

Cultivating Meaningful Conversations to Guide End-of-Life Care

“For patients and families facing advanced illness, the medical interventions and quality of life that lie ahead are largely determined through a series of conversations they have with their physicians and other health care providers.”

(Larson DF, Tobin DR. End-of-life conversations: evolving practice and theory. *JAMA* 2000;284(12):1573-1578.)

Collaborative conversations between patients and their healthcare providers are crucial to respecting patients’ values and honoring their wishes for care at the end-of-life. Health care providers need to listen to, share information with, and ask questions of our patients to establish overall goals of care and to anticipate specific treatment decisions that will likely arise in a terminal illness. Advance care planning allows us to avoid making some of the most challenging decisions in a time of chaos, under a shadow of grief, or when communication may be compromised by stress, exhaustion and misunderstanding.

Aspects to discuss with patients and their families, in the setting of terminal illness, include:

- *“What do you understand about your condition?”*
- *“What do you expect to happen?”*
- *“What is most important for you in the time you have left?”*
- *“What do you hope for in the time remaining?”*
- *“What experiences have shaped your thoughts and feelings about medical treatments?”*
- *“What are your fears?”*
- *“What are your concerns?”*
- *“What frightens you most about medical treatment?”*
- *“Along a spectrum with ‘quality of life’ at one end and ‘prolongation of life’ at the other end, where do you place yourself?”*
- *“What will help bring joy and meaning into your life?”*
- *“What quality of life would you find acceptable or unacceptable?”*
- *“Under what circumstances would you want the goals and efforts of your care to switch from prolonging your life to focusing on your comfort?”*
- *“If treatment does not go as we hope, what is most important to you?”*
- *“In what setting (where) would you like to die?”*
- *“If you wish to die in a hospital, would you want to be treated in an intensive care unit?”*
 - *“If you became unable to breathe, would you want to have a tube placed down your throat into your windpipe so that a machine could pump air into and out of your lungs, or do you want to be made comfortable with medications and die peacefully?”*
 - *“If your breathing and heart stop, do you want treatments attempted to reverse your death and bring you back to life?”*
 - *“Could you tell me what you understand about CPR (cardiopulmonary Resuscitation?)”*
- *“If you are unable to eat or drink, would you want to receive artificial nutrition/fluids through a tube and/or intravenous line?” (Note, it is important to explain risks and benefits.)*
- *“Would it be helpful for you and/or your family to speak with other members of our team (nurse, social worker, chaplain, care-coordinator?)”*
- *“What fears have we not talked about?”*
- *“What can I help you better understand?”*
- *“Whom would you want to speak for you if you became unable to communicate?”*

For patients who lack decision-making capacity:

- *“What do you believe _____ (the patient) would have wanted in this situation?”*

(For more information about mechanical ventilation, CPR, and artificial nutrition and hydration, see Hank Dunn's, **Hard Choices for Loving People** which is available free for patients to download online at: www.hardchoices.com. Healthcare professionals are asked not to download to distribute it, but to purchase at very minimal cost.

References

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- The American Academy of Physician and Patient (www.physicianpatient.org)
- Conversations in Care (www.conversationsincare.com)
- Education for Physicians on End-of-Life Care (www.EPEC.net)