What Matters Most: Ensuring Residents Goals of Care ESPECIALLY at journey's end

John G. Carney, MEd, Former President and CEO, Center for Practical Bioethics (Retired)
2025 Missouri Association of Nursing Home Administrators Conference
Lodge of the Four Seasons – Lake of the Ozarks
June 9, 2025 - 11:00A

Missouri Association of Nursing Home Administrators

Center for Practical Bioethics

Community based organization founded in 1984.

No conflicts of interest to report

CPB Offers services and programs in advance care planning and ethics education and training to health systems, providers and families

All fees and honoraria inure to benefit of the organization

Return to mission

Declarations and COI Statement

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Discuss Purpose and Goals of TPOPP/POLST in integrating resident Tx preferences so ACP and shared decision making can be honored and protected.

Access resources for clinical and social services staff to impact culture and integrate EOL goals to improve satisfaction and well being.

Session Objectives

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For many older adults and their families…

Goals of care discussions don’t take place when they should.

Conversations about advancing chronic illness often only occur after a crisis.

Discussions often narrows to medical treatments rather than values, meaning, and purpose in life.

Most older people know they are mortal…
  Why do we not have these conversations when we should?
  How do we think about progressive chronic conditions?
  What exactly are Goals of Care?

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What is language we should be using?

How can we make it not so intimidating/dreaded?

What cultural issues do we need to observe and respect?

What can Palliative Care teach us?

How do we use those tools to guide shared decision making?

Questions to ask ourselves

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Distinguish among "palliative care” and "curative“ and “disease management” measures for persons diagnosed with chronic conditions that will progress over time

Engage with care providers using ACP resources that assist in clarifying values and preferences.

Describe how what is most important needs to be respected, honored and protected .

Additional benefits from improving in-house Staff skills - Going beyond “clinical”

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Tell me about your Mother…

Getting started

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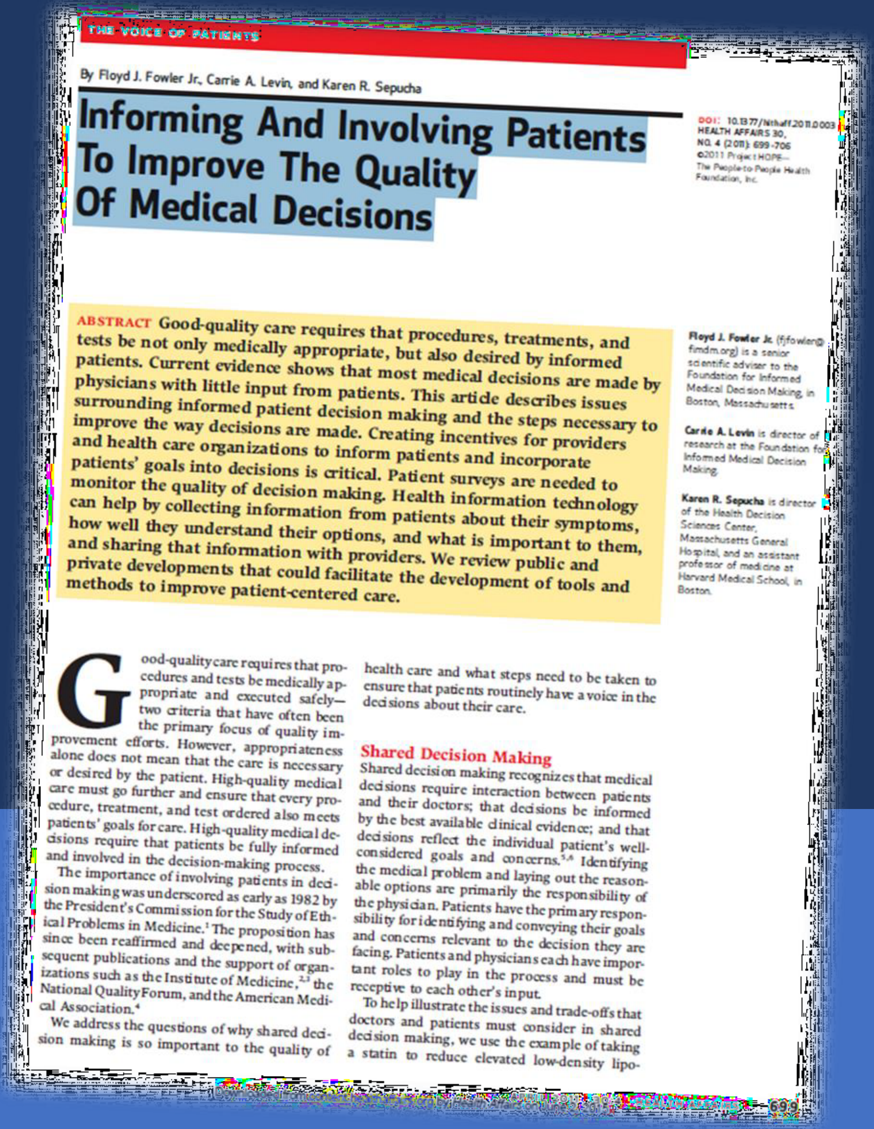
What do I need to know about
what she needs to know?

Getting started



THE VOICE OF PATIENTS

By Floyd J. Fowler Jr., Carrie A. Levin, and Karen R. Sepucha

Informing And Involving Patients To Improve The Quality Of Medical Decisions

DOI: 10.1377/hlthaff.2011.0003
HEALTH AFFAIRS 30,
NO. 4 (2011): 699-706

ABSTRACT Good-quality care requires that procedures, treatments, and tests be not only medically appropriate, but also desired by informed patients. Current evidence shows that most medical decisions are made by physicians with little input from patients. This article describes issues surrounding informed patient decision making and the steps necessary to improve the way decisions are made. Creating incentives for providers and health care organizations to inform patients and incorporate patients' goals into decisions is critical. Patient surveys are needed to monitor the quality of decision making. Health information technology can help by collecting information from patients about their symptoms, how well they understand their options, and what is important to them, and sharing that information with providers. We review public and private developments that could facilitate the development of tools and methods to improve patient-centered care.

Floyd J. Fowler Jr. (fjfowler@fimdm.org) is a senior scientific adviser to the Foundation for Informed Medical Decision Making, in Boston, Massachusetts.

Carrie A. Levin is director of research at the Foundation for Informed Medical Decision Making.

Karen R. Sepucha is director of the Health Decision Sciences Center, Massachusetts General Hospital, and an assistant professor of medicine at Harvard Medical School, in Boston.

Good-quality care requires that procedures and tests be medically appropriate and executed safely—two criteria that have often been the primary focus of quality improvement efforts. However, appropriateness alone does not mean that the care is necessary or desired by the patient. High-quality medical care must go further and ensure that every procedure, treatment, and test ordered also meets patients' goals for care. High-quality medical decisions require that patients be fully informed and involved in the decision-making process.

The importance of involving patients in decision making was underscored as early as 1982 by the President's Commission for the Study of Ethical Problems in Medicine.[1] The proposition has since been reaffirmed and deepened, with subsequent publications and the support of organizations such as the Institute of Medicine,[2,3] the National Quality Forum, and the American Medical Association.[4]

We address the questions of why shared decision making is so important to the quality of health care and what steps need to be taken to ensure that patients routinely have a voice in the decisions about their care.

Shared Decision Making

Shared decision making recognizes that medical decisions require interaction between patients and their doctors; that decisions be informed by the best available clinical evidence; and that decisions reflect the individual patient's well-considered goals and concerns.[5,6] Identifying the medical problem and laying out the reasonable options are primarily the responsibility of the physician. Patients have the primary responsibility for identifying and conveying their goals and concerns relevant to the decision they are facing. Patients and physicians each have important roles to play in the process and must be receptive to each other's input.

To help illustrate the issues and trade-offs that doctors and patients must consider in shared decision making, we use the example of taking a statin to reduce elevated low-density lipo-

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ENGAGING PATIENTS IN CLINICAL CARE

By Karen R. Sepucha, Leigh H. Simmons, Michael J. Barry, Susan Edgman-Levitan, Adam M. Licurse, and Sreekanth K. Chaguturu

Ten Years, Forty Decision Aids, And Thousands Of Patient Uses: Shared Decision Making At Massachusetts General Hospital

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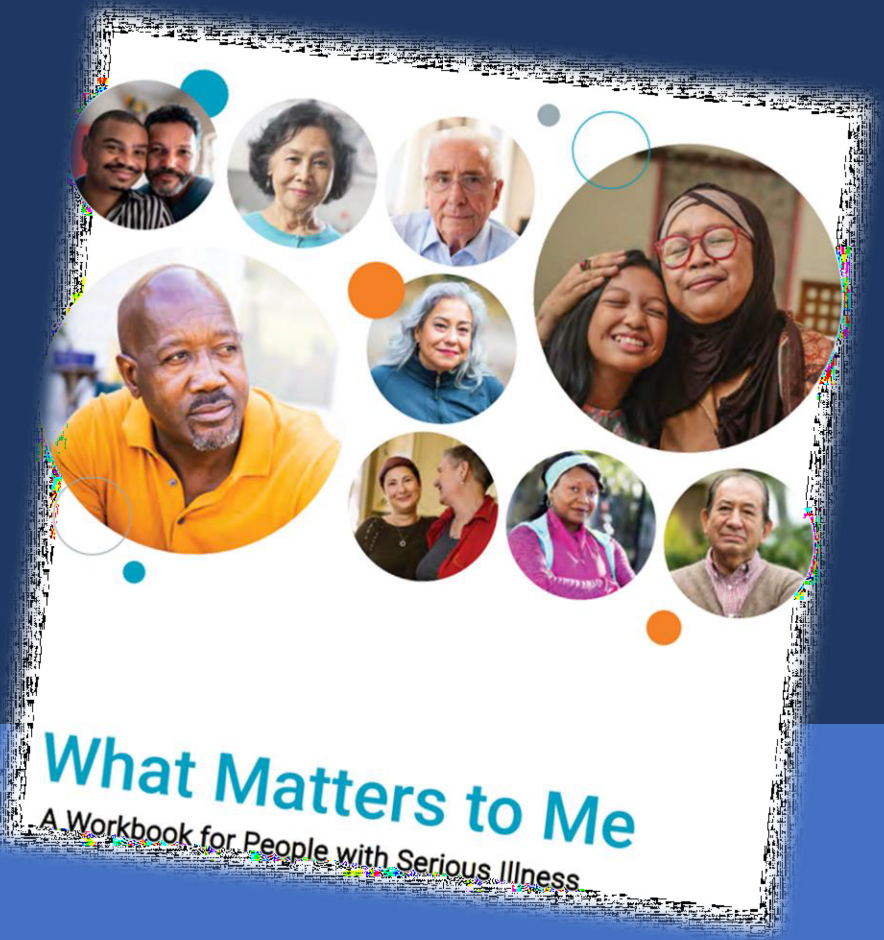
What do I need to know about
what she wants to me know?

Getting started



What Matters to Me

A Workbook for People with Serious Illness

DOWNLOAD THE WORKBOOK (ENGLISH)
DOWNLOAD THE WORKBOOK (CHINESE)
DOWNLOAD THE WORKBOOK (SPANISH)

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Steps in the process

- Rationale for systematic approach to improving conversations about patient values and priorities in serious illness
- Understand functional trajectories and key variables to identify patients where these conversations become important
- Recognize benefit of using Serious Illness Conversation guides
- Describe supports needed to honor results of SICP

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Gap between what patients *want* and what they *get*

Most people want to be at home and prefer comfort-focused care at the end of life, but that is often *not* the reality.

- 86% Medicare beneficiaries want to spend final days at home (Barnato 2007)
- 25-39% die in an acute care hospital (Teno, JAMA 2013; Silveira NEJM 2010)
- 70% are hospitalized in the last 90 days (Teno JM JAMA 2013)
- 29% receive intensive care in the last 30 days (Teno JM JAMA 2013)
- Multiple care transitions & short hospice stays (Teno JM JAMA 2013)

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Gap between what patients *want* and what they *get*

Patients with serious illness have priorities besides living longer.

- Symptom management and “quality of life”
- Sense of control and completion
- Strengthening relationships

(Singer JAMA 1999; Steinhauser JAMA 2000; Heyland, Palliative Medicine 2015)

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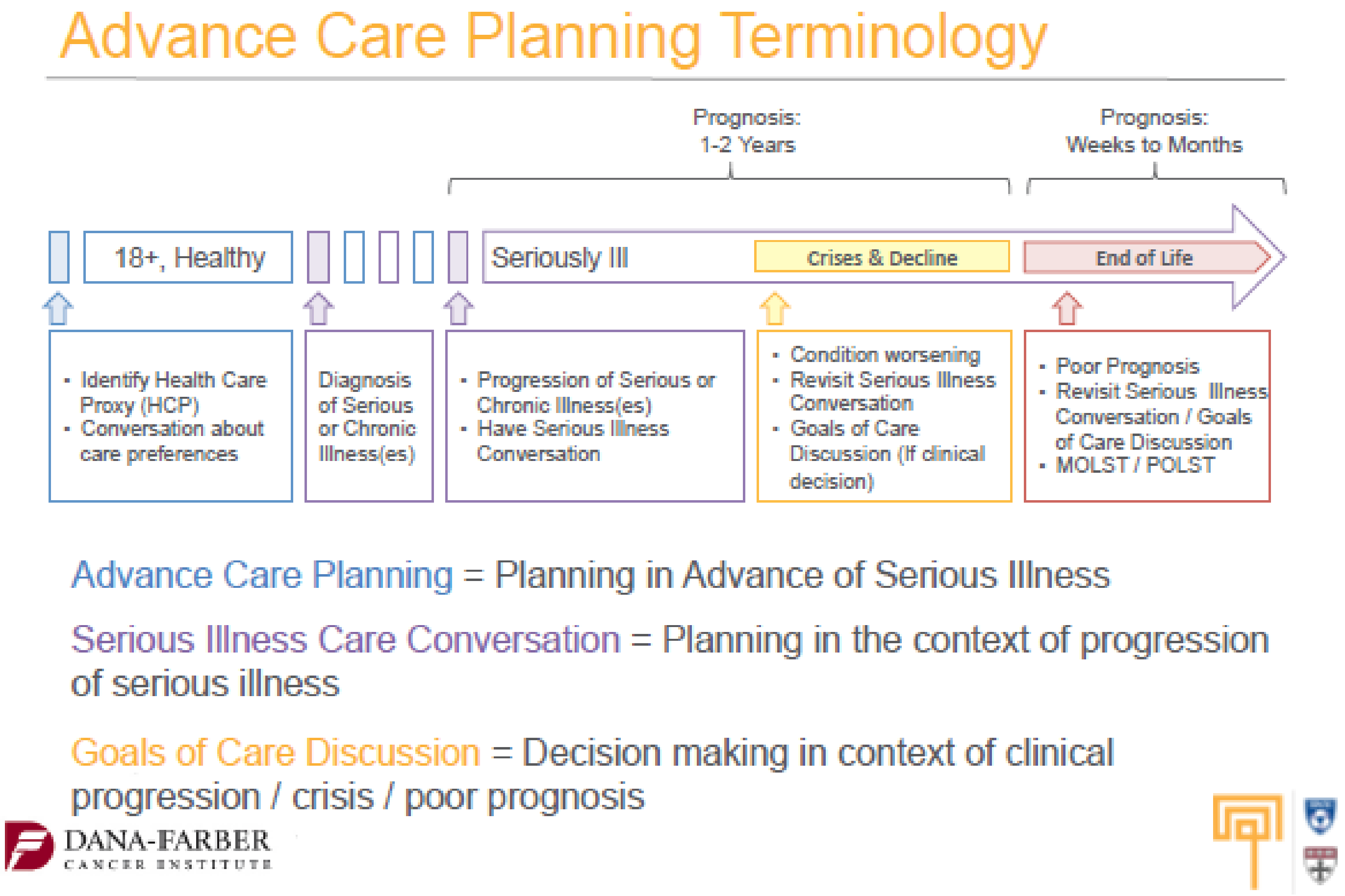
What do I call this?
When do I do it?

Advance Care Planning

Goals of Care Discussion

Medical Orders



Advance Care Planning Terminology

Prognosis:
1-2 Years

Prognosis:
Weeks to Months

18+, Healthy

Seriously Ill

Crises & Decline

End of Life

- Identify Health Care Proxy (HCP)
- Conversation about care preferences

Diagnosis of Serious or Chronic Illness(es)

- Progression of Serious or Chronic Illness(es)
- Have Serious Illness Conversation

- Condition worsening
- Revisit Serious Illness Conversation
- Goals of Care Discussion (If clinical decision)

- Poor Prognosis
- Revisit Serious Illness Conversation / Goals of Care Discussion
- MOLST / POLST

Advance Care Planning = Planning in Advance of Serious Illness

Serious Illness Care Conversation = Planning in the context of progression of serious illness

Goals of Care Discussion = Decision making in context of clinical progression / crisis / poor prognosis

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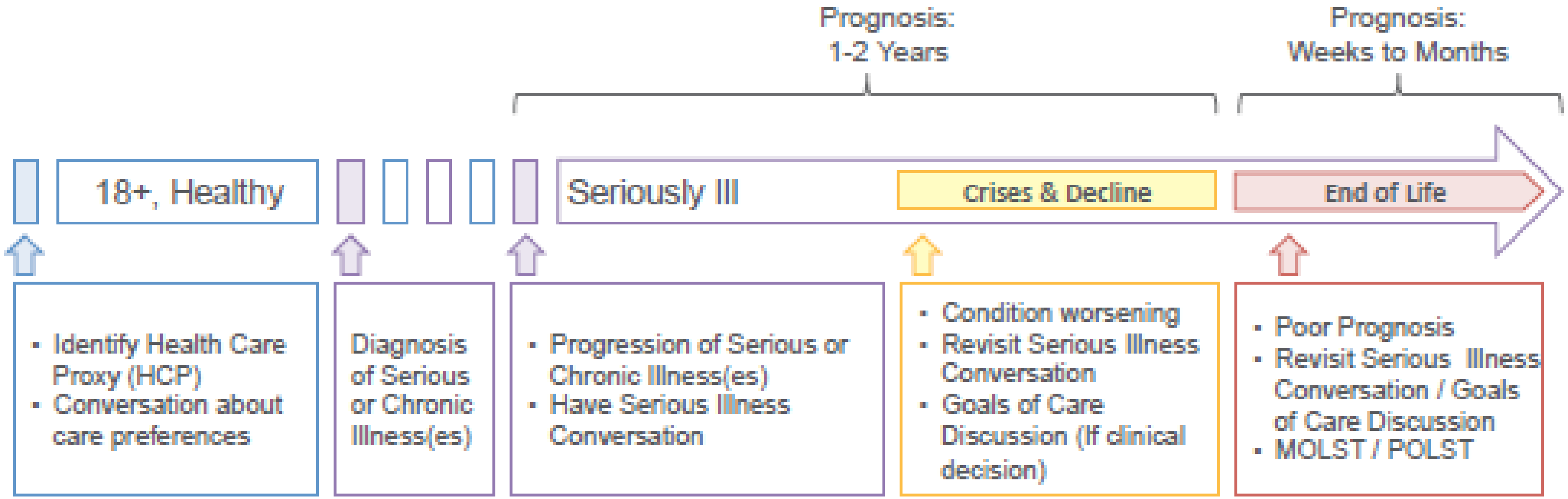
Advance Care Planning Terminology



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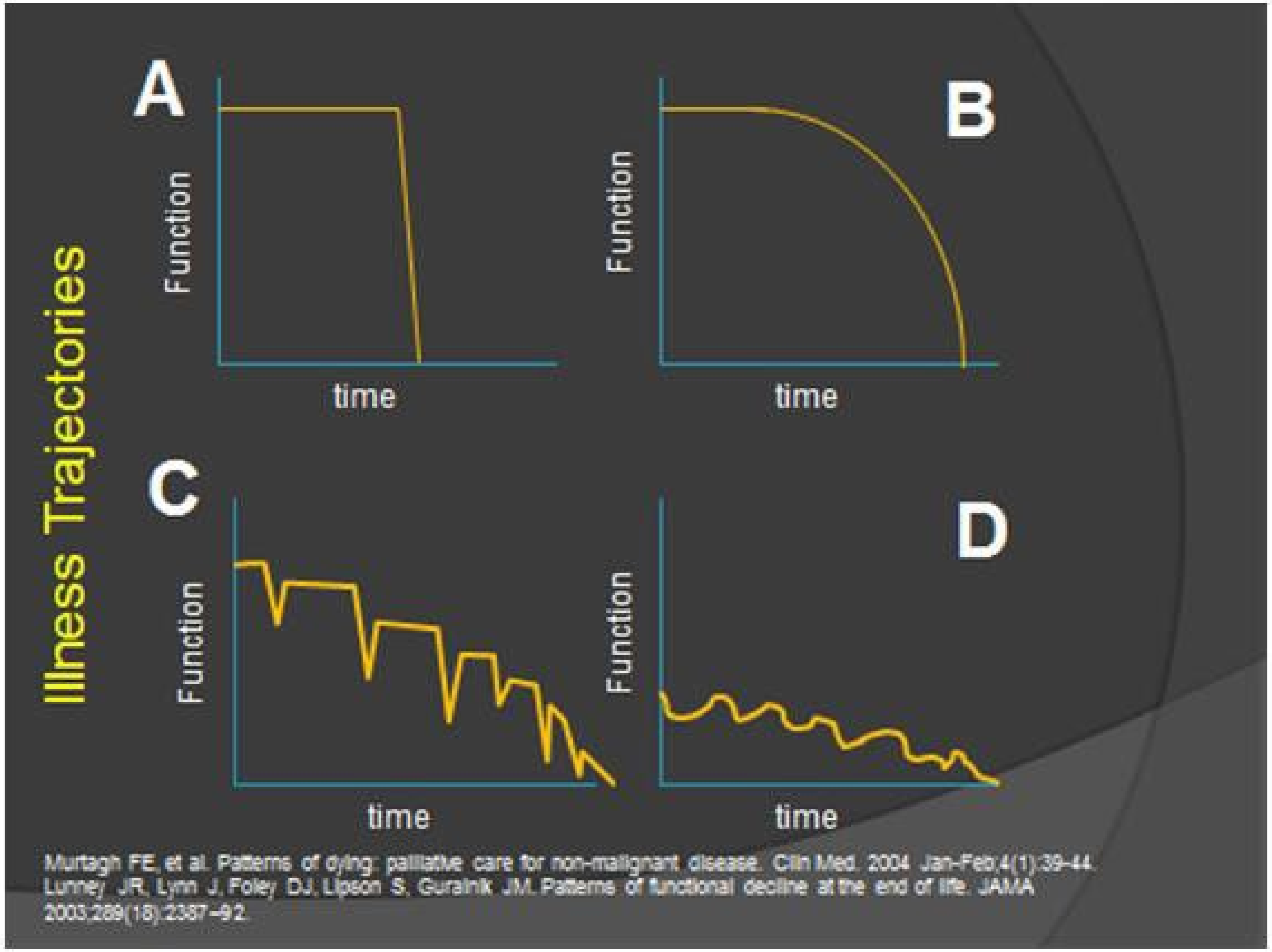
What is Traditional ACP?

- For Healthy people
- Goal is educational and reflective, for them to ponder their values related to a potential future reality
- Provide resources for them to think through and discuss with their family
  - MyDirectives.com, Caring Conversations, 5 Wishes
- Potential outcomes:
  - Good family conversation only
  - DPOA-HC, Advance Directive

- This is something that people do on their own

Trajectories of Illness

- Trauma or Sudden Death
- Neoplasm/Advanced Cancer
- Heart Failure or Progressive Chronic
- Dementia/Neuro



Murtagh FE, et al. Patterns of dying: palliative care for non-malignant disease. Clin Med. 2004 Jan-Feb;4(1):39-44.
Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. JAMA 2003;289(18):2387–92.

Conversations too little, too late, and not great

- Studies show patients with serious illnesses do not discuss EOL preferences, or first discuss them only in the last days to month of life (Wright 2008, Dow 2010, Halpern 2011)
- Among patients with advanced cancer:
    - First EOL discussion occurred median 33 days before death (Mack AIM 2012)
    - 55% of initial EOL discussions occurred in the hospital
    - Only 25% of these discussions were conducted by the patient's oncologist (Mack AIM 2012)
- Conversations fail to address key elements of quality discussion, especially prognosis

What patients *get* can harm them and their family

Aggressive care for patients with advanced illness can be harmful:

- For patients:
  - Lower quality of life
  - Greater physical and psychological distress
    (Wright, AA JAMA 2008; Mack JCO 2010)
- For caregivers:
  - More major depression
  - Lower satisfaction
    (Wright, AA JAMA 2008; Teno JM JAMA 2004)

Clinicians, medical system barriers to conversations and care planning

- Clinicians lack communication competencies, training and confidence Baile Cancer 1999; Sullivan JGIM 2003; Buss Cancer 2011
- Culture of medicine does not value key elements of effective care:
  - Accepts late or non-existent conversations
    - Low priority
    - No accountability
  - Tolerates poor end-of-life care
  - Focuses on avoidance of emotions; these are inherently emotionally-intense discussions
- Clinicians feel they do not have enough time

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It's Time to Rename and Reframe

- Not about "End of Life" discussions. These conversations are…
  - About a priorities for how to LIVE
  - Intended to help prepare over a course of months, even a year or two
  - Not about people right now. Goals over time (last chapters not hours)

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Conversations are Key

Earlier conversations about goals and priorities are associated with:

- Enhanced goal-concordant care
  Mack JCO 2010
- Improved quality of life
- Reduced suffering
- Better patient and family coping
- Higher patient/family satisfaction Detering BMJ 2010
- Less non-beneficial care & costs
  Wright 2008, Zhang 2009

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Identifying Seriously Ill population

CAPC

Serious Illness Strategies for Health Plans and Accountable Care Organizations, 2017

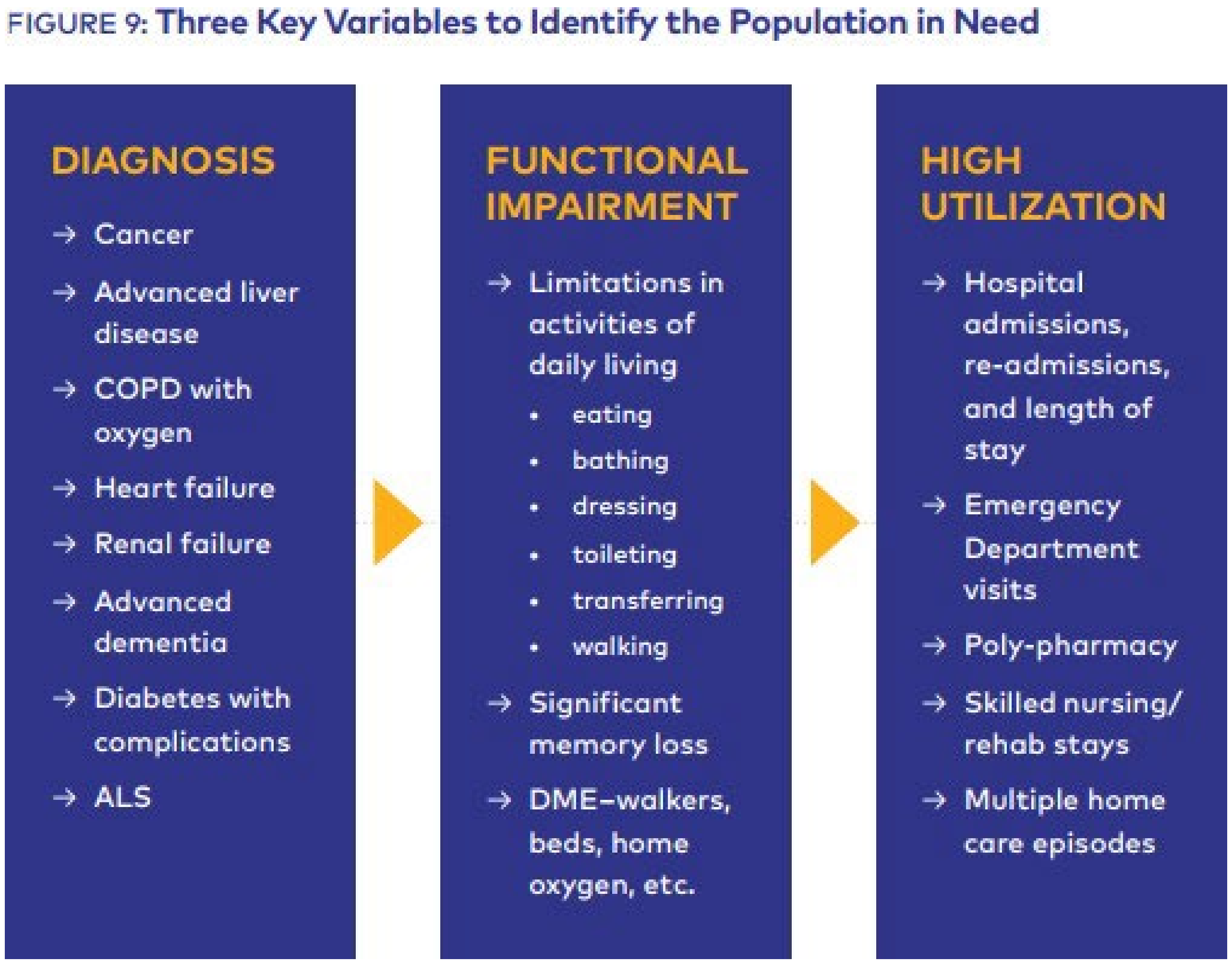

FIGURE 9: **Three Key Variables to Identify the Population in Need**

DIAGNOSIS

- → Cancer
- → Advanced liver disease
- → COPD with oxygen
- → Heart failure
- → Renal failure
- → Advanced dementia
- → Diabetes with complications
- → ALS

FUNCTIONAL IMPAIRMENT

- → Limitations in activities of daily living
  - eating
  - bathing
  - dressing
  - toileting
  - transferring
  - walking
- → Significant memory loss
- → DME–walkers, beds, home oxygen, etc.

HIGH UTILIZATION

- → Hospital admissions, re-admissions, and length of stay
- → Emergency Department visits
- → Poly-pharmacy
- → Skilled nursing/rehab stays
- → Multiple home care episodes

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Planning on trajectory: What people need to know

If patients want to die "at home," they and family need to know trajectory; make a plan for next “crash”

Requires system/provider to recognize trend and discuss it

Requires planning from hospital, provider’s office, **Nursing Home** and sharing

Requires support of community systems in a coordinated effort for preferences to be known across continuum of care (TPOPP/POLST)

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How to bridge gap between what patients *want* and what they *get*?

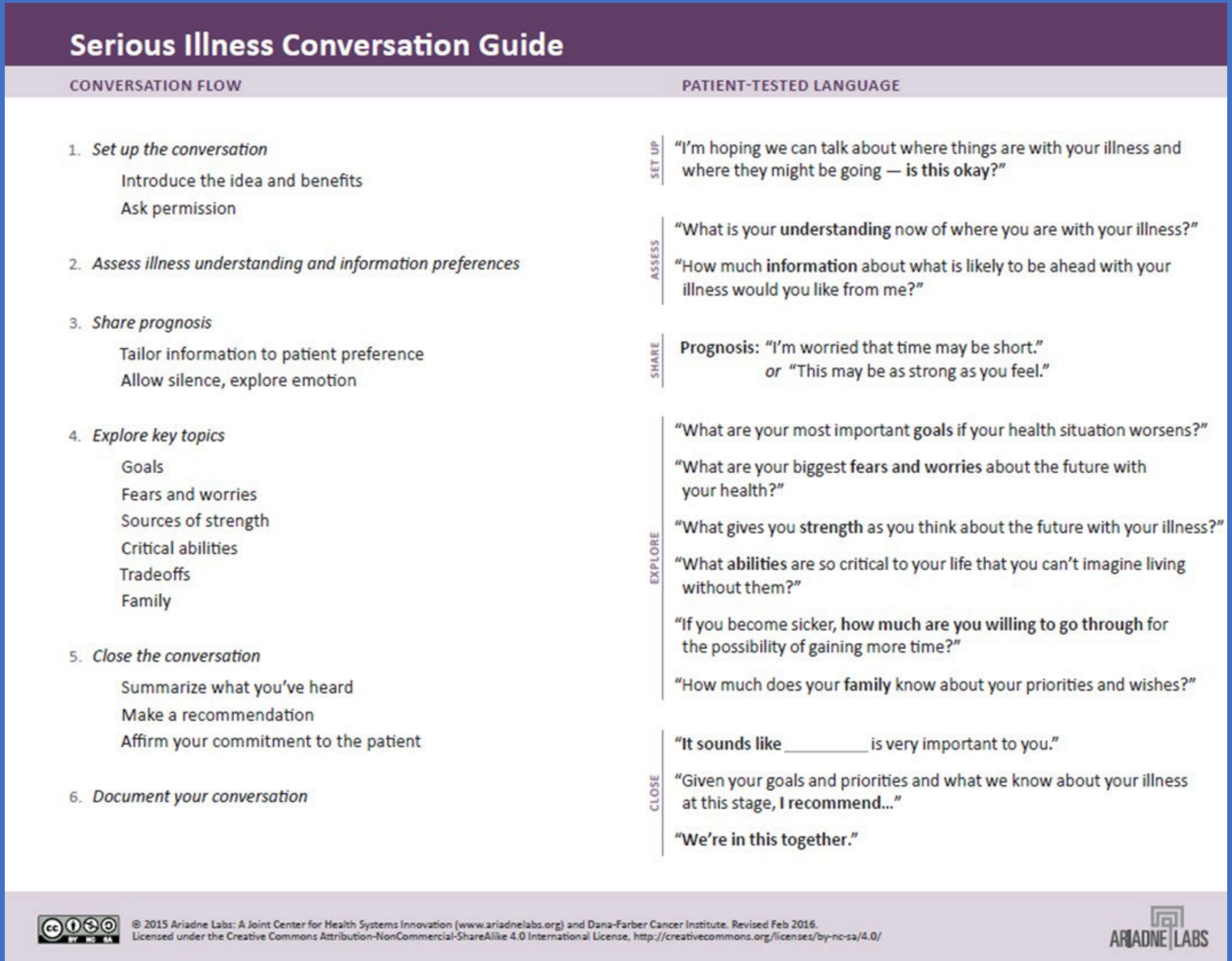
FIRST and FOREMOST…

Ask patients about their values and priorities.

What is Most Important?

Rely on Guides, Decision Aids, Ask for PC consult

(Serious Illness Conversation Guide)



Serious Illness Conversation Guide

CONVERSATION FLOW		PATIENT-TESTED LANGUAGE
1. *Set up the conversation* Introduce the idea and benefits Ask permission	SET UP	"I'm hoping we can talk about where things are with your illness and where they might be going — **is this okay?**"
2. *Assess illness understanding and information preferences*	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?"
3. *Share prognosis* Tailor information to patient preference Allow silence, explore emotion	SHARE	**Prognosis:** "I'm worried that time may be short." *or* "This may be as strong as you feel."
4. *Explore key topics* Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family	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?"
5. *Close the conversation* Summarize what you've heard Make a recommendation Affirm your commitment to the patient 6. *Document your conversation*	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."**

ARIADNE LABS

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What do checklists or guides do?

- Bridge gap between evidence and “real world” implementation
- Assure adherence to key processes
- Achieve higher level of baseline performance
- Ensure completion of necessary tasks during complex, stressful situations

Perspectives of those using tool

- “Gives me actual words when I feel stuck”
- “Reminds me to cover elements of the conversation more systematically”
- “I have to remember this is a guide for our conversation, not a form to complete”
- “Gives me structure to conversation that naturally triggers meaningful responses from patient.”

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Principles of these conversations

Patients want truth about prognosis.

Patient won’t be harmed by talking about end-of-life issues. (Culturally sensitive)

Normalize anxiety for both patient and clinician

Explore patient’s goals and priorities beyond living longer

Give patients opportunity to express fears and worries. It can be therapeutic.

Practical Advice

Ask for honest prognosis

Explore time frames uncertainties and progression

Sit with silence

Acknowledge emotions (Sad is not always bad)

Focus on fears, and concerns, hopes and dreams

Differentiate between expectations and above

Have someone take notes

Avoid desire to make it all better

Focus solely on treatments. Be OK with Being.

Ideas to facilitate conversation

Ask patient ?s using the 3 Ws:
Wish (or Hope), Worry, and Wonder

Explore meanings behind each

Express empathy not sympathy
- Don’t rescue

Potential Outcomes of Serious Illness Conversations

No decision; conversation documented & archived

Needs to be EASILY accessible and vernacular

Creation of health directive &/or Agent appt.

Creation of actionable medical order set

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Where do I find the tools and resources?

Center for Practical Bioethics

Caring Conversations® & …Continued

Conversation Project

Vital Talk

Ariadne Labs - Serious Illness Care Planning

What Matters to Me Workbook (slide7)

*My*Directives (A/D Vault)

Get Palliative Care

Prepare for Your Care (video tools)

Five Wishes (many languages)

Thank you!

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John G. Carney, MEd
Former President &CEO (Retired)
316.214.6253
(personal –voice and text)
jgcarney@gmail.com