Making the Connection: Serious Illness Conversations

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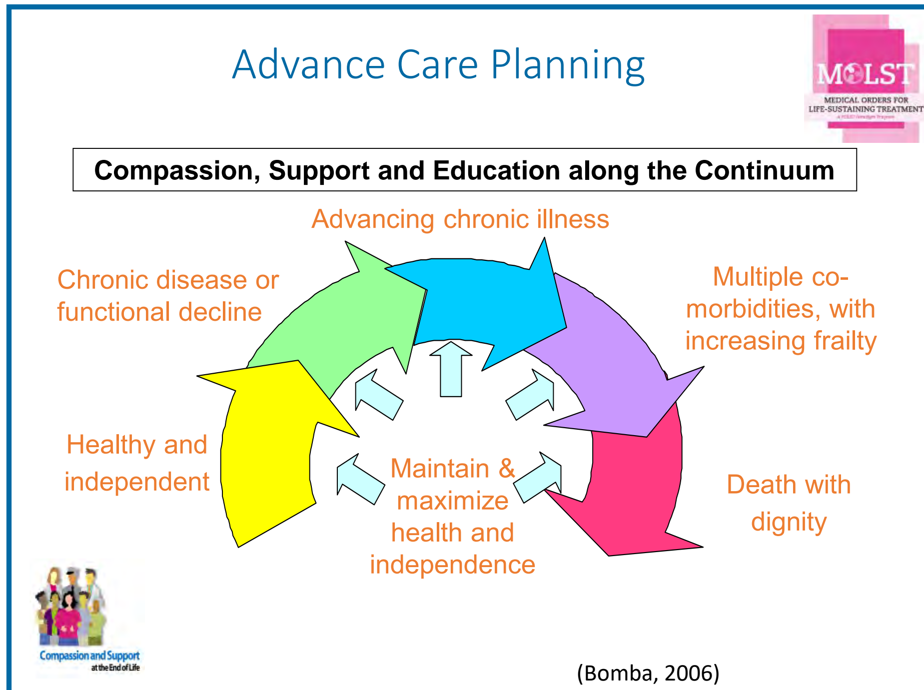
Objectives

- Describe the benefits of high quality, earlier serious illness conversations with patients and families.
- Identify the six steps involved with evidence based Serious Illness Conversations.
- Explain the best ways to use and promote the Serious Illness Conversation Guide (SICG).



Flaws with Advance Care Planning (ACP) and Healthcare Directives

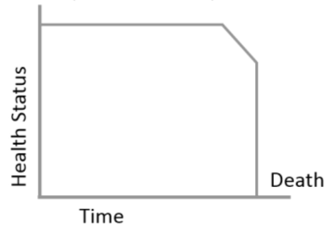
- Not all situations can be envisioned → Health care agent (HCA)
- Patients do not communicate with HCA) → Lay ACP programs
- Preferences are not acted upon → POLST
- Advance Healthcare Directives inaccessible → POLST appropriate?
- Preferences change over time → Longitudinal ACP
- Providers don't know how to have these conversations→

Serious Illness Conversation Guide (SICG)

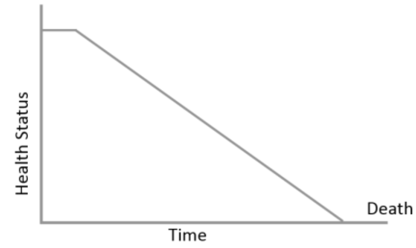
(Morrison, 2020)

Illness/Dying Trajectories Sudden Death, Unexpected Cause

< 10% (MI, accident, etc.)

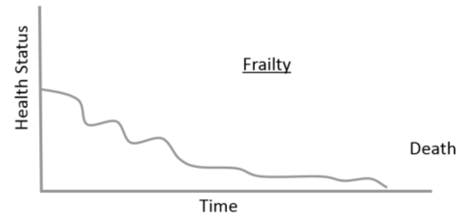


Illness/Dying Trajectories Steady Decline, Short Terminal Phase



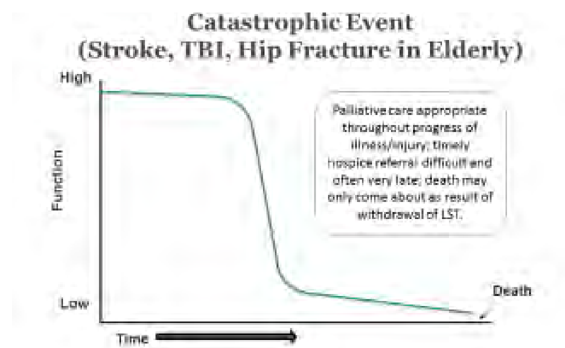
Illness/Dying Trajectories Chronic Illness, Periodic Crises, Death

Illness/Dying Trajectories, Progressive Deterioration Expected Death



ELNEC, 2019

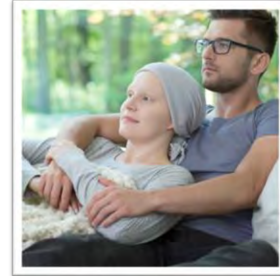
The 5th Trajectory- Like COVID



Ballentine, 2018- The Five Trajectories- Supporting Patients During Serious Illness

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 caregiver.*



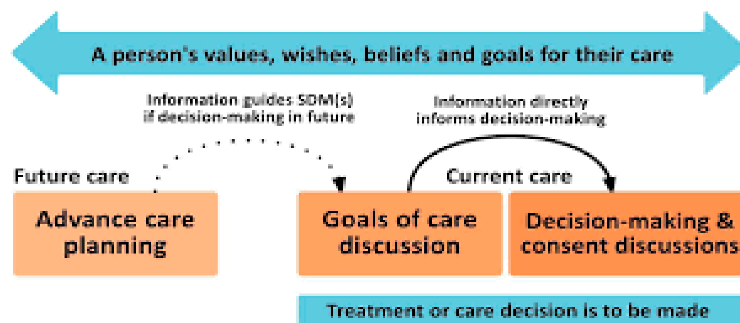
*Kelley, AS, Bollens-Lund, E. Identifying the population with serious illness: the "denominator" challenge. Journal of Palliative Medicine. Volume: 21 Issue S2: March 1, 2018.

Who Initiates the Discussion?

- Many physicians feel they lack experience in discussing the issues that come with progressive, debilitating illnesses
- The more a provider/healthcare professional prepares for discussions and practices, the more skilled that provider becomes

Communication and Goals of Care

- Patient's wishes, preferences
- Goals of Care Planning
- Code Level Discussion
- POLST
- Resuscitative Statistics
- Healthcare Directives



Why "What Matters" Matters Most?

- For older adults
  - Variation in "What Matters" Most
  - Feel more engaged and listened to
  - Avoids unwanted treatment while receiving wa
  - Comfort care Always, not just Only
- For Health systems
  - Better patient experience scores & retention
  - Avoids unnecessary utilization
- For Everyone (patients, families, caregivers, providers, health systems)
  - Everyone is on the same page
  - Improved relationships
  - It is the basis of everything else

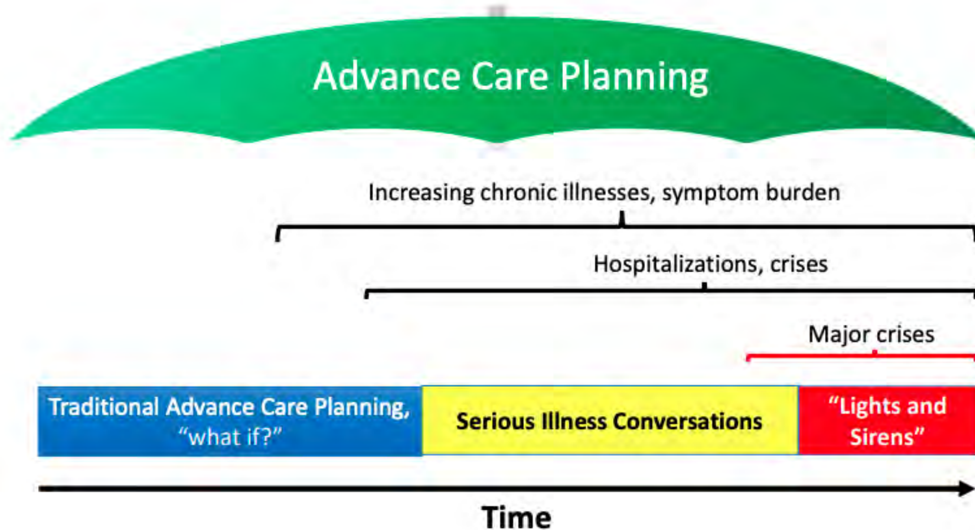
Checklist for Culturally Appropriate "What Matters" Conversations

- Learn the preferred term for their cultural identity
- Determine appropriate degree of formality-how to address
- Determine preferred language. Include an interpreter/materials
- Be respectful of nonverbal communication
- Address issues linked to culture- lack of trust, fear (medical experience, side effects, Western medicine)
- Review history- trauma, violence, survivors of racism (very sensitive)
- Recognize health beliefs- alternative therapies
- Consider decision-making factors and individual autonomy

Goals of Care & Treatment Options Discussion

- What is the one thing about your health care you most want to focus on so that you can do [fill in desired activity] more often or more easily?
- What are your most important goals now and as you think about the future with your health?
- What concerns you most when you think about your health and health care in the future?
- What are your fears or concerns for your family?
- What are your most important goals if your health situation worsens?
- What things about your health care do you think aren't helping you and you find too bothersome or difficult?
- Is there anyone who should be part of this conversation with us?

Moving Serious Illness Conversations upstream



Resource People

- Providers, Nurses, Social Workers, Chaplains, Hospital Supervisors, Palliative Care Team
- Provide information about healthcare directives to patients/families who wish to have more information
- Assist patients in completing healthcare directives
- Other staff are not designated to do Healthcare Directives.

Tools to Get Started

- Go Wish Game
- Hard Choices For Loving People (Hank Dunn)
- Serious Illness Care Resources
- The Conversation Project Starter Kits
- National Healthcare Decisions Day- April 16
- MyDirectives app
- Honoring Choices® North Dakota

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Serious Illness Conversation Guide

CONVERSATION FLOW

1. **Set up the conversation**
   - Introduce purpose
   - Prepare for future decisions
   - Ask permission
2. **Assess understanding and preferences**
3. **Share prognosis**
   - Share prognosis
   - Frame as a "wish...worry", "hope...worry" statement
   - Allow silence, explore emotion
4. **Explore key topics**
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family
5. **Close the conversation**
   - Summarize
   - Make a recommendation
   - Check in with patient
   - Affirm commitment
6. **Document your conversation**
7. **Communicate with key clinicians**

Treatment Choices:

- CPR
- Medical Interventions
- Tube Feedings/IV Fluids

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

"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 ahead with your illness would you like from me?"

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

Uncertain: "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'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility."
OR
Time: "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year)*."
OR
Function: "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."

"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?"

"I've heard you say that ___ is really important to you. 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."

"How does this plan seem to you?"

"I will do everything I can to help you through this."

Serious Illness Conversation Guide Demonstration- Case Study

- Serious Illness Care
- Part 2: The Serious Illness Conversation Guide

Bringing Up Prognosis

Gone From My Sight
By
Barbara Karnes

Translating Patient Wishes into Medical Orders

Honoring the wishes of those with serious illness and frailty

About National POLST

Case Study: Jane Jones

- 77-year-old woman with stage 4 cancer, on chemotherapy
- Presents to Emergency Department at 1 AM with perforated bowel
- Surgeon consulted
- No documented end-of-life conversations
- Surgeon needs to have informed consent discussion with patient

What would make the conversation about treatment options easier for the surgeon?

a. Having her code status – would that help or not?
b. Patient is alert, competent, and understands gravity of illness
c. Patient is in distress, delirious, and proxy is present
d. Documentation of a serious illness conversation

What is POLST?

- Medical Order
- Signed by the patient or their Agent
- Signed by a Physician or Advanced Practice Provider
- PORTABLE from one facility to another and honored by EMS

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT

North Dakota POLST: Physician Orders for Life Sustaining Treatment

Physician Orders for Life-Sustaining Treatment (POLST)

FIRST follow these orders, THEN Call the appropriate medical contact. These medical orders are based on the patient's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Patient's Last Name

Patient's First Name/Middle Initial

Patient's Date of Birth (mm/dd/yyyy)

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and is not breathing.**

☐ CPR/ATTEMPT RESUSCITATION ☐ DNR/DO NOT ATTEMPT RESUSCITATION (Allow Natural Death)

When not in cardiopulmonary arrest, follow orders in B and C.

B Check One — **MEDICAL INTERVENTIONS: Patient has pulse and/or is breathing.**

Comfort Measures always provided regardless of level of care chosen.

☐ **COMFORT MEASURES ONLY** - Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.

☐ Avoid calling 911, call ______ instead (e.g. hospice)

☐ If possible, do not transport to ER (when patient can be made comfortable at residence)

☐ If possible, do not admit to the hospital from ER (e.g. when patient can be made comfortable at residence)

☐ **LIMIT INTERVENTIONS AND TREAT REVERSIBLE CONDITIONS** - Provide interventions aimed at treatment of new or reversible illness/injury or non life-threatening chronic conditions. In addition to treatment described in Comfort Measures Only, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Duration of invasive or uncomfortable interventions should be limited. (Generally, avoid intensive care)

☐ **FULL TREATMENT** - Use all appropriate medical and surgical interventions as indicated to support life. Transfer to hospital if indicated. Includes intensive care.

Additional Orders: (e.g. dialysis, etc.)

C Check One — **Artificially Administered Fluids and Nutrition:** Always offer food/fluids by mouth if feasible and desired.

Check One

☐ No artificial nutrition by tube.

☐ Defined trial period of artificial nutrition by tube.

☐ Artificial nutrition and hydration unless it provides no benefit

☐ Long-term artificial nutrition by tube.

Additional Orders:

D Must fill out — **DOCUMENTATION OF DISCUSSION (Required)**

☐ Patient (if patient has capacity) If patient lacks capacity:

☐ A Health Care Directive

☐ Health Care Agent

☐ Person legally authorized to provide informed consent (See reverse)

Health Care Agent/Legal Representative Name Relationship

E — **PATIENT or Health Care Agent/Legal Representative (Required)**

Signature (Form Does Not Expire) Date of signature

F — **ATTESTATION OF MD/DO/APRN/PA (Required)** By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient's current medical condition and preferences.

Print Name of MD/DO/APRN/PA Name Signer Phone Number Signer License Number

MD/DO/PRN/PA Signature: required Date: required Time: required

2018 North Dakota POLST SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED 1

Conclusion: It is Our Responsibility to:

- Provide high quality, earlier serious illness conversations with patients and families.
- Utilize evidence based Serious Illness Conversation Guide
- Complete Healthcare Directives and POLST forms AFTER comprehensive conversations

Why?

- Patients and families will have more time to plan, to complete what is unfinished
- Better goal-concordant care

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