

ESRD NETWORK 13

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Peritoneal Dialysis as a First Therapy

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<http://www.homedialysis.org>

When your kidneys fail, the job of dialysis is to help you live longer, feel well, and have a good quality of life. You may have one or more transplants in your life with kidney failure, and try more than one type of dialysis. You can also switch treatments if one you choose does not fit your life. So, which one should you try first?

With peritoneal dialysis (PD), you can:

- Keep your remaining kidney function longer
- Improve your chance of getting a transplant
- Keep your job more easily
- Start Medicare coverage right away
- Care for your children
- Learn the treatment quickly—and regain control of your life
- Get a fistula placed so you're ready for hemodialysis if you ever need it

You should be very involved in the decision of which type of dialysis to do, as it has a huge impact on your lifestyle. In this article, we'll explain each of these reasons why PD may be a good first choice treatment—if it will otherwise suit your needs, health, and lifestyle.

How PD Works

PD is a self-care treatment. It uses the sac that lines the abdomen, called the *peritoneum*, as a filter to clean your blood. In training, you learn to put *dialysate* (cleansing fluid) into your peritoneum through a soft, plastic *catheter* (tube) that is placed in your abdomen or chest by a surgeon. Wastes and excess water slowly flow into the dialysate.

You drain out used dialysate and replace it with fresh

a few times each day. This process is called an *exchange*. You can do exchanges by hand—at breakfast, lunch, dinner, and bedtime—or with a cyclor machine at night while you sleep. Since your blood never leaves your body, no needles are used for PD.

Most people can do PD. You may not be able to if you have had abdominal surgeries, or if you don't have a clean, dry place in your home to store the bags of dialysate. You will need to come for clinic visits once a month for a check up and blood tests. You'll need to keep pets out of the room and control the air flow when you do an exchange. And, you must care for your catheter and do each exchange with care to avoid infection.

Preserve Kidney Function Longer with PD

In most cases, kidneys don't lose 100% of their function when they fail—at least not right away. Having some residual kidney function (RKF) can help you to feel better, have fewer diet and fluid limits, and live longer. In fact, one study found that each 1% of GFR (kidney filtering) you keep cuts your risk of death in half.

PD may help you maintain RKF longer than standard hemodialysis* (HD). It is vital to do CAPD just as you are taught and avoid *peritonitis* infection, though. Peritonitis can cause a *faster* loss of RKF.

RKF does tend to drop over time. If you choose PD, your RKF will be checked with a 24 hour urine test quite often until you don't make urine any more. Your PD dose will need to be adjusted as your RKF drops.

*HD should be done with biocompatible dialyzer membranes and ultrapure dialysate to maintain RKF.

PD Improves Chance of Transplant

If you plan to get a kidney transplant, PD may be good news for you. A study of more than 252,000 adult U.S. dialysis and transplant patients found that people on PD were about 50% more likely to get a

transplant than people on in-center HD. This was true even though the same number of people in both groups were listed for transplant.

PD is an excellent 'bridge' to transplant, because you do the treatments yourself. With a transplant, you will need to take a number of drugs correctly. Doing PD shows the transplant team that you can handle responsibility and will care for a transplant well.

PD is Work-friendly

How old are you? Each year, half of all new dialysis patients are under 65, or "working-age." Yet, fewer than 1 in 4 keep a job after they start treatment. For many, this means taking Social Security Disability, which pays only about 35% of what they earned before.

Job loss can push a family into poverty. But standard in-center HD, which is done by 91% of U.S. patients, is not work-friendly. To keep a job on in-center HD, you need a very understanding boss, a flexible work schedule, and a dialysis slot that fits your work times. You may miss work because you feel "washed out" for hours after a treatment or have other symptoms.

PD is work-friendly. You can do an exchange at work or use a cyclor at night, so your days are free for work. Some patients do not even tell their employers that they are on dialysis, and they live a rather normal life. It is easy to travel on PD. And, because PD is very gentle and going on most or all of the time, you won't have ups-and-downs in how you feel from day to day—so you may miss less work. Among more than 163,000 working-age people with kidney failure, people who chose PD or had a transplant were significantly more likely to keep their jobs than those who did in-center HD.

Keeping a job may also mean keeping an employer group health plan (EGHP). An EGHP will pay first for your first 33 months of PD. This means you should have fewer out-of-pocket costs to pay for (and more income to do it with).

Medicare Starts Sooner with PD

There is another plus of PD—or any form of home dialysis. You can get Medicare to cover your treatments in the first month if you start home training before the 3rd month. With in-center HD, on the other hand, Medicare will not kick in until the first day of your *third* month of treatment. The dialysis bills can really add up for you in those first three months, especially if you don't have other insurance.

PD Makes Parenting Easier

If you have very young or even school-aged children, there will be days when an in-center HD schedule will simply not fit your life. A child can become ill in the middle of the night and need to stay home from school or daycare. There may be a play, band concert, or sports event that you would have to miss because it's on a treatment day. It can be hard — and costly — to find child care for school days off, vacations, and summer break.

The beauty of PD is the flexibility to fit with your needs. With PD, you can shift your exchange times a bit if you need to, so you *can* go to those special events with your child. If you use a cyclor at night, an extra-long tubing set will allow you to reach your child if he or she has a bad dream or a stomach ache.

Children can and do get used to a parent doing dialysis—it just becomes another part of life.

PD is Easy to Learn

PD is easy to learn and to do. In most cases, you can learn it in a week or two, with a PD nurse on call 24 hours a day for your questions. You don't need a partner for PD, unless you can't lift the bags of dialysate. If your hands or eyes don't work well, you may also prefer to do PD with a helper. There are assist devices, though, and people who are blind can and do perform PD alone.

Learning to do your own treatments puts you in charge of your life—it gives you back the control you lost when you found out you had kidney failure. And, feeling in control improves quality of life for people on dialysis. A study of more than 4,000 patients found that a sense of personal control also significantly increased the chance of living longer *and* of getting a kidney transplant.

Fistula First

Even if you choose PD, a day may come when you must switch to HD. To do HD, you will need a *vascular access*—a way to get the blood to the artificial kidney and back to your body. The "gold standard" type of access is called a *fistula*. It is a direct link between your own artery and vein, made by a surgeon. Fistulas are best because they are your own tissue; they are least likely to get blood clots or infections, and they can work well for decades.

Choosing PD first can allow you time to get a fistula placed and have it ready to go, just in case. This is important, because it means you may be able to avoid a *central venous catheter* (CVC)—a tube placed into a central vein in your neck or chest. It's

best to not to have a CVC; they have a very high risk of blood infection. In fact, a study of more than 5,500 people on dialysis found that patients who had a CVC were 54%-70% more likely to die than people who had a fistula.

Medicare believes that fistulas are so vital to the health and quality of life of people on dialysis that they started a "Breakthrough Initiative" called **Fistula First**, in which the whole kidney community has come together to be sure that more fistulas are done.

Conclusion

You need to choose a treatment that will fit into your life, and allow you to feel your best. If it will work for you, PD can be a good choice as a first treatment for kidney failure.

This article does not necessarily reflect the views and opinions of ESRD Network 13. You are encouraged to discuss your health care questions with your medical professionals.

**Kidney End-of Life Coalition
has a new Web site**

www.kidneyeol.org

Please help spread the word.

Compare Drug Plans Tool

Kidney Medicare Drugs Awareness and Education Initiative

The Kidney Medicare Drugs Awareness and Education Initiative has developed a **Compare Drug Plans packet**. Information on coverage, tiers, and limits in the packet is based on data posted in the Medicare Prescription Drug Plan Finder and Formulary Finder databases on www.medicare.gov. Medicare updates these databases monthly on the first Monday of the month. The Compare Drug Plans packet was revised effective April 5, 2006 and can be found at www.kidneydrugcoverage.org/choose.htm. This packet includes a Frequently Asked Questions on how drugs and plans were chosen, search tips, and two charts that allow you to search for what drugs a specific plan covers (by plan) and what plans cover a specific drug (by drug).

We hope that the updated Compare Drug Plans packet will save you time when seeking information on drug plans. Look for other labor-saving tools, educational materials, resources or links, and much more on www.kidneydrugcoverage.org.

Ingenuity The Mother of Invention

Joe Allen Williams

My name is Joe Allen Williams, age 61, and my experience with ESRD started in 2000 when a doctor asked me if I was aware that I had poor kidney function and my kidneys had been failing for years. This was a total surprise to me. I had been going to doctors for high blood pressure and none of them could tell me why my blood pressure was high. None of the doctors had mentioned kidney failure. The doctor told me that my entire medical records for the past 15 years showed declining kidney function. He suggested I attend a renal clinic at the Oklahoma University Medical Center in Oklahoma City. It was at the clinic I learned I had polycystic kidney disease (PKD) and would be on dialysis within a year's time.

Polycystic kidney disease is an inherited disease, although I do not know anyone in my family ever having it. It is a disease that causes cysts to form in the kidney and eventually causes kidney failure.

I started dialysis in March of 2001 in Oklahoma City and was informed I was a candidate for peritoneal dialysis (PD). I started PD training in April 2001 and chose to dialyze with a continuous cycle peritoneal dialysis machine or CCPD. This type of dialysis requires a catheter be placed into the abdomen for access to your peritoneum. A little over one foot of this catheter protrudes from the abdomen, and it is very important to keep it clean and secure at all times. I started out taping the catheter to my body, but the glue from the tape collected dirt and debris, which created a haven for germs, a PD patient's worse enemy. It came to me that there was a problem with what to do with the catheter when you were not using it. My sister made me a very nice belt out of denim, but it fell down around my hips and was bulky under clothes. Finally, I came upon an idea of using women's panty hose legs as a catheter belt. I just cut the legs off, tie the ends and cut a small hole to slide the catheter into. You can trim the knot and it is hardly noticeable that you are wearing it. You can mark the access hole with tape or fingernail polish for ease in locating it. I found this type of belt keeps my catheter clean and secure. The hose come in many colors and it is inexpensive enough that you can keep plenty on hand for convenience. They can be showered in and can be laundered. I suggest that anyone use the coarse hose as it works best and lasts longer. This simple idea solved my catheter problem and I've used it now for almost five years. "A positive thinker and inventor patient from Oklahoma."

Free Patient Education Materials

The non-profit Medical Education Institute, Inc. (MEI) reminds everyone that free chronic kidney disease (CKD) materials are available for your education.

Free materials from the Life Options Program can be downloaded or ordered at <http://www.lifeoptions.org>. These booklets, fact sheets, newsletters, video and audiotapes, and posters--based on research with thousands of people with CKD--provide valuable information about how to live long and live well with kidney disease.

Also available for free is Kidney School, <http://www.kidneyschool.org>, an interactive kidney learning center tailored to meet the needs of patients and families. Written at the 7th-9th grade level and loaded with information on topics like treatment options, diet, coping, sexuality and fertility, and much more, Kidney School's 16, 30-minute modules attract more than 10,000 unique visitors a month. Kidney School is available 24 hours a day without log-in or registration, and all of the modules can also be downloaded.

Did you know that dialysis can be done at home? It's true--and home patients have fewer diet and fluid limits, more freedom and flexibility, and are better able to keep their jobs. MEI provides free information on user-friendly home treatment options on Home Dialysis Central, <http://www.homedialysis.org>. Visitors can learn about home treatments, compare pros and cons, read real-life patient stories, find a nearby center, and talk with home patients and professionals.

The Medical Education Institute, Inc. is a non-profit, 501(c)3 private foundation dedicated to helping people with chronic diseases learn to manage and improve their health. For reliable, unbiased information about CKD, you can turn to the MEI. To learn more, call 608-833-8033, email info@meiresearch.org, or visit <http://www.medicaleducationinstitute.org>.

Establishment of the Medicare Beneficiary (Ombudsman's Open Door Forum)

The Centers for Medicare & Medicaid Services (CMS) announces the establishment of the Medicare Beneficiary Ombudsman's Open Door Forum (ODF). Daniel J. Schreiner, the Medicare Beneficiary Ombudsman, coordinates with CMS to oversee beneficiary concerns including appeals, complaints, grievances and requests for assistance.

The Medicare Prescription Drug Improvement and Modernization Act of 2003 (MMA), Section 923, <http://www.cms.hhs.gov/MMAUpdate/downloads/PL108-173summary.pdf>, mandated the creation of the Medicare Beneficiary Ombudsman position to ensure that people with Medicare get the information and help they need to understand their Medicare options and to apply their rights and protections.

The Medicare Beneficiary Ombudsman's ODF will provide an opportunity for beneficiaries, their caregivers and advocates to publicly interact with the Medicare Beneficiary Ombudsman to discuss issues and concerns regarding ways to improve the systems and processes within the Medicare program.

Each ODF will focus on one or two specific topics, at the Ombudsman's discretion, based on issues that advocacy groups and others bring to his attention. CMS subject matter experts will participate in the ODFs to give status and engage in discussion on key issues, as appropriate.

To subscribe to the new ODF's listserv, visit <http://www.cms.hhs.gov/apps/maillinglists/default.asp?audience=4> and follow the instructions. Listserv subscribers will receive notifications of the first and subsequent Medicare Beneficiary Ombudsman's ODFs and other communications from the Ombudsman.

For more information on the Medicare Beneficiary Ombudsman's role and responsibilities, read the press release, ***CMS Hires Medicare Ombudsman Dan Schreiner to be "Voice" for Medicare Beneficiaries*** (March 22, 2005), at <http://www.cms.hhs.gov/apps/media/press/release.asp?Counter=1393>.

As The Hot Weather Approaches

Heather Powell

Summer is just around the corner. When it is hot outside, you may find yourself tempted to drink more. With the fluid restrictions we have, that can be a problem. Our fluids are restricted for a purpose and if you have ever "drank" too many fluids then you know what I am talking about. When we consume too much fluid, not only do our nurses fret...our bodies do too. You may experience puffy eyelids, shortness of breath, high blood pressure, and swelling in your feet and ankles. Even if you don't experience these symptoms, your body knows it and it IS affected. If you have a tendency to drink more than you are allotted often, you should know that it is hard on your heart and lungs. It can also make

dialysis unpleasant when you have a lot of fluid to pull off.

Let's discuss about some tips to avoid "drinking" too much. You can:

- * Keep a mist bottle handy when outside and spray yourself
- * Eat chilled applesauce or freeze your favorite fruit (be aware of high potassium)
- * Eat crushed ice (it counts as fluid, but it lasts longer)
- * Limit your sodium, high sodium makes you thirsty
- * Brush your teeth or rinse with chilled mouth-wash
- * Drink beverages ice cold: use a smaller cup, fill it with ice, then add your beverage
- * Suck on lemon wedges or hard candy or chew gum
- * Wear clothes that breathe and freeze a bandana to wear around your head

Know your measurements: 1 ice cube = 1 oz.,
½ cup = 4 oz., 1 cup = 8 oz., 4 cups = 32 oz. or
1 quart, 1 gallon = 4 quarts or 16 cups.

It is helpful to remember that some foods count as liquid: soup, Jello, pudding, popsicles, ice cream, salad dressing, gravy, many fruits and vegetables. Don't forget to count them in your fluid allotment. Staying within your fluid limit will help you to fill better and make your dialysis run more smoothly.

Recipe on Cranberry Sparkle.

A punch that is good for you and very refreshing.

Cranberry Sparkle

1 quart cranberry juice cocktail, chilled
4 ounces frozen pink lemonade concentrate, thawed
12 ounces ginger ale

Mix cranberry juice cocktail and lemonade in container. Add ginger ale just before serving.

Serves 12 (4 oz each)

Nutritional Information: Protein: 0.1 g, Sodium: 8 mg, Potassium: 42 mg, Phosphorus: 5 mg

"Exercise: it will improve your life"

Heather Powell

Exercise is a word that generally brings about groans and thoughts of dread, but the benefits of exercise are undeniable. We all need it, yet we make excuses as to why we can't do it. You may not feel like doing it, don't want to do it, or don't care about doing it. Guess what- that is one of the best reasons in the world TO exercise. The truth is it will help you TO FEEL BETTER and give you MORE ENERGY. Let's look at some of the numerous benefits that exercise

has for our mind, bodies and soul.

Ten (10) Benefits of Exercise:

- Help you to sleep better
- Improve your physical functioning in day to day activity
- Build up muscle strength
- Help control blood pressure and anemia
- Allow you to lose excess weight or maintain a healthy weight
- Lower cholesterol levels
- Reduce your risk of heart problems
- Combat depression and improve your mood
- Give you a sense of satisfaction
- Make you feel good about yourself.

Ten (10) Reasons for Exercise:

1. Who can argue the benefits, they speak for themselves
2. The fact is that everyone can benefit from a little exercise. Research says that people who regularly work and condition their muscles gain strength and energy.
3. Have you ever heard the phrase "use it or lose it", it is true for your muscles. A muscle that is not being used on a regular basis loses its strength.
4. The heart is a muscle; exercise will help your heart to be healthier and stronger.
5. Improved strength improves your immune system.
6. Your body becomes stronger with exercise and thus it is better prepared to fight off illness and infection. When you do get ill, your recovery time is better.
7. The less illness and infection you have; the fewer hospital stays you will have and fewer missed workdays.
8. Exercise releases your bodies natural "feel good" chemicals.
9. The more energy and greater strength you have, the more you will feel like socializing with friends and family.
10. You will reap rewards from exercise that you can't even imagine.

Ten (10) Tips to get you started:

- **Check** with your doctor for an exercise plan that's right for you
- **Start** out slow
- **Be consistent**, 2-3X a week is recommended for at least 30 min.
- **Increase** time as appropriate
- **Get** an exercise buddy for encouragement and accountability

- **Do** something you enjoy: water aerobics, walking, bicycling
- **Think** realistically and don't get discouraged
- **Plan** it into your schedule
- **Choose** an exercise place for convenience and affordability
- **Wear** comfortable clothes and get a good pair of shoes

I challenge you to get started and see the benefits for yourself.

MEDICARE Consumer Alert

Medicare Beneficiaries Urged to be on the Lookout for Phone Scams

The Centers for Medicare & Medicaid Services (CMS) warns seniors and people with disabilities to be aware of a scheme that asks Medicare beneficiaries for money and checking account information to help them enroll in a Medicare Prescription Drug Plan.

This scheme is called the "\$299 Ring" for the typical amount of money Medicare beneficiaries are talked into withdrawing from their checking accounts to pay for a non-existent prescription drug plan. Consumers can report these cases to their local law enforcement agencies or 1-877-7SAFERX (1-877-772-3379).

Medicare has received complaints from Indiana, Michigan, Pennsylvania, Massachusetts, New Jersey and Georgia. Complaints have been made against a number of different companies, but authorities believe that the companies are the same and are typically based outside the U. S. As soon as CMS receives these complaints, they are investigated and referred to federal law enforcement authorities.

No Medicare drug plan can ask a person with Medicare for bank account or other personal information over the telephone. No beneficiary should ever provide that kind of information to a caller. They should contact their local police department if they believe someone is trying to take money or information from them illegally.

People with Medicare should also remember that they should be on the lookout for anyone trying to take advantage of them and take steps to protect themselves by remembering:

- * No one can come into your home uninvited.
- * No one can ask you for personal information during their marketing activities.
- * Always keep all personal information, such as your Medicare number, safe, just as you would

a credit card or a bank account number.

- * Whenever you have a question or concern about any activity regarding Medicare, call 1-800-MEDICARE.

In addition, legitimate Medicare drug plans will not ask for payment over the telephone or the Internet. They must bill the beneficiary for the monthly premium. Typically, that amount is set up as an automatic withdrawal from the beneficiary's monthly Social Security check. Beneficiaries may also opt to pay the monthly premiums in other ways such as writing a check or setting up automatic payments from their checking accounts.

Dialysis Facility Compare

Where do you go when you need information on other dialysis facilities? You ask what unit offers peritoneal dialysis or home dialysis, do you know whom to contact? You need evening dialysis due to your job, could you tell what unit offers evening hours? You want to compare your facility's quality measures with the units in your area, is there a place to go to find this? Now you can. The Dialysis Facility Compare (DFC) Web site www.medicare.gov provides both demographic information and 'quality measures' data about dialysis facilities that have been approved by Medicare.

What are the three quality measures?

- ✦ The percent of patients at a facility with Urea Reduction Ratio (URR) of 65 or greater (known as 'adequacy of hemodialysis').
- ✦ The percent of patients treated with Epogen® with a Hematocrit of 33 or greater. (URR and Hematocrit are based on 2002 data).
- ✦ Patient survival information. The survival data is based on the period from January 1999 to December 2002.

The Web site also offers the dialysis facility characteristics.

- ✦ Address and telephone number of the facility
- ✦ The facility's initial date of Medicare certification
- ✦ Shifts starting at 5 PM or later (if you need your treatments in the evening)
- ✦ The number of treatment stations
- ✦ The types of dialysis offered (in-center hemodialysis, peritoneal dialysis, and home hemodialysis training)
- ✦ Facility ownership type (profit or non-profit)
- ✦ Chain name (if applicable)

AAKP Release Brochure on Peritoneal Dialysis Option

TAMPA, Fla. – The American Association of Kidney Patients (AAKP) is pleased to announce the release of its newest educational brochure – *Understanding Your Peritoneal Dialysis Options*. The brochure is part of AAKP’s “Options” series, which provides information on dialysis treatments available to kidney disease patients.

Understanding Your Peritoneal Dialysis Options discusses the peritoneal dialysis process from start to finish, including how a dialysis access is placed, how it should be properly cared for, and the benefits and drawbacks of each type of treatment. An overview of each treatment option is provided along with a description of how dialysis is performed.

The brochure also features a Self-Assessment Tool, which includes 10 questions a potential patient should answer and take to their physician to help decide if peritoneal dialysis may fit into their health and lifestyle needs.

AAKP created this brochure to inform and educate current and potential dialysis patients and their loved ones. AAKP would like to thank Baxter Healthcare Corporation for its generous support of the development and distribution of this brochure.

For more information or to order complimentary copies, contact AAKP at (800) 749-2257 or info@aakp.org. The brochure is also available to download at www.aakp.org.

AAKP is the voluntary, patient organization, which for more than 35 years, has been dedicated to improving the lives of fellow kidney patients and their families by helping them deal with the physical, emotional and social impact of kidney disease. The programs offered by AAKP inform and inspire patients and their families to better understand their condition, adjust more readily to their circumstances, and assume more normal, productive lives in their communities.

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☆☆ **Sign up for Part D Medicare by May 15, 2006** ☆☆
☆☆ **to avoid paying a penalty on your premium.** ☆☆
☆☆ **See your social worker or State Health** ☆☆
☆☆ **Insurance Assistance Program for Help.** ☆☆
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☆☆ **Arkansas: 800.224.6330** ☆☆
☆☆ **Louisiana: 800.259.5301** ☆☆
☆☆ **Oklahoma: 800.763.2828** ☆☆
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What Are My Options If I Have A Grievance?

STEP 1
Try your facility first...
Contact your facility’s social worker...
Ask for and follow the facility’s written grievance procedures...
If not satisfied...

STEP 2
Contact the Network...
Ask for the Patient Grievance Policy...
Visit our Web site for a copy of the policy...
Speak with the person in charge of Patient Services.

What is a grievance?
A grievance is any concern about treatment in a dialysis or transplant facility.

A grievance may be filed by the patient, a family member, or another person acting on the patient’s behalf (per Health Insurance Portability and Accountability Act (HIPAA) guidelines).

Grievances referred to the Network are processed according to written grievance procedures.

What is the Network?
Network 13 is under contract with the Centers for Medicare & Medicaid Services to serve the states of Arkansas, Louisiana, and Oklahoma. The Network collects patient information and works to improve patient care in dialysis and transplant facilities. Processing written grievances and trying to resolve patient concerns is an important part of the patient services program.

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Kidney Concern 04/2006

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**KIDNEY
CONCERNS
NEEDS YOU!**

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for **Summer/July**. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

Kidney Concerns

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