

Dana: I thank everybody. My name is Dana and I'm one of the nephrologists at Tufts Medical Center. The way this session is going to work, we're going to have slides for 20-30 minutes and I'm a physician. I'll give you, my perspective. Then we'll have Jerry who's a patient, give his perspective about living on dialysis. And then we'll have 15 minutes for questions. Okay, so first slide here. The key point I want to make on this slide is that Polycystic Kidney Disease makes up a very small proportion of the dialysis population in the United States.

So, any statistics that you hear about the United States renal data system or dialysis patients, population wise, usually don't apply it to the PKD population. And why I'm saying this is because you'll hear this statistic that the median survival of a dialysis patient once they start is four years meaning 50% live for years and 50% go beyond that. But that really doesn't apply to PKD. Okay, PKD patients are younger and healthier. They tend to do much better than the average dialysis patient. Next slide. Can you advance Jerry? Please? Not sure he is, Jerry, can you hear me? Can you advance please?

Wayne: I think he may be frozen up there we go.

Dana: Okay. There was a slide in the middle. Yeah, it was a little bigger there-

Jerry: Unfortunately-

Dana: Yeah, that's fine Junko back, it was just showing. So, the first slide I showed you was cause of kidney failure but grouped on the X axis there and the and we can see that 3% of the of the dialysis population was PKD. Okay, now here, what I'm showing you is the number who have transplant by cause of doubt, kidney failure. So, first column here, diabetes, the dark blue is the modality of that they're using for the renal replacement therapies. The modalities include, blue is in center, hemodialysis red is home dialysis, gray is peritoneal dialysis and green is transplant. So, these are data from 2019. That's the most recent data we have available to us at this time fromUSRDS.

Basically, you can see here, like I said earlier beginning are quite unusual compared to other patients on dialysis, a vast majority of which are diabetics and hypertensive. The vast majority of our PKD patients actually are transplanted here you can see it's about 60% PD makes up a larger proportion than mild sort of actually the same. home dialysis is lower than the than the other group. So, a lot of PKD patients end up getting transplanted. Next slide, please. But this talk is about dialysis. And so, I had four tips I was going to give you about how to do well on dialysis. And I'm just waiting for Jerry to advance the slide.

But the first tip I have for you is to is really work on getting a kidney transplant, your survival will be longer, and your quality of life will be improved by transplant. For the vast majority of patients who have end stage renal disease, they will do better to have a transplant. And so, what that means is you work on getting a potential living donor in case you ask your family or friends, if any of them are interested in giving you a kidney, it's unusual, it's harder in a PKD family because there's so many patients, so many people want relatives affected with PKD. But even if there's a friend, we'd be interested in these people, friends, distant relatives, etc. Even if they're not a match to you, they could be a match to a potential other recipient and there's a match paired exchange program in the United States where we can actually swap kidneys around so there's lots of stuff, we can do with living donors.

So, first see if there's a living donor potential then get yourself waitlisted, so you visit a transplant center and you undergo an evaluation and then you officially get wait listed on the deceased donor list. And you should do this even if you haven't living donor potential because you never know what may happen living donor. Although if it's a young person, they're usually going to be just fine. But anyways, just there's you can be waitlisted as soon as your GFR is 20. So, you don't have to be on dialysis to start accruing wait days, you start accruing that time once your GFR hits 20. So, you should start getting evaluated done. Get yourself on the list.

Let's go to the next slide please. The next slide is going to talks about doing home dialysis. So, I mentioned on the earlier slide with the blue, red and gray

colors, the three main types of dialysis we offer in United States in an outpatient facility. And those are in center hemodialysis, where you go to the center three times a week, you get your dialysis treatment done by a nurse. Usually, the sessions are three and a half, four hours, and then you go home. The second kind of dialysis we offer is PD peritoneal dialysis. This is where you have a catheter inserted into your abdominal wall, sort of anchored in the abdominal wall, the end of it sits down in your pelvis, we fill your this this space between sort of your abdominal wall and your intestinal contents like your liver and intestines and all that there's a space there, we can fill it with fluid.

And this little machine usually does this for you while you're sleeping. It's called a cycler. So, it'll fill you with fluid. The blood vessels lining the intestines carry all the toxins into this fluid dwelling there and the toxins diffuse out in the fluid. And then the machine after an hour and a half usually kicks into drain mode and drains this empty, dirty kind of dialysate fluid and then refills you again and usually you get cycles like this four or five times a night while you're sleeping. Some people have referred to that as a third kidney, it's very physiologic. It's replicating more closely than hemodialysis what your kidneys actually do. And the third kind of dialysis is at home hemodialysis. So, the reason I want you to think about home is for a number of things. The first being that in center hemodialysis is really very exhausting for people. Just the schlepping back and forth is quite taxing. You have to get to the dialysis center.

If you don't have a ride there, then you have to have a ride take you there wait for the ride. It's almost like going to an airport waiting for the one of those shuttle buses. That happens three times that week for you. And then you have to wait for them to pick you up. Then you're sitting in this chair for three and a half, four to four hours. And it's very aggressive, It's very invasive. So, we're basically taking all of water your body running it through a washing machine, taking all the fluid off that you gain between treatments putting it back into your body. It's not very physiologic and people often feel very exhausted after in-center hemodialysis. When you do PD in particular, it's a

daily therapy. But it's gentle. There's not these abrupt changes in in solutes and in volume. So, it's usually people don't feel drained as much as they do on the instant or hemodialysis, which are the short, aggressive therapy in treatments.

The it just so happens it's the next slide Jerry. The third kind of dialysis is home hemodialysis that takes more work to learn at home. But ultimately, we can teach you how to do that as well. The training for PD is usually on the order of about a week. So, not very long. You go every day for the week, learn how to do the exchanges and then we'll send you on your way and you do it at home by yourself. Usually, people learn that very quickly. Hemodialysis usually takes more like six weeks the main issue is learning how to cannulate your fistula and how to run the circuit and all this but it's not nothing that you couldn't learn. We've had lots of people train in home hemodialysis. And a key advantage of doing dialysis at home is self-involvement. Okay, if you're in charge of things and you're doing it yourself, you're more aware of what your numbers are.

Your clearance your electrolytes, your bone mineral metabolic parameters, all these things that MDs watching you're actually watching this stuff yourself and you'll do better for it because you'll be more aware of what causes these things to be off and what you would do to fix these things. It's always the case of medicine the more involved a patient is in their care, the better they do. So, that's a huge advantage of doing dialysis at home either peritoneal or home hemodialysis.

Okay, now this the third slide I was going to have my third point for you was to watch your fluids. So, what happens when you start dialysis? Depends what kind of dialysis you start basically when you start hemodialysis, I told you already it's fairly invasive, fairly aggressive. You know we're taking two three kilograms of fluid off your blood pressure can drop just your blood running through this plastic tubing all this incites inflammation possibly and this can cause your kidneys to fail. So, you become a uric okay meaning you don't make urine anymore and with a hemodialysis patient that usually happens fairly early on one to three months after starting dialysis on the with

the peritoneal dialysis patient, usually that lasts much longer, we don't fully understand why that's the case. But on average, I'd say our PD patients are maintaining urine output for good one and a half, two years.

Now, there's not a whole lot of solute clearance happening with that urine output. But what the advantage is that there that there's volume getting out of you, you're making urine. So, you don't have to be as strict about the fluid that you gain between treatments, also the treatments every day, so that will limit it reduce the amount you have to restrict your fluids. That's a huge advantage to you. I think one of the hardest things for patients on dialysis is to try to restrict their fluids, it can be really tough, you're thirsty, but you can't drink, you can drink 32 fluid ounces a day is what we recommend, because that's what we can safely pull off and a three out three and a half, four-hour session. If you drink more than that, what happens is your heart gets overloaded.

And you can imagine you go the dialysis session, your heart is full, like a balloon you can imagine is what I want you think about the balloon is stretched out, you pull off the two and a half, three kilos in that treatment, maybe more, you've gained more. And then the blue, the heart rapidly shrinks down. And you keep doing this repeatedly, every three, you know three times a week, this stretching and rapid shrinking of the heart over a very short space of time three and a half hours, it's probably not good for the heart. In fact, we have studies showing that this leads to stunning of the heart is a muscle no. So, it gets stretched out, it loses its elasticity. So, it's called stunning eventually you have too much stunning there be there you develop fibrosis sort of irreversible change on the heart.

That's quite extreme, I have to say volume overload chronically that would do that. That is that phenomenon volume overload has been associated with earlier death of a dialysis patients is extremely important to control your volume. The other problem with pulling too much fluid is that you crash your blood pressure. So, you imagine you're trying to take quite a bit of fluid out of your intravascular space, there's only so much there and you have to refill the intravascular space from your tissue all that takes time. And so, you can

drop your blood pressure precipitously, that's not good for any your organs, your brain probably has a mild lack of blood flow to the brain is probably not good for a long time.

Long term heart as well. So, these things we know are very detrimental, in fact, I'd say are the biggest sort of challenge we have with our dialysis patients, especially in center hemodialysis, because the treatments are so infrequent three times a week. So, whatever kind of dialysis you choose, I will say to you a key principle that you got to sort of tackle is to figure out how you can drink less when we want you to drink usually about a liter a day. If you're still making urine you, don't you won't have as strict fluid restriction. But if you've stopped making your that is the general rule of thumb not to drink more than a liter a day. Okay, and the final point I'll make is just be healthy. And this is stuff you already know you're doing it before you started dialysis, keep doing it.

So, eat unprocessed foods, maintain a healthy weight. If you're overweight, we want you to lose it. But safe place you'd work with a dietitian do that. If you're underweight, you should gain weight, I will say this dialysis is catabolic, it's taxing on the body. So, a lot of patients actually lose weight when they're on dialysis.

There can be various reasons for a law that we actually don't understand. And I have to say I find that more to be in diabetics and sort of patients with chronic infections. Diabetic has lots of other problems other than just kidney failure. They've got infections in their feet and bad heart disease and all the rest of it. So, those patients are the ones typically are losing weight. Regardless, the principal stance if you're overweight, you want to lose weight, if you're underweight you gain weight. And there's a dietician dedicated in the dialysis unit to work on this and other issues with diet for the dialysis patients. And then the last thing is, stay physically mentally active. Mental Health usually is persistent.

It persists, which is remarkable actually, dialysis patients are really resilient bunch is what I'm going to say they're tough, their mental health usually

doesn't decline once they start dialysis from all the studies that we've done, what declines is their physical health. So, I said, it can be a wasting process, you start to lose your muscle mass, you start to get very sedentary, maybe because you're exhausted. But you got to somehow overcome that and keep walking, keep walking stairs. More than that if you if you were doing this before you would keep going to the gym, whatever you can do physically, to keep your muscle mass and keep strong. Keep your bones in good shape, so that when the day comes that they call you with a transplant, you want to be strong physically, that you're going to do well after surgery.

Okay, so that's what I'm, I have to say about sort of four tips on how to stay healthy on dialysis. I'm going to turn over to Jerry, who's going to give you the patient perspective Oh, Jerry, you're muted. There you go.

Jerry:

Good morning. So, I have to first apologize, Dana, for the slides freezing up on me and hopefully, we're over that obstacle. No, we're not. So, I'm going to have to work with without a slide, I'm going to stop sharing. And I'm actually going to go to the slide so that I can read off the slides. So, I'm going to talk about hemodialysis, which is the choice of dialysis I chose. And before I get started, I want to make a disclaimer that hemodialysis at a center is no way a recommendation or a promotion for the hemodialysis. What I would say that, in my case, I did research with my nephrologist very closely with my nephrologist and came to the conclusion that based on pros and cons the best way, the best means of dialysis, hemodialysis, in fact, others that are approaching dialysis, I would highly recommend that you do the same thing.

Look at the pros and cons of dialysis with your hemodialysis and choose what's best suited for you. As an example, my father who had PKD, he chose hemodialysis at home and my mother was his technician. My sister on the other hand, she chose peritoneal dialysis at home. So, we all chose different routes of dialysis. And it can and it comes down to is what's best suited for the individual.

So, getting started, I had kidney failure at the age of 54 and became began hemodialysis. And one comment is working very closely with my

nephrologist, we were mapping out and plotting out and getting an estimate when I would go into failure in about a year estimated to failure. I took action to get a fiscal install because a fiscal it does take months to develop. And in addition, I took steps to be tested and placed on the transplant list. And that was again about a year before I had failure. So, prior to hemodialysis again, I did searching for pros and cons of the hemo and my pros with hemodialysis and outside center where I needed some flexibility because at the time, I was doing extensive traveling for work.

And in fact, I had probably more than 30 treatments across the United States and more than a dozen treatments in Europe. So, it was very easy for me just to pick up and go and scheduled the treatments. Across this the States and in Europe. Also want to train techs and nurses for my care. As I mentioned, my father had my mother is the tech, I didn't want to bring that to the house. And that's just a personal opinion, you may have different ideas and thoughts. Personal choice, I didn't want supplies and equipment at home, and I didn't want a dedicated treatment room. And again, that's a personal choice because I didn't want a constant reminder of the dialysis. Cons and there are a significant amount of cons that come with hemodialysis, as Dana mentioned, first is the fistula.

It's the first is the installation of the fistula. And as I mentioned, it takes months for it to develop. And it also takes maintenance. In fact, the first fistula that I had failed, and I had to have a second fistula installed. The second is the needles and I would say that that was a big issue for me because I had a phobia of needles, so it took me quite a bit of time to overcome the needle in search and insertions. Another issue with the needles is what's called an infiltration that which the needles actually are placed into the fistula and outside go through the wall and when the machine starts, you're pumping blood into the arm. These are all cons with hemo dialysis and then the bandaging after the treatment. There can be bandaging with bleeding after the treatment.

So, all these needs to be taken into consideration. In addition, it's very strict diet and liquid intake and I learned early on that if I minimize my diet and



my liquid intake, I actually felt much better, much less fatigue if at all fatigued after the treatment so strict diet and liquid and intake was extremely important as how you feel after your treatment.

Wayne: 10 minutes Jerry, 10 minutes.

Dana: Living the best life on hemodialysis and I think the most important is maintain a positive mental attitude for me die I view dialysis as a steppingstone for a transplant. And indeed, that's exactly what happened for me. As Dana mentioned exercise, I walked twice a day, and they continue to walk a mile each period of time or get regardless of the weather. I continued to work to keep occupied and luckily it wasn't physical labor. It was basically I could work off of a computer anyway, anywhere. Travel, it was easy for me to schedule hemodialysis again across the US and Europe. And I've traveled from Florida out to Washington State. And as I've mentioned, trips to Europe, I hiked the Grand Canyon while I was on dialysis and took many, I enjoy riding motorcycles.

So, it took us several motorcycle trips. So, after four and a half years, I received the call that a kidney had been come had become available. So, I did have a transplant. It's now going on six and a half years since I've had to transplant. So, that ends my presentation. I believe that would open the floor up for questions.

Wayne: Okay, thanks, Jerry, we've got a couple of questions already. For those of you haven't had a chance to please type any questions you have into the chat box. And I'll read them out for our presenters, please remain on mute wouldn't mind. So, the first question that's come up is regarding the match pair program that you mentioned, Dana, what's the best results to find out more about how the match pair exchange program works? Someone's got sort of different blood types. How does that match up with the different blood types work?

Dana: Yeah, what I'd say to this person has talked to their transplant program. And that's your best resource. Okay, they're the ones who are going to have to

submit your pair to the to the pairing exchange program to begin with, I would refer this person to their transplant coordinator.

Wayne: Okay, thanks. The next one, is it possible to do PD manually? Like when you go travel?

Dana: Yeah. Oh, for sure. Yeah. So, the Cyclor is only one way to do PD, you can actually do manual exchanges, you have this IV pole or whatever hanging off a shower or any kind of high object in a hotel room, whatever you have available, I guess we had patient was even camping in a clean way, they hung it off a tree branch, just something that's high, that'll grab, it'll pull the fluid in your belly. So, the bag hanging there you connect, make your sterile connection to your PD catheter. And still the two-liter bag or however much volume you're going to put in disconnect, go on your merry way for three hours, do your thing. And then when you cut you do three hours a day, come back and connect to your discard bag and you drain and then refill again. So yeah, definitely, that's one of the advantages. I mean, it's Jerry, you were lucky.

You had no problem arranging he would also sessions over the US and Europe. I don't know if any of you can sometimes be tough depending on what location you're going to. In my experience a PD one of the advantages we always say is you can go traveling and arrange everything yourself you just get back to deliver the boxes of your, your bag, the fluid exchange dialysate to wherever your location is they can do that all your Baxter's all over the world. So, you pretty much just go with it with just the catheter in your belly and you arrive and have everything there that you need to do your PD with. So, that's one of the advantages also I think of PD.

Wayne: Okay, great. And another one here, basically about comparing and contrasting the different experiences PD, hemo and in the center. Jerry, I think that was probably two.

Jerry: Again, everybody needs to do this very closely with their nephrologist way out and we basically for my because I was traveling quite a bit and just to

comment on scheduling, I had a very good in center group, and there was a person that was the function was to help me schedule these trips, what I would do is go on the website, and I would choose about three different centers. And I would, based on the city that I was visiting and send those three centers and provide a time and that in person would then schedule the trips for me and it usually in I would say, very infrequent that I could get a schedule.

Wayne: And your sister and dad had different experiences, then?

Jerry: My sister on perineal, she didn't really travel a lot to begin with. So, most of that was done at home. And but she did have success with perineal.

Dana: I can answer that. Jerry, are you done? Sorry, I might be pulling off.

Jerry: Yes.

Dana: There's never been a head-to-head well done, head-to-head study of the three modalities. It's, they tried even to randomize patients, if you can imagine, to your dialysis modality, this was done in China, but they failed. And there's bias, if you try to compare hemo to insulin or hemo, they're different patients serve the most motivated and healthier patients would be at home because if you crash a lot on dialysis, we're not going to let you go home. So, you can't make these comparisons with existing data. So, most of what we know is well, I will say there is one randomized trial it is three times a week in center versus six times a week short in center. And that was supposed to be close to home the six times a week, short treatments, and it showed improved survival and reduced left ventricular mass or heart mass in the people who are during the short daily treatments.

The same thing was found actually with long nocturnal sessions, so I didn't mention this, but you can't some centers allow nocturnal dialysis, so you would be running at night, you work in the day, and then three times a week, you would go to the inpatient center, then it's an outpatient facility, but you would go to dialysis, a pm and hook up until one to like, whatever 5am. And

everybody's got a different schedule. You can also even allow for nocturnal dialysis at home with monitoring and pay remotely. That actually was better than three times a week. So, these very long sessions that showed benefit. So, I have to say, I think we do have decent data to say that three times a week in center is the worst of compared to the short daily at home or short Dalian center.

PD versus human, we don't have data. And here's my personal opinion on this, when you have residual renal function, i.e., your kidneys are still working a little bit, i.e., you're still making urine, that actually helps so much for volume, there's a little bit of hormonal function still coming from kidneys, you still make estrogen for example. And you maintaining that kidney function is just very critical, I think. So, while your kidneys are still working a little bit, even though it's not enough to be without dialysis, but they're doing something and they're definitely producing urine.

So, your volume restriction isn't as much, I'd say your best to stay on PD, if you like it, and if you tolerate it, you will tolerate it's just do you like it, okay. And then once your residual renal function wears out, I would say your best to switch to home email, you already know how to you've already used to the home kind of dialysis, sort of mantra that you're taking care of yourself, okay. It is going to be more involved to do the home dialysis. But I think these people can learn it more readily. They're already quite they've shown such motivation to doing the PD.

So, that's how I personally feel about once your residual renal function wears off, you're going to end up being tied to that PD machine quite a bit or like having to do quite a bit of exchanges. So, at that point, I personally would suggest you try on hemo then, or start off with home hemo is another way to do this. They're all better those two are for sure, six times a week versus three times every randomized clinical trial. No question. That's better. The PD versus in center, we don't have a trial. But all of our observational data suggest it's better. And it's been my personal experiences. Well, I've had patients who've done all three like 30-year end stage renal disease patients, and they definitely feel much better at home on hemo or and that's doing four

times a week, usually at least four to six times a week than they did three times a week in center, or PD even felt better than three times a week.

Wayne: Okay, thanks, Dana. Got a few more questions coming in. Now, a couple here are also related to PD. So, let's do with those first. First, I'll ask him both to get it up for now not somehow you wish, do people with huge kidneys have trouble with being so full from being on PD? And secondly, how dangerous is PD if you want to swim in the ocean a lot?

Dana: Okay, great questions. Yeah, remarkably, we can still do PD and PKD patients. So, and I say this to everybody, you can't really know to try it. So, one good thing about all this is you just pick your modality and, and it, it's not the end all be all, you don't like it, or it's catheters not working well, for whatever reason, they reposition it and you're just tired of it, whatever. And that's unusual, by the way that we would have to reposition to counter but sometimes they have, or you just feel too full on, they can't get enough volume in to make these exchanges efficient, which I think is quite rare. By the way, even in PKD, we met remarkably, we can get PD to work, then you would switch to hemo. But no PKD is not a contraindication. PD, you would try it, we do it. It works.

And the other thing about swim in the ocean, once the catheter is healed, which is two to three weeks. Okay, so that tunnel seals over so basically of this catheter that I already told you is like inserted through the abdominal wall. And then there's a tunnel maybe three inches long, that thing seals off, usually two to three weeks. After that we say you can go swimming in an ocean. And in a private chlorinated pool. We don't like to swim in public pools and no saunas. That's the rule of thumb. So, if you want to go swim in the ocean, you do as much as you want a bit as long as you're catheters two to three weeks old, sealed up.

Wayne: Great stuff. And here's a question that related to hemo unpoached specifically what why are poached not done more for hemo as opposed to fistulas?

Dana: The ports get infected. They get all this quite literally slime all of the end of it. It's called a venous sheath and a biofilm. You take a catheter out, it's covered in bacterial biofilm, even if it hadn't been there for more than a couple of weeks. So, they do develop infections over time because it's exogenous material, you know, it's basically a very specialized kind of plastic that's going in your body. The other problem is that they caught you develop these clots, the end of the catheter has two or three holes in the end of the catheter. And it's sitting in a vein, right. So, at the end of that you end up getting caught and fibrous material developing, so the flow goes down, they eventually have to take the thing out and replace it. So, we don't like ports they're not durable in the sense they caught off easily, and they also get infected. And those infections are serious.

It's a bloodstream infection. And by the way, that catheter tip sits right at the top of your heart. It's right in the superior vena cava, usually or in the right atrium. So, you're at risk to develop endocarditis, which is an infection of the heart valve. If you have a Katheryn infection, we see it all the time. So, it really is advisable not to does with a catheter, unless it's a temporary thing where you got a living donor setup or something you know, and you're going to get that in a couple months, otherwise get a fistula.

Wayne: Okay, there's no more questions in the chat. So please, if you have a burning question in the back of your mind, add it into the chat and we can ask it. I'll add a question myself, well, give people a chance to type and once you've had a transplant and you've been on hemo, do people change, how fistula is removed? Or do they tend to keep them in afterwards?

Dana: Jerry, do you still have your fistula?

Jerry: In my case? It's six and a half years, and I still have my fistula. And it's a question me, the nephrologist keeps asking me, how's it feel? And it feels fine. I mean, obviously, it's athletics with the fiscal on the arm, but other than that might actually minimal in size. So, rather than then doing that, what I chose to do is have to nephrectomies I had to first in three years prior to the transplant and I had the second one done six months after the transplant, and

I found that removing the large disease kidneys made a huge difference for me.

Dana: We generally don't remove a fistula unless there's a complication with it. The complicated complication would be that it becomes so large, and what we call aneurism hole that the walls of the vein are so stretched out that they're at risk to rupture and the skin would be thinning, and it can have white patches on it. And we would we want to train like your doctor is Monty, you're officially Jerry wondering about that. that's more typical and an upper arm than a lower arm fistula. Okay, so that would be a reason we would quote ligate that we don't take him out what we do is quote, cut, tie them off. The other would be if you had an infection, it would be unusual to develop an infection official. It's only your native veins.

If you have a graft official, it could be an infection could be more likely, but those, we would not do it unless there was an indication, or I suppose the other thing was if you had steel to a hand that you weren't getting enough blood flow to your distal lamb. Okay, because the thing was growing with time, we would also like it official for that reason.

Wayne: What if anything, do you do with a graft after a transplant? It's a follow up question.

Dana: Same thing.

Wayne: There's a question Jerry, can you show us your fistula? Didn't get in front of a camera?

Jerry: Let me see if I could pull up my sleeve.

Wayne: But as a bonus, while Jerry is doing it.

Dana: Oh, I see.

Wayne: And I've had a transplant now so that this is an old fistula in my case. There you go. A bonus from the host. Oh, there we go. Thank you, Jerry. I just

we've just got a couple of minutes left. Jerry any chance you can talk about your nephrectomy experience briefly?

Jerry: Yes, I the same team that did my transplant actually did the nephrectomy, and I was getting a lot of cysts hemorrhages on my left, not left kidney. And it was determined that I had quite a few very large cysts. And when the cysts would hemorrhage. It was extremely painful. So, it was decision early on to take out the left one first. And then the thought process was that I would get the sack the right one taken out during the transplant process. However, the kidney that I got was from far and they didn't have enough time to do both surgeries. That's why I went back in six months. But after before the nephrectomy, I was, it was very uncomfortable, especially sleeping. If you would roll over on those large cysts, it would wake me up and after I had those both removed it the comfort level was significant. As far as the surgery itself, I did. In all three cases, the two nephrectomy and its transplant, I bounced back very quickly. I was it was a three-day procedure in the hospital for three days. And then I literally in all three cases did not have to go on pain meds and it was very successful for me.

Wayne: One final question, are fistula's painful. I concern, mine was not. I think.

Dana: If it is, you need to seek medical attention. There's something wrong with it. It shouldn't be painful.

Jerry: Yeah, mine was not painful.

Wayne: Okay, thanks for that looks like we've covered all the questions. Dana and Jerry. Any additional comments before we finally wrap up?

Dana: Well, I'll just say this, I think it's scary to be thinking about starting dialysis. But we do really our patients do really, really well on dialysis. And you got two people here who were on dialysis previously look amazing. Here proof of concept, but I would say learn. Educate yourself about these about dialysis. The modalities, like Jerry said, work with your doctor to figure out which one is right for you. Go with it. And then if you don't like it, you can always



switch, I really encourage you to try to stay home, it is just good for you mentally, physically, everything wise. If you can manage to do it at home that I think patients will be just happier and do better in this way. And PKD patients are most savvy, engaged, motivated, like educated, kind of Intuit patients we have so PKD patients are the ones that I really think can be at home.

Jerry: I would just add a comment. It's so important to try to keep a positive attitude and try to keep occupied outside of dialysis and the other. The other thing is I view like I said I viewed in my case since I was very healthy going into this is I view dialysis as a steppingstone to get a transplant and to try to keep I tried to keep exercising so as much as I could, and I was quite healthy going into each of the surgeries.

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