

Home Hemodialysis Patient Advocate George Harper Doesn't Let Retirement Slow Him Down

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Introduction

One thing you can say about George Harper, MEd, EdS, a retired high school counselor and premier home hemodialysis (HHD) patient advocate: he doesn't let retirement slow him down. You could even say his dedication to taking frequent trips in his spacious motor home is downright awe-inspiring. Consider this...

George and his wife, Irene, have a two-story house in their hometown of Rome, GA, a town of about 50,000 in the foothills of the Appalachian Mountains approximately 65 miles northwest of Atlanta. As a HHD patient, his dialysis room is on the second floor. It houses a large, 250-pound dialysis machine with volumetric control. George says it's an excellent machine that provides every-other-day dialysis for him, but it's not exactly ideal for frequent travel—particularly from a second-story perspective. There's also a 100-pound reverse osmosis (RO) system for water treatment.

But George and Irene are not only dedicated to each other—they downright love their vacation time.

They have a porch on the second floor with a hoist mounted on it. The winch has a steel cable.

"We roll the machine through another bedroom onto the porch," Harper explained to *FPO*. "Then we hook up a sling to the machine. The hoist is swung out, lowering the machine to the ground."

Since they live on a hill, the motor home has to be driven down to the street and parked perpendicular to the driveway. Four eight-foot long boards are used as ramps. In between the two sets of boards, two two-foot stepladders are set up. Two of the ramps lead from the ground up to the stepladders while the remaining two ramps go from the ladders to the entrance of the motor home. The long ramps cut down on having to struggle up a sharp incline.

Then George and Irene carefully roll the dialysis and RO machines down the driveway

"We tie a rope around them, and Irene gets up in the motor home," George remarked. "Then she pulls, and I push them up those ramps. We decided we would have to be gone at least a week to make it worthwhile going through all that. Nonetheless, it has been a wonderful source of satisfaction and psychological freedom to know I can still travel [and dialyze at the same time]."



"ON THE ROAD AGAIN"—When George and Irene Harper leave on vacation in their spacious motor home, they have to hoist George's large dialysis machine from the second story of their Rome, GA,



house. Unless they plan to be away at least a week, George says, it's a real hassle. But, then, they've been doing it for about 15 years...

"On the Road Again..."

The Harpers take it all in good humor, and, by now, they ought to be used to it. They have been doing it since 1982. For 10 years, they had a small motor home. Then, in 1993, they bought a much larger, bus-sized one, making the moves easier—or, at least, with more space. Fortunately, motor homes have the three basics for dialysis—electric, water, and sewer capabilities. Even so, George had to make some electrical and plumbing modifications.

But, as any patient who travels while doing dialysis knows, you can occasionally have some "hair-raising" experiences. Apparently, the water at spots in the Appalachians has a very low mineral content, George believes, and "the RO thinks it is not doing its job. An alarm sounds. Then I have to take a pair of alligator clips and short out the alarm. The RO measures the conductivity of both the incoming raw water and the product water. There should be a difference indicating the machine cleans the water. If you have water with a low ionic content,

however, there's not much difference. Therefore, the machine thinks it hasn't done its job and sounds the alarm. That shuts it down, and you can't use it."

There can also be voltage problems. Irene said a number of the campgrounds were built many years ago, "when there weren't so many motor homes with air conditioners and microwave ovens" and other equipment dependent upon drawing extra voltage. Therefore, there is sometimes not enough power to accommodate a lot of motor homes in an older campground. The voltage "trips out," sounding the alarms on the dialysis equipment. "Then we have to turn things off in the motor home," including the air conditioner, and, at times, even the refrigerator.

"Getting Backup Treatment"

But it's all been worth it. George and Irene have traveled a lot since he has been on dialysis. One favorite jaunt has been to Key West, FL, during Christmas vacation when they were still working. They have also motored to Bar Harbor, ME, Plymouth, MA, through New Hampshire, and Cabot Trail, Nova Scotia, Canada. Last September, they drove their motor home to Denver, CO, for the annual meeting of the [American Association of Kidney Patients \(AAKP\)](#). (See *FPO*, July/August 1996, pg. 12). From there, they met some friends in Rocky Mountain National Park and also visited the Grand Tetons and Yellowstone National park in Wyoming. And, last month (February), George and Irene left yet another vacation spot in Tampa, FL, and flew out to Denver again—this time to participate with Zyblut J. Twardowski, MD, FACP, PhD, in a presentation on the "buttonhole" method of needle insertion, in which one or more permanent "needlestick" sites are used with each dialysis treatment and which George has been using for the past eight or so years, at the Seventeenth Annual Conference on Peritoneal Dialysis. (See *Contemporary Dialysis & Nephrology*, February 1997, pg. 18).

Most of the time, there have been no major problems. A couple of years ago, however, they were motoring through Lenoir, NC, in the Great

Smokey Mountains, when the dialysis equipment broke down, and George needed a treatment. The local dialysis unit, however, would not treat him because of its 30-day notification policy. But the company that services George's dialysis machines sent a technician who worked on the machine, and everyone thought it was fixed. That night, however, it malfunctioned again. Even though he didn't normally work on weekends, the technician came to the rescue again. He even had to order a part, then pick it up at the airport, and deliver it to the motor home, on Saturday. Just in time, too, because George hadn't had a treatment since Wednesday. The Harpers will always remember the kindness of strangers.

"A Long Haul"

But it's been a long haul for George. There has never been a time when kidney disease was not a part of his life. His first brush with it came in 1946, the year he was born. His brother Billy died that year at the young age of 15 from what was then called "chronic hereditary nephritis. George is pretty sure it was really Alport's Syndrome because he and his two male siblings contracted it.

Then, in 1960, his surviving brother, Tommy, succumbed from the disease the same month (March) that Belding Scribner, MD, the father of continuous dialysis, began dialyzing the first patient with his revolutionary chronic dialysis shunt. Tommy had gone to Peter Bent Brigham Hospital in Boston, MA, and was cared for by nephrology and transplant pioneers, John B. Merrill, MD, and Joseph E. Murray, MD (a Nobel Prize recipient). In one of the early transplant operations, he received an infant kidney, but there were no effective immunosuppressant drugs back then, and he had to receive total body irradiation. Along with nine other patients in an experimental group of 11, Tommy died.

When George was only four, he was diagnosed with hematuria (an abnormal amount of blood in the urine). At nine, it was acute nephritis,

and he was ordered home from school for three months of total bed rest. Two months after Tommy died, he went to Boston himself and saw Merrill, who put him on an experimental program in which he took Imuran and "massive doses of prednisone." At first, they thought he was suffering from some sort of autoimmune disease, and "they were trying to treat me like a transplant patient." He was only 14.

High School Counselor

Other than these early setbacks, Harper's life was pretty normal for about the next two decades. He began working as a high school counselor in the Atlanta area in 1974. He met Irene at a high school in Lithonia, a suburb of Atlanta where they were both employed. They were married on Valentine's Day, 1976, and he and Irene moved back to Rome that August. Then he began a 19-year counseling career at Tepperell High School, retiring in 1995.

George counseled students in a number of areas, including college placement and personal matters such as family and child abuse problems. But, later on, he specialized in conflict resolution.

"I did a lot of work with angry teenagers who were about to get into a fight," George stated. "I would negotiate a settlement between them. That work was very satisfying, and I could see immediate results. I discovered that most people who are upset and angry don't really want to fight. They just want their feelings to be protected and given an adequate airing. If they are given a respectable solution, it preserves their self-respect, integrity and dignity. Students are very happy with that."

Beginning Dialysis

Harper began dialysis in Rome on October 1, 1980. His nephrologist thought he would be a good candidate for HHD, and he was trained for that. Even today, he believes HHD has the longest-term survival rate, but the key is "your helper. I have to give credit to Irene for being such

an able and devoted aid during these 16+ years. It can put a real strain on a relationship."

Irene admitted it was a "real strain" at first, particularly since she was fearful she might do something to jeopardize her husband's well-being, and, even, survival.

"For the first few months, it was real scary and was one of the hardest things I have ever done," she remarked. "Now, I think it was the best decision we ever made together. I believe George has been happier and more in control of his life. He always sought the best treatment alternatives. He wouldn't settle for second best. I believe patients at home do take more control of their lives. George is very responsible concerning his diet, fluid control, and weight gain. We can watch television and do the things together while he's dialyzing that we would be doing anyhow. But it is George who has always been the one in charge of his own treatment. I was only there to assist him. That has worked very well for us." The interest of both George and Irene in not only their own welfare as a chronic dialysis family but as strong patient advocates earned them, in October 1991, what was then the AAKP's highest honor—the Samuel J. Orenstein Award for "extraordinary service and contributions toward the advancement of AAKP's goals."

How About a Transplant?

It is obvious that George loves his life in his hometown of Rome, GA. He lives in what he calls "a very beautiful setting"—where two rivers with Cherokee Indian names, the Etowah and Oostanaula, come together to form a third—the Coosa. The rivers, he said, "are very important to the community," which has started developing attractive walking paths along the river banks while an excursion boat navigates the waterways.

It was during a recent walk with Irene along one of these paths that George began to reconsider his decades-long conflict as to whether or not he should place himself on the transplant waiting list.

Some of his close friends in the AAKP—including A. Peter Lundin III, MD, and John Newmann, PhD, both past presidents—as well as numerous others had all gotten transplanted, and he began to think that maybe his was a lone voice in the wilderness still extolling the virtues of dialysis. But he had been skeptical of transplantation for himself for a long time. When he first started dialysis, the one-year graft survival rate was only about 50%, with the patient mortality rate close to 30%. Now, of course, both are well up in the 90% percentile range. He began thinking: while a transplant would free him from dialysis, he didn't have a bad lifestyle on it at all. He was able to travel and do just about anything he wanted to do. Besides, "one of the nice things about dialysis is that it is very predictable. When I get on the machine, I know what it is going to do. I know I am going to feel a whole lot better when I get off."

"Then," he said, "as we were walking one day on one of the river trails, I turned to Irene and said: 'Now, wait a minute. I just had another thought about this. What if the hospital called and said they could give me a six-antigen match organ? I'd probably be a fool to say 'no' to that. So, I listed myself for a perfect match.'"

So, George and Irene Harper are ready for yet another challenge, no matter what. George Harper just may be the exception to the rule that you can't have your cake and eat it, too.