

Being an Active Member of My Health Care Team

*By Reidaone Bourjolly, DPC
Education Center Board Member*

When it comes to Chronic Kidney Disease (CKD) and end-stage renal disease (ESRD) there are many reasons to be proactive in your health care. Writing this article is quite therapeutic for me, and I hope it can serve as an eye opener for those who can use it for prevention and for those already living with ESRD.

My newfound knowledge and new love for myself came to me after having to go through what I lived through. *Lived* is the word that stands out to me. Special is the fact that I have the gift of life—my kidney transplant—which also allows me to serve others. My condition taught me how to be a better and educated active member of my health care team. Living through CKD, then ESRD, dialysis, and now a successful kidney transplant has taught me the importance of information. I found myself realizing that I needed to help myself survive this illness because there were so many things I still wanted to do and accomplish, and I wanted to help others.

Being an active member of my health care team took a lot of effort and



support from my family and friends for me to be proactive with my doctors and nutrition choices. The steps I took can help serve as a blueprint for helping ourselves, not only survive, but draw a map on how to move forward. Becoming acquainted and proactive with the path that needs to be taken can lead you toward being blessed with a new road of opportunities toward living and having a quality lifestyle.

We have a chance to work with our doctors in making decisions that work best for our lives. I can't stress enough the importance of keeping records and notes to attack this illness head on. According to science, the chances of survival can be slim without being proactive and having a will to live; arming yourself with information can only add fuel to your courage.

Assembling a binder, titling it, "Beating CKD, ESRD, & Dialysis" and sectioning it off with "Survival Techniques" labels is what I developed for myself to serve as a blueprint to follow. I encourage you to develop your own binder as you go through the journey of this illness.

Section 1: TEAM

After being diagnosed and going through the emotions of denial, shock, heartbreak, and despair, my first section did not come easy. It came after the support, comfort and love poured in from others who were my team. I formed a team. Some members of that team were volunteers, and others were chosen. This section was called *TEAM*, and we all need a support group when trying to advocate for our health. There will be times that you will not have the will power to advocate for yourself. That is when your members will give you that extra push and that occasional reminder that you have more to live for and that you are bigger than your illness.

Section 2: NOTES

Being a good team leader is also admitting to yourself that you may not be as strong as you thought emotionally. I needed to understand what I was dealing with after getting diagnosed. This section is called *NOTES*. I realized after hearing "CKD" come out of my



doctor's mouth that all my listening senses stopped working; it would be like that during my whole process. At times I was able to retain what I heard, and at other times I couldn't remember what had been said to me. That is where section 1 (*TEAM*) came in handy. My brother or my dear friend volunteered to escort me to all my doctor visits, and we both had a notebook to take notes so we could go over what I was told. After each visit, I added these notes to my binder.

Section 3: RECORD KEEPING

I wanted to be a good patient, and I came to the realization that being a good patient meant understanding the course of action my doctor wanted for me. This section of my binder is called *RECORD KEEPING*. In this section I kept a record of all my doctor's information, all the blood work reports, exams, results, and list of medications. Keeping track of these reports is my duty as my own managed care worker. As a good patient, it is not in your best interest to make things difficult for yourself or your specialist. I have learned that not all your doctors will be in communication during your illness, and you will need to bring this information with you to your visits. You will also need to refer to this information for comparison so that you can gain a grasp of what works for

you and what does not. I kept all my report cards given to me by my dialysis nutritionist after blood work was done. By keeping them, I was able to refer to previous months when my numbers were great and months where I received an unhappy face sticker because my phosphorus level was too high. By doing so, I was able to realize where I went wrong with my diet and make the proper adjustments needed.

Section 4: COURSE OF ACTION

COURSE OF ACTION was the name of section 4. With the help of sections 1, 2, and 3 of my binder, I was able to develop a plan. In order to improve the quality of life I had and to not allow ESRD to dictate how long I was going to live, I had to have a strategic plan of attack. There was a war going on against my body, mind and soul. With the course of action I developed in this section, I had faith that I would make it through—even on my most trying days. When developing this section, I realized I needed sub-sections:

Physical Fitness: Prior to CKD, I joined a fitness center and hired a trainer and life coach. With my newfound lifestyle, I lost 50 pounds and was at the best health of my life. I did not know at the time that my fitness trainer prepared me physically and mentally to deal with the news of



because it also included the part of needing a blessing of what I called receiving a transplant. There are many ESRD patients who need a kidney transplant, and there are also many patients ineligible for a transplant who must continue to receive their treatments through dialysis. The only way to find out if you are eligible is to ask your healthcare team about undergoing a transplant evaluation. A member of my health care team helped me to find out the steps required to get listed. When my family and friends found out I was sick, many of them took time out of their schedule to get tested to be donors. There were times that I found it very difficult to spread the word or ask people to consider doing this life-saving gesture. That is where my team and prayer warriors came into play. During the times that I felt weak, they were strong and knew the importance of asking others and strangers to get tested. It was also my job to find ways to get listed in other states. By acquiring this knowledge, additional people volunteered information toward my effort.

Those are the sections of my binder, and it is always within my reach at home. You may want to add or change the titles of your sections and subsections in order to make it work for you. The binder will help you stay organized and knowledgeable. Additionally, you will find you are adding to it as your treatment changes, as you learn new tips and as new people come into your life.

Advocating for my health did not come without a lot of effort on my part. You can only survive this illness by having a full understanding of what steps to take to improve your quality of life. Being a proactive member of your health care team not only benefits you, it also benefits your family, those who support you, and most of all, those you can pay it forward to. After receiving my transplant, I can say that I have been on many different sides of this illness. The effort I have made to learn how to be an advocate for my health allows me to continue to be a leader for my own health and to teach others to advocate for their health.

having CKD and later ESRD. My healthy lifestyle allowed me to put dialysis on hold for over a year after being diagnosed with CKD and later to easily make adjustments to continue training even on the days I received dialysis. Without this section, I would not be as healthy as I am today.

Nutrition: After my initial diagnosis of CKD, I had to make a few adjustments to my diet. After starting dialysis, there was another set of adjustments that had to be done to have the proper numbers. I needed to get listed on a transplant list with the hospital of my choice. With this section, I was able to insert all the information my nutritionist provided me with along with my own research.

Education: In order to survive dialysis, I had to educate myself. This is also where section 1 and 4 came into action. My team, which included my support members and my life coach, demanded that I set my laziness aside, become aware of what was happening to me and figure out what my odds were to surviving this life-threatening disease. I decided after starting dialysis that I would get a better understanding of my illness and the process of dialysis by enrolling in a dialysis technician course. That way, I would be educated on the process of the dialysis machine and the nurse/technician's role in my treatment. I

wanted to be an active, informed and involved participant in my dialysis treatment. This is what helped me make the right decisions. I also dedicated hours of research pertaining to CKD, ESRD, transplantation and nutrition. Without this knowledge and having faith, I would not have been placed in the proper position to be in charge as a member of my health care team.

Faith and Trust: This chapter in my life has showed me the power of believing, staying positive, and keeping faith. This section is a place I had to refer to often. There were days that were tougher than others physically and mentally, and I needed a place to refer to my notes on those topics. I became more spiritual, and I became acquainted with Bible verses that I was able to use for healing. In this section I had a list of people who I knew I could count on for the extra motivation. I needed to look past my pain and sympathy for myself. These people were my *Prayer Warriors* team. These people were my brother, friends and relatives who knew how to pray and knew the meaning of praying together for a greater purpose. There were times I didn't know how to pray for myself, and these teammates knew the meaning of faith—even when my body was discouraging me.

Transplantation: Being a member of my health care team was not easy