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DIALYSIS 101

Family Focus

The Renal Community's Newspaper

VOLUME 8

NUMBER 2

WHAT DOES DIALYSIS MEAN TO YOU?



Dialysis, Past, Present and Future

by Richard F. Drake, MD

In the Beginning

It is hard to believe today that only 38 years ago there was no medical treatment for patients with permanent kidney failure. There were very few kidney transplants at the time and no chronic dialysis treatment. Initially, in the early 1960s, treating patients with the artificial kidney was considered research. The University of Washington Medical School, which had a nephrology research department,



A 1968 home hemodialysis machine.

had five patients who were being treated for kidney failure. This is a far cry from today, when 20 to 30 people dialyze on each shift in dialysis units across the nation. The initial dialysis patient treatment schedule was 16 to 20 hours twice a week. Most of the complications that arose were related to waste products building up in the body during the time between dialysis treatments, and special diets were devised to help cut down the amount of substances taken into the body.

The machines were also quite different in the early days. The equipment consisted of a large refrigerated tank filled with dialysis fluid. The kidney, which was made of large plastic boards about 3 feet long and 1½ feet wide, was placed on top of the tank. Blood lines were connected to the patient by a cannula, which consisted of two tubes that were inserted in the arm, one tube in the artery and one in the vein. This cannula could be used as often as needed and could be used without a blood pump.

New Treatments at Home

The next period in the treatment of kidney disease extended from the mid-1960s through the 1970s. Insurance did not pay for treatment, and cost became a central issue. As a result, foundations were started in many states to help fund patients on dialysis. Not all patients with kidney failure could be treated, however, as the funds raised from public donations were limited. This resulted in patients being screened for treatment selection. Since home hemodialysis was the treatment of choice because it was less

“As dialysis techniques continue to improve, major advances are also continuing with transplantation.”

expensive than in-hospital dialysis, the screening primarily involved making sure that those in need of treatment could have home dialysis with appropriate volunteer help.

Home hemodialysis required different equipment from that used in the hospital. Machines were designed to reduce the time family members spent assisting with the procedure. The machines used tap water for the dialysis solution, which eliminated the need for the large refrigerated mixing tank. Many of the basic concepts related to the machines that were developed during that period remain in use today. Patients dialyzed at least three times a week for eight hours each treatment, usually running during the night. This proved to be a very successful treatment plan.

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The NKF's Patient & Family Council Annual Meeting Program
October 23 - 25, 1998 • Philadelphia, Pennsylvania



TOPICS INCLUDE

Taking Control:

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- Stress Management
- Rehabilitation
- Depression Before and After Transplant

Moving Into Wellness: Knowledge, Choice, Control:

- Exercise and a Healthy Attitude

Self-Empowerment: Coping:

- NKF-DOQI: Adequacy, Anemia and You
- The Patient As a Member of the Healthcare Team
- ...because Dad needs dialysis (guidance for the family)

Meeting registration fee: \$10

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FROM THE EDITOR



Karren King

It is with pleasure, yet also trepidation, that I write this, my first column as editor of *Family Focus*. I will be attempting to follow in some extremely able footsteps left by

the originating editor, Nancy Spinozzi. Her vision and tremendous effort, coupled with very dedicated, talented Editorial Board members and National Kidney Foundation staff, have taken this publication from its inception to what it is today, the renal community's most widely disseminated constituency newsletter, with a circulation of approximately 155,000. So to Nancy and all of those who have worked with her over the past eight years, I give a very heartfelt thank you on behalf of myself and all of the readers of *Family Focus*! What a tradition you have begun!

Annually, a new Editorial Board is formed to direct the efforts of *Family Focus* for the forthcoming year. A terrific group of individuals has agreed to be a part of our efforts for 1998. I know you

will enjoy hearing from them. As always, we want to hear from you, too. The Editorial Board desires *Family Focus* to be a communication vehicle, and successful communication is dependent upon it being a "two way street"!

This issue of *Family Focus* is titled "Dialysis 101." The idea is to take us back to the basics of dialysis care and treatment. If you are beginning dialysis, this is the information you need to make informed decisions and guide your health care in the direction that will allow you to live a full, satisfying life. If you are currently receiving dialysis or have been transplanted, you may initially believe that this issue has nothing to offer you. I would urge you to reconsider. We know all too well that many individuals begin treatment with very little information. And even if you were one of the fortunate individuals who received education about dialysis, there may be new information and breakthroughs of which you are unaware, or you may learn of some aspects about an alternative dialysis modality that piques your interest. Additionally, there is so much information to learn when starting treatment, it is impossible to retain all

of it, and you could view this as your "refresher course."

The Patient/Family Corner article (p. 10) provides an excellent overview of the various dialysis modalities available. Three people share with you why their particular treatment is ideal for them. The key to keep in mind is that this is the best treatment for **them**. You are unique, as are they, and what is best suited for one individual may or may not be the answer for another. You know yourself, your particular needs, desires and circumstances far better than anyone else. You have the responsibility to examine those things about you that make you unique and then, preferably in consultation with your health care team, to select a treatment that is best suited for you.

Regardless of the treatment selected, whether in a dialysis facility or at home, you can and should be actively involved with your treatment. Ask questions, get involved! By all means, do not be passive recipients of care. Remember that this is your life, and you are much too special to turn it over to anyone else. **FF**

*Karren King
For the Editorial Board*



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Are we missing you?

We'd like to make sure that NKF Family Focus is making its way to every dialysis unit and transplant center in the country. If we're missing anyone, or if you would like to receive a copy at your home, please let us know by dropping us a note or by giving us a call at (800) 622-9010.

Next Issue

NKF Family Focus Spotlights NKF-Dialysis Outcomes Quality Initiative (NKF-DOQI)

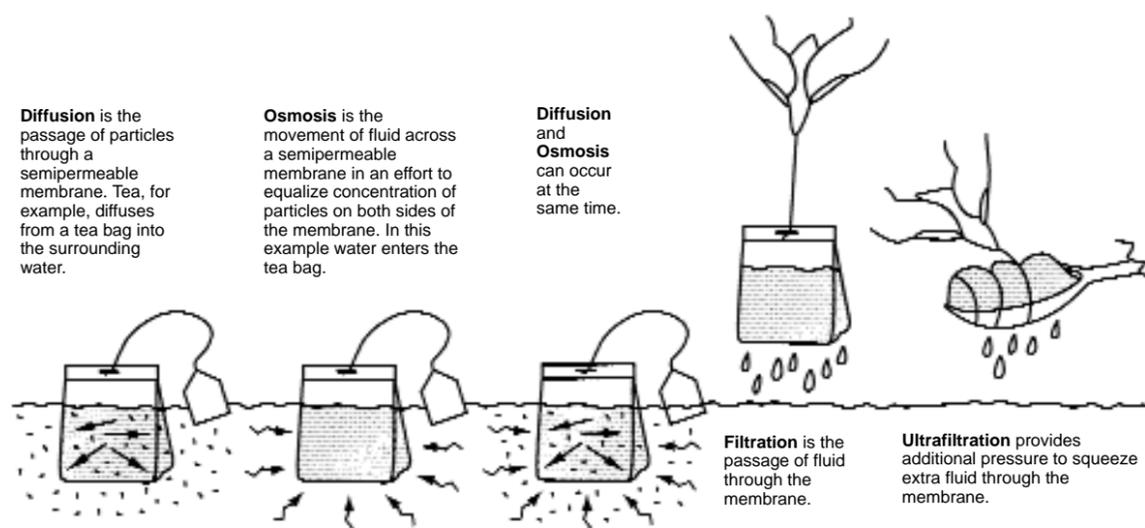
Editor's Note: Our next two issues will spotlight NKF-DOQI and the Health Care Team. We invite readers and health care providers to submit their contributions to the editorial board in c/o the National Kidney Foundation, 30 East 33rd Street, New York, NY, 10016.

How Dialysis Works: The Process

Chances are, if you are a renal patient, you remember the flood of questions that went through your mind when you were told that you have a chronic and progressive kidney disease. New, as well as long-term, dialysis patients have unanswered questions. These articles will help you to understand better exactly how your dialysis treatments aid in keeping you healthy. Remember that your physician and your dialysis staff are also good resources to answer your questions.

HEMODIALYSIS

by Barbara Kay Woodruff, BS, RN, CNN



Reprinted with permission from the Core Curriculum for The Dialysis Technician by Amgen

Dialysis therapy, although not as efficient as the human kidney, uses some of the same principles to remove excess water and build-up of waste products (uremic toxins). The process of diffusion removes the toxins. Osmosis and ultrafiltration remove the water.

During hemodialysis your blood flows through a special filter called an artificial kidney or dialyzer, which has a semipermeable membrane. This means that the membrane allows small and middle-sized solutes such as urea, creatinine, potassium, calcium, phosphate, hydrogen and bicarbonate to pass through its pores. Meanwhile, the dialysis machine pumps dialysate (purified water with a chemical composition similar to normal blood) through your dialyzer. As the dialysate bathes the fibers that contain your blood, the toxins and solutes cross the membrane and are disposed of in the fluid. This is called diffusion. Sometimes you may need to take some of the components in the special fluid into your blood, such as bicarbonate. In that case, the needed solutes move from the dialysate across the membrane to you. Large particles such as bacteria, viruses and blood cannot pass through the tiny pores of the semipermeable membrane, so the

shift in solutes is not only safe but very beneficial to you.

In addition to the toxins, you also need to lose the excess fluid that has built up since your last treatment. As your blood passes through the dialyzer it puts pressure on the membrane—venous pressure. This pressure forces fluid across the membrane. The amount of fluid that passes across depends on the size of your dialyzer, how easily your type of dialyzer membrane gives up fluid and your venous pressure. If you need to lose more fluid than would be pushed through the membrane, the dialysis machine applies a negative pressure to the dialyzer to pull the additional fluid across. This is called ultrafiltration. Most dialysis machines have the ability to measure how much fluid you are losing; they adjust their “pull” to make certain that you lose the proper amount.

Since blood must flow through the dialyzer in hemodialysis, you must have needles placed in your fistula or graft, or have a catheter inserted into a large vein, to provide adequate blood flow. The dialysis machine accurately monitors your blood flow through the dialyzer. When your blood flow drops, or your access is not flowing properly, the machine will let you and your

caregiver know that an adjustment or correction is necessary. Your caregiver can determine such problems as a malpositioned needle, a kinked blood line, a catheter that is not functioning properly, or an indication that your dialyzer is about to clot.

Not every dialysis treatment is uneventful. Occasionally you may experience hypotension (a drop in blood pressure) or muscle cramps. Hypotension occurs when your body is unable to shift fluid into your blood vessels as quickly as it is being removed, or when you have lost all of your fluid gain. Muscle cramps usually occur toward the end of your treatment. This is due to water and sodium removal during ultrafiltration. As your volume rapidly decreases, the fluid shifts to your internal organs, stealing it from your arms and legs. Helpful measures to prevent cramps and hypotension can be ordered by your physician as part of your dialysis prescription. A nephrology nurse will teach you and your family what you can do to decrease the chance of discomfort during hemodialysis.

Barbara Kay Woodruff is a clinical specialist at B. Braun Medical in Bethlehem, Pennsylvania.

DIALYSIS: GLOSSARY AT A GLANCE

Diffusion—toxins and solutes pass across the membrane of the dialyzer into the dialysis fluid

Osmosis—excess water passes across the membrane of the dialyzer and leaves your body

Ultrafiltration—pressure is put on the membrane to squeeze excess fluid across and make sure you lose the proper amount of fluid

Filtration—fluid passes through the membrane into the dialyzer

continued on page 5

Dialysis 101

PERITONEAL DIALYSIS

by Janice Seftick, RN, CNN

How Dialysis Works, continued from p. 4

Peritoneal dialysis (PD) is another form of dialysis. PD takes place inside the body. The peritoneum, a thin plastic-like membrane that lines the abdominal cavity and covers the abdominal organs, acts as the semipermeable membrane. A tube, also known as a catheter, is surgically placed through the abdominal wall. Approximately two to three liters of dialysis solution pass through the tube into the empty peritoneal cavity. Waste products and extra fluid will pass through the membrane and into the dialysis solution during the dwell period, the time fluid remains inside you. Then it is drained out and replaced with fresh solution during the fill. These three steps are called an exchange or cycle. Several such exchanges or cycles will cleanse the waste products from the blood. As in hemodialysis, waste products are removed by diffusion. In PD, fluid removal occurs through osmosis using different strengths of solutions - 1.5%, 2.5% and 4.25% dextrose.

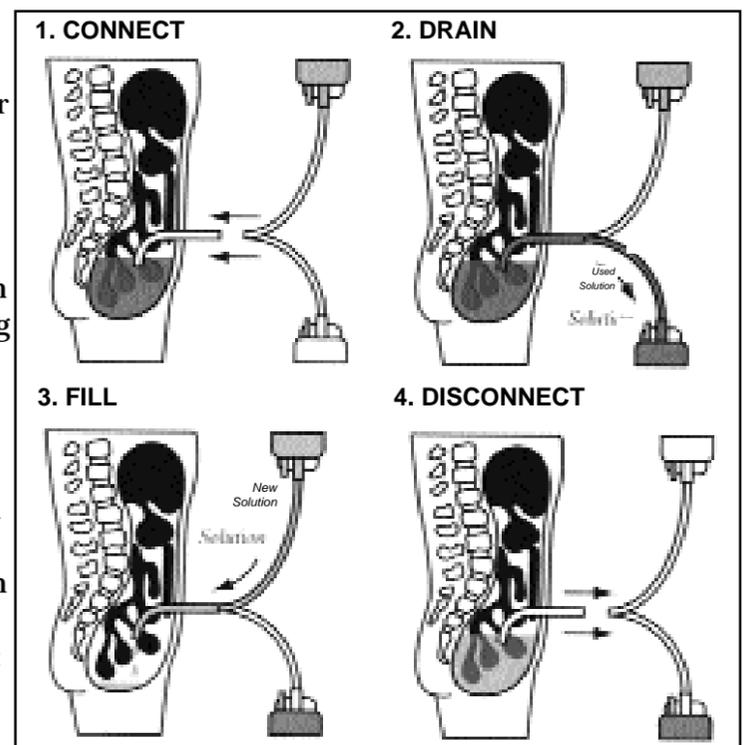
There are two types of PD. Continuous ambulatory peritoneal dialysis (CAPD) is performed seven days a week, with four to five exchanges a day, and without the use of a machine. A system of bags and tubing is attached to the catheter only during the exchange. Each exchange, or draining of the used solution and

replacement with fresh solution, lasts about 30 minutes and is done every four to six hours. The last (or evening) exchange remains inside the peritoneal cavity overnight. In automated peritoneal dialysis (APD), the exchanges of dialysis solution are done by a machine during sleep. These exchanges are called cycles, and thus the machine is often referred to as a cycler. With this form of PD, the catheter is connected to the cycler seven nights a week for about 10 hours each night. The machine controls all three phases of the cycles: draining used solution, refilling with fresh solution and monitoring the dwell time. A final fill is performed in the morning. Generally, once the patient is disconnected from the cycler, no additional dialysis is required until the evening treatment.

Both forms of peritoneal dialysis are self-care therapies. A nephrology nurse will teach the proper skills to perform the treatment safely at home. This training takes between five and eight days. Once the patient is home, the dialysis center will provide 24-hour on-call service to address any questions or concerns.

For more information on these

CAPD EXCHANGE



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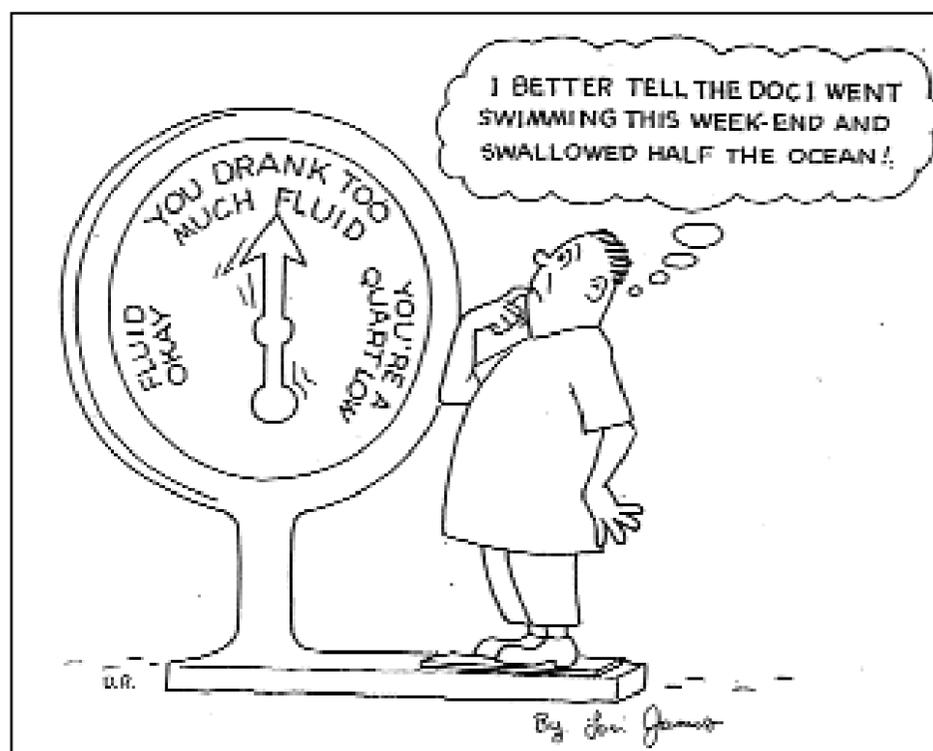
dialysis treatments, see the following NKF patient educational brochures: "Dialysis" (English or Spanish), "People Like Us" (videos and brochures), "Hemodialysis: Choosing a Treatment That's Right for You," "Peritoneal Dialysis: Choosing a Treatment That's Right for You" and "Peritoneal Dialysis: An Alternative to Hemodialysis."

Call the NKF at (800) 622 - 9010 to receive any of these brochures.

Janice Seftick is a clinical specialist with Baxter Healthcare in Michigan. 

C A R T O O N

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Lori James is a product specialist in Riverdale, Utah.

Look for another of her cartoons on page 14.

Keeping You Covered: 25 Years of Benefits for ESRD Patients

by Dolph Chianchiano, JD, MPA

July 1, 1998 was the 25th anniversary of the date on which Medicare coverage for dialysis and kidney transplant patients went into effect. As we celebrate this landmark event, we should appreciate and take pride in the success of the Medicare End Stage Renal Disease (ESRD) program. We should also remember the tremendous efforts by so many people that helped make this entitlement possible.

It would be easy to assume that the Medicare ESRD program was born with the stroke of a pen on October 30, 1972, when President Nixon signed Public Law 92-603. Nevertheless, the enactment was the result of many developments and at least five years of advocacy. There were many moving events during those five years: Shep Glazer underwent a dialysis treatment at a committee meeting in the U.S. House of Representatives; and a *Life* magazine article starkly portrayed the members of a Seattle committee who had the responsibility to decide which patients could receive dialysis treatments and live and which could not receive treatment and would therefore die. In addition, standard advocacy techniques, like newspaper ads placed by the National Kidney Foundation (NKF), played an important role in this policy change.

Advances in medical science and technology in the early 1960s were the fundamental driving force behind the Medicare ESRD program. Chronic dialysis treatments had just become feasible, while improvements in kidney transplantation were making it a viable option for many more patients. The movement gained momentum in 1967, however, when a respected government committee issued a report urging the creation of a national program to provide either a transplant or the use of an artificial kidney machine to individuals with chronic kidney disease. The committee argued that it was inappropriate to

discriminate against patients based on access to renal replacement therapy.

Some say that the Medicare ESRD program was made possible because people expected that national health insurance was going to become available and would cover the program. Others suggest that Congress might not have acted if the ultimate cost of the program had been more accurately predicted. (It was projected in 1972 that no more than 100,000 Americans would be entitled to Medicare benefits because of kidney failure at any point in time.)

Twenty-five years later, we can be grateful that the Medicare ESRD program has saved hundreds of thousands of lives. A quarter of a million people currently receive dialysis treatments or transplant benefits thanks to Medicare coverage for End Stage Renal Disease. ESRD care is coordinated by specialized teams, including nephrologists, nephrology social workers, renal dietitians, registered nurses, licensed practical nurses and dialysis technicians. ESRD treatment is monitored by 18 End Stage Renal Disease Networks that are supported by the federal government. Peritoneal dialysis was approved as a new treatment option in 1980. Other developments in coverage include new methods for treating anemia and bone disease in dialysis patients and new medications that prolong the life of transplanted kidneys. Medicare began paying for the newly developed anti-rejection medications in 1987, and Congress extended the benefit from one year to three years in 1993.

In preparation for the next quarter century, Congress and the Administration are focusing on general Medicare issues. One-seventh of the entire U.S. population now looks to Medicare to pay for its health care, and it is projected that the Medicare trust fund, which pays for hospital bills (but not dialysis treatments) could run out of money in 2010. With

this in mind, Congress created a National Bipartisan Commission on the Future of Medicare last year. The Commission members have been appointed by the president and the Congressional leadership.

Their duties include making recommendations (a) for establishing the appropriate financial structure of the Medicare program as a whole, (b) for establishing the appropriate balance of benefits covered and beneficiary contributions to the Medicare program and (c) on the impact of chronic disease and disability trends on future costs and quality of services. While it only met for the first time on March 6, 1998, the Commission must submit a report to the president and Congress by March of 1999. The Commission's deliberations will provide an opportunity to review Medicare benefits, but it is unlikely that the Commission will recommend canceling the ESRD entitlement. On the other hand, the Commission may make recommendations that could have an economic impact on ESRD patients, such as an increase in Medicare premiums or a policy of relating those premiums to the income level of beneficiaries. House Speaker Newt Gingrich got a pledge from his appointees to the panel that they will not support a tax increase as a solution to Medicare's financial problems.

The future holds many challenges and opportunities to continue and expand Medicare benefits for individuals with kidney disease. This will require ongoing patient advocacy by the NKF and the renal community. For more information on legislation relating to kidney disease and how you can become involved in advocacy efforts, call the NKF Office of Scientific and Public Policy at (800) 889-9559.

Dolph Chianchiano is the director of Scientific and Public Policy at the National Kidney Foundation. 

COVER STORY

Dialysis, Past, Present and Future

continued from page 1

There were problems, though, despite the success of artificial kidney treatment. One problem was anemia (low blood count), which resulted in the patient experiencing fatigue in addition to other symptoms. This often required the person to receive blood transfusions. Fortunately for those dialyzing today, the hormone erythropoietin (EPO) can be given to correct anemia. This was a major development in the course of treatment of End Stage Renal Disease.

MORE CHOICES

In 1972 a rider was placed on a Congressional bill that extended coverage of chronic renal failure under Medicare. A fixed fee (capitated) for each dialysis session was initiated. Since the government was funding dialysis, screening for treatment selection was no longer an issue. During this period outpatient center dialysis as we know it today began to develop. Due to increased access to these hemo-dialysis centers, home hemodialysis declined.

However, doing dialysis at home experienced a resurgence in the 1980s with the introduction of peritoneal dialysis (PD), and PD soon became more popular than home hemo-dialysis. One reason for this was that the procedure was simpler to learn than home hemodialysis. The initial form of PD used with chronic kidney failure was called continuous ambulatory peritoneal dialysis (CAPD) because dialysis was a continuous, machine-free process. Cleansing fluid is pumped into your belly through a



Michael Nardoza smiles for the camera while dialyzing at the Mount Sinai Dialysis Center.

catheter and later drained. Another form of peritoneal dialysis, called continuous cycling peritoneal dialysis (CCPD) is now growing in popularity, partly due to the availability of newer and smaller cyclor machines. In this type of PD, a machine delivers and drains the cleansing fluid. These peritoneal treatments give individuals greater flexibility for working and traveling.

TREATMENTS OF TODAY

Today, unlike 1960, people with kidney failure can be treated. In fact, patients now need to learn about the various types of treatment options available to them, including transplantation, hemodialysis and peritoneal dialysis. This era can be referred to as the "computer age." The new devices in peritoneal dialysis

cyclers, which are small, automated, electronically and mechanically sophisticated, but appear extremely simple, are good examples of advancing technology. Hemodialysis equipment also continues to improve with an overall goal of making dialysis less labor intensive for the staff and safer for the patient. Dialysis units are becoming totally automated and paperless charting is a reality. As dialysis techniques continue to improve, major advances are also continuing with transplantation.

The future must continue to address the issue that first began in 1960: how much dialysis does a patient need to feel well and do well? In response to this question, the National Kidney Foundation (NKF), with the support of others, sponsored a large project that reviewed the latest research and has led to practice guidelines ultimately intended to improve patient care and quality of life. These guidelines are called the NKF-Dialysis Outcomes Quality Initiative (NKF-DOQI). Despite the continuing economic restraints to treatment, the future for treating patients with chronic renal failure is very promising.

Richard Drake is a retired nephrologist and the co-inventor of the Drake Willock Dialysis Machine.

Editor's Note: The next issue of Family Focus will be devoted to NKF-DOQI. The NKF-DOQI guidelines can be viewed on the Internet at www.kidney.org/doqi/ or you can call (800) 622-9010 for more information. 



POETRY

CORNER

You need dialysis when your kidneys fail
At times it can make you tired and pale
The treatments can seem long and boring
Especially when you hear other people snoring

The center smells like vinegar and bleach
You can hear the machines screech
You have to watch how much fluid you gain
'Cause taking off too much can cause you pain

Dialysis

by Erin Maher
Succasunna, NJ

Limit your potassium, phosphorus and salty foods
Or else your doctor will be in one of those moods
Always keep your access dry and clean
The hospital is one place you don't want to be seen
You get sick of hearing the machines alarming
What makes you feel better are the nurses who are
so charming
So try to keep your blood pressure low and your
spirits high
That should make the hours fly by 



PATIENT AND FAMILY CORNER

YOU BE THE JUDGE

Pros and Cons of Home Hemodialysis, In-Center Hemodialysis and Peritoneal Dialysis

The following three articles were written by dialysis patients giving their opinions about in-center hemodialysis, peritoneal dialysis and home hemodialysis. The authors provide strong logic for why they favor their type of treatment, but in the end individuals must judge which type of dialysis will be best for them.

In-Center Hemodialysis

KathleneAnne J. Reilly

Options. What a wonderful concept. When I first suffered from renal failure 22 years ago, there were no options. You were automatically registered with the local hemodialysis satellite (non-hospital) center. And, unless you were fortunate enough to have an available, willing, compatible "relative" donor, in-center hemodialysis was your only option.

In-center hemodialysis	CAPD
<p>Treatment Duration -3 times/week -length of treatment is based on the individual, generally 3 to 4 hours per treatment</p>	<p>Treatment Duration -7 days/week -number of exchanges is based on the individual, generally 4 to 5 times per day</p>
<p>Scheduling -must be at the center for your scheduled time unless previous arrangements have been made with the unit for a schedule change</p>	<p>Scheduling -have a little more flexibility but must make the prescribed number of exchanges in an appropriate environment</p>
<p>Medical Follow-Up* -see a caregiver for each treatment</p>	<p>Medical Follow-Up* -once a month clinical visits</p>
<p>Travel -must prepare in advance to set up treatment -restricted to schedule available at transient unit</p>	<p>Travel -can have required supplies sent to destination if flying; if driving, bring sufficient supplies for trip</p>
<p>*24-hour emergency assistance is available for any modality</p>	

In-center hemodialysis has several advantages over CAPD. In general, choosing in-center hemodialysis allows for good friends to share the experience with, treatment three times a week versus four to five times per day, and a caring staff to help do the work and offer personal support.

Although most units try to avoid a hospital environment, in-center hemodialysis provides hospital-like medical supervision. Staff members can become your personal confidantes, parental figures and good friends due to the length of time spent together. Staff, for the most part, are caring, compassionate individuals who have dedicated themselves to providing the patient with quality care. These caregivers help patients control chemistries, understand the

importance of completing prescribed treatments, answer questions and/or concerns and willingly take a personal interest in the patient as a person. In-center hemodialysis generally provides for a patient to be routinely scheduled for the same shift. Seeing fellow patients on a regular basis allows close friendships to develop.

In-center hemodialysis requires discipline in maintaining more stringent diet and fluid control, as well as taking precautions to protect access sites (whether catheter, graft/shunt or fistula). But in time, diet and fluid restrictions become fairly routine for either type of dialysis. Going to in-center hemo can also become routine—it is just a place you need to be at a specific time, like going to work or school.

Peritoneal Dialysis

Anne Louise Pelto

Having been on hemodialysis for eight years, continuous ambulatory peritoneal dialysis (CAPD) and now continuous cycling peritoneal dialysis (CCPD) for two years, the benefits and freedom of PD are clear by comparison.

The peritoneal dialysis diet is a definite advantage for those who find diet to be an important issue. The peritoneal dialysis diet does allow a more liberal intake of potassium, sodium and fluids. Protein intake is usually increased as well. As long as you practice moderation, gone are the days of measuring fluids and soaking potatoes. The peritoneal dialysis diet does not, however, allow an increase in foods high in phosphorous.

Travel is another advantage of peritoneal dialysis. Some medical supply companies can provide a cyclor that is portable and these companies will also ship bags of peritoneal solution to the traveler's destination free of charge for both CAPD and CCPD. Whether your destination is a residence or hotel, these companies will confirm the arrival of your supplies in advance. International travel is also possible.

In addition, peritoneal dialysis is less stressful physically. This can be good for consumers with heart problems, as it makes for a smoother "ride." Rarely will you experience the blood pressure highs and lows, the weak and dizzy feelings, and nausea associated with hemodialysis.



The greatest advantage of peritoneal dialysis is control. Treatment is your responsibility, although a PD nurse is available 24 hours a day, every day. The PD medical team offers any help needed and will thoroughly train you in proper procedures. Ultimately, you are in control and responsible for following a regimen specially suited to your needs, which is prescribed by the doctor. PD allows you to plan dialysis around activities rather than plan activities around dialysis.

As with all forms of dialysis treatment, peritoneal dialysis has its disadvantages. You must always be as clean as possible and follow treatment procedures exactly to avoid contracting peritonitis, a potentially painful and serious infection of the peritoneal lining. Adjusting to having a catheter in your abdomen, which may affect your body image, is difficult. In addition, you must adjust to the "full-bellied" feeling of constantly having the peritoneal lining filled with dialysate solution. Another problem is storage. You must have space to store a month's supply of bags of solution and ancillary items. Also, the large amount of outgoing trash can be bothersome.

Consumers who take an active and informed role in their treatment tend to cope and adjust best. Although the pros and cons of all treatments should be weighed carefully by you, your family and doctors, for many the scales tip in favor of peritoneal dialysis.

Home Hemodialysis

Ted Latour

All hemodialysis patients start treatments in a clinic or hospital, but you do not have to continue there. You can choose to do hemodialysis at home with your own machine, known as "home hemo." When most people talk of home dialysis, they mean peritoneal dialysis. But you can use a hemodialysis machine at home just like those used in clinics.

In home hemodialysis, the clinic provides a two- or three-month training program for you and your spouse, family member or other person committed to being your care provider. This person becomes your own dialysis technician. Then the clinic loans you a machine and usually delivers a new one to your home. Your home must have a source of water and a drain close to

where you put the machine. This could involve installing a washing machine connection box with a cold water tap and drain in a bedroom wall, or faucet connections on a nearby sink. Your home must also have sufficient electrical power and outlets, although the power demand is low. Medicare will cover most costs incurred from making a house or apartment fit for a kidney machine.



Delores Carter tries to keep busy during dialysis at the Mount Sinai Dialysis Center.

A monthly visit to the clinic is required for several reasons. You turn in "run sheets" so the clinic can bill Medicare and other insurance companies in the normal way, without forms or special requirements. These sheets also let the medical team see how your treatments are going. You pick up supplies such as needles, bicarbonate, EPO, heparin, etc. And you give a blood sample for monthly chemistries, which is the only time you are stuck with a needle beyond the dialysis sticks. During the visit, you also have the opportunity to meet with your treatment team. The clinic staff is always available for questions, machine problems, emergency help and backup in case your "tech" is sick or away from home. The clinic arranges for a biohazard service to pick up used needles and other waste from your home.

The benefits of home hemodialysis include a much greater sense of freedom and self determination than in a clinic setting because you can set your own schedule.

On a more personal level, a closeness usually develops with your "tech," who is a loved one or special friend. The psychological support is important, with the closeness and bonding that develop when both of you need and assist each other.

Home hemodialysis allows for greater flexibility. With home hemodialysis, transportation is not a problem. You have control of the TV and thermostat. The chair and bed are your own. EPO is administered at home in the blood lines as usual, eliminating numerous trips to the clinic and duplicate needle sticks. You can easily lengthen the treatment time, if you wish, for example, to finish a movie or simply to feel better, without delaying the next waiting patient. (You may want to check with your physician about lengthening treatments if you feel you need to.) And you use a new dialyzer, or kidney, each time with no reuse. Medicare and the clinic benefit from less overhead, salary and utility costs. The facility also has the ability to treat more patients without having to expand physical facilities for growing dialysis populations.

There are also some negatives involved in home hemodialysis. The most important is the requirement of a dependable partner at home who is committed to be your caregiver. Many patients have no partner, or live with someone who is not willing or able to assume the responsibility. Home hemodialysis requires you or your partner to spend a small amount of time mixing the bicarbonate solution before each treatment, and cleaning and disinfecting afterwards, but this is usually less than the commuting and waiting times for clinic treatments. And some patients feel a strong need for social support from fellow patients, which is more available in a clinic than at home.

One other significant disadvantage is the need for training and experience for both the patient and the caregiver. New patients are just starting on the learning curve. Most new patients do not even know what questions need to be asked unless prompted by medical professionals. So start in a clinic and stay in one until you really understand what happens. That point is the ideal time to switch to home hemodialysis. **FF**

Check with your health care team to learn more about these treatments and which may be right for you.

People Like Us, Live!



“Your kidneys aren’t functioning well...you have a condition called ‘end stage kidney failure’ that may require dialysis treatment or kidney transplant.”

What went through your mind when you heard these or similar words? Perhaps you asked yourself, “What’s going to happen to me?...How will I survive?...What about my family, my job, my life?” Maybe you believed your doctor was wrong—certainly he must have you mixed up with someone else. Were you angry, fearful, depressed, insecure or confused about what to do and who to talk to?

Many kidney patients and their loved ones experience these emotions as they face tremendous obstacles imposed by kidney disease. It is important that kidney patients and their families have resources where they can get essential information about their disease and treatment options in order for them to make vital decisions about their disease and treatment. Studies show that feelings of fear, anxiety, stress and depression are reduced with proper education. Patients who are adequately informed about their condition and treatment options generally feel more in control of their lives and less dependent on others.

The National Kidney Foundation (NKF) has developed many patient education programs under what is called the “Family Focus” banner. Any NKF patient education program under the “Family Focus” banner is designed with the idea that patients and families are the most important members of the health care team, and that they need to be informed about their disease and treatment options in a clear, simple, and unbiased manner so they can make vital decisions that affect their quality of life.

One of the “Family Focus” programs offered by the NKF is called People

Like Us, Live! (PLUL!). PLUL! was adapted from the highly successful Patient Education Program provided by the Missouri Kidney Program, and has been offered in many areas around the country since 1995. The purpose of PLUL! is to educate patients and families about kidney disease and treatment options so they are more able to take an active role in choosing a treatment that is best for them. Patients and families also learn how to live, and live well, with kidney disease.

Topics included in the PLUL! program are: Introduction to Kidney Disease and its Treatment, Hemodialysis, Peritoneal Dialysis, Transplantation, Good Nutrition, and Coping and Other Lifestyle Issues. Each of the six topics is covered in a 1 ½ -hour presentation.

All PLUL! classes are provided by a team of experts, both professional and patient presenters. The patient presenters are individuals currently on treatment; they have already gone through the experience of diagnosis and choosing the best treatment for themselves. The patient presenters share with class participants their unique perspectives about why they chose their particular treatment, its advantages and disadvantages for them, and other related issues.

The success of PLUL! is well documented. Eighty-five programs have been offered across the country since 1995, with well over 1,000 kidney patients and their family members participating. Participants gained new knowledge as a result of attending these programs. In addition, all participants rated these programs as “excellent.” Comments about PLUL! include:

“Excellent! A well thought out program. We were happy to be a part of this.”

“Patients and family members seemed to leave with more of a sense of control and not so much apprehension.”

“The PLUL! Program did assist in making us aware of what to expect when we started dialysis.”

“The PLUL! program was excellent!”

Without a doubt, patients and their family members have benefitted from participating in the People Like Us, Live! program. For more information about this and other “Family Focus” programs, call your local NKF affiliate, or the National Kidney Foundation at (800) 622-9010. 

THE GOALS OF PLUL! ARE TO:

- ☛ **Provide unbiased information about available treatment options to individuals not yet on treatment, thus helping them to make well-informed choices**
- ☛ **Provide education to individuals who are already receiving treatment and may be interested in changing treatment or increasing their knowledge**
- ☛ **Reduce anxiety, fear, misinformation and stress**
- ☛ **Provide a forum for questions and discussion**
- ☛ **Work toward making daily activities easier for patients**
- ☛ **Provide an environment and support system that will help people adapt to living with kidney disease**
- ☛ **Provide education for health care staff who are new to a dialysis or transplant facility**

Speaking From Experience

by Bill Coleman

Eighteen years ago, six weeks before my first child was born, I went on dialysis. There were many questions that I should have asked, or at least questions that I might have asked more directly had I been in the proper frame of mind. My baby is now a young woman about to start college in the fall and my younger child is finishing ninth grade. My nephrologist was right that I could live a quality life on dialysis and that I would live to see my children grow up.

After twelve years and nine months on dialysis, I had a transplant. While for me the transplant is the better option, it is not or cannot be the option for some. Dialysis can work, but you as the patient must take it one day at a time and take control of your life and your treatment. As a first step, it is essential to learn as much as possible about kidney failure, treatment options and ways to assess and improve your quality of life on dialysis.

Don't be afraid to ask **any** question that you may have. If you, your family or friends have a question and don't know or understand the answer, the question is not silly. You should address your concerns, whether they relate to dialysis, coping with long-term illness or financial issues, with your nephrologist, nurse, dietitian or social worker.

Remember, you are not alone in having questions and concerns. There are over 260,000 other people with ESRD with similar questions and concerns. You should also remember that your condition may not be the same as the person who dialyzes next to you. Specific medical advice should come from the renal care team.

What follows are some of the questions and thoughts that I've had over the years, and the answers I came up with. I share them with you because you may have similar questions. I also urge you to discuss them with your care team, family and friends.

Im scared! Im angry! Why did this happen to me? A normal reaction. I found it was best to express these fears and anger and not hold them in.

Why don't you give me something to make me well? The answer is that they wish that there was something, but there isn't, and we as patients just have to get beyond that point and deal with it.

What! You mean that I have to stay on dialysis the rest of my life? The reality is difficult. My answer was to live one day at a time.

How can I fit dialysis time into my life? I have other things to do. You deal with it, you have to.

If I don't feel well, I can skip a few treatments, can't I? No, sorry the answer will never be yes, no matter how you ask it. My wife has a shirt that says "just what don't you understand about no?"

What happens if I decide not to go on dialysis? You will eventually die if you do not receive either dialysis or a transplant.

Do I have a choice not to go on dialysis? Yes. It is your decision whether to go on dialysis. You should seek all information possible regarding the benefits of dialysis, the burdens that you may experience, and the prognosis if you do not go on dialysis. You may, but certainly do not have to, discuss this with your nephrologist, health care team and family. Additionally, you may wish to discuss this matter with a spiritual or ethical adviser.

If I am uncertain whether to start dialysis and want to try it to see how it works, can I do that? It is your right to ask for a trial to see how you adjust to dialysis. A normal trial should be 30 to 60 days, depending upon your medical and emotional condition. You need to give it enough time for your condition to stabilize and to determine whether the treatment is effective and tolerable for you. In making a decision

after the trial, you should consider whether to continue with the selected treatment, change to an alternative means of dialysis treatment, attempt a transplant, or whether you should withdraw from treatment, knowing that death will be the result.

If you were me, what type of treatment would you choose? This is a question that should be asked of your nephrologist who knows and understands your particular medical situation. You should also be very involved in this decision, as you know yourself best.

Can I do dialysis at home? Both hemodialysis and peritoneal dialysis can be done at home. I chose home hemodialysis, and my wife was my partner. I estimate that we did 1,500 treatments at home. It was worth it. We dialyzed when we wanted to or could, given that we both worked. I stayed on extra time when I ate or drank too much. It gave us much more flexibility than in-center dialysis. I will admit that burnout after 10 years affected both of us. We needed the change that the transplant gave us.

May I have a choice of treatments? Units are supposed to give you the choice of all treatments that would benefit you, including hemodialysis, home hemodialysis, peritoneal dialysis in several forms and transplantation. That does not mean that they do this. It is your right to ask about these treatment alternatives and to ask for referrals to another unit that does provide the treatments if your unit does not.

There are many more questions about such important things as your diet, coping with all of this and the specifics of your treatment. It is important to know that your health care team is there to provide you with information and assistance. All you have to do is ask! 

Dear Family Focus Reader:

The Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) are in the process of developing a practice guideline to provide recommendations to physicians and other health care team members when dealing with issues that relate to the initiation of and/or withdrawal from dialysis treatment. This involves the patient's right not to start dialysis treatment or the decision to stop dialysis at any time.

The group working on this project represents many organizations including the National Kidney

Foundation. As a member of the working group, I'd like to invite our readers' comments and/or experiences in dealing with these topics. Here is your chance to let health care professionals know how you feel these issues should be dealt with. Please send your comments to Cynthia Mulrow, M.D., Msc, San Antonio Evidence-Based Practice Center, ALMD-Ambulatory Care 11C6, 7400 Merton Minter Blvd., San Antonio, Texas 78284. Comments can also be sent by e-mail to rpa@verdict.uthscsa.edu.

Sincerely,

Karren King, MSW, ACSW, LCSW



Good Nutrition

Please Pass (Up) the Salt: Taking a Patient's Perspective

by Marilyn Gammarino, RD, LD

Changing My Diet

Adjusting to a new diet and habits while on dialysis can be difficult, especially for a patient with diabetes. I was happy that my first meeting with the renal dietitian went pretty well. We talked about the foods I like and how my diet would be different now.

I started changing my diet one food at a time. During the first month of hemodialysis, my blood work needed some improvement in the phosphorous department, which meant giving up dairy products. I needed to replace them with other high protein, lower phosphorous meats each day. I agreed to use non-dairy creamer for my cold cereal and I only bought four ounces of cheese at the deli—no tempting blocks of cheese anymore. If I wanted ice cream, I would order only one scoop. Of course, I also started taking phosphate binders after every meal and snack.

Something that really surprised me was the amount of sodium I had been eating. I thought because I never used the salt shaker, that was enough. I really started paying attention to food labels. But what I really had a hard time with was fast foods. Those salty, high potassium french fries smell so good! How would I resist? Well, I agreed to buy a small order once a month without any salt and use only one packet of catsup.

Now I am doing pretty well with my diet. Changing what I like to eat is very hard, but the dietitian has helped me make better choices. She has explained to me how important my diet is to staying healthy and managing my dialysis treatments.

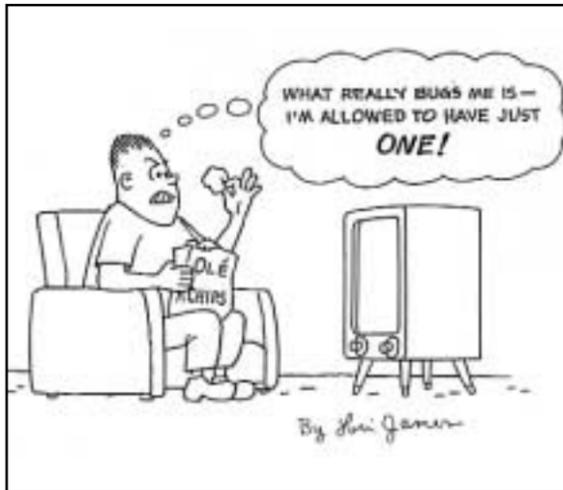
Changing My Treatment

But while my diet was coming along, my treatment was a problem. Hemodialysis just wasn't working out for me. Even though I was feeling great, I was having a lot of problems with clotted accesses. I was talking with my doctor during my yearly care plan meeting about how frustrated I was, when he suggested I might want to consider peritoneal dialysis (PD). The first thing I wanted to know was how it would affect my diabetes and what changes I would have to make in my diet.

I talked with my nurse and dietitian who convinced me to give PD a try. One thing I really liked about this kind of

dialysis was that I would be allowed to eat oranges, bananas, potatoes, tomatoes and spinach (yes, I love spinach), but I would still have to limit salt and phosphorous. The dietitian explained that PD is always removing poisons from my blood, unlike hemodialysis, which does this only three times a week.

I was able to talk with some other patients on PD who have diabetes. They told me they only needed a small amount of extra insulin each day to cover the extra sugar in the PD fluid. Most everyone thought their diabetes was not a problem on PD. One patient told me that the hardest part of her diet was adding extra protein each day.



Before PD she only ate vegetarian-type foods. I knew I was going to like this type of dialysis. I couldn't wait to start traveling and eating bananas!

My Transplant—Changing My Outlook

After three years of waiting for a kidney and only five days in the hospital, I was on my way home with a new transplant. I kept thinking what my days without dialysis would be like. The

doctor said I could eat anything I wanted except, of course, the salt.

Before my transplant, my dietitian and I had talked about some diet pitfalls of other transplant patients. I knew steroids could cause weight gain and an increase in appetite. My cholesterol level was already a little high. My plan was to allow myself a "treat" once a week so that I wasn't feeling deprived. I also knew that if I ate mostly chicken and fish (if they aren't fried), I could help maintain my weight and my cholesterol.

Avoiding the salt was not a real problem for me since I had not used it for years. The meals out have been the hardest. I have learned to ask for foods to be prepared without salt or seasonings, such as plain salads with only oil, vinegar, a little pepper and fresh red onion.

When they told me I could eat dairy products again, I almost flipped. For so long I had to avoid the phosphorous and now I was told my allowance was unlimited. I even have a medicine to take that gives my body extra phosphorous. Even though milk and cheese are allowed, I know they contain lots of saturated fats and calories, so I'm trying to avoid them as much as possible.

Wow, all of the things your healthy kidneys do for you are really amazing. I am so lucky to have gotten this transplant. Sure, I'll splurge the first few weeks with some of those forbidden foods I haven't eaten for years. After that I am going to do my best to eat healthy and start exercising. I am so thankful for my new kidney. **F**

Marilyn Gammarino is a dietitian at Total Renal Care in Rockville, Maryland.

CAJUN SEASONING

Enjoy this spicy seasoning adapted from the National Pork Board's recipe for pork tenderloin. You can adjust the "heat" by adjusting the cumin and cayenne. Make up a batch and use with chicken breasts or pork tenderloin, try sprinkling on popcorn after a light buttering, or use to season toasted, buttered bread.

3 tablespoons paprika
1/2 teaspoon cayenne
1 tablespoon garlic powder
2 teaspoons oregano
2 teaspoons thyme
1/2 teaspoon ground pepper
1/2 teaspoon cumin
1/4 teaspoon nutmeg

Mix all seasonings together. Rub surface of two pounds of pork tenderloin or chicken lightly with oil or use oil spray. Cover surface with seasoning blend. Bake uncovered at 350 degrees for 45 minutes for pork, 25 minutes for chicken. Makes 4 to 6 servings.

Reprinted with permission from the National Pork Board.

Focus on Exercise

by Susan Carey, MS

You may be hearing more and more about the importance of exercise, as the dialysis community is becoming more aware of the benefits of exercise for people on dialysis.

WHY EXERCISE?

The benefits of exercise are well documented. You may already know that regular exercise can help to reduce your risk of cardiovascular disease by enhancing your blood pressure control and improving your lipid profile (increasing HDL cholesterol by reducing triglyceride levels). Exercise can also make your quality of life better by decreasing anxiety and depression and giving you the muscular strength and endurance to do those things that you enjoy the most.

These are the general benefits everyone can expect from an exercise program. However, there are other benefits of exercise specifically related to people on dialysis. Dialysis treatment may allow you to change your diet to include an increase in protein intake. Protein is the substance our bodies need to build muscle. If you are inactive and are not using your muscles, you will soon lose them. Exercise and proper diet, then, play an important role in maintaining muscle mass and strength. Participating in weight-bearing exercise not only builds muscle, but may also help keep your bones strong and healthy. Exercises such as walking may help to slow the development or progression of renal osteodystrophy. And for diabetics, exercise will also help improve glucose regulation.

People on dialysis who participate in regular exercise often state that they are able to tolerate their treatment better. They do not feel as exhausted after treatment and are able to do more activities on their dialysis days because they feel better. Others find that exercise helps to maintain their desired body weight. For people who are awaiting a transplant and have been advised by their doctors to lose weight, exercise can help to shed those extra pounds by increasing the number of calories burned. And many people find that stretching exercises help reduce stiffness and tightness felt in the neck, shoulders and back that can occur from sitting in the treatment chair.

Most important, however, is the sense of control that can be achieved by exercise. Exercise may be one of the few aspects of your health care that requires that you take the initiative. It

empowers you to control a portion of your well-being.

WHAT & HOW?

To achieve the most benefit from exercise, a complete aerobic program should be started. This would include some form of endurance (or aerobic) activity, stretching exercises and strengthening exercises.

Endurance activities include those that use large muscle groups in a rhythmic manner and can be sustained for increased periods of time. These would include walking, bicycling, swimming, aerobic dancing, jogging, cross-country skiing and the like. Bicycling, swimming or water aerobics are good exercises for people with bone or joint problems, as weight-bearing activities may aggravate the problem.



There are also various exercise machines designed for endurance exercise. In order to get the benefits of endurance exercise, some form of endurance activity should be done a minimum of three days per week, gradually working yourself up to doing at least 30 minutes each session. You may only be able to start with five minutes of walking, but just continue to add two to three minutes to each exercise session until you work your way up to your goal. You may even want to try to exercise twice a day if you are only able to tolerate short bouts of exercise. Just remember, the key to success is to start slowly and progress gradually.

Strengthening exercises improve your ability to lift, push, carry or simply get around by increasing your muscular strength. These should be done two to three times per week on non-consecutive days. Stretching exercises help you to increase your flexibility, making it easier for you to reach, bend or stoop. They are easy and should be done daily.

WHEN & WHERE?

Most people on hemodialysis find that it is easier for them to do endurance exercise on their non-treatment days because they feel

stronger. However, others find that they are able to tolerate exercise even on their treatment days if they do it beforehand or a few hours after treatment. You know your body the best, and if exercise is only possible on the days you do not receive treatment, that's okay. You will still be able to get the minimum of three days per week that is recommended.

Strengthening exercises also seem to be better tolerated on non-treatment days when you are feeling stronger. Because the stretching exercises are easy to do, they can be done easily every day. You may want to make a point of doing them before and after treatment to help relieve the stiff, sore muscles that may develop from sitting in the treatment chair.

Many hemodialysis clinics are now providing exercise bicycles at the unit so that patients may exercise during their dialysis treatments. Most patients tolerate this well and find that it helps to keep blood pressure stable, may decrease cramping and makes the time pass more quickly. Look around your unit for an exercycle and ask if you can begin using it during treatment. If there is not one in the unit, ask the staff if the facility could get one. Generally, most people find that cycling within the first hour and a half of treatment is comfortable and enjoyable.

YES, YOU CAN!

Being on dialysis doesn't mean that you shouldn't exercise. It actually gives you even more reason to exercise! Moderate exercise will allow you to maintain your stamina and strength so that you will more easily be able to continue doing those activities that you enjoy most. Just because your doctor or nurse has not told you that you should exercise does not mean that you should not. They just may not know that you are interested in doing so. Be sure to ask your doctor about exercise. Chances are he or she will be very supportive of your taking control of your well-being. If you simply start slowly and progress gradually you find that YES, YOU CAN!

*Check with your physician before starting an exercise program.

For additional information, refer to the NKF brochure "Staying Fit With Kidney Disease." To get a copy, call the NKF at (800) 622-9010.

Susan Carey is an exercise physiologist at the University of California, San Francisco. 



MAIL BOX

Dear Editor:

I'm writing this letter in response to your asking readers of *Family Focus* to relate our experience of having a family member who was or is on dialysis. Until my husband's kidneys failed due to complications of diabetes, I had not thought much about the treatment one way or another. Soon, though, I was about to embark on a very extraordinary emotional learning experience through my husband, Bob's, illness.

When his kidneys failed I took him to Ogden, Utah, to get him started on dialysis. We live across the Utah border in Burley, Idaho, which is a $2\frac{1}{2}$ -hour drive. After getting him started on dialysis, we had to find the nearest unit to our home in Idaho. There is a unit in Jerome, Idaho, which is almost an hour in distance. Now that doesn't seem far, but when there's a blinding snowstorm and icy roads, it just as well may have been a hundred miles. We did what we had to do. Our morning started at 4 a.m. (three days a week) to be there by 6 a.m.

I had no idea what my dear husband was experiencing personally, with his illness and treatment, although I was going through the motions to get him there. Slowly but surely though, I was beginning to feel a greater love and respect for him. I also love and have as much compassion for the other people who were there for treatment. They became my friends.

Bob was a very active man before his illness. He was a farmer all his adult life. Birds and animals were his whole life, second only to his family. It was difficult to give up some of his farming operation, but he did, without looking back.

Bob also made friends at the Jerome unit. Those dear people raised his spirits as we joked and laughed and reminisced about the "good ol' days."

I grew to love him more dearly as time went on. Bob was an inspiration to his family and friends. His example of enduring through hard times until the end will stay with me forever. We were married 42 years. We have five children and 17 grandchildren. Bob passed away April 29, 1995 at the age of 70.

I praise all the workers everywhere who work in dialysis units. Without them and the machines, there would be no life for the people who need these life-saving units.

Julia B. Brown
Burley, ID

Dear Editor:

My daughter's name is Shelly Jean Garza, and she is 22 years old. She had a kidney transplant in March 1990. It functioned well for two years, but in the summer of 1993, she had the donated kidney surgically removed. She has been on dialysis since then. She feels good 80 percent of the time; she goes to school, drives, has a boyfriend and loves to shop. She is an inspiration to me and amazes me all the time with her courage, strength and ability to go on after being through so much. She has adapted well, considering she has a disease that will not get better, but can only be controlled. Shelly hopes the future will bring better results to new kidney recipients. Your newsletter is very interesting and educational as well. I read it all the time. Keep up the good work!

Jean Garza
Corpus Christi, TX