



Advanced Care Planning:

Turning “What If?” Into “Here’s How”



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A number of years ago, I attended a lecture on Advance Care Planning.

The speaker was a very engaging man who had recently dealt with end-of-life issues for a loved one. There were about 150 people in attendance at the lecture, which began with a series of questions:

“How many of you have life insurance?”
Virtually every hand in the room went up.

“How many of you have a will?”
About three quarters of the hands were

raised.
“How many of you have a living will?”
About 10% of hands were raised in response to this question.

I think that this illustrates the fact that we all make certain plans to provide for future events, but very few of us include our health care considerations among them. Patients with kidney disease are faced quite often with making decisions related to their healthcare; thinking about those issues and documenting our wishes in a formal manner can alleviate much of the uncertainty and stress when a major health event occurs. Advance Care Planning is the process of defining a patient’s wishes pertaining to their

healthcare and is designed to cover the continuum of their healthcare experience through end-of-life. It involves reflection, communication, and discussion among the patient, family or healthcare proxy, and healthcare professionals. Advance Care Planning may include important legal documents such as an advance directive, which provides clear instruction for the healthcare team about choices and goals of care in the event that a person becomes unable to make those decisions actively at the time of a major health event.

The Center for Medicare and Medicaid Services (CMS) has addressed patients’ rights with respect to advance directives.

CMS regulation 494.70(a) (6) Patients' Rights states that patients must be informed about their right to have advance directives and about the dialysis facility's policies regarding them. In addition, CMS requires that facilities document in the patient's medical record whether or not an advance directive has been executed.

There are several important elements to Advance Care Planning. A healthcare proxy is a person chosen to make medical decisions for a patient who has lost decision-making capacity. An example of when this may apply is in the event of an accident where the patient is rendered unconscious and cannot respond to questions. Physician Orders for Life-Sustaining Treatment (POLST) are another example and are completed when a physician has held a conversation with the patient and documents the patient's wishes regarding choices of care at the time of a significant medical event or at end-of-life. I have said many times that it is impossible for me to honor a patient's wishes if I have not asked what they are.

These discussions can be difficult for patients, family members, caregivers, and clinicians alike. They involve emotions, faith and values, support systems and most importantly, patients' wishes. It is always best to have these conversations at non-urgent times and to ask them as a series of "What if" questions. For example, "Twenty years from now, if you had a stroke, would you want ..." In this manner, the event is clearly non-urgent, and the discussion is rendered much less frightening. But the important information is conveyed. It is also important to remember that this is a dynamic process that is not completed in a single conversation, but is instead the product of ongoing interactions among the patient, family, care team, and physician that evolves over time. Any time a major health event occurs, it is wise to review the Advance Care Plans.

In many instances, particularly for elderly patients, conservative care is chosen as the preferred management of kidney disease and kidney failure.



Treatment consists of preserving existing kidney function and controlling symptoms without pursuing dialysis or transplant. Conservative care allows the patient to have control over their quality of life when life expectancy is limited.

Palliative care is care which is focused on quality of life. Many patients may experience a slow progression of disease rather than a sudden catastrophic event. As disease progresses, many patients will elect palliative or supporting care which has the following goals:

- Relief of symptoms
- Control of pain
- Facilitation of meaningful interactions between patients and their loved ones
- Increased emotional and spiritual wellbeing
- Reduction of caregiver burden

Perhaps the greatest benefit of palliative care is the focus on improving the patient's quality of life.

Finally, hospice care involves a team-oriented approach to medical care, pain management, and emotional and spiritual support as the patient approaches the end of life. Many times, the decision by an end-

stage kidney disease (ESKD) patient to pursue hospice care can be confusing and intimidating. Patients are often not aware of hospice benefits available in the setting of ESKD. Patients and families may welcome an opportunity to discuss preferences for care, particularly if they are fearful of a terminal diagnosis. ESKD patients who are Medicare beneficiaries often benefit from hospice care and should inquire about benefits for which they may qualify.

The primary goal in patient care should be to achieve the best healthcare-related quality of life. By seeking to understand the patient's goals and desires, we have the greatest opportunity to provide the best possible quality of life in accordance with the patient's wishes. Advance Care Planning is essentially the process of documenting the patient's wishes so that they may be honored.

For more information about Advance Care Planning, speak with your social worker or physician.