

What is advance care planning and why is it important for dialysis patients?

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I am a nephrologist. About five years ago, my father had a sudden cardiac arrest in front of me. I was able to quickly initiate CPR. By the time the ambulance arrived, he had regained consciousness. He lived for another two years, but unfortunately became critically ill after developing leukemia. An infection had overtaken his body. He was then in the intensive care unit (ICU) on multiple antibiotics and drugs to treat the infection and keep his blood pressure up so that his organs could continue to get blood flow. His kidneys started failing quickly. I remember the ICU team calling me and telling me he was not doing well. We gathered the family and went to his hospital room. Upon speaking with the intensive care unit doctor and nephrologist, my family and I were left with the difficult decision of whether to start dialysis. As a physician, I knew his prognosis was not good. As a nephrologist, I knew dialysis would not fix what was killing my father. And yet, even with this background knowledge, I hesitated to answer when the nephrologist asked me whether my father, who could no longer answer for himself, would want to proceed with dialysis. His condition was deteriorating quickly. I instructed the ICU team not to perform any life saving measures and allow him to pass away naturally. He died within minutes.

When I think back to my father's last days and moments with us, I ask myself, "Why didn't we talk to Dad more about what he would want if he could not tell us for himself?" He had had two cardiac bypass surgeries in the past, but we never talked about it. I actually tried to start a conversation with him about his care goals after his cardiac arrest, but he didn't want to talk about it. He never made a will or outlined his goals of care. I don't think he wanted to think about his own death. As a doc-

tor, I felt somewhat ashamed that we did not talk about these important issues. As a son, it was not a conversation I wanted to have. I can't tell you why I didn't push harder to have these conversations. I knew it would just be very uncomfortable. I did not want to push the conversation if he did not want to have it. But, I know that the anguish my family members and



I went through in terms of how aggressive to be with his care would have been lessened if my father had talked to us about what he wanted for his goals of care.

Advance care planning, as described by the Renal Physicians Association's Guideline on Shared Decision Making, is a process wherein the patient (or his healthcare power of attorney or healthcare proxy) and the physician hold a discussion to:

- help the patient understand his/her condition
- identify his/her goals of care
- prepare for the decisions that may have to be made as the condition progresses over time



These are not easy conversations to have, but many dialysis patients feel better knowing that they have had this discussion with their family, physician and/or social worker. By engaging in advance care planning, patients are able to maintain their autonomy and sense of control over their future. Patients have some peace of mind knowing that they have lifted the burden of family members having to make difficult healthcare decisions on their behalf.

There are different ways in which a patient can make his wishes for future healthcare known. Some examples are outlining the wishes in the form of an advanced healthcare directive, designating a healthcare power of attorney or by completing a Medical Order for Life-Sustaining Treatment (MOLST) form. Most states in America have some type of MOLST or similar form that can be filled out by the doctor and patient and be kept on record so that the patient's wishes can be reviewed if and when they are not able to communicate this information to the healthcare team. The MOLST is a portable and enduring medical order form covering options for cardiopulmonary resuscitation (CPR) and

other life-sustaining treatments. These orders are based on the patient's wishes about future medical treatments. Having a MOLST form will increase the likelihood that the patient's wishes regarding life-sustaining treatments are adhered to across the continuum of healthcare. For example, the orders would carry over from the dialysis unit to the hospital and vice versa.

Looking back at my experience with my father's death, I can say that the decision process would have been less difficult had my father had these discussions with us and his doctors well ahead of time. Dialysis patients should take the opportunity to talk to doctors about expectations for life span and quality of life, and speak to family about what they would and would not want done if they are no longer able to decide for themselves.

More information on advanced directives for dialysis patients can be found online at the Coalition for Supportive Care of the Kidney Patient's website (www.kidneysupportivecare.org).