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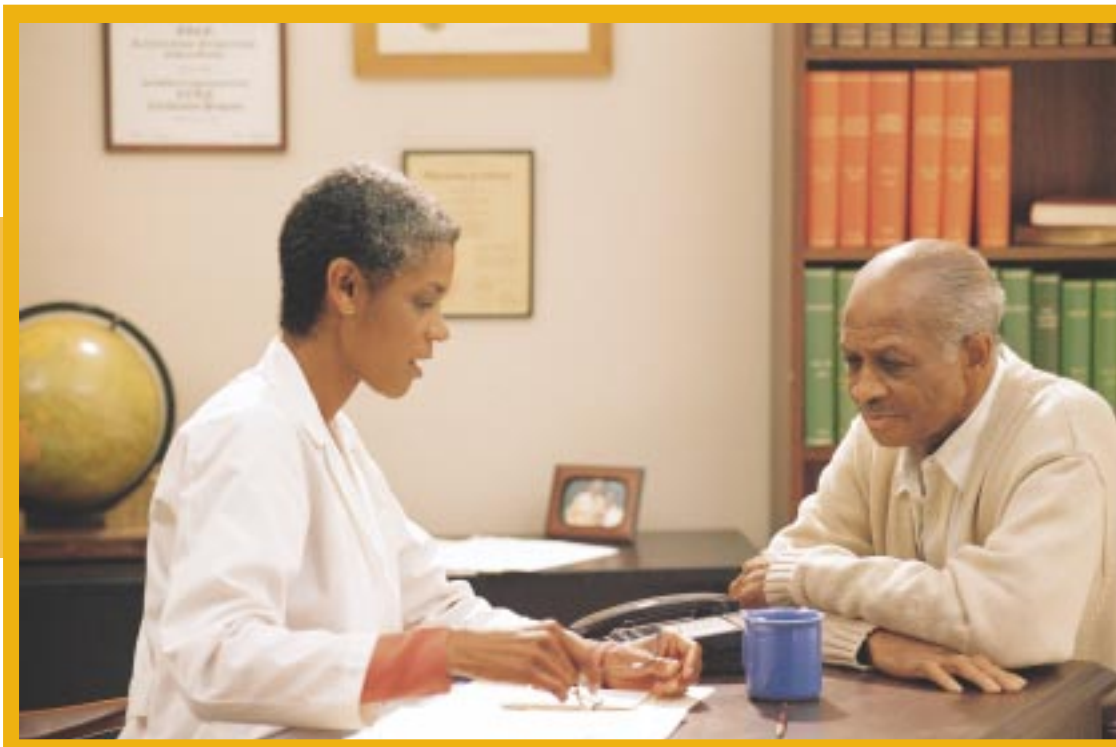
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HOME HEMODIALYSIS

Have You Ever Considered Home Dialysis?

By Bobbie Knotek, RN, BSN, CNN

Your training nurse will review all aspects of home hemodialysis with you.



- Would you like to:*
- Have more control over how chronic kidney disease (CKD) affects your life?
 - Spend more time at home with your family?
 - Schedule your dialysis treatments around work, school or other activities?

If you answered yes to these questions, you might want to consider learning how to do hemodialysis or peritoneal dialysis at home.

There are three types of hemodialysis (HD) treatments and two types of peritoneal dialysis (PD) treatments that can be done at home. All HD and PD treatments remove waste products and extra fluid that build up in kidney failure, but the number of hours per treatment and the number of treatments per week will be dif-

ferent for each type of dialysis because each removes waste products and extra fluid from the blood at a different speed.

The three types of home hemodialysis are:

- **Standard hemodialysis**—four to five hour treatments, three times per week
- **Nocturnal hemodialysis**—eight to 10 hour treatments, three to five times per week
- **Short, daily hemodialysis**—two to three hour treatments, five to seven nights per week

The two types of home peritoneal dialysis are:

- **CAPD**—four to five fluid exchanges during the day
- **CCPD**—four to 10 fluid exchanges during the night (using a machine)

What are the advantages of home dialysis?

- 1) Fewer trips to the dialysis clinic. Unless you have a special problem that has to be watched closely, you will probably only need to make monthly visits to the clinic for checkups.
- 2) You can arrange dialysis treatments around your life. You still need to dialyze the prescribed number of days and hours, but you get to pick the days and times.
- 3) You can dialyze in the privacy of your home. You decide such things as if and when you want visitors during dialysis and when you eat your meals.
- 4) Many people feel better on home dialysis because they have more control over their life and their treatment.

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This publication is a part of the National Kidney Foundation's Kidney Learning System (KLS)™ and is made possible through an educational grant from **AMGEN**.

This issue of *Family Focus* will highlight several different modes of treatment that have at least one thing in common—each of them can be done in the comfort of your own home. You will learn about the different ways you could perform either hemodialysis or peritoneal dialysis without visiting the dialysis center except for regular clinic visits.

When first faced with the prospect of beginning dialysis, it is not unusual to be frightened. The fear of the unknown is a very natural and logical reaction. This fear applies to the concept of dialyzing anywhere, including the dialysis center where trained staff is available to you. When a health care professional offers the option of performing dialysis either alone or with the assistance of a helper, usually a family member, it is again a very common response to feel even more frightened by the idea of dialyzing at home. However, after exploring this option with the staff, one realizes that a person must be thoroughly trained by the facility's home dialysis staff and will not dialyze at home until both the person requiring dialysis, their helper, if appropriate, and the staff feel that the individual(s) is absolutely competent and comfortable with whatever form of home dialysis has been selected. It also helps

to know that the staff will be available 24 hours a day to all who dialyze in their homes.

There was a time when many more people were on home dialysis. In the earlier days of dialysis, there were fewer dialysis facilities. As a result, if someone lived far from a facility, and most were located in urban areas, the only other dialysis option was to perform it at home. Home hemodialysis was the only form of home treatment available until the 1980's. When peritoneal dialysis was first available, the only form of chronic treatment offered to most people was Continuous Ambulatory Peritoneal Dialysis (CAPD). Although home treatment options have continued to increase over time, the number of people who chose any form of home dialysis began to go down as more and more dialysis facilities opened throughout all areas of the country.

Home dialysis offers many advantages, although—as with all things—it may also have disadvantages. All people who are either facing dialysis or are already on dialysis have a responsibility to look at all of



Karren King

the advantages and disadvantages from their own personal perspectives. What is a positive treatment option for one person may not be the best for another.

However, only 49 percent of them were offered CAPD, 27 percent were offered home hemodialysis and 23 percent were offered automated peritoneal dialysis. If those findings are an accurate reflection of what is happening in the United States, it should not be surprising that only a small percentage of those with CKD actually dialyze at home.

It is our hope that this issue on home dialysis will be enlightening and informational whether someone is just beginning to consider dialysis options or has been receiving dialysis for many years. It is never too late to learn, as well as make changes should you decide that a form of home treatment is for you!



*Karren King, MSW, ACSW, LCSW
For the Editorial Board*

It is the right of all individuals with chronic kidney disease (CKD) to have every treatment option for which they are medically suitable offered to them. *Family Focus* conducted a survey of its readers in 1995 to learn about the factors affecting their treatment choices. Of the 844 who responded, 83.6 percent reported that center hemodialysis had been presented to them as an option before they began dialysis treatments.

CORRECTION

In the Winter 2005 issue, the byline for the article entitled "Speaking Up For Your Good Health" was printed as being authored by Mary Beth Callahan, ACSW, LICSW. This was an editorial error and the article was actually authored by Mark Meier, MSW, LICSW. We apologize to Mr. Meier for the error.



Mark Meier, MSW, LICSW is the Consumer Services Coordinator for the Renal Network of the Upper Midwest, Inc., of St. Paul, MN.



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Home Dialysis...

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They learn how to assess and/or prevent health or dialysis-related problems (for example, people on home hemodialysis tend to have fewer blood pressure drops during their treatments because they are watching their blood pressure closely).

- 5) People on nocturnal hemodialysis or short daily hemodialysis often have fewer diet restrictions. When your kidneys are healthy, they clean waste products from your blood 24 hours a day, seven days per week (for a total of 168 hours of “cleaning time” per week). Unlike healthy kidneys, however, standard dialysis only gives 15 hours of “cleaning time” every week. This is why people on standard hemodialysis have strict diet and fluid restrictions. People on nocturnal hemodialysis, however, get 24–48 hours of “cleaning time” per week and those on short daily hemodialysis get 2 ½–3 hours of “cleaning time” on a daily basis.
- 6) There are usually fewer problems with your fistula or graft because the same person inserts needles every time and knows your access.
- 7) There is more freedom to travel with peritoneal dialysis.

What would I learn during home dialysis training?

That depends on the type of home dialysis you choose, although everyone on home dialysis learns to:

- Take blood pressure and pulse
- Set up a safe dialysis treatment room (or area)

- Control fluid and diet
- Care for the dialysis access
- Order and store dialysis supplies
- Keep treatment records
- Learn how to fix dialysis problems, including machine alarms (for CCPD and HD), low blood pressure and gaining too much fluid.

How many people in the United States do home dialysis?

Most of the people in the United States with CKD go to dialysis clinics for their dialysis treatments. Less than 10 percent of the people do peritoneal dialysis and only 1 percent do home hemodialysis.

Why don't more people choose home dialysis?

- Many people never get education from their doctor about the full range of treatments available for people with CKD. Because they are never told about anything besides in-center hemodialysis, they do not know it is possible to do dialysis at home.
- Not every dialysis facility has a home dialysis program. Facilities that do not have home dialysis programs may not encourage home dialysis.
- At the current time, Medicare does not reimburse dialysis facilities for the cost of daily dialysis. Medicare will only pay for three HD treatments per week. Sometimes Medicare will approve payment for a fourth treatment.
- People are often nervous about doing dialysis at home. When talking about home dialysis, people with CKD often say:
 - “I am afraid to put needles in my fistula or graft for hemodialysis.”

- “There is too much to learn— I am not smart enough to learn home dialysis.”
- “What happens when I have problems during a home dialysis treatment?”

It is normal to have concerns and fears when starting home dialysis training. By the time home dialysis training is done, however, people are almost as good at putting in needles and handling machine problems as the dialysis staff. It is also reassuring to know that home dialysis clinics provide these services to those who are on home treatment: a) a treatment team that consists of the kidney doctor, social worker, dietitian and home dialysis nurse; b) home dialysis staff available or on call 24 hours a day for dialysis medical problems and c) back-up dialysis at the outpatient dialysis center in case you have machine problems or get too sick to do dialysis at home.

How can I find out more about home dialysis?

- Tell your kidney doctor, nurse or social worker you are interested in home dialysis and ask for more information.
- Go to www.kidney.org (National Kidney Foundation Web site)
- Go to www.homedialysis.org (Home Dialysis Central Web site)
- To find home dialysis clinics that are Medicare certified to offer training, go to Medicare’s Dialysis Facility Compare at www.medicare.gov and follow these steps:
 - 1) Look for “Search Tools,” then, click “Compare Dialysis Facilities In Your Area.”
 - 2) Search for dialysis clinics near your city. Type in the name of the city and state and how many miles outside the city you wish to look.
 - 3) Choose home hemodialysis or peritoneal dialysis.

You will get the names, addresses and phone numbers of the home dialysis training facilities in your area.

DID YOU KNOW that if you have CKD, you have the right to:

- **BE TOLD** about ALL treatment options for CKD, including kidney transplant, peritoneal dialysis, in-center hemodialysis and home hemodialysis? (This is a Medicare law.)
- **BE EVALUATED** for home dialysis?
- **BE GIVEN** the names and phone numbers of clinics that offer home hemodialysis or peritoneal dialysis training (if your clinic does not offer this service)?
- **TRANSFER** to another clinic for home dialysis training and follow-up if your clinic does not offer the kind of home dialysis you choose?

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letters to the editor

Dear Editor,

Kudos to *Family Focus* for the themes you are choosing to highlight in your publication. Patient empowerment and home dialysis are two concepts that, when implemented, have the ability to significantly shape people’s lives for the better. This year, I celebrate 30 years of dialysis. Half of that time has been at home; first on CAPD and for the past two years on nocturnal home hemodialysis. From those first few months as a teenager, I understood that I must take responsibility for the management of my health care needs. I learned very quickly that I have the most invested in the quality of my care, thus the imperative to take action. This seemingly obvious statement is highly challenging to communicate to both patients and professionals.

Thank you for doing your part to enlighten others.

Best regards,
Judy Weintraub, MS Ed
Los Angeles, CA

Dear Editor,

I am on peritoneal dialysis and needed to find a way to hold the peritoneal catheter in place. I bought ladies’ tube tops and wear one around my stomach. It sits nice and snug over the catheter. I do not have to worry about the exit site being exposed or having something pull on the catheter. I thought this idea might help others. My dialysis nurse has passed this tip on to several other people in her care.

Julie Murphy

Julie Murphy receives her dialysis care in Ardmore, OK.

WHEN CHRONIC HEMODIALYSIS first began in the late 1950's patients were treated for 24 hours at a time a few days a week. Over the next several years treatments were shortened, so by the 1970's most were on dialysis for four hours three times a week. Even though the original, longer treatments were very effective, they were inconvenient for both those on dialysis and caregivers and were very expensive. In the late 1970's and 1980's a few kidney doctors in Europe tried to restart more frequent, longer dialysis. These trials were usually practiced as part of a research trial or were paid for by private funding. Dialysis was performed at home or in-center for eight to 10 hours, three to five times a week. These programs were all eventually discontinued either for financial practical, or social reasons. This type of therapy was more expensive due to the greater use of the dialysis machine and use of more dialysate, and the therapy was more labor intensive either for the in-center staff or for the caregiver if the treatment was practiced at home. Success came in the early 1990's when Dr. Uldall and Dr. Pierratos from Canada started their nocturnal dialysis (dialysis at night) program. They are currently the most experienced in the world with this therapy and have been providing it for over 10 years to more than 90 individuals with kidney failure.

SINCE NATIVE KIDNEYS FUNCTION 24 hours a day, seven days a week, Drs. Uldall and Pierratos felt that more frequent, longer dialysis would allow people on dialysis to feel healthier and live more normal lives. However, those on dialysis also needed free time for such things as work and being with their families. Thus, the idea of long-time overnight dialysis was born.

Nocturnal Hemodialysis

By Mary Gellens, MD

Nocturnal hemodialysis can be an ideal dialysis option for some.

ALTHOUGH MORE AND MORE CENTERS in the United States—approximately 50—now offer nocturnal dialysis, there are usually only a few individuals using it in each center. There are currently about 140 patients in Canada on nocturnal dialysis and about 200 in the United States. There is no national registry for this type of therapy, so the actual numbers are



not known. Since nocturnal hemodialysis is performed while the person is asleep, this constitutes an entirely different kind of therapy than regular in-center dialysis. Extensive training of the person on dialysis and the nephrologist are required, careful attention to safety is necessary and the cost is higher than standard hemodialysis and Medicare does not reimburse for the extra treatments performed per week. Many people with chronic kidney disease are not interested in the therapy because of the extensive training required.

NOCTURNAL HEMODIALYSIS is usually done six or seven nights a week for about eight hours each night while the person sleeps. The dialysis machine is usually in the

home, but some centers practice in-center nocturnal hemodialysis. If it is done at home, it is helpful to have a partner there. The partner usually does not participate in the therapy, but if there is an emergency where the individual on dialysis is unable to get to a phone, the partner could perform that task. Although some programs require that a partner be present, it is not required by all programs. Some programs also monitor the dialysis session over the Internet, but this is becoming increasingly less common. Several centers have shown that remote monitoring is not necessary because people are so stable during the treatment they do not need to be monitored. Practicing dialysis six days a week for eight to 10 hours per treatment provides for very slow fluid removal. Therefore, there is minimal, if any, hypotension (low blood pressure) and no need for continued monitoring during treatment.

Also, if there

are any machine or flow problems the machine will stop and alarm.

Finally, remote monitoring is an additional expense not

covered by Medicare. The individual who will do nocturnal dialysis follows an extensive six-week training program for about five or six hours a day during their chronic dialysis treatments three times a week. All aspects of dialysis therapy are taught, including cannulation (putting needles in your

access), setting up and taking down the machine and troubleshooting when problems arise. All aspects of the water system, which provides the dialysis solution to the dialysis machine, are also explained.

BLOOD PRESSURE is only recorded at the beginning and end of treatment by the person on dialysis. Weight or fluid gains between treatments are usually small so there are typically not problems with low blood pressure. In addition, low blood pressure is often avoided with longer treatments and slower fluid removal in nocturnal dialysis. For these reasons, there is no need to check blood pressure during treatment.

INDIVIDUALS WHO PRACTICE nocturnal therapy usually eat a regular diet without fluid restriction. Since nocturnal dialysis treatments are much longer and much more frequent than traditional dialysis, more fluid and waste products are removed per week, allowing for a very liberal diet. Most people on this form of treatment no longer take phosphate binders, since there is adequate phosphate

removal with dialysis. Many patients stop their blood pressure medicines because of better fluid control.

Restless leg syndrome, that constant jumping and involuntary contraction of the leg muscles, also often goes away due to better control

of uremia. Quality of life is often much improved, with more energy and better sleep because the patient's blood pressure is more stable. People on nocturnal dialysis have more time for other activities since dialysis is only at night.

Quality of life is often much improved, with more energy and better sleep.

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THE DECISION TO BEGIN KIDNEY REPLACEMENT THERAPY for a child with kidney failure is a clinical decision made by the health care team. However, the type of kidney replacement therapy to use is a team decision that includes input from the child and his or her family. The available treatment options are hemodialysis, peritoneal dialysis and transplant. This article will focus on home peritoneal dialysis (PD) as kidney replacement treatment for children with kidney failure (CKD Stage 5).

PD became available as a home therapy for children with kidney failure in the early 1980's. Since that time, because of improved technology, PD has become more user-friendly. PD is managed by the child with CKD and his or her family at home. This type of dialysis takes place inside the abdominal cavity (belly) using the peritoneal membrane, which lines the abdomen, as a filter. The dialysis process consists of several "exchanges." The exchange begins with dialysis fluid entering the abdominal cavity through a small plastic tube (a PD catheter), which has been surgically placed, usually as an outpatient procedure. The "fill" process only lasts a few minutes and is followed by a "dwell" phase, during which time the fluid stays in the cavity. It is during this "dwell" phase that the filtering process takes place, clearing the blood of waste products and extra fluid. Once the dwell period is complete, the fluid is "drained" from the cavity through the same PD catheter into a drain bag. The exchange process is repeated many times over 24 hours to imitate some of the functions of a normal kidney.

There are two types of PD: Continuous Ambulatory Peritoneal Dialysis (CAPD) and Automated Peritoneal Dialysis (APD), which includes continu-

ous cycling peritoneal dialysis (CCPD). CAPD consists of four exchanges (draining "old" fluid from the peritoneal cavity followed by draining new fluid in) done manually over 24 hours from the time the child wakes up until the time he or she goes to sleep. There is usually a six hour dwell time between exchanges. Each new exchange takes about 20 to 30 minutes. APD uses a small cyclor machine about the size of a VCR to do the exchanges, approximately four to six exchanges over eight to 10 hours while the child sleeps.

Family education for home PD covers all of the necessary information to ensure that the caregiver(s) is comfortable managing the treatment at home.

There are many advantages over center hemodialysis to either CAPD or APD for children and their families. The two main advantages are freedom from a set schedule and the ability to do dialysis at home rather than traveling to and from a dialysis center. CAPD and APD may be done on a flexible daily schedule, making it possible for the child to attend school on a regular basis and participate in everyday activities. Children on PD

Home Peritoneal Dialysis For Children

By Barbara Case, RN, CNN

Learn the facts about home PD for your child with CKD.

are able to bike, swim and enjoy non-contact sports. In addition, PD requires few if any dietary restrictions, a plus in optimizing caloric intake to achieve optimal growth. This home therapy is free of needles and pain. Therefore, the fear element is quickly removed once the child understands that PD is a painless procedure, and if using APD, that it typically occurs while he or she is asleep. Since PD equipment is portable, traveling is easier. From a clinical standpoint, PD is a good kidney replacement therapy because it occurs 24 hours a day, seven days a week, and therefore works in a way that is similar to the body's own kidneys.

Once the decision is made to begin PD, outpatient surgery will be scheduled to place the PD catheter. In most cases after surgery, dialysis is not done for one week to allow healing and to begin PD training. Family education for home

PD covers all of the necessary information to ensure that the caregiver(s) is comfortable managing the treatment at home. Programs may vary from one center to another, but training usually includes five to 10 sessions with the PD nurse. The child is assigned age appropriate jobs to help, and is encouraged to take an active role in his or her treatment.

In conclusion, it is important to remember that home peritoneal dialysis is a great treatment option for children with kidney failure. The most important feature is that it allows the child to remain at home with his or her family and be part of the family environment on a day-to-day basis.

Advantages of Peritoneal Dialysis:

- Flexible schedule
- Liberal diet
- Needle-free
- Can attend school regularly
- Easier travel
- Participation in non-contact sports and other activities

Barbara Case, RN, CNN, has been a pediatric nephrology nurse at the Johns Hopkins Hospital in Baltimore, Maryland for 20 years.



PATIENT & FAMILY COUNCIL'S MESSAGE BOARD!

If you have chronic kidney disease, are on dialysis, have a kidney transplant, or are a family member, friend or health care professional, we invite you to share your stories and experiences, network and get support from others.

Follow the simple instructions below and you will be there in no time:

Go to: www.kidney.org



Select a topic:
Message Boards and Chats

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IF YOU ARE CONSIDERING HOME DIALYSIS, one of the things you might want to think about is diet. This article will briefly review the types of home dialysis and the best diet for each type. There are two types of peritoneal dialysis (PD): continuous ambulatory peritoneal dialysis (CAPD) and continuous cycling peritoneal dialysis (CCPD) or automated peritoneal dialysis (APD). There are also three types of home hemodialysis: conventional home hemodialysis, daily home hemodialysis and nocturnal home hemodialysis (1).

PD uses the lining of your abdomen, called the peritoneum, to filter fluid and wastes out of your blood. About two liters of fluid, called dialysate, is placed into the peritoneal cavity (belly) through an abdominal catheter and allowed to remain for a period of time. During this time wastes and extra fluids travel from the body into the dialysis solution and are then removed when the solution is drained. This process, called an exchange, is done several times a day. It can be done manually using gravity (CAPD) or with a machine (CCPD or APD) called a cycler that typically does the exchanges while you sleep (2).

Both CAPD and CCPD have the same diet restrictions. During PD, protein and waste products are lost with each exchange, so protein needs to be replaced. The high protein diet is needed to build, maintain and repair body tissues. High-quality protein such as eggs, chicken, fish and lean red meats should be eaten at each meal (3).

Potassium, a mineral in many foods, is more liberal or less strict in PD compared to in-center hemodialysis (HD). In PD, potassium leaves the body and needs to be replaced daily. Too much or too little potassium in your body can be dangerous

Diet Comparisons in Home Dialysis

By Valerie Wong, RD

One of the keys to successful home dialysis is following the proper diet.

and harmful to your heart. Although potassium is found in salt substitutes, fruits and vegetables, milk, meat, chocolate and nuts, fruits and vegetables are the best choices for keeping potassium in the normal range. Many on PD are able to eat an orange, half of a banana or one tomato daily to keep their potassium in normal range. Milk, chocolate and nuts are high in phosphorus and salt substitutes are not recommended. (3).

For people on PD, fluids and sodium restrictions are more liberal. Moderate intake of fluid can help improve dialysis and flush out wastes.

Sodium, a mineral that can affect your blood pressure, is found in table salt, canned foods and processed, pickled and cured foods. It is usually best to limit table salt and salty foods to prevent too much fluid weight gain, which can cause high blood pressure and heart trouble.

Phosphorus, a mineral found in milk, cheese, nuts, dried beans, lentils, peas and corn products, is limited in PD. You need to take phosphate binders with each meal to remove phosphorus from foods eaten. Calories give your body energy. Most of your calories come from the foods you eat, but with PD the sugar in the dialysate gives you more calories. Your body takes in the sugar and can cause weight gain (3).

Conventional home HD, similar to in-center HD, is done three times a week but at home. The diet, equivalent to in-center HD, is limited in terms of one's intake of sodium, potassium, phosphorus and fluids (1).

Daily home HD consists of two- to three-hour treatments done five to six days a week totaling about 12 hours of dialysis per week. Since daily home HD is done more often, more toxins and fluid are removed. Those on

daily home HD have increased energy levels and decreased use of blood pressure medications. Phosphorus, potassium, sodium and fluid restrictions are more liberal than in-center HD (4).

In nocturnal home HD, treatment is done eight to 10 hours during the night, six to seven nights a week. One of the benefits of nocturnal home HD is there are almost no dietary restrictions. Because phosphorus removal is improved, many people can stop taking phosphate binders and are encouraged to eat more phosphate and dairy products. Since dialysis is done nightly, there is usually no fluid, sodium and potassium restriction. Appetite is also improved due to better and frequent removal of toxins and wastes. (5, 6, 7) Daily home HD and nocturnal home HD are offered in limited clinics in the United States, Canada and Europe. Studies have shown

many benefits and few disadvantages (6, 7, 8). Currently, the Federal Government reimburses dialysis facilities for three treatments per week. Some private insurance companies may cover extra treatments. For nocturnal and daily HD treatments to be used on a larger scale, the Federal Government and Congress need to develop reimbursement methods that support them.(8)

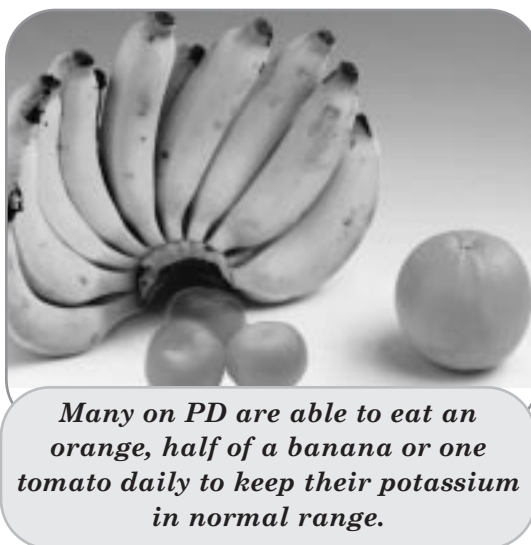
The five types of home dialysis have different dietary considerations to think about. Whatever type of home dialysis you choose, your health care team will continue to be available and serve as a valuable asset to you.

Valerie Wong, RD, has been a practicing dietitian for 17 years. She currently works as a renal dietitian specializing in PD at an outpatient facility in Fresno, CA.

References

- Types of home dialysis. www.homedialysis.org/v1/types/index.shtml
- Kidney Directions: Choices. www.kidneydirectins.com/us/patients/choices/periton/twotypes.htm
- National Kidney Foundation A to Z Health Guide, Nutrition and Peritoneal Dialysis. www.kidney.org/atoz/atozprint.cfm?id=97
- Curtis, J: Daily short and nightly nocturnal home hemodialysis: state of the art. *Dialysis & Transplantation* 33:2:64-71, 2004.
- Hartwell, L. Nocturnal Home Hemodialysis. 2001 <www.ikidney.com/ikidney/Community/Pro2Pro/Clinicians/Printer/NocturnalHomeH
- Frequently asked questions about nocturnal Home Hemodialysis, 2000. www.renalweb.com/guest/lit/mwilliams/FAQs.htm
- Pierratos, A. Nocturnal home hemodialysis: An update on a 5-year experience. *Nephrol Dial Transplant* 14:2835-2840, 1999.
- Pederson, ML: Discussing final wishes: nightly home hemodialysis.
- Aakp. *RENALIFE* 18:6, 2003. www.aakp.org/AAKP/renalife/Art/2003/finalwighes.htm

Family Focus



Many on PD are able to eat an orange, half of a banana or one tomato daily to keep their potassium in normal range.

Self-Care Dialysis—What Medicare Pays

By Roberta Bachelder, MA

What does Medicare cover? For how long?

Your questions are answered here.

IN SPITE OF ALL THAT IS SAID AND WRITTEN about its limitations, the Social Security and Medicare systems in this country benefit many people. In fact, ESRD (End Stage Renal Disease) or kidney failure is the only specific disease that allows a person to receive Medicare coverage regardless of age or receipt of Social Security Disability Insurance (SSDI) as long as he or she is a citizen or permanent legal resident and has worked enough to qualify or can qualify under a spouse's work record. A child can qualify at any age under a parent's work record. When someone first learns they have kidney failure and is facing dialysis or a transplant, they are often worried about how much treatment will cost. It is reassuring to know Medicare will pay for much of the cost of dialysis or transplant.

When starting treatment for kidney failure, doctors should offer all treatment options medically suited to each person's unique health situation and psychosocial needs, including center hemodialysis, transplantation and home treatments—hemodialysis (HD) and peritoneal dialysis (PD). When you are deciding the best treatment choice for you and your family, you may be interested in learning how Medicare pays for self-care dialysis in a clinic or at home.

If you need dialysis or a transplant, you may qualify for ESRD Medicare by having paid into Social Security and earning enough credits. How many credits you need to qualify for Medicare based on your work depends on your age. You earn work credits based on how much you earn in each calendar quarter. Every year the amount you need to earn to equal one credit goes up. You can read more about earning credits and how many you need to get Medicare in the

booklet *How You Earn Credits*. There are two parts to Medicare—Part A and Part B. Part A covers in-patient hospital stays for a certain amount of days after a deductible is met. Part B covers 80 percent of allowable expenses, after meeting a deductible, for a variety of outpatient services, such as dialysis, and physicians' fees if Medicare is responsible for paying first. You or your secondary insurance, such as Medicaid, Medigap or individual health insurance, will be responsible for the remaining 20 percent. If you are covered by an employer group insurance, it must pay first for 30 months that you could have Medicare (whether you chose to take Medicare or not). If you have Medicare during this 30 months, Medicare may pay some charges left after your group insurance pays. When you have Medicare, your dialysis clinic or transplant program must accept what Medicare allows as payment in full and cannot bill you for any charges over that amount for Medicare covered services.

If you qualify for but do not already have Medicare when you start in-center dialysis, your Medicare coverage will not start until the first day of the third full month of dialysis. During those first months, if you have other health insurance, it will be billed. If you have no other insurance, your dialysis clinic will make payment arrangements with you.

However, if you choose to start a self-care in-center or home dialysis training program for either PD or HD in those first months, your Medicare coverage can be backdated to start

the first of the month that your dialysis began. Medicare covers home training charges, the dialysis machine (if needed) and supplies and minor home changes to hook a machine into existing plumbing and electricity. You may have to pay some charges for other changes if needed.

If you choose to do home dialysis (HD or PD), you will be asked to choose one of two Medicare billing options, Method 1 or Method 2. You receive all home dialysis services, equipment and supplies directly from a dialysis facility under Method 1. Under Method 2, all equipment and supplies are delivered to your home directly from the supplier who bills Medicare for them. Your dialysis clinic bills for support services from your nurse, social worker, and dietitian. If you need help understanding these options, ask your home training nurse to explain them to you. Regardless of whether you choose Method 1 or 2, training and ongoing clinical support from your doctors, nurses, social workers and dietitians must be provided by a Medicare certified ESRD facility.

Whether you have chronic kidney disease (CKD) and are not on dialysis or have a transplant or have kidney failure and are already having treatment, you should talk with the social worker at the dialysis center about Medicare coverage of home dialysis. You can also call or e-mail the Patient Services Professional from the ESRD Network in your state to get more information.

NETWORK 1
(CT, ME, MA, NH, RI, VT)
Phone: (203) 387-9332
rbachelder@nw1.esrd.net

NETWORK 2
(NY)
ESRD Network of New York, Inc.
Phone: (212) 289-4524
rrosso@nw2.esrd.net

NETWORK 3
(NJ, PR, VI)
Phone: (609) 490-0310
jhuhn@nw3.esrd.net

NETWORK 4
(DE, PA)
Phone: (412) 325-2250
dmorris@nw4.esrd.net

NETWORK 5
(DC, MD, VA, WV)
Phone: (804) 794-3757
rbova-collis@nw5.esrd.net

NETWORK 6
(GA, NC, SC)
Phone: (919) 855-0882
moneal@nw6.esrd.net

NETWORK 7
(FL)
Phone: (813) 383-1530
ldrossos@nw7.esrd.net

NETWORK 8
(AL, MS, TN)
(601) 936-9260
bdyson@nw8.esrd.net

NETWORK 9/10
(IL, IN, KY, OH)
Phone: (317) 257-8265
kniccum@nw9.esrd.net

NETWORK 11
(MI, MN, ND, SD, WI)
Phone: (651) 644-9877
mmeier@nw11.esrd.net

NETWORK 12
(IA, KS, MO, NE)
Phone: (816) 880-9990
kthompson@nw12.esrd.net

NETWORK 13
(AR, LA, OK)
Phone: (405) 942-6000
pmurphy@nw13.esrd.net

NETWORK 14
(TX)
Phone: (972) 503-3215
rvaldez@nw14.esrd.net

NETWORK 15
(AZ, CO, NV, NM, UT, WY)
Phone: (303) 831-8818
bcampbell@nw15.esrd.net

NETWORK 16
(AK, ID, MT, OR, WA)
Phone: (206) 923-0714
mpederson@nw16.esrd.net

NETWORK 17
(AS, Guam, HI, Mariana Islands, N. CA)
Phone: (415) 472-8590
lalpert@nw17.esrd.net
fryan@nw17.esrd.net

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Good Years on Home Hemodialysis

By George Harper, MEd, EdS

AS I LOOK BACK ON 21 YEARS OF HOME HEMODIALYSIS (HHD), I have to say that I believe it is the dialysis therapy that has the potential to give the healthiest and longest life. Also, I chose HHD because I do not believe dialysis is something I want to outsource to others. Who has the greatest interest in the quality of my dialysis care? I do—the patient. So keeping control of my own treatment has been my goal.

When my kidneys failed in 1980 at age 34 from hereditary kidney disease, I was very glad chronic dialysis treatments were available. I wanted to take full advantage of the opportunity to survive—something my brothers were not able to do because their kidney failure occurred at an earlier time when neither the technology nor the Medicare End Stage Renal Disease (ESRD) program to help pay for dialysis was available. I chose HHD primarily because it allowed me to keep working; I had control of my treatment schedule, which accommodated my job as a school counselor. I considered peritoneal dialysis, but inevitably rejected it due to often high peritonitis (infection) rates. I also considered transplant, but rejected it as well due to the high failure rates of kidney grafts in the early 1980's.

After initially choosing HHD in order to keep working, I later realized it had other benefits. I found that I was better able to control the quality of the treatment I got. I could avoid infections that can be acquired in a dialysis facility, and I was able to avoid the

psychological toll that sometimes happens at an institutional environment. I could do my own needle “sticks,” thus better preserving my fistula (the original one is now 24 years old). I could enjoy using the time on dialysis to eat dinner, read mail and the newspaper and hold my dog in my lap, all in the comfort of my own home. After a couple of years my wife and I even fitted out an RV for dialysis and traveled the country while I dialyzed on the campgrounds.

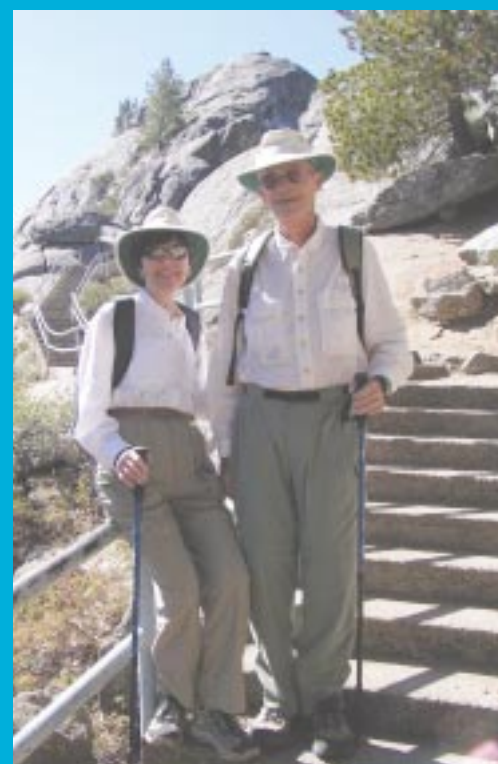
Another important advantage of HHD was the ability to dialyze longer and more often than was offered in most dialysis facilities. As soon as I learned that it is difficult to get too much dialysis and learned of the high mortality rate with too little dialysis, I lengthened my dialysis sessions. I did as much as five hours per session at one time. Later I abandoned the traditional schedule of three times per week and began dialyzing every other day for four hours per session. This schedule not only gave me more total dialysis time, but I also had lower uremic peaks and valleys—I felt less washed out after each treatment. This regimen also allowed me to eat a little more protein and my fluid intake was a little more liberal.

One of the essential keys to most HHD (an exception may be nocturnal hemodialysis) is the availability of a reliable partner to assist with treatments. I am very lucky to have a wonderful wife who devoted herself to helping all these years. Learning to take over the dialysis treatment at home was pretty scary for both of us at first, but mastering it gave us confidence and

allowed us to go on with a good life together. We were fortunate to have a training nurse who was both knowledgeable and supportive. We trained for about eight weeks and learned how to perform safe dialysis. We also learned how to manage emergencies. We were both taught how to stick the access. At first my wife would do one stick and I would do the other, but later I took over all my own sticks.

The first 15 years were pretty much smooth sailing, and I continued working full time while maintaining our yard and doing basic home repairs. After 15 years I started to experience some of the inevitable long-term complications of hemodialysis. I had joint pain and had to have carpal tunnel surgery. I began to feel the wear and tear of so many years of dialysis, but I was getting older too. I was so successful with HHD that old age finally caught up with me!

Three years ago the advances in transplantation, coupled with my long-term complications of dialysis, led me to decide to have a transplant. I have done very well and the joint pain has pretty much resolved. I am certainly enjoying the freedom of wider travel options, and the more liberal diet is also quite enjoyable. But, considering the risks involved with a transplant, and though I believe I am doing better with the transplant, I do not think the difference between good HHD and a transplant is all that drastic.



George and wife Irene hike in Sequoia National Park.

Transplant recipients always live with the possibility of losing the graft. But, if I had to go back to dialysis, there is no question in my mind that I would want to go back to the road less traveled that leads back home—back home to comfort, security, quality, safety and a long survival on dialysis: all the things that HHD can provide. Looking back on it after three years with a successful transplant, it was a good life. We worked, we vacationed in the RV or on dialysis cruises and we led what we considered to be a more regular lifestyle than the other dialysis options offered us. For us, choosing the road less traveled HAS made all the difference.

A retired high school counselor from Rome, Georgia, George Harper currently works as a civil mediator. He was on home hemodialysis for 21 years and has had a transplant for three years. He founded the Georgia Association of Kidney Patients, Inc., and serves on the editorial advisory board of Nephrology News and Issues.

Family
focus

IT WAS A LITTLE OVER TWO YEARS AGO WHEN MY DOCTOR TOLD ME that my kidney function was so poor I would need dialysis. I cried because my health had been steadily deteriorating for some time, and this marked a long feared milestone. The doctor described the types of dialysis available at my center at that time, which were in-center hemodialysis or peritoneal dialysis (PD).

I LIKED THE FREEDOM and personal control that PD offered, so I selected PD. There are two types of PD: continuous ambulatory peritoneal dialysis (CAPD), which requires exchanges of fluid a number of times during the day, and Automated Peritoneal Dialysis (APD), which includes continuous cycling peritoneal dialysis (CCPD), and involves a number of exchanges done continuously and automatically by a “cyclor” machine, usually at night. The flexibility and freedom of CCPD



Eduardo Colmenares

to one and a half hours, and then a drain cycle. Fortunately, I have not had any infections of my exit site or abdominal cavity over the past two years.

AS I GAINED EXPERIENCE with PD, I discovered that I could control my blood pressure by managing the concentration

Eduardo Speaks Out About Peritoneal Dialysis

By Eduardo Colmenares

example, as long as I take my phosphate binders, I can occasionally eat moderate amounts of dairy products, tomatoes and nuts. Again, each person’s diet varies and should be discussed with your doctor and dietitian.

THE ADEQUACY OF MY PD TREATMENTS is easy to monitor, like hemodialysis, with periodic blood tests such as potassium, creatinine and B.U.N. If they are not considered to be in the normal levels for me, the doctor makes changes in my dialysate formula or in my number of exchanges. I visit my kidney doctor every month to monitor my blood and kidney function.

ANOTHER ADVANTAGE OF PD is the portability of the treatment. I can travel and bring my dialysis machine,

GENERALLY, CCPD IS DONE at night while you sleep, so that can be a disadvantage for some. In my case, I am an amateur astronomer, and my therapy has eaten into my available nighttime observation hours. However, PD is an evolving process and I hope improved machines and dialysate will shorten the time required for each exchange. Already I have a new machine that is much quieter, making it much easier and more comfortable to sleep while dialyzing.

TODAY I REGARD PD as a blessing, which makes my long wait for a transplant quite bearable. Some people have chosen to stay on dialysis, as opposed to being on the waiting list for a transplant, and now I can understand why.

Eduardo Colmenares is a retired vice president of a major national bank. He has a BS from the University of California-Berkeley and a MBA from University of Chicago. He currently lives in Chicago.

Family Focus

Some people have chosen to stay on dialysis, as opposed to being on the waiting list for a transplant, and now I can understand why.

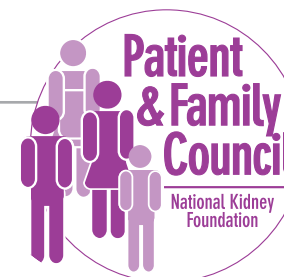
appealed to me, so I chose it. A catheter, through which the exchanges of fluid take place, was placed in my abdomen within just a few weeks. My actual dialysis was started soon thereafter. The therapy was not only painless but it was hard to even notice that fluid was flowing in and out of my peritoneum, or abdominal cavity.

I STARTED WITH TREATMENTS of 10 hours a day, seven days a week, with six cycles of the machine occurring during the 10 hour period. Each cycle consists of a “fill” of dialysate into the abdominal area, a “dwell” time for the fluid in the abdominal cavity of one

of dextrose in the dialysate. I have had high blood pressure for the past 20 years, treated first with one medication, then finally with a combination of drugs. Now, whenever my blood pressure goes up, I raise the dextrose concentration, which effectively dehydrates me without side effects. Of course, any adjustments that you make should be discussed with your doctor first.

CCPD GIVES ME A SENSE of well-being, improves my appetite and gives me more energy. Another benefit is the flexibility of my diet: I have almost no dietary restrictions (I am not diabetic). For

which is comparable in size to an early-model VCR. When you travel with your PD machine, be sure to tell your clinic staff about your plans. If you will be away for a short time, you can take the supplies you will need for treatment with you. If you will be gone for a longer period of time, you can alert your dialysate supplier of the places you will visit and they can have the dialysate solution shipped to your destinations. It is often a good idea to have the solution delivered prior to your visit so that you can assure it has arrived prior to departing on your travels.



To find out about the many services and activities offered in your community or to join the Patient and Family Council at no cost, contact us at

800-622-9010

or visit us at

www.nkfkidneypatient.org

MEMBERS GET FAMILY FOCUS DELIVERED DIRECTLY TO THEIR HOMES

IN 2002, 91 PERCENT OF PEOPLE with kidney failure in the United States did in-center hemodialysis. Only 8 percent did peritoneal dialysis (PD), while less than 1 percent did home hemodialysis (HHD). Most nephrologists (kidney doctors) say they would choose home dialysis if their kidneys failed—and not just because they have medical training.⁽¹⁾ Nephrologists are aware of the positive impact that home dialysis can have on people who choose it, and many believe that home dialysis is used too little. In fact, nephrologists say that survival rates would improve if 25 percent of people on dialysis in the United States did PD and 11 percent did HHD.⁽³⁾

Life Options Rehabilitation Program research has looked at why some patients live for decades on dialysis, while others die earlier. In a study of people who lived for 15 years or longer on any type of hemodialysis, all of the participants were active self-managers of their disease and their treatment. They learned how the treatment worked and how to speak up if something was wrong, how to track their lab tests, what each of their medications was for and how to follow their treatment plans. How did they learn so much? Most had done home dialysis at some point in their lives.

Although any type of dialysis you choose will have a major effect on many areas of your life, taking charge of your treatment is one way to feel in greater control. You may find that the benefits of home dialysis outweigh its burdens for you and your family. This article may help you decide.

TECHNICIANS LEARN DIALYSIS. YOU CAN TOO!

Fear of medical tasks scares some people away from home

A New Look at Home Dialysis: A Psychosocial Perspective

By Dori Schatell, MS and Beth Witten, MSW, ACSW, LCSW

Choosing home hemodialysis can have positive psychological results for you. Read on.

dialysis. But most dialysis technicians have no medical background before they learn dialysis. If technicians can learn to do dialysis, so can you. Dialysis is their job, but it is your life! You will be able to dialyze at home only after your training nurse knows you can handle it. Once home, you will have phone back-up and monthly visits with your doctor, nurse, dietitian and social worker.

You are self-managing every time you do a treatment, take your medications, follow your diet and fluid limits and report symptoms.

SELF-MANAGEMENT AND SURVIVAL

Even if you do in-center hemodialysis and spend 14 hours each week at the clinic, the other 154 hours—92 percent of your time—you are on your own to self-manage your kidney failure. You are self-managing every time you do a treatment, take your medications, follow your diet and fluid limits and report symptoms. Research shows that if you learn a lot about dialysis and take an active role in your own care, you will be more likely to feel better and live longer. Home dialysis is the

highest level of self-management, which may be one reason why people who do home dialysis often live longer.

THE IMPORTANCE OF CONTROL

Independence is a core value in American culture, but one of the first things people feel when their kidneys fail is a loss of control over their lives. Home dialysis gives you control over when and where to dialyze, room temperature, who is present, whether to eat or drink during treatment, how to spend your time while dialyzing and even whether to lengthen your treatment to feel better. You can change your schedule to fit dialysis into your life—and you may have more energy, so it is easier to work full-time. With PD, traveling is easier: you can bring your supplies or have them shipped. People who do PD or longer or more frequent hemodialysis have a much easier diet and fewer fluid limits. In fact, people on daily HHD or nocturnal HHD may even be able to eat a normal diet. Instead of spending time in a clinic, you can spend dialysis time with your own family and friends.

On the other hand, home dialysis has its burdens. Most clinics require HHD patients to have a helper in the home when they dialyze, which can limit a helper's activities. Needing to cope with emergencies, taking deliveries, storing supplies and dealing with machine problems are extra tasks that people on PD or HHD or their helpers need to



Technicians learn dialysis. You can too!

do. Some home dialysis helpers even place hemodialysis needles or do PD exchanges for their loved one. Worried about the burden of home dialysis on your helper? The more you do yourself, the less of a burden your helper will feel. If you choose HHD, you can do back-up dialysis in-center if your helper needs a break.

AVAILABILITY OF HOME DIALYSIS

In 2004, the nonprofit Medical Education Institute launched a new Web site called Home Dialysis Central (www.home-dialysis.org), with the goal of raising awareness and an increased use of home therapies. As of March 2005, the "Find a Center" database on the site lists 1,515 clinics with CAPD; 1,485 with CCPD; 319 with conventional HHD; 46 with daily HHD; and 81 with nocturnal HHD. As new clinics open and others add new home treatments, they add or edit their listing. The growth in clinics offering home treatment provides more choices.

ASSESSING YOUR OWN NEEDS

See if home dialysis would fit into your life. Use the **Patients (P) and Caregivers (C) Checklist** on the next page. The patient and caregiver should each assign 0 (no burden at all) to 10 points (heavy burden) to each item. Add up the points to see which type of dialysis is the best fit

Continued on page 11

A New Look at Home Dialysis...

Continued from page 10

Burdens of Dialysis Checklist

IN-CENTER HEMODIALYSIS			HOME PD (CAPD, CCPD) Home Hemo (Conventional, Daily, Nocturnal)		
<u>P</u>	<u>C</u>		<u>P</u>	<u>C</u>	
<input type="checkbox"/>	<input type="checkbox"/>	Little or no control over schedule	<input type="checkbox"/>	<input type="checkbox"/>	Time needed to train for home treatment
<input type="checkbox"/>	<input type="checkbox"/>	No control over physical setting	<input type="checkbox"/>	<input type="checkbox"/>	Ordering & storing supplies
<input type="checkbox"/>	<input type="checkbox"/>	Getting to/from clinic 3 times a week	<input type="checkbox"/>	<input type="checkbox"/>	Making space for machine (CCPD, HHD)
<input type="checkbox"/>	<input type="checkbox"/>	Time spent waiting for dialysis	<input type="checkbox"/>	<input type="checkbox"/>	Wiring &/or plumbing changes (HHD)
<input type="checkbox"/>	<input type="checkbox"/>	Time away from home for dialysis	<input type="checkbox"/>	<input type="checkbox"/>	Putting in needles or connecting catheter
<input type="checkbox"/>	<input type="checkbox"/>	Time off from work/school for dialysis	<input type="checkbox"/>	<input type="checkbox"/>	Being responsible for doing dialysis
<input type="checkbox"/>	<input type="checkbox"/>	Little/no control over who does needle sticks or provides care	<input type="checkbox"/>	<input type="checkbox"/>	Doing treatments more than 3 times a week (all but conventional HHD)
<input type="checkbox"/>	<input type="checkbox"/>	Living with symptoms during and between dialysis treatments	<input type="checkbox"/>	<input type="checkbox"/>	Staying home during dialysis (HHD)
<input type="checkbox"/>	<input type="checkbox"/>	Very restricted diet and fluid	<input type="checkbox"/>	<input type="checkbox"/>	Living with symptoms during and between dialysis treatments (conventional HHD)
<input type="checkbox"/>	<input type="checkbox"/>	Coping with in-center events (e.g., deaths, needle problems, conflicts)	<input type="checkbox"/>	<input type="checkbox"/>	Very restricted diet and fluid (conventional HHD)
<input type="checkbox"/>	<input type="checkbox"/>	Longer planning time for travel	<input type="checkbox"/>	<input type="checkbox"/>	Troubleshooting equipment (CCPD, HHD)
<input type="checkbox"/>	<input type="checkbox"/>	3-month delay to get Medicare	<input type="checkbox"/>	<input type="checkbox"/>	Alarms at night (CCPD, nocturnal HHD)
<input type="checkbox"/>	<input type="checkbox"/>	Worrying about dialysis emergencies	<input type="checkbox"/>	<input type="checkbox"/>	Coping with dialysis emergencies
_____ TOTAL			_____ TOTAL		

P = Patient

C = Caregiver

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Resources:

Home Dialysis Central
[<http://www.homedialysis.org>]
offers information on five types of PD and HHD, a database of clinics that offer home dialysis, patient message boards, patient stories and more.

Peritoneal Dialysis, National Kidney Foundation (brochure)
Home Hemodialysis, National Kidney Foundation (brochure)

¹ U.S. Renal Data System: USRDS 2004 Annual Data Report: Atlas of End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of

Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2004, p. 365.

² Mendelssohn DC, Mullaney SR, Jung B, Blake PG, Mehta RL: What do American nephrologists think about dialysis modality selection? *Am J Kidney Dis* 37:22-29, 2001.

³ Curtin RB, Mapes D, Petillo M, Oberley E: Long-term dialysis survivors: A transformational experience. *Qual Health Res.* 12:609-24, 2002.

⁴ Curtin RB, Sitter DC, Schatell D, Chewing BA. Self-management, Knowledge, and Functioning and Well-being of Patients on Hemodialysis. *Nephrol Nurs J* 31:378-386, quiz 387, 2004.

About the authors

Beth Witten, MSW, ACSW, LSCSW worked for 18 years as a clinical social worker in dialysis and transplant clinics. Beth serves as resource and policy associate for Medical Education Institute, Inc., staffs the Rehabilitation Resource Center and coordinates Missouri Kidney Program Patient Education Program classes.

Dori Schatell is Executive Director of the non-profit Medical Education Institute, Inc. She has worked in the renal field for 16 years and is Director of the Life Options Rehabilitation Program.



Self-Care Dialysis...

Continued from page 7

NETWORK 18

(Southern CA)

Phone: (323) 962-2020

ctorres-correa@nw18.esrd.net

Other Resources

Medicare at 800-MEDICARE

Medicare Coverage for Kidney Dialysis and Kidney Transplant Services

www.medicare.gov/publications/pubs/pdf/esrdcoverage.pdf

Choosing a Medigap Policy

www.medicare.gov/Publications/Pubs/pdf/02110.pdf

State Insurance Department listed in your phone book

Life Options Rehabilitation Program

www.lifeoptions.org

Employment: A Kidney Patient's Guide to Working and Paying for Treatment

www.medicare.gov/Publications/Pubs/pdf/02110.pdf



The National Kidney Foundation's new brochure *Home Hemodialysis* is available for order by calling 800-622-9010, ext. 175.

Once again, *Family Focus* Voices featured questions that related to this issue's theme, Home Dialysis.

Respondents were asked to share why they had or had not selected a form of home dialysis, as well as if this type of treatment had been offered as a treatment option.

There were 34 total respondents, 20 males and 14 females. Twenty-five of the 34 were offered some form of home dialysis with three informed only about peritoneal dialysis and one told only of home hemodialysis. Eight of the 25 who were educated about a form of home treatment being available to them chose to start treatment on center hemodialysis, while 15 of them selected a home dialysis modality. Eight of those who responded stated they were not given the option of home hemodialysis. One of these individuals sought out information independently, however, and is now on home hemodialysis. Three individuals initially were not offered any form of home dialysis but two of them subsequently have utilized some form of home treatment.

The respondents' reasons for selecting their particular treatments varied greatly. As one individual stated, "I have been taught 'To each their own.' What is right for one may not be right for another." That is the key thing to remember as you read about the factors that

Home Dialysis: Is It Right For Me?

By Karren King, MSW, ACSW, LCSW

influenced treatment decisions. Keep an open but critical mind, and remember that you know best if any of them are relevant for you and your unique situation.

Those who selected center hemodialysis often referred to the desire to have a separation between dialysis treatments and their home environment. One individual who responded shared, "I liked coming home and leaving all of the smells, needles, solutions and machines at the unit." Another said, "My treatment and my home were to be kept separate." One person voiced concern about the emotional strain performing home hemodialysis might place on his family. Storage space for dialysis supplies and equipment was a negative factor for others. Another reason given for selecting center dialysis was that it afforded the opportunity to slow down and relax after a busy workday. This person preferred to have the center staff perform the treatment, with the exception of the needle stick, which she chose to do. Hemodialysis needles were the reason another individual elected to remain in-center. Her particular access proved to be a challenge even for the dialysis nurses. The ability to have a closer working relationship with the dialysis staff was

why one respondent elected to remain in-center. In addition, several individuals stressed the importance of having medical assistance available should an emergency arise. Several people pointed out that having no one to assist with treatments prevented home hemodialysis for them. One person shared that, initially, while seeing people with various medical situations at the center frightened her, once she began dialyzing in the center those same individuals became like family to her through their mutual support. Lastly, it was pointed out that medical issues can result in fewer treatment options. Peritoneal dialysis was not an option for one individual due to abdominal adhesions.

Several people shared why they had selected center hemodialysis over peritoneal dialysis. A teenager was concerned about how a peritoneal catheter would affect his body image. Another respondent preferred going to the center three days per week, leaving the rest of his week free from dialysis.

Some people also expressed why they selected peritoneal dialysis. Using the cycler allowed several individuals to dialyze at night and work full-time during the day. Someone else pointed out that while being on hemodialysis does not prevent full-time employment, it proved problematic for him because he frequently did not feel well following treatment. A person who began on continuous ambulatory peritoneal dialysis (CAPD) but changed to a cycler form of peritoneal dialysis shared that not only did the extra freedom of dialyzing

at night allow her to work full-time, she also attends college part time, is active with her church and family and exercises regularly. She also enjoys being in control of her treatment. Another reason for selecting peritoneal dialysis was to avoid the hemodialysis needles. A woman who often traveled preferred the ease of peritoneal dialysis compared to the need to arrange hemodialysis treatments. Another person explained how peritoneal dialysis allowed her to maintain interests like fishing and exploring. If an exchange is needed during those times, she simply does it in her car (using sterile technique to avoid infection!) and then resumes her activity. She also views the time spent doing an exchange as a time to relax and take time for herself. A mother of a four year old with chronic kidney disease was directed to peritoneal dialysis because her daughter retained some kidney function. They were able to perform dialysis while she slept, thus not restricting her activity during the day. They also enjoy peritoneal dialysis' fewer dietary restrictions.

A common reason that home hemodialysis was chosen was that it offers the ability to maintain control over one's health. Several people chose to lengthen their treatment time and dialyze more often, resulting in feeling better physically. Being on home hemodialysis also means that one does not have to worry about transportation problems. Several individuals credited home hemodialysis for allowing them to remain employed full time due to its scheduling flexibility. Dialyzing in the comfort of one's home was another reason given for selecting this form of treatment. One individual dealt with the issue of needing someone to assist with treatment by hiring a nurse to

Continued on page 13

Family Focus VOICES

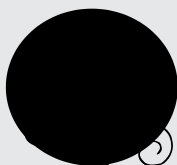
WE LOVE TO HEAR FROM OUR READERS, so every issue of *Family Focus* includes a special question.

Read the question below, also posted online at www.familyfocusvoices.org, and let us know what you think.

How do you cope with the mental health challenges related to having CKD?

You may visit the Web site above to share your thoughts, or send your response in writing to:

Family Focus Voices
30 East 33rd Street
New York, NY 10016



QUESTIONS THAT ARE OFTEN ASKED by people who are starting an exercise program are “What is the difference between walking, running, swimming or using a bicycle, and which one is best for me?” There are obvious differences between them, but the effect on your heart is just the same: They are good for you! The specificity training principle states that your body’s short-term and long-term benefits from exercise are specific to the muscles that are being used during your exercise session. For example, the muscles in your legs grow stronger as you run, the muscles in your back grow stronger when you swim, the muscles in your arms grow stronger if you use an arm cycle and the muscles in your thighs grow stronger when you ride a bike.

Although it is true that specific muscle groups benefit from exercises that involve those muscle groups, there is one muscle that will always benefit from exercise: your heart. Your

Family Focus Voices

Continued from page 12

perform dialysis. She felt home hemodialysis was ideal because it afforded minimal disruption in the lives of her three young children. Several of those who responded had put considerable effort into making home hemodialysis a reality. Since home hemodialysis is not offered at every dialysis facility, one respondent faced a lengthy waiting period to be trained. Another person was forced to transfer to a new doctor and dialysis facility where home hemodialysis was available. While researching treatment options, one individual arranged to meet with someone who was on home hemodialysis. After the meeting, not only did this person begin home hemodialysis,

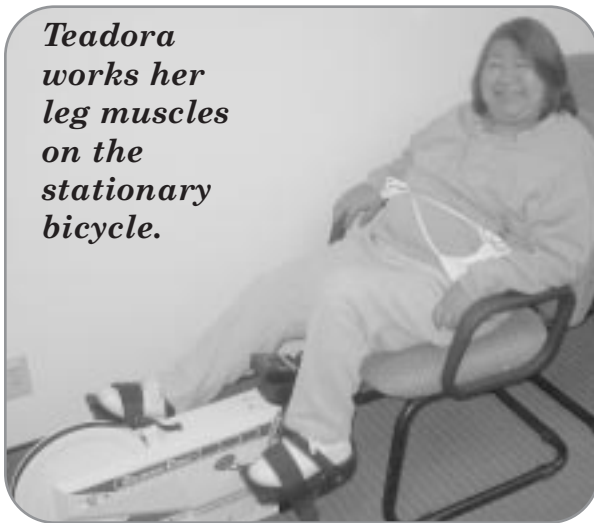
Which Type of Exercise Is Best For You?

By Pedro Recalde, MS

Teadora Mendez has learned the key to good CKD health: Exercise!


heart gets its exercise by beating faster to supply energy to those working muscles. It does not matter which exercise you choose, as long as you enjoy it and do it safely.

Teadora works her leg muscles on the stationary bicycle.



Teadora Mendez is an example of someone who is in an active exercise program while also balancing the responsibility of taking care of her home dialysis needs. She is 57 years old and the proud mother of five

which allowed her to care for two children, work full time and complete a graduate degree, she also married the gentleman who had shared his home dialysis experiences with her! A mother of a nine year old girl on home hemodialysis summed up her feelings about this form of treatment by saying that it had been a “blessing sent from heaven.”

Many of those who answered our questions had been on several, if not all, of the available treatment options, selecting them based on their needs and particular circumstances at that time. Remember that you, too, have a choice. Make it an informed one! 

children and grandmother of six children. Teadora started dialysis treatments at her local dialysis center in 2002, but later switched to home hemodialysis. She was trained by a home training nurse; little by little she learned how to do home hemodialysis by herself.

When asked about the main reasons for choosing home hemodialysis and the impact it has had on her life, Teadora says that her doctor recommended it, so she did it. She feels that the

doctor’s recommendation was made in her best interest, so she followed his suggestion. Teadora also likes the freedom of not having to go to the dialysis center three times a week. “I don’t have to deal with the dialysis center environment,” she says. “At home, my mind is calm and tranquil, while the grandkids help me with chores around the house.”

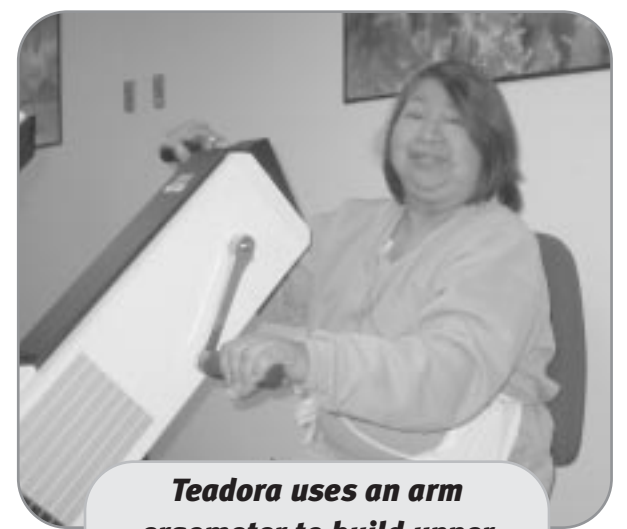
Teadora underwent coronary artery bypass surgery in 2004. Since the surgery, she participates in a hospital based rehabilitation program three times a week near her home in Los Angeles. In addition, she takes occasional walks outdoors when California weather permits. When asked about her attitude and energy level for exercise, she says “Sometimes I feel good, sometimes not so good, but I always put in an effort to go to the exercise class. Sometimes it is difficult

because of the pain in my legs and in my bones, or because my blood pressure drops after the exercise. I usually just drink a little bit of soup and I feel better. When the pain in my legs and feet is too high, I try different exercises that are less painful.

“My legs have problems, primarily due to my diabetes, and I know that exercising helps keep my circulation up and my legs strong. Also, I’m on the transplant list and if they call me, I want to be in the best shape that I can possibly be.”

Finally, I asked Teadora if she had any advice for others who might be in a position to choose among treatment options. “Most importantly is what the doctor orders. I wouldn’t want to change my option because it is practical for me, but I still speak with the nurse on the phone when I have questions. It’s important to remember that conserving your body is of primary concern and the exercise is a large percentage of the rehabilitation. Every time I speak to any doctor, they always recommend exercise, exercise, exercise!”

Thank you, Teadora! 



Teadora uses an arm ergometer to build upper body strength.

THE NATIONAL KIDNEY FOUNDATION (NKF) has joined the two dozen member organizations that comprise the "Kidney Care Partners" coalition to advocate the enactment of the Kidney Care Quality and Improvement Act of 2005. The draft legislation was introduced by Senator Rick Santorum (R. PA) as S.635. The bill number in the U. S. House of Representatives is H. R. 1298. The House bill was introduced by Representative Dave Camp (R. MI). Two provisions of the Kidney Care Quality and Improvement Act are of particular interest.

Section 401, "Improving the Home Dialysis Benefit," calls upon the Secretary of Health and Human Services (HHS) to provide incentives to improve the home dialysis benefit for Medicare beneficiaries. Section 402 requires the Institute of Medicine (IOM) to conduct an evaluation of the barriers that exist to increasing the number of individuals with chronic kidney disease (CKD) who elect to receive home dialysis services under the Medicare program. In conducting that evaluation the Institute shall:

- (A) Compare current Medicare home dialysis costs and payments with current in-center and hospital dialysis costs and payments;
- (B) Catalogue and evaluate the incentives and disincentives in the current reimbursement system that influence whether individuals with CKD receive home dialysis services;
- (C) Evaluate patient education services and how such services impact treatment choices.

Advocacy Stimulates Government Interest in the Option of Home Dialysis

By Dolph Chianchiano, JD, MPH

The House of Representatives is actively working towards improvements in home hemodialysis.

Medicare pays dialysis clinics such a small fee for home dialysis training that many believe it is a disincentive or discour-



Dolph Chianchiano, JD, MPH

ages centers from referring people to home dialysis. NKF plans to bring that to the attention of the IOM panel that will undertake this analysis if and when the legislation passes.


Looking at home dialysis from another viewpoint, the National Institute of Diabetes and

Digestive and Kidney Diseases (NIDDK) has announced a new research study that will be the first step towards comparing long nocturnal (nighttime) dialysis at home with conventional in-center dialysis. This is known as the "Frequent Hemodialysis Clinical Trial." The research will provide preliminary data on the impact of long nocturnal dialysis on anemia, nutritional status, blood pressure, left ventricular hypertrophy (enlargement of the heart related to anemia), exercise tolerance, medication use and hospitalizations. The following Coordinating Clinical Centers will begin recruiting patients for this study late in the summer of 2005:

- The Renal Research Institute in New York City, led by Dr. Nathan W. Levin.

- The University of California, San Francisco, led by Dr. Glenn Chertow.
- Wake Forest University, in Winston-Salem, N.C. led by Dr. Michael Rocco.

Finally, Representative Jim McDermott, (D. WA) will be reintroducing the Kidney Patient Daily Dialysis Quality Act in the 109th Congress. His proposal would require the Secretary of HHS to publish regulations to establish a payment rate for more frequent hemodialysis done at home. The Secretary would also need to document (1) Medicare savings resulting from more frequent hemodialysis due to fewer medications, hospitalizations and doctor's visits being needed; and (2) the improved quality of care and improved outcomes that more frequent hemodialysis may bring to individuals.

The National Kidney Foundation has advocated funding for the NIDDK Frequent Hemodialysis Clinical Trial in testimony to the U. S. House of Representatives and sent a letter of support for Representative McDermott's bill. 

Nocturnal Hemodialysis

Continued from page 4


INDIVIDUALS WHO WANT to do nocturnal dialysis must be very interested in taking an active role in their care. One of the biggest problems is finding a center that offers nocturnal dialysis. In addition, Medicare does not cover all of the extra costs of this therapy. Supplemental insurance may cover some of the costs not covered by Medicare. Individual units have different policies regarding coverage of extra costs.

Some centers will absorb the cost, some will only offer the

therapy if there is supplemental insurance and some may bill the patient. A large study sponsored by the federal government is now underway which looks at the effectiveness of daily dialysis. If the study proves that outcomes are better for people using daily dialysis, it is hoped that Medicare may then pay for the extra cost. The study began in 2004 with some results hopefully available by 2006. This still-preliminary study will compare short daily dialysis, nocturnal

dialysis and conventional dialysis with regards to efficacy and benefits for those on dialysis. Once these issues are established, then a larger study will be undertaken; its results will not be available until about 2008.

About the author:

Mary Gellens, MD is Director of Dialysis Services and Associate Professor of Internal Medicine at Saint Louis University in Saint Louis, MO. 

JOYCE AND I HAVE ENJOYED MANY TRIPS AND VACATIONS in our 54 years together—all of the United States and Canada, Europe and Mexico. We had plans to keep it up until we heard that dreaded word, “dialysis.” We thought that meant the end of extended travel for sure. NOT SO!

Since we found that it could be done, we have taken four trips of three weeks or longer. Actually, I am writing this now on the balcony of a resort in Fort Myers Beach, Florida at the beginning of a four-week stay. We have learned a lot, and I would like to share my experience with other people who are on dialysis.

SUPPLIES

Planning and double-checking is the key to a no problem trip. Make a checklist! Talk with your dialysis supplier about shipping the solution bags and some accessories to your destination. When you call, they will explain the requirements. You will need a confirmation number and a person to contact at your destination, and you should speak to the person who will receive the shipment to confirm they will accept the supplies. You will need a separate bag for your own accessories. Among those to consider are: a flashlight, a ¼ inch piece of plywood (I will explain why later), an 18 x 24 heavy duty extension cord, duct tape, scissors and a pen knife.

BY AIR:

Plan on checking the accessory bag at the airport and ask for a PRIORITY sticker so it will be sure to go with you. Expect this bag to be opened for inspection, so do not lock it. Include a laminated letter by your doctor explaining the contents.

Traveling with Peritoneal Dialysis

By Richard A. Hagen

If you use a cyclor machine, it should always be a carry-on. Have a letter from your doctor explaining that this is medical equipment. Your nurse may be able to get a custom case for the cyclor, or you can use any sturdy case and fill out any space with foam blocks. The cyclor should be well padded and protected. You do not want it to get damaged.

Tell the airline in advance that you are traveling with a piece of medical equipment, and they will flag your name for special attention.

BY CAR

You have more flexibility with car travel. You may need to take the solution bags that you will need to use on the way; they fit nicely out of the cartons on your back seat floor. That is the best place for the cyclor too. Request a first floor or “Handicapped” room if you stop at a hotel or motel.

IMPROVISING

I mentioned a piece of plywood. When the cyclor is in a nightstand, you need to support the solution bags. If there is a folding luggage rack, the plywood makes a solid surface for this purpose. You can also put the plywood on a chair or use the cardboard insert from the cassette carton to bridge between two chairs. The carton itself makes a useful platform. I have even used a motel ironing board. My program requires one manual exchange at the end of the cycle. Hauling an IV pole is out of the question. You can use the hook on the back of a door. A bathroom hook works well. You can use a wire hanger to position the desired height of the bag. I have used the sectioned pole from a spiral Christmas

tree. Tape an “S” hook to the top and tape the pole to a chair back or floor lamp. The butt section of a bait-chasing rod would work too.



CRUISES

Unless you are on hemodialysis, the specialized cruises are not needed. Almost any line will accept delivery from your dialysis supplier and will accommodate you. You must

have very specific delivery instructions from the ship personnel to relay to the supplier. The ship should store the supplies and bring them to your cabin as needed.

I do not want to minimize the seriousness of kidney failure. A “normal” life is history for us. But if you are in reasonably good health otherwise, traveling with dialysis is more of a nuisance than a handicap. Do not miss out on the fun because of the inconvenience.

I work out four times per week at a gym and, when I can, while on the road. It keeps me able to handle the 30-pound cyclor. I just turned 80 years old in January 2005. If I can do it, you can too!

Richard Hagen has been on PD for 2 ½ years. He lives in New Jersey.



Living Donors Web Site

If you are a transplant candidate, you may already know that you can receive a transplant in two ways: from a deceased donor (through the national waiting list) or from a living donor. Living donation is when a living person donates a kidney, or part of a liver or lung, to another person. Potential donors can find extensive information, support and other resources on the National Kidney Foundation’s Web site on living donation at www.livingdonors.org

The Web site includes a detailed Q&A section featuring commonly-asked questions about the process, risks, evaluation, making the decision, the surgery and recovery. Living and potential donors, as well as their families and friends, can connect with one another in many different ways through the Web site. These include a message board, regular online chats, an e-mail group and a pen pal program where participants can ask questions, seek support and encouragement or share their experiences with one another.

Site visitors can also find ways to honor those who have already donated, learn more about professional conferences on living donation, sign up for free newsletters and learn about upcoming events related to donation and transplantation. Please visit www.livingdonors.org to learn more! For more information about transplantation, visit us at www.transplantrecipients.org

Quick Guide to Home Dialysis (cont'd from page 3)

Quick Guide to Home Dialysis	Standard Home Hemodialysis	Short Daily Hemodialysis	Nocturnal Hemodialysis	CAPD	CCPD
*Treatment days (or nights) per week	3 days/week	5-6 days/week	4-6 nights/week	7 days/week	7 nights/week
*Hours per treatment (including average set-up time before the treatment and clean-up time after the treatment; set-up time varies with each machine)	4-6 hours Set-up=30-45 min. After=30-45 min.	2½-3 hours Set-up=30-45 min. After=30-45 min.	6-8 hours Set-up=30-45 min. After=30-45 min.	4-5 bag exchanges spaced evenly throughout the day (About 30-45 min./exchange).	7-10 hours Set-up=30-45 min. After=30-45 min.
Machine(s) needed to do treatment	Yes			No	Yes
Water system needed to do treatment	Yes			No	
Type of dialysis access	Fistula, graft, or catheter			PD Catheter	
Needles inserted for the treatment	Yes (unless a catheter is used for dialysis)			No	
Back-up (helper) needed	Most home dialysis clinics require that you train with a helper who will stay close by during home treatment. If you do nocturnal dialysis, you may not need to have a helper.			A helper is not needed for peritoneal dialysis unless the person getting dialysis cannot do the treatment steps independently.	
Maximum training days paid by Medicare. (Payment policies may vary depending on your Medicare payer or fiscal intermediary)	Medicare pays for approximately 3 training treatments per week for a month. If more days are needed, an exception request can be submitted,			15 days (If more days are needed, an exception request can be submitted to Medicare.)	
Space and storage needs	Machine, water system and supplies			Supplies	Machine and supplies
Plumbing/electrical changes	May be necessary for home hemodialysis (Ask the home dialysis unit that is responsible about minor changes that may be needed to accommodate home dialysis.)			No	Grounded electrical outlet
Utilities needed	Home hemodialysis requires water, plumbing and electricity.			Peritoneal dialysis requires running water for hand washing.	
Possible increase in water or electrical bills	Yes			No	Yes

* Number of treatment days, hours and exchange times described in this chart represent the average prescription.

THERE'S ONLY ONE WAY TO FACE DIALYSIS. TOGETHER.

No one should have to face dialysis alone, and thanks to Amgen, no one has to. Because Amgen—the world's largest biotech company—is dedicated to helping you deal with the many issues that can go along with kidney failure and dialysis.

For example, many people with chronic kidney disease on dialysis develop *anemia*, a shortage of red blood cells. Anemia can make you very tired and unable to complete routine daily tasks. Anemia may also lead to more serious problems like heart disease.

An important gland called the *parathyroid* can also be affected by kidney disease, leading to a condition called *secondary hyperparathyroidism (secondary HPT, for short)*—which can cause serious problems in your bones and blood vessels.

Amgen offers an entire family of products and services to help support people on dialysis and the people who love them. Because we're not just dedicated to improving the lives of people with kidney failure, we're dedicated to protecting them.

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Find out more about our work at www.amgen.com.

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