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*Cultivating a Culture
of Caring for Older Adults*

Serious Illness Conversation Guide for Primary Care Providers

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- ABIM Disclosure

Objectives

- Summarize the rationale for a systematic approach to improving conversations about patient values and priorities in serious illness.
- Define the structure of the Serious Illness Care intervention and its components.
- Watch demonstration of the guide

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Care seriously ill receive often may harm them and their families

Aggressive care for patients with advanced illness is often harmful:

- For patients:
 - Lower quality of life
 - Greater physical and psychological distress
- For caregivers:
 - More major depression
 - Lower satisfaction

Wright, AA JAMA 2008; Mack JCO 2010

Wright, AA JAMA 2008; Teno JM JAMA 2004

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Many patients do not discuss their goals with clinicians

- Fewer than one third of patients with end-stage medical diagnoses discussed end-of-life (EOL) preferences with physicians
- 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

Why are earlier conversations associated with better outcomes?

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Palliative Care is a high value but limited resource

- Palliative care – with strong emphasis on quality communication – is a high-value intervention
 - Better quality of life
 - Less use of aggressive care
 - 25% increase in survival
 - Lower costs
- Not enough palliative care clinicians to reach all patients
- Scalable interventions targeted at non-palliative care clinicians needed for universal access to serious illness 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

What are the downsides of using a guide?

Serious Illness Conversation Guide

CONVERSATION FLOW

1. *Set up the conversation*

- Introduce the idea and benefits
- Ask permission

2. *Assess illness understanding and information preferences*

3. *Share prognosis*

- Tailor information to patient preference
- Allow silence, explore emotion

4. *Explore key topics*

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

5. *Close the conversation*

- Summarize what you've heard
- Make a recommendation
- Affirm your commitment to the patient

6. *Document your conversation*

PATIENT-TESTED LANGUAGE

SET UP

"I'm hoping we can talk about where things are with your illness and where they might be going — **is this okay?**"

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?"

SHARE

Prognosis: "I'm worried that time may be short."
or "This may be as strong as you feel."

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?"

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.**"



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Set up the conversation

Setting up the conversation builds trust

- Take a step back:
 - *“I’d like to take a step back today and talk together about where things are with your illness and where they might be going. I like to do this with all my patients.”*
- Ask permission:
 - *“Is this ok?”*
- Offer rationale:
 - *“The goal is to make sure that I have all of the information I need about what matters most to you so I can provide you with the care you want, and so I can best support your family if they ever have to make decisions for you.”*

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5. <i>Close the conversation</i> 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. ”
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- *“What is your understanding now of where you are with your illness?”*
- *“How much information about what is likely to be ahead would you like from me?”*
 - Some people want to know about time; others want to know what to expect; others like to know both

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6. <i>Document your conversation</i>	

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1. Time, expressed as a range:

- *“I wish it were different, but I’m worried that, in terms of time, we may be talking about months to a year.”*

2. Time, as a function of uncertainty

- *“Although you could have a lot of time, it’s also possible that something could happen suddenly. It would be helpful to know what you would want if you became very sick quickly.”*

3. Function:

- *“I wish it were different, but I worry that this may be as strong as you feel. I’m worried that in the future, you may not be able to manage as well as you are right now, and it is important that we plan for future changes.”*

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Expect 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

- *“If your health situation worsens, what are your most important goals?”*
- *“What are your biggest fears and worries about the future with your health?”*

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Explore sources of strength

- *“What gives you strength as you think about the future with your illness?”*
 - For some patients, it is their religious faith, or family and community support

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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?”*

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Close the conversation

1. Summarize:

- *“It sounds like being at home is really important...”*

2. Recommend:

- *“Given your goals and priorities, and what we know about your illness at this stage, I recommend...”*

3. Affirm commitment:

- *“I will do whatever I can to help you through this.”*

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Document the conversation

- Document the conversation in the medical records

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Common missteps: Not discussing prognosis

- The purpose of prognosis 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 missteps: Getting of 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

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Resist the urge to...

✗ Provide premature reassurance

✗ Talk more than listen

✗ Avoid addressing the patient's emotions

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https://www.youtube.com/watch?v=fhwa9f5O_U4&feature=youtu.be

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Try using the guide in your clinic!

- <https://portal.ariadnelabs.net>
- Sign up for the Serious Illness Guide Community of Practice and get access to videos/papers/more guidance to use the guide
- Lakin et al. Health Affairs 36, no.7 (2017):1258-1264
- Lakin et al. JAMA Internal Medicine 2016.3212.E1-E8