



## Chronic Kidney Disease: Achieving Better Outcomes

By Derek L. Forfang

I was recently honored to be one of the patients at a roundtable discussion on care models for early detection and better management of chronic kidney disease (CKD). The Rogosin Institute sponsored this roundtable to bring together key stakeholders from the kidney community and the leaders of the local community in Brooklyn, New York. The discussion centered on how to achieve better outcomes for patients at earlier stages of CKD.

My kidneys failed 20 years ago when I was 32 years old. I was told in my mid-20s that I was spilling protein into my urine but did not understand what that meant. I was never told about CKD or the stages of CKD. As a matter of fact, I did not hear those terms until I started advocating about kidney disease 5 years after my kidneys failed. Although I am a type 1 diabetic, I had never been told about my risks of kidney failure, and no one ever discussed steps that might slow its progression or diet precautions after I was diagnosed.

Like many of us with kidney disease, I “crashed” into the emergency department.

I had 42 pounds of fluid on. I went into the hospital weighing 215 lbs. and left 4 days later weighing 173 lbs. I was able to breathe and move my legs again, and there was a catheter in my neck. I remember my son saying, “There you are, I knew you were in there.”

This scenario happens much too frequently: 52% of renal patients crash into dialysis or start dialysis in an inpatient setting (1), and 24% of patients crash without ever being diagnosed with CKD (2). Crashes increase costs per patient by approximately

\$53,000 during the first year on dialysis (3), and 74% of patients start dialysis without the preferred vascular access in place (4).

Although I was seeing physicians for my kidney disease, there was little to no coordination of my care with specialists. I was one of the 25% of new ESRD patients who had not seen a nephrologist (5). It is strange as a patient advocate that I see a lot of statistics and sometimes forget that I am part of them, but I remember the start of treatment for my kidney failure clearly: it was a horrible experience for both me and my family.

Therefore, I am very passionate that others with CKD do not share my experiences. The first year or so on dialysis, I just struggled to survive; I felt like my body was falling apart. I see how smoother starts on renal replacement therapies (RRTs) can improve patient outcomes.

Here is a list of issues that I feel need to be included in a CKD care model:

- Patient activation to assist each patient in being active in his or her own care;
- Patient-centered care planning, focusing on that patient’s life goals, values, and culture;
- Education on diet, disease, medications, RRT options (including preemptive transplantation), and palliative care if appropriate;
- Preserving residual kidney function: we like to pee!
- Mental health care;
- Coordination of care;
- Hope.

I watched my grandfather and mother struggle with kidney disease. They had bouts of depression, and I could see in their eyes when they had just lost hope. My mother only lived about a year after starting dialysis, passing at 60 years old. My grandfather lasted about 4 years after his diagnosis. I often think of them both, especially knowing what could have been done better in their care. I have also seen that, when other patients lose hope, their outcomes are never good.

Many questions and topics were discussed at the roundtable and will be shared in upcoming issues of *Kidney News*. From my point of view, we have many things to do, and we need to think big.

Perhaps we should focus on the stages of CKD individually, looking at a model for early detection and slowing progression or halting CKD. Or maybe we focus on a separate model that improves transition to ESRD and a smooth start to RRT. Or we focus on one model that encompasses it all. We cannot leave out people with any stage of CKD.

I feel such a sense of urgency to address CKD and the vulnerable people who have it and do not even know they have it. CKD affects more than 30 million people in the United States, and astonishingly, 96% of those with early kidney disease do not know they have it. People at the highest risk include those with diabetes and hypertension. Minority populations are also disproportionately affected by CKD: Compared with Caucasians, four times as many African Americans and twice as many Hispanics develop CKD.

One thing we can all do immediately is engage patients in their own care. A provider recently said to me, “I keep telling my patients exactly what they need to do to improve their care, but they don’t listen to me. How can I get my patients engaged?”

My answer is, stop talking and listen. Put down the laboratory values and start the conversation with “How have you been doing; are you able to do the things you like or need to do?” If we as patients understand the steps we need to take to keep working, camping, doing a hobby that we enjoy, traveling, etc., then you have a better chance to get us engaged. We are all individuals, and having a care plan that is developed with our interests in mind is key. This also applies to a more palliative approach. Some patients (e.g., the elderly or those with a short life expectancy) may not want to transition to RRT at all. The plan should start with us (the patients) and our families. Be sure that we have the information needed to make shared decisions and set goals. ■

*Derek L. Forfang is a member of the National Kidney Foundation’s Public Policy Committee as well as its Kidney Advocacy Committee. He also serves as Chair of the National Forum of ESRD Networks’ Kidney Patient Advisory Council and Chair of the ESRD Network 17 Patient Advisory Committee. He is a member of the Kidney Health Initiative Patient Advisory Committee.*

### References

1. Medicare 5% sample data average.
2. DaVita HCP NV Analysis.
3. 2009–2012 Medicare 5% sample data weighted average across all states for patient costs in first twelve months of dialysis.
4. 2009–2012 Medicare 5% sample data weighted average across all states.
5. USRDS. *USRDS Annual Data Report*, 2015.