A plan ‘C’ for seniors

Very few physicians highlight ‘conservative management’ over dialysis

PAULA SPAN

John Everdell had lived most of his life with kidney disease. As a young man awaiting a transplant, he had briefly undergone dialysis. That’s how he knew, when the prospect of kidney failure loomed again in his late 60s, that he would refuse dialysis this round.

“He was a very independent man, with an idea of how he was going to live his life,” said Trix Oakley, his partner of 22 years.

A woodworker and furniture maker, Mr. Everdell had been in his 30s when he was first diagnosed with kidney disease. By his 60s, he had received two transplants, with kidneys donated by his siblings.

But in recent years, living in Cambridge, Mass., he and Ms. Oakley could see that his second transplant-damaged kidney was faltering. The readings on his monthly blood tests grew troubling; he felt cold and tired; his hands and feet began to swell. His doctors again suggested dialysis.

In the meantime, he and Ms. Oakley enjoyed road trips, particularly seeking out ferry routes from Canada to Florida. Mr. Everdell, who had once sailed across the Atlantic, was no longer strong enough to handle a boat, Ms. Oakley said. “So we took as many ferries as we could, because he loved being on the water.”

The data

Developed as a temporary measure to keep patients with kidney disease alive until they could receive transplants, dialysis instead often becomes a way of life. More than 104,000 people over age 75 were receiving dialysis in 2016, the United States Renal Data System has reported; so were more than 130,000 patients aged 65 to 74.

It’s a safe bet most never learned about an alternative: managing their disease and its symptoms medically, with frequent physician monitoring and consultation – but without dialysis.

Dialysis prolongs survival, but it also imposes burdens – like travelling to a clinic three times a week for four-hour sessions of haemodialysis, or doing multiple fluid exchanges daily for peritoneal dialysis, which can be performed at home. Conservative management can help patients avoid those routines.

Moreover, while some studies show that older patients undergoing dialysis survive longer than those using conservative management, those differences fade among people over age 75 who also contend with other serious health problems, as most do.

And survival, of course, is not the only thing patients value. Conservative management may allow greater freedom to pursue what matters to them, even if they live fewer weeks or months.

“Dialysis is a life-changing event,” Dr. Susan Wong, a nephrologist at the Veterans Affairs Health Services Research and Development Center in Seattle, and lead author of a new study in JAMA Internal Medicine. “It’s a very demanding form of treatment. It involves medical issues, spiritual issues, quality of life. It’s a big decision.”

Yet patients often tell researchers that they don’t recall making a decision, or even discussing one. Physicians frequently present dialysis as inevitable; in a small study of nephrologists, only a third routinely informed patients about conservative management.

“Patients didn’t recognize it as a choice – ‘My doctor told me I’d die if I didn’t do dialysis,’” said Keren Ladin, director of an ageing and ethics programme at Tufts University, who has interviewed both patients and nephrologists. “Or they’d say that it wasn’t their choice, that their doctor made the choice.”

Those patients might have wanted to know, for example, that at the end of life, patients using conservative management were less likely to be hospitalised than dialysis patients, less apt to undergo aggressive procedures, and less likely to die in a hospital.

For now, patients interested in conservative management, or whatever we decide to call it, won’t find supportive doctors easy to locate. A few nephrologists have launched programmes at New York University, the University of Washington, the University of Rochester and U.P.M.C. in Pittsburgh, among other medical centres.

Organisations like the Coalition for Supportive Care of Kidney Patients and the American Association of Kidney Patients have useful websites.