Goals of Care Conversations Training

Goals of Care Conversations about Life-Sustaining Treatment Decisions

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Required for Successful Goals of Care Conversations

Knowledge
“The What”
• Steps
• Facts
• Data

Skills
“The How”
• Words
• Clarity
• Empathy
Why Are Conversations About Goals of Care and Life-sustaining Treatment (LST) Hard?

- Don’t know the right words say
- Discussions are about death and sadness
- Emotions are strong, don’t know how to respond
- Uncertainty about outcomes
- Lack of a framework within which to enter the conversation
What are Some Unintended Consequences of the Following Questions/Phrases When Discussing LST?

• Would you like us to try to **restart** your heart?

• Would you like us to do **everything possible** if your father’s heart stops beating and he stops breathing?

• I think it is time to **withdraw care**.
What are Some Unintended Consequences of the Following When Discussing LST?

• Would you like us, in what would naturally be your final moments, to press on your chest and break your ribs, shove a tube down your throat and poke you with needles in lots of places in a chaotic attempt that has a very small chance of giving you more time to be technically alive but unlikely to ever return to meaningful communication with others?
Our Role

Ensure patients receive treatment consistent with their values and goals by helping them...

- Define what is important to them
- Understand the possible outcomes of treatment
- Make informed decisions to support their goals
• **Capacity**

• **Authorized Surrogate and Advance Directives**

• **Perception of Illness and Prognosis**

• **Target Patient’s VALUES and GOALS**

• **Unite VALUES and GOALS with Treatment Options**

• **Recommendations**

• **Empathize and Explore Challenges**

• **Summarize the Plan**
• Capacity = A clinical judgment about a patient’s ability to make a particular health care decision at a particular point in time.

• A patient is considered to have decision-making capacity when they can do all of the following:
  • Understand the relevant information
  • Appreciate the situation and its consequences
  • Reason about treatment options
  • Communicate a choice
• If the patient lacks decision-making capacity and a goals of care conversation is warranted, conduct the discussion with the patient’s authorized surrogate.

• Capacity to make decisions about goals and life-sustaining treatments can be assessed throughout the goals of care conversation.
It’s important for me to understand what matters most to you as we look ahead and make plans for your care. This helps me make sure you get the care that helps you reach your goals.

Can we spend a little time talking about this?
• Verify who the patient wants to make decisions on their behalf if they lose decision-making capacity.

It’s helpful for me to know who you would like to make decisions for you if you were ever unable to make decisions for yourself. Have you thought about who you would like this to be?

Have you completed an advance directive to name this person as your decision maker?
Without an advance directive naming a health care agent, the patient’s authorized surrogate is the person at the top of the Utah surrogate hierarchy:

- **The Utah Surrogate Hierarchy:**
  1. A health care agent appointed by the adult.
  2. Legal or special guardian appointed by a court of law.
  3. Next of kin, 18+ years of age, in the following order of priority: spouse, child(ren), parent(s), sibling(s), grandchild(ren), grandparent(s).
  4. An adult who has exhibited special care and concern for the patient and knows the patient and the patient’s personal values.
Since you haven’t completed an advance directive naming a health care agent, in certain circumstances, your health care team may need to turn to your [next of kin] to make health care decisions for you.

If you don’t want your [next of kin] to make health care decisions for you, you can name someone else in an advance directive. Would you like [our social worker] to help you with that?
**NOTE:** If the patient has Utah POLST orders, and has not given their surrogate leeway to make decisions – in general, the surrogate should not be asked to make decisions.
Patients cannot make informed decisions about goals and treatments when they don’t know what to expect with their illness.

If the patient is not aware of their prognosis, discuss prognosis with them and allow them time to adjust to the news before proceeding with decisions, especially about life-sustaining treatment.

Goals of care should not be discussed at the same time as really serious news.
I have reviewed your chart and it would help me if you shared what other doctors have told you about your [name medical condition]?

Tell me what you think the future might look like with your [medical condition].
• If the patient has a different perception of their illness or prognosis then the medical team, spend time reframing prognosis

• The message:
  • You have an illness that could get worse in the coming days, weeks or months - we need to think about the future
Given where you are in your illness, it seems like a good time to talk about where to go from here.

We’re in a different place than we were [X] months ago.
Most patients will have an emotional response to hearing the reframe. This is normal.

The emotional response may sound like a factual question:
  - “Isn’t there something else you can do?”
  - “Are you sure we’ve looked into everything?”

Respond to these questions with empathic statements.

Ask permission before moving on.
• I can see that you are really concerned.

• I get a sense that this is not what you were expecting to hear today.

• Is it OK for us to talk about what this means?
“Why words that work, they are so scripted?”

- If you wanted me to teach you a phrase in another language:
  - What would you ask me to do to teach you?
  - What would you do to remember the phrase the next day?
- Have the teacher:
  - Write the phrase
  - Say the phrase so you could hear it
  - Listen to you saying the phrase and give you feedback on if you are saying it correctly
- You would:
  - Practice by repeating the phrase many times so that you could say it fluently and remember it
  - Use the phrase often in real life settings
• Divide into pairs

• Practice the drill script (person with bigger feet goes first)

• Switch roles

• Debrief with one another:
  • How did it feel to say the words?
  • One thing clinician noticed
  • One thing patient noticed
Reframe and Respond to Emotion

Clinician

• Tell me what you understand about your lung disease.

• I wish we had more effective treatments.

Patient

• I’m not getting better with this treatment, but there’s got to be something else out there.
Reframe and Respond to Emotion

Clinician

• What is your sense about where things are?

Patient

• I know I have COPD and my breathing has gotten worse over the last several weeks. But I’ve had this for quite a while, and it will probably get better...
### Reframe and Respond to Emotion

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- You’ve been living with this disease a long time and I think we’re in a different place now.
- So, what are you saying – that I’m supposed to give up?
Reframe and Respond to Emotion

**Clinician**
- I can’t imagine what it’s like to live with an illness that keeps getting worse.

**Patient**
- I’m a fighter. I know I can still beat this thing.
Reframe and Respond to Emotion

- You are a fighter. I really admire your spirit and everything you’ve done to fight this illness. This must be tough.

- I can see how disappointing this is. Would it be all right if we talked about where we go from here?

- I’ve just kept hoping that I would get better.

- I think that would be OK.
Drill: Swap Roles

Patient

Clinician
Drill: Debrief

• How did it feel to say the words?
• One thing clinician noticed
• One thing patient noticed
CAPTURES: Target 🌐 Patient’s Values and Goals

• You must know the patient’s goals and values before creating a plan with them. The only way to know is by asking.

• If asked correctly, the question makes sense and isn’t scary.

• The patient’s values and priorities will help determine which treatment plan is right for the patient.
Patient’s Goal = The Destination

Treatments = The Route
Given this situation, what matters the most to you?

If it turns out that time is limited, what things would you want to do?

As you think about the future, what are you worried about?
Example One: Patient Knows Values

**Clinician**
- Given this situation, what’s most important?
- I see that in you and admire your fight. Tell me what you mean when you say you don’t want to give up.

**Patient**
- It’s important to me that I don’t give up – I don’t want to look back and regret that I didn’t give it everything I had.
CAPTURES: Target → Patient’s Values and Goals

Example Two: Patient Not Sure

Clinician:
- Given this situation, what’s most important?
- What if you start with the things in your life that matter the most to you?

Patient:
- I’m not sure what to tell you.
Example Three: Patient Not Sure

Clinician

• Given this situation, what’s most important?
• This is a tough situation for anyone. What worries you most about talking about this?

Patient

• I don’t feel ready to talk about this. It’s hard...
### CAPTURES: Target ➔ Patient’s Values and Goals

**Example Four: Explore Worries**

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- As you think about the future, is there anything you worry about?
- That helps me better understand what you’re thinking.

- I worry that I’ll be too sick to take care of myself or stay at home. I don’t want to be stuck on a breathing machine in the hospital like last time. I want to be at home with my family.
Drill: Swap Roles

Patient

Clinician
Drill: Debrief

- How did it feel to say the words?
- One thing clinician noticed
- One thing patient noticed
CAPTURES: Unite Goals with Treatment Options

- Unite the patient’s goals/preferences with treatment options that support their goals and are relevant to their medical condition.

- Asking patients if they would or wouldn’t want an LST without discussing whether it supports their goals can lead to poorly informed decisions.
CAPTURES: Unite Goals with Treatment Options

• Assess the patient’s understanding of the LST and readiness to discuss the intervention by asking an open-ended question such as, “has anyone talked to you about CPR; can you tell me what you know about it,” instead of asking, “would you want CPR?”

• If the patient does not have a basic understanding of the LST, provide information to fill in the gaps.
  • Be clear and direct and avoid medical jargon.
  • Give 1-2 pieces of information at a time, then stop and wait for the patient to respond.
CAPTURES: Recommendations

• Making a recommendation about an LST can be a very effective way to unite the patient’s values and goals with treatment options.
• Ask permission before making a recommendation.
• Recommend treatments that may help meet the goals
  • Focus on what can be achieved
  • Focus on what might be possible
  • Discuss what you will not do because it will not meet the goal
• After making recommendation, ask patient or family whether it feels right
CAPTURES: Recommendations

• For medical trainees and some health care professionals, it may not be possible to immediately formulate a recommendation.

• In these situations, map out goals.

• Inform your team of the patient’s goal.

• Return later with the recommendation from your team:

  The information you shared with me about what matters most to you is very helpful. I’ll share this with [our team/your doctors/etc.] and [I/we] will meet with you [X timeframe] to talk about a plan.
CPR Example: Unite Goals with Treatment Options and Make Recommendation

Clinician

- I want to be sure you get the care that helps achieve your goals. It’s helpful to know in advance whether you would or wouldn’t want certain procedures. One of these procedures is CPR. Has anyone talked to you about CPR or have you seen it on TV?

Patient

- No one has really talked about CPR with me. I’ve seen it on TV but I don’t know that much about it.
CPR Example: Unite Goals with Treatment Options and Make Recommendation

Clinician

- CPR is used only when someone’s heart and breathing have stopped. Sometimes the heart and breathing stop as a natural part of the dying process. Other times it happens unexpectedly.

- Basic CPR involves forcefully pushing on the chest, and blowing air into the lungs to try to restart the heart and breathing. Advanced life support can include shocking the heart and putting a tube down the throat.
CPR Example: Unite Goals with Treatment Options and Make Recommendation

Clinician

• Would you like me to make a recommendation about CPR based on what you shared matters most to you and what I know about your health, or would you prefer to let me know your thoughts?

Patient

• A recommendation would be fine.
CPR Example: Unite Goals with Treatment Options and Make Recommendation

Clinician

That sounds right.

Based on your goals to stay at home with your family, be able to take care of yourself, and not be stuck on a breathing machine like the last time you were in the hospital, I would not recommend CPR. Does that sound right to you?

Patient

That sounds right.
Drill: Swap Roles

Patient

Clinician
Drill: Debrief

- How did it feel to say the words?
- One thing clinician noticed
- One thing patient noticed
Remember these conversations can be emotional
Clinicians must attend to emotion BEFORE moving on to anything else
Emotional responses often sound like a factual question
Do not respond to feelings with facts – respond with empathy
  • “NURSE” Statements
  • “I Wish” Statements
If a decision about LST appears inconsistent with the patient’s goals or the patient is hesitant to make decisions, explore the reasons why and respond appropriately.

- Empathic responses and time
- Expected rates of survival or potential risks
- Information related to spiritual concerns, etc.
• Tell me more about what you are hoping for with [intervention X].

• Is there a situation you could imagine when you [would /would not] want [intervention X]?

• Some people find it helpful to know how many people survive after receiving CPR, or what the risks might be. What information would be helpful to you as we talk about CPR?
On average 17 out of 100 adults survive inpatient CPR to hospital discharge.

Survival is lower for arrests in the outpatient setting.

Factors associated with failure to survive CPR to hospital discharge:
- Serum Creatinine >1.5 mg/dl
- Metastatic Cancer
- Dementia
- Dependent Status
- Sepsis the day prior to the CPR event

Also see [http://www.gofarcalc.com](http://www.gofarcalc.com)
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- Would you like me to make a recommendation about CPR based on what you shared matters most to you and what I know about your health, or would you prefer to let me know your thoughts?

- A recommendation would be fine.
Explore When Choices Conflict with Goals
Example One

Clinician

• Based on your goals to stay at home with your family, be able take care of yourself, and not be stuck on a breathing machine like the last time you were in the hospital, I would not recommend CPR. Does that sound right to you?

Patient

• I think I would still want CPR.
Explore When Choices Conflict with Goals
Example One

Clinician

- Tell me more about what you are hoping for with CPR.

Patient

- I am not sure.
Explore When Choices Conflict with Goals
Example One

Clinician

• Some people find it helpful to know how many people with similar health problems survive after receiving CPR, or what the risks might be. What information would be helpful to you?

Patient

• I guess I worry that saying no to CPR would be against my faith.
**Explore When Choices Conflict with Goals**

**Example One**

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- It sounds like you might want to talk to someone who could help figure that out. Our chaplain would be able to provide some helpful information. Would you like to speak with him?

- That would be helpful.
Drill: Swap Roles

Patient

Clinician
Drill: Debrief

• How did it feel to say the words?

• One thing clinician noticed

• One thing patient noticed
Explore When Choices Conflict with Goals
Example Two

Clinician

- Tell me more about what you are hoping for with CPR.

Patient

- CPR will bring me back, so why wouldn’t I want it?
Explore When Choices Conflict with Goals

Example Two

Clinician

• Some people find it helpful to know how many people with similar health problems survive after receiving CPR, or what the risks might be. Would this information be helpful to you?

Patient

• I thought it worked for just about everybody?
Explore When Choices Conflict with Goals

Example Two

Clinician

- For people with health problems like yours, about $X$ out of 100 people survive when they receive CPR in the hospital. That means that $Y$ out of 100 people die. Survival is lower for CPR outside of the hospital.

- It surprises a lot of people.

Patient

- That’s a lot less than I expected!
## Explore When Choices Conflict with Goals

### Example Two

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- What is your understanding of some of the problems that can occur after CPR?
- I’ve heard that CPR can break ribs.
## Explore When Choices Conflict with Goals
### Example Two

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- Yes that’s right. There are also risks of permanent brain damage and disability after CPR. Although a person’s heart might restart, they may not be able to make decisions for themselves, recognize family or return home. For people like you whose memory and thinking are sharp, these risks are low.
- I guess even if there’s just a small chance that CPR could help me live longer, I’d want to give it a shot.
Explore When Choices Conflict with Goals
Example Two

Clinician

- Can you think of a situation when you wouldn’t want CPR?
- That’s very helpful to know. Let’s make sure [name of surrogate] knows what you want.

Patient

- If I couldn’t recognize my family or make decisions for myself, in that situation I wouldn’t want CPR.
Drill: Swap Roles

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Drill: Debrief

• How did it feel to say the words?
• One thing clinician noticed
• One thing patient noticed
Explore Hesitations to Discuss LSTs and Make Decisions [Not Urgent]

<table>
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<tr>
<td>• Can you tell me what worries you about talking about CPR?</td>
<td>• I would just like some more time to think about it. I’d like to talk with my family before making any decisions.</td>
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Explore Hesitations to Discuss LSTs and Make Decisions [Not Urgent]

- This topic deserves time and attention. We don’t need to make decisions today.
- Let’s set up a time to talk again when you are ready. In the meantime here is some material you may want to review.

• That sounds good.
• Thank you.
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<tr>
<td>Can you tell me what worries you about talking about CPR?</td>
<td>I’m just afraid to talk about this. I really prefer not to think about it at all.</td>
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Explore Hesitations to Discuss LSTs and Make Decisions [URGENT]

Clinician

• It is hard to talk about this and it’s also very important so we understand your wishes. If you don’t want to talk about it, can I speak with [authorized surrogate] to help make decisions for you now since we need to make decisions right away?

Patient

• Yes that would be fine.
Drill: Swap Roles

Patient

Clinician
Drill: Debrief

• How did it feel to say the words?

• One thing clinician noticed

• One thing patient noticed
CAPTURES: **Summarize the Plan**

- To ensure shared understanding, summarize the plan and ask the patient to confirm.
- Repeat what the patient has just told you; communicates you have listened.
- Identify next steps.
• So it sounds like you [would/would not] want [X, Y, Z] [under A, B, C circumstances]. Do I have that right?

• I will put an order in your health record to make sure that staff knows what you want.

• Thank you for taking the time to have this important conversation with me.
Reviewing and Verifying Preferences

• With changes in condition you may need to review and verify the patient’s preferences with the patient or their surrogate.

• Your recommendation may not have changed and you may want to review and verify the orders without casting doubt on decisions.

• The clinical situation may have changed and you may need to re-conduct the conversation by reframing perception.
Reviewing and Verifying Preferences: No Changes to Recommendations

• [You/your loved one] expressed that [X goals and preferences] were important to [you/them] when we discussed goals and treatment options on [date].

• At that time [you/they] chose [review POLST order choices – e.g. that you would not want an attempt at resuscitation if your heart stopped], which is still appropriate given [your/their] goals and health.

• We plan to honor your decisions. Is there any additional information that I should know?
Reviewing and Verifying Preferences: Changes to Recommendations

• [You/your loved one] expressed that [X goals and preferences] were important to [you/them] when we discussed goals and treatment options on [date].

• At that time [you/they] chose [review POLST order choices].

• We are in a different place now then when we talked about this.

• Can we spend sometime talking about what is most important to [you/your loved one] now and where we should go from here?
CPR

CAPTURES: A Process Map for Goals of Care Conversations about LST

- Capacity
- Authorized Surrogate and Advance Directives
- Perception of illness and Prognosis
- Target patient’s VALUES and GOALS
- Unite VALUES and GOALS with treatment options
- Recommendations
- Empathize and Explore challenges
- Summarize the plan
What surprised you?
Anywhere you might get stuck?
What do you want to take forward (and try this week)?
Goals of Care Conversations

Goals of Care Conversations training materials were developed and made available for public use through a U. S. Department of Veterans Affairs contract with VitalTalk.

[Order VA777-14-P-0400]

Materials are available for download from VA National Center for Ethics in Health Care at vaww.ethics.va.gov/goalsofcaretraining.asp.