

Organized Chaos

As presented by Maggie Carey, ESRD Forum BAC Chair
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Hi, I'm Maggie Carey and I am here representing more than half a million ESRD patients that can't be here today. I want to start out by saying THANK YOU to Dr. Jay Ginsberg for bending over backwards to bring patients forward and give them an opportunity for their voices to be heard.

And I want to thank Diane Carlson, the Executive Director of my home Network (Network 11) for encouraging, and financing my involvement in the conference and for all the wonderful support and hand holding she and the Network Staff have done to help me step forward and represent the patient perspective.

I am the ESRD Forum Beneficiary Advisory Council (BAC) chair. Do you know what the BAC is? If not, check out our poster. It rocks! And I give full credit for it to Katie Smith at Network 11 for the graphic design. She took a rough idea and turned it into a piece of magic.

So, bottom line, I am a patient. I am the 2nd of four generations of a polycystic kidney family. My mother died on hemodialysis from sepsis. I have done hemo, PD and am currently transplant. My son is about a year out from dialysis and my 11 year old granddaughter was diagnosed about 2 years ago. We are hopeful that with the current research findings she will never see the inside of a dialysis unit unless she is wearing scrubs and tending to patients.

Outside this whole kidney thing, we, as patients, have full lives. We have careers, families, hobbies, problems, and health issues outside of ESRD. We have everything you have in your life – plus this kidney thing.

Today I am going to talk a little bit about my personal experiences with Transitions of Care. A lot is being said and done right now nationally on this topic, but it is focusing primarily on transitions from hospitals to home and to and from long term care environments. But as ESRD patients we can truly have dozens of transitions and multiplying THAT by half a million patients and you get a glimpse of the magnitude of transitions we are dealing with. I am going to talk specifically about two of my transitions and the contrast between them.

I am going to talk FIRST about my transition from the hospital to the dialysis ward. And I want to stress that from a Provider standpoint this was a textbook transition. No problems, no concerns, no drama.

So let me set the stage. I was 41 years old and I was hospitalized with a simple UTI that had worked itself up into one of my polycystic kidneys. I spent six weeks in the hospital. A lot of it was a blur, but some things I remember clearly.

First off, God bless the inventor of the morphine pump. And here is a little tip if you are ever in a similar hospital situation and plugged into one of those marvels. You are handed a button to push when you are in pain and it releases a little dose of morphine. But it is tied to a timer and no matter how often you push the button, it will only release every so many minutes – in my case it was 6 minutes. Well, not wanting to miss a second of relief, I tucked the button up under my hip and had the button constantly pressed. I did learn, however, not to talk about all the extra people I saw in the room. It seemed to upset the nurses.

Long story short, the kidney had to be removed to contain the infection and I started dialysis in the hospital. Now I was fairly well educated, career oriented, family driven and hopelessly optimistic. And I was TERRIFIED!!! Even though this was my family legacy, I was terrified. My mother had DIED on dialysis at way to young an age!

Now in my experience, fear can take on either of two forms when it gets ahold of you. You can EXTERNALIZE it and it can come out as hostility, aggression or just plain bitchiness. Or you can INTERNALIZE it where you will hold it in and panic quietly to yourself. It is pretty easy to spot externalized fear, but it is not so easy to see internalized fear unless you are looking for it. And BOTH forms of fear shut down your ability to process information.

So back to my story, the hospital did everything correct in preparing my Transition of Care. They provided print material, handouts and videos that I could and did watch from my hospital bed. I know that I went through it all – but I remembered little if anything. I DO remember one afternoon lying there panicking about the decisions that I had to make. I knew that I wanted to do peritoneal dialysis as soon as I was able, but I also knew that I would have to continue hemodialysis until my abdominal surgery healed. Anyway, I was laying there kind of crying when my nurse came in to ask what my modality choice was and I blurted out that I wanted PD but that I was scared I wouldn't be able to handle it. She said "Don't worry, Hon. My dad does it and he is 90 and blind."

20 years later I still remember that as an ahaha moment. I can't remember her name, but I can picture her in my mind. She has NO idea how profoundly she affected my life with that one comment, genuinely made.

I had two more dialysis sessions in an isolated room in the hospital and was discharged with instructions to show up on Wednesday at 10:00 am at the dialysis unit. Now remember, this was a textbook perfect transition according to my health care providers. I was compliant, I seemed to be in control of myself and my decisions and I did what I was told. I was told that I would have to weight in and they would take over from there.

I was still pretty sick – recovering from a nephrectomy where they had removed a 17 pound polycystic kidney. My kids only weighed 7 pounds at birth! I had staples from stem to stern. AND I WAS ON DIALYSIS – MY WORST NIGHTMARE HAD COME TRUE 10 YEARS BEFORE I WAS EXPECTING IT.

On Tuesday morning I got a call postponing my dialysis until Thursday afternoon. I'm a good girl and I don't make waves. I HAD NOT FOUND MY VOICE. But fear took over big time.

- Did they know when my last dialysis was?
- Was I going to die? I knew you couldn't miss a treatment or you would die.
- Should I call someone and tell them?
- Who should I call?

I went through that the next two days in a constant state of vigilance for any symptom that I was about to die.

Thursday afternoon came and I showed up at the unit and got shuffled around from person to person, moved from chair to chair and got kind of overpowered by all the bells and whistles going off. Machine sirens kept going off and people were scurrying around every which way. I saw a young 20 something with these great big bumps on her arm and when I asked about them was told that it was a side effect of the needles going into her fistula. I decided then and there that I would NEVER have a fistula (sorry Jan). But I know better now. Anyway, there was a lot of frailty and shivering and moaning going on around me. Actually, there probably wasn't that much but it was what my eyes focused on.

I got my regular schedule which was Tuesday, Thursday and Saturday nights from 6 to 11 so that I could continue to work my 9-5 job. And I dialyzed in the unit for 3 months while my abdominal cavity healed.

Textbook Perfect, right? Well at least from the provider standpoint. I don't think any of them EVER knew how terrified I was most of the time.

Transition #2 – Hemo to PD

So during a regular hemo session this tiny little Dynamo named Lee came and sat down beside me. She introduced herself and said she was in charge of the unit's PD program. She took my hand and held it and said she was going to take care of me. And we talked. And we talked. And we talked some more. We talked about everything under the sun. She had me come in the next day to the PD unit and meet the other two nurses. I looked at all the equipment and she made arrangements with my surgeon for my abdominal catheter. She followed up with me during that healing process and she oversaw my training. She DRILLED ME and we laughed a lot – maybe for the first time in months. She made sure that my equipment was delivered and was on the phone with me after I did my first solo exchange at home.

In my textbook perfect transition #2, there was trepidation – but NO FEAR.

- Was it because a 90 year old blind man could do it?
- Was it because Lee held my hand and said she would take care of me?
- Or was it just that I was feeling better and could process information again.

I don't know – but those two transitions were only 3 months apart chronologically and worlds apart in my memories.