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A NEWSLETTER FOR PATIENT ADVISORY COMMITTEE REPRESENTATIVES

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Treatments

Why I Do Not Skip Dialysis Treatments

by Laverne M. Washington, PAC Representative and Patient Subject Matter Expert

When I was first diagnosed with End Stage Kidney Disease I felt real sick most of the time. Once I had begun treatments, I still felt sick. It took a while for me to begin to feel better. I asked the kidney doctor what I could expect from these treatments. He said, "You will have a better quality of life".

I have had to make a lot of personal adjustments in order to be a compliant dialysis patient. I have to take nine different prescribed medications daily; I have had to change the types of foods I eat; I have had to control my fluid intake daily; I have had to decrease my socialization. With all of these changes in effect, I must say I do have a better quality of life, and I am not as sick, one day at a time.

Today is August 11, 2016, and I have been a dialysis patient at Rockwell Dialysis which is affiliated with Brooklyn Hospital for the past seven years. I go for treatment three times a week, for four hours each time. I have diabetes and chronic high blood pressure. Some treatment days my blood pressure drops real low and I feel bad, but I have made a commitment to see this process through. I have not missed a treatment appointment yet. I have a very supportive wife and family. I have an understanding network of friends who encourage me to follow the demands of my treatment requirements. I love my life and I have had some wonderful adventures in this life. I feel blessed to have been diagnosed with end stage kidney disease. I have learned that dialysis is a treatment for this disease, and not a cure. I can accept that without feeling victimized.

Throughout the years that I have been a patient at Rockwell, I have made friends with a lot of fellow patients. We become pretty friendly with each other. But on occasion some of my friends die. Often times the cause of death is related to medical issues. I wonder if cutting their treatment times too often or skipping treatment appointment contributes to the main cause of death. When this happens I feel real sad, like I have lost a close family member or something. It leaves a big hole in our community. That is a feeling that lingers.

I live in Brooklyn New York. We have four seasons in Brooklyn. I must confess that when the winter is cold and the snow is all over the ground, I do not feel like leaving my warm house, and in the summer, during those 90 degree heatwaves, I would like to remain in the house and listen to some sweet music and just relax. But I get up and go come rain or come shine.

Patient Advisory Committee (PAC):

The Patient Advisory Committee, through its representatives in dialysis and transplant units, provides a link between patients and unit staff and opens opportunities for Network area communication for those in the renal community.

Patient Subject Matter Experts (SMEs):

SMEs assist the Network in developing patient-centered materials and projects, by attending conference calls, assisting in material development and reviewing and discussing materials.

To become a PAC Member or Patient Subject Matter Expert (SME) please contact the IPRO ESRD Network of New York: 800-238-3773 or visit our website: esrd.ipro.org/PAC

So with this said I hope I have written something that has encouraged people to think twice about skipping dialysis treatments or cutting their treatment times. For me it is not worth the gamble – you may take some time away from your treatment, but the risk is either toxin/fluid buildup or death.



Laverne M. Washington, *PAC Representative, Rockwell Dialysis; Patient SME*

My name is Laverne M. Washington. I am a Licensed Master Social Worker (LMSW), a Credentialed Alcoholism and Substance Abuse Counselor (CASAC), a Masters of Addiction Counselor (MAC), and I am certified in Critical Incident Stress Maintenance (CISM). I have specialized working with the chemical dependent population for the past 35 years. I have worked in both inpatient and outpatient substance abuse treatment settings. For 10 years I was the clinical supervisor at Breakthrough Concepts Inc., at Gracie Square Hospital. From 1990 through 2002 I was employed as an Employee Assistance Program Counselor/Representative for major transportation industries, namely AMTRAK, New York City Transit, and American Airlines.

I have directed and co-directed psychodrama workshops at American Society for Group Psychotherapy and Psychodrama (ASGPP) conferences, hospitals, and correctional facilities. I am the co-creator of a therapeutic treatment approach, which utilizes psychodrama and the 12 steps of Alcoholics Anonymous to which I was awarded the American Society of Group Psychotherapy and Psychodrama 1998 Innovator's Award. In 2002, The Long Island Chapter of Employee Assistance Professional Association (EAPA) honored me with the presentation of The Monica Wright Lifetime Outstanding Achievement Award. I have also lectured extensively at professional chemical dependency conferences on topics related to the treatment of alcoholism and drug addiction.

From 1990 through 2005 I was an Adjunct Professor at Long Island University Health Careers School of Continuing Studies where I taught the CASAC curriculum to non-credited students. From 2005 thru 2012 I facilitated a recovery support group for musicians and people in the music industry. In 2012 I retired from all professional work activities due to a failure in my health.

What if I can't sit through my treatment time?

Here are some "TIPs"* (The Informed Patient) from PAC Chair/ Patient SME Stephanie Dixon:

Knowledge is power! When I was first diagnosed I had no idea what dialysis was & was told "if you don't do dialysis you will die!" The only word I heard was "die" and I thought my life was over. 14 years later I now know that is not true. Being an educated, informed, engaged patient enables me to live my best life dealing with chronic illness. Learn about the different treatment modalities. Only you can decide what's best for you & fits your lifestyle.

Maintain fluid balance: "I'm thirsty!" Though difficult, maintaining your fluid intake may mean the difference between a gentle, low or no incident treatment or feeling completely wiped out, unable to function, go home & pass out type of treatment. **Remember: what goes in needs to come out.** Other organs in your body are also affected: heart, lungs, vascular system, legs, etc. Know what that excess fluid is doing to your body & its long term effects.

Occupy your mind: Bring something to do, read, knit, crochet, color, do puzzles, play computer games, compute, exercise, pay bills write a book, poem, etc. **Your choices are endless. Time spent on the machine is the best time to ask questions & learn about your treatment, the machine & kidney disease.**