Communications with the Seriously Ill: A Guide for the Health Care Team

Rachelle Bernacki, MD, MS
Director of Quality Initiatives, Psychosocial Oncology and Palliative Care
Dana-Farber Cancer Institute;
Associate Director, Serious Illness Care Program
Ariadne Labs

Learning Objectives

- Define the role of the health care team, in particular primary care clinicians, in driving conversations with seriously ill patients and their families to enable them to make informed choices that reflect their values, reduce suffering and improve quality of life
- Identify barriers impeding communication and decision-making about goals of care with seriously ill patients
- Outline effective and appropriate communication strategies for seriously ill patients and their families including when and how to initiate these difficult conversations
- Evaluate the impact of the use of the Serious Illness Care Program within a health care organization and state how it provides guidance for the health care team to facilitate conversations in the right way and at the right time

Goal: Better Care

Where we are now

Doing *some* of the right things
some of the time
for *some* of our patients
with serious illness

→

Where we want to be

Doing *all of* the right things
all of the time
for *all* of our patients
with serious illness

Serious Illness Care Program: Mission

Improve the lives of all people with serious illness by increasing meaningful conversations with their clinicians about their values and priorities.

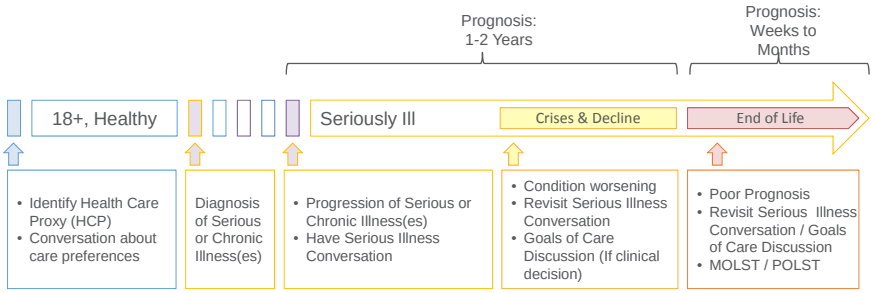
High quality communication is linked to better serious illness care

Early conversations about patient goals and priorities in serious illness are associated with:

- Enhanced goal-concordant care
  - Time to make informed decisions and fulfill personal goals
- Improved quality of life/patient well-being
- Fewer hospitalizations
  - More and earlier hospice care
- Better patient and family coping
  - Eased burden of decision-making for families
  - Improved bereavement outcomes

Mack JCO 2010; Wright JAMA 2008; Chiarchiaro AATS 2015; Detering BMJ 2010; Zhang Annals 2009

Advance Care Planning Terminology



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

Terminology

The **Serious Illness Conversation** is a clinician-initiated discussion that:

- Focuses on values and goals and de-emphasizes procedures and treatments
- Offers an honest prognosis, according to patient preferences
- Occurs early in the course of serious illness
- Provides a foundation for making decisions in the future
- Should be reviewed/revised over time

Conversations are often absent, inadequate, or occur late in the course of serious illness

- Fewer than one-third of patients with end-stage medical diagnoses reported discussing end-of-life (EOL) preferences with clinicians
- Patients with advanced cancer:
  - First EOL discussion occurred median 33 days before death
  - 55% of initial EOL discussions occurred in the hospital
- Conversations often fail to address key elements of quality discussions

Heyland DK Open Med 2009; Mack AIM 2012; Wright 2008

Initiating these conversations can be a challenge for clinicians

- Time constraints
- Poor clinician training in communication skills
- Attitudes about serious illness conversations
  - Uncertainty about timing; concerns about harming patients
- Prognostication challenges
- Ambiguity about who is responsible (multiple specialists)

Palliative Care is one model for improvement, but it is a limited resource

- Palliative care — with strong emphasis on high quality communication — is a high value intervention
  - Better quality of life
  - Less use of aggressive care
  - 25% increase in survival
  - Lower costs
- We do not and we will not have enough palliative care providers to reach all patients who would benefit

Temel NEJM 2010; Zimmerman Lancet 2014; Bakitas JAMA 2009; Higginson Cancer J 2010; Jacobsen JPM 2011;
Back JPM 2014; Lupu JPSM 2010

Who has a critical role in improving serious illness care?

- Rough calculation: Conservatively, palliative care services see less than 13% of the approximately 2.4 million patients in the U.S who die each year (hospice sees about 50%, but has median LOS of 17 days)
- To reach patients earlier, we need new approaches to identifying and serving this population earlier in the course of their illness
- We need scalable interventions for generalists and non-palliative care specialists of all disciplines (anyone who takes care of seriously ill patients)

- ☑ More Conversations
- ☑ Earlier Conversations
- ☑ Better Conversations

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

The Serious Illness Care Program

1. Training Clinicians
2. Screening/Identifying Patients
3. Patient and Family Support
4. Serious Illness Conversation(s)
5. Documenting Conversations in a in EHR template
6. Monitoring and Evaluation
7. Coaching and performance/process improvement

Research

- Randomized Controlled Trial
  - **Oncology (Dana-Farber Cancer Institute)**
- Implementation trial
  - **High-risk Medicare patients Integrated Care Management Program (iCMP)**
  - High-risk primary care (Atrius)
- Feasibility and Acceptability Pilots
  - Chronic Critical Illness (Spaulding)
  - Rural African American patients (South Carolina)
  - Native Spanish speakers

DFCI Serious Illness Care Trial

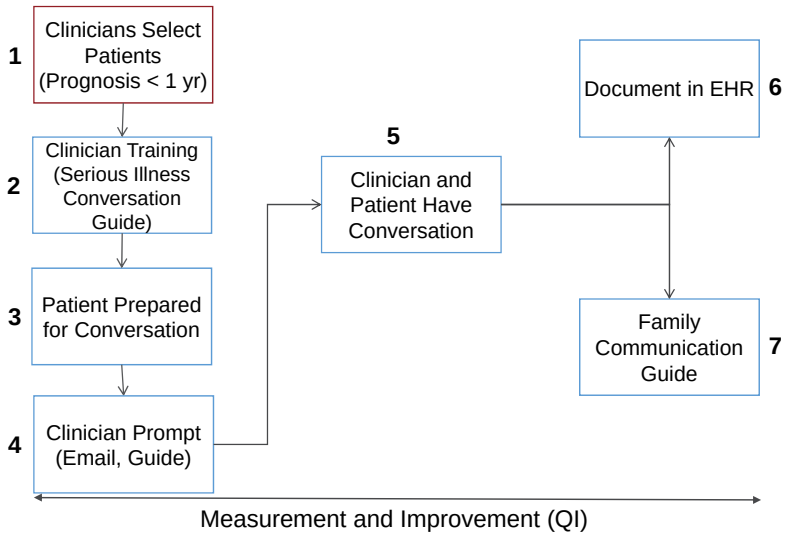
A cluster-randomized controlled trial of a multi-component intervention in outpatient oncology

Primary Outcomes	Measures
Goal-concordant care	Life Priorities Survey and chart review
Peacefulness	PEACE questionnaire

72% of all Adult outpatient oncology clinicians (MDs, NPs, PAs) volunteered and were randomized in clusters:

Intervention group (n=47)
Control group (n=43)

Multi-component intervention: Workflow

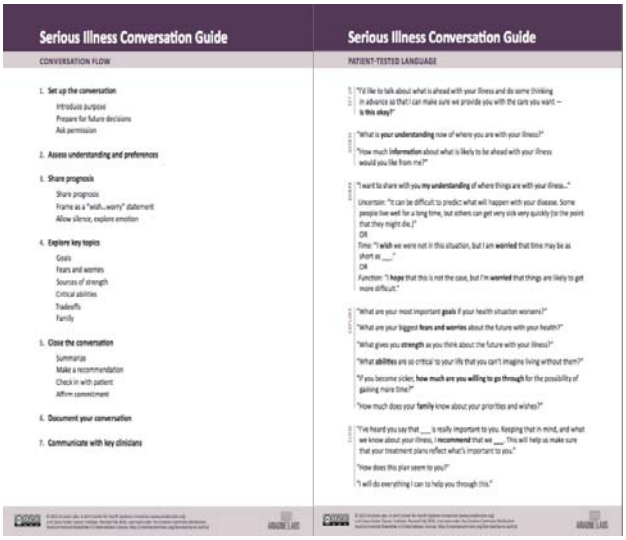


Identifying patients in need of conversation

There are multiple disease-specific prognostic tools, but the simplest tool is the 'Surprise' Question:

"Would I be surprised if this patient died within 1 year?"

The Serious Illness Conversation Guide is a framework for best communication practices



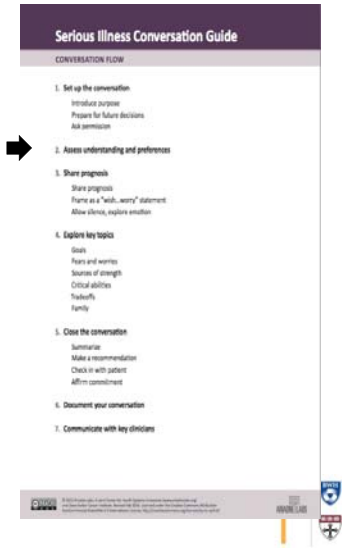
Set up the conversation

Setting up the conversation builds trust

- Take a step back:
  - *"I'd like to talk about what is ahead with your illness and do some thinking in advance so that I can make sure we provide you with the care you want -*
- Ask permission:
  - *"Is this ok?*"

Assess illness understanding and information preferences

- *"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?"*
  - Some people want to know about time; others want to know what to expect; others like to know both



Give a prognosis

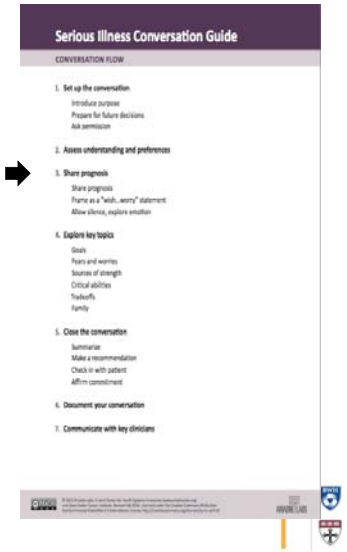
- *"I want to share with you my understanding of where things are with your illness…"*

Consider what kind of information they want.

Consider how uncertain or certain you are.

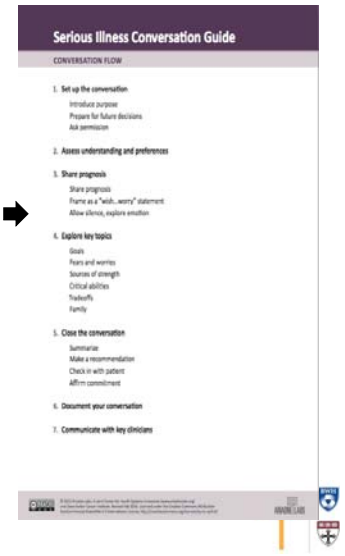
Use a wish-worry or hope-worry framework.

(Don't use the word prognosis)



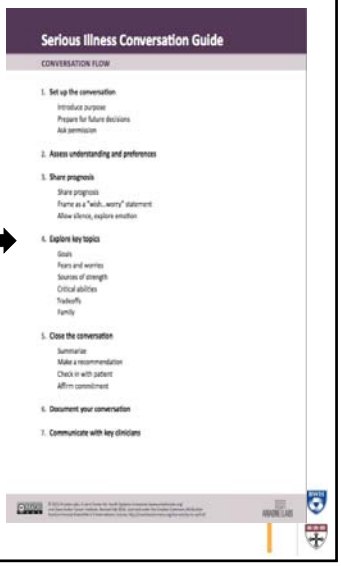
Expect and explore emotion

- Allow silence immediately after giving prognosis
  - It is therapeutic to give a patient time to process emotions after hearing difficult news.
- Respond to emotion by naming it and exploring:
  - *"You seem really upset. Tell me more about what you are feeling."*
  - *"You seem surprised. Tell me about what you were expecting to hear."*
  - *"This is really hard to hear. Tell me what you're thinking about."*



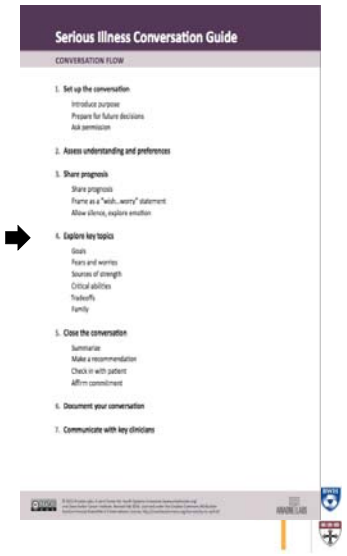
Explore goals and fears

- *"What are your most important goals if your health situation worsens?"*
- *"What are your biggest fears and worries about the future with your health?"*



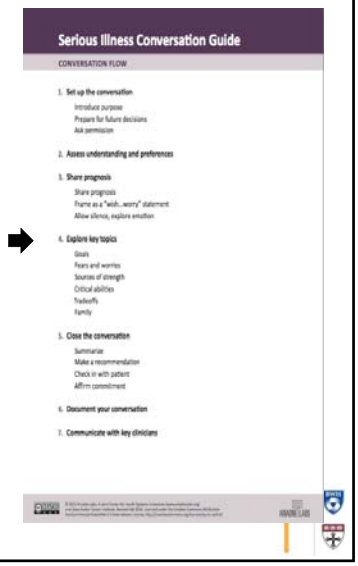
Assess strengths

- *"What gives you strength as you think about the future with your illness?"*



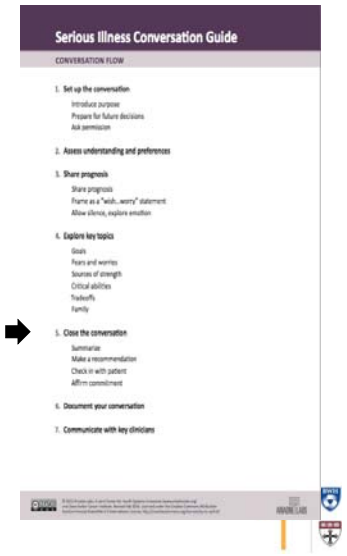
Explore function, tradeoffs, and family

- *"What abilities are so critical to your life that you can't imagine living without them?"*
- *"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?"*



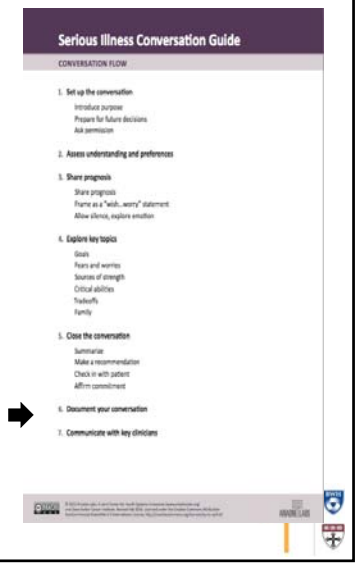
Close the conversation

1. Summarize:
   - *"I've heard you say that _____ is really important to you."*
2. Recommend:
   - *"Keeping that in mind, and what we know about your illness, I recommend that we _____. This will help us make sure that your treatment plans reflect what's important to you."*
3. Affirm commitment:
   - *"I will do everything I can to help you through this."*



Document and communicate

- Where is the "single source of truth"
- Who are the key clinicians with whom you should communicate?



Most common training missteps

- Not discussing prognosis or giving a vague prognosis
- Getting off track (not following the Guide)

Common misstep: Not discussing prognosis or giving a vague prognosis

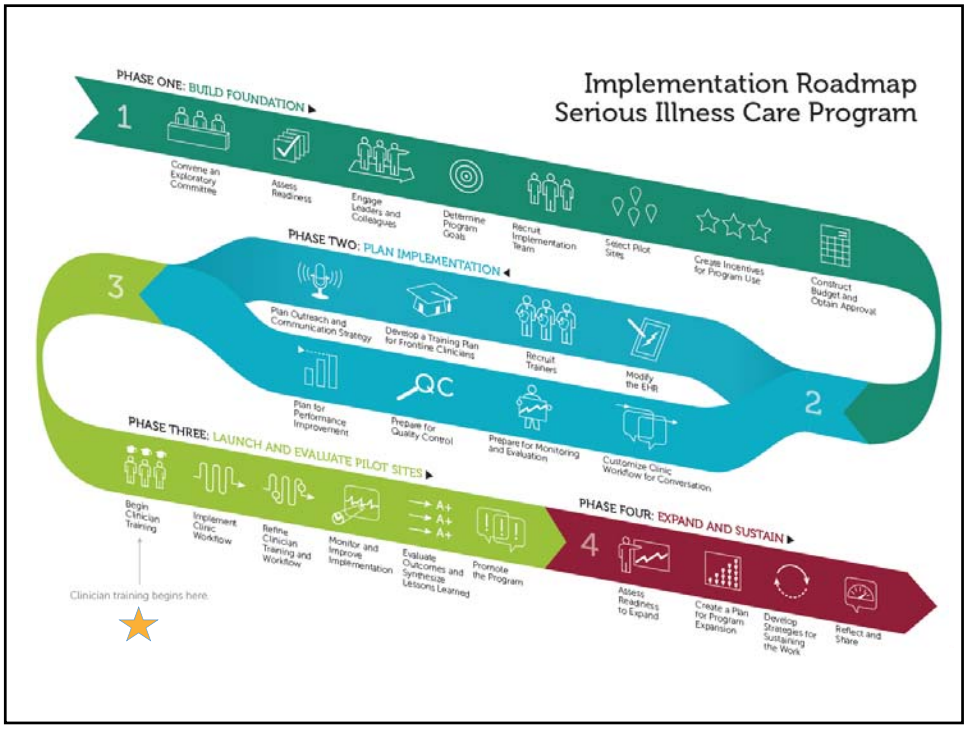
The purpose of prognostication is…	• To help patients begin a planning process 'just in case,' not to be right or wrong
Discussing prognosis is hard; clinicians are afraid of…	• Being wrong/losing patient trust • Provoking anger, anxiety or sadness
Research on prognostication demonstrates that...	• Most patients want to know their prognosis • Patients realize that clinicians are not perfect prognosticators • Prognostic information can reduce anxiety and depression (*knowledge is power*) • Patients do not "die sooner" after receiving prognostic information

Common misstep: Getting off track

The order of the questions is important…	• Conversation Guide questions and order of the questions are based on research
The topics addressed might not feel right at first…	• Reverting to what you are comfortable talking about is natural
The first priority is learning about the patient's values and goals…	• Discussion of treatments, interventions, and the care plan comes *after* the serious illness conversation rather than in the middle

Resist the urge to...

- ✕ Provide premature reassurance
- ✕ Talk more than listen
- ✕ Avoid addressing the patient's emotions



Phase 1

- Set program goals
- Build a multidisciplinary team
- Engage leaders and colleagues face-to-face
- Identify pilot sites (start small)
- Get the financial support/resources you need

Phase 2, etc.

- Customize implementation plan to fit the context
- Get the system ready before training
  - Trainers, systematic patient identification, workflows, documentation, reporting...
- Measure and learn – 'never stop looking'
- Coach to better performance
- Celebrate success

A new set of standards for serious illness care

- All clinicians who care for seriously ill patients are trained and coached to have high quality conversations
- Regular screening identifies patients who would benefit from serious illness conversations
- Innovative workflows support frontline clinicians to deliver high quality conversations and care within their own context
- Accessible 'single source of truth' documentation communicates patient goals to all providers (and supports reporting)
- Real-time metrics on high-risk patients, conversations, and documentation are collected, synthesized, and fed back
- Resources and infrastructure to sustain clinical training, measurement, and quality improvement are in place

Greatest challenges

- Lack of qualified trainers and clinician FTE time for training
- No ideal way to identify patients at high risk of dying
- Lack of well-established, evidence-based measures (both process and outcome) in serious illness care
- Confusion about what conversation is most appropriate for whom, and when
- Threats to a sustainable workforce (burnout, turnover, organizational culture)
- Silos that result in the need to 'reinvent the wheel'

To Join Serious Illness Care Community of Practice:

1. Open your web browser (Safari, Chrome, Firefox, Internet Explorer, etc.)
2. Go to: https://portal.ariadnelabs.org
3. Click "Create an Account" on the right side of the page
4. Complete the account information page. You will receive an email to authenticate your account.
5. Return to https://portal.ariadnelabs.org and click on Serious Illness Community of Practice on the bottom left of the page.
6. Click "Request Membership." Complete the additional profile information.
7. You will receive an email once the Administrator has accepted your request.