

## Journeys in Dialysis

Troyce Crucchiola

*Carolyn Jeskey:* We have the privilege of having Troyce Crucchiola, who is a professional story teller. He is in a rock band. He lives in Portland, Oregon. And he is also 22 years on dialysis. And I had the privilege of meeting him a couple months ago because Ride Connection, the awesome design thinkers of the world—you guys, you really embody the process—pulled in several dialysis patients to be a part of their journey of building new solutions and I was just awed by what he had to share and now we would like to share Troyce with you.

*Troyce Crucchiola:* I can't thank you all enough for having me out from Portland to speak to you all. I've been a kidney patient for 22 plus years. And the whole adventure for me started when I was ten years old and got diagnosed with kidney failure going in for a sports physical in grade school to play basketball with all my friends. So in 1976 our technology wasn't quite what it is now. It's interesting when the gentleman from New Jersey was talking that we used to see folks that would come and go pretty quickly. And his analogy is very, very true. We get much better treatment nowadays in many ways so people do live a lot longer, but unfortunately the rub to that is at its best, our current treatment system gives patients about 15% replacement of what one kidney will do. So when you look at dialysis patients as your clients, we are a different population to serve. And because it's chronic, it doesn't go away. So this is an ongoing thing.

We provided 80,000 rides in Portland, Oregon for dialysis patients last year. And we're not a big city. So the demand is there. And with the part of diabetes and hypertension in this world, the demand is growing, and this population is getting much much bigger.

Just to give you an example of what the difference is in a day of a life for somebody and a day in a life for me. I want you guys to think about your travel day yesterday or today, what it took for you to get on the plane and make your arrangements to get here. I have to do all of that stuff for myself, and then I've got to make sure a month ahead of time I call the travel service with my dialysis company and get some dialysis here because I can't go three days without treatment. I've got to have dialysis while I'm here. I've got to have transportation to and from, I have no idea about where that might be in a city, and I have to make sure that I'm there and I've got to get back because I need to be here in the morning. So these are things -- and then I've got to take into consideration my diet. I love to splurge but I can't eat everything I want while I'm in a hotel. Just what it takes for me to get enough rest, get my treatment scheduled, to get all my transportation worked out, all of that comes ancillary in the job that I'm going to come do in speaking to you.

So if you can imagine what it's like for a person to have to live their life with everything. Your life doesn't start until you've completed that treatment and recovered. And the reality of this system—and this is where you're going to get dialysis 101 right now—most people in this world, unless you have a relative that's on dialysis or you've really known someone close, you're pretty clueless about what kidney function is about and what it takes to be on dialysis. Your kidneys are the most amazing organ in the body. Not to short the heart. I love my blood pumping, but kidneys are the master chemists of our body. The amount of chemistry that goes through our kidneys that keeps us alive on a daily basis is phenomenal. The reality is these two beautiful organs will keep us going to the point that you can lose 80 percent of your kidney function and not feel symptomatic at all. So lots of people can wander around out there with one kidney and never know it. When your kidneys fail and you have lost your kidney function, when you get to 15 percent, then Medicare says we can go on dialysis. And then you begin

three days a week for four hours sitting in a chair, two very big needles in your arm. You can put the end of your ballpoint pen in one. You've got to get the blood out of you, it's got to go through a filter and it's got to go back into you. As many times as you can circulate the blood in a body 24 hours a day, 7 days a week of kidney function and you're reducing it to four hours, three days a week. Which is cramming an awful lot of very important work into a very short period of time. The result is that everything a person drinks from . . . Like I dialyzed . . . I flew into town yesterday, got to my hotel, got organized, got something to eat, and then went to treatment last night. I got on dialysis at 8:30. I was done about 2:30 this morning, and how did I get there? I had to have transportation. I had a cab both ways. And awesome transportation. Took me through the White Castle drive through at 2:30 in the morning. Cannot beat that. Not that I should be eating White Castle at 2:30 in the morning, but we're not at home, so this is a great treat. But if just you look at the reality of that, it's 2:30 in the morning, and I'm able to have a private ride and be able to go through White Castle. That's a fabulous thing. Luckily, I'm not having to pay for it. But it's a great thing. And I wish every patient would have the luxury of that kind of transportation.

But you can see the amount of time involved. And so for the average person doing this four hours, three days a week, they always feel symptomatic. You're always a little flu like. You're always a little achy. You never have enough energy to go really where you want to go and do what you want to do. As Carolyn said, I play in a band. I'm an actor, I do a lot of voice work in Portland. I love my job, and I love my mom and dad. They are 80 and 88. I spend a ton of time with them. I have a huge life I want to live, and I have to do it around this dialysis schedule. And I am dialyzed to live my life. I don't live my life to go to the dialysis unit. And this is a lot of what we're dealing with folks that are older, more co-morbid. A lot of these folks are going from their bed to the dialysis unit, back home to sit down, to get some hours with their family. And so to give you an idea of what this is about, it's fabulous that we get to stay alive. That's wonderful.

But when you're looking at a system that keeps us kind of minimally going along, we want so desperately to live. And if it wasn't for the great people that took care of us, we would be in rough shape. We have amazing professionals that take care of us. But the reality is to live a life, you've got to have this treatment. To have this treatment, you have to get there, and you have to get home. When I look at the system—and dialysis isn't like we go and sit down, watch a movie and we go home—you put two huge needles in somebody's arm, and we get two cups of blood a minute in our access, through the machine and back into us, you can see probably from there the vessel in my arm is quite larger than the rest of yours. This started out as a normal vein. We do a little surgery and it starts to grow. And it allows eventually to put a 15 gauge needle in there and suck two cups of blood out of me a minute.

My doctor got really excited when I told her I was going back to mountain biking a few years ago. She was insistent you go get a tourniquet and carry it with you. Even worse when I started skateboarding again. But I wear a lot of pads. It's really cool. It's totally fun. I was going to do some skating right before I came here, and I thought if I took a dump and hurt something and couldn't be here for this I would feel like a complete idiot. So I'm here in one piece.

The reality with this big vessel and these big needles when we're done, when those needles come out, you have to hold pressure on it to stop bleeding. The longer it takes the older you are. Seven to ten minutes I'm clotted up and taped up and I can go out the door. There are people that have to sit there 20 minutes at times. They can't stop bleeding. The reality is we have to wait for stasis to happen.

Everything that I drink, from the moment I finish treatment last night until I go back to treatment on Wednesday, everything stays in me, which means it goes into my blood system, it raises my blood pressure, it starts causing damage. Wednesday I'll fly home in the morning and I'm going right from the airport to my dialysis unit. They will be ready for me.

I've been doing this for years very well, but could not avoid the high blood pressure damage that has worked havoc on one of my heart vessels. So eventually I'm going to have to have valve replacements. And I'm a very good patient. Most of us don't live this long much less become active and do all this stuff. I've been very, very blessed. It's a combination of things that's done it. I have a tremendous will to life, I love people, and I've had a tremendous family that could support me in this. Most people that are doing dialysis are struggling to eat every day and get to their treatment. And they can't help it if they can't quit bleeding on time. They can't help if they have been dehydrated from that machine sucking all the fluid out of them in two days in four hours. I can't tell you what that's like, unless you've been out in the sun to the point you've gotten heat stroke or you're a wrestler in high school and you like to purge for weight stuff like that, you don't know what this is like. You feel like crap, it's hard to walk at times. You only want to sit down.

So let me tell you why this is important to me and ultimately why I'm standing in front of you. When I see that little 80-year-old lady that I've sat with that's just like my mother that is this beautiful soul that has got grandchildren she talks about and a husband she's been with 50 years, she's got to get up at five in the morning so have a bite to eat. Nausea is a general thing we deal with. To get picked up by her ride to get taken to a dialysis unit, to sit down in a chair where somebody puts two big needles in you and says sit still for four hours, and they are wonderful people that take care of us, but the patience it takes to sit for four hours straight and not move is great. The patience to do it three days in a week indefinitely is a mental challenge. You have to come to grips with your position, your place. And for me, my place in the universe, I truly believe it's what I'm supposed to do but that's not acceptable for everybody. So when I see that little lady sit there for four hours, I would think if that's my mom, I want to get her right in the car and get her home and make her lunch and get her comfortable. So if that little lady bleeds too long or she can't get up out of that chair because her blood pressure is 90 over 50 they have got to get somebody else to provide the ride, because they have originally given her a five or six minute window. So that little lady can sit in that waiting room for two or three hours until we call another ride, get somebody that can get there. When it's all said and done, mom has sat there for 7 hours in this unit without eating, she's completely dehydrated because all the fluid has been sucked out of her body and now she's going to get on to a transport and potentially go another hour or more to get home because we don't take people straight home. We've got people over here that we have to pick up. People over here we have to drop off and we have a great population to serve.

But we're not the average person who is aging and wants to go shopping. We have to have this to stay alive. And we have all these repercussions. So in Portland, we're working hard to put a system together that will allow patients to get to and from treatment in a timely manner, which is going to make life better for the patient, it's going to make life better for our staff because in this day of corporate dialysis, speed is everything. They want my technicians to get me on in 15 minutes and they want them to get me off in 15 minutes so that we can have them take care of four people in a one hour block of time so they have all the other time to get everything prepared and ready for the rest of what's happening in the unit. So it's this constant pace. And we can get really lost in the shuffle.

We're fabulous people that live great lives that unfortunately can have our great lives dictated by our rides to and from places. And when I hear the creative stuff that's going on out there that people are

doing, it makes me so happy, and it warms my heart, and for the folks that just bought the boat, yeah, I'm a great lover the first nation history and mythology, and I'm a great boat driver. I started when I was about ten years old so if you ever need backup drivers let me know. That sounds like the coolest thing in the world. I can't imagine getting a 45-minute boat ride to treatment. That would be great. You talk about something that would perk you up. A little sea breeze afterwards and somebody helping you in and out of the boat. That's awesome. I absolutely love that. So as you're going through this focus on mobility, all of these classes and people that you're going to hear about that are trying to make things better for disabled folks and aging folks, think about my story and think about my 80-year-old mother and what it takes just for us to live our lives. I want to go home and see my mom and dad on the thirtieth of this month. It's my best friend's birthday and he leads the band so we're going to have a jam all night long at a local pub. I'll be doing shows in the fall. I have a big life planned and I have a lot of people I love. And I don't want to stop that because I can't get enough treatment getting to and from my dialysis unit.

And the real heart break in this is that we have got people that because they are afraid of sitting there for that extra three hours, because they may not have the money out of their disability at the end of the month, they will skip dialysis. So they are taking -- and already, you're minimally getting kidney function, you've got 15 percent of what one kidney will do. So now you're going to skip four hours, and you're going to go five or six days without treatment. The potential for being admitted into the hospital at that point is huge. The potential to have a catastrophic heart issue is great. And it's completely unnecessary for that little person to say I can't have my treatment today because I can't afford \$2.50 to get there and \$2.50 to get back. And with us, Medicaid pays for our rides but Medicare, which pays for our treatment, does not pay for our rides. So if we're not Medicaid eligible we're not getting a ride, we're paying for it. And that is a travesty. You put us in the hospital, it means we've had serious issues and we can't take that. You can seriously take a good knock to your heart and hurt it in a five day period of time without treatment.

So the thought of these folks going without treatment or even cutting their time short because they know that ride is going to be there, take me off a half hour early, all sign a form that says I'm going against medical advice. Those are things that should not have to happen again. And I believe that we have everything in place in this country in most places to create a system that will work excellently for dialysis patients. It's a matter of getting education and the programming and getting people all on board. So at this point, think about my story and think about those folks as you're going through your days and if you have any questions I am an open book.

*Audience question:* In Southern Illinois, by us, I'm hearing that they could do -- or they are starting to do dialysis at home throughout the night. Have you heard?

*Troyce Crucchiola:* Yeah, actually, home dialysis and nocturnal dialysis are two current options that we have. And home dialysis is fabulous. You go through home training and instead of your Medicare going to your dialysis clinic it goes to the home unit. They provide your machine and supplies. You get trained how to do your treatment. Have to go through it with a partner, so usually it's a family member. So overnight is a tremendous way to dialyze, and I actually in the last two months switched to overnight dialysis. So I do it in centers. I go to clinics and do it overnight, but it's a wonderful way to treat. The problem is the access to home training and the limitations of certain people. Less than 10 percent of our patients out there that are on home dialysis. And even less that are doing nocturnal currently. And nocturnal is a really nice schedule to transport people because like I go in about 7:00 pm and I get on about 7:30 pm and I'm done about 3:00 in the morning so there's no traffic, you don't have tons of

things going on out there and lots of demands for transportation -- it's a great way. And I promote both those forms of treatment as much as I can for folks. We've had home programs for 25, 30 years, so really what it is, it's a matter of getting our doctors to push it more.

*Audience question:* Troyce, given your experience and the challenges that we in the transportation business are facing with being able to accommodate growing demand, I wanted to get your opinion about the use of two different types of one way transportation. In other words, the use of transit modes on the inbound trip, with the more specialized modes being used on the return trip as a way of accommodating the bleed out and tired feelings afterwards.

*Troyce:* It's a fabulous idea. And the difficulty there is right now the way we see it, we've got about 3% of our population in Portland that has got it in them to walk from their home to the bus stop and from the unit to the bus stop to get back. So there are people that can do it. And I'm somebody that could certainly 90% of the time accommodate that. But it is a relatively small percentage of folks that you're going to get that are going to be able to do that. And the more folks we can get to do it the better. I would love to see folks get a public transit ride instead of a \$22.50 pick-up ride. But the reality is at this point we're not terribly ambulatory population for that.

*Carolyn Jeskey:* So one of the questions that I see come up a lot is about grouping people who live in similar areas. From what you've seen in the dialysis clinics you've worked with, what are the opportunities for grouping patients who live in similar areas to make the transportation easier? Or why doesn't that happen?

*Troyce:* I think there's great potential. And one of the most frustrating things that I see and that we've seen as we looked into this, it is very, very, very rare that you will see a transportation provider come to the unit, drop off a patient or patients, and then pick people up from that same unit and take them home. They bring people, they drop them off, they leave empty. They come back empty, they pick people up, they take them home. Geographically, we try to get people as close to their units as possible.

I'm 7 miles away from my unit. In my last unit, my condo was like ten minutes away or less. But getting these things organized could make such a huge difference. And the other thing is showing the doctors that if they will place their patients in more geographically located areas central to their homes that we will be able to accommodate more of this. But it could make a huge difference.

And before we had all of the legality that we had, I had some friends in Kansas whose dialysis unit bought a van, hired a driver, created a route, and they got a lot of their patients that couldn't get around to and from dialysis. Today the liability and insurance and all that would probably kill it but it was fabulous at the time. But it's something that could work very well in a lot of cases.

*Carolyn Jeskey:* Thank you so much for coming out here first of all. We really appreciate this expertise. I was just doing the math. Three days a week, four hours a day, 22 years, that's 13,000 hours of dialysis. You know you probably thought more about this subject than anybody in this room, and I just want to tell you how much we appreciate that.

*Troyce:* Oh, thank you very, very much. And it's interesting you did the math because I play with that kind of stuff, too, and to give you a picture of really my whole life I was 21 when I started this. I did 18 months in a dialysis center. I got a transplant. I got two years out of my transplant because back in the '80s we did not know hardly anything compared to what we know today. That kidney failed. I went back

into a center for two years, then I went to home dialysis for a couple years. Then I went to another form of dialysis called peritoneal dialysis for six years until my next transplant. I got five years on that one and I've been back on dialysis for five years. I've been stuck almost 3,000 times in my left arm.

*Carolyn Jeskey:* I do have a question for you. We often talk about this as if we're trying to minimize the cost of transportation, that is, the reason we're talking about grouping trips is because we're treating the transportation part as the piece that we're trying to minimize. And I think we're missing a big opportunity. And you hit on this when you said if if you bleed out, or if you miss an appointment, you're having an emergency room visit or follow-up visits and intuitively to me it makes sense that the cost of that seems like that should far exceed the cost of a 20-dollar taxi ride or a 30-dollar taxi ride. To the tune of thousands of dollars, right? So my question is, why aren't we having that conversation? Why aren't we connecting the cost of the care to the cost of the transportation and having a bigger picture conversation and how viable is that? Clearly you've spent time thinking about that. Illuminate this for us, please.

*Troyce:* Okay. What you're dealing with is that dialysis has become 90 percent corporatized. And there's two major companies that own most of the clinics in this country, and in the world, realistically. Until they buy into what you just said, it's going to be very, very very difficult to ever make that progress. And this is one of the things I've seen for years and years. You know, I've come to grips with corporate America. It's here. It's what we deal with. I do everything I can do to help people in my little corner of the world because I see how the system can hurt people. But the reality is, like I said with the 15 minutes, they want the technicians to get us off and on . . . I mean, it's 15 minutes. It doesn't matter if you're coming in a wheelchair. You have no legs we've got to put you in that chair. Or you're like me, you can dance into the unit, sit in the chair and be happy. Not everybody is like this. I mean, so the reality -- and this is what I try to do is show management that there is greater profit in getting your patients there on time and getting them home on time. Because the longer your patient sits in that chair waiting to get done, the longer that next patient has to wait to get into the chair. So showing them, look, if we get them here on time, out on time, your techs are going to have more time. Until we get direct buy in from these companies to take an interest, it's going to be tough. We can do it, and we're going to do it in Portland, but the greater cooperation we get -- and we're already seeing and trying to get a pilot done of what it takes to get these companies to cooperate with us. So that is a big part of the barrier and that's a big part what have we're trying to overcome.