

True Dialysis Stories

by Jordan Nichols and Scott Bogren

The issues raised in this issue of *Community Transportation* focus on how public and community transportation providers are connecting thousands of Americans everyday with both continuing and life-saving medical care. But the real impact of these services are on people.

As Gloria Burns, 77, of Portland, Maine says, “I was oblivious to the need for transportation until I got sick. Now I know that it is essential — and in the case of dialysis, it is life saving.”

The following are profiles of real people, in Maine, West Virginia and Massachusetts, needing transportation to medical care. But we know that these people could be anywhere.

“People Who are Ill Need Transportation”

Dorothy Bougie is 73 years old, and lives in rural Alfred, Maine. Her home, in which she’s lived for the past 50 years, is somewhat isolated in the southern-most part of the state, about 40 miles southwest of Portland.

Three times a week, Dorothy heads to Sanford for dialysis. She’s been a dialysis patient for three years now. Up until recently, Dorothy still drove anywhere she needed to go, including to her dialysis treatments. But then she had an accident, totaling the car. She bought a new car, and then had another accident, totaling another car.

“I got a lecture from my son when I had the second accident,” says Dorothy. “He made me feel like a highway menace. But I did think that, perhaps, it was a sign that I shouldn’t be driving. Problem was, there was no other way to go.”

Dorothy doesn’t qualify for Medicaid, as her income puts her just over the limit. With her husband’s pension from General Electric and Social Security, her modest income makes her ineligible for Medicaid which she’s come to learn is a distinct disadvantage.

“The people who make the rules in Washington — and in Maine — they should focus on the need and not the income guidelines,” says Dorothy. “People who are ill need some transportation if they need it.”

Thankfully for Dorothy, just when she couldn’t figure how to get around anymore, she found a solution. She had begun to really hate having to ask neighbors and friends for rides, most of whom are as old as she and experiencing their own medical challenges. What’s more, her two sons live too far away in New Hampshire and Connecticut, and there was no church service to provide the service.

Enter the York County Community Action Agency in nearby Sanford, riding to the rescue offering a regular trip to dialysis

“The service is great and I was getting desperate. You know, the only good thing about dialysis is that if you ever decide that you just can’t deal with getting there anymore, you’ve only got five days before you lapse into a coma,” says Dorothy.

But more than anything else, Dorothy has grown to learn just as critical mobility is to both her independence and quality of life.

“Living in my home is important to me,” says Dorothy. “It’s peaceful and quiet and the idea of moving into one of those... facilities where everyone just sits around and complains, well, it’s not for me.”

“How to Get Around?”

The car wreck was enough. James Mearnf, 69, of Clarksburg, W.V. (in the central part of the state) recalls. “I couldn’t feel the break pedal, and I didn’t want to kill anyone.”

So he stopped driving two years ago. But that raised another quandary: how to get around? And for James, it was a matter of life and death because he is diabetic and has been receiving dialysis treatments at the local dialysis clinic about 15 minutes from his house.

His wife does not drive and they both rely on Central West Virginia Transit Authority (CWVTA) for much of their transportation needs.

“You can’t beat it,” says the former Sports Editor of the Clarksburg Exponent who also spent 30 years as a social studies teacher. “I’d seen the vehicles around town for years but never really knew what they were doing. Now I rely upon them.”

Besides allowing James to access life-sustaining dialysis treatment, the transit authority allows he and his wife to get just about anywhere they need to in the county.

“People who have readily available transportation take it for granted. But you like to get out a little bit,” says James. He also adds that community transportation services have helped him and his wife remain in the house they have lived in for the past 36 years, which to him is crucial.

James acknowledges that they are fortunate to have such services available at a reasonable cost. “It’s a really great help to our overall quality of my life. Without it, I couldn’t take part in anything at all.”

“You Have No Choice”

“After four hours hooked up to that machine, you’re pretty weak,” says Norman Naimey, 72, of Cape Elizabeth, Maine about his thrice-weekly dialysis treatments in nearby Portland. “I used to drive, but it just go to be too much.”

Norman knows that it’s hard for most people to understand what it means to be dependent upon dialysis to stay alive. The four-hour treatments leave him weak-legged and terribly chilled. But he knows that literally he has no choice.

Today, Norman relies on Portland’s Regional Transportation Program to get to his dialysis. It is an agency for which he has much admiration.

“I really depend on the Regional Transportation Program, it helps my wife and I remain independent and it’s helping to keep me alive,” he says.

“When you go on dialysis, you pretty much go on for life. And you go three times a week, period. You can’t put it off. You can’t postpone it. You have no choice,” says Norman.

What the local transit program does three times a week, according to Norman, is save his life and help maintain his independence.

“I don’t have to worry about transit at all now. They get me there and back,” says Norman. “I’d like to see the system get some newer vehicles. The small bus I rode yesterday had 175,000 miles on it.”

“I Don’t Know What We’d Do”

Eloise and Donald Beuhring live in Huntington, W.V., not far from the Kentucky and Ohio borders. Married since 1945, the couple had retired to Florida, but returned to West Virginia to be closer to family and the help they could provide.

Eloise, 79, has been on dialysis since December 1997.

“I used to drive her myself, but I can’t do that anymore” says Donald, an 82-year-old former postal worker and WWII veteran. Physically, Donald can no longer manage to transport Eloise, who requires the use of a wheelchair. They now rely on the Wayne County Transportation Authority to access the treatments that keep her alive.

Unlike Medicaid, which the Beuhrings are not eligible for, Medicare does not cover the cost of transportation to and from dialysis treatment. If it weren’t for the services provided by Wayne County, Donald says he and Eloise would have few options.

“I don’t know what we’d do. We’d have to get help from somebody.” Their daughter works full time, but still makes time to help out with sorting their bills, do Eloise’s hair and “get her all prettied up” according to Donald. But she would not be able to take the time off from work to drive Eloise to dialysis three times per week even if she had the physical ability, and Donald says the couple would not feel good about having to rely on neighbors.

Donald is grateful for the service provided for his wife by Wayne County Transit Authority. “They do it very well, there’s nothing they could really do to improve. They do it very well.”

“I’d Rather Be Home”

“I’d rather be home, here with my wife and family,” says Benjamin Leighton of Windham, Maine. “Going into one of those senior homes just isn’t for me.”

But it seemed that remaining independent and in his own home was increasingly not realistic for Benjamin. Already reliant on portable oxygen, last August he was placed on dialysis treatments three times a week. At first, his wife drove him, but she soon underwent surgery on her arm that made driving unbearable. Thankfully, a nurse and a social worker had both spoken to Benjamin about transportation through Portland’s Regional Transportation Program.

“Thankfully, I knew about the transportation, so they were able to set me up with a volunteer driver in his own car, who takes me and another gentleman from Yarmouth down to Portland for treatments,” says Benjamin. “He’s an 80-year old former World War II fighter pilot in amazingly good health.” All told, the trip is 45 minutes, one-way.

“Some people I know are able to drive after dialysis, but I really don’t know how they do it,” says Benjamin. “I’m right dead after it.”

For Benjamin, the only problem he’s had with his transportation is that the ride down to Portland often aggravates his bad back, and then he has to sit in the chair for dialysis for four-to-five hours. But he’s hesitant to complain too loudly.

“Hey, I can’t complain because I had no other way to get there and their trip is much better than nothing,” he says.

“It’s Saving My Life”

When told that some areas of the country don’t have the kind of community transportation she relies on to get to her dialysis treatments, Sylvia Thompson’s reply was simple: “Tell them to get it. It’s saving my life.”

Sylvia, like many dialysis patients, suffers from diabetes and has not been able to drive for over two years. She cannot get into or out of the car and receives door through door transportation from the Wayne County (W.V.) Transit Authority.

Three times per week she makes the nearly 80 mile roundtrip to the dialysis clinic for the three-to-four-hour treatments that remove toxins from her blood and keep her alive. The treatments, however, take a toll.

“By the time it’s done I’m ready for bed,” says Sylvia. She has been doing this for the past year.

Sylvia is 72 and has lived in her current home with her husband Clifford for the past 22 years. She recently became eligible for Medicaid and it covers the cost of her dialysis transportation, which Medicare did not.

“The van service is wonderful,” says Sylvia, “the drivers are excellent. They come no matter what the weather... I couldn’t be treated any better”.

Sylvia also notes that, “a lot of people rely on Wayne Co. Transit for cancer treatment and things like that.” She says, “I don’t know what would have happened if they weren’t there.”

“Transit is Something Great”

Randall Pierce lives 10 minutes from the dialysis center that he must visit three times per week, but since he can no longer drive, the distance might as well be 1,000 miles.

He lives with his wife in Clarksburg, W.V. A former heavy equipment operator, Randall is paraplegic and has been on dialysis for a year and a half. He had to stop driving his own lift-equipped van last year

because of medical complications exacerbated by driving, and his wife tried driving him to his treatments — but that interfered with her job. The Central West Virginia Transit Authority (CWVTA) now helps Randall access dialysis.

The transit authority also allows Randall to go other places when his wife is not available to drive him. “It’s county-wide transportation,” he says. “They have many of lift-equipped vehicles.”

To Randall, and others with similar needs, community transportation is, “Something great. Especially in the more rural counties.”

An Avoidable Tragedy

Our final story is too real. A veteran of the Korean War, a decorated sailor who reached the rank of Ship’s Serviceman, Third Class, recently died in Shelburne Falls, Mass. He was 68 years old, and he was ill — his kidneys were failing and he needed dialysis treatments three times a week.

“He’d still be alive today if he had adequate transportation,” says Leo Parent, director of Veterans Services with the Central Franklin County (Mass.) District in Turners Falls.

This gentleman — whose name we will not use out of respect for his privacy — lived too far outside the service area of any public or community transit systems and didn’t qualify for Medicaid.

The veteran used to drive himself the 10 miles, one-way, to his dialysis appointments on Tuesdays, Thursdays and Saturdays. This much we know, because it was the local police department that first notified the local Veterans Administration that some alternate form of transportation was necessary. According to the police, he was simply too weak to safely drive home from his four-hour dialysis sessions. A home health care worker agreed, noting that the veteran was at-risk for automobile accidents and falls. They were forced to take away his driver’s license.

“Now I can’t go anywhere, I’m stuck in this house,” says Parent, recalling the gentleman’s reaction to having his driving privileges revoked.

The VA contracted with a driver to take him into Greenfield, Mass., and for a little while all seemed well. But officials with the VA didn’t realize that she, too, was ill and uncomfortable driving in the snow and ice that is inevitable in Western Massachusetts in the winter. Sometimes, when she couldn’t take him, Parent himself would actually go and get the veteran and take him to dialysis.

“He didn’t want to call and be an inconvenience,” recalls Parent.

Tragically, the volunteer driver died of her illness, and the veteran was stranded once again, this time with dire results. Parent estimates he missed two-to-three weeks of treatments before the VA could contract with a local taxi company to reinstate the life-saving transportation services.

He died, not long after, from complications that most assuredly arose from his missing dialysis. He died for a lack of transportation.

“If our vets don’t drive, than it’s a serious transportation problem, particularly in the rural areas of Western Massachusetts,” says George Ponte of the Veteran’s Administration office in Northampton, Mass. “We need to find the resources to make sure this doesn’t happen again.”

Dialysis patients are not the only ones in dire need of transportation. The recent health care trend of increasing outpatient services, coupled with the overall aging of the American population, make for a serious disconnect. How to get people to continuing and life-saving care they need? Public and community transportation are the only answer