

Welcome. My name is Linda Curry and I am so pleased to join other patients and family members in addressing concerns regarding hemodialysis treatment centers. We at Association of Dialysis Advocates hope that you, too, will help in our work to improve conditions in the facilities.

I have varied experiences as an ESRD patient. I was treated in free-standing facilities for 9.5 years (in states of Arkansas, Louisiana, Maryland and Texas), was a home dialysis patient for 1.5 years, and have had a transplant for 3.5 years. I am very blessed to have received a transplant and pray for the same blessing for other patients. Memories of former experiences in the dialysis facilities remain with me and caused my joining ADA in attempt to improve conditions for patients who remain in centers.

When one has lost kidney function and becomes dependent on life-sustaining dialysis treatments, a whole new lifestyle has to be adopted and involves changes related to diet, physical activity, and collaboration with a host of medical providers. Such demands can become overwhelming to patients, but it is possible to make the best of the new medical conditions if patients assume appreciable responsibility for their care. Patients, with help of their family members, doctors, and dialysis staff, must become educated so that they can take care of themselves and be involved in their dialysis treatments. Many patients try to be actively involved in their treatments, but there may be problems at facility level that interfere with their doing so.

Dialysis patients should have the right to ask questions of their physicians and dialysis staff without being afraid to do so. Patients are afraid at times to ask questions or comment about their treatments because they fear being thrown out of the treatment center or threatened about same. This fear of retaliation hampers the patient in being actively involved in his or her care and poses unnecessary stress on a patient who is already undergoing challenges related to kidney failure and dialysis treatments. I hope that I will be able, working as member of the ADA leadership team, to make some impact for improving relationship and interaction between patients and their providers.

Unfortunately, perception of many patients is that money takes priority to quality care in dialysis facilities. This perception is based on observations such as (1) providing treatments without individualized parameters – that is, dialyzing all patients by some standard that may not be applicable to all patients, (2) inadequate staffing to treat and monitor patients during dialysis procedures, (3) failure to educate and interact with patients so that they are better equipped to protect themselves during dialysis, and (4) failure to collaborate with other physicians/specialists caring for patients so that there is a holistic approach to treating patients. We understand that for-profit dialysis facilities, in which most patients are treated, are in the business of making “profit” for their investors; however, we believe that there can be “profit” and quality care at the same time. “Profit” should not take precedence to safe and quality dialysis treatments.

Medicare office, facility leaders and staff, and physicians are failing many dialysis patients by not insuring that patients are being treated in safe environments, thereby exposing patients to conditions that cause added illnesses and hospitalizations. Some facilities are dirty with minimal attention to accumulated trash and waste, janitorial and housekeeping activities, and neglect to use infection controls to prevent transmission of bacteria between staff and patients or patients

and patients. These are conditions that patients can see. It stands to reason that if facility staffs are derelict in these areas that patients, families and the public can visually observe, that there is question about those activities that we cannot see – i.e., water and dialysate quality, equipment disinfection and sterilization, infection rates, etc. We believe that our Medicare office must improve in its oversight of dialysis facilities so that there is more accountability for public funds being spent to care for dialysis patients.

I hope that viewers of our website will share and help us improve conditions in facilities for all patients.

Linda Curry
Texarkana, Arkansas