

Respecting Choices®

PERSON-CENTERED CARE

Proactive Care Planning for COVID-19

What matters most to you matters to us

Note to User: This guide is for use by clinicians to proactively help healthcare agents or dedicated decision maker (DDM) of individuals at risk for complications associated with COVID-19 express their desires for care, in the event the individual develops the infection. This information will allow clinicians to create plans for care that will honor each individual's preferences and decisions.

This conversation can be delivered through telecommunication, video conference, in-person, etc. If a previous introduction conversation has occurred, start at #3 below.

1. The invitation (virtual or in person)

"It is important that the healthcare team understands what matters most to [name of individual] in the event that [name of individual] becomes seriously ill as a result of COVID-19. We are eager to make sure we understand what they would want."

"As the healthcare agent/DDM for [name of individual], your role is to help the healthcare team:

- *Follow [name of individual's] previous decisions and*
- *Make decisions in difficult moments (e.g., stressful times, differing opinions, crisis situations) that are in line with [name of individual's] goals, values, and preferences.*

"I know this is a lot to take in all at once. I want to support you any way I can. These can be tough decisions to make and talk about especially in these uncertain times. Think of these conversations as a gift of love to [name of individual], making sure their goals and values are honored by the decisions you make."

"We are here to help you get started today. What questions do you have?"

2. Provide the context for having further conversation

"There's no way to tell if a sudden illness, such as COVID-19, could leave [name of individual] seriously ill and you, as their healthcare agent/DDM, may need to make decisions about treatment options. By giving direction ahead of time, the doctors will know what matters most to [name of individual] and can recommend treatments that match [name of individual's] goals and values."

"Has [name of individual] completed a POLST form?"

- **If yes:** *"It is important to review this document with the care team now to understand what matters most in the event [name of individual] becomes seriously ill."*
- **If no:** *"We are here to help you have a conversation with the care team."*

- 3. Explore goals, values, and preferences about what the person would want if they became very ill** (Ask exploratory questions using communication skills; clinicians work to top of license; if unable to answer a question/support making a decision, create list of questions for physician, advanced practitioner.)

“What do you understand about COVID-19?”

“What do you understand about the complications of COVID-19 in the context of [name of individual’s] current medical condition(s)?” Provide education per your organization’s guidance (e.g., CDC guidelines).

“What is most important for [name of individual] to live well? For example, if they were having a good day, what would happen on that day?”

“What personal, cultural, or spiritual beliefs does [name of individual] have, if any, that would impact their care?”

“What worries you most about the situation? What fears do you have?”

- 4. Summarize the conversation so far**

“Thank you for helping me better understand what matters most to [name of individual]. You have said [describe themes from the conversation, e.g., goals, values, beliefs]. Does this summary capture our conversation accurately, so far?” If no, amend. If yes, continue.

- 5. Priorities for Medical Care and Treatment Options**

(Start with the priority that best matches what matters most to the individual.)

“If a sudden illness, such as COVID-19, left [name of individual] seriously ill, there may be a need to make decisions about treatment options and where [name of individual] might receive care, such as at home, hospital, or care facility. By giving direction ahead of time, the doctors will know what matters most to [name of individual], and the treatments that will best match their goals and values.”

“Let’s begin by defining [name of individual’s] priorities for medical care.”

PRIORITIES FOR MEDICAL CARE		
LIVING LONGER	MAINTAINING CURRENT HEALTH	COMFORT
<ul style="list-style-type: none"> • Live as long as possible, even if I do not know who I am or who I am with • Be in the hospital and receive all care my doctors think will help me, even if it means relying on machines to keep me alive 	<ul style="list-style-type: none"> • Live longer, if quality of life and comfort can be achieved • Be in the hospital, if needed, for effective care • Stop treatment that does not work or makes me feel worse • Allow a natural death if my heart or breathing stops 	<ul style="list-style-type: none"> • Live the rest of my life focusing on my comfort and quality of life • Avoid the hospital and being on machines • Allow a natural death if my heart or breathing stops

“Tell me what you understand about focusing on [Living Longer, Maintaining Current Health, Comfort].”

“It sounds like focusing on [Living Longer, Maintaining Current Health, Comfort] fits with what you’ve told me.”

6. Make a decision about serious illness treatment options

“Based on what you have told me about what is important to [name of individual] and what we have discussed about COVID-19, let’s explore treatment options if [name of individual] becomes seriously ill and discuss the ones that best meet their goals.”

“The priorities for medical care seem to fit with a [Full, Selective, Comfort-Focused] treatment. Like we did for [name of individual’s] priorities, let’s go through the treatment options to see which one meets their goals. Whatever the choice, [name of individual] will be treated with respect, dignity, and be kept comfortable.”

Note to User: Use Help with Breathing and/or CPR Decision Aid for individuals with underlying serious illness, if available.

TREATMENT OPTIONS FOR SERIOUS ILLNESS		
FULL TREATMENT Sustaining life by all medically effective means	SELECTIVE TREATMENT Maintaining health while avoiding burdensome treatments	COMFORT-FOCUSED TREATMENT Maximizing comfort through symptom management
Includes: <ul style="list-style-type: none"> Medication and treatment to keep you comfortable Emotional and spiritual care 	Includes: <ul style="list-style-type: none"> Medication and treatment to keep you comfortable Emotional and spiritual care 	Includes: <ul style="list-style-type: none"> Medication and treatment to keep you comfortable Emotional and spiritual care
May include: <ul style="list-style-type: none"> Being in the hospital and Intensive Care Unit (ICU) A trial of full treatment, if desired, e.g., ventilator IV medications and IV fluids Long-term tube feedings CPR, intubation, and/or ventilator 	May include: <ul style="list-style-type: none"> Being in the hospital but AVOIDING the ICU Non-invasive positive airway pressure A trial of select treatment, if desired, e.g., non-invasive positive airway pressure IV medications and IV fluids Short-term tube feedings 	May include: <ul style="list-style-type: none"> Being in the hospital ONLY if comfort needs not met Oxygen, suction, and manual treatment of airway for comfort Medications by mouth Food and fluids by mouth, if able
	Does <u>NOT</u> include: <ul style="list-style-type: none"> CPR, intubation, and/or ventilator 	Does <u>NOT</u> include: <ul style="list-style-type: none"> CPR, intubation, and/or ventilator

7. Summarize and validate their decision

“Just so I understand you correctly, if [name of individual] becomes ill with COVID-19 and a treatment decision needs to be made, you would prefer [Full treatment, Selective Treatment, Comfort-Focused Care].”

“What else would you want us to know about what is important to you and [name of individual] at this time?”

“What questions do you have?”

Reaffirm: “I appreciate having this conversation with you today. It is a lot to take in all at once. I want to support you any way I can. These can be tough decisions to make and talk about especially

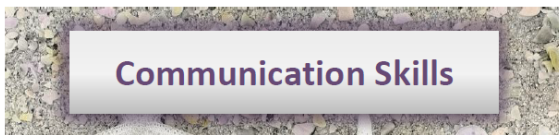
in these uncertain times. Think of these conversations as a gift of love to [name of individual] making sure their goals and values are honored by the decisions you make.”

If relevant, i.e. when treatment options are full or selective treatment AND crisis standards of care are a real possibility, add, *“In the current crisis, we can’t **promise** that resources will always be available to provide any and all interventions. However, we will always do our best to provide interventions that give reliable benefits, and we will always care for all individuals with compassion and dignity.”*

8. Create a care plan that will honor the individual’s preferences and decisions

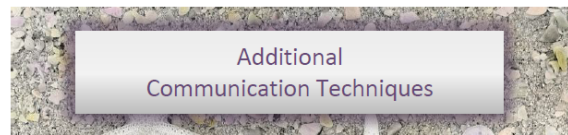
- a. For those who prefer not to be hospitalized, you **must** ensure medical plans of care are available and in place to provide aggressive symptom management in desired care location. Make arrangement/referrals as appropriate to ensure those resources are available in the desired care location.
- b. Modify physician orders and update/create POLST form, as appropriate.
- c. Document conversation and decision in the medical record.

Available resources found on the COVID-19 page of the Respecting Choices website (<https://respectingchoices.org>).



- **Explore meaning of words/phrases**
“What does, ‘I feel like a burden’ mean to you?”
- **Paraphrase/clarify**
“You were frustrated being in the hospital; tell me more.”
- **Ask, “Anything else?”**
“You have said you are weak, tired, and frustrated. Anything else?”
- **Listen for and summarize themes**
“You have talked about how difficult it was making decisions when your father was seriously ill. This conversation can help better prepare your family.”
- **Affirm/reaffirm purpose of conversation**
“You say this conversation is hard for you. I hope to help you today, to make it easier to learn how to talk to each other.”
- **Verbalize empathy**
“I’m sorry to hear you lost your job. I see that this is very upsetting.”

(over)



- **Use the Ask-Teach-Ask technique**
When providing information:
 1. First, ASK... what the individual understands.
 2. Then, TEACH...provide information to fill in gaps in understanding.
 3. Last, ASK (i.e., Teach-Back)...assess understanding of information before moving on.*“These are new ideas for many people, so I want to make sure I was clear. Can you tell me what you now understand about _____?”*
- **Remain value-neutral**
Avoid words, phrases, or nonverbal expressions that may communicate personal biases or values.
- **Pay attention to nonverbal communication**
(facial expressions, body movements)

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