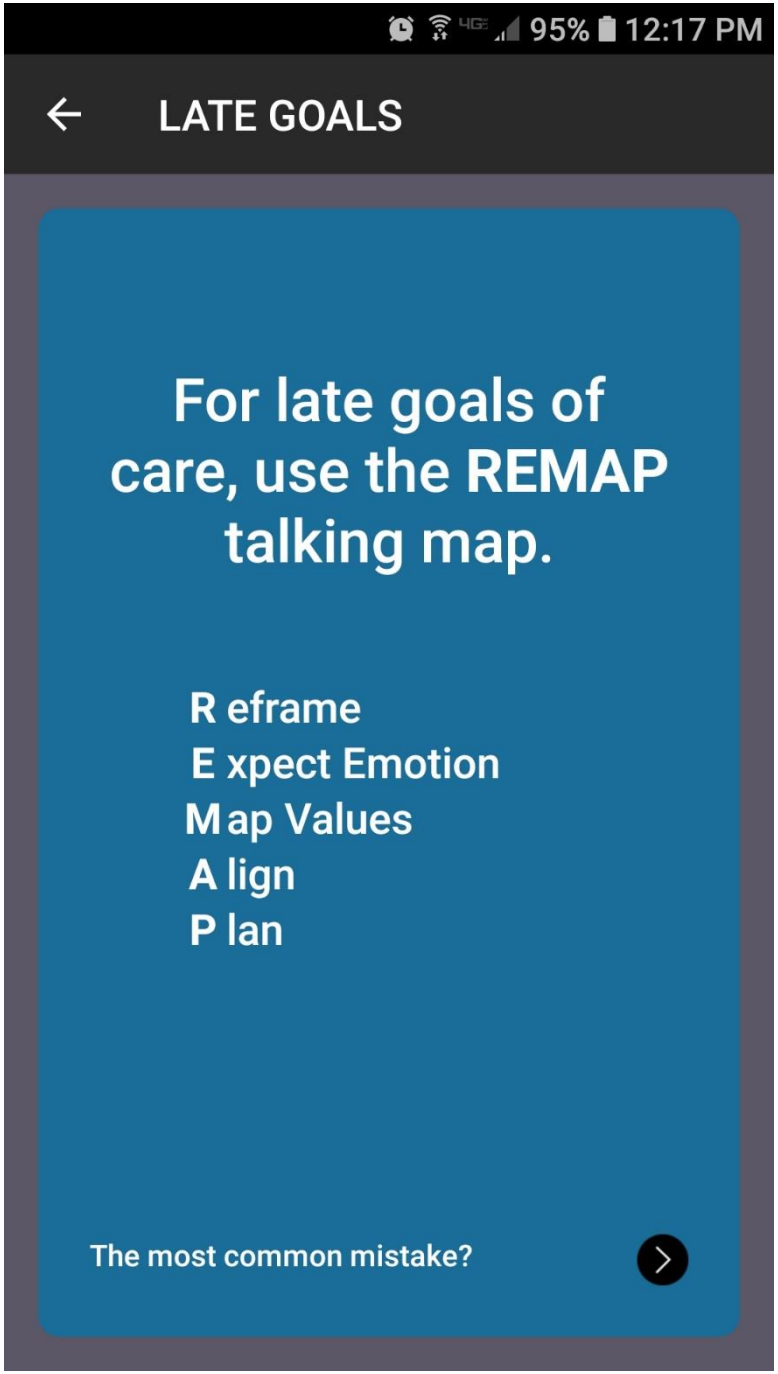
EXAMPLES

As long as I can at least sit up on the bed and occasionally talk to my grandchildren • As long as I can eat ice cream and watch the football game on TV • As long as I can recognize my loved ones • As long as my heart is beating, even though I'm not conscious

If you become sicker, which matters more to you: the possibility of a longer life, or the possibility of a better quality of life? Please explain.



https://www.vitaltalk.org/



Step	What you say or do
1. Reframe why the status quo isn't working.	You may need to discuss serious news (eg a scan result) first. "Given this news, it seems like a good time to talk about what to do now." "We're in a different place."
2. Expect emotion & empathize.	"It's hard to deal with all this." "I can see you are really concerned about [x]." "Tell me more about that—what are you worried about?" "Is it ok for us to talk about what this means?"
3. Map the future.	"Given this situation, what's most important for you?" "When you think about the future, are there things you want to do?" "As you think towards the future, what concerns you?"
4. Align with the patient's values.	As I listen to you, it sounds the most important things are [x,y,z].
5. Plan medical treatments that match patient values.	Here's what I can do now that will help you do those important things. What do you think about it?

REMAP

Introducing the "Reframe"

Ask what the patient/family knows

"What have the doctors told you?"

Give a "Headline"

Language at 4-5 grade level

Then stop

REMAP

Reframe: current plan isn't working

"We're in a different place than before."

"We are worried the treatments are not working."

"We're at a point where more treatments are unlikely to help, and they may make her worse."

R Arnold, MJHS Webinar 2018

2. **EXPECT EMOTION:** respond empathically

Robert Arnold, MD

Professor of Medicine in the Division of General Internal Medicine; Chief, Section of Palliative Care and Medical Ethics at the University of Pittsburgh School of Medicine; Assistant Director for Education, University of Pittsburgh Center for Bioethics and Health Law; Assistant Medical Director of Palliative Care for the Institute for Quality Improvement at the University of Pittsburgh Medical Center

REMAP

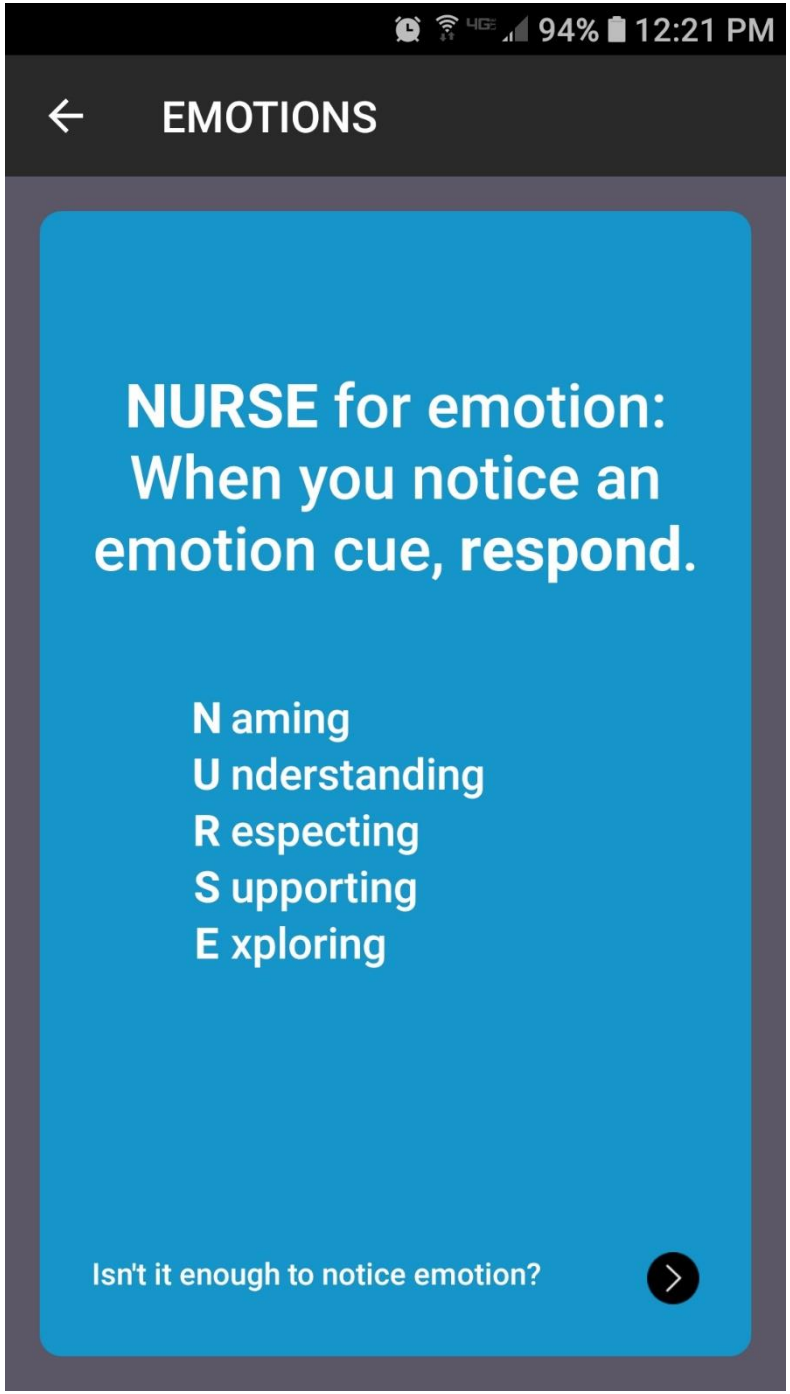
Expect emotion even if it is in the form of a question
Emotions make it hard to hear more information

"This is not what you wanted to hear..."

"I can see how much you love your dad"
"I wish we had better news"

Listen for emotion expressed as a question

"Was explaining disease findings to patient with still frame angiogram. Patient asked why this happened again. I explained he has a long standing documented hx of noncompliance. He got enraged and threatened me. "



Naming	"It sounds like you are frustrated"
Understanding	"This helps me understand what you are thinking"
Respecting	"I can see you have really been trying to follow our instructions"
Supporting	"I will do my best to make sure you have what you need"
Exploring	"Could you say more about what you mean when you say that…"

REMAP

Transition to Mapping

"Can we talk about what comes next?"

"Let's step back and talk about what is most important to your mom given the medical situation."

R Arnold, MJHS Webinar 2018

REMAP

Map out the future

STEP BACK from talking about any specific therapy

Focus on the patient values

Previous reflection & experience

"Given what we have said, as you think about the future what is most important?"

"Given what we have said, as you think about the future what is most concerning?

R Arnold, MJHS Webinar 2018

REMAP

Map out the future – when talking to family, when the patient is unable to participate

“Given this situation, what would your dad think?”

“Given what we have said, what would be most important to your dad?”

“If your dad was sitting here, what would be his biggest concerns?

“Did he ever fill out a living will”

R Arnold, MJHS Webinar 2018

REMAP

Align with values

“As I listen, it sounds like what’s important is...”

“Your dad would want to avoid…”

“It sounds like your dad wanted both x and y. Is there one he would think is more important...”

REMAP

Plan treatments that match values

“Can I make a suggestion based on what you have told me ?”

<u>Start with what you will do….</u>
“Given how important comfort is to you, we should do…”

“Given your dad would not want to live on machines, we should not…”

“What do you think?”

R Arnold, MJHS Webinar 2018

"Time Will Tell"

Allow time for …

The clinical picture to unfold

- Time limited trials

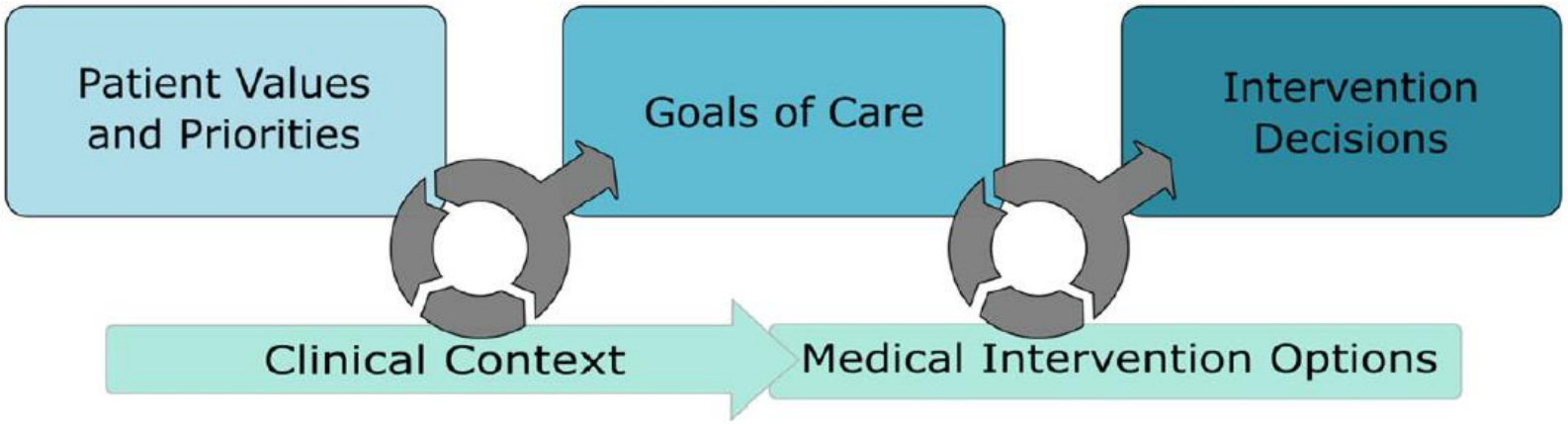
The patient/family story will be revealed

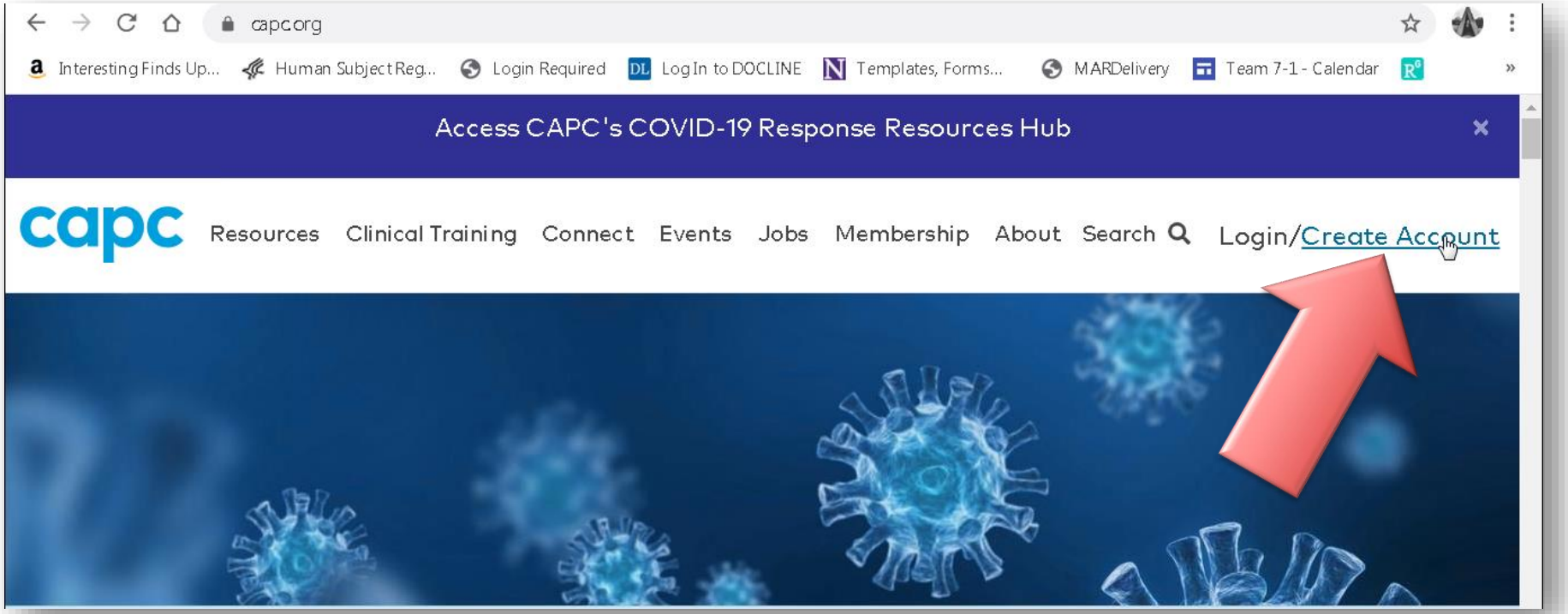
- More stories
- Additional family enter the picture

Trust to be built

“REMAP ” our mindset

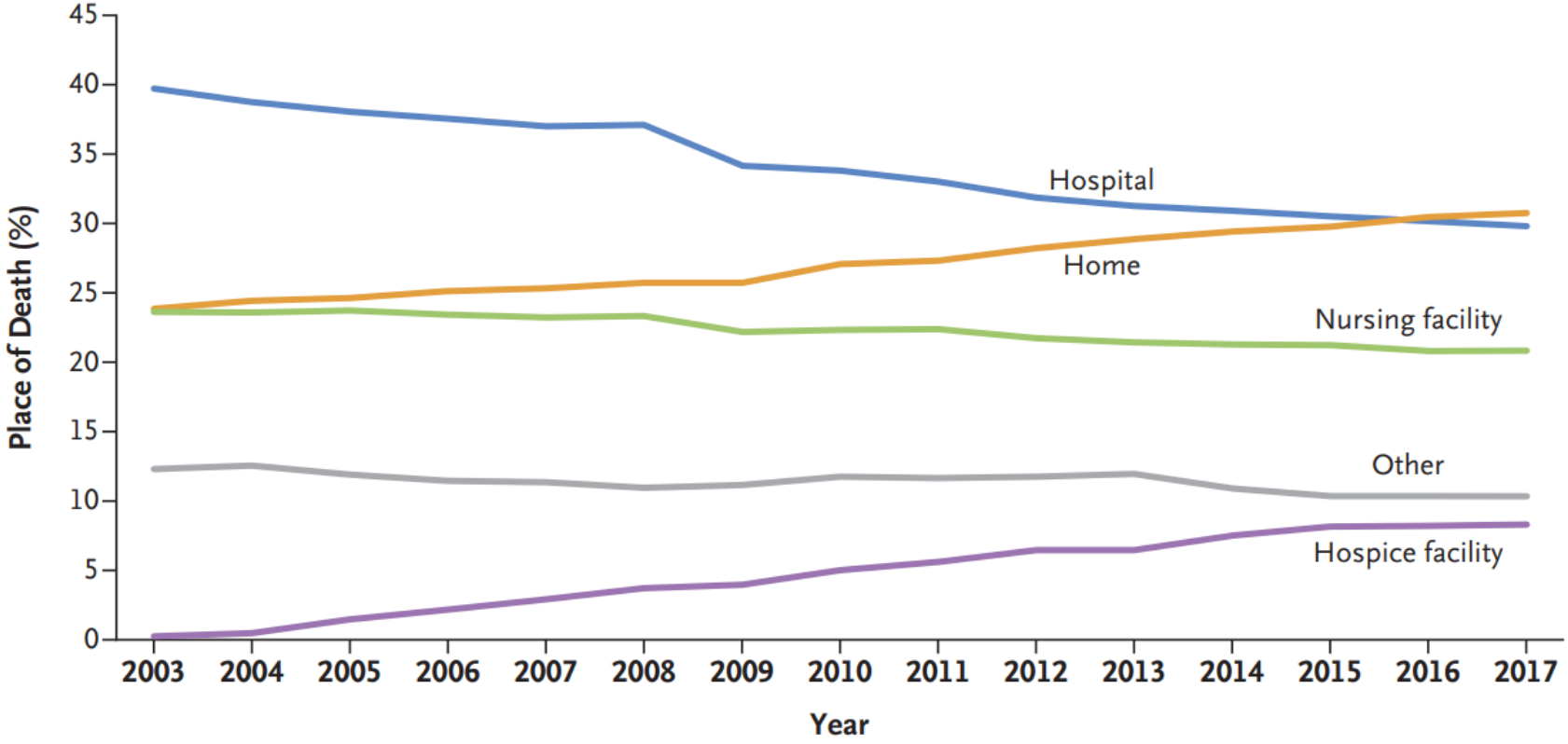
- Clinician Telling ….. Clinician Learning
- Clinician Talking ….. Clinician Listening
- Laser focus on a specific agenda ….”Let” the process unfold
- Focus on Treatments …. Focus on values
- One & Done …. Revisit, it’s a process


Patient Values and Priorities
Goals of Care
Intervention Decisions
Clinical Context
Medical Intervention Options



To register for free CAPC access through Ellis, go to CAPC.org, click "Create Account", and set up your account using your ellismedicine.org email address. Don't have an Ellis email address? Running into registration issues? Contact Emily at harte@ellismedicine.org.

A **Changes in the Place of Death in the United States**



NEJM December 12, 2019

Frequent Misperceptions about Hospice

- Families think that we are going to or asking us to medicate their family member (euthanasia)
- We are a supportive service-Families believe we will be in their homes 24/7
- Patients/families think if they come onto Hospice we are going to stop all of their medications
- Families think that if a patient is expected to pass in a few weeks they should be allowed to remain in the hospital
- Difficult for families/clinicians to understand that patients that are dying comfortably do not qualify for general inpatient services.
- Hospice is misunderstood as it’s the immediate end to one’s life when its about adding quality to what time a patient has left.
- Patient's think they cannot continue to see their primary physician once on hospice
- Patient's don’t realize they can come off Hospice at any time.
- Patient's can actually improve/stabilize at times to discharge

Palliative Care Partners
Interdisciplinary approach to care

Inpatient Teams

- Physician
- Nurse Practitioner
- Physician Assistant
- Social Work

Chaplain

Ethics

Community Teams

- Nurse Practitioner
- Social Work
- Physician oversight

Adding: RN and chaplain in July 2022

What is Palliative Care?

- **An extra layer of support for patients at any stage of serious illness**
- **Specialized medical care**
- **A multidisciplinary approach**
- **A focus on the unique needs of each patient**

The goal is to improve quality of life for both the patient and the family.

Palliative care can be provided at any stage of illness, even when patients are actively seeking treatment.

We don't replace your physician, but work closely in partnership to coordinate care.

Patients who recieve palliative care early in their illness have the opportunity to benefit the most.

Phone:
518-525-6561

Fax:
518-525-6515

e-mail:
palliativecarepartners@sphp.com

TESTIMONIALS

"The team was able to identify useful and timely pain management for my wife's serious illness"

"They were there to listen, provide support, and help us emotionally"

"My only regret is that I did not engage with the palliative team sooner"

St Peter's Health Partners
Medical Associates
A Member of Trinity Health

Palliative Care patient Preston Patterson and his wife Helen

Palliative Care

Treating the symptoms and stress of a serious illness

518-525-6561

Palliative Care patient Archie Ritson

Palliative Care patient Pam Perez

What will the palliative care team do?

- Manage symptoms of your disease and the side effects of treatment
- Let you know what to anticipate with your illness
- Help you match the treatment options to your goals
- Assist you with advanced care planning
- Help to coordinate your care
- Provide support to your family and caregiviers

What do we offer?

- Palliative care trained nurse practitioners to help manage your symptoms
- Social workers to help access community services
- Support for you and your family
- Assistance with health care decisions
- Coordination with your other providers
- 24/7 on call availability
- Oversight from a palliative care trained physician

You can benefit from palliative care even if you have a certified home health agency involved in your care.

Where do we care for you?

- We will come to your home if you live in Albany, Schenectady, Southern Saratoga or Rensselaer counties
- Support provided outside regularly scheduled home visits by telemedicine
- Our palliative care teams provide support if you are admitted to St. Peter's, Ellis or Samaritan Hospital

Who is eligible?

- Patients with Cancer and chronic diseases such as heart failure, COPD, liver or kidney disease, dementia

Copayment may be associated with NP/MD visits per your specific insurance plan

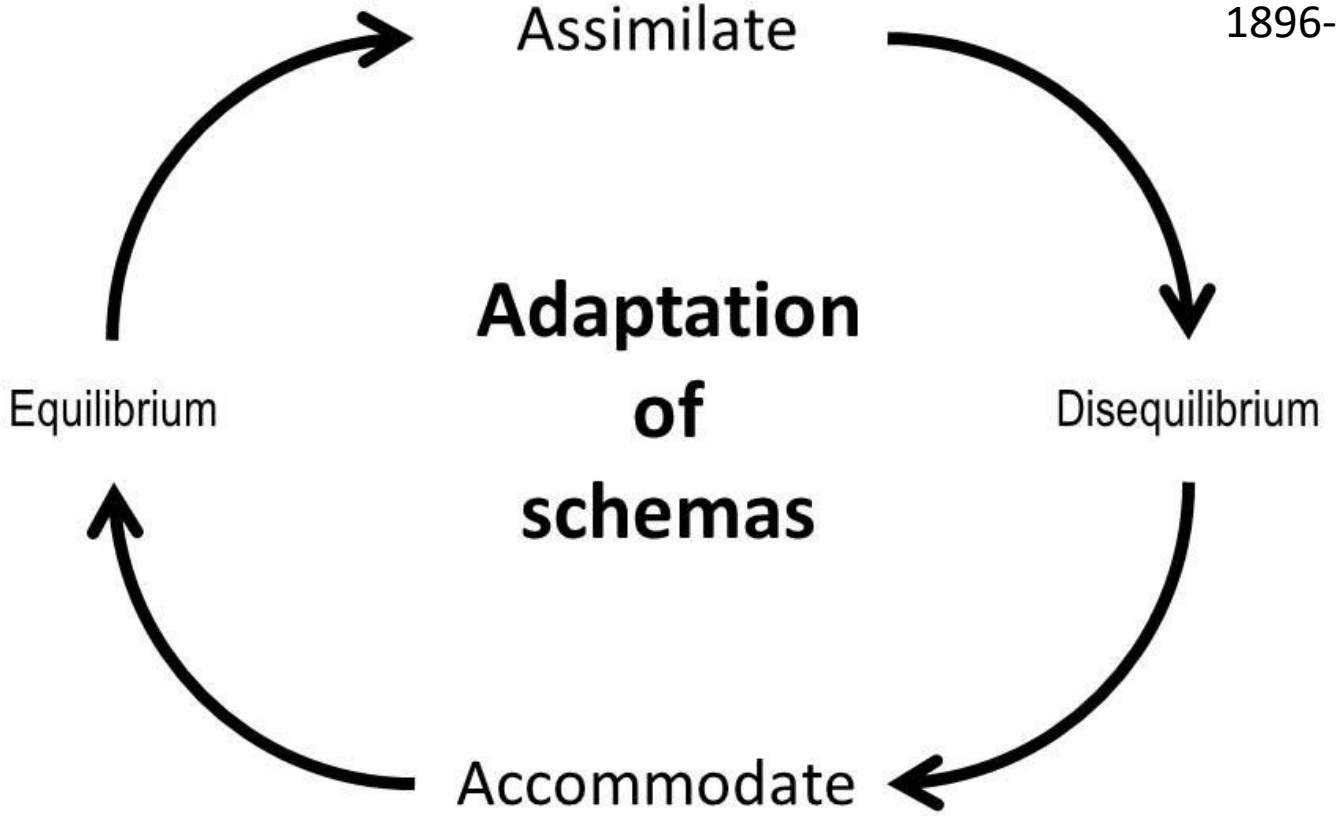
Coping & Hoping with Serious Illness

The Existential Work of Serious Illness

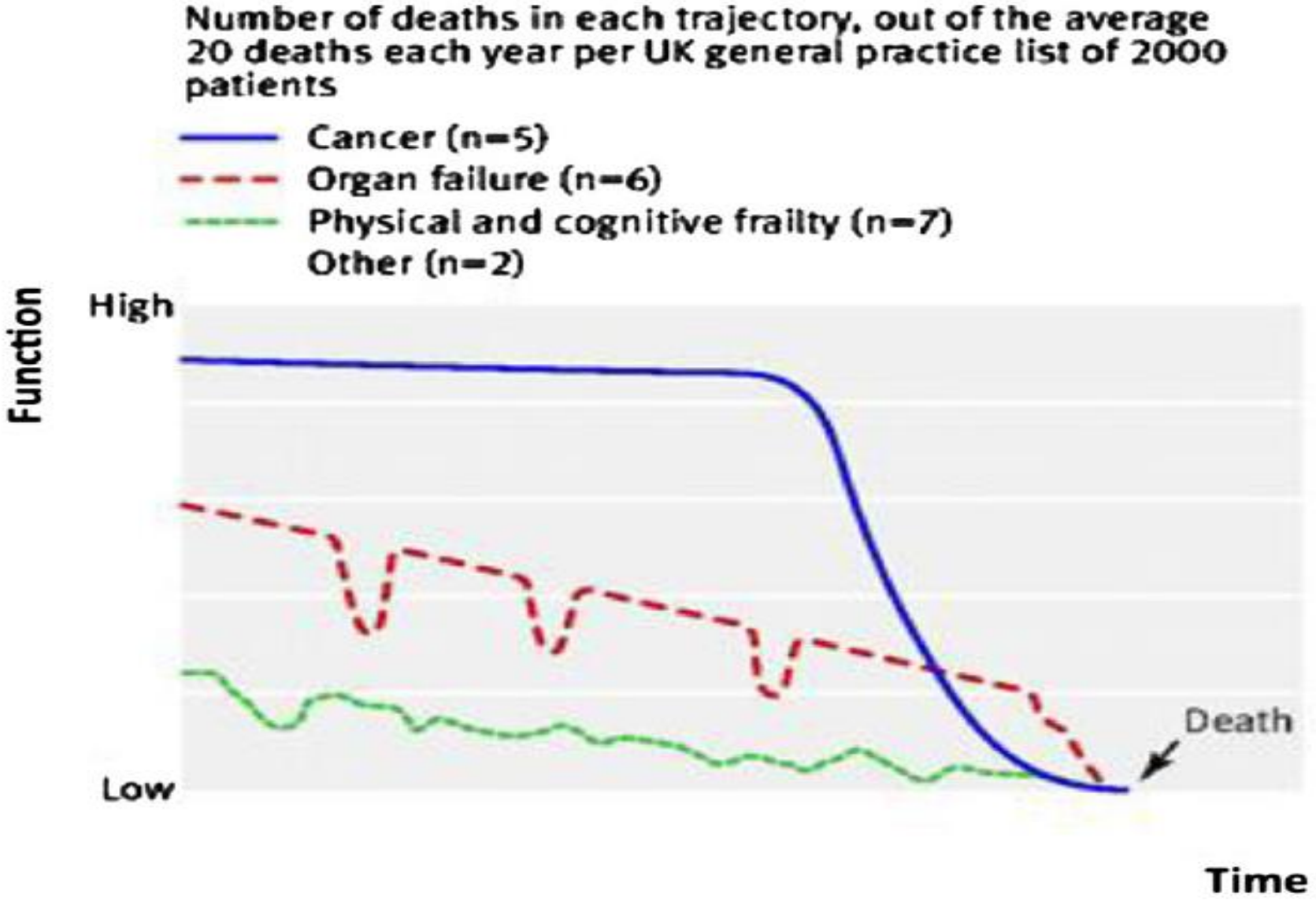
"...slowly learning to cope with illness and prognosis by finding a way to balance hopes for the future and a perspective of life engagement with a growing awareness of the possibility of experiencing advanced disease and illness or dying."

Jacobsen et al JAMA 2022

Jean Piaget
1896-1980



C Nickerson. Understanding Accomodation and Assimilation in Psychology. Simply Psychology. Dec 2021

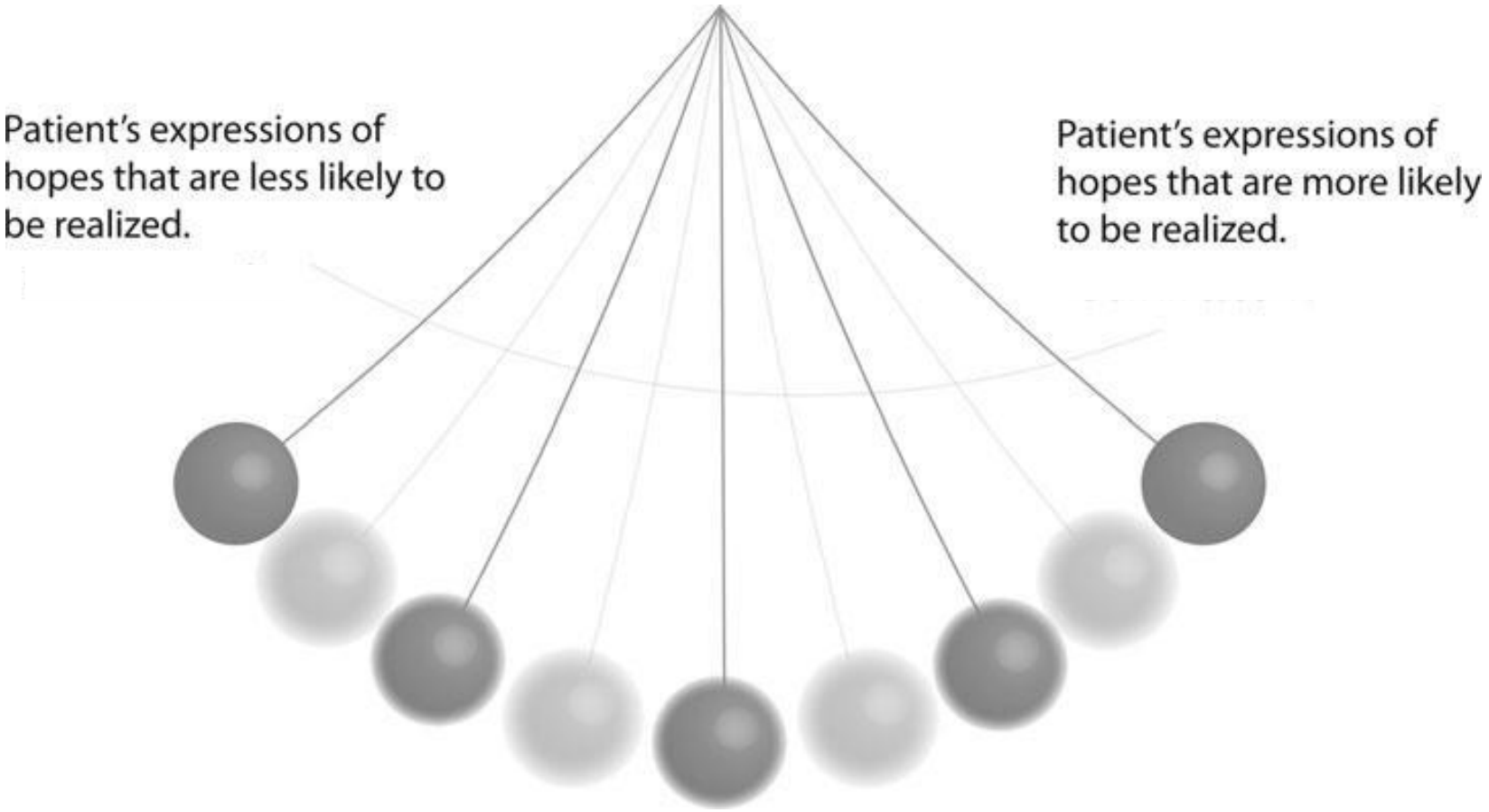


Murray SA, and Sheikh A BMJ 2008:336:958-959

	Cancer	CHF/COPD	Frailty
Onset	Sudden event	Variable	Functional decline
Living with Advanced Illness	Hope for return to normal, fear for relapse. Death backstage with occasional appearance	Uncertainty between exacerbations. Trying to live normally with frustrating limitations.	Normalizing and adapting; fear of dementia or nursing home admission. Worries about fates worse than death
Dying	Death Center Stage	Might die, might not, so why discuss it?	Death will happen in due course

M Kendall, et al. Different Experiences and Goals in Different Advanced Diseases: Comparing Serial Interviews With Patients With Cancer, Organ Failure, or Frailty and Their Family and Professional Carers. JPSM 2015

Model of coping with serious illness: a pendulum in which the patient's expressions swing through varying degrees of prognostic awareness.



V Jackson, Journal of Palliative Medicine 2013

“Rather than being concerned that hope is either so fragile that it can be lost, or so powerful that it can overwhelm decision-making, clinicians should remember that hope is protective, if not necessary, for managing serious illness.

Hope is fluid, expandable, and persistent.

Holding complex, flexible, and diverse hopes enables patients to believe in the unlikely while simultaneously accepting the inevitable. The role of the clinician is to support both.”

R Rosenberg, RM Arnold, R Schenker. Holding Hope for Patients with Serious Illness. JAMA Sept 2021.

Sources and Resources

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Serious Illness Conversation Guide for Clinicians https://www.ariadnelabs.org/serious-illness-care/for-clinicians/

Serious Illness Conversation Workbook for Patients https://www.ariadnelabs.org/2021/11/16/what-matters-to-me-workbook/

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