

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 individuals at risk for complications associated with COVID-19 express their desires for care in the event they develop the infection. This information will allow clinicians to create plans for care that will honor each individual's preferences and decisions.

Include healthcare agent, if possible. This conversation could 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)

"During so much uncertainty amid the COVID-19 pandemic, one thing you can control is who you ask to speak for you if you can't speak for yourself. We help individuals and their healthcare agents/families talk about and plan for their care, before a medical crisis occurs. We want to know your values and preferences which will help us understand what matters most to you should you become ill due to complications from COVID-19."

"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 those close to you. Knowing your decisions, goals, and values will be a great comfort to them. They won't have to wonder if they are making a decision you would want them to make."

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

2. Explore prior conversations about planning for future healthcare decisions

(Skip first part of this question if healthcare agent is present.)

a. *"Have you chosen a person who would make decisions for you if you were unable to speak for yourself?"*

- **If yes:** *"What conversations have you had with them?"*
- **If no:** Proceed to #3.

b. *"Have you completed an advance directive document or POLST form?"*

- **If yes:** *"We will update these today following our conversation, if needed."*
- **If no:** Proceed to #3.

3. For individuals who have NOT chosen a healthcare agent (e.g., legally appointed healthcare representative), provide information on how to choose this person

"One of the most important decisions we encourage people to make is choosing someone you trust to make decisions for you. We call this person a healthcare agent. This person would make decisions for you in the future if you are unable to speak for yourself."

"There are four qualities you should look for. A healthcare agent should be willing to:

- *Accept this role,*
- *Talk with you about your goals, values, and preferences,*
- *Follow your decisions (even if they do not agree with them), and*
- *Make decisions in difficult moments (e.g., stressful times, differing opinions; crisis situations)."*

“Do you know anyone who could do this?” If the answer is no, assist individual in creating an advance directive that clearly articulates their goals, values, and treatment decisions. Inform clinical team there is no decision maker.

“We can help you have a conversation with this person (and other loved ones) about what matters the most to you in the event you become ill and cannot speak for yourself.”

- 4. Explore goals, values, and preferences about what the person would want if they became very ill**
 (Ask exploratory questions using communication skills; clinician 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 your current medical condition(s)?” Provide education per your organization’s guidance (e.g., CDC guidelines).

“What is most important for you to you to live well? For example, if you were having a good day, what would happen on that day?”

“What personal, cultural, or spiritual beliefs do you have, if any, that would impact your care?”

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

- 5. Summarize the conversation so far**

“Thank you for helping me better understand what matters most to you. 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.

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

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

“There’s no way to tell if a sudden illness, such as COVID-19, could leave you unable to make your own decisions. Your healthcare agent and loved ones may need to make decisions about treatment options and where you might receive care, such as in your home, hospital, or care facility. By giving direction ahead of time, your agent, loved ones, and doctors will know what matters most to you, treatments you want, and treatments that match your goals and values.”

“Let’s begin by defining your 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.”

7. Make a decision about serious illness treatment options

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

*“Your priorities for medical care seem to fit with a [Full, Selective, Comfort-Focused] treatment. Like we did for your priorities, let’s go through the treatment options to see which one meets your goals.”
Whatever your choice, you 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 NOT include: <ul style="list-style-type: none"> • CPR, intubation, and/or ventilator 	

8. Summarize and validate their decision

“Just so I understand you correctly, if you become 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 at this time?”

“What questions do you have?”

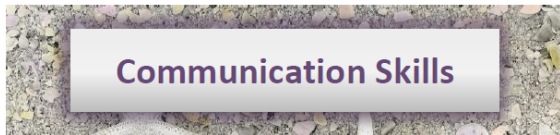
Reaffirm: *“I appreciate having this conversation with you today. It is a lot to take in all at once. I want to support you any way I can. These can be tough decisions to make and talk about especially in these uncertain times. Think of these conversations as a gift of love to those close to you. Knowing your decisions, goals, and values will be a great comfort to them. They won’t have to wonder if they are making a decision you would want them to make.”*

If relevant, i.e., when individual selects 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.”*

9. Create a care plan that will honor their preferences and decisions

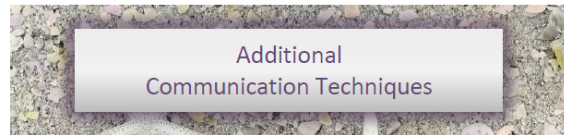
- a. For those who prefer not to be hospitalized, you **must** ensure medical plans of care are available and in place to provide aggressive symptom management in desired care location. Make arrangements/referrals as appropriate to ensure those resources are available in the desired care location.
- b. Modify physician orders and update/create POLST form, as appropriate.
- c. Update healthcare agent and other loved ones, if not present in the conversation.
- d. Document conversation and decisions in 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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www.respectingchoices.org

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