# Specific Phrases & Word Choices that Can Be Helpful When Dealing with COVID19

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COVID19 has demanded that staff across settings and geography integrate primary palliative care skills whether answering phones, standing security, disinfecting space, hooking up ventilators, providing treatments and guidance through recovery or death. The following circumstances, words and phrases can never capture the full landscape of experiences, conversations, dilemmas, emotions and thoughts COVID 19 has brought into our worlds. They are a sampling - suggestions that might ease the anxiety of those who “do not know what to say”, raise the voice and compassion of those who provide care as well as inviting the voice of those who are cared for.

# Phrases & word choices that can be helpful when dealing with COVID19

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| **Helpful responses to patients/families during times of restrictive visiting** | |
| **Common questions/concerns** | **Suggested response** |
| I am dying and my family can't come to be with me. | We hear that this is not what you had imagined at the end of this life. Let's see how we can create sharing time, memories or legacy through phone or skype.<br><br>**Suggestions:** Record messages on a smart phone to give to family; have the patient dictate a note that can be given to family, assist staff when time allows to share thoughts about the patient and their death that can be given to family |
| Why can't anyone or more than one person come and be with my family member while they are dying? | We hear that this is not what you had imagined at the end of their life. I'm happy to ask if we can make an exception (if patient is not COVID19 positive). In the meantime, we encourage you to talk with family and think about ways you can honor them even from a distance.<br><br>**Suggestions**: Use technology to connect. If acceptable bring pictures, comforting objects infused with meaning. Advocate for a visitor policy that sets criteria to allow exceptions. |
| I'm scared, they are discharging my family member to a nursing home and I won't be able to visit. | This is a frightening time and your reaction is common and understandable. Usually patients and families would have more choices; this is not a usual time for any of us.<br><br>**Suggestion:** Let's get you connected by phone to the social worker or nurse on the unit where your family member will be cared for and think together about ways you might stay connected. |

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| I'm worried my family member will die alone in pain and suffering. | That must be a hard thing to think about. We know we can manage their pain and symptoms; they will have nurses caring for them. Perhaps there are ways that we can create presence even if you are physically distant. Can you tell me about them as a person?<br><br>**Suggestions:** Think of ways to reminisce, share feelings and create a soothing environment (prayer, music, a favorite movie, reading a book over the phone etc.) Do they have pictures or a favorite object at home that we could put in the room to provide comfort? Send ecards that reflect shared memory. |
| My children (young ones and teens) are not able to come say goodbye to a parent, grandparent or treasured person. I don't know what to tell them. | I can image it is hard to come up with the right words. It may help to tell them why they cannot come to the hospital.<br>I'm wondering what have you told them already about why they aren't going to school?<br>Help me to understand a bit about each of your children and their relationship to the patient so we can think together about how to help.<br><br>**Suggestions:** Sometimes children draw pictures, write notes, sing a favorite song over the phone; read their favorite book, the staff can also help make hand or thumb prints of the patient, so the children have this as a memory that has meaning in the future. |
| My family member is dying and with the travel restrictions I won't be able to have a proper funeral. | It sounds like you really want to honor them. Most immediately funeral homes can help you to coordinate a virtual honoring with family and friends.<br><br>**Suggestion**: Reinforce that memorials and memories transcend time and when travel is allowed again there will be a way to honor their legacy in person.<br>Psychoeducation focused on the procedures and community resources that are evolving related to deaths from<br>COVID19. |

## Guide to virtual family meetings

While family meetings during COVID19 may not be prioritized this illness is, for many, an endof-life process and assumptions about goals and treatment preferences may not be coherent with patient's values and beliefs. Thus, even in the midst of crisis, engaging family in the setting of life-threatening illness is essential to care, setting goals which also may impact allocation of resources. While in general, clinicians are challenged to tolerate silence thus inviting the family's voice, the pressures of COVID19 may require adaptation of family meeting structure. Beginning with a medical provider acknowledging the crisis and the proliferation of information may serve to create a shared framework for discussion of the evolving clinical situation of an individual patient.

### Brief pre-meeting with involved staff

| **Suggestions** | **Examples and rationale** |
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| Acknowledge with families the restrictions which preclude in person meetings with all families, so they do not feel singled out.<br>1. Decide which teams and team members are going to participate, either in person or virtually.<br>2. Agree on medical recommendations and a consistent message if possible, consider how to handle divergent opinions.<br>3. In the setting of a stressful COVID19 environment, prepare to use deep breathing or other techniques to contain anxiety, avoid interrupting, and listen. | Decide on a meeting facilitator who is able with empathy to guide discussion and contain interruption and reinforce focus, which can be particularly challenging in virtual meetings.<br><br>Remember to check in with the family about their expectations, using questions such as, "what would you each like to talk about?" or, "what information would be most helpful?" |

### Setting and start of the meeting

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| Find a quiet space to sit, mute cell phones and beepers, position team members to maximize visual and voice connections. | Model managing anxiety for family and each other by using a calm voice and not interrupting. |

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| **Introductions** | |
| Clarify that under most circumstances we would meet in person – we need to work together to ensure that everyone is heard, and each person's questions receive the best response.<br><br>Providers can take turns explaining their role in patient care and learn who from the family is present. | Think about making a statement, "I wish we could be meeting in person."<br><br>Work to move or adjust technology from person to person to maximize connection of voice to name and role.<br><br>If there is no visual component to the meeting, remember to repeat your name and role when speaking.<br><br>Ask the families members to mute their lines to avoid excessive noise. |
| **Medical update** | |
| In most family meetings the patient or family convey their understanding or perceptions first. Given the crisis nature of COVID19 and the limits on visitation, it may be less anxiety provoking for the doctor to briefly share the medical and care context.<br><br>Providers clarify medical information and answer questions. | Consider using the word *dying* when appropriate to condition, prognostic awareness, culture and spiritual belief.<br>Avoid medical jargon or a typical systems review.<br><br>Acknowledge the uncertainty and growing knowledge about COVID19 while affirming what is known about a specific patient's condition. |
| **Allow for silence** | |
| Give patients and families the opportunity to begin to process complex feelings and thoughts during the meeting.<br><br>If in person, observe nonverbal responses and know that family may be observing yours as well. | Let the silence last longer than you are comfortable with.<br><br>Think about asking, "what haven't we covered or asked? What do we need to know about patient or your family to be most helpful?" |

| Invite and clarify values & goals | |
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| Identifying patient and family values and goals during the meeting will help to inform the medical recommendation. Ask specifically about end-of-life values, advance directives, conversations, how family makes decisions as a family, individually, etc. Acknowledge the patient by name or relationship. | In an effort to understand the patient as person and garner more information, "Tell us about your family member."<br><br>"Can you share a picture (if video technology) or a cherished story that helps us to know a bit about your grandmother."<br><br>"Have you had conversations about serious illness or dying in the past?" |
| **Medical recommendation** | |
| Clinicians impart their medical recommendation based on patient's values, advance directive, goals or share what is possible given available treatments and resources.<br><br>Acknowledge what we know and do not know about COVID19.<br><br>Clearly establish treatment plan and outcomes anticipated and hoped for and plan for next meeting to weigh outcomes and plan further. | Consider discussing medical options not as menu options; rather provide the best medical judgment in the setting of uncertainty. I f death is expected, engage family to share and adapt their hopes for the death they had imagined and maximize what is possible to create. |

| Post family meeting | |
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| **Debrief & Document** | |
| **Suggestions** | **Examples of question to inform debriefing** |
| This is a chance for the team to review the meeting, share thoughts and feelings. Decide how and who will document in addition to the doctor and who is responsible for moving the varied aspects of the treatment plan forward.<br><br>Clear documentation of treatment plan, goals and any advance directive guidance will help teams to build an evolving plan of care. | "How do you think that meeting went?" "What do we want to acknowledge and celebrate in our own work and the work of others?"<br>"Are there things we can improve, ideas to maximize the effective use of technology? What words would we change for the next meeting?"<br>"Are there other words we could have used?" |

## End-of-Life topics that may arise*

| Phrases to avoid | Consider instead | Rationale |
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| You are failing the treatment. | The ventilator (or other therapy) has not helped to achieve the goals we talked about; to make breathing better. | Removes blame from patient and focuses on the progressing disease or therapy that had not achieved what we hoped for or expected. |
| You are not a candidate for, surgery, dialysis etc. | Surgery (or medication, or procedure, etc.) will not help you achieve the goals that we have talked about. Or your hopes for recovery. | Focuses conversation on interventions which best fit with patient's condition, goals and hopes, rather than on patient. Aligns clinician with patient and or family to participate in shared decision making. |
| There's nothing more we can do for you. They are not going to make it. | There is no effective therapy to cure (or, mitigate, slow, temporize, etc.) the disease<br>I'm worried you may be coming to the end of this life.<br>We have done all we can to mitigate the disease.<br>What else matters most to you right now? | There is always something that can be done to help even when death is imminent. Replaces clinician helplessness and patient fear of abandonment with shared end of life planning. |
| Withholding/withdrawing care | The interventions are no longer helping.<br><br>There are many things we can do. Can we talk about what is most important for you right now? | Care is always continued, even when these therapies are contraindicated. |

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| Keep them comfortable | We will focus our care on managing pain and other symptoms of disease progression and assisting your family to come together as possible to create a unique and meaningful time. | The meaning of "Comfort care" varies between clinicians and does not reflect the specifics of comprehensive care at end of life; implies comfort is not a priority until end of life. |

## Supporting staff

| **Common questions/concerns** | **Suggested response** |
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| I'm scared | I think a lot of people are feeling scared, what worries you the most? |
| I'm worried we won't have enough ventilators to care for patients | I cannot imagine the difficulty of making these kinds of decisions – they will be shared with others, so you are not in this alone. |
| I'm worried I will bring COVID19 home to my family | Your family knows you are being vigilant and using your best knowledge and practice to protect them. |
| I'm worried I will get COVID19 | A lot of people are worried, and I think most of us have thought about this. We can remind ourselves we are taking every precaution available. |

| Team support | |
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| Think about offering "open" times for team members to voice their worries; and share their self and stress management ideas or self-care strategies.<br>Invite and acknowledge the moments of compassion, humor, absurdity. | Share suggestions that have worked for yourself and may work for your team.<br><br>Normalize the increase in anxiety given the circumstances.<br><br>Remind folks of the usual strategies such as exercise (walk/run outside); prayer, rethinking how to get the social support we all need via skype, zoom, group calls, etc.<br><br>Share meditation apps like Headspace; Insight Timer etc.<br><br>Work on modeling dealing with anxiety; trying not to spread the contagion of anxiety. |
| I'm feeling anxious. | Sometimes it helps to put aside some minutes a couple of times a shift just to focus on the worry –alone or with others - for some it keeps the worry from invading our every minute. |

*(Modified from Kelemen, A., Groninger, & H., Ruiz, G. (2016). Choosing words wisely in communication with patients with heart failure and families. American Journal of Cardiology, 117 (11), 1779-82.)