Improving quality and outcomes with alternative dialysis modalities

Two years ago, Bruce Cosaboom, a retired civil engineer in the Philadelphia area, was told his kidneys were failing.

It wasn’t a complete surprise to Cosaboom, who’d had a lifetime of kidney and other health issues. He was born with polycystic kidney disease and began monitoring it in his 30s, when a few small cysts were beginning to form. Cosaboom started to see a nephrologist, led an active lifestyle, and watched his diet. Still, he developed high blood pressure, and the cysts in his kidneys were growing, creating pressure on his stomach.

At 64, Cosaboom felt his stamina and energy ebbing. After some blood tests, his nephrologist, Afshin Hannani of University Hospital in Hamilton, N.J. and medical director for the Satellite WellBound home dialysis center there, said his health was deteriorating and that Cosaboom would soon have to go on dialysis.

“It was a shock,” says Cosaboom. “No matter how prepared you think you are for a diagnosis like that, you suddenly find you can’t think straight.”

Straight thinking, however, is exactly what patients such as Cosaboom need when they’re diagnosed. A lot is riding on the decisions kidney patients face.

There is a wide range of options, including kidney transplant. But, a transplant means getting on a donor list and hoping for a match. If the choice is dialysis, then what kind? And where? In a dialysis center? At home?

At-home means patients must administer and monitor the treatments themselves, injecting needles, measuring fluids, operating equipment. For those in weakened physical and emotional states, that can quickly feel overwhelming. It’s natural to ask, “Can I do it? Do I have the knowledge, discipline and dexterity? What if I make a mistake? What if I live alone and have a problem?”

For those reasons, treatment in a dialysis center may be a safe and manageable option to many. It shifts most of the treatment responsibilities and issues from the patient to white-coat professionals. So, to reduce patient anxiety and for other reasons, many physicians simply recommend dialysis centers as the best or only choice.

Hannani was not, however, one of those physicians. “He patiently counseled me about all my options,” says another kidney disease patient, Mary Giovannini, a retired English teacher in Hamilton Township, N.J. She was told five years ago by Hannani, “I’d rather put you on dialysis now than wait until you get too ill.” She had ignored the symptoms of her diabetes for years until her hemoglobin was so low that she was admitted to the hospital.

“It’s not if your kidneys will fail,” Hannani told her at the time, “it’s when they’ll fail.”

He discussed her options with her, explaining that administering her own dialysis treatments at home was more than a medical decision. It was a lifestyle decision.

“There’s flexibility to at-home treatments,” Giovannini said. “You can set your own hours and conditions, treating yourself overnight while you sleep or for a few hours while you watch TV or read a book or work at your computer. You can travel. You don’t have to worry if a snowstorm or traffic jam prevents you from keeping an appointment at a dialysis center.”

Satellite Healthcare’s Satellite WellBound division educates, trains and supports patients who choose dialysis at home. WellBound believes that home dialysis patients live longer, enjoy better outcomes and reduce the cost of health care. To do that, patients need support and guidance, and that means providing accurate information. The goal is to lessen some of the emotion so people with CKD can make informed, clear-headed choices.

“The first thing we ask the patient is, ‘Why do you think you’re here?’” says Maureen Holland, one of WellBound’s regional directors of operations. “We want to determine what they think they know and what their doctors are telling them. We’re probing for misconceptions patients might have.”

One of the biggest patient misconceptions, says Holland, is that they think they’ll do dialysis for a little while and they’ll be fixed. “We make it clear to them that this is what they’ll do for a lifetime,” she says.

That’s the key part of the decision, Holland says, because the purpose of dialysis is to continue to live the life you enjoy—not just to live.

And that leads to the next question for patients: “What is important to you in your life?” WellBound’s philosophy is that patients ought to fit dialysis around their lives and not the other way around. “We stress that if they’re active and independent—if they travel, they spend time with family or friends, or perhaps they’re still working—they might prefer the independence and flexibility that at-home treatment offers.”

One of the key advantages of at-home treatment is that patients set their own dialysis schedules. In-center dialysis, on the other hand, requires fixed schedules with almost no deviation.

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**Pre-Dialysis**

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Holland says one WellBound patient dialyzed while fulfilling a life’s dream—white-water rafting on Oregon’s Rogue River.

WellBound also explains all the options the patient faces—not just at-home versus in-center, but also the treatment options of peritoneal dialysis versus hemodialysis.

“Each one has its advantages and disadvantages, and the patient has to know that,” Holland says. “But the benefits of home dialysis—flexibility, control, better knowledge and involvement, the availability of personal training, improved heart health, better blood pressure control, fewer dietary and fluid restrictions, quicker recovery time, fewer hospitalizations—have to be balanced with a steeper learning curve and some details, like the need to learn the process and store equipment and supplies at home.”

WellBound counselors also deal with the emotional consequences of doing dialysis at home. For example, patients get personal one-on-one training with a WellBound facility nurse, covering the risks of complications like infection and how best to minimize those. Perhaps most important, with WellBound, patients get a support network of trusted advocates who answer questions and solve problems—24 hours a day, every day.

Mary Giovannini, who says the prospect of doing her dialysis at home “scared the heck out of me,” now realizes “you’re crazy if you’re not frightened.”

But six years later, she’s thrilled with her decision. And, she says she owes much of that to the service she received from WellBound.

“It’s been a one-stop shop for me,” she says. “It’s a teacher, nurse, social worker, technician and dietician, and all on 24-hour call.”

(Continued from page 1)

**Why patient participation in modality choice is important**

It is a known fact that informed patients choose a home modality 50% of the time. We have seen this in our own studies. Most patients gain quality of life through independence and flexibility. The transformation of switching from conventional HD to short daily or nocturnal HD has convinced many professionals to consider these alternative therapies more closely.

This is a start. However the continuum of CKD/ESRD care requires access to all modalities and expert knowledge among all caregivers, a prerequisite not guaranteed at this time in all parts of the United States. Moreover, it requires an open mind to allow a patient’s voice to be a full part of the decision-making. Does a five-year survival rate for 35% of our patients require us to embrace informed consent similar to what oncologists and other specialists have long practiced? Clearly a patient who objects to a home modality or longer/more frequent therapy shouldn’t be pushed into it, but any patient who voices interest should be given the option to do so.

Indeed a one-size-fits all approach is fading—and this change is overdue. Patients should be supported to choose their most suitable modality for themselves and their family. Early education with clear disclosure of the pros and cons of all modalities incorporating all the medical and psychosocial characteristics changes the modality choice. Access to and continued support for home modalities and in-center alternative schedules facilitate the transition for patients, and delivers the long proclaimed continuum of CKD care.

Early and ongoing education and ongoing re-evaluation of patients’ well-being will empower patients to choose the best modality for themselves. With a joint effort from nephrologists and providers to support these choices along the way, one may head into a future ESRD world, where in-center conventional HD might be the “alternative” therapy. As more evidence becomes available about the advantages of more frequent and longer HD, the conventional in-center HD of the future is likely to consist of thrice-weekly sessions of more than 4 hours. Add a more coordinated care delivery to it and we may well have found the “secret recipe” to improving outcomes.

**References**