



# Ethics Resource Toolkit for Those Caring for the Frail or Seriously Ill

Arizona Coalition to Transform Serious Illness Care

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To: Healthcare Providers Caring for the Seriously Ill  
Subject: Ethics Resource Toolkit

Dear Colleagues,

We are amid a global pandemic that challenges and strains all of us, our institutions, and the entire fabric of healthcare in every setting. It is disorienting for all and paralyzing for the populations we serve. We as healthcare leaders must empathically lead ethical decision-making. **There has never been a more important time to be ambassadors of kind, person-centered, serious illness care.**

These resources are offered as a tool to assist healthcare organizations and professionals in having critical conversations to develop their organizational standards and ethics policies/practices. We know you are working hard. We know you need help. In our attempt to support you we have compiled resources developed by subject matter experts into this toolkit. This is a living document and will be revised with feedback from you and others.

A fundamental premise is circumstances do not dictate our ethical principles. We apply our ethical principles to whatever circumstances we encounter, and when the circumstances are extraordinary, we need our ethical principles even more than we did before. Your organizational decision making is best served when grounded in and structured by ethics and values that all are bound to uphold.

Ethical foundations help drive the use of resources. We all have limited resources and using them efficiently is imperative, especially in the face of a pandemic.

This document is not intended to be the final word but is offered as a starting point for an on-going and evolving dialogue. Differences in practice settings, patient and family characteristics, agency type, availability of resources, etc. all come into play and must be considered when developing, reviewing, or updating organizational ethics standards. These guidelines are not intended to be, and should not be considered, a substitute for clinical ethics consultation or other medical, legal, or other professional advice on individual cases or for healthcare organizations.

The Coalition to Transform Serious Illness Care goal is to improve care for those with serious illness. None of us can do this work alone. Serious illness care has the best impact when we are working together to improve the patient's quality of life.

A huge thank you to the contributors to the development of this toolkit for sharing your time, knowledge and expertise: Vicki Buchda, Care Improvement Director, Arizona Hospital and Healthcare Association, Lou Gagliano, Strategic Advisor, Coalition to Transform Advanced Illness Care, Kay Huff, Quality Director, Arizona Healthcare Association, Pam Koester, CEO, Leading Age, Patricia Mayer, MD, MS, Clinical Ethics, Banner Health, Chikal Patel, MD, Medical Director, Complex Care, Optum

Sandy Severson

# Background

Ethical challenges in health care are common because health care responds to human suffering. To act ethically should be integral to professionalism in health care. However, professionals often experience uncertainty or distress about how to proceed, Berlinger et al. (2020). Moral distress occurs when principles are in conflict or when one knows what should be done but is unable to effect changes such that the right thing is done.

Cases involving patients with life-threatening illness, including those who lack capacity to make decisions concerning life-sustaining interventions and other medical treatment, often give rise to uncertainty. If treatment wishes are not known, we err on the side of life sustaining interventions and ask later. Issues arise when advance care planning documents are completed but not available. On occasion a family member acts out of emotion and directs healthcare professionals to “do everything” which also causes distress for family, loved ones and healthcare providers, particularly when such requests conflict with patients wishes and/or advance directives. Institutional ethics services, such as clinical ethics consultant teams and ethics committees, respond to this practical reality by helping professionals, patients/residents (as able), and family members to reflect on choices and make informed decisions, with reference to the rights and preferences of patients and the duties of professionals to avoid harm, benefit patients, and act fairly while maintaining professional integrity.

A public health emergency, such as a surge of persons seeking health care as well as critically ill patients with COVID-19 disrupts normal processes for supporting ethically sound patient care. Clinical care is patient-centered, with the ethical course of action aligned, as far as possible, with the preferences and values of the individual patient.

Public health practice aims to promote the health of the population by minimizing community morbidity and mortality through the prudent use of resources and strategies, Berlinger et al. (2020). Ensuring the health of the population, especially in an emergency, can require limitations on individual rights and preferences. Public health ethics guides us in balancing this tension between the needs of the individual and those of the group.

While all health care resources are limited, public health emergencies in which triage is invoked may feature tragically limited resources that are insufficient to save lives that under normal conditions could be saved. There is a basic tension between the patient-centered approach of clinical care under normal conditions and the public-centered approach of clinical care under emergency conditions.

Significant moral distress is likely to arise for all providers, EMS, acute care, post-acute care, who must adhere to disaster-based protocols that require withdrawing or withholding treatment, especially life-sustaining treatment, over the objections of patients or families.

# Ethical principles

- 1. Autonomy:** In medicine, autonomy refers to the right of the patient to retain control over his or her body. A health care professional can suggest or advise, but any actions that aggressively attempt to persuade or coerce the patient into making a choice are violations of this principle. In the end, the patient must be allowed to make his or her own decisions – whether or not the medical provider believes these choices are in that patient’s best interests – independently and according to his or her personal values and beliefs. To exert autonomy a patient must have decision making capacity.
- 2. Beneficence:** This principle states that health care providers must do what they can to benefit the patient in each situation. All procedures and treatments recommended must be with the intention to do the most good for the patient. To ensure beneficence, medical practitioners must develop and maintain a high level of skill and knowledge, make sure that they are trained in the most current and best medical practices, and must consider their patients’ individual circumstances; what is good for one patient will not necessary benefit another.
- 3. Non-Maleficence:** Non-maleficence is probably the best known of the four principles. In short, it means, “to do no harm.” This principle is intended to be the end goal for all of a practitioner’s decisions and means that medical providers must consider whether other people or society could be harmed by a decision made, even if it is made for the benefit of an individual patient.
- 4. Justice:** The principle of justice states that there should be fairness in medical decisions. This includes fairness in the distribution of burdens and benefits, as well as fair distribution of scarce resources and new treatments. Justice assumes medical practitioners will uphold applicable laws and legislation when making choices. In general, the fair allocation of scarce resources in an emergency is not accomplished by the treating provider, but by public health officials and protocols.
- 5. Utilitarianism:** The doctrine that promotes producing the greatest good for the greatest number. This is the primary principle underlying triage in medicine.

6. **Efficiency:** minimizing the resources needed to produce a particular result or maximizing results with the resources available.
7. **Fairness/Equity:** Treating like cases alike. When cases are treated differently, it must be due to medical reasons and not morally irrelevant reasons such as race, sexual orientation, religion, ethnicity, or national origin. Gender is also normally irrelevant except for specific medical situations such as obstetrics.
8. **Liberty:** One should impose the least burden on a person's self-determination that is necessary to achieve a legitimate goal. This includes using the "least restrictive" means to obtain the outcome.
9. **Transparency:** Information about the processes and basis of decisions should be made available to the affected population and those that care for them.
10. **Participation:** -The stakeholders should be involved in the processes of formulating the plan.

# Ethical duties of healthcare leaders

***The duty of care that is foundational to health care.*** There is a duty to care for all patients.

This duty requires fidelity to the patient (non-abandonment as an ethical and legal obligation), the relief of suffering, and respect for the rights and preferences of patients, Berlinger et al. (2020).

These include the duty to:

- benefit the patient by providing treatments that provide more benefit than harm to them and avoiding what does not benefit them.
- respect patients as individuals and moral agents
- allow patients with capacity to make decisions regarding their healthcare based on full information

The duty of care and its ramifications are the primary focus of clinical ethics, through bedside clinical ethics consultation services, institutional policy development, and ethics education and training for clinicians.

***Duties to promote moral equality of persons and equity (fairness relative to need) in the distribution of risks and benefits in society.*** These duties generate subsidiary duties to promote public safety, protect community health, and fairly allocate among other activities. These duties and their ramifications are the primary focus of public health ethics, Berlinger et al. (2020).

Clinicians, such as physicians and nurses, are trained to care for individuals. Public health emergencies require clinicians to abide by public health measures, including, in some situations, acting to prioritize the community above the individual in fairly allocating scarce resources. The shift from patient-centered practice supported by clinical ethics to patient care guided by public health ethics creates great tension and moral distress for clinicians. Treating caregivers must be allowed to continue caring for patients; others are tasked with making difficult decisions that can be required in a triage situation. Such decisions must be based on criteria that are fair, transparent, clear, and consistently applied. If the situation is emergent and does not allow time for stakeholder input, the criteria and their ethical justification should at least be made widely available.

Health care institutions should acknowledge the tension between sources of authority for health care and public health in the contexts in which these tensions are most likely to arise in clinical practice. The duties of health care leaders to clinicians and community can be expressed as follows: to plan, to safeguard, to guide.

## The Duty to Plan:

### Managing Uncertainty

Health care leaders have a duty to plan for the management of foreseeable ethical challenges. Ethical challenges arise when there is uncertainty about how to “do the right thing” when duties or values conflict. These challenges affect the health care workforce and how a health care institution serves the public and collaborates with public officials, Berlinger et al. (2020). An example of this would be treating providers’ duty to provide the best care possible for an individual and public health officials duty to steward scarce resources carefully in an emergency with shortages of vital equipment or therapies.

Planning for foreseeable ethical challenges includes the identification of potential triage decisions, tools, and processes. In a health emergency decisions may have to be made about level of care including initiation of life-sustaining treatment (including CPR and ventilation support); withdrawal of life-sustaining treatment; and referral to palliative or even solely comfort-focused care if life-sustaining treatment will not be initiated or is withdrawn. Having a plan and resources removes the burden of decision making under pressure for clinicians providing direct care. Generally, a triage team composed on non-treating persons are responsible for making the difficult decisions in triage. The bedside clinician’s responsibility, therefore, remains to care and advocate for the patient in front of him/her.

Unfortunately in advanced triage situations, the usual standards of care will be breached (See the Arizona Crisis Standards of Care document at <https://www.azdhs.gov/documents/preparedness/emergency-preparedness/response-plans/azcsc-plan.pdf>). The COVID19 State Addendum has been created and released by the Arizona Department of Health Services. Under Crisis Standards some patients may not have access to equipment or therapies usually available. This means some will suffer, and some may die because of the emergency. It is therefore the duty of all involved in triage to ensure the process is fair.

## The Duty to Safeguard:

### Supporting Workers and Protecting Vulnerable Populations

Health care organizations across the continuum of care are major employers. Responding to organizational or public health emergencies includes safeguarding the health care workforce. During a surge of infectious illness, clinicians and nonclinicians, such as maintenance staff, may be at heightened risk of occupational harms, Berlinger et al. (2020). Vulnerable populations include those at higher risk due to factors such as age or underlying health conditions, and those with preexisting barriers to health care access, due to factors such as insurance status or immigration status. Health care organizations that employ trainees, such a medical students and nursing students, should recognize these workers as a vulnerable population.

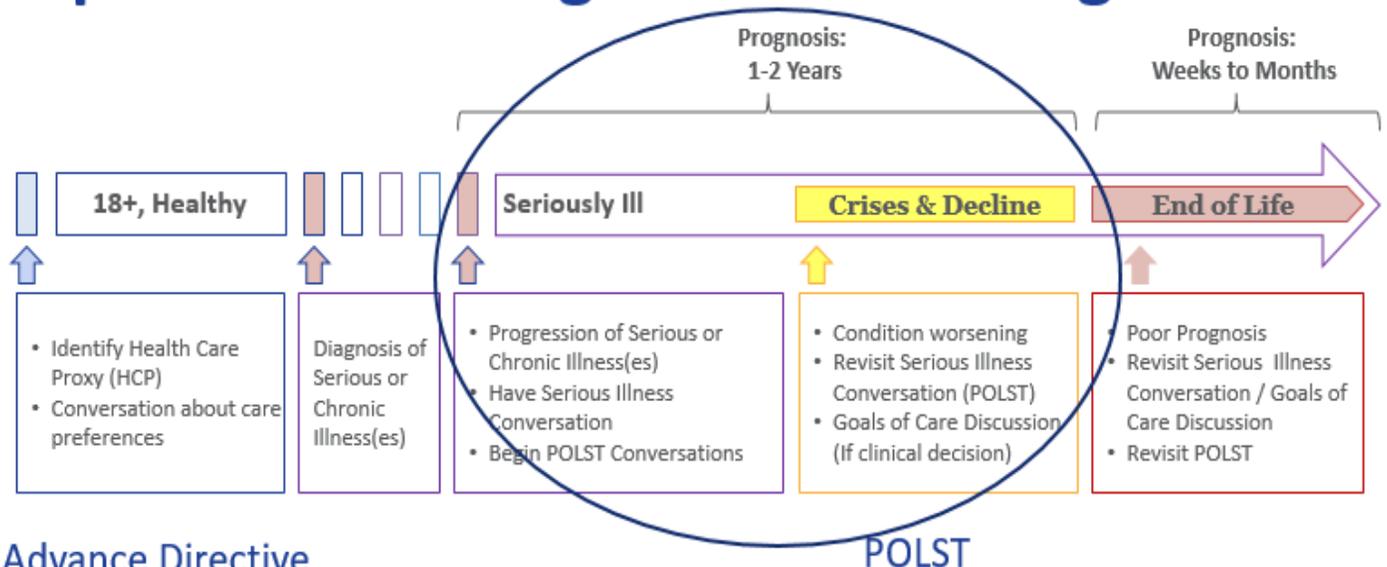
## The Duty to Guide:

An organizational or public health emergency requires planning for and potentially implementing a range of contingencies to manage the increased demand for care and the allocation of resources. All healthcare organizations across the continuum of care should have in place a process for ethics consultation. The consultations can function as a resource for clinicians experiencing uncertainty and distress as well as to assist in resolving ethical dilemmas in patient care. Focused preparation that includes organizational ethics resources are helpful in a public health emergency since there are clear differences between ethics consultation for individual patient issues and those related to public health emergencies. Ethics

consultations can augment, but not replace, written protocols including triage and other processes.

## Resources

# The right conversation at the right time... helps ensure the right care at the right time



### Advance Directive

- Planning for future care

Serious Illness Conversations begin - planning in the context of progression of serious illness  
Goals of Care Discussion = Decision making in context of clinical progression/crisis/poor prognosis

Adapted from Ariadne Labs, 2019

Planning for future healthcare needs is important for everyone over the age of 18. It becomes more important for those who have been diagnosed with a serious illness or frailty. A healthy person completes their own Living Will and Healthcare Power of attorney as a plan for future care. When diagnosed with a chronic illness or frailty it is time to talk to your healthcare provider about your future healthcare needs and your goals. Conversations between patients and healthcare providers about what matters most lead to higher quality care and improved quality of life for patients and those who care for them.

The COVID-19 pandemic makes communication both more difficult and more important than ever, particularly for people who are at highest risk of becoming very sick. Advance care planning becomes critical in the face of a pandemic. At a minimum, all patients should have an identified, documented Medical Power of Attorney so decisions can be made efficiently and effectively in keeping with the patient's wishes if the patient loses capacity. In addition, an honest discussion of Code Status as part of Goals of Care should occur with all patients.

This must include information specific to that patient's medical condition – including the likelihood of failure or success with CPR, and the possible and probable outcomes of CPR. Information regarding CPR success rates should include a disclosure that CPR can result in a dramatic decrease in quality of life (on life support, for example). The patient must be allowed to think about the risks and benefits of CPR (if it is being offered) and decide whether to accept (Full Code) or reject (DNR) that treatment. Patients should also be counseled that a DNR does not mean “no treatment” and that comfort care may never ethically be withheld.

## **Advance Care Planning Resources**

Forms for Advance Care Planning are a Living Will, Healthcare Power of Attorney and POLST. POLST is a set of portable medical orders documenting a person's wishes for advanced medical care (or informed refusal of such treatments), arrived through a shared decision-making discussion with a healthcare provider. Advance care planning could help in several areas, crisis or not – reduced ED visits, hospitalizations, ICU utilization, and increased home health and hospice use. Most importantly, advance care planning helps ensure the patient receives the treatments wanted and is spared the treatments that are unwanted.

The following advance care planning documents have all been revised to be person and family centered.

- [Arizona Living Will and Healthcare Power of Attorney short forms](#): A short one-page living will be followed by a one-page Healthcare Power of Attorney with Mental Health Authority option. This is a document that is understandable for all and still meets the legal requirements.
- [Arizona Prepare for Your Care Healthcare Directives](#): Large print, 4<sup>th</sup> grade reading level advance care planning documents. Includes the Prehospital Medical Care Directive and POLST directions.
- [Arizona Attorney General Healthcare Directives: Newly revised documents including POLST.](#)
- [Arizona POLST Form](#): Arizona POLST is aligned with National POLST using their standardized form.

## Arizona POLST In Action

Arizona POLST is part of the [National POLST Program](#) that helps patients get the medical treatments they want, and avoid medical treatments they do not want, when they are seriously ill or frail. It's about helping people live the way they want until they die. POLST is only for the seriously ill and frail and is different than an advance directive because it is a portable medical order completed by a healthcare provider after a goals of care conversation and shared decision making about current treatment preferences. POLST exists because other advance care planning documents (advance directives and DNR forms) do not meet the needs of all seriously ill and frail individuals. Visit the [AzPOLST](#) website to learn more about POLST and review educational modules available.

There are things we can do now to help relieve at least some of the moral distress we as healthcare providers are facing that will also help relieve anxiety and fear for those we serve. Every organization should have advance care planning resources and practices in place. Here are a few favorite resources to help healthcare providers and individuals:

[Thoughtful Life Conversations](#) – a program of the Arizona Hospital and Healthcare Association provides advance care planning resources and educational programs for individuals and clinicians.

## SERIOUS ILLNESS CONVERSATION GUIDE

### CLINICIAN STEPS 1-2-3

|   |   |
|---|---|
| <b>#1 Set up:</b>   |   |
| <ul style="list-style-type: none"> <li>Thinking in advance</li> <li>Is this okay?</li> <li>I will be using this guide, so I don't forget anything. Is that OK?</li> <li>Hope for best, prepare for worst</li> <li>Benefit for patient/family</li> <li>No decisions necessary today</li> </ul>   |   |
| <p>FOR EXAMPLE:<br/>         "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? We will hope for the best and prepare for the worst. This conversation will be a benefit to you and your family. Fortunately, no decisions are necessary today."</p> |   |
| <b>#2 Conversation:</b>   |   |
| <b>Understanding</b>  | What is your understanding now of where you are with your illness?  |
| <b>Information preferences</b>  | How much information about what is likely to be ahead with your illness would you like from me? FOR EXAMPLE:<br>Some patients like to know about time, others like to know what to expect, and other like to know both. |
| <b>Prognosis</b>  | <b>Share prognosis as a range, tailored to information preferences</b><br>E.g.: "I <b>wish</b> we were not in this situation, but I am <b>worried</b> that time may be as short as months to a year."                   |
| <b>Goals</b>  | If your health situation worsens, what are your most important goals?   |
| <b>Fears/Worries</b>  | What are your biggest fears and worries about the future with your health?  |
| <b>Function</b>   | What abilities are so critical to your life that you can't imagine living without them?   |
| <b>Trade-offs</b>   | If you become sicker, how much are you willing to go through for the possibility of gaining more time?  |
| <b>Family</b>   | How much does your family know about your priorities and wishes?  |
| <b>#3 Act:</b>  |   |
| <ul style="list-style-type: none"> <li>Make recommendations about next steps                             <ul style="list-style-type: none"> <li>Acknowledge medical realities</li> <li>Summarize key goals /priorities</li> <li>Describe treatment options that reflect both</li> </ul> </li> <li>Provide patient with "Family Communication Guide"</li> </ul>  |   |
| <p>FOR EXAMPLE:<br/>         "I've heard you say that _____ is really important to you. Keeping that in mind, and what we know about your illness, I <b>recommend</b> 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."</p>                                   |   |



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# SERIOUS ILLNESS CONVERSATION GUIDE

## Surrogate Language

|  |   |
|--|---|
| <b>#1 Set up:</b>  |   |
| <ul style="list-style-type: none"> <li>Thinking in advance</li> <li>Is this okay?</li> <li>I will be using this guide, so I don't forget anything. Is that OK?</li> </ul>  | <ul style="list-style-type: none"> <li>Hope for best, prepare for worst</li> <li>Benefit for patient/family</li> <li>No decisions necessary today</li> </ul>  |
| FOR EXAMPLE:<br>"I am hoping we can talk about where things are with your _____'s [e.g. wife's, husband's, other relationship description or name] illness and where they might be going. Is this okay?"   |   |
| <b>#2 Conversation:</b>  |   |
| <b>Understanding</b>   | "What is your understanding about where things are now with your _____'s illness?"  |
| <b>Information Preferences</b>   | "How much information about what is likely to be ahead with their illness would you like from me?"  |
| <b>Prognosis</b>   | <p><b>Share prognosis as a range, tailored to information preferences</b></p> <p>"I'd like to share my understanding of where things are now with your _____'s illness. Is that ok?" (PAUSE to assess/respond to emotion or surrogate questions)</p> <ul style="list-style-type: none"> <li>Discuss uncertainty: "It can be difficult to predict what will happen with _____'s illness. I hope he/she will be stable for a long time, but I'm worried that he/she could get sicker quickly. I think it's important to prepare for that possibility."</li> <li>Share and discuss time-based prognosis: "I wish we weren't in this situation, but I am worried that time might be as short as (days-weeks, weeks-months, months to a year)."</li> <li>Discuss function and progression of illness: "I hope this isn't the case, but I'm worried that this may be as strong as your _____ feels, and that things are likely to get more difficult for him/her."</li> </ul> |
| <b>Goals</b>   | "What is your sense of what your _____'s most important goals are if his/her health situation worsens?" "Are those your goals as well?"   |
| <b>Fears/Worries</b>   | <p>"What would your _____ say are his/her biggest fears and worries about his/her health?" "What gives your _____ strength in difficult times?"</p> <p>"And what gives you strength as you think about the future with your _____'s illness?"</p>   |
| <b>Function</b>  | "What abilities are so critical to your _____'s life that he/she could not imagine living without them?"  |
| <b>Trade-offs</b>  | "If your _____ would become sicker, how much do you think he/she would be willing to go through for the possibility of gaining more time?"  |
| <b>Family</b>  | How much does your family know about your priorities and wishes?  |
| <b>#3 Act:</b>   |   |
| <ul style="list-style-type: none"> <li>Make recommendations about next steps                             <ul style="list-style-type: none"> <li>Acknowledge medical realities</li> <li>Summarize key goals /priorities</li> <li>Describe treatment options that reflect both</li> </ul> </li> <li>Provide patient with "Family Communication Guide"</li> </ul> |   |
| FOR EXAMPLE:<br>"It sounds like _____ is very important to your _____ (or you and your _____)."<br>"Given _____'s goals and priorities and what we know about his/her illness at this stage, I recommend _____."<br>"Please know that we are here to help and that we will continue to work together to help your _____ meet his/her goals."                   |   |



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**\*\*\*EMPATHIC RESPONSES\*\*\***

|  | <b>Understanding</b>  | <b>Respecting</b>   | <b>Supporting</b>   | <b>Exploring</b>  | <b>"I Wish"</b>   |
|--|---|---|---|---|---|
| This must be... <ul style="list-style-type: none"> <li>• Frustrating</li> <li>• Overwhelming</li> <li>• Scary</li> <li>• Difficult</li> <li>• Challenging</li> <li>• Hard</li> </ul>                               | What you just said really helps me understand the situation better.   | I really admire your <ul style="list-style-type: none"> <li>• Faith</li> <li>• Strength</li> <li>• Commitment to your family</li> <li>• Thoughtfulness</li> <li>• Love for your family</li> </ul> | We will do our very best to make sure you have what you need. | Could you say more about what you mean when you say... <ul style="list-style-type: none"> <li>• I don't want to give up</li> <li>• I am hoping for a miracle</li> </ul> | I wish we had a treatment that would cure you (make your illness go away).<br><br>*[Remember we do have palliative treatments to offer the patient] |
| I'm wondering if you are feeling ... <ul style="list-style-type: none"> <li>• Sad</li> <li>• Scared</li> <li>• Frustrated</li> <li>• Overwhelmed</li> <li>• Anxious</li> <li>• Nervous</li> <li>• Angry</li> </ul> | This really helps me better understand what you are thinking.   | You (or your dad, mom, child, spouse) are/is such a strong person and have/has been through so much.  | Our team is here to help you with this.                       | Help me understand more about....   | I wish I had better news.   |
| It sounds like you may be feeling ...  | I can see how dealing with this might be ... <ul style="list-style-type: none"> <li>• hard on you</li> <li>• frustrating</li> <li>• challenging</li> <li>• scary</li> </ul> | I can really see how (strong, dedicated, loving, caring, etc.) you are.   | We will work hard to get you the support that you need.       | Tell me more...   | I wish the situation were different.  |
| In this situation some people might feel ...   | I can see how important this is to you.   | You are such a (strong, caring, dedicated) person.  | We are committed to help you in any way we can.               | Tell me more about what [a miracle, fighting, not giving up, etc.] might look like for you?   | I wish that for you too.<br><br>[In response to what a patient or family members wishes, such as a miracle]   |

|  |   |  |                             |                              |   |
|--|---|--|-----------------------------|------------------------------|---|
| I can't even imagine how ( <b>NAME EMOTION</b> ) this must be. | Dealing with this illness has been such a big part of your life and taken so much energy. | I'm really impressed by all that you've done to manage your illness (help your loved one deal with their illness). | We will go be here for you. | Can you say more about that? | I wish we weren't in this spot right now. |
|--|---|--|-----------------------------|------------------------------|---|

**\*\*\*RESPONSES TO CHALLENGING QUESTIONS\*\*\***

|   |   |  |
|---|---|--|
| <p><b>God's going to bring me a miracle:</b></p> <ul style="list-style-type: none"> <li>I hope that for you, too. (<b>Remember: no buts!</b>) (<b>SUPPORTING</b>)</li> <li>I really admire and respect. your faith (<b>RESPECTING</b>)</li> <li>Having faith is very important. (<b>RESPECTING</b>)</li> <li>Can you share with me what a miracle might look like for you? (<b>EXPLORING</b>)</li> </ul>      | <p><b>How much time do I have left?</b></p> <p><i><b>NOTE: This question may mean many things – they are scared, they want to know so they can plan, they are suffering, etc. Exploring what they want to know can be very helpful.</b></i></p> <ul style="list-style-type: none"> <li>That is a great question. I am going to answer it the best that I can. Can you tell me what you are worried about? (<b>EXPLORING</b>)</li> <li>That is a great question. I am going to answer it the best that I can. Can you tell me what information would be most helpful to you? (<b>EXPLORING</b>)</li> </ul> | <p><b>Are you saying there is nothing more you can do?</b></p> <ul style="list-style-type: none"> <li>I can't even imagine how (<b>NAME EMOTION</b>) this must be. (<b>NAMING</b>)</li> <li>It sounds like you might be feeling ... (<b>NAMING/EXPLORING</b>) <ul style="list-style-type: none"> <li>Alone</li> <li>Scared</li> <li>Frustrated</li> <li>Etc.</li> </ul> </li> <li>I wish we had a treatment that would cure you. Our team is here to help you through this. (<b>SUPPORTING</b>)</li> </ul> |
| <p><b>Are you telling me my dad is dying?</b></p> <p><i><b>NOTE: These responses will affirm the question empathically – so do not use them if the patient is not dying.</b></i></p> <ul style="list-style-type: none"> <li>I wish I had better news.</li> <li>This must be such a shock for you. (<b>NAMING</b>)</li> <li>I can't even imagine how difficult this must be. (<b>UNDERSTANDING</b>)</li> </ul> | <p><b>Are you giving up on me?</b></p> <ul style="list-style-type: none"> <li>I wish we had more curative treatments to offer. Our team is committed to help you in every way we can. (<b>SUPPORTING</b>)</li> <li>We will be here for you. (<b>SUPPORTING</b>)</li> <li>It sounds like you might be feeling ... (<b>NAMING/EXPLORING</b>) <ul style="list-style-type: none"> <li>Alone</li> <li>Scared</li> <li>Etc.</li> </ul> </li> <li>We will work hard to get you the support that you need. (<b>SUPPORTING</b>)</li> </ul>   | <p><b>My dad is a fighter!</b></p> <ul style="list-style-type: none"> <li>He is. He is such a strong person and he has been through so much. (<b>RESPECTING</b>)</li> <li>I admire that about him. (<b>RESPECTING</b>)</li> <li>I really admire how much you care about your dad. (<b>RESPECTING</b>)</li> <li>It must be (<b>NAME EMOTION</b>) to see him so sick. (<b>NAMING</b>)</li> <li>Tell me more about your dad and what matters most to him. (<b>EXPLORING</b>)</li> </ul>                       |

Goals of Care Conversations training materials were developed and made available for public use through U.S. Department of Veterans Affairs contracts with Vital Talk [Orders VA777-14-P-0400 and VA777-16-C-0015].

## Addressing Goals of Care: “REMAP”

We designed this talking map to give you a just-in-time route through a complex conversation. Think of it as a series of signposts—you might find that not all apply to a particular patient.

| Step   | What you say or do  |
|--|---|
| 1. Reframe why the status quo isn't working.                             | You may need to discuss serious news (e.g. a scan result) first. “Given this news, it seems like a good time to talk about what to do now.”<br>“We’re in a different place.”  |
| 2. Expect emotion & empathize.   | “It’s hard to deal with all this.”<br>“I can see you are really concerned about [x].”<br>“Tell me more about that—what are you worried about?” “Is it ok for us to talk about what this means?”   |
| 3. Map the future.   | “Given this situation, what’s most important for you?”<br>“When you think about the future, are there things you want to do?” “As you think towards the future, what concerns you?”   |
| 4. Align with the patient’s values.                                      | As I listen to you, it sounds the most important things are [x, y,z].   |
| 5. Plan medical treatments that match patient values.                    | Here’s what I can do now that will help you do those important things. What do you think about it?  |
| EXTRA:<br>Expect questions about more anticancer treatment.              | Here are the pros and cons of what you are asking about.<br>Overall, my experience tells me that more chemo would do more harm than good at this point.<br>It’s hard to say that though.  |
| EXTRA:<br>Talk about services that would help before introducing hospice | We’ve talked about wanting to conserve your energy for important things.<br>One thing that can help us is having a nurse come to your house to help us adjust your medicines, so you don’t have to come into clinic so often.<br>The best way I have to do that is to call hospice, because they can provide this service for us, and more. |



## Breaking Bad News Map: “SPIKES”

| <i>Step</i> | <i>Overview</i>  | <i>What you do</i>  |
|-------------|--|---|
| 1           | <b>Setting</b>   | Find a quiet location, private if possible,<br>Invite the important people to be present<br>Have tissues available<br>Have enough chairs<br>Turn off the ringer on your phone/pager   |
| 2           | <b>Perception</b> -- what the patient knows already    | “Tell me what you understand about your illness.”<br>“What have the other doctors told you about your illness?”<br><br>Look for knowledge and emotional information while the patient responds  |
| 3           | <b>Invitation</b> – information sharing preferences    | “Would it be okay for me to discuss the results of your tests with you now?”<br>“How do you prefer to discuss medical information in your family?”<br>“Some people prefer a global picture of what is happening and others like all the details, what do you prefer?” |
| 4           | <b>Knowledge</b> – give the information                | Give a warning... “I have something serious we need to discuss”<br>Avoid medical jargon.<br>Say it simply and stop. (e.g. “Your cancer has spread to your liver. It is getting worse despite our treatments.”)  |
| 5           | <b>Empathy</b> – respond to emotion                    | Wait quietly for the patient.<br>“I know this is not what you expected to hear today.”<br>“This is very difficult news.”  |
| 6           | <b>Summary</b> – discuss next steps and follow up plan | “We’ve talked about a lot of things today; can you please tell me what you understand.”<br>“Let’s set up a follow-up appointment.”  |



VITALtalk



## Discussing Prognosis "ADAPT"

We designed this talking map to give you a just-in-time route through a complex conversation. Think of it as a series of signposts—you might find that not all apply to a particular patient.

| Step   | What you say  |
|--|---|
| 1. <b>Ask</b> what the patient knows, what they want to know             | <p>What have other doctors told you about what your prognosis, or the future?<br/>How much have you been thinking about the future?</p>   |
| 2. <b>Discover</b> what info about the future would be useful for the pt | <p>For some people prognosis is numbers or statistics about how long they will live.<br/>For other people, prognosis is about living to a particular date. What would be more helpful for you?</p>  |
| 3. <b>Anticipate</b> ambivalence   | <p>Talking about the future can be a little scary.<br/>If you're not sure, maybe you could tell me how you see the pros and cons of discussing this.<br/>If clinically deteriorating: From what I know of you, talking about this information might affect decisions you are thinking about.</p>  |
| 4. <b>Provide</b> information in the form the patient wants              | <p>To provide using statistics:<br/>The worst-case scenario is [25<sup>th</sup> percentile], and the best-case scenario is [75<sup>th</sup> percentile].<br/>If I had 100 people with a similar situation, by [median survival], 50 would have died of cancer and 50 would still be alive with cancer.</p> <p>To provide without statistics:<br/>From my knowledge of your situation and how your cancer has been changing /responding, I think there is a good/50-50/slim chance that you will be able to be around [on that date/for that event].</p> |
| 5. <b>Track</b> emotion  | <p>I can see this is not what you were hoping for. I wish I had better news.<br/>I can only imagine how this information feels to you.<br/>I appreciate that you want to know what to expect.</p>   |



## Defuse conflicts

Running into conflict is inevitable. The pivot point is how you respond. If you habitually withdraw, you're not giving your best. If you feel you've got to win every time, you're creating resentment. Adapted from our paper in JAMA.

| Step  | What you say  |
|---|---|
| 1. <b>Notice the conflict</b>   | <p>This is an internal step—you might notice that you feel irritation, anger, boredom; or you might notice body language like eye rolling or a sideways glance.</p> <p>You can ignore conflict, but you run the risk that it will reemerge later.</p> |
| 2. <b>Find a non-judgmental starting point</b>  | <p>“Could we talk about what’s happening here?” Find a way to raise the issue without attacking.</p> <p>You need to pause before you rush to judgment, and you need to create space for the other person.</p>   |
| 3. <b>Listen to their story first</b>   | <p>“Tell me your perspective on this.”</p> <p>Give the other person your full attention.</p> <p>Don’t start mentally preparing your arguments.</p>  |
| 4. <b>Identify what the conflict is about, and articulate it as a shared interest</b> | <p>“Here is my take on the issue.”</p> <p>It seems to me that we are both interested in _____ [the patient’s well-being].”</p>  |
| 5. <b>Brainstorm options</b>  | <p>Could we list a couple of options, then spend a minute talking about the pros and cons?”</p>   |
| 6. <b>Look for options that recognize the interests of all involved</b>               | <p>“I see how this meets your interest in _____.”</p> <p>Perhaps we should consider to be a good marker of whether we are going in the right direction?” [proposing a trial of something for a defined period of time may be worthwhile]</p>          |
| 7. <b>Remember that some conflicts cannot be resolved</b>                             | <p>We talk about defusing because not every conflict has a solution that everyone feels good about. Sometimes you need to agree that you don’t agree.</p>   |



## NURSE statements for articulating empathy

|                     | Example  | Notes  |
|---------------------|--|--|
| Naming              | “It sounds like you are frustrated”  | In general, turn down the intensity a notch when you name the emotion  |
| Understanding       | “This helps me understand what you are thinking”   | Think of this as another kind of acknowledgment but stop short of suggesting you understand everything (you don’t) |
| Respecting          | “I can see you have really been trying to follow our instructions”                         | Remember that praise also fits in here e.g. “I think you have done a great job with this”                          |
| Supporting          | “I will do my best to make sure you have what you need”                                    | Making this kind of commitment is a powerful statement   |
| Exploring           | “Could you say more about what you mean when you say that...”                              | Asking a focused question prevents this from seeming too obvious   |
|                     | Three fundamental skills   |  |
|                     | Example  | Notes  |
| Tell me more        | “Tell me more about...”  | Use when you are not sure what someone is talking about (rather than jump to an assumption).                       |
| Ask-tell-ask        | “What do you think about...”<br>“Here’s what the tests show”<br>“Does that make sense...?” | Related to Assess-Knowledge-Respond in SPIKES. Think of this as one unit of information transfer                   |
| “I wish” statements | “I wish I could say that the chemo always works”   | Enables you to align with the patient while acknowledging the reality of the situation                             |



## Get to Know Me

Things I use at home  
(eyeglasses, contacts,  
hearing aid, dentures)

People who are  
important to me

Things I'm proud  
of

Things I dislike

My favorite  
artists, movies,  
etc.

Things I like to do

My spiritual  
beliefs

I like to be called:

My profession is/or was:

## The Four Box Model

### The Four Principles of Bioethics

| <b>Medical Indications</b>   | <b>Preferences of Patients</b>  |
|--|---|
| <p style="text-align: center;"><i>Beneficence and Nonmaleficence</i></p> <ol style="list-style-type: none"> <li>1. What is the patient's medical problem?</li> <li>2. Is the problem acute? Chronic? Critical? Reversible? Emergent? Terminal?</li> <li>3. What are the goals of treatment?</li> <li>4. In what circumstances are medical treatments not indicated?</li> <li>5. What are the probabilities of success of various treatment options?</li> <li>6. What are the risks of treatment?</li> <li>7. In sum, how can this patient be benefited by medical, nursing or therapy care, and how can harm be avoided?</li> </ol>  | <p style="text-align: center;"><i>Respect for Autonomy</i></p> <ol style="list-style-type: none"> <li>1. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?</li> <li>2. Has the patient been informed of benefits and risks of diagnostic and treatment recommendations, understood this information, and communicated consent?</li> <li>3. Is the patient mentally capable (decision making capacity) and legally competent?</li> <li>4. If mentally capable/competent, what are the patient's preferences?</li> <li>5. If incapacitated, has the patient expressed prior preferences?</li> <li>6. Who is the appropriate surrogate to make decisions for an incapacitated patient?</li> <li>7. What standards should govern the surrogate's decisions?</li> </ol>  |
| <b>Quality of Life</b>   | <b>Contextual Features</b>  |
| <p style="text-align: center;"><i>Beneficence and Nonmaleficence and Respect for Autonomy</i></p> <ol style="list-style-type: none"> <li>1. What are the prospects, with or without treatment, for a return to an acceptable quality of life and what physical, mental, and social deficits might the patient experience even if treatment succeeds?</li> <li>2. On what grounds or by what criteria should evaluate the quality of life of a patient who cannot make or express such a judgment?</li> <li>3. Are there biases that might prejudice the provider's evaluation of the patient's quality of life?</li> <li>4. What ethical issues arise concerning improving or enhancing a patient's quality of life?</li> <li>5. Do quality of life assessment raise any questions that might contribute to a change of treatment plan, such as forgoing life-sustaining treatment?</li> <li>6. Are there plans to provide pain relief and provide comfort after a decision has been made to forgo life-sustaining interventions?</li> <li>7. Is medically assisted dying ethically or legally permissible?</li> </ol> | <p style="text-align: center;"><i>Justice</i></p> <ol style="list-style-type: none"> <li>1. Do decisions about treatment and diagnosis raise issues of fairness?</li> <li>2. Are there professional, interprofessional, personal, interpersonal, or business interests that might create conflicts of interest in the clinical treatment of patients?</li> <li>3. Are there parties other than clinicians and patient, such as family members, who have a legitimate interest in clinical decisions?</li> <li>4. What are the limits imposed on patient confidentiality by the legitimate interests of third parties?</li> <li>5. Are there financial factors that create conflicts of interest in clinical decisions?</li> <li>6. Are there problems of allocation of resources that affect clinical decisions?</li> <li>7. Are there religious factors that might influence clinical decisions?</li> <li>8. What are the legal issues that might affect clinical decisions?</li> <li>9. Are there considerations of clinical research and medical education that affect clinical decisions?</li> <li>10. Are there considerations of public health and safety that influence clinical decisions?</li> <li>11. Does institutional affiliation create conflicts of interest that might influence clinical decisions?</li> </ol> |

Jonsen et al. (2020)

If you are experiencing a clinical ethical problem The Four Box Model is an operational tool that can be used in any care setting to assist in providing essential information to begin a thoughtful review of the facts and issues. These four topics provide a method to collect, sort, and order the facts and opinions regarding the ethical dilemma.

The four topics or boxes are: 1) Medical indication refer to the diagnostic and therapeutic interventions that are being used to evaluate and treat the medical problem. 2) Patient preferences state the express choices of the patient about their treatment, or the decisions of those who are authorized to speak for the patient if they are incapable of doing so. 3) Quality of Life describes the satisfaction, pleasure and well-being or the degree of distress and malfunction that people experience in their life prior to and following treatment. 4) Contextual features identify the social, institutional, financial, and legal settings, within which any particular case of patient care takes place and influence medical decision-making.

Cases that present ethical challenges may begin as disagreements between parties who all want the best outcome for the patient. We want to take a practical approach but must go beyond simply identifying the problem by collecting and sorting the facts of the case. We must identify solutions to manage the problem. Clinical ethics is seldom about right and wrong. It also involves finding the better, more right, and more reasonable solutions among several options, Jonsen et al. (2020)

As you work to gather information about the case, you must identify the most relevant and important issues. Working through the boxes help to do this sorting. Next steps are a moral reasoning that help to produce clarification of the issues and options. One must consider a range of options and work to find ones that are?

After the ethical problem is identified and assessed, a resolution must be reached. The recommended resolution usually takes the form of an opinion by the clinician as a recommendation to the patient or other decision-makers in the case, based on the facts related to the ethical principles.

In complex ethical issues once must weigh and measure the moral issues with other colleagues or an ethics committee. Clinical medicine can be messy and there is not always a clear solution. One must weigh all four topics and principles in this model with relevant circumstances considered. The resolution must consider the “whole” or “all things considered”.

We are reminded of Dr. William Osler’s observation, made more than 100 years ago but still relevant: “medicine is a science of uncertainty and an art of probability”. And Dr Francis Peabody who noted in 1927: “the secret of the care of the patient is in caring for the patient” Jonsen et al. (2020).

## Informed Consent Example

### Assess person's values and goals

- Elicit values and preferences for therapies and outcomes from the person or designated family member and formulate overall therapeutic goals

"Is it important to your mother to live as long as possible, no matter what her quality of life, or are there circumstances in which she would not want to receive live support, such as a prolonged nursing home stay?"

Yes

Is longevity the person's primary value above all else, including quality of life?

No

Proceed with informed consent

Informed assent not appropriate

### Discuss prognosis and treatment options

- Describe prognosis and all treatment options, including life sustaining treatments and supportive care with risk, benefits, and alternatives

"We want to be sure we are taking the best possible care of your mother, so I would like to talk to you about her health, treatment options and future care."

### Present a definitive informed consent statement

- Inform the person or the person's family what life sustaining treatments (describe specifics) will be offered.

"Since life sustaining treatments (describe specifics) may work to achieve your mother's goals in this situation, we will provide them. "

### Assess understanding and allow for objection

- Discuss the person's or family's understanding of the informed consent statement, the decisions made, and verify their understanding

"I want to make sure you understand. Do you have any questions?"

## Informed Assent Example

### Assess person's values and goals

- Elicit values and preferences for therapies and outcomes from the person or designated family member and formulate overall therapeutic goals

"Is it important to your mother to live as long as possible, no matter what her quality of life, or are there circumstances in which she would not want to receive live support, such as a prolonged nursing home stay?"

No

Is longevity the person's primary value above all else, including quality of life?

Yes

Proceed with informed assent

Informed assent not appropriate

### Discuss treatment options

- Describe all treatment options, including life sustaining treatments and supportive care

"We want to be sure we are taking the best possible care of your mother, so I would like to talk to you about treatment options and future care."

### Present a definitive assent statement

- Inform the person or the person's family that life sustaining treatments (describe specifics) will not be offered.

"Since life sustaining treatments (describe specifics) will not work to achieve your mother's goals in this situation, we do not provide it. "

### Assess understanding and allow for objection

- Discuss the person's or family's understanding of the assent statement, the decisions made, and any objections they may have

"I want to make sure you understand. Do you have any questions?"

# COVID Resources

## COVID Ready Communication Playbook



### Screening

WHEN SOMEONE IS WORRIED, THEY MIGHT BE INFECTED

---

#### What They Say

Why aren't they testing everybody?

Why do the tests take so long?

How come the basketball players got tested?

#### What You Say

We don't have enough test kits. **I wish it were different.**

The lab is doing them as fast as they can. **I know it's hard to wait.**

I can imagine it feels unfair. I don't know the details, but what I can tell you is that was a different time. **The situation is changing so fast that what we did a week ago is not what we are doing today.**

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## Preferencing

### WHEN SOMEONE MAY WANT TO OPT OUT OF HOSPITALIZATION

---

I am worried about this new virus. What should I be doing?

**You are right to be concerned. Here's what you can do.** Please limit your contact with others—we call it social distancing. **Then you should pick a person who knows you well enough to talk to doctors for you if you did get really sick.** That person is your proxy. Finally, if you are the kind of person who would say, no thanks, I don't want to go to the hospital and end up dying on machines, you should tell us and your proxy.

I realize that I'm not doing well medically even without this new virus. I want to take my chances at home / in this long-term care facility.

Thank you for telling me that. **What I am hearing is that you would rather not go to the hospital if we suspected that you have the virus.** Did I get that right?

I don't want to come to the end of my life like a vegetable being kept alive on a machine. [in a long-term care facility or at home]

I respect that. Here's what I'd like to propose. We will continue to take care of you. The best case is that you don't get the virus. The worst case is that you get the virus despite our precautions—and then we will keep you here and make sure you are comfortable for as long as you are with us.

I am this person's proxy / health care agent. I know their medical condition is bad—that they probably wouldn't survive the virus. Do you have to take them to the hospital?

It is so helpful for you to speak for them, thank you. If their medical condition did get worse, we could arrange for hospice (or palliative care) to see them where they are. We can hope for the best and plan for the worst.

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## Triaging

### WHEN YOU ARE DECIDING WHERE A PATIENT SHOULD GO

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#### What They Say

Why shouldn't I just go to the hospital?

Why are you keeping me out of the hospital?

#### What You Say

Our primary concern is your safety. We are trying to organize how people come in. Please fill out the questions online. **You can help speed up the process for yourself and everyone else.**

**I imagine you are worried and want the best possible care.** Right now, the hospital has become a dangerous place unless you really, really need it. The safest thing for you is to take them to the hospital.

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## Admitting

### WHEN YOUR PATIENT NEEDS THE HOSPITAL, OR THE ICU

---

Does this mean I have COVID19?

How bad is this?

Is my grandfather going to make it?

Are you saying that no one can visit me?

We will need to test you with a nasal swab, and we will know the result by tomorrow. **It is normal to feel stressed when you are waiting for results,** so do things that help you keep your balance.

From the information I have now and from my exam, your situation is serious enough that you should be in the hospital. **We will know more in the next day,** and we will update you.

**I imagine you are scared.** Here's what I can say: because he is 90, and is already dealing with other illnesses, **it is quite possible that he will not make it out of the hospital. Honestly, it is too soon to say for certain.**

**I know it is hard to not have visitors.** The risk of spreading the virus is so high that I am sorry to say we cannot allow visitors. **They will be in more danger if they come into the hospital.** I wish things were different. You can use your phone, although I realize that is not quite the same.

How can you not let me in for a visit?

The risk of spreading the virus is so high that I am sorry to say we cannot allow visitors. We can help you be in contact electronically. **I wish I could let you visit because I know it's important. Sadly, it is not possible now.**

## Counseling

### WHEN COPING NEEDS A BOOST, OR EMOTIONS ARE RUNNING HIGH

---

#### What They Say

I'm scared.

#### What You Say

This is such a tough situation. **I think anyone would be scared.** Could you share more with me?

I need some hope.

Tell me about the things you are hoping for? **I want to understand more.**

You people are incompetent!

I can see why you are not happy with things. **I am willing to do what is in my power to improve things for you.** What could I do that would help?

I want to talk to your boss.

I can see you are frustrated. **I will ask my boss to come by as soon as they can. Please realize that they are juggling many things right now.**

Do I need to say my goodbyes?

I'm hoping that's not the case. And I worry time could indeed be short. What is most pressing on your mind?

---

## Deciding

### WHEN THINGS AREN'T GOING WELL, GOALS OF CARE, CODE STATUS

---

I want everything possible. I want to live.

We are doing everything we can. This is a tough situation. Could we step back for a moment so I can learn more about you? **What do I need to know about you to do a better job taking care of you?**

I don't think my spouse would have wanted this.

Well, let's pause and talk about what they would have wanted. Can you tell me what they considered most important in their life? **What meant the most to them, gave their life meaning?**

I don't want to end up being a vegetable or on a machine.

I am not sure what my spouse wanted — we never spoke about it.

Thank you, it is very important for me to know that. **Can you say more about what you mean?**

You know, many people find themselves in the same boat. This is a hard situation. To be honest, given their overall condition now, if we need to put them on a breathing machine or do CPR, they will not make it. The odds are just against us. **My recommendation is that we accept that he will not live much longer and allow him to pass on peacefully. I suspect that may be hard to hear.** What do you think?

## Resourcing

### WHEN LIMITATIONS FORCE YOU TO CHOOSE, AND EVEN RATION

#### What They Say

Why can't my 90-year-old grandmother go to the ICU?

Shouldn't I be in an intensive care unit?

My grandmother needs the ICU! Or she is going to die!

Are you just discriminating against her because she is old?

You're treating us differently because of the color of our skin.

#### What You Say

**This is an extraordinary time. We are trying to use resources in a way that is fair for everyone.** Your grandmother's situation does not meet the criteria for the ICU today. I wish things were different.

Your situation does not meet criteria for the ICU right now. The hospital is using special rules about the ICU because we are trying to use our resources in a way that is fair for everyone. **If this were a year ago, we might be making a different decision. This is an extraordinary time.** I wish I had more resources.

I know this is a scary situation, and I am worried for your grandmother myself. **This virus is so deadly that even if we could transfer her to the ICU, I am not sure she would make it.** So, we need to be prepared that she could die. We will do everything we can for her.

I can see how it might seem like that. No, we are not discriminating. **We are using guidelines that were developed by people in this community to prepare for an event like this.** The guidelines have been developed over the years, involving health care professionals, ethicists, and lay people to consider all the pros and cons. I can see that you really care about her.

**I can imagine that you may have had negative experiences in the past with health care simply because of who you are.** That is not fair, and I wish things had been different. The situation today is that our medical resources are stretched so thin that we are using guidelines that were developed by people in this community, including people of color, so that we can be fair. I do not want people to be treated by the color of their skin either.

## What They Say

## What You Say

---

It sounds like you are rationing.

What we are doing is trying to spread out our resources in the

You are playing God. You can't do that.

Best way possible. **This is a time where I wish we had more for every single person** in this hospital.

I am sorry. I did not mean to give you that feeling. Across the city, every hospital is working together to try to use resources in a way that is fair for everyone. I realize that we don't have enough. I wish we had more. Please understand that we are all working as hard as possible.

## Notifying

WHEN YOU ARE TELLING SOMEONE OVER THE PHONE

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Yes, I'm his daughter. I am 5 hours away.

I have something serious to talk about with you. Are you in a place where you can talk?

What is going on? Has something happened?

I am calling about your father. He died a short time ago. The cause was COVID19.

[Crying]

I am so sorry for your loss. **[Silence] [If you feel you must say something: Take your time. I am here.]**

I knew this was coming, but I didn't realize it would happen this fast.

I can only imagine how shocking this must be. It is sad. **[Silence] [Wait for them to restart]**

---

## Anticipating

WHEN YOU'RE WORRYING ABOUT WHAT MIGHT HAPPEN

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### What You Fear

That patient's son is going to be very angry.

### What You Can Do

Before you go in the room, take a moment for one deep breath.

**What's the anger about?** Love, responsibility, fear?

## What You Fear

I don't know how to tell this adorable grandmother that I can't put her in the ICU and that she is going to die.

I have been working all day with infected people and I am worried I could be passing this on to the people who matter most.

I am afraid of burnout, and of losing my heart.

I'm worried that I will be overwhelmed and that I won't be able to do what is really the best for my patients.

## What You Can Do

**Remember what you can do:** you can hear what she's concerned about, you can explain what's happening, you can help her prepare, you can be present. These are gifts.

Talk to them about what you are worried about. You can decide together about what is best. There are no simple answers. **But worries are easier to bear when you share them.**

Can you look for moments every day where you connect with someone, share something, enjoy something? **It is possible to find little pockets of peace even in the middle of a maelstrom.**

Check your own state of being, even if you only have a moment. If one extreme is wiped out, and the other is feeling strong, where am I now? **Remember that whatever your own state, that these feelings are inextricable to our human condition.** Can you accept them, not try to push them away, and then decide what you need?

# Grieving

## WHEN YOU'VE LOST SOMEONE

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### What You're Thinking

I should have been able to save that person.

OMG I cannot believe we don't have the right equipment / how mean that person was to me / how everything I do seems like its blowing up.

### What You Can Do

Notice: **am I talking to myself the way I would talk to a good friend?** Could I step back and just feel? Maybe it's sadness, or frustration, or just fatigue. Those feelings are normal. And these times are distinctly abnormal.

Notice: **am I letting everything get to me?** Is all this analyzing really about something else? Like how sad this is, how powerless I feel, how puny our efforts look? Under these conditions, such thoughts are to be expected. But we don't have to let them suck us under. Can we notice them, and feel them, maybe share them?

And then ask ourselves: **can I step into a less reactive, more balanced place even as I move into the next thing?**

# New Talking Maps for Contingency and Crisis

## PROACTIVE PLANNING

### FOR PROACTIVE PLANNING IN CONTINGENCY: “CALMER”

The COVID-As-A-Starter Preferences or Goals Talk For Patients In A Health Care Setting.

- C** — **Check In**
  - “How are you doing with all this?” (Take their emotional temperature.)
- A** — **Ask About COVID**
  - “What have you been thinking about COVID and your situation?”
  - (Just listen)
- L** — **Lay Out Issues**
  - “Here is something I want us to be prepared for.” / “You mentioned COVID. I agree.”
  - “Is there anything you want us to know if you got COVID / if your COVID gets really bad?”
- M** — **Motivate Them to Choose A Proxy And Talk About What Matters**
  - “If things took a turn for the worse, what you say now can help your family / loved ones”
  - “Who is your backup person — who helps us make decisions if you can’t speak? Who else?  
(having 2 backup people is best)
  - “We’re in an extraordinary situation. Given that, what matters to you? (About any part of your life? About your health care?)
  - Make a recommendation — if they would be able to hear it. “Based on what I’ve heard, I’d recommend [this]. What do you think?”
- E** — **Expect Emotion**
  - Watch for this — acknowledge at any point
  - “This can be hard to think about.”
- R** — **Record the Discussion**
  - Any documentation — even brief — will help your colleagues and your patient
  - “I’ll write what you said in the chart. It’s really helpful, thank you.”

## New Talking Maps for Contingency and Crisis

### RESOURCE LIMITS

#### FOR CRISIS ONLY: “SHARE”

Talking About Resource Allocation (I.e. Rationing).

- S** — **Show the guideline**
- “Here’s what our institution / system / region is doing for patients with this condition.”
  - (Start the part directly relevant to that person.)
- H** — **Headline What It Means for The Patient’s Care**
- “So, for you, what this means is that we care for you on the floor and do everything we can to help you feel better and fight this illness. What we won’t do is to transfer you to the ICU or do CPR if your heart stops.
  - (Note that you talk about what you *will* do first, then what you won’t do)
- A** — **Affirm the Care You Will Provide**
- “We will be doing [the care plan], and we hope you will recover.”
- R** — **Respond to Emotion**
- “I can see that you are concerned.”
- E** — **Emphasize That The Same Rules Apply To Everyone**
- “We are using the same rules with every other patient in this hospital / system / institution. We are not singling you out.”

---

This talking map is only used when an institution has declared use of crisis standards of care, or a surge state. When the crisis standards or surge are discontinued, this map should no longer be used.

---

# New Talking Maps for Contingency and Crisis

## THE LAST FAMILY CALL

### When You Need To **Talk** To A Family Member: “LOVE”

On the Phone / Video To Saying Goodbye To A Patient Who Is In Their Last Hours Or Minutes.

- L** — **Lead the Way Forward**
- “I am [Name], one of the [professionals] on the team.”
  - “For most people, this is a tough situation.”
  - “I’m here to walk you through it if you’d like.”
- O** — **Offer the Four Things That Matter To Most People**
- “So, we have the opportunity to make this time special.”
  - “Here are five things you might want to say. Only use the ones that ring true for you.”
    1. Please forgive me
    2. I forgive you
    3. Thank you
    4. I love you
    5. Goodbye
  - “Do any of those sound good?”
- V** — **Validate What They Want to Say**
- “I think that is a beautiful thing to say”
  - “If my [daughter] were saying that to me, I would feel so valued and so touched.”
  - “I think he/she can hear you even if they can’t say anything back”
  - “Go ahead, just say one thing at a time. Take your time.”
- E** — **Expect Emotion**
- “I can see that he/she meant a lot to you.”
  - “Can you stay on the line a minute? I just want to check on how you’re doing”

# Communication Skills for Bridging Inequity

COVID-Ready Communication Playbook by VitalTalk.

Never before have the levels of inequity in our society been more clearly visible than now, as we deal with the COVID pandemic. These communication skills, developed in conjunction with VitalTalk collaborators & friends with expertise and experience in this space, are meant to provide tools for front-line clinicians. We recognize that communication skills alone are not going to fix structural racism. But we think these skills could enable clinicians to understand our patients' experiences better, and to meet them where they are.

We acknowledge that these skills don't address social determinants more broadly. But we felt that racism is important enough to call out specifically as a skills focus. As before, we welcome your feedback, ideas, and contributions. Thank you!

## 1. Watch for behaviors that signal mistrust.

(Principle: mistrust is often expressed nonverbally—we call these mistrust cues)

| What the patient does or says   | What the clinician says   |
|---|---|
| Gestures that say 'I don't really want to be here' such as closed posture, folded arms, stern glances, or eye rolls | "It looks as if you might have something on your mind. Is it something that might help me understand your situation better?"                            |
| "I am concerned that I am not being told everything about COVID".   | "There is a lot of information out there, and some of it is not factual. Let's start with your most important concerns. Your trust is important to me." |

## 2. Probe for experiences of racism.

(Principle: naming racism explicitly show that you recognize that it exists)

| What the patient does or says   | What the clinician does and says   |
|---|--|
| Patient recounts something they have seen in the news about how COVID affects black people, e.g. "I have read that black people are more impacted by COVID."            | "I have read that also. Are you concerned that racism may be involved?"<br><br>A follow-up: "What does racism look like from your perspective?"                |
| Patient describes an instance where a family member had a negative outcome with care, e.g., "My aunt did what they told her to do, but still ended up in the hospital." | "Anybody would be concerned about that. I would be concerned too. What happened?... Do you think she was being treated differently because of her background?" |

### 3. Acknowledge harms that occurred from prior care.

(Principle: acknowledging racism explicitly can build trust)

| What the patient does or says   | What the clinician does and says   |
|---|--|
| Patient describes frustration or lack of engagement with health care, e.g., “I went to the emergency room, but they didn’t really do anything.” | “I have heard from other black patients that they have had negative experiences with health care that make it hard to trust the medical system. I realize that racism exists in medical care. How much has it affected you?” |
| Patient describes frustration with a clinician, e.g., “That doctor did not seem to listen to me.”   | “That sounds frustrating. I acknowledge that we clinicians don’t always listen well, and sometimes racism is involved. I want to do what I can to help you get the care you need.”   |

### 4. Offer to partner in the way the patient wants.

(Principle: allow the patient to describe what they would like before you jump in)

| What the patient does or says   | What the clinician does and says  |
|---|---|
| Patient voices interest in their own health, e.g. “I have been trying to take care of myself.”                            | “I am glad to hear that you take care of yourself. How could we work together on your health?”  |
| Patient voices understanding of recent diagnostic tests (after clinician has explained them). “Ok, what do I need to do?” | <p>“I’m going to explain a plan that would be the best treatment for your medical condition. Then I want to hear your thoughts and concerns about the plan because we can customize it for you.”</p> <p>And: “Please don’t hesitate to ask for clarity on the words I use. We medical people sometimes speak in another language. My goal is to help you in the best possible way.”</p> |

### 5. Invite the patient to bring in important people from their community.

(Principle: cultural norms may involve decisions by an extended social group, rather than an individual)

| What the patient does or says  | What the clinician does and says   |
|--|--|
| After hearing the treatment recommendation, the patient says, “I’ll think about that.” | “Many of my patients want to include someone from their family or faith or community in medical decisions, and I welcome that. If there is someone that you want to bring into this discussion, we can do that.” |

## National POLST: Completing POLST Forms in Crisis Standards of Care

COVID-19 is an emergency health crisis declared by public health officials worldwide, in the US and throughout the country at the State and national and local levels. Patients who have a POLST, who may be POLST appropriate but never engaged in advance care planning conversations, or who may be diagnosed with conditions that put them at high risk of dying from COVID-19, should be approached about their treatment wishes and POLST. For many, resource limitations (e.g., ventilator shortages) and the high mortality for older adults infected with COVID-19 may mean the treatment decisions these patients make may apply only to the current health crisis and may change once the crisis abates. In the face of a crisis, responsible health leaders may establish response measures for clinicians that fall outside their normal procedure or protocol. When surge demands exceed the ability of providers to respond normally, this may impact the types of treatments certain affected populations may receive.

POLST forms were created to be dynamic. As currently drafted, POLST forms easily meet the challenges of COVID-19 and treating patients during crisis standards of care. The patient can void their POLST forms at any time.

National POLST encourages facilities to consider the following guidance for completing POLST Forms during surge or crisis standards of care times:

1. Ensure all appropriate staff are educated about having and documenting effective POLST conversations about the patient's goals of care considering the current diagnosis, prognosis, and treatment options (including risks and benefits), discussion of the crisis standards of care, any unique risks or challenges about transfers to hospitals, and how to complete a POLST form. Resources are available at [www.polst.org/covid](http://www.polst.org/covid)
2. Be proactive and approach patients who do not have a POLST form about POLST if they are considered to be at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty. [See here for additional information and examples of appropriate people to approach about POLST](#). Make certain that the clinical indicators are used, and that age is not a sole criterion.
3. Maintain a master list of all patients who completed a POLST (regardless of whether it was their first POLST or a modification from a previous POLST) during the COVID-19 crisis. After resolution of the crisis, review their POLST forms with these patients and determine if any change in the orders are needed.
4. If the form is completed because of a change from normal to surge or crisis standards, consider ways to document this fact on the form itself and/or to other providers using other medical or chart records. If the form was completed in the context of the COVID-19 threat or its imminent spread, and the orders do not necessarily reflect what the individual would choose under normal conditions, signatories should note it on the form.

# Meet My Loved One

## A Tool To Help Bedside Care Team Deliver Person-Centered Compassionate Care during COVID-19

Dear Caregivers and Families,

We understand the COVID-19 Visitor Restriction has been implemented in our hospital to protect you and your loved ones from potential exposure. We wanted to assure you that we strive to provide the best care to your loved one during his/her hospital stay. We know you know your loved one the best and wanted to partner with you to provide person-centered, supportive, compassionate care for him/her as if you were at the bedside. Please use this tool to provide information you want us to know about your loved one as a person and his/her care needs.

Thank you,

Enter Your Organization Name

### Meet My Loved One

Hi Team!

My name is: \_\_\_\_\_ Please meet my: \_\_\_\_\_  
(relationship to you)

His/Her/Their preferred name is: \_\_\_\_\_

She/He/They enjoys: \_\_\_\_\_  
(Hobbies, activities, special interests)

His/Her/Their favorite things are: \_\_\_\_\_  
(Food, drinks, music, conversation topics)

Other important aspects I want you to know about my loved one:

---

Tips to care for Her/Him/Them:

- 1.
- 2.
- 3.
- 4.

I'd like to be contacted via phone. Please contact me at: \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

Provided by:

 CENTER FOR PALLIATIVE  
AND SUPPORTIVE CARE



## Phone Call to Family/Loved Ones After Death

End-of-Life Information for Family Support Follow-up calls: Any information or story you can briefly share about a patient's death will assist in making a follow-up call to family:

**Which staff came by or were present during last hour of patient's life/end-of-life journey?**

**Was anything specific to the patient offered during death?** -i.e. was blanket from home on patient, any kind of music playing, family photo displayed at bedside table, a prayer or blessing given?

**Was a "Code Pause" (moment of silence in honor of the patient's life) offered?**

**As the care provider, what did you appreciate about this patient?**

*Resource Unknown*

# COVID-19 Conversation Guide for Inpatient Care

## CONTEXT AND DESCRIPTION

**What?** This communication tool offers language to assist clinicians in having conversations with patients who have suspected or confirmed Covid-19 about their values and preferences. This can inform decisions about life-sustaining treatments and ensure the highest quality care.

**Why?** Communication with hospitalized patients with confirmed or suspected Covid-19 about their treatment preferences presents unique challenges. These include uncertainty about illness trajectory, [high risk of critical illness or death](#) for some, high levels of distress, and use of virtual communication platforms. High quality conversations that help patients understand their specific vulnerabilities and share their worries and priorities can inform shared decision-making about life sustaining treatments.

**Who?** The Guide is for all inpatient clinicians who take care of patients with Covid-19. This conversation is for all patients in the hospital who have suspected or confirmed Covid-19. *NOTE: If using crisis standards of care, use a tool adapted for that purpose.*

**Where?** Inpatient setting: emergency department, the medical floor, or ICU.

**When?** As early in the admission as possible, given the uncertainty of the clinical trajectory.

### Tips for successful use:

1. Watch the demo video [here](#).
2. Read the guide aloud before using it with a patient or surrogate.
3. Use the exact words on the Guide to reduce your cognitive load
4. Use silence and acknowledge [emotions](#) when they arise.
5. When working with surrogates, consider using video where possible rather than phone.
6. When working with interpreters, have a discussion with the interpreter in advance to review the Guide and discuss potential challenges.
7. Never struggle alone: Debrief with a colleague for support and self-care.



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SI- COVID-Telehealth 2020-05-14



This is a difficult and scary time with the coronavirus. I'm hoping we can talk about the upcoming hours and days and what's important to you so we can provide you with the best care. **Is that okay?**

Is there anyone that you would want to join us by phone or video?

What about your health are you **most worried about** right now? Thank you for sharing that with me.

**Can I share** some information with you about how this illness might affect you?

Many people will recover from this infection. We will do everything we can to help you recover. As you've probably heard, some people get so sick that they do not survive. **[Pause]**

**[If Normal Risk]** Because there is some uncertainty about how this illness affects people, we are asking **everyone** to share what would be important if they became very sick and couldn't speak for themselves.

**[If High Risk]** Because of your [high risk condition], if **you** get really sick, I worry that the treatments that we can use to try to help people get better, like breathing machines or CPR, are not likely to work or get you back to the quality of life you had before. **[Pause] This must be hard to hear.**

What is **most important** for your loved ones and medical team to know if you were to get very sick? What **abilities** are so important to your life that you can't imagine living without them?

Some people are willing to go through a lot, including being on machines for many weeks, even if there is only a small chance that this could help them survive. Others avoid these treatments to focus primarily on comfort, especially if the medical team thought the treatments wouldn't work or would leave someone unable to do things that are important to them. **How do you think about this?**

If you couldn't speak for yourself, **who do you trust** to make medical decisions for you?

**How much do they know** about what is important to you?

This can be hard to talk about. I really appreciate your sharing this information with me.

I heard you say that \_\_\_\_\_ is really important to you. Given what you told me, and what we know about your current health, I would recommend that we... **[CHOOSE A or B]**

- A. use intensive care if necessary, including CPR or breathing machines.** If something changes to make us worry that these treatments are not likely to work, we will tell you or your [trusted decision maker]. Is that okay?
- B. provide only treatments that we think will be helpful.** This means that we would not do CPR or breathing machines but will provide all other available treatments to help you recover and be comfortable. Is that okay?

We can revisit this at any time. We will do everything we can to help you and your family through this.

# COVID-19 Conversation Guide for Outpatient Care

## CONTEXT AND DESCRIPTION

**Why?** Communicating with patients about serious illness is challenging under the best of circumstances. The COVID-19 pandemic reinforces the need for conversations that enable patients with serious illness or other risk factors to understand the potential impact of COVID-19 on their health, to share their worries, values, and priorities, and to make informed decisions. This tool aims to make it easier for clinicians to have these discussions in a trustworthy and compassionate way during this time of uncertainty and distress.

**Who?** Patients in the community who have underlying health conditions are at increased risk of critical illness or death from COVID-19 infection. While there is still a lot to learn about this infection, the highest risk patients may include **older adults**, those who are **immunocompromised**, and/or **patients with one or more** of the following underlying conditions:

- Cardiovascular or cerebrovascular disease
- Pulmonary disease
- Advanced cancer
- Chronic renal disease
- Diabetes and hypertension
- Frailty

**What?** Engage in a conversation with the patient or surrogate to:

1. Discuss [protective measures](#) to prevent infection
2. Share the risk of critical illness due to COVID-19 because of underlying health conditions
3. Understand their priorities, values, and preferences in this context
4. Acknowledge and respond to emotions
5. Make a recommendation about next steps
6. Document the conversation and care plan in the EHR

**Where?** Ambulatory care via telehealth

**When?** Early! Ideally at a time when the patient is feeling well. Build this into an existing telehealth visit or schedule a separate telehealth visit for this conversation.

**How?**

1. Watch the [demo video](#) and review the guide
2. Try the Guide language for the conversation
3. Use silence to allow emotions to be shared
4. Acknowledge emotions with [empathic statements](#)
5. Recommend next steps, such as completing a healthcare proxy
6. Reiterate your ongoing support to the patient and family
7. Use advance care planning billing codes - 99497 and 99498
8. Don't struggle alone: Debrief with a colleague for support and self-care



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SI- COVID-Telehealth 2020-05-04



This is a difficult and scary time with the coronavirus. I'm hoping we can talk about **what is important to you**, so that we can provide you with the best care possible. **Is that okay?**

**What do you understand about how the coronavirus could affect your health? What are you currently doing to protect yourself from getting the virus?**

May I share with you **my understanding** of how the coronavirus could affect your health?

Most people who get the coronavirus get better on their own. However, people who are older or have other health problems **like yours** can get very sick and may not survive. The treatments that we use to try to help people live, like breathing machines, may not work. If they do work, recovery from the illness is uncertain. **[Pause, respond to emotion].**

**We really hope** that you don't get the virus, but it is important **to prepare** in case you do.

**Given your [medical condition]/age, I'd like to think together about what would be important to you if you became very sick and couldn't speak for yourself.**

What would be **most important** for your healthcare providers or loved ones to know if you became very sick and couldn't speak for yourself?

With all that's going on, what are you most **worried** about?

What **abilities** are so important to you that you can't imagine living without them?

If we think they may not help or may cause suffering, some people make decisions to avoid treatments like breathing machines or CPR if they get very sick. If that happened to you, have you thought about **medical treatments** that you may or may not want?

How much do your **loved ones** know about your priorities and wishes?

This can be hard to talk about. At the same time, this conversation can help us ensure that **what matters most to you** guides your care if you get sick.

I've heard you say\_\_\_\_. I think it's important to **share this information with your loved ones** so they can speak for you if you can't. I recommend that we complete a healthcare proxy so we know who you trust to make decisions if you can't.

[If additional recommendations] I also recommend\_\_\_\_\_.

This is an uncertain time for all of us. **We will do everything we can** to help you and your family through this.

# COVID-19 Recommendation Aid

## A RESOURCE FOR MAKING RECOMMENDATIONS FOR OUTPATIENT CARE

This aid provides a framework to create holistic recommendations after a conversation with a patient who has underlying health conditions that put them at higher risk of severe complications of COVID-19, should they contract it. For many patients, these conversations may not result in firm decisions about ventilation or resuscitation. Rather, the goal is to open a dialogue and connect your patient's needs, values, and priorities to therapeutic options.

"Thank you for sharing that with me. I'd like to reflect together on what you've shared and make a plan moving forward. Would that be ok?"

"I've heard you say that \_\_\_\_ is really important to you. Based on your priorities and what we know about your illness and this current situation with the coronavirus, I recommend..."

### **Wellbeing** (consider the following options)

**Share facts about COVID-19 and counsel the patient on protective measures to prevent infection.**

**Assure the patient that you will document and honor what matters most to them.**

- Revisit the conversation when needed.
- Involve members of the patient's support system (family, friends) in the next conversation, if the patient desires.

**If the patient has urgent distress (e.g. anxiety, depression, isolation) consider:**

- Referrals to social work, palliative care, and/or psychiatry.
- Involving other members of the patient's medical care team in the next conversation.
- **Having additional discussions to clarify next steps**

**Ask the patient to identify someone they trust to make decisions if they can't (called a healthcare proxy) and encourage them to have a conversation with their decision-maker.**

- The goal is for the patient to identify a loved one they trust to make medical decisions if they are unable and to talk to their loved one about their priorities, values, and preferences.
- Share resources to support patients and families in talking about priorities and preferences, e.g. [prepareforyourcare.org](https://prepareforyourcare.org).

**For patients who may be ready to make decisions, recommend for or against life-sustaining treatments based on the patient's priorities and the medical situation.**

For example: *"Based on what you shared about what's important to you and your desire to avoid treatments that may not benefit and may lead to suffering, I recommend that if you get sick with COVID-19, it makes sense for you to be in the hospital, and we will do everything we can to keep you from getting sicker and to make you feel better. If you get worse and become critically ill with COVID-*

*19, I would recommend that we change the focus of your care to making sure you are comfortable and don't put you in the ICU or on a ventilator."*

## **Illness and care management** (consider the following options)

### **Consider the impact of social distancing on illnesses and well-being.**

- While necessary for public health and personal protection, social distancing can lead to **isolation and depression for some patients.**
- **Enact strategies to support those who are isolated (e.g. frequent contact via telehealth with patients and caregivers).**
- **Involve social work and community resources (e.g. grocery delivery, medication delivery, etc.).**

### **Consider increasing access to home care services (e.g. home-based palliative care).**

- **Consider hospice for those who qualify and have expressed preferences for comfort-focused care.**
- Ensure access to comprehensive symptom management and psychosocial and spiritual support.

### **Consider completing a POLST for those with clear preferences: [POLST.org](https://www.polst.org) is portable across settings and is appropriate for patients of any age with advanced illness. It should be:**

- Completed after a conversation with a clinician about the patients' priorities and preferences.
- Signed by the patient or surrogate AND a medical provider (doctor, physician's assistant, or nurse practitioner) to specify patient wishes for:
  - CPR
  - Mechanical ventilation, CPAP, and other procedures
  - Transfer to a hospital

## **Support System** (consider the following options)

### **Consider who else should be involved to help your patient navigate their worries and to provide support during this difficult and uncertain time.**

- Identify the patient's support system and what helps them cope.
- If the patient lacks a support system, refer to social work, chaplain, hospital volunteer, patient advocate, etc.
- Involve members of the patient's support system (family, friends) in the next conversation, if the patient desires.

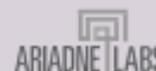
## **Help**

- "Thank you for taking the time to talk to me about this."
- "Does this sound ok? Is there anything else we should think about?"
- "We will do everything we can to help you through this."



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# COVID-19 Telehealth Communication Tips

A RESOURCE FOR CONDUCTING COVID-19 CONVERSATIONS VIRTUALLY\*

## Opening a COVID-19 Outpatient Conversation visit: environment and privacy

**Patients may or may not want family members involved when discussing their priorities.** Make sure to cue the patient to invite those they want to be involved and/or to consider moving to a private setting, if possible and desired.

## Techniques for responding to emotion: verbal and non-verbal

**Normalizing and validating positive and negative emotions:** This response can help patients feel heard and understood. For example: *“It makes perfect sense that it feels difficult to live with this uncertainty.”* OR: *“I’m so glad that you’ve been able to laugh with your family during this difficult time.”*

**Silence:** Pausing with silence after sharing hard news allows time for patients to process their emotions. During silence, continue to look into the camera and use head-nodding to maintain connection. Patients will break the silence by re-initiating eye contact or talking again. You can also put your hand to your heart as a gesture of empathy.

**Reflection and curiosity:** Allowing patients the space to explore their emotions and thoughts supports relationship and connection. Statements like *“I hear how sad it is to think about this”* or *“Tell me more about what you’re thinking”* enable patients to share their complex experiences during this difficult time.

## Attending to cues during the visit

**Since patients are in their home, their environment may change during the visit.** For example: their kids or grandkids may enter the room. You can check in with patients to make sure they are ok to continue the discussion.

**Pay attention to signs that the patient is struggling with the discussion.** If they are breaking eye contact, shifting in their seat, or appear uncomfortable, you can say: *“I know this is hard to talk about, and I think we covered a lot today. Thank you so much for sharing. What are your thoughts about shifting gears and talking about something else?”*

## Ending the session

Ending a telehealth session, especially one that focuses on a potentially sensitive discussion, can feel unnatural and abrupt. **Toward the end, begin to wind down the conversation so the patient can feel more integrated and less emotional.** For example: *“We are committed to caring for you and will do everything we can to support you through this.”*

**Consider naming when you have a short amount of time left:** *“I see that we have 10 minutes remaining. I wonder what might be most helpful to discuss as we finish up our appointment for today?”*

# COVID-19 Conversation Guide for Long Term Care

FOR LONG-TERM CARE OR NURSING FACILITY RESIDENTS, AND THEIR FAMILY OR OTHER CAREGIVERS

**What?** This communication tool assists health professionals in having conversations about values and care preferences with patients who reside in long-term care or other skilled nursing facilities or their caregivers. These conversations can help ensure the highest quality care.

**Why?** Communication with patients and/or surrogates about Covid-19 presents unique challenges in long-term care or other nursing facilities. If Covid-19 enters a facility, the speed with which it spreads can result in significant fear and distress among residents, surrogates, and staff. Frail nursing home residents are at higher risk of death and disability from Covid-19.

Family members experience disconnection from their loved ones and worry about their safety and care. Nursing facility teams face daily challenges: understaffing, infection control, and changing workflows and protocols. Proactive conversations can facilitate shared decision-making and care planning.

**Who?** The guide is for all health professionals who work in long-term care and other skilled nursing facilities. This conversation is for all residents in long-term care or other nursing facilities who are able to participate and/or family or other caregivers.

## Tips for successful use

### *To prepare for the conversation*

- When planning to speak with a caregiver, review the patient chart or examine the patient in advance so you can provide an up-to-date clinical assessment.
- Review the currently available supportive treatments in the facility (e.g. oxygen, fluids, antibiotics) so you have a sense of what is possible to provide there.
- Review the latest facility policies for infection control, visitation, safety, and transfer. Consider arranging a video call if possible.

### *To prepare to use the Conversation Guide*

Watch the [demo video](#) of the conversation guide. Read the guide aloud slowly.

When working with interpreters, review plan and guide with the interpreter beforehand to discuss potential challenges.

### *During the conversation*

Use the exact words on the Conversation Guide to reduce your cognitive load Use silence and acknowledge [emotions](#) when they arise

### *After the conversation*

- Document what you heard, including information about what is important to patients and their treatment preferences.
- Never struggle alone: Debrief with a colleague for support and self-care.



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SI-COVID-Telehealth 2020-05-14

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This is a difficult and scary time because of the coronavirus. We know that it is made worse by the need to be separated from family and friends. I wanted to speak because... **[A or B]**

**A. Covid *present*:** Despite our best efforts, some of our staff/residents tested positive for coronavirus.

**B. Covid *absent*:** We are doing our best to prevent infection in our residents and staff but are preparing for the possibility that it may affect our facility.

I'm hoping we can talk about how to provide the best care for you/[resident] if you/he/she became sick. **Is that okay?**

What have you heard about how the coronavirus might affect your/his/her health?

May I share with you **my understanding** of how the coronavirus could affect your/[resident]'s health?

Most people in nursing facilities who get the coronavirus get better on their own. But if they become very sick, people who live in nursing facilities are less likely to survive. **[Pause, respond to emotion]**

I'd like to make sure that we continue to provide you/[resident] with the best care possible. This includes talking about whether or not to send you/him/her to the hospital if you/he/she became very sick. Can I ask some questions to help us think about that?

Tell me about some of the things that are important in your/his/her life. What are you **most worried about** right now with the coronavirus?

If you/he/she became very sick due to the coronavirus, how much would you/he/she be willing to go through to try to get better?

**Prompt:** Some people would want any treatment to survive, even if it was unlikely to work. Others would want to stay here, with treatment focused on comfort, even if they might not survive.

This can be hard to talk about. And it is so helpful for us to know what matters most for your/[resident]'s care at this time.

I've heard you say\_\_\_. Keeping this in mind, and given the treatments that we can provide at [facility] I recommend that we... **[A or B]**

**A. Focus on supporting you/[resident] here at [facility].** We will provide treatments to help you/him/her get better and not suffer. If you/[resident] became very sick, we would **not send** you/him/her to the hospital. We would focus on your/his/her comfort here. *Is that ok?*

**B. Provide as much supportive care as possible here at [facility] but send you/[resident] to the hospital to receive additional treatment, if necessary.** We can let the hospital know if there are certain treatments you/he/she would want to avoid. *Is that okay?*

We will do everything we can to help you/[resident] and your family through this.

## **Decision-making for patients in Arizona (once the patient lacks capacity)**

Establish a decision maker for every patient in case that patient loses medical decision-making capacity and cannot speak for him/herself. The decision maker's task would be to tell us what the patient would say if s/he could speak. This is critically important as staff must know whom to call for updates and decisions.

Go down the list until you find the first one that exists for that patient.

- 1) Court appointed guardian (rare)
- 2) Durable Healthcare Power of Attorney – this is a signed, dated, witnessed document present in the chart or in your possession. If the patient has no Durable Healthcare Power of Attorney but has capacity – have them complete one asap. In the absence of an actual document - there is no Durable Healthcare Power of Attorney.
- 3) If there is no Durable Healthcare Power of Attorney proceed to the Arizona Statutory surrogate list. This is Arizona state law. You must take the first one on the list who is “willing to serve and reasonably available” – phone contact only is always acceptable. If a person declines, you go to the next one on the list, a person who declines cannot “assign” the duty to another person.
  - a. Spouse, unless legally separated
  - b. Majority of biological and/or legally adopted adult children
  - c. Parent(s)
  - d. Domestic partner of unmarried patient
  - e. Adult sibling
  - f. Close friend
- 4) If none of the above can be found (due diligence must occur in the search): Attending Physician
  - a. In consultation with ethics committee (EC)
  - b. If EC is not possible – attending must consult with a second physician

# Palliative Care Referral Criteria: COVID-19 Context

Following is guidance on when to refer patients with COVID-19 or pre-existing serious illnesses for specialty palliative care.

## COVID-19 Criteria

- Pre-existing palliative care patient
- Symptoms refractory to palliative symptom protocols
- On ventilatory support
- Difficult-to-control emotional symptoms
- Patient, family, or physician uncertainty regarding prognosis
- Patient, family, or physician uncertainty regarding non-beneficial treatment options
- Patient or family psychological or spiritual/existential distress
- Patient or family request

## General Referral Criteria

Presence of a serious illness and one or more of the following:

- New diagnosis of life-limiting illness for symptom control, patient/family support
- Declining ability to complete activities of daily living
- Weight loss
- Progressive metastatic cancer
- Admission from long-term care facility (nursing home or assisted living)
- Two or more hospitalizations for illness within three months
- Difficult-to-control physical or emotional symptoms
- Patient, family, or physician uncertainty regarding prognosis
- Patient, family, or physician uncertainty regarding appropriateness of treatment options
- Family request for non-beneficial treatments or therapies
- DNR order conflicts
- Conflicts or uncertainty regarding the use of non-oral feeding/hydration in cognitively impaired, patients over 65, seriously ill, or dying patients
- Limited social support in setting of a serious illness (e.g., homeless, no family or friends, chronic mental illness, overwhelmed family caregivers)
- Patient, family, or physician request for information regarding hospice appropriateness
- Patient or family psychological or spiritual/existential distress
- Palliative Performance Scale of 60 or less

## Cancer Criteria

Presence of any of the above, and/or:

- Metastatic or locally advanced cancer progressing despite systemic treatments
- Karnofsky < 50 or ECOG > 3
- Brain metastases, spinal cord compression, or neoplastic meningitis
- Malignant hypercalcemia
- Progressive pleural/peritoneal or pericardial effusions

# Neurological Criteria

Presence of any of the above, and/or:

- Folstein Mini Mental score < 20
- Feeding tube is being considered for any neurological condition
- Status Epilepticus > 24 hrs.
- ALS or other neuromuscular disease and/or decision surrounding mechanical ventilation
- Any recurrent brain neoplasm
- Parkinson's disease with poor functional status or dementia
- Advanced dementia with dependence in all activities of daily living

Centers to Advance Palliative Care

# FAQs

1. Can a person change their Advance Directive once it has been completed?

- Yes, if the person has decision making capacity, they can change their Living Will or Healthcare Power of Attorney. They must complete new documents and void their previous documents.

**Living Will** is a written statement that expresses your wishes about medical treatment that you want or don't want. It speaks for you in the event you cannot communicate. A living will **must be signed** by the patient **and** a witness or notary.

**Durable Healthcare Power of Attorney** allows you to choose another person, called a representative or agent, to make healthcare decisions for you if you can no longer make them for yourself. You can choose how much authority you will give your representative. It can also cover autopsy, organ donation, funeral and burial disposition, HIPAA waiver, and whether you have a prehospital medical care directive (out of hospital DNR). A healthcare power of attorney **must be signed** by the patient **and** a witness or notary.

- Ethical Principle: Autonomy

2. Can a person change their Pre-hospital Medical Care Directive (orange form)?

- The person can change their mind about their treatment wishes but must meet with their healthcare provider to have the Pre-hospital Medical Care Directive updated, as it is a medical order.

**Prehospital Medical Care Directive** is an out of hospital do not resuscitate form. It **must be signed by the patient, a licensed healthcare provider, and a witness**. It is **only valid** if it is on **bright orange paper**. It is recommended this form be posted on the refrigerator at home and that a copy be placed in the medical record.

- Ethical Principle: Autonomy, Beneficence, Non-maleficence.

3. Can a person change their POLST form?

- The person can change their mind about their treatment wishes but must meet with their healthcare provider to discuss their prognosis and goals of care. The POLST form can only be updated by a healthcare professional because it is a portable medical order.

**POLST:** A POLST form helps individuals who are considered to be at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty, for whom their health care professional wouldn't be surprised if they died within 1-2 years, communicate their treatment decisions. It is designed to improve patient care by creating a **portable medical order** form (the POLST form) that records patients' treatment wishes so that emergency personnel know what treatments the patient wants in the event of a medical emergency. The current standard of care during an emergency is for emergency medical services (EMS) to attempt everything possible to attempt to save a life. Not all patients who are seriously ill want this treatment and the POLST form provides the option for them to: (1) confirm this is the treatment they want or (2) to state what level of treatment they do want. POLST is always

voluntary. Because it is a medical order it helps give patients more control over receiving treatments they do want to receive and avoid treatments they do not want to receive, even if they cannot speak for themselves during a medical crisis.

- Ethical Principle: Autonomy, Beneficence, Non-maleficence.
4. If the patient lacks capacity and does not have a Durable Healthcare Power of Attorney who makes healthcare decisions for them?
- Go down the list until you find the first one that exists for that patient.
    1. Court appointed guardian (rare)
    2. Durable Healthcare Power of Attorney – this is a signed, dated, witnessed document present in the chart or in your possession. If the patient has no Durable Healthcare Power of Attorney but has capacity – have them complete one asap. In the absence of an actual document - there is no Durable Healthcare Power of Attorney.
    3. If there is no Durable Healthcare Power of Attorney proceed to the Arizona Statutory surrogate list. This is Arizona state law. You must take the first one on the list who is “willing to serve and reasonably available” – phone contact only is always acceptable. If a person declines, you go to the next one on the list, a person who declines cannot “assign” the duty to another person.
      - a. Spouse, unless legally separated
      - b. Majority of biological and/or legally adopted adult children
      - c. Parent(s)
      - d. Domestic partner of unmarried patient
      - e. Adult sibling
      - f. Close friend
    4. If none of the above can be found (due diligence must occur in the search): Attending Physician
      - a. In consultation with ethics committee (EC)
      - b. If EC is not possible – attending must consult with a second physician
  - Ethical Principle: Autonomy, Beneficence, Non-maleficence, Justice, Efficiency, Fairness-Equity, Liberty, Transparency, Participation

# Case Scenarios

The case scenarios were developed from actual cases, provided by staff working in their respective care setting.

## Hospital

1. 46 y.o. single woman with history of hypertension, diabetes, and asthma is admitted to the hospital with COVID-19. Within 24 hours she is transferred to ICU and ventilated. The intensivist looks to see if she has an advance directive and is unable to locate one. Through old records they identify there is a sister who lives out of state and place a call to her. The sister reports she is the only living relative and communicates her sister would “want everything done”. A few days later a friend calls the hospital and tells the nurse she is the patient’s power of attorney. She reports the patient is a DNR and never wanted to be on a ventilator. The friend faxes the advance directive paperwork to the hospital and its validity is noted. An ethics team meets and recommends the patient continue the ventilator as the physician reports she is doing better. The team hopes she will improve enough to articulate her own wishes. After 7 days on the ventilator the patient is extubated. Initially she is angry, saying she never wanted to be on the ventilator. The hospital staff share they did not have a copy of her advance directive, so they contacted the sister who instructed them to “do everything” to sustain her life. She is discharged the next week to the friend’s home. A copy of the woman’s advance directive is now within the hospital’s EMR.
2. 72 y.o. male in the ED with a myocardial infarction. When reviewing the patient’s history, the physician finds a Living Will on file and the code status is “Do Not Resuscitate”. The physician states, “You’ve had a mild heart attack and your condition is stable for now. I would like to talk to you about your future treatment wishes so we can provide the care you want in case your condition worsens. Is it ok for us to talk about this?” The patient agrees and the patient communicates if his heart should stop while in the hospital he does want to be resuscitated if there is a chance he will recover and still be able to play golf. The physician documents the conversation in the medical record.

Later the same day the patient has a second myocardial infarction. He is emergently taken to surgery for a quadruple bypass and subsequently suffers a hemorrhagic stroke with acute kidney failure. The patient is no longer responsive and has a poor prognosis of recovery. The physician calls the son, who is the durable healthcare power of attorney and shares the poor prognosis, the patient’s treatment wishes as discussed and living will. The physician recommends the father be transferred out of the acute care hospital with hospice services. The son agrees knowing this is what his father wanted.

## Post-Acute Care (Including SNF)

1. 69 y.o. male resident with CHF and COPD is diagnosed with COVID19. The patient declined to complete an Advance Directive on admission and listed his ex-wife as the contact person. The skilled nursing facility asks the resident what his treatment wishes are if his health should continue to decline. The resident wants everything done to sustain his life if there is a chance of recovery as he wants to attend his daughter's wedding in the fall. A Living Will and Healthcare Power of Attorney are completed naming his daughter as the decision-maker. His condition worsens and he is transferred to the hospital. He no longer has decision making capacity and the hospital is thankful to have his advance directive paperwork.
2. 88 y.o. woman with frailty newly admitted to the SNF from home with assistance of her adult son who reports she is no longer safe at home. She does not have advance directives completed, has decision making capacity and refuses to talk about completing her advance directives. She says if she talks about it, something bad will happen. Her health is stable for the first nine months but then her frailty worsens when she is diagnosed with pneumonia and the flu. She no longer has decision making capacity and the son is called. The SNF social worker identifies the woman's spouse and siblings are deceased. There are two living children of which one is "in the wind", with no one having heard from them for 10+ years, and no available contact information. The son does not want to make decisions for his mother as he feels it would haunt him. The physician has an informed assent discussion communicating that his mother is likely not to survive the pneumonia and flu. The son agrees to keeping his mom comfortable and she dies the next day.

## Home Health

1. 52-year-old male with a history of end-stage heart disease and alcoholic cirrhosis of the liver. He lives alone and has a patient care tech (PCT) come in twice a week to assist him with ADL's. He admits to falling twice in the past week due to increasing weakness and now is experiencing shortness of breath and symptoms of COVID19 which he thinks he got from the local bar. There is no family in the state and patient reports he has never gotten around to completing an advance directive. The PCT notifies her charge nurse and the patient is tested for COVID19 with results being positive. A goals of care conversation occurs, and advance directives completed through telehealth and a e-notary service. The patient does not want an attempt at resuscitation or be put on a ventilator should his condition worsen. His condition does worsen but the Home Health agency is unable to locate a SNF or Hospice that can immediately accept a COVID19 positive patient. He is transferred by EMS to a hospital for comfort care until arrangements can be made for hospice care at a facility.
2. A Nurse Practitioner is visiting a woman at her home. She is 82 years old with a history of emphysema who is now oxygen dependent with limited mobility. She is requiring more assistance for shopping and cleaning as she is too short of breath to attempt these tasks on her own. The patient was recently hospitalized with pneumonia, and a daughter just arrived from out of town to help. You ask if an advance directive has been completed and are told no. You ask if it is ok to have a conversation about future treatment plans and Mrs. Johnson agrees. A goals of care conversation occurs, and Mrs. Johnson

does not want any heroic measures as says she is ready to go anytime. She is elderly and frail, with life expectancy of two years or less. The NP helps the patient complete a Living Will, Durable Healthcare Power of Attorney naming the visiting daughter the Durable Healthcare Power of Attorney. A POLST form is also completed with Mrs. Johnson. Two days later you receive a call from Mrs. Johnson's other daughter who has just learned of the life care planning documents and informs you those documents should be ripped up as her mom was confused. This daughter now wants to be the healthcare decision maker and wants everything done for her mother.

You visit Mrs. Johnson and the visiting daughter a second time and find she has decision making capacity. You discuss her goals of care and treatment decisions and find nothing has changed. You ask Mrs. Johnson if it is ok if you call her daughter together and discuss. Mrs. Johnson agrees but wants all four of her children on the call. A phone call with all children is arranged and all are informed of Mrs. Johnson's goals of care and treatment wishes. Several of the children were not aware of Mrs. Johnson's deteriorating health and plan a visit within the next month.

## Hospice

1. 29 y.o. woman wife and mother of two with stage four colon cancer in home Hospice is experiencing symptoms of COVID19. She notifies her hospice aide via phone and receives a call from her physician checking on her. She has her advance directives complete and communicates she only wants to be comfortable. The hospice cannot provide 24-hour service in the home. Her husband insists she be transferred to the hospital as feels that is safer for the family. The hospice agency located a bed for her at a local skilled nursing facility where she can receive palliative care and hospice services through telemedicine but won't be able to have visits from her husband and children. She wants to remain at home but agrees to the transfer to keep her family safe. The hospice agency monitors her progress daily speaking with the SNF staff and resident. They also set up twice daily facetime visits with husband and children to address social isolation.
2. 49 y.o. male with pancreatic cancer is referred to hospice after a 3-day hospital stay. He asks the home hospice nurse what hospice is? The nurse asks him what he understands about his illness. He responds he knows he has pancreatic cancer but thinks he can beat it. A meeting is set for later the same day with the hospice physician to discuss his prognosis and goals of care. The gentleman was surprised as did not comprehend he had a prognosis of less than six months to live. He requested help telling his wife and together the physician, patient and wife discussed his prognosis, goals of care and through shared decision making decided on comfort care. The advance directive and POLST were completed.

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