



## Working with Families Facing Undesired Outcomes During the COVID-19 Crisis

Tip Sheet No. 01

Unfortunately, many families will be facing sudden, severe, catastrophic illness in the weeks to come. Palliative social workers and other health professionals prepared to deal with stress and trauma can be invaluable at this time.

It helps, of course, to know the facts of the situation the families are facing: for example, it could be helpful to know what the decision criteria are for the distribution of scarce ventilators, etc. For example, if the decisions are made based on what is referred to as “quality-adjusted life-years” or age; or on a lottery. If you know the policy, it becomes your professional judgment as to whether this becomes part of your conversation. If you don’t know it and can’t find out, you can share that information as well, if you think it’s appropriate.<sup>1</sup>

The suggestions below are just that—suggestions. It is by no means a complete listing of approaches or ideas. Feel free to practice educated improvisation.

Also, please remember that language matters! See the recent [VitalTalk document](#) on how to address patients and families’ concerns over triage, deciding, counseling, resource allocation, anticipating and grieving.

1. Try to find a quiet, private place—or have the family find as quiet a place as possible if you’re using telemedicine.
2. Stay grounded
  - Try to remain calm, assured, gentle and present despite the chaos around us and them.
3. Listen to the family’s concerns.
  - Start with your version of “this is a difficult time for many people. How can I help you right now?”
  - Your interpretation of the situation may not be theirs. Don’t jump to conclusions.
  - As with “terminal extubation”, there may be some relief—which can lead to guilty feelings. Sometimes, anger at an outside ‘force’ may cover up that sense of guilt.

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<sup>1</sup> *Guidelines for ethical allocation of scarce medical resources and services during public health emergencies in Michigan, V. 2*; State of Michigan, Department of Community Health, Office of Public Health Preparedness.

4. No bandwagons allowed. Allow family to criticize, demean, whatever they need to do, and listen sympathetically—but don't join them in blaming
  - E.g., you don't know if the staff they might accuse really did what they said they did. It may be confusion; misunderstanding; hospital policy; or it may be a real mistake.
  - It makes sense to agree with facts such as: this is a frightening time; there is so much uncertainty; everything we expected has been turned on its head.
  - Anger, guilt, grief etc. are likely to be common experiences, but too much normalizing trivializes the family's authentic reactions.
5. Active listening techniques (reflecting feelings, summarizing thoughts) are of course helpful here. But be careful with "reflecting" too much; I find that highly stressed individuals, who feel that time is not on their side, do not appreciate formal reflection. Just let them know you genuinely hear them. It can be as simple and quick as "I hear so much love right now..."
6. Explore family's cultural and religious views. If possible and if it's desired, seek a spiritual counselor for the patient and family.
7. Provide information that is honest and accurate and appropriate for the understanding level of the people to whom you are speaking.
  - Explain visiting policy, unless it's too much information at one time (but be sure there will be a follow-up). At this time, many hospitals do not allow visitors to COVID patients, even those who are dying, though they may be willing to bend the rule for non-COVID patients at end of life.
  - Reassure, as appropriate, that proper measures can help reduce the risk to family members.
  - Reassure, as appropriate, that the loved one's suffering will be minimized as much as possible.
  - Discuss, as appropriate, that death occurs as a consequence of the underlying disease.

### Miscellaneous Considerations

For OUR information: Ventilators were shown in China to save only about 30% of those sick enough to warrant their use. Patients need to be on them for weeks and those who are extubated may be deconditioned and "not the same" when they come off. Policies in our hospitals are likely to take into consideration who is most likely to benefit when allocating scarce resources.

A VitalTalk suggestion for how to express this: 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 them. My recommendation is that we accept that they

will not live much longer and allow them to pass on peacefully. I know that is hard to hear. What do you think?

Remember that our families are experiencing an avalanche of experiences: Unexpected loss; traumatic loss; social stigma and now, actual social distancing—the family may be treated as ‘untouchable’ due to contamination, and in fact we and their families and friends must implement social distancing; combined losses: loss of one’s own job, income, future and loved one.

While generally we counsel that most people are able to deal with a death on their own and in their own time, unusual circumstances like this may lead to increased levels of depression and PTSD. It is nonetheless helpful to the clients to encourage them to lean on their own strengths and supports to the degree possible. Let family know where they can find bereavement resources, including Somatization Experiencing professionals; our grief and bereavement colleagues may also become overwhelmed with clients, so once again

### Helpful Resources for General Information

- [VitalTalk tips](#)
- [Ventilator shortage](#)
- Breaking bad news (applied to cancer, but can be generalized): Baile, W.F., Buckman, R., Lenzi R., Glober, G., Beale, E.A., & Kudelka, A.P. (2000). [SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer](#). *Oncologist*, 5(4), 302-11.
- Information for families on Extubation: Harborview Medical Center, University of Washington Physicians. [Withdrawal of life support orders \[PDF document\]](#). CAPC Central™ IPAL-ICU. Retrieved 27 July 2016, from
- Curtis, J. & Rubenfeld, G. (2001). [Managing death in the ICU](#) (pp. 127-147). New York: Oxford University Press.
- Really [general information for helping children cope](#).

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