



**National Kidney  
Foundation®**

*Making Lives Better*

**THIS ISSUE**

**TOOLBOX FOR LIFE, PART I:  
Your Life in the  
Dialysis Unit**

Ideas and information to help make the time you spend in the dialysis unit as positive and productive as it can possibly be for you.

*Inside this issue:*

**YOUR ACCESS**



Your access is your life-line, making dialysis treatment possible. Learn about the different types of vascular access, and how to take care of yours.

—Page 3

**SAFETY CHECKLISTS**



Take charge of your care! These four simple checklists will help you make sure some of the most common mistakes never happen.

—Pages 8–9

**FAMILY FOCUS VOICES**



Read this issue's special question, then log onto the Internet to share your thoughts with the kidney community!

—Page 10

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# Family FOCUS

A Publication of the National Kidney Foundation

Vol 13, No 1 • Winter 2004

## My Experience: A Men's Group in the Dialysis Unit

By Craig Thompson



For Craig Thompson (second from left), taking part in a men's group at his dialysis clinic was "worth its weight in gold." He is pictured here with two other members of the men's group, as well as Cheryl Weller, MSW, (left) and John Long, MSW, (right), social workers at the San Diego dialysis unit where the men's group formed.

**F**ORWARD THINKING IN MY DIALYSIS CLINIC LED TO A MEN'S GROUP THAT IS DETERMINED TO MAKE A DIFFERENCE. We gathered in a back room of the dialysis floor to discuss our issues and concerns. It was an opportunity to speak out about how we truly feel about our kidney disease and how it has affected our lives.

I encourage any man to dig deep within himself and realize, if you are chronically ill, you are not alone. This realization became clear as soon as the door was closed. We started talking about everything under the sun. For brief moments I would break away from the conversation only to see that those who came reluctantly looked as if there was no other place they would rather be.

Each time we met, we came earlier and stayed later! We were able to explain our situations to each other. But the most exciting part for me was knowing that I was not alone and that the things I was experiencing were not just happening to me.

Kidney failure is an uphill battle no matter how you cut it, but being in this men's group

helped all of us grow and want to fight for another day. The camaraderie generated has led to the attitude of "Leave no man behind!" The social workers at our clinic have been "top drawer" in terms of listening to our men's group and addressing our concerns. I applaud their forward thinking and their willingness to view their patients not just as patients, but also as people—flesh and bones, packed with multiple emotions that sometimes seem to collide all at the same time. It has led all of us to a better understanding of ourselves and our treatments. It has given the social workers

*Continued on page 2*

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

I would imagine that those of you who dialyze at a dialysis unit often feel like it is a part-time job. When you consider the time it takes to get to and from the dialysis unit, the time it takes to prepare to go on and come off of the hemodialysis machine and the time you actually dialyze, it is indeed close to 20 hours per week! It is precisely because of this that we decided to dedicate this issue of *Family Focus* to information that we hope will help make the time you spend in the dialysis unit as positive and productive as it can possibly be for you. If you dialyze at home with either hemodialysis or peritoneal dialysis, do not feel as if this issue has no information for you, as indeed it does. Be sure to read about the *Dialysis Patients' Bill of Rights*, things you can do to prepare for a transplant and any additional article that you find is relevant to your particular situation.

I hope that you have taken the time to read our most recent issue of *Family Focus* on communication. I want to point out that while the cover story did not focus specifically on the role of the Patient Care Technician (PCT), the Editorial Board did not forget this very important person who helps make everything in the dialysis unit run smoothly. Those of you who completed the survey



Karren King

upon which the cover story is based know that the article did not review all of the information that the survey covered. The PCT is included in several of the questions addressing issues about staff in the dialysis unit, and this information, as well as other points not covered in the cover story, will be included in an article that will be written for future publication in a nephrology journal.

The next issue of *Family Focus* is entitled, "Toolbox for Life, Part II: Dialyze to Live, Don't Live to Dialyze." While this current issue mainly focuses on life in the dialysis center, the next issue recognizes that although dialysis is a part of your life, it does not define your entire life and being. With that as background, I want to encourage you to let us know your thoughts about what has made your life

outside of the dialysis unit better by helping you cope with the challenges you may face with such things as personal relationships, meal planning or employment. You may share your thoughts by mailing them to us or by going to [www.kidney.org/patients/voices.cfm](http://www.kidney.org/patients/voices.cfm). You are the ones who live with kidney failure and its treatments every day, and we would love to share your insights with all of our readers. Please let us learn from you by responding to our question.

I want to thank each and every one of you, those on dialysis or transplanted, family members of individuals with chronic kidney disease and the health care staff, for continuing to send us such wonderful articles and poems about your experiences and feelings. Much of the positive feedback we receive from our readers focuses on the inspiration they receive from reading what you are submitting. We do our best to publish what you send as soon as we can, so please keep them coming. We do love to hear from you!

On behalf of the *Family Focus* Editorial Board, we want to wish everyone a happy and peaceful 2004! 

Karren King  
For the Editorial Board

# Family Focus

NKF *Family Focus* is published quarterly by the National Kidney Foundation.

Opinions expressed in this newspaper do not necessarily represent the position of the National Kidney Foundation

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## My Experience... from page 1

an inside look at what we truly experience as men, not only at the dialysis clinic, but also in our private lives.

I want to tell you more, but I cannot put in words what this group has done for us. If there is not already a group like this in your unit I encourage the men on dialysis to start one and to adopt the "Leave no man behind" attitude. Our group has been so successful that we have planned events to share our experiences and ideas with other patients and direct them to the resources they need in order to have a clear understanding of their illness and how to address their concerns.

Working with the social workers has been a win-win situation



for all of us. Not only does it benefit us as patients, it benefits the staff to learn more about us as patients and as people. The therapeutic energy produced by this

group was worth its weight in gold. I made many new friends who share my same concerns. We listen to one another and not only hear what is said but we feel it. Beginning the men's group was a great move and should be a model for all clinics. I learned that I may have kidney failure, but kidney failure does not have me. Until next time, my friends, stay strong!

### About the Author

Craig Thompson, of San Diego, received a kidney transplant in December 2003.

**Editor's Note:** Women's groups and co-ed groups at dialysis units are equally encouraged.

In order for hemodialysis to be done, there has to be a way for blood to go through the artificial kidney (dialyzer) so poisons can be removed, and for the cleaned blood to be returned to the body. This is done through what is called a “dialysis access” or “vascular access for dialysis.” There are three different types of access, and the type that is used depends on how quickly dialysis has to be done. We will describe the kinds of dialysis access that are used, why each is used, the good and bad things about each one, how to take care of each and what kinds of problems you should tell your dialysis doctor or nurse about.

### DIALYSIS CATHETER

A dialysis catheter is like a big intravenous (IV) needle like the kind you might get in your arm for medications when you are sick in the hospital. This is used when you need dialysis either today or in the next few days and do not have a permanent dialysis access yet. You might also get a catheter if your permanent dialysis access does not work and you need a way to dialyze until you get a new permanent access. A doctor will put the dialysis catheter in the side of your neck, in your chest below the collarbone or in your

groin. The decision about where to place the catheter depends on how long the catheter has to remain in place.



### *The Good and Bad about Dialysis Catheters*

The good thing about a catheter is that it can be placed and removed easily and used right away. Unfortunately, catheters get infected easily, do not always work as well as they should, are often uncomfortable, have to be kept clean and dry and can scar the vein they are in, so that vein does not work for a dialysis access if you need it later.

### *Taking Care of a Dialysis Catheter*

It is important to keep the catheter site clean by keeping a bandage on it all of the time. The staff in the dialysis clinic will change the bandage every time you dialyze. Only the dialysis team should be using your dialysis catheter. Do not let anyone else, even a doctor or nurse, use your dialysis catheter unless it is an emergency. You should wear clothing that will not tug or

## Access Options for Dialysis

By Randy Breiterman-White, MS, RN, CNN and William Nylander, MD

*Understanding your vascular access is a first step toward getting the best care possible.*

pull on the catheter. If your catheter is in your neck or chest, wear a buttoned shirt when you go to dialysis so the staff can use the catheter without pulling on it.

### *Problems to Report*

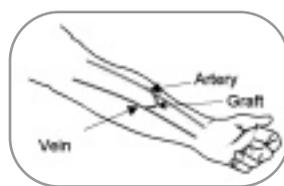
Let the dialysis nurse or doctor know if your catheter is hurting you, if you see any blood or other fluid on the bandage, if you feel ill or have a fever. Let them know if you have pulled or tugged on your catheter by mistake so it can be examined closely. Also, tell the nurse or doctor if someone else used the catheter (even though you tried to prevent it).

### DIALYSIS GRAFT

A dialysis graft is a more permanent kind of dialysis access. It may be called a “gore-tex graft,” “synthetic access,” “shunt” or just “graft.” This is often used if your own veins are very small. It is a piece of man-made material shaped like a plastic straw. It is very bendable and soft. A surgeon inserts it under the skin in your arm, either below or above the elbow in a way that the dialysis nurse or technician can put dialysis needles in it just like starting an IV needle.

### *The Good and Bad about Dialysis Grafts*

Grafts are easy to use and are usually ready as soon as the surgical swelling in your arm goes down. This usually takes two to three weeks. A graft can be placed in almost anybody. They usually work very well and allow good dialysis treatments. Each time you dialyze, a dialysis nurse or technician will put two needles in your graft. Unfortunately, because it is artificial, when dialysis is finished and the needles are removed, the hole will not heal (remember, it is man-made.) After needle sticks for many dialysis treatments, there will be a lot of holes on the graft. The graft may need to be replaced in the operating room once every year to year and a half. Also, your graft can get infected if your arm is not cleaned well before the needles are placed for dialysis.



### *Taking Care of Your Graft*

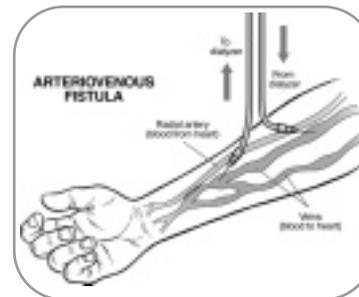
Try never to sleep on the arm that has the graft. Any time you get in a position where your arm might “fall asleep,” blood circulation stops and the graft will stop working. For the same reason, do not wear anything that has tight sleeves or let anyone, even a doctor, take your blood pressure or stick you for blood in your graft arm. You should always try to wash your graft arm with soap and water when you get to dialysis and before needles are placed to help prevent infection. Your dialysis nurses and technicians will teach you how to “feel the thrill,” which is a vibration in your graft. Do this every day when you get out of bed in the morning and before you go to sleep every night to make sure your graft is working.

### *Problems to Report*

You know your graft the best. Let the dialysis nurse or technician know if something feels different. Report any redness, swelling, oozing or bleeding. Let them know if you feel ill or think you have had a fever. If you notice the thrill is gone, call the dialysis clinic as soon as possible. The sooner it gets reported, the easier it is to fix and the easier it is to avoid a dialysis catheter.

### ARTERIOVENOUS FISTULA FOR DIALYSIS

Usually this dialysis access is called a “fistula.” Sometimes you may hear the term “AVF,” “AV fistula,” “native vein fistula,” “native” or “shunt.” This is the best kind of dialysis access, because they can last for so long. Unfortunately it can-



not be placed in everyone. A fistula is created by joining together your own native arm vein and artery in an operation. When it is ready to use, the dialysis nurse or technician will place dialysis needles in your arm just like starting an intravenous or IV needle.

### *The Good and the Bad About an AV Fistula*

AV fistula surgery does not make your arm swell too much and does not hurt very much; they do not get infected very often and, with good care and careful needle sticks, can last for years. Unfortunately, it takes three to four months for the vein to get big and strong enough to use for

*Continued on page 4*

## Eating on the Run

By Jamie Shish, RD, LD, ATC/L

*It will be much easier to meet your nutritional needs if nutritious food is readily available.*

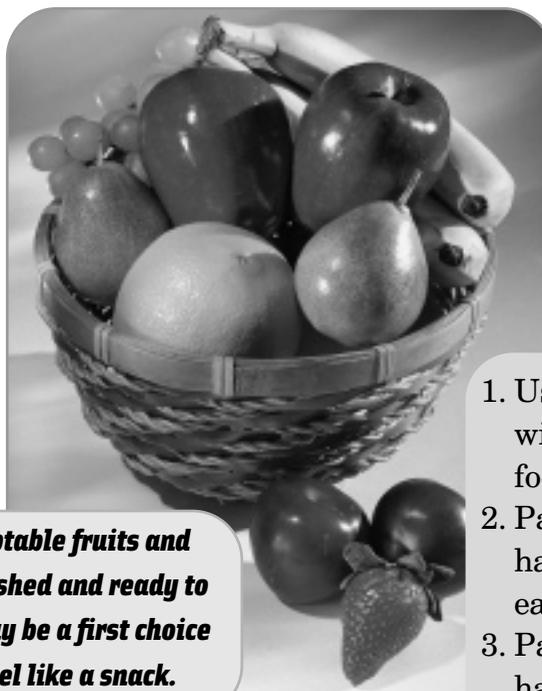
Do you ever feel like you are running from dialysis treatments to doctor's appointments and other commitments without a break to eat? Starting dialysis is certainly a lifestyle change; spending 12 or more hours a week at dialysis is like working a part-time job. You may feel pressed for time until you can figure out how to work everything into your schedule. You may think that it would not hurt to miss a few meals as one way to save time. In fact, your nutrition could not be more important than when you are on dialysis. Proper nutrition is necessary for your bones, muscles, energy level and teeth, and can even lower your risk of infection.

Your body likely needs more calories and more protein on dialysis than it did before you started dialysis, because you may lose some protein in treatment, particularly peritoneal dialysis. Your body stores and uses protein to help fight infections, for energy and for building and repairing muscle tissue. If you are taking medication for diabetes it may be even more important to eat properly. Diabetic medication works to lower blood sugar, and without eating regularly scheduled meals and snacks there is a risk your blood sugar may go too low.

It will be much easier to meet your nutritional needs if nutritious food is readily available. If the only quick and easy things to eat in your kitchen are chips

and cookies, that is what you are going to eat when you are hungry. If, on the other hand, you have pre-washed fresh grapes, leftover turkey and rice in

**Keep acceptable fruits and vegetables washed and ready to eat, so they may be a first choice when you feel like a snack.**



your refrigerator, there is a better chance you will choose one of those instead.

Do a little "food" research concerning your unit and your transportation to and from the unit. Ask your unit manager or dietitian if snacking is permitted at the unit. Some units may allow a can of nutritional supplement or a sandwich. If you use a transportation service, ask if you may have a snack during the ride to treatment or during the ride home.

If snacking at your unit or during transit is permissible, read the tips in the box below.

The following are a few snack ideas for eating in the unit that are neat and nutritious:

1. Use an insulated lunch bag with an ice pack to keep food cold.
2. Pack hand wipes to wash hands before and after eating.
3. Pack napkins to keep your hands and area clean.
4. Pack a straw if drinking is difficult while in a semi-reclined position.
5. Pack a snack that is neat. (Barbeque ribs are not a good idea!)
6. Remember your phosphorus binder. It is important for keeping your lab values on target.

half of a turkey sandwich, bite size salt free crackers, half of a bagel with cream cheese, cottage cheese, one can of nutritional supplement or one protein bar (ask your dietitian which one would be best based on your personal medical history), grapes, apple sauce and tuna salad.

If these options are not available to you, planning meals around treatment times is

another option to help keep meals and snacks on a regular schedule. For example, say you leave for treatment at 10:30 am. You may eat breakfast around 7:00 am, have a mid-morning snack around 10:15 am, and a mid-afternoon snack at 3:30 pm.

Mid-day snacks should be prepared ahead of time so they are available on the run. For example, make a sandwich in the morning cut it in half and keep it refrigerated. Keep

acceptable fruits and vegetables washed and ready to eat. Store leftovers in single serving microwaveable containers ready to be re-heated for mid-day snacks. If you get hungry, your food will be ready for you!

Your body will thank you for eating nutritious meals and snacks by feeling more energetic, fighting off infections and keeping bones and muscles strong even when you are living

life on the run. 

### About the Author

Jamie Shish, RD, LD, ATC/L is a Registered Dietitian working in an outpatient dialysis center in Illinois. Jamie is also a Licensed Athletic Trainer and has a bachelor's degree in Kinesiology.

## Access Options for Dialysis

Continued from page 3

dialysis. In order to make the vein grow big and strong, you will have to do arm exercises that the dialysis staff will teach you. The exercises are really easy. If your fistula is not yet ready when you need dialysis, you may temporarily use a catheter.

### Taking Care of Your AV Fistula

The same rules apply for an AV fistula as for a graft. Try

never to sleep on the arm that has the AV fistula and do not wear anything that has tight sleeves or let anyone, even a doctor, take your blood pressure or stick you for blood in your AV fistula arm. Wash your AV fistula arm with soap and water when you get to dialysis before needles are placed. This will help to prevent infection. Your dialysis nurses and technicians will teach you how to "feel the

thrill" in your AV fistula. Do this every day when you get out of bed in the morning and before you go to sleep every night.

### Problems to Report

Let the dialysis nurse or technician know if something feels different. Report any redness, swelling, oozing or bleeding, if you feel ill or think you have had a fever. If you notice the thrill is gone, call the dialysis clinic as soon as possible. The sooner it gets reported,

the easier it is to fix and the easier it is to avoid a dialysis catheter. 

### About the Authors

Randee Breiterman-White MS, RN, CNN, is Clinical Specialist/ Case Manager of nephrology at Vanderbilt University Medical Center. William Nylander, MD, is Transplant Physician for VA Tennessee Valley Healthcare System at Vanderbilt University Medical Center.

When there is a problem, how do you fix it? It depends upon the type of problem. If your car breaks down, you use tools to take apart broken pieces and then put repaired items back, so the same car now becomes dependable and reliable again. Sometimes the tools we use are more mental, like behaviors and attitudes. I have found that some tools have improved my life, and I believe that these tools can make your life better, too.

Let's create a toolbox of your own, loaded with useful tools! There are many mental tools that can be used to help shape personal attitudes and beliefs, which, in turn, can help you feel more in control of your life.

**Knowledge** is the first tool to place in your toolbox. Just as a car mechanic must be armed with knowledge before he or she even attempts to begin any repair, so must you educate yourself about dialysis and how to live well with kidney disease. This includes learning the good and bad effects of medications

## Tools For Improving Life

By Dale Ester

*Some of the most important tools for maintaining control are in your mind.*

you are prescribed and why you are taking them. Do not just take medicine because the doctor prescribed it. Learn how medicines may react with one another, what not to eat or drink when taking them and take them on time as prescribed.

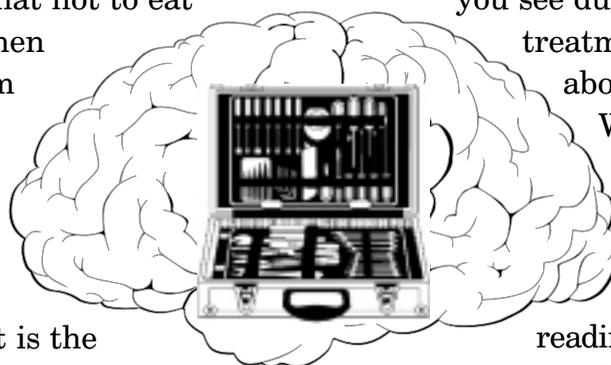
**Respect** is the second tool to go into the toolbox. Having respect for yourself, as well as for the members of your health care team, and other individuals in the unit, will help to create an environment that is pleasant and relaxed.

The next tool you will want to add to your toolbox is **responsibility**. It is your responsibility to learn how the

hemodialysis machine operates well enough so you can fully understand exactly what the readings mean about your personal treatment. The displays you see during your treatment are all about you.

Watching these readings and knowing what each reading means may prevent a mishap from occurring. Accept personal responsibility and learn about what is happening to you while you are on dialysis. Become involved in YOUR treatment.

Once you understand what is happening during dialysis, take charge by speaking up about what is happening to you. **Communication** is the next tool in your personal toolbox.



Talking with members of the health care team will improve many aspects of your care. By adding communication to your toolbox, you will see your relationships with members of the health care team get better, leading to improved monitoring of your treatment sessions together, in a team approach. A team is successful because members work together to accomplish one common goal. Become an important part of this team and you will win!

One of the most important tools is personal **control**. Each person must control his or her fluid and dietary intake. This means manage what you eat and drink as you are advised, to stay as healthy as possible. Yes, control is difficult, but learning how best to use control will lead you on a path toward a long life filled with pleasure and satisfaction.

Now your toolbox is full. Remember to bring it along with you to the dialysis center every time you go. Do not leave home without it! 

## Know Your Rights and Your Responsibilities

The National Kidney Foundation is Pleased to Announce...

...the release of the *Dialysis Patients' Bill of Rights and Responsibilities*. A complimentary copy of this booklet was mailed to dialysis centers in early January. The booklet outlines the rights of dialysis patients on topics such as treatment options, access to information, dietary counseling and a whole lot more. It also addresses the responsibilities patients have to their dialysis facility, health care staff and fellow patients.

This booklet serves as a comprehensive, unbiased guide for dialysis patients everywhere. We all know that educated and empowered patients are more involved in their care, resulting in better health outcomes. Therefore, we recommend that patients, family members and members of the health care team read the *Dialysis Patients' Bill of Rights and Responsibilities*. To get a copy of the booklet, please contact Crystal Tucker, Material Resources Coordinator at 800-622-9010 or visit the Patient and Family Councils' Web site: [www.nkfkidneypatients.org](http://www.nkfkidneypatients.org) to download a copy.

### Dialysis Patients' Bill of Rights and Responsibilities



**NKF** National Kidney Foundation®  
Making Lives Better

dear  
*editors*



Since December 2002, my husband has been on dialysis and I have been involved as his caregiver. During this time I have made some observations about information sharing which are of concern to me and other caregivers with whom I have discussed the subject.

Some of the people on dialysis, because of their serious illnesses, are not always capable of understanding instructions. Some suffer from short-term memory loss and do not retain information well. For this reason, I feel it is important that all instructions regarding procedures, appointments, medications, test results and any changes in condition be done in the presence of the caregiver, so that proper action or adherence can be assured. The clinic's involvement with a person on dialysis is about 15 hours per week, while ours is considerably longer. Our participation in the health and well being of those we care for is the larger responsibility. I feel that caregivers are, or should be, working as a team to provide the best quality of life possible. We cannot do that if we are not "in the loop."

Dolores Easley, Caregiver

**Editor's Note:** Caregivers do indeed play a very significant role. However, due to Health Insurance Portability and

Dear Editors,

For years we've been told, "We are changing over," yet no one has received much education about the relationship of kilograms to pounds. For most people, it is a mystery.

For the benefit of many patients (especially those on dialysis) and care providers, I have developed a conversion chart for kilograms to pounds. I hope it helps take the mystery out of these "change overs."

Very truly yours,  
Joseph P. Finnegan

P.S. My wife, Josephine, (age 78) is a survivor of almost five years as a dialysis patient.

To convert kilograms to pounds, multiply by 2.2:

25 kg = 55 pounds  
50 kg = 110 pounds

75 kg = 165 pounds  
100 kg = 220 pounds

To convert pounds to kilograms, multiply by 0.45:

74 pounds = 22.74 kg  
100 pounds = 45 kg

150 pounds = 68 kg  
200 pounds = 90 kg

*Accountability Act (HIPAA) guidelines, the health care staff can not legally discuss a patient's care with anyone, without the patient's written permission.*

As a dialysis patient for 17 years, there have been many changes in my mental and physical health. Prayer has been a tremendous help to me.

My mother and three of her brothers had polycystic kidney disease, so our family physician suggested that her six children have an intravenous pyelogram study test. These tests revealed that three of us, including me, had inherited the disease.

Through the 1960s and '70s, I watched two of my brothers struggle courageously with numerous operations, dialysis and transplants. In 1984, I experienced kidney failure and began continuous ambulatory peritoneal dialysis (CAPD). In 1990, I switched to hemodialysis, which continues to the present time. It is my hope that some of my experiences will help present and future patients.

As a CAPD patient, I learned that cleanliness is essential in preparing for treatment. It is also important to have a regular

## Tips I Picked Up Along the Way

By Richard Epes McMurrin

schedule for your treatments. I had a tendency to rush my treatments instead of sticking to my schedule.

I became very conscious of the importance of sticking to a CAPD diet, and later to a hemodialysis diet. The nephrologist and dietitian monitor my diet through my monthly blood tests.

Exercise has also been very important for my well-being. I walk and play tennis with my friends, and enjoy both activities.

As a six-year CAPD patient, I experienced a number of attacks of peritonitis that were extremely painful. My nephrologist and nurse suggested that the cause of peritonitis was from a germ getting into the tubing leading to my peritoneum. In 1990 I finally gave up CAPD due to an

infection that could not be identified by my nephrologist. It was also in 1990 that my long-time friend gave me this valuable advice: "Be patient, be flexible and think positively."

Since 1990 I have been on hemodialysis and my regimen has changed considerably. During my years on the dialysis machine, the nurses and dietitian have given me the following excellent advice:

- Keep a log of how much food and liquid is consumed.
- Have an eight-ounce cup filled with ice. This is equal to four ounces of fluid. My nephrologist allows me to have 32 ounces of fluid per day. During the past year, my nephrologist lowered the sodium intake for the machine, and this has cured my thirst problem.
- Have a pillow wrapped and

taped around your arm and hand to prevent movement while on dialysis.

- Keep a log while on dialysis. I record my sodium level and the amount of fluid to be taken off while on the machine, based on my weight when I begin to dialyze. In addition, I record my blood pressure, pulse, venous and arterial pressures and dialysis machine pump speed.

In closing, I am most appreciative of the medical care provided by the doctors, nurses, dietitians, social workers and other staff members at my dialysis center. I would also like to thank the ministers, friends and relatives who have been so kind to me since 1984. 

### About the Author

Richard E. McMurrin lives in Newport News, Virginia.

This article was edited by Agnes McMurrin Johnson and Jane Saunders McMurrin.

## Flowers of Apprehension

By Delores Cribbs

Sometimes when I dialyze  
I know someone has died  
I see the pretty flower bouquets  
But sadly, they are funeral sprays

I look around at all the faces  
Making sure, the ones I know, are in their places  
Wondering if the one the flowers were brought for  
Would be someone I had grown to adore?

Was it the lady that lived alone  
Sold her house and went to live in a nursing home?  
Could it be the little old man who sat across from me  
Always smiling, never talking, happy just watching TV?  
Praying, I asked that it wouldn't be a young mother with babies

Holding my breath while dreading the answer, I asked the nurse  
Do you know who the flowers are for?  
She answers, "One of the patients on another shift"  
Their family brought the flowers as a gift

Sad but relieved, that I didn't know any of the bereaved  
I let out a sigh and began to breathe  
Thinking to myself that when I die  
I want my family to find another way to say goodbye

I used to love getting flowers on special occasions  
Now they are a source of apprehension  
Reminders that none of us are here to stay  
That we will all eventually pass away

So today I do decree...  
That if anyone cares to remember me  
I hope you'll think I was a sweetie  
Laugh, joke and have a party  
Or simply have a piece of candy

*Delores Cribbs lives in Sloan, Iowa, and dialyzes in Sioux City.*



By Joseph Yopez

Vapors of love rise in the air  
summer waits for spring to care  
where it left off the fall  
complimenting each other's work in all.

Winter keeps you at a chill  
so you would appreciate the thrill  
of an early morning hug  
as coffee spills on your rug  
window kisses and cotton cake  
poured with milk chocolate so it won't look fake  
happy hiccups while I drive

It's so very good to be Alive!

*Joseph Yopez is a dialysis patient care technician in Macomb, Michigan.*

## Walking Down the Hall Again

By L.B. McCormick

Here I go, walking down the hall again,  
going to kidney dialysis, once again.  
Walking to my treatment once again,  
to keep me from passing on,  
for another day more,  
so I can see sunshine, for another day more.

For those I got to know, life seems to cheat them so.  
Sometimes, we lose ourselves and take  
everything in vain,  
and it seems nothing will ever be the same.

So I keep walking down the hall again, to kidney dialysis,  
'til the day when we all will win.  
Though sometimes life seems so unfair,  
sometimes it's so hard to bear.  
But as we look into the eyes of some,  
there are those who seem to really care.  
So we continue, to walk these halls once more,  
in hope to find a cure to help us all.  
'Til then, we keep hoping in dreams, in thought,  
though that day seems it may never be sought.

So we keep walking down the hall again, to  
another day of treatment, once again.  
Walking towards another sunshine,  
in hope, when we all will be free,  
and our lives to cope, with hope, once again.

*Lloyd Blaine McCormick dialyzes in Zanesville, Ohio.*

## When I am on This Journey, Remember Me, Lord

By Gregory L. McCollum

Remember me, Lord, as I go through life's journey.  
Have love and mercy on me when  
I don't obey, or hear your voice or do your will.  
Never leave me, Lord, with this sickness that I have.  
Help me to overcome the aches and pains that some days  
Are more than I can bear.

Comfort me, Lord, when I'm in tears,  
When I'm mourning the loss of a family member or friend,  
Hoping they had the victory in the end.

Lord, as I go through this journey of life, lead and guide me.  
Help me travel the righteous path.  
And when my journey here is finished,  
I pray that everything I have done was to your pleasing.  
Remember me, Lord, while I'm on this journey.

*Gregory L. McCollum lives in Burlington, N.C.*

## Making Your Clinic A Safer Place

By Bobbie Knotek, RN, BSN

*These four checklists will help you prevent mistakes before they occur.*

Your doctors and dialysis clinic staff work hard to give you safe, high-quality care. They try to do things the right way with no mistakes. However, because your doctors and staff are human beings, mistakes can happen. YOU can help make your dialysis clinic a safer place by working with your dialysis staff to find and prevent mistakes before they occur. Use

these safety checklists to focus on areas where mistakes are most likely to occur.

Read these checklists to see if you are aware of potential problems. If you want to have any checklists with you as a reminder, clip them out and take them with you!



### Know Your Medicines

- ✓ Keep a current list of ALL medicines you take, including prescription medicines, herbs, vitamins, supplements and over-the-counter drugs like cold, cough, headache or pain medicines.
  - List the medicine (both generic and brand name), dose, when you take it, why you take it and the date you started taking it.
  - List medicines you get during dialysis.
  - List drug allergies.
  - Carry these lists with you. Show them to your doctor(s) during appointments, emergency room visits or admissions to the hospital or outpatient surgery.
  - When asked to do so, bring your medicines to the dialysis unit to be double-checked for accuracy.
- ✓ Ask these questions when your doctor writes a new prescription:
  - Does the new prescription replace medicine I have been taking?
  - How long will I need to take the new medicine?
  - When should I take the medicine—"around the clock" or just during the daytime?
  - Should it be taken before, during or after meals?
  - What if I miss a dose?
  - What are possible side effects? How can I avoid or manage side effects?
  - Should I avoid any foods, drugs or activities while taking the medicine(s)?
  - If the medicine is a liquid, can the pharmacist give me a medicine measuring cup or spoon (household spoons do not measure the right dose).
- ✓ When you pick up new and/or old prescriptions:
  - Read prescription bottle labels, especially the warnings.
  - Make sure medicine is the correct drug and dose. If either the bottle label or the medicine look different than usual, talk to the pharmacist before leaving the counter.

### Vascular Access

✓ If you are on dialysis or will soon be starting, learn about your vascular access.

- Read about the different types of access on pages 8 and 9 of this issue!
- Ask your facility for brochures or go to these Web sites: [www.kidney.org](http://www.kidney.org) (National Kidney Foundation) or [www.aakp.org](http://www.aakp.org) (American Association of Kidney Patients).
- Read vascular access recommendations at [www.kidney.org/professionals/kdoqi/guidelines\\_updates/doqi\\_uptoc.html#va](http://www.kidney.org/professionals/kdoqi/guidelines_updates/doqi_uptoc.html#va)

✓ If you have a new fistula, it needs to be treated "special" for the first three to four weeks. This means using thinner needles and a lower blood flow. If your facility does not have a procedure for new fistulas, let your doctor or nurse know their End Stage Renal Disease Network has written procedures available.

✓ To help prevent problems with your fistula or graft, learn to put your own dialysis needles in at the start of dialysis (self-cannulation). Read about the benefits of self-cannulation at [www.nephron.com/judy.html](http://www.nephron.com/judy.html)

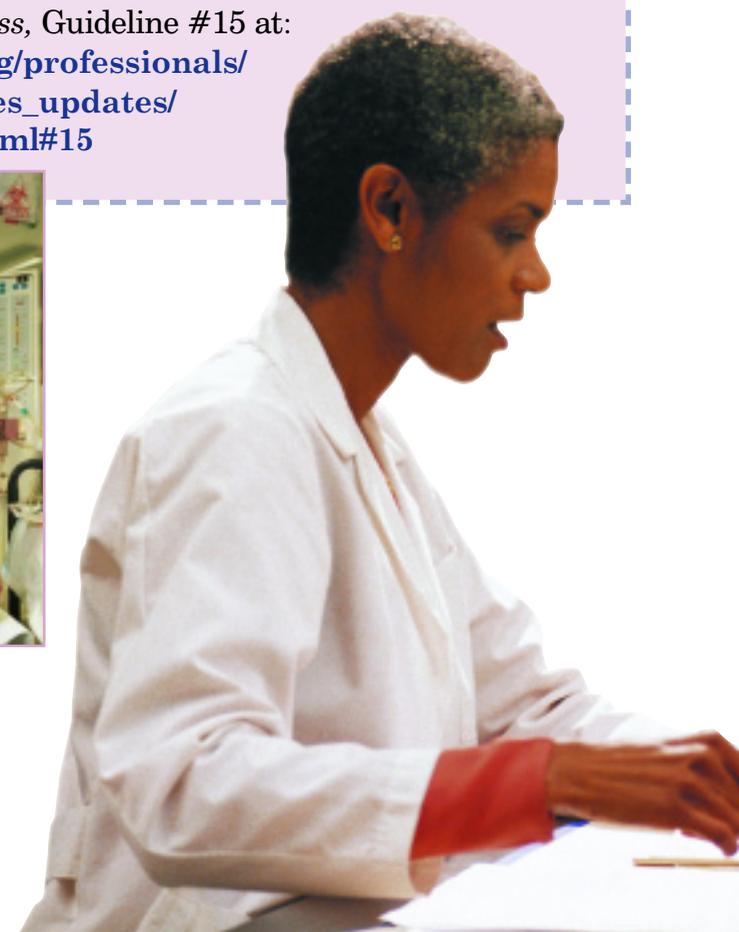
✓ If you have a U-shaped graft, ask your dialysis nurse which side is the artery and which side is the vein. The needle on the artery side of your graft should always be hooked to the tubing going to the blood pump. If the tubings get switched, you will not get a good dialysis treatment.

✓ If you have a graft, ask your kidney doctor if your graft could be made into a fistula if your graft starts to fail.

✓ Dialysis catheters can cause serious life-threatening infections. If you use a dialysis catheter, talk to your kidney doctor about getting a fistula, or if a fistula is not an option, a graft.

✓ If you use a catheter, help to prevent infection:

- You and your caregiver should wear facemasks whenever the catheter is uncapped and open to the air (i.e., starting and stopping dialysis).
- Keep your catheter site covered with a sterile gauze dressing between treatments.
- Read more about preventing catheter infections in the K/DOQI *Clinical Practice Guidelines for Vascular Access*, Guideline #15 at: [www.kidney.org/professionals/kdoqi/guidelines\\_updates/doqiupva\\_iii.html#15](http://www.kidney.org/professionals/kdoqi/guidelines_updates/doqiupva_iii.html#15)



## Before, During and After Dialysis



- ✓ Ask family members or the dialysis staff to help you walk to and from your dialysis chair if you feel weak or have vision problems.
- ✓ Learn your heparin dose. Double-check the type (beef or pork) and the dose with your caregiver every treatment.
- ✓ Double-check your dialysis solution with your caregiver. Make the amounts of electrolytes (especially potassium and sodium) printed on the package match what has been ordered for you.
- ✓ If your facility re-uses dialyzers, ask to double-check two things every time:
  - Look to see that the dialyzer connected to your machine has a label with your name.
  - Make sure the test for dialysis cleaner is negative before your treatment is started.
- ✓ Do NOT cover your needle sites and the needle/bloodline connection with a blanket or clothing. If a needle slips out or a bloodline comes loose under a blanket, you could lose a lot of blood very quickly before it is noticed.
- ✓ Any time you are given medicine through your dialysis tubing, ask the name of the medicine. If it does not sound familiar, ask your caregiver to double-check your chart. If you normally get medicine during dialysis and the medicine is not given, ask why the medicine was not given.
- ✓ Learn about infection control for dialysis units. Read the Centers for Disease Control Web site at [www.cdc.gov/mmwr/preview/mmwrhtml/rr5005a1.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5005a1.htm)
- ✓ Ask dialysis staff to teach you about the dialysis machine's monitors and alarms and your usual readings. Every treatment, check to make sure the alarm limits are set on your machine's monitors.

## Last, But Not Least



- ✓ Learn about kidney failure and the treatments for kidney failure.
  - Go to kidney patient education Web sites on the Internet – [www.kidney.org](http://www.kidney.org) (click on patient and family education), [www.aakp.org](http://www.aakp.org) and [www.medicare.gov/Publications/Pubs/pdf/02119.pdf](http://www.medicare.gov/Publications/Pubs/pdf/02119.pdf)
  - Read clinical practice guidelines (expert recommendations) about dialysis care. The National Kidney Foundation (NKF) has guidelines for vascular access, dialysis adequacy, treating anemia, preventing and treating bone disease and control of lipids. NKF guidelines are at [www.kdoqi.org](http://www.kdoqi.org) (click on Clinical Practice Guidelines at top of Web page). Guidelines have also been written by other groups for diabetes care, preventing amputations, wound care and many other medical conditions. To read these guidelines, go to [www.guideline.gov](http://www.guideline.gov) and type the disease or condition in search box.
- ✓ Make a “health history” list and keep it current.
- ✓ Ask your doctors, nurses, dietitians and social workers about things you do not understand. Where your health is concerned, no question is too silly, too little or too “stupid.”
  - Write your questions so you will not forget them.
  - Make sure you understand answers to your questions. If you do not understand, ask the staff person to use an example, draw a picture or explain it your family member.
  - If you are on dialysis, go to your scheduled patient care conference. This is your chance to discuss your dialysis care with the entire care team.

To learn more about safety, visit [www.esrdpatientsafety.com/fact\\_sheet.html](http://www.esrdpatientsafety.com/fact_sheet.html) for a listing of available safety fact sheets.



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

**1-800-622-9010**

or visit us at

**[www.kidney.org](http://www.kidney.org)**



**MEMBERS GET FAMILY FOCUS DELIVERED DIRECTLY TO THEIR HOMES**

As you make decisions to be highly active and involved within your dialysis unit, you should be giving equal thought to your exercise program.

Closing the gap between what you want to do and what you can do is done by setting your goals, knowing your body and having the discipline to follow through with your goals. Sometimes people forget that, although exercise is done to become or stay healthy, proper measures must be taken to stay healthy enough to exercise. It is discouraging to begin an exercise program, become successful, then be forced to take an unwanted break due to unnecessary injuries. So before you begin your program, review these tips to help keep you fit and exercising towards better health.



*Rolling your wrist up and down, as if signaling someone to come over to you, can stimulate your forearm muscles. In time, you may add some light weight, like a ball or can.*

As you well know, your vascular access is your lifeline for hemodialysis. It is very important to maintain the health of your access. There is some debate among health care professionals as to whether or not exercise training should involve your body part containing the access. After consulting with your personal health care provider, you might consider doing some exercises that involve strengthening the muscles around your access. These exercises can be done without the use of heavy weights. For example, if exercising your

## Protecting Your Hemodialysis Access

By Pedro Recalde, MS, ACSM

*Gentle exercise of the access arm may be beneficial for some on dialysis.*

forearm, simply sit in a comfortable chair and rest your arm to your side with the access side up. Rolling your wrist up and down, as if signaling someone to come over to you, can stimulate your forearm muscles. With time, if you want to add a bit of resistance, hold a can of soup in the palm of your hand while exercising to help increase your strength. Exercising your upper arm (bicep) can be done in a similar fashion. Hold a can of soup in the palm of your hand and raise it up and down, bending at the elbow.

Consider these additional helpful hints for protecting your access.

■ Although the dialysis clinic is the perfect place to begin an exercise program, exercises involving your access site must not be done while dialyzing. In order to keep a smooth and rapid flow of blood, your access should be kept as still as possible.

■ While doing any kind of exercise, you should not wear any tight bands or jewelry around your access. There is a lot of movement involved when exercising, so special care should be taken to make sure that your access site is not being hit, rubbed or cut during your routine.

■ Remember to wash your hands often, especially when handling weights in public places, to keep yourself and your access clean.

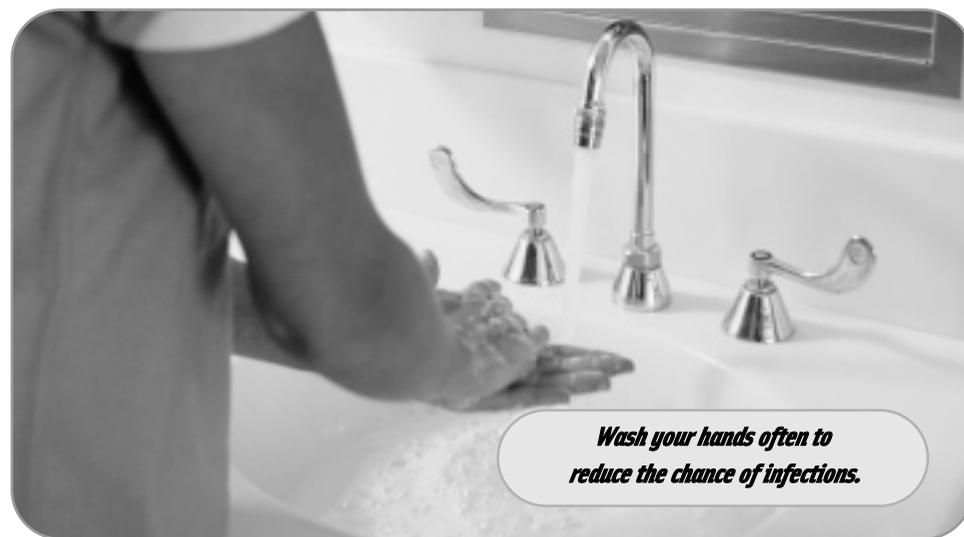
Although there are risks involved in exercising (bumping or straining your access arm could damage the access), keep in mind that there are also risks involved in not exercising.

When you protect your access to the point where you avoid using that arm in all activities, you might be harming yourself more than helping. The strength of your muscles has to do with the amount

those muscles are used. Muscles that are never used will actually shrink in size. In fact, muscles will lose their ability to complete normal activities with each month that passes if they are not used. It is true what they say: "Use it, or lose it."

Notify your doctor or nurse if you notice changes in your access. These changes might include, but are not limited to: unusual pain, numbness, bleeding, redness or abnormal bulging in the areas of the access.

Remember, the more you prepare yourself now, the stronger you will feel, making your exercise sessions more successful and a positive experience. 



## Family Focus VOICES

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

Read the question below and let us know what you think. You will also find this question posted online at [www.familyfocusvoices.org](http://www.familyfocusvoices.org)

You may visit the Web site and share your thoughts there, or send your response in writing to *Family Focus* Voices, 30 East 33<sup>rd</sup> Street, New York, NY 10016.

*What has made your life outside of the dialysis unit better by helping you cope with the challenges you may face with such things as personal relationships, meal planning or employment?*



Transplantation is just one treatment for chronic kidney disease. Your health care team can help you decide if it is the right one for you.

Not everyone is a candidate for a kidney transplant because of his or her medical condition. But if you are interested in one, you should ask questions and find out more about this treatment. If your physician recommends that you consider transplantation, he or she will refer you to a transplant center for evaluation.

Before you meet with the transplant team, there are a few basic medical exams, x-rays and tests you should have if you have not already had them in the past year. Getting these done, or at least scheduled, will help you get on the transplant list sooner.

**The things** you should have done include:

- Physical exam
- Mammogram (women)
- Electrocardiogram (EKG)
- Dental exam
- Chest x-ray
- PAP test (women)
- Stool sample
- Prostate Specific Antigen (PSA) test (men)

All of these are part of health screening that everyone needs regularly. Ask your doctor or nurse for copies of the results to take with you to your transplant appointments. The transplant team will order additional testing depending on your specific health needs.

If there is someone who wishes to donate a kidney to you, this potential donor will have to be screened and tested to make sure their donation will be suitable for you.

## Kidney Transplantation: Am I Ready?

By Linda Harte, RN, BSN, MA, CNN, CCT

*Consider these important questions if you are interested in a kidney transplant.*

The transplant team will arrange for you to talk with a social worker or psychologist to discuss how you are coping with your disease and treatments, how well you take care of yourself and to be sure you are “mentally” healthy enough to go through transplant surgery and care afterwards. You should ask yourself these questions to prepare for a possible transplant:

- ✓ Do I take my medications regularly as prescribed?
- ✓ Do I dialyze regularly and attend all medical appointments?
- ✓ Will I be able to take care of myself when I go home from the hospital?
- ✓ Do I have someone to take me to my appointments after the transplant until I can drive myself?
- ✓ Do I have a telephone so I can call if I have questions or so the transplant nurse can notify me of all test results and possible changes in my medication after the transplant?
- ✓ Does my health insurance have certain transplant programs I must use?
- ✓ Have I talked with someone at my insurance company about my transplant benefits?
- ✓ Does my health insurance cover the anti-rejection and anti-viral medications?
- ✓ Will I be able to pay the co-pay?
- ✓ Will I be able to afford the cost of anti-rejection medications, or have insurance coverage, when Medicare coverage expires?
- ✓ Does the transplant center have my current address and phone number?
- ✓ Do they have alternative numbers or people to call to find me (cell phone, pager, work number) when a kidney is available?
- ✓ Do I let them know when I am going to be out of town or unavailable?
- ✓ Has my insurance coverage changed and, if so, do they have my new information?



The answers to these questions are just as important as the physical part of your evaluation.

After you are on the transplant list and waiting for that call, you need to be ready. You might want to periodically ask yourself these questions:

- ✓ Have I called to let them know about any changes in my health, hospital stays, or new medications?
- ✓ Have I kept my appointments for re-evaluation every 6 to 12 months? a transplant, or they discover that you never went to the dentist to get that cavity filled. Be sure to stay in touch with the transplant coordinator about any changes in your life.

It is very upsetting to both you and the transplant team when a call has been made to inform you that a kidney is available for you and they are not able to find you, or you do not have insurance approval. A successful transplant may greatly improve the quality of your life. Be sure you are ready by being an active part of your health care team! 

# JUMP START

## HOPE.

There are lots of reasons to donate a car to the National Kidney Foundation.

A possible tax deduction\* is only one.

## Call

**1-800-488-CARS**

*Make Your Car a Kidney Car.*

*Cars That Save Lives.*



\*Consult your tax advisor for details.

We have all had emergencies in our lives—some big, some small—and most of them are scary. People on dialysis and their families may need to take a few extra steps in preparing for emergencies.

Any emergency calls for quick, calm action; as a person on dialysis you will need to respond to the immediate situation AND consider your dialysis needs at the same time. Emergencies can happen anywhere! If you are on dialysis you have probably experienced a practice drill of “quick evacuation” in your clinic. These drills help prepare people on dialysis and staff for emergencies such as fire, storms or loss of power. It is a good idea to do practice drills in the dialysis clinic and in your home.

**Know your medications, and make sure you have adequate supplies.**



The National Kidney Foundation has a few informational booklets that give important information about planning for emergency situations: *Planning for Natural Disasters and Other Emergencies* comes in two versions – one is a guide for those on dialysis and one is

## Preparing for Emergencies: A Basic Tool for Life

By Roberta Bachelder, MA

*A little reading and a little planning can make you ready for anything*

for facilities. *Emergency Meal Planning* gives information to be used in the event of a natural disaster when dialysis may not be available, with a grocery list and three-day meal plan included. To request a copy of these booklets contact the NKF at 1-800-622-9010 or visit [www.kidney.org](http://www.kidney.org) to download a copy. Just enter the word ‘emergency’ into the search box to view other NKF publications about emergencies for those on dialysis.

CMS (Centers for Medicare and Medicaid Services) has also published an important booklet to help you prepare for emergencies. The booklet is written

specifically for the special needs of individuals on dialysis. *Preparing for Emergencies: A Guide for People on Dialysis* (government publication number 10150) is a free 35-page booklet with useful information about how to:

- prepare an emergency box
- create a brief accessible “medical record” about your specific dialysis needs
- control fluid and diet for a few days (if necessary)
- disinfect water.

To get this booklet, you can either download it from the Medicare Web site, [www.medicare.gov](http://www.medicare.gov), or request one from the ESRD Network [www.esrdnetworks.org](http://www.esrdnetworks.org) that serves your state or ask your dialysis clinic.

Preparing for emergencies could save your life, and will help you have a complete “Tool Box For Life.” Plan today—some day you might be glad you did!



## National Kidney Foundation Grant Recipient Studies Use of Nutritional Supplement for People on Hemodialysis

Good nutritional status is one of the key factors determining how well you do on dialysis. Because of this, there is a need for research to find ways of improving nutritional status for those on dialysis. The National Kidney Foundation’s (NKF) Council on Renal Nutrition (CRN) is funding a multi-center study to evaluate the nutritional effects of taking a supplement containing amino acids, the building blocks of protein, for people on hemodialysis. The study is being conducted by Nancy Ginsberg, MS, RD, a renal dietitian at the Renal Research Institute in New York. Ms. Ginsberg plans to use measures such as serum albumin level to evaluate the nutritional status of people

on hemodialysis after six months of taking the supplement. Albumin is a type of protein that plays an important role in helping to maintain your body’s health.

### **Research is a Top Priority for NKF**

More than 20 million Americans have chronic kidney disease (CKD) and another 20 million are at increased risk for developing kidney disease. Research is the only way we will find the answers that can turn these statistics around. Each year, the NKF provides close to \$5 million to fund research. The NKF’s research program has many levels including Research Fellowships and Young Investigator Grants, which support young medical scientists at

the beginning of their research careers, and Clinical Scientist Awards, which permit established investigators to devote more time to their research. Grants are also made to nurses, dietitians and social workers to help them improve the quality of

patient care. The NKF is proud to continue its support of research as another important means of achieving its vision of Making Lives Better.

For more information on NKF’s research program visit [www.kidney.org/professionals/research/](http://www.kidney.org/professionals/research/)



*Nancy Ginsberg is studying the effects of a new nutritional supplement.*

Children who receive hemodialysis usually spend 12 to 16 hours each week at the dialysis center. Only a few units specialize and cater to the needs of children, and these units are not often available to many children with chronic kidney disease (CKD). As a result, most children dialyze in centers that mainly serve adults. Because of this situation, this article describes how children's needs may be met in centers that treat both adults and children.

### THE BENEFITS OF RECREATIONAL ACTIVITIES DURING DIALYSIS TREATMENT

Children often complain of boredom while on dialysis and pass the time by sleeping. For many children, a daytime nap can disrupt their nighttime sleep and consequently their ability to function optimally during the day. A backpack or activity bag with some of your child's favorite card or board games, arts and crafts supplies, books and books on tape, handheld video games and approved snacks (if the unit allows eating during dialysis) may be very useful in preventing the "boredom" nap. Change the contents of the activity bag every few weeks and let your child help decide what to pack.

### THE BENEFITS OF EDUCATION ABOUT CKD AND DIALYSIS DURING DIALYSIS TREATMENT

Most people have heard the expression, "knowledge is power." This is especially true in the management of kidney disease and there is a lot to know. Children need to understand how and why hemodialysis works, the importance of taking their medicine, how they can stay healthy in between treatments, the importance of protecting their graft and keeping the graft area clean, the importance of eating the right foods and consuming the correct amount of fluid and

## Time Well Spent on Hemodialysis

By Beth Bounds, LCSW-C and Arlene C. Gerson, PhD

*How can you make the most of your child's time on dialysis?*

alternatives to hemodialysis. This information should be given in language that the child will understand, a little at a time and with frequent review and opportunity for questions. Many dialysis units have books, pamphlets and videotapes with drawings and charts that can be used and there may also be educational materials that are designed specifically for children.

### THE BENEFITS OF OPTIMISM DURING DIALYSIS TREATMENT

Keeping a positive attitude in the face of continued and frequent hemodialysis is sometimes a very difficult thing to do. It is important for children and parents to get emotional support, especially if emotions or attitudes get in

*Positive attitudes by parents and staff members can help keep children smiling*



the way of full treatment. Emotional support helps in keeping a hopeful attitude about the future. Schedule an appointment with your unit's social worker to discuss your child's adjustment to dialysis. Try to get connected with other patients and families in the unit in order to increase your social support network. Your child might also benefit from talking with other children who have CKD. If you cannot find the support you need in your center, ask a health care team member for a referral to a

health professional who specializes in working with chronically ill children.

### THE BENEFITS OF FOCUSING ON EDUCATION DURING DIALYSIS TREATMENT

Children of all ages on hemodialysis can take advantage of their time on dialysis by working on educational and school assignments. For many children, missed school is an unfortunate result of chronic hemodialysis. It is important that parents and health care team members advocate for the child to get educational and vocational services suitable to their level of need. In fact, it is required under Federal Public Law that all children receive

a fair and appropriate education in keeping with their medical needs. Talk to the unit manager and counselors at your child's school to find out if tutoring or academic instruction can be set up at the dialysis unit by

the school system. If formal instruction is not available in the dialysis unit, parents and unit staff should create an atmosphere to encourage studying and homework at the clinic. It is important to praise your child for academic and vocational interests. Older teens can use dialysis run time to study for standardized tests (GED, SAT, GRE), to search the Internet (if the Internet is available) for educational and vocational opportunities and/or to work on college coursework.

### THE BENEFITS OF ADVOCACY DURING DIALYSIS TREATMENT

Parents, as well as the child, are important members of the health care team and can positively influence their child's treatment experience. One of the most important things you can do for yourself and your child is to be an advocate for your child's needs within the hemodialysis center.

Learning about hemodialysis, nutrition and medication can help parents be good advocates for their child. Hemodialysis is a major commitment and will be a big part of your child's life. Encouraging a child-friendly atmosphere in the dialysis unit will help make runs more pleasant. Consider talking to the nurse manager, social worker or doctor about creative ways to better meet the needs of your child in the unit. This can range from asking the center for videos or pamphlets about kidney disease that are targeted to children, to helping the child be more comfortable in the clinic, through decorations, activities or music. Your help can make all the difference in creating a pleasant dialysis experience for your child. 

### About the Authors

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**Dolph  
Chianchiano,  
JD, MPH**

## Disease Management: New Programs Being Tested

By Dolph Chianchiano, JD, MPH

*The government is helping clinics explore new tools to help those on dialysis manage their kidney disease.*

Disease management programs have become a popular way of coordinating and improving the care of people with chronic illnesses. The goal is to stop complications and lower rates of hospitalization or emergency room visits. Disease management programs support the patient's role as a vital member of the health care team. Typically, the disease management approach uses a system of tools that makes it easier for patients and health care professionals to understand and follow treatment plans.

Common examples of disease management tools are educational materials and programs, alerts, reminders and feedback activities. For instance, a disease management system would alert a kidney doctor when another doctor has prescribed a drug that might affect the person's dialysis treatment. Reminders might include notices to individuals that they need to refill a prescription or to doctors that a prescription has expired and ought to be renewed. These reminders can be mailed, sent over the telephone (with a live or pre-recorded message) or delivered by e-mail.

More unusual solutions may also be used in the disease management process. For example, in order to assist people with kidney disease in reaching dietary goals, one disease management program delivered food scales for use in all participants' kitchens. Some disease management programs assign care managers to coordinate services. These care managers serve as a communications link between

the patient and health care professionals.

On June 4, 2003, the U. S. Centers for Medicare and Medicaid Services (CMS) announced plans for a program of pilot projects to test if disease management helps to increase quality of care for people who are receiving in-center dialysis. (This is known as the CMS ESRD Disease Management Demonstration

*Common examples of disease management tools are educational materials and programs, alerts, reminders and feedback activities.*

Project.) Some health care organizations applied to participate before the fall of 2003, and those selected will pilot test their programs over the next four years. If these programs prove to be useful, it is possible they will become more widespread.

People on in-center hemodialysis may learn that their clinic is testing a disease management program, and if so, they may be asked if they would like to participate. While disease management can be used with any kind of health insurance, the CMS ESRD Disease Management Demonstration Project will also test the effectiveness of paying for health care services in new ways. As a result, people receiving dialysis who choose to enroll could find their options expanded in some ways and restricted in others. For example, participating organizations

may choose to pay for services that are not currently reimbursed by Medicare, like transportation (to and from dialysis treatments), mammography and nutritional supplementation. On the other hand, patients participating in the demonstration may be allowed to see only certain specified health care providers and may have to pay additional premiums or cover different levels of

deductibles and co-payments than Medicare would normally require. This is an important consideration since Medicare beneficiaries who have Medigap insurance should probably plan to pay premiums to keep those policies in force during the demonstration project. Otherwise the same coverage might not be available at the end of the demonstration.

Medicare beneficiaries with chronic kidney disease (CKD), but who have not reached the stage where they need dialysis treatments or a kidney transplant, may not enroll in this disease management program. The Centers for Medicare and Medicaid Services may develop a new pilot project in the future to evaluate the impact of disease

management for those with CKD who are not yet on dialysis.

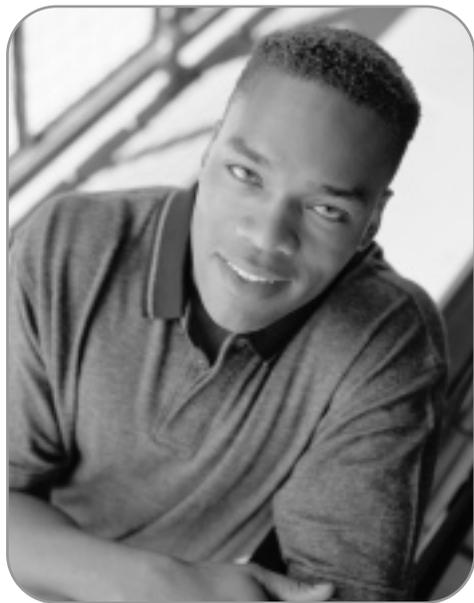
There are some similarities between the CMS ESRD Disease Management Demonstration Project and an earlier pilot program, the ESRD Managed Care Demonstration, conducted by the Health Care Financing Administration from 1996 through 2000. Those who participated in the earlier demonstration reported higher satisfaction with health plan benefits than a representative sample of people who were covered by traditional Medicare arrangements. Also, when contrasted with people in the comparison groups, demonstration participants experienced some improvement in quality of life, particularly with regard to mental well being. The new demonstration may similarly find ways to improve the health and well being of those on dialysis.

For more information about the Medicare ESRD Disease Management Project, patients and family members may contact Brady A. Augustine at the Centers for Medicare and Medicaid Services. Mr. Augustine is the Medicare Program Executive for ESRD. His e-mail address is [baugustine@cms.hhs.gov](mailto:baugustine@cms.hhs.gov)



**Some disease management programs may explore ways to use the phone or e-mail to send reminder messages to people on dialysis.**

It is unlikely that you would choose to have chronic kidney disease (CKD) and that you would welcome the need for dialysis. However, having CKD and living with dialysis may be just where you are today. Finding the strength within yourself to live life to the fullest in spite of CKD may not come easy, but it is very possible. Over the last 20 years, I have seen strength beyond belief in people who were at difficult times in their life. This strength can be defined as “resilience.”



The basic characteristics of “resilience”<sup>1</sup> should be part of your “dialysis toolbox.” I bet you have some, if not all, of these characteristics. You can probably think of other helpful personality traits that you see others using to adjust to dialysis, or that you recognize yourself using daily to make the best of your time on dialysis. Some of these include:

**Honest Insight:** Asking tough questions and giving honest answers. At times it may seem a bit overwhelming to ask the doctor a question or share a fear or concern with a staff member, however, communication can help you to be an active part of your care.

**Independence:** Being self-reliant. Being different from the group sometimes is

## Making the Shoe Fit: Seeing the Potential Instead of the Problem

By Mary Beth Callahan, ACSW/LMSW-ACP

*Resilience is needed to live your life to the fullest.*

hard. A different treatment like peritoneal dialysis or transplant may be right for someone else, but may not be what you want. Keeping true to yourself usually feels best.

usually makes others want to be around you and makes you feel better about yourself.

**Morality:** Being in agreement with standards of

*Thinking of your strengths, skills and resources instead of weaknesses has come to be known as the “Strengths Perspective”*

**Relationships:** Making connections to other people. Connecting with other people on dialysis and their families and dialysis staff often gives people something to look forward to at the dialysis center. Having the support and friendship of others can make each step of life easier to manage.

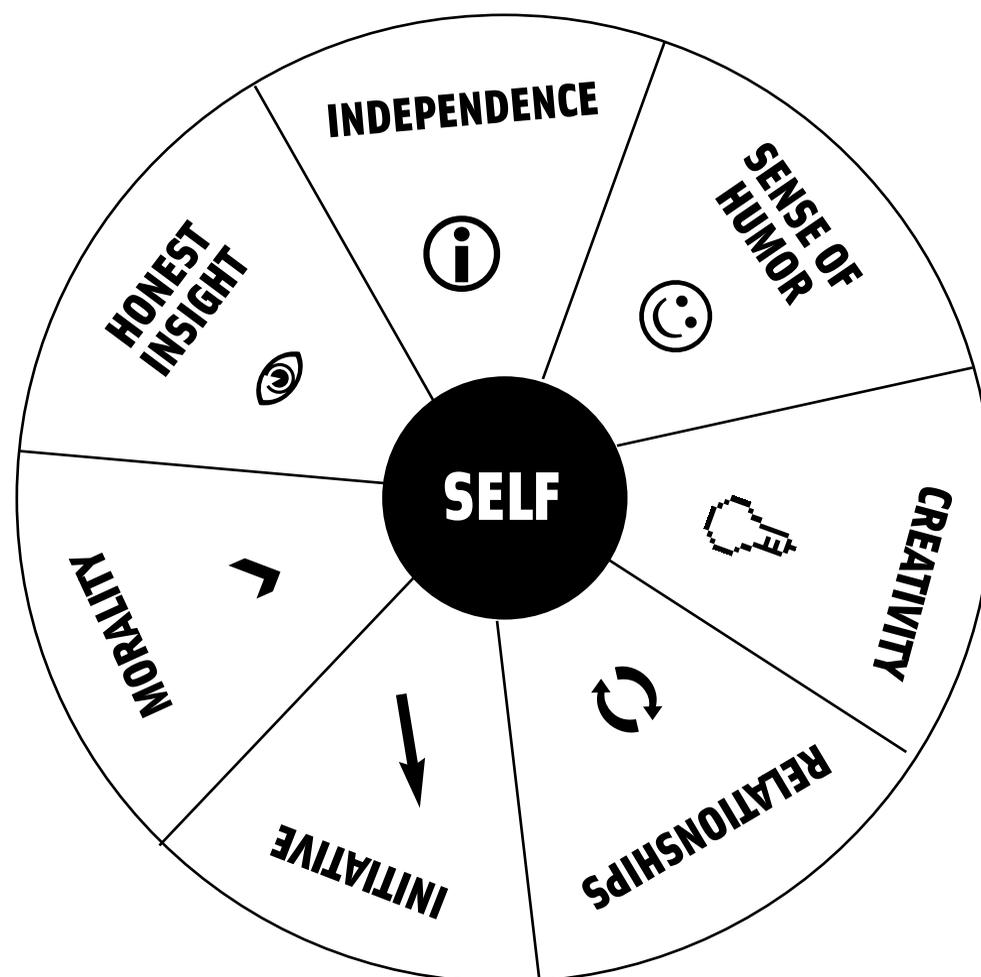
**Initiative:** Taking charge of problems. Sometimes it may feel like many things about CKD are out of your control. However, the more involved you are in your care, the more control you will likely feel.

**Creativity:** Using your imagination. Problem solving takes creativity. CKD and its treatment offer opportunities to look at problems in different ways and draw on your strengths to adjust to the changes that come with CKD.

**Sense of Humor:** Being able to laugh and find the bright side whenever possible. Having a positive attitude

right or good conduct. The Dialysis Patients’ Bill of Rights and Responsibilities may help you to think about your life in the dialysis center and how you can use your strengths and life experiences to make dialysis fit into your lifestyle.

Thinking of your strengths, skills and resources instead of weaknesses has come to be known as the “Strengths Perspective”<sup>2</sup>. This idea suggests that every individual, group or family has strengths. Illness and struggle, though difficult, may be sources of challenge and opportunity. Focusing on your strengths and how you have handled other difficult times in your life may give you new hope for the future. It may not be the same vision you had as a child, young adult, parent or senior before you were diagnosed with CKD, but focusing on your strengths may open doors you could not have imagined earlier. 



1. “Vocabulary of Strengths: The Seven Resiliences”. [www.ProjectResilience.com](http://www.ProjectResilience.com).

2. Saleebey, Dennis. *The Strengths Perspective in Social Work Practice*. Boston: Allyn & Bacon, 2002.

Each year the Patient and Family Council receives numerous outstanding submissions for the annual Wayne Nix Memorial Award, and this year will be no exception. The award seeks to recognize an individual with chronic kidney disease who, through life experience and activity, has proven that he or she is committed to improving the lives of all those affected by kidney disease.

Last year's winner of the 2003 NKF-PFC Wayne Nix Memorial Award was Richard Salick. Richard was diagnosed with kidney disease at the age of 23 while pursuing his career as a professional surfer. Today, 30 years and three kidney transplants later, he refuses to let this disease slow him down. Richard has worked actively with the National Kidney Foundation (NKF) for the past 18 years and currently serves

as the Director of Community Relations for the NKF of Florida, Inc.

While in his position as Director, Richard created an educational program designed to introduce seventh and eighth graders in Florida to kidney disease, as well as developed an

annual surfing festival that has raised more than \$4 million for the NKF of Florida. Despite his personal health problems, Richard continues to maintain a positive attitude. He knows that his main goal is to continue his tireless work to improve the lives of those with kidney disease.

## The NKF-PFC 4th Annual Wayne Nix Memorial Award

*Are you 2004's Winner?*



*Richard Salick receives the 2003 Wayne Nix Award from Linda McCann.*

Like Richard, there are many more individuals who feel that by improving the lives of those with kidney disease they are meeting their life's mission. If you know that special individual who makes the lives of individuals with kidney disease just a little brighter, we encourage you to submit an application on their behalf. For a complete list of criteria and to submit a nomination, please visit the Patient and Family Council's Web site [www.nkfkidneypatients.org](http://www.nkfkidneypatients.org) and click on Wayne Nix Memorial Award. If you would like an application mailed to you please contact the National Kidney Foundation at 800-622-9010. The deadline for applications is Friday, July 30, 2004. 

In the next issue of  
**Family Focus...**

**TOOLBOX FOR LIFE, PART II:  
Dialyze to Live, Don't Live  
to Dialyze**

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