A SHARED DECISION-MAKING APPROACH TO GOALS OF CARE

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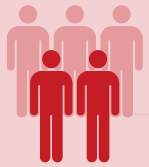
- **Other**: None

Objectives

- Discuss shared decision-making approach to advance care planning.
- Explore strategies to individualize goals of care.

Despite Advances in HF Therapy…

HF is one of the most common causes of hospitalization for patients aged **>65 years** in developed countries[1]



Nearly **44%** of all HF patients are readmitted within **1 year** after discharge[2]

Nearly 40% of patients will die within a year of their first hospitalization [3]

HF, heart failure

1. Bui et al. Nat Rev Cardiol 2011;8:30–41;
2. 2. Maggioni et al. Eur J Heart Fail 2013;15:808–17;
3. 3. L. Liu, H.J. Eisen**Epidemiology of heart failure and scope of the problem** Cardiol Clin, 32 (2014), pp. 1-8 vii

HF associated with a high symptom burden

High burden of physical and emotional symptoms, loss of independence, and disruptions to social roles, all of which severely degrade quality of life.[1,2]

Physical symptoms in advanced HF, such as pain, are highly distressing for patients and caregivers, yet remain under-recognized and undertreated[3,4]

Patients and their caregivers often face decisions about high-risk and complex treatments, such as cardiac devices, without adequate prognosis communication and decision support.[5,6]

HF associated with in-hospital death

Patients with advanced HF enroll in hospice at lower rates than those with cancer[1] and late in the course of their disease (within 3 days of death)[2].

The majority of patients with HF die in hospital[3,4], despite evidence that most individuals prefer to die at home[5,6].

1. D.B. Bekelman, C.T. Nowels, L.A. Allen, S. Shakar, J.S. Kutner, D.D. Matlock**Outpatient palliative care for chronic heart failure: a case series** J Palliat Med, 14 (2011), pp. 815-821
2. W.Y. Cheung, K. Schaefer, C.W. May, *et al.***Enrollment and events of hospice patients with heart failure vs. cancer**J Pain Symptom Manage, 45 (2013), pp. 552-560
3. Al-Kindi SG, Koniaris C, Oliveira GH, Robinson MR. Where Patients with Heart Failure Die: Trends in Location of Death of Patients with Heart Failure in the United States. J Card Fail. 2017 Sep;23 (9):713-714.
4. Quinn KL, Hsu AT, Smith G. et al. Association Between Palliative Care and Death at Home in Adults with Heart Failure. J Am Heart Assoc. 2020 Mar 3;9(5):e013844.
5. Pollock K. Is home always the best and preferred place of death? BMJ 2015;351:h4855.
6. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliative Care. 2013;12(1):7.

The New York Times

Failing Patients With Heart Failure

By Haider Javed Warraich

Aug. 10, 2015

HEART disease is the world's No. 1 killer, despite advances in medical technology, as well as public health initiatives that have eased the burden of heart disease drastically. While one marvels at the progress, we often ignore how heart-disease patients die.

Patients with heart disease are more likely to suffer excessively at the end of life than those with other conditions. While surveys show that people overwhelmingly want to die at home, patients with cardiovascular disorders are much less likely to do so than patients with other diseases, such as cancer.

The New York Times

DOCTORS

The Time for 'The Talk' Is Now

During the Covid-19 pandemic, it's critical to discuss end-of-life plans before you get sick.

Difficult discussions now will simplify difficult discussions in the future.

Source-Allen, 2012[11]

Guidelines support the integration of Palliative Care

SOCIETY GUIDELINES | VOLUME 33, ISSUE 11, P1342-1433, NOVEMBER 01, 2017

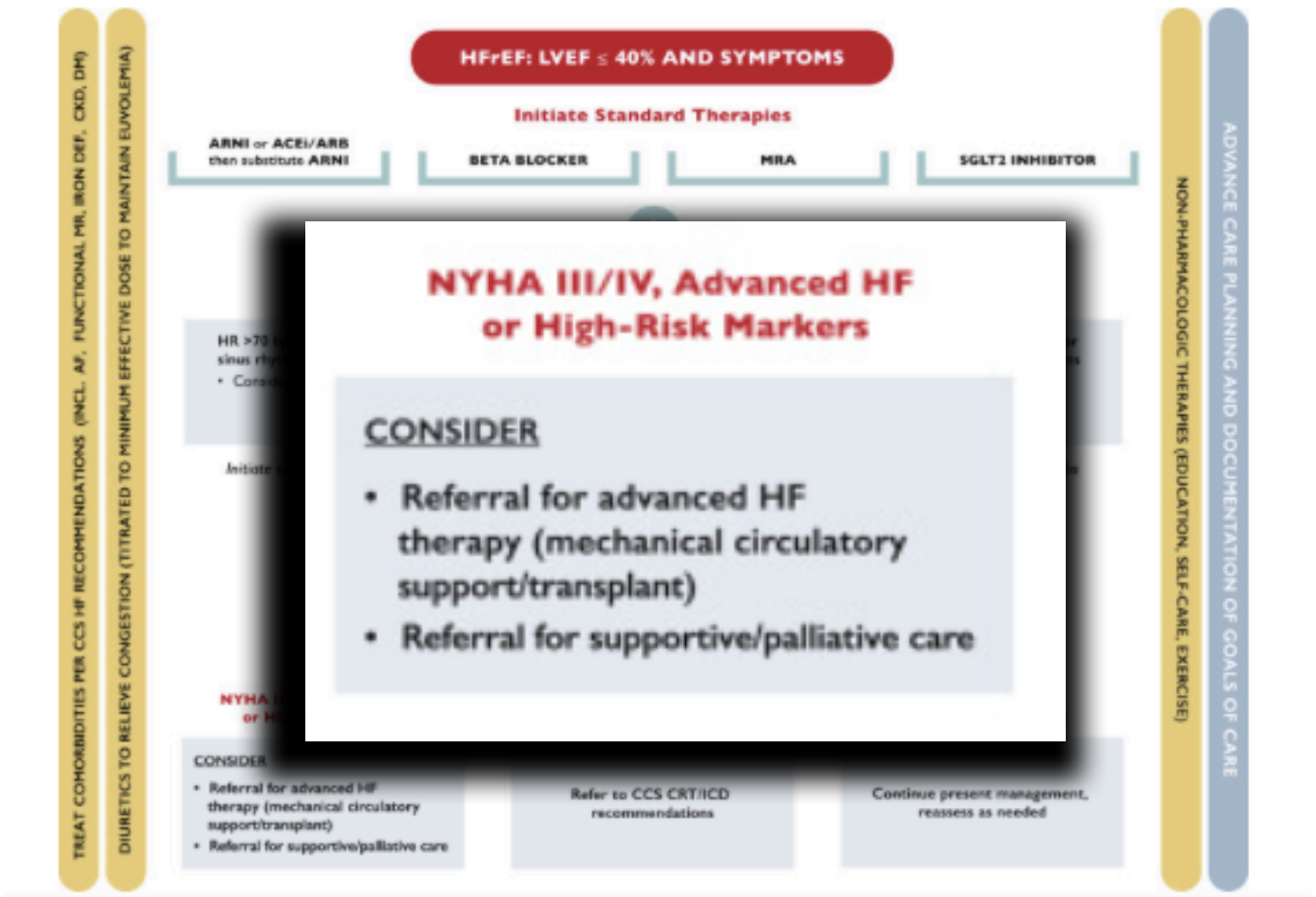
2017 Comprehensive Update of the Canadian Cardiovascular Society Guidelines for the Management of Heart Failure

Justin A. Ezekowitz, MBBCh • Eileen O'Meara, MD • Michael A. McDonald, MD • ...

- Recommendation

169. We recommend that clinicians caring for patients with HF should initiate and facilitate regular, ongoing, and repeated discussions with patients and family regarding advance care planning (Strong Recommendation; Very Low-Quality Evidence).

170. We recommend that the provision of palliative care to patients with HF should be on the basis of a thorough assessment of needs and symptoms, rather than on individual estimates of remaining life expectancy (Strong Recommendation; Very Low-Quality Evidence).



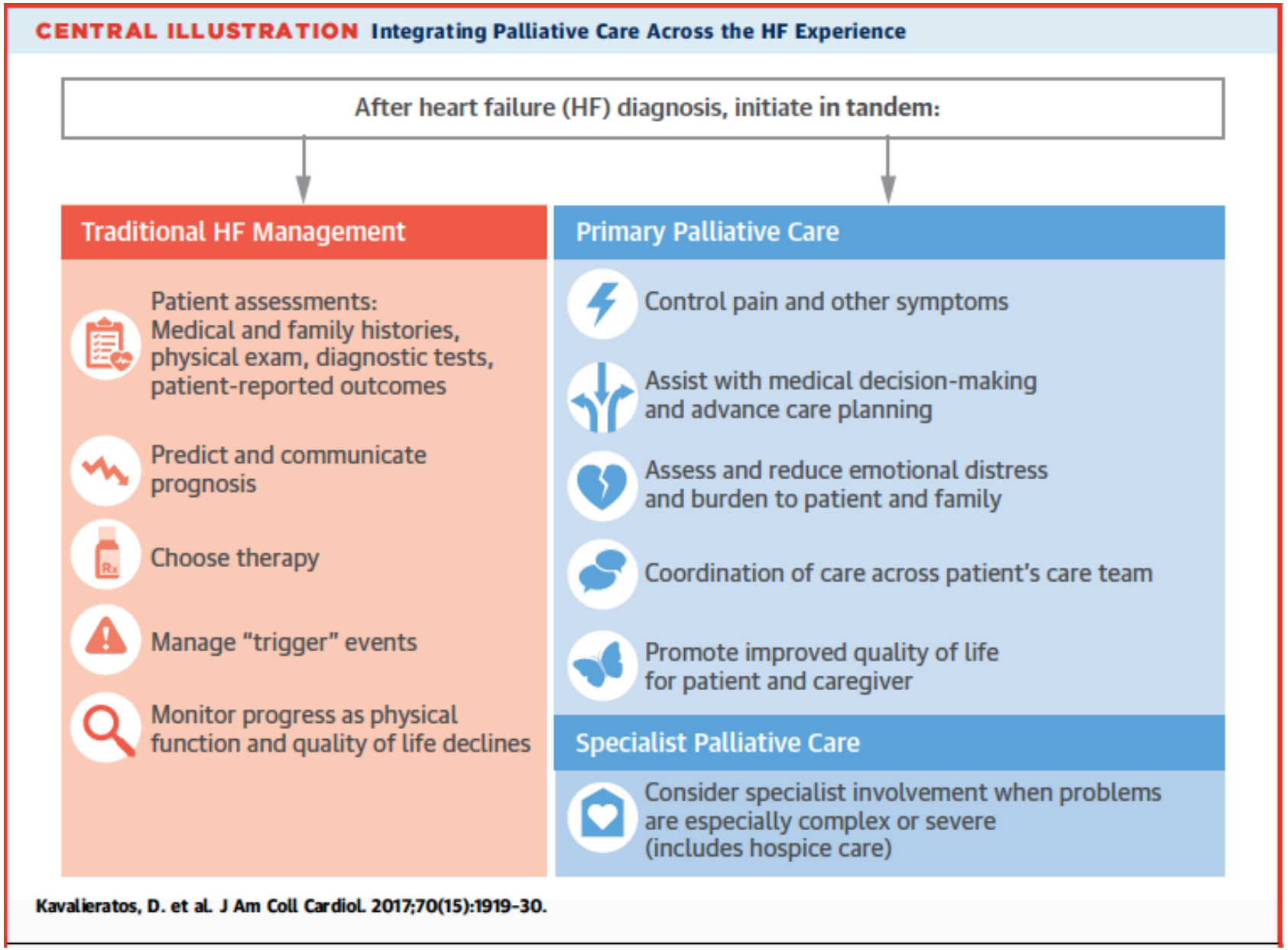
Framework of Palliative Care in Canada

What Success Looks Like - Shifts in Palliative Care Policies and Programming

Less of...	More of....
Palliative care treatment plans are decided by the health care provider(s).	Palliative care is developed in partnership with the person living with life-limiting illness and their family, and respects their values, culture and preferences.
Palliative care is discussed only after all other medical interventions are exhausted.	Palliative care is provided in conjunction with other medical interventions. Treatment plans are designed to improve quality of life through to the end of life.

Framework on Palliative Care in Canada Act. Canada.ca

Palliative Care Model in HF



Improving Communication - Advance Care Planning

Advance Care Planning - Patient Perspective

- Patients want to discuss prognosis
- They want to discuss it early in the disease process
- They want US to initiate the discussion
- They want to be included in the decision making process.

Can J Cardiol. 2007 Aug;23(10):791-6.
JAMA. 1999; 281:163–168
J Hosp Med. 2006; 1:161–167
J Gen Intern Med. 2008; 23:1602–1607

Advance Care Planning

Evidence suggests:

- Improved patient symptoms and anxiety
- Reduced psychiatric comorbidity among family members
- Reduces costs to the healthcare system
- Increased palliative and hospice use
- No evidence to support increase in patient distress

Shadowitz et al. *Arch Int Med* 2006

Wright et al. JAMA 2008

J Gen Intern Med. 2008; 23:1602–1607

Barriers to Serious Illness Conversations

Unpredictable trajectory

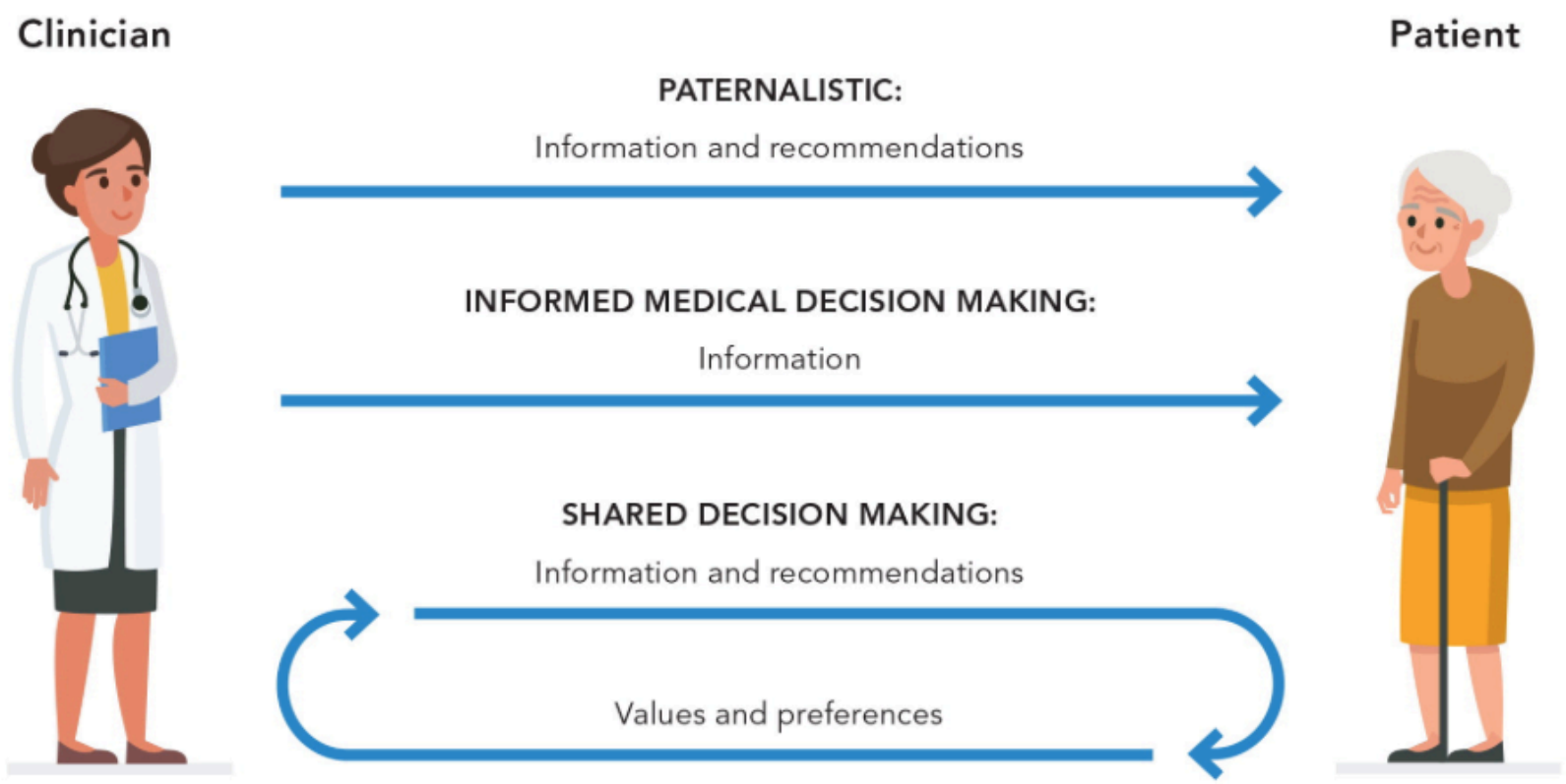
Patients overestimate survival

Lack of training
Discomfort of providers
Time

Difficult prognostication

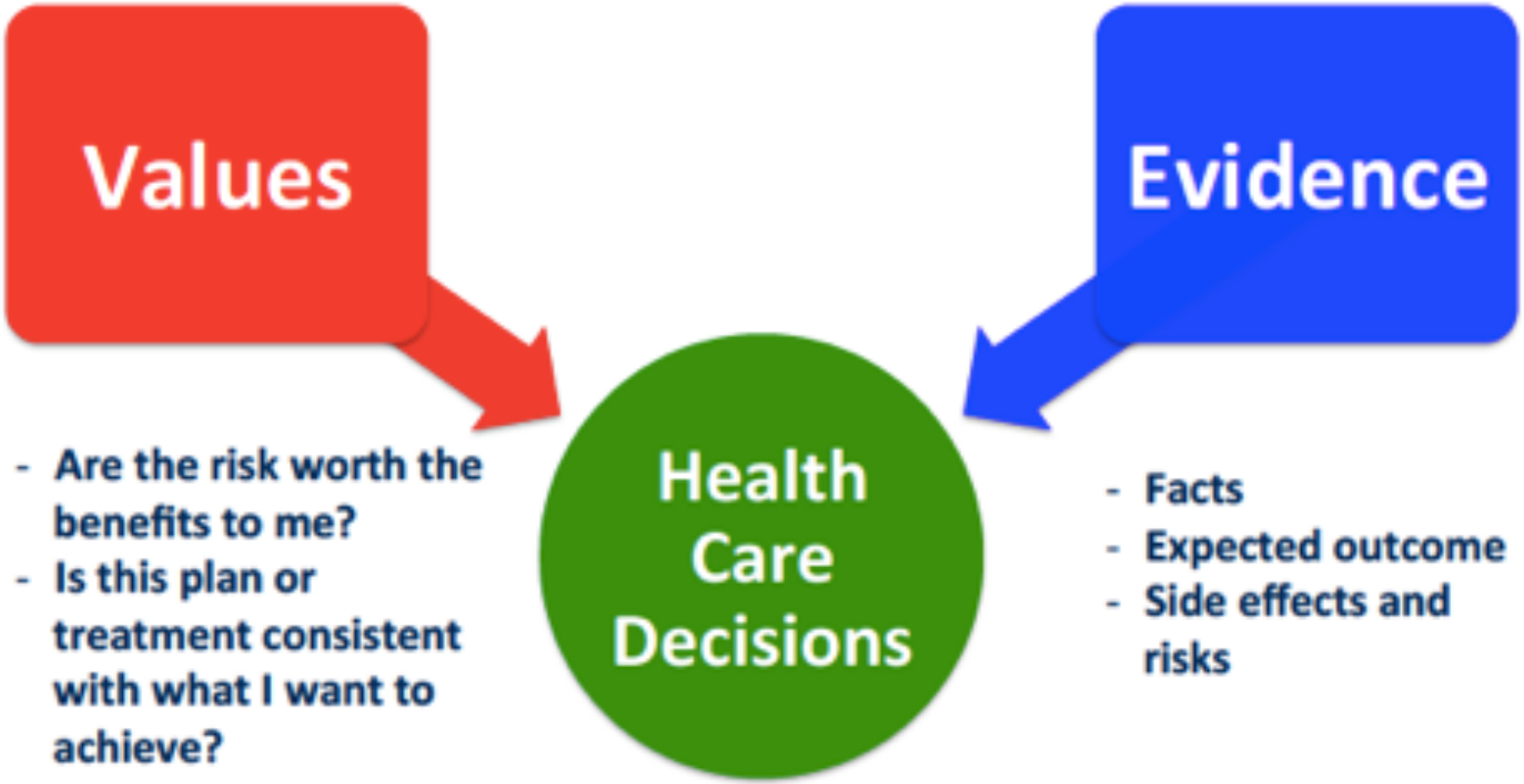
- Keisuke Kida, Shunichi Doi, Norio Suzuki,Palliative Care in Patients with Advanced Heart Failure,Heart Failure Clinics,Volume 16, Issue 2, 2020,Pages 243-254

Shared-Decision Making



Fam Pract Manag. 2017 May-June;24(3):5-10.

Tailoring Treatments to Goals



“How to Talk End-of-Life Care”

1- Does your patient know their prognosis?

2 – What are their fears about what is to come?

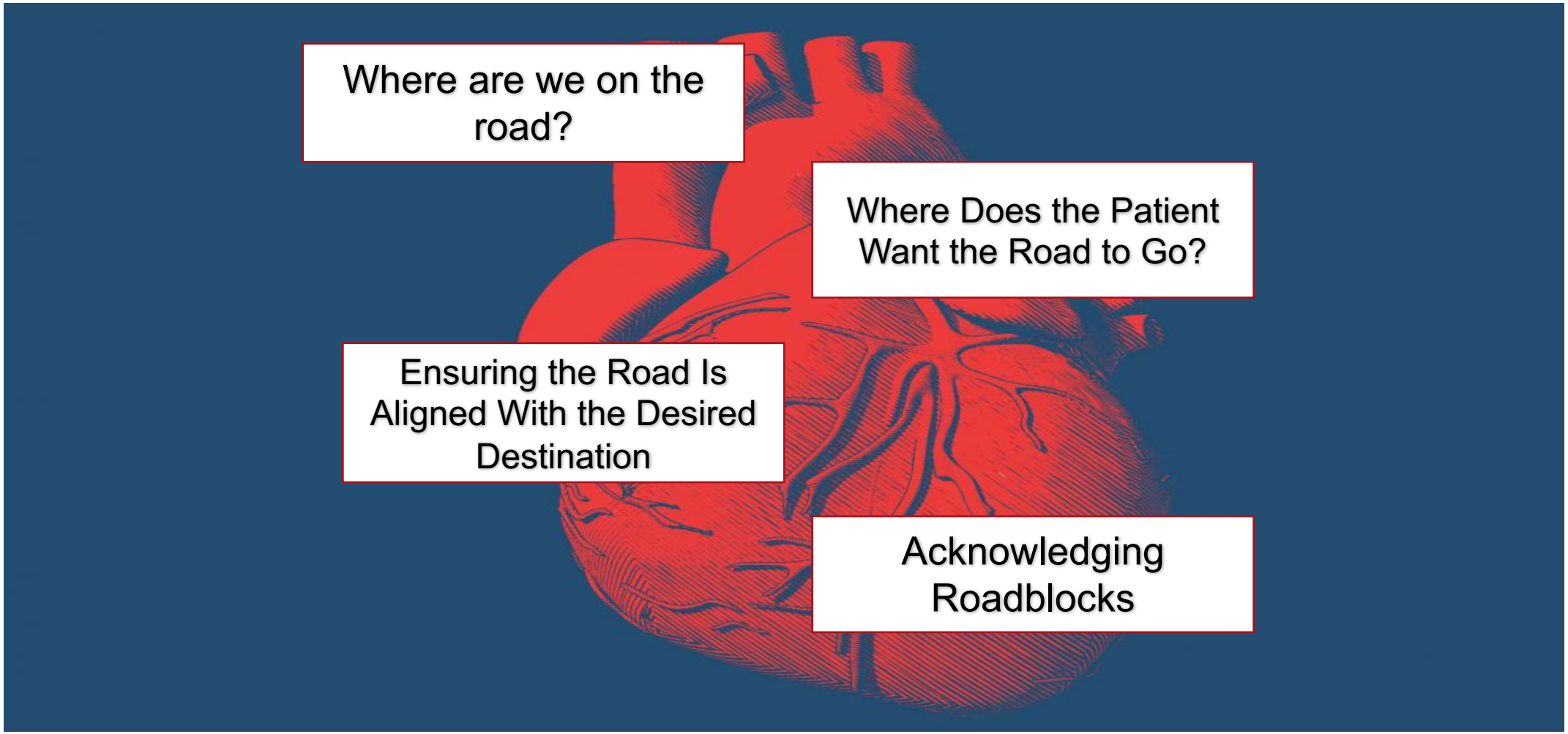
3 – What are their goals as time runs short?

4 - What trade-offs are they willing to make?

Dr. Atul Gawande

Practical Approach to Difficult Conversations

- AHA “Roadmap to Guide Conversations”



Circulation. 2012 April 17; 125(15): 1928–1952

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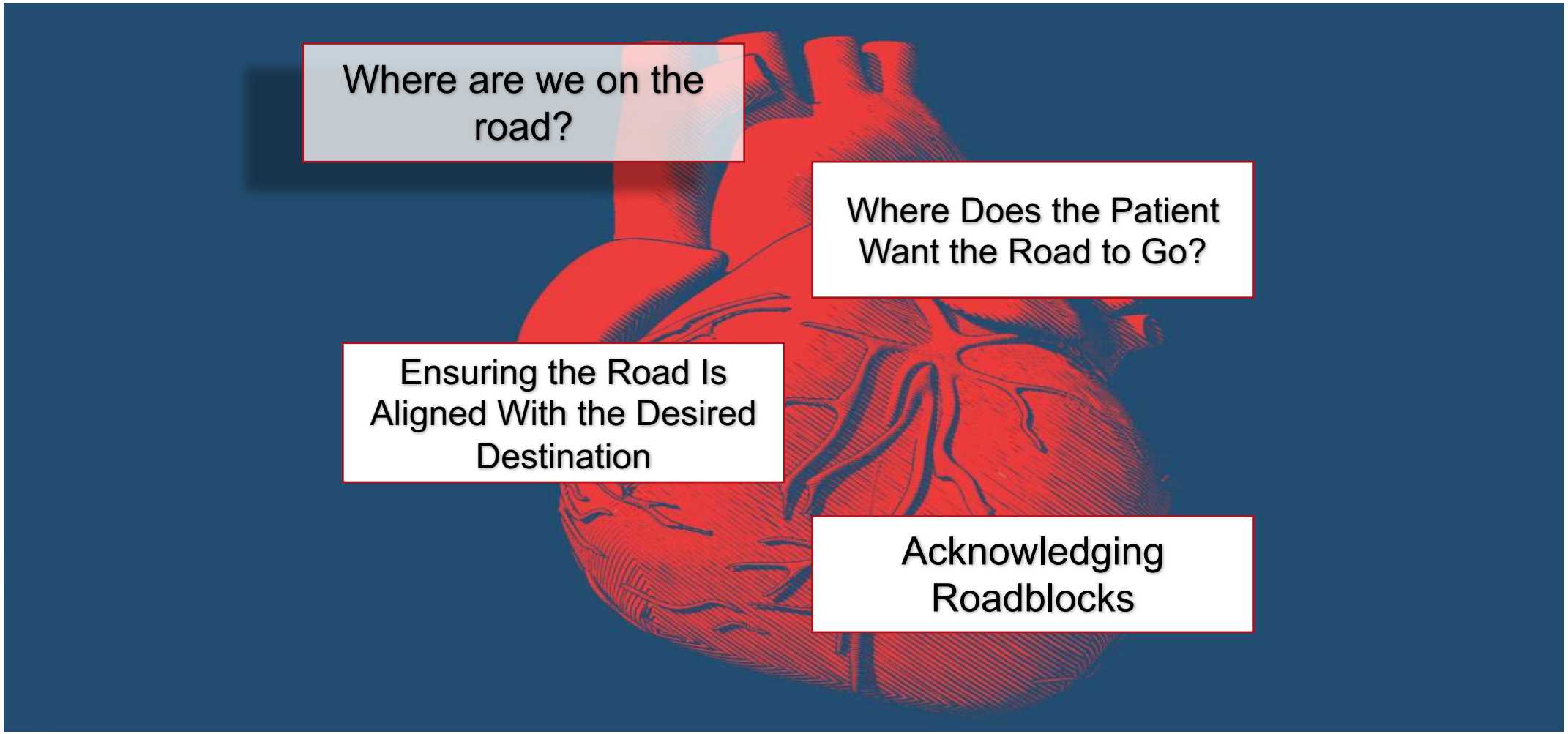

Circulation. 2012 April 17; 125(15): 1928–1952

Assess Illness Understanding

- ASK-TELL-ASK
- Ask:
  - What they know.
  - What they want to know: “Would you want to know everything about your illness or the treatments we are considering, even if it wasn’t good news?”
- Tell:
  - Inform.
- Ask
  - Determine the level of understanding.

Circulation. 2012 April 17; 125(15): 1928–1952

Assess Illness Understanding

“I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want – is this okay?“

“What is your understanding now of where you are with your illness?“

“How much information about what is likely to be your illness would you like from me?’

Circulation. 2012 April 17; 125(15): 1928–1952
Serious Illness Conversation Guide, Ariadne Labs

Sharing Prognosis

- *"It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I **worry** that you could get sick quickly and I think it's important to prepare for that possibility."*

- *"I **wish** we were not in this situation, but I am worried that time may be as short as (days to weeks, weeks to months, months to a year)."*

Serious Illness Conversation Guide
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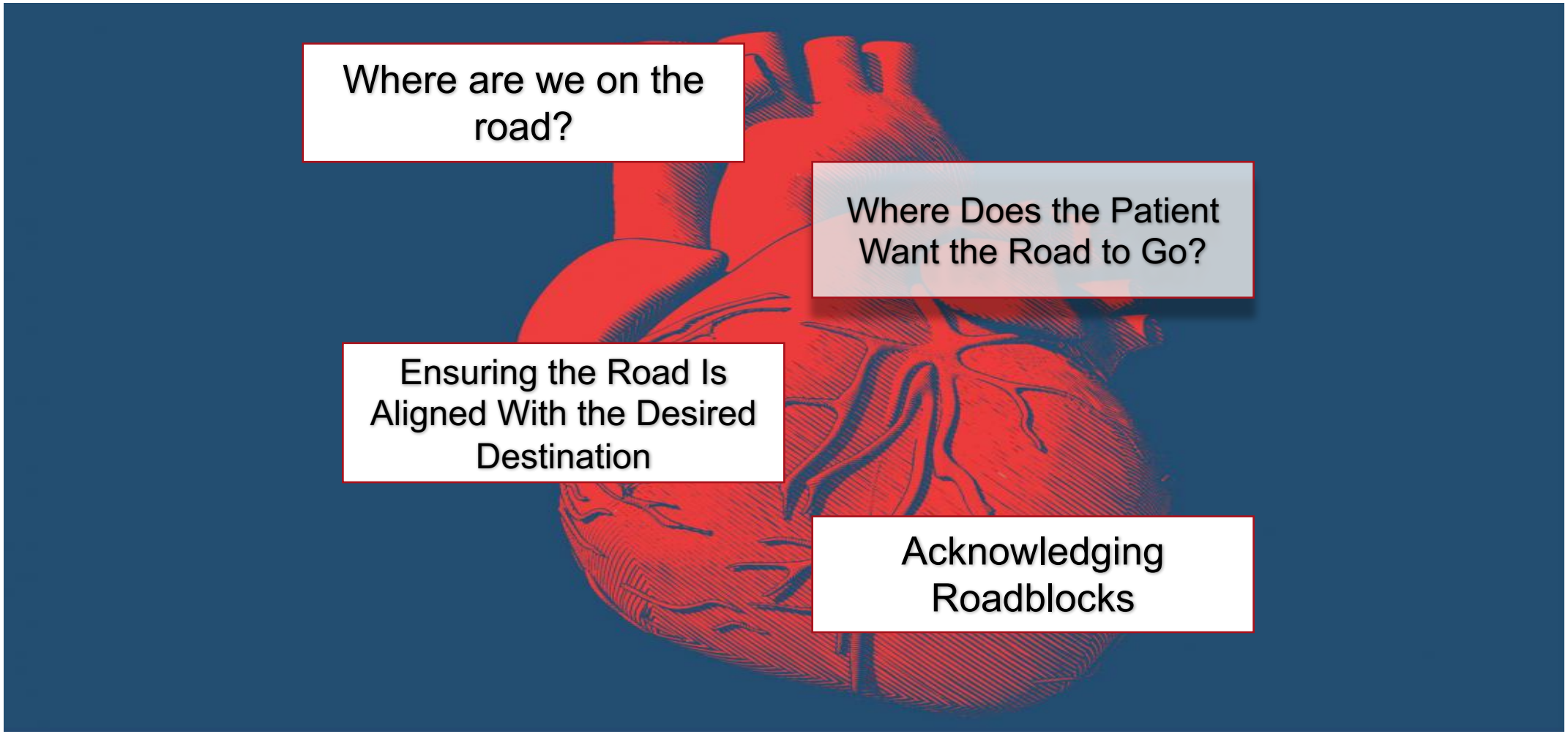

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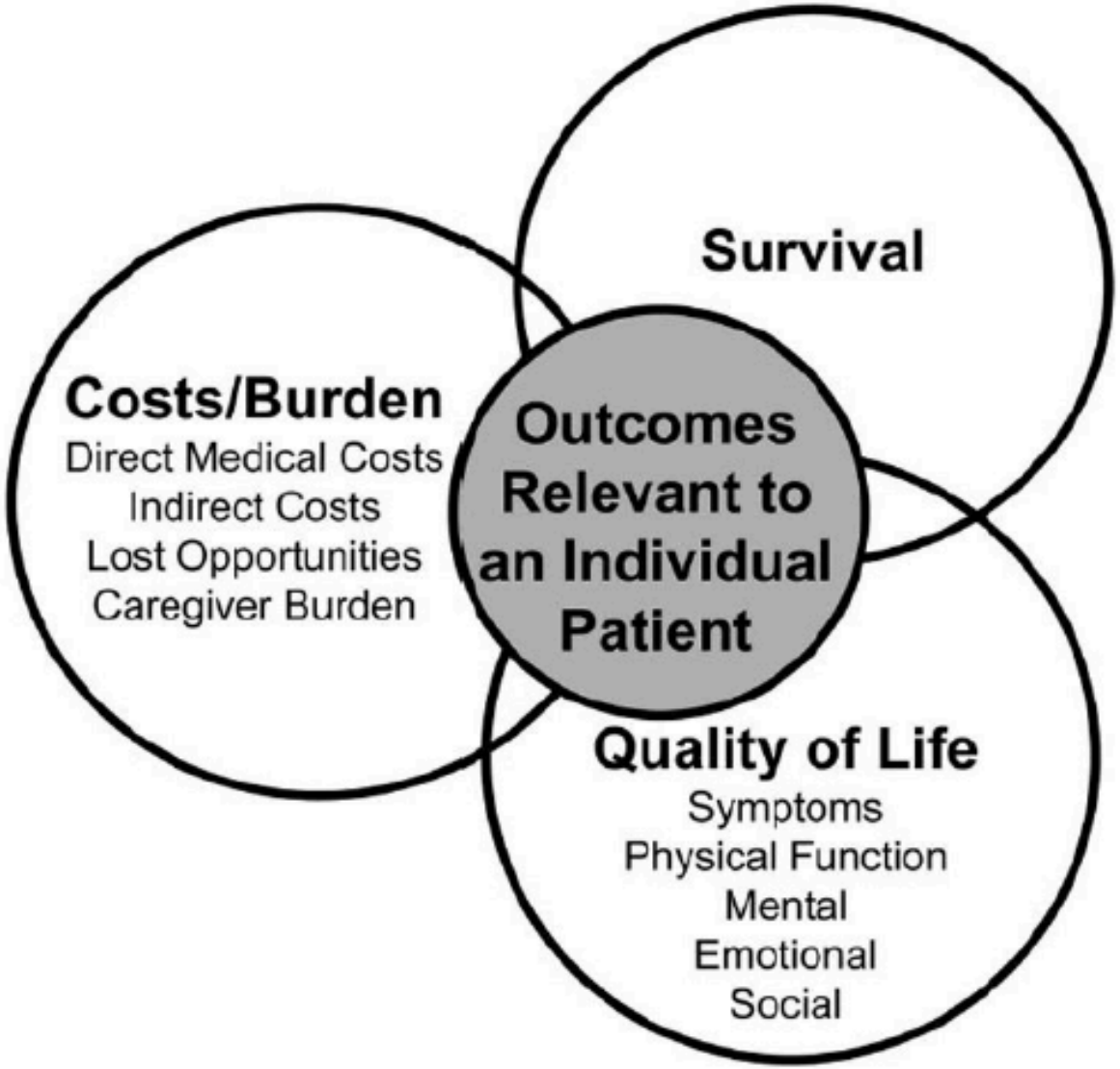
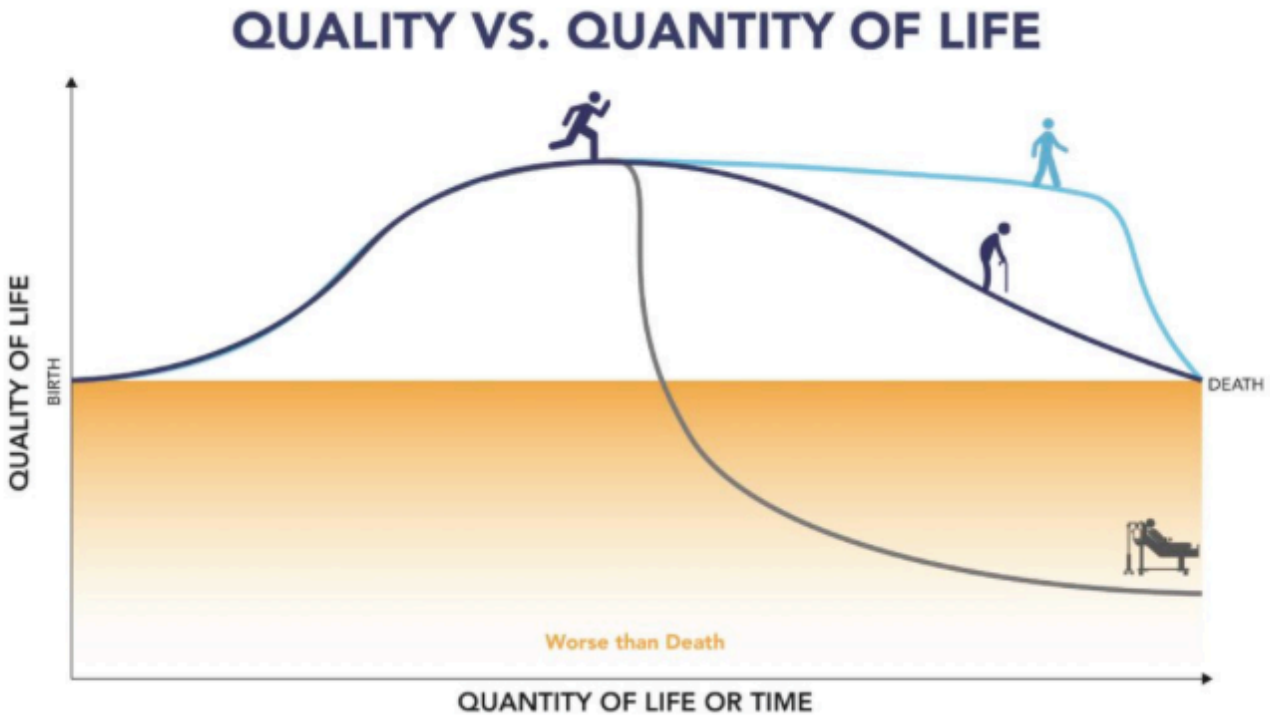
Explore Goals and Values



Circulation. 2012 April 17; 125(15): 1928–1952

Establishing Goals and Values



Establishing Goals and Values

"What are your most important goals if your health situation worsens?"

"What abilities are so critical to your life that you cannot imagine living without them?"

"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"

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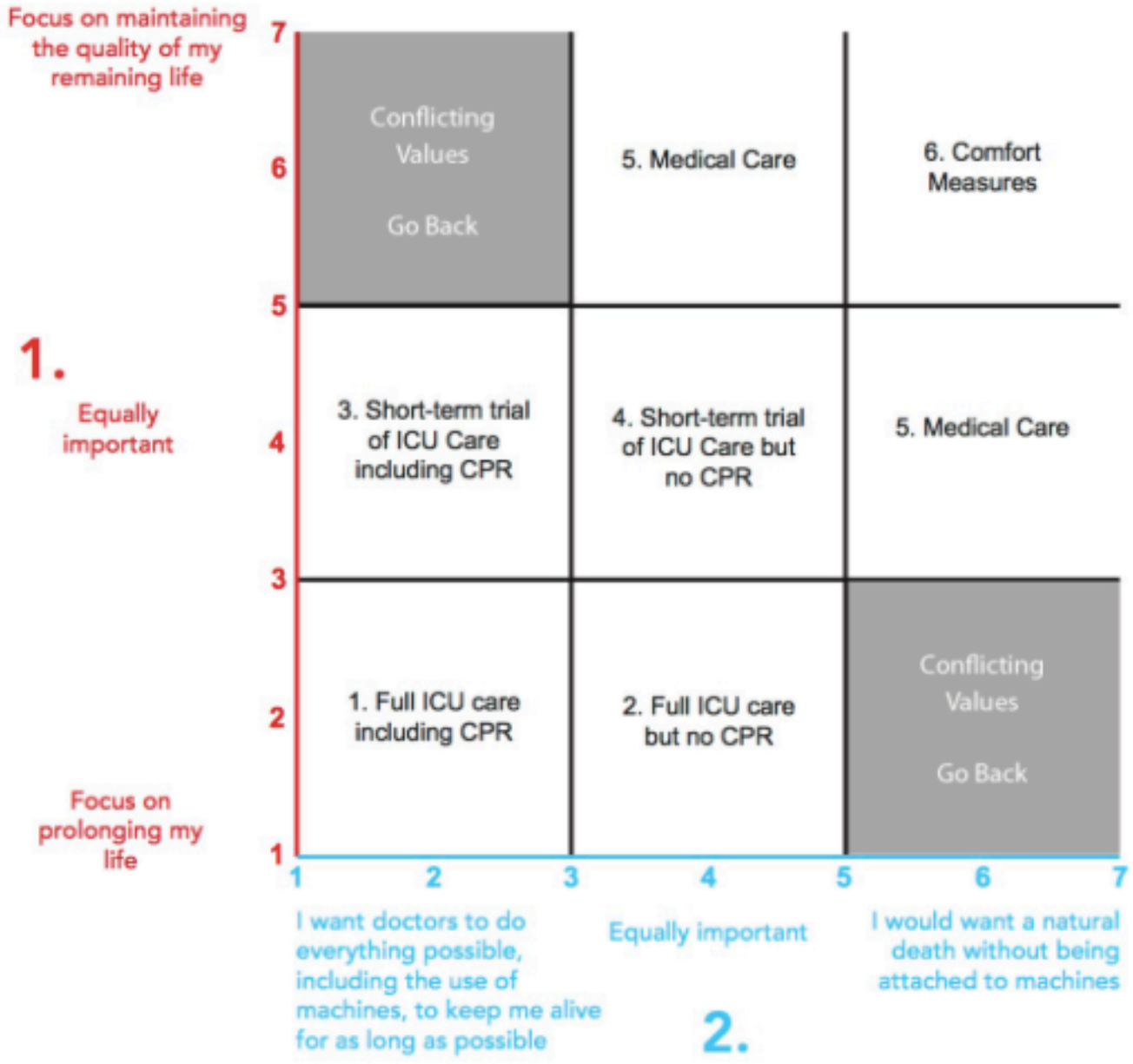
Serious Illness Conversation Guide

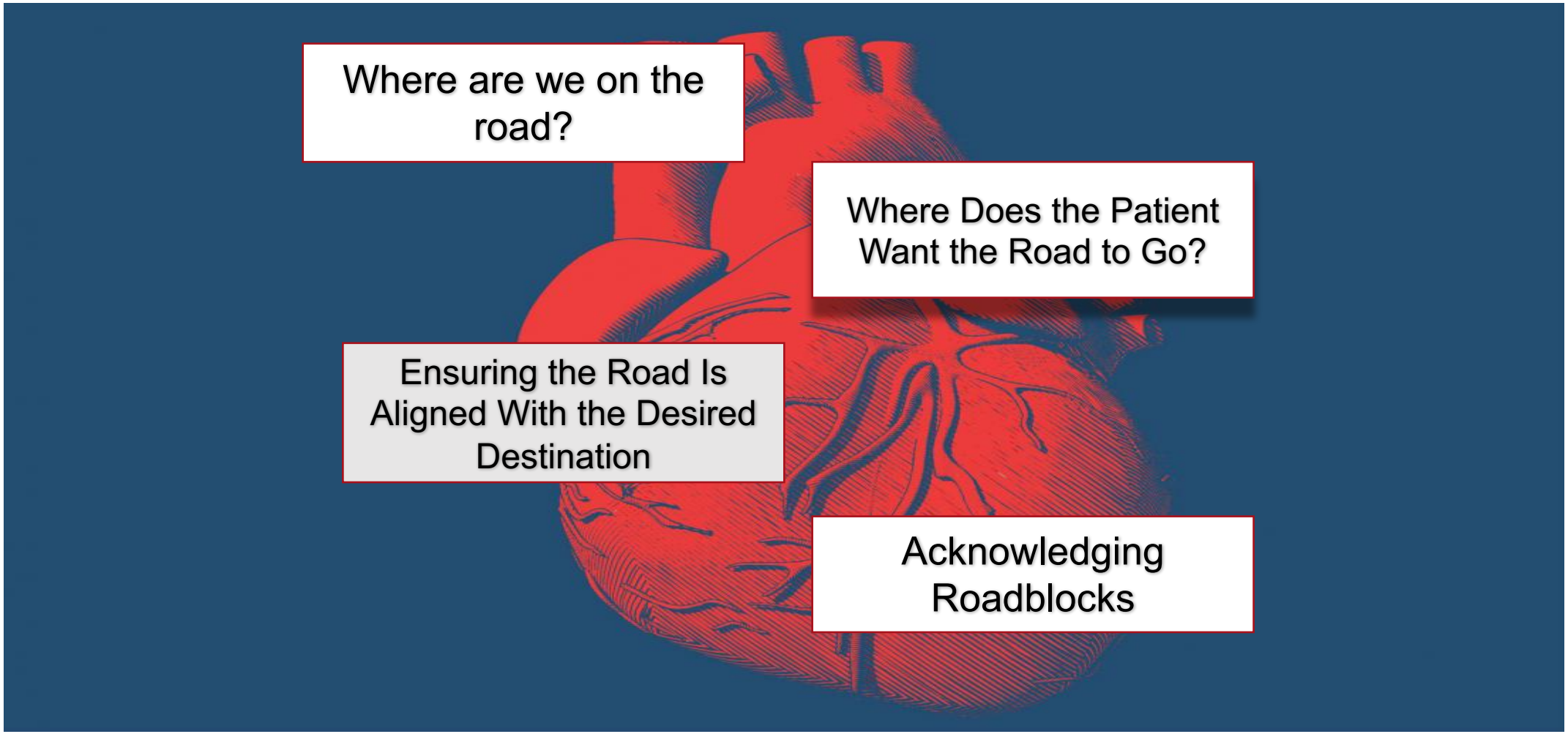
Establishing Goals and Values



Plan Well Guide. Dr D. Heyland 2019

Practical Approach to Difficult Conversations

- AHA “Roadmap to Guide Conversations”



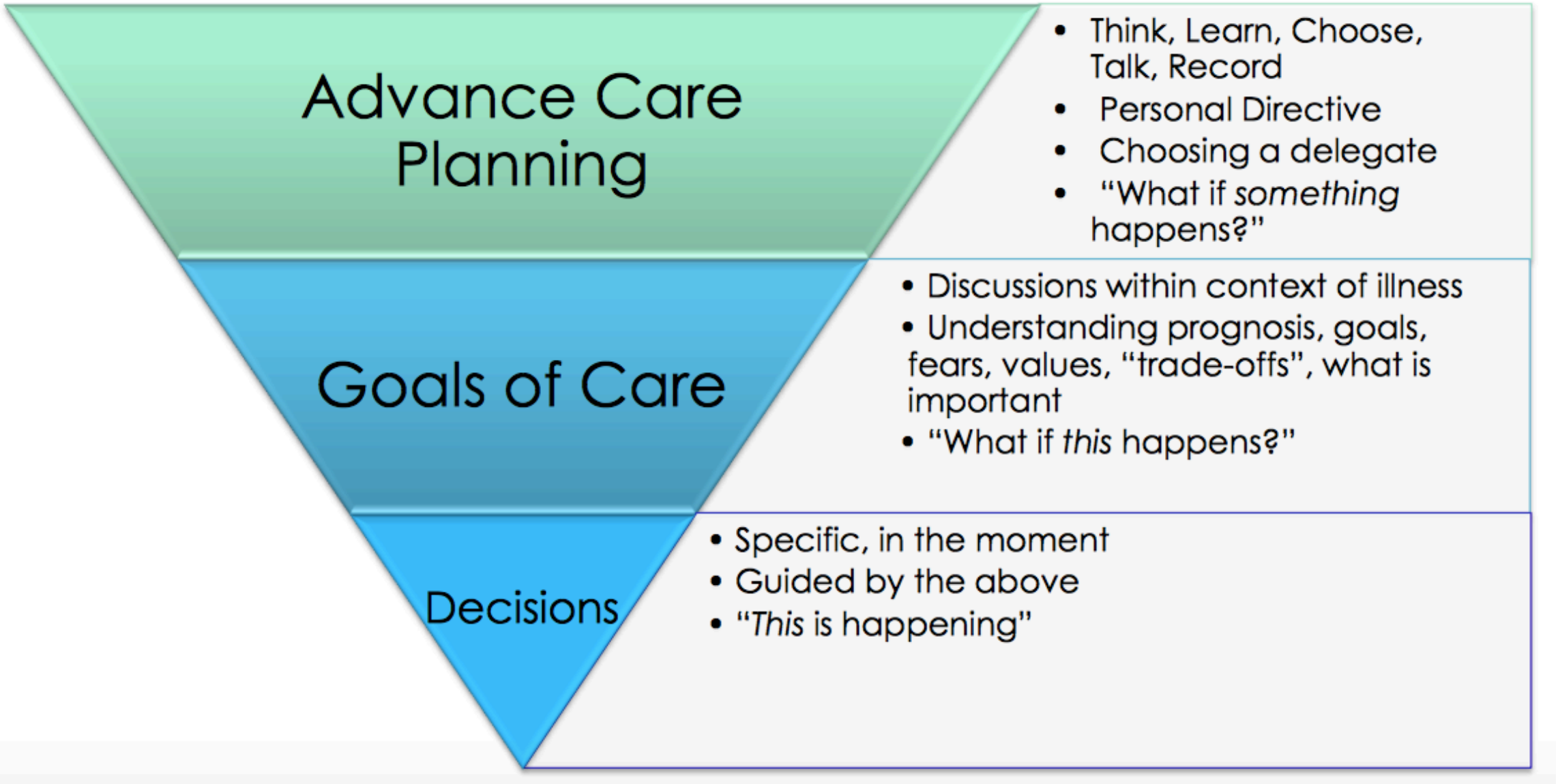
Circulation. 2012 April 17; 125(15): 1928–1952

Making a Shared Decision

"I've heard you say that ___ is really important to you. Keeping that in mind and where we are with your illness,

I recommend __."

Circulation. 2012 April 17; 125(15): 1928–1952
Serious Illness Conversation Guide, Ariadne Labs 2015


Advance Care Planning
• Think, Learn, Choose, Talk, Record
• Personal Directive
• Choosing a delegate
• "What if *something* happens?"
Goals of Care
• Discussions within context of illness
• Understanding prognosis, goals, fears, values, "trade-offs", what is important
• "What if *this* happens?"
Decisions
• Specific, in the moment
• Guided by the above
• "*This* is happening"

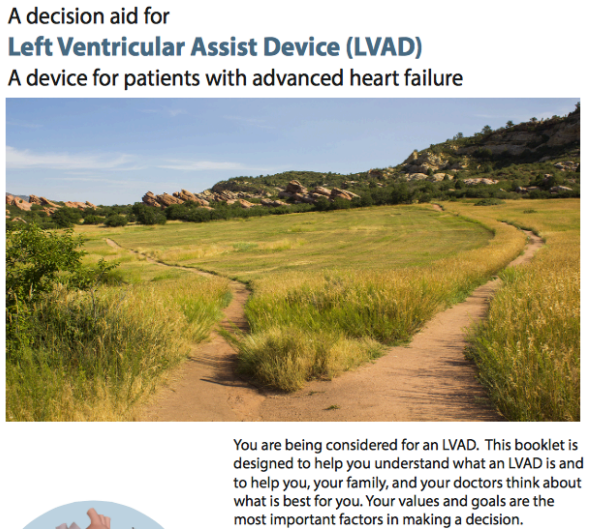
Serious Illness Conversation Guide

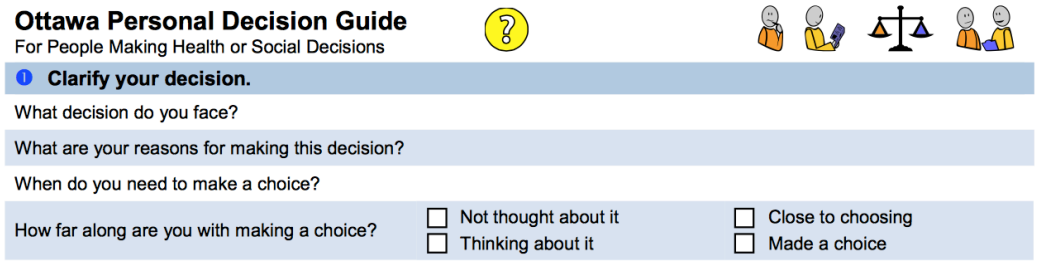
CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. *Set up the conversation* Introduce the idea and benefits Ask permission	SET UP: "I'm hoping we can talk about where things are with your illness and where they might be going — **is this okay**?"
2. *Assess illness understanding and information preferences*	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	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**."
6. *Document your conversation*	

ARIADNE LABS

Patient Decision Aid

- Improved patient knowledge
- Reduced decisional conflict
- Increased patient decision making





Circulation. 2012 April 17; 125(15): 1928–1952

Colorado Program for Patient Centered Decisions 2018

Cochrane Database Syst Rev. 2009; (3) CD001431.

Advance Care Planning – Resources

www.myspeakupplan.ca

PlanWellGuide.com

Thank you!