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FROM THE
QIRN3 PATIENT ADVISORY

Living a Full Life While on Dialysis

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All dialysis patients have a story about the day they learned they would need dialysis. For some people, this news came as a total shock. Maybe they weren't feeling well and thought they had the flu. After seeking care at an emergency room, they learn they are in Stage 5 Chronic Kidney Disease (CKD) and need to have a catheter inserted to begin hemodialysis. For others, they had been seeing a nephrologist in the office and were aware that they would need to begin dialysis at some time in the future. They weren't prepared for the day the nephrologist told them they needed to start "now".

For many people the first thought is this can't be true. Emotionally they feel drained and disheartened. They think, "How am I going to live like this? How am I going to stay involved in my family and keep my job?" These are normal thoughts that create fear and uncertainty for many of these individuals. For all these individuals, the time has come to create a "new normal" in their lives. Adjustments will need to occur in order to create a life that is satisfying and fulfilling and addresses the needs of a dialysis patient.

One of the most important things dialysis patients have to remember is they are still a complete person. They have all the same hopes and desires as "healthy" people. Dialysis patients are faced with challenges that create time constraints. They need to work to incorporate dialysis into their lifestyle without allowing it to take over their lives. Maintaining the activities of life that were fulfilling before dialysis began can be the key to creating a "new normal".

Now, how can a dialysis patient accomplish this?

For many the time constraints brought on by dialysis make it difficult to maintain their past activities. The onset of Stage 5 CKD has to be approached with an understanding of treatment options. For an individual who is employed full-time and prefers out-patient hemodialysis, an evening shift or nocturnal dialysis may be the best option. Some may opt for home hemodialysis if they have a partner who can be available to train and assist them at home. Others may choose peritoneal dialysis and run a cyclor at home at night. This will allow the individual to be free from dialysis during the day.

For some individuals home dialysis is not an option and they need to be home in the afternoons and evenings for their family responsibilities. Out-patient hemodialysis during the day may be the best option that will allow them to maintain their regular activities and commitments.

All dialysis patients need to work with their treatment team to ensure they are receiving adequate erythropoietin stimulating agents (ESAs) such as Epogen to maintain adequate hemoglobin levels. Proper nutrition with adequate protein intake along with regular exercise will also help dialysis patients maintain the activities of life they find fulfilling.

The overall goal needs to be developing a treatment plan that will allow the individuals to maintain the activities of life that are important to them. The treatment plan also needs to ensure the patients will receive adequate dialysis to maintain their well-being. The blending of these two goals is the development of the individual's "new normal".

Eat Right to Feel Right on Dialysis

NIH Publication No. 08-4274

When you start hemodialysis, you must make many changes in your life. Watching the foods you eat will make you healthier.

Food gives you energy and helps your body repair itself. Food is broken down in your stomach and intestines. Your blood picks up nutrients from the digested food and carries them to all your body cells. These cells take nutrients from your blood and put waste products back into the bloodstream. When your kidneys were healthy, they worked around the clock to remove wastes from your blood. The wastes left your body when you urinated. Other wastes are removed in bowel movement. Now that your kidneys have stopped working, hemodialysis removes wastes from your blood. But between dialysis sessions, wastes can build up in your blood and make you sick. You can reduce the amount of wastes by watching what you eat and drink. A good meal plan can improve your dialysis and your health.

You already know you need to watch how much you drink. Any food that is liquid at room temperature also contains water. These foods include soup, Jell-O, and ice cream. Many fruits and vegetables contain lots of water, too. They include melons, grapes, apples, oranges, tomatoes, lettuce, and celery. All these foods add to your fluid intake.

Fluid can build up between dialysis sessions, causing swelling and weight gain. The extra fluid affects your blood pressure and can make your heart work harder. You could have serious heart trouble from overloading your system with fluid. Your dry weight is your weight after a dialysis session when all of the extra fluid in your body has been removed. If you let too much fluid build up between sessions, it is harder to get down to your proper dry weight. Talk with your doctor regularly about what your dry

weight should be and work with your dietitian to develop strategies for controlling your fluid intake.

Potassium and phosphorus are monitored when you on dialysis. Your dietitian will meet with you monthly to discuss your lab results. It is important you understand what your levels are and what you can do to control them and keep them at a healthy level for your body.

Potassium is a mineral found in many foods, especially milk, fruits, and vegetables. It affects how steadily your heart beats. Healthy kidneys keep the right amount of potassium in the blood to keep the heart beating at a steady pace. Potassium levels can rise between dialysis sessions and affect your heartbeat. To control potassium levels in your blood, avoid foods like avocados, bananas, kiwis, and dried fruit, which are very high in potassium. Also, eat smaller portions of other high-potassium foods.

Phosphorus is a mineral found in many foods. If you have too much phosphorus in your blood, it pulls calcium from your bones. Losing calcium will make your bones weak and likely to break. Also, too much phosphorus may make your skin itch. Foods like milk and cheese, dried beans, peas, colas, nuts, and peanut butter are high in phosphorus. You probably will need to take a phosphate binder like Renvela, PhosLo, Tums, or calcium carbonate to control the phosphorus in your blood between dialysis sessions. These medications act like sponges to soak up, or bind, phosphorus while it is in the stomach. Because it is bound, the phosphorus does not get into the blood. Instead, it is passed out of the body in the stool.

Speak with your dietitian to learn what is best for you!

JOIN THE PAC TODAY!



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We're on the
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www.qirn3.org

The Patient Advisory Committee (PAC) for QIRN3 consists of dialysis patients and those who have received transplants. The committee meets quarterly to discuss issues relevant to ESRD patients. The PAC members have a genuine concern for quality of care issues and encourage patients to be involved in their healthcare. They are willing to share skills and experience with others. Each facility is encouraged to have a PAC representative. Talk to your social worker to volunteer!