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CHRONIC KIDNEY DISEASE AND THE LIFE CYCLE

# Family Focus

The Renal Community's Newspaper

VOLUME 10 NUMBER 4

FALL 2001

WHAT DO CHRONIC KIDNEY  
DISEASE AND THE LIFE CYCLE  
MEAN TO YOU?



The staff and volunteers of the National Kidney Foundation's national office in New York City would like to thank all of our members and friends for your calls, e-mails and letters following the attacks on the World Trade Center. We take comfort in knowing that, just as in the streets of New York and Washington, family and friends across the nation are keeping one another in their thoughts, prayers and hearts.

## Youth is Wasted on the Young

By Sharon Anderson, MD

As the baby boomer generation approaches mid-life and beyond, they are no doubt learning first-hand that the normal aging process takes its toll. Growing older usually means the appearance of new aches and pains accompanied by an increased risk of developing heart disease, fragile bones, urinary problems and some types of cancer. The kidney is no exception; even healthy older people lose some kidney function as they age. Most healthy patients will lose 20 to 30 percent of kidney function through aging, and this process may be accelerated if the patient has hypertension, smokes cigarettes or has other serious medical problems. Fortunately, we are born with more kidney function than we need and so for many of us, this small age-related loss in function will not cause serious problems by itself.

Heart disease and cancer remain the leading causes of death in the elderly in this country. Heart disease often comes from atherosclerosis (hardening of the arteries), which is due to a buildup of material inside the blood vessels that supply the heart. If a vessel becomes completely blocked or develops a clot, the blood supply is cut off and this causes a heart attack. Another type of heart disease happens when the heart muscle becomes damaged from lack of blood supply. As the heart muscle weakens, it cannot pump blood as well as it should. This

is called congestive heart failure, and it is very common in older people.

Heart disease is even more common in people with chronic kidney disease, including those with kidney failure who are on dialysis or are transplant recipients. The good news is that with a healthy lifestyle, much heart disease

**Risk factors for getting heart disease include cigarette smoking, high blood cholesterol levels, high blood pressure and lack of exercise.**

can be prevented. In fact, since the percentage of adults who are smokers has been declining over the past two decades, the number of deaths from heart disease has been falling. Risk factors for getting heart disease include cigarette smoking, high blood cholesterol levels, high blood pressure and lack of exercise. People who stop smoking, control their cholesterol (through diet, exercise and sometimes drugs) and their blood pressure and engage in regular physical exercise can cut down their chances of having a heart attack. One aspirin a day can also help prevent heart attacks in some cases. However, since aspirin can cause complications in those with chronic kidney disease, you should

ask your doctor before taking it. There is some evidence that in postmenopausal women, estrogen therapy may reduce the risk of heart attacks. However, we do not know for sure if estrogen therapy is effective in dialysis patients. People who have congestive heart failure need to limit salt intake, since too much salt in the diet places more of a burden on the damaged heart muscle. If you are on dialysis and have heart failure, you must be very careful to limit your weight gains, because the extra fluid in your system also places a burden on your heart's ability to pump blood.

Atherosclerosis can also occur in other blood vessels, including those that send blood to the brain and to the legs. In the case of the brain, atherosclerosis can cause strokes. When it involves the legs, atherosclerosis can cause pain with walking (claudication), foot ulcers and eventually the need for amputation. The same things that help to limit the risk of heart disease, such as stopping smoking, controlling cholesterol, controlling blood pressure and regular exercise, can help to reduce your risk of strokes and other circulation problems.

Cancer is the other leading cause of death for the elderly in this country. The presence of kidney disease will not increase your risk of getting cancer.

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Making Lives Better

# FROM THE EDITOR



Karren King

**T**his issue of *Family Focus* is entitled Chronic Kidney Disease and the Life Cycle. What are the messages that we, the Editorial Board, hope to impart with this theme? To us, the messages are twofold. The first and most obvious one is that chronic kidney disease and kidney failure can and do affect people of all ages, races and sexes. In other words, it is universal and does not discriminate. The other message we want to impart is that a person with chronic kidney disease can persevere and live a life of quality and longevity. In other words, to borrow a phrase from our friends at the Life Options Rehabilitation Program, you can "live long and live well" with kidney disease.

There are articles that focus on aspects of living with dialysis that affect individuals throughout the various phases of their lives. The topics range from how you transition from being a child with chronic kidney failure to a young adult, to those that discuss how you plan for the end of life, as well as the years that fall between. We are especially pleased to highlight tips about how to live a long and enjoyable life from those who have actually "been there and done that." Many of you from around the country who have been on dialysis and/or transplanted for 25 years or longer have shared the "secrets of your success" with us. We are indebted to you for sharing your words of wisdom.

This issue also brings to a conclusion the current life cycle of our 2000-2001 Editorial Board. We will be losing two valuable members, Susan Carey, fitness editor, and Beth Witten, social work editor. These two individuals were wonderful contributors and will be greatly missed. The remainder of your Editorial Board has graciously agreed to continue. They will be joined by two new additions. Mary Beth

Callahan and Tiffany Shubert are, respectively the incoming social work and fitness editors. I am confident that this new Editorial Board will continue to bring you, our readers, the same high quality publication that you have come to expect.

Lastly, I cannot end without disclosing that I am writing this editorial two days after the horrid terrorist attacks that have occurred in the United States. As a nation, our hearts are heavy and, I know, will remain so for a very long time. This nightmare has resulted in much soul searching. In thinking about whether there are any lessons that we in the kidney community might learn, I think there are several. The first is that just as our country is realizing that it is indeed strong in the face of adversity, so too are you. You have been diagnosed with a chronic disease and have faced adversity of a different type, but nonetheless adversity and hardship. Yet, you have persevered. The other lesson I believe we have all learned is that life is valuable and precious. None of us ever knows the future with certainty. What we do know is that we have the present, and that wherever any of us are in the cycle of life, we should enjoy it and live our life to the fullest. **FF**

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



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

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## Making Lives Better Campaign

**FOR THE FIRST TIME IN OUR HISTORY**, the National Kidney Foundation is conducting a major nationwide fund raising drive. With this initiative, we hope to offer more programs in clinical science and research and services for patients and families.

During our 50-plus years of service, the National Kidney Foundation has become a source of information, support and advocacy for the many thousands of individuals and families who turn to us for help. Today's NKF faces the challenges of its second half-century to fulfill its vision of *Making Lives Better* for all of our constituencies — patients and families affected by chronic kidney disease, transplant recipients of all organs, and donor family members. We are asking you for your support to help us to achieve our mission.

## Youth is Wasted on the Young

*continued from page 1*

Getting older will increase your risk of cancer, but there are many things you can do to reduce your risk. Early detection is very important. For example, women should have breast examinations, mammograms and Pap smears; men should have prostate exams; and all of us should have regular checks for blood in the stool (a sign of colon cancer). Stopping smoking will decrease your risk of lung cancer. You should discuss your cancer risks with your doctor and get more information about what you can do to limit your risk.

Another common problem associated with aging is difficulty controlling urination. Some women have bladder difficulties, especially if they have had several children. For men, the prostate can enlarge and cause some blockage of the urine, making the stream hard to start or stop or causing dribbling. These conditions are embarrassing, but they can usually be treated. Ask your doctor.

As we grow older, our bones may get more fragile, sometimes leading to a condition called osteoporosis. When bones are fragile, they can break easily. For example, hip fractures are common in the elderly. You can lower your risk of developing osteoporosis by exercising regularly and maintaining an adequate calcium intake beginning when you are young. Osteoporosis can be treated with diet; medication and exercise can also help. For postmenopausal women, estrogen therapy can help prevent osteoporosis. Bone problems can be even more difficult for people with kidney failure who are on dialysis, because they are prone to developing other kinds of bone problems related to calcium, phosphate, Vitamin D and parathyroid hormone (PTH). Transplant recipients are also prone to osteoporosis because of the anti-rejection drugs. Your doctor and dietitian are watching your levels of calcium and phosphate and can discuss your bone problems with you.

Most of us develop some memory problems as we age. Fortunately for many people, the worst problem is forgetting where you left your car keys. For others, Alzheimer's disease is a serious problem. Right now there are no proven ways to prevent Alzheimer's disease, but there are new drugs that may be helpful in limiting the symptoms. If you or a family member

are experiencing memory problems, please tell your doctor. He or she can help determine if there is a serious problem, and, if so, suggest ways to help.

Good nutrition is a key to healthy living at any age. Many older people find that their appetite has decreased with age. You can increase your risk of developing malnutrition if the proper intake of calories and protein is not maintained. But be careful with herbal remedies and "miracle" dietary supplements. Many of these are not effective, and some can cause serious side effects and complications, especially in people with kidney disease. If you are having trouble

finding foods that appeal to you, or if you want more information about herbal remedies, speak with your dietitian.

As more Americans are following a healthy lifestyle, we are living longer. These lifestyle changes, including diet, exercise and not smoking, can also contribute to a healthier old age, enabling us to continue the active lifestyle that we all enjoy. **FF**

*Sharon Anderson, MD, is currently professor of medicine in the Division of Nephrology and Hypertension at the Oregon Health and Science University in Portland, OR. In addition to practicing nephrology, she is very involved in teaching students, residents and fellows and in performing basic research related to chronic kidney failure.*

### Age-Related Changes in Organ Function

<u>Organ</u>	<u>Changes</u>
Kidney	Mild loss of kidney function
Bladder and prostate	Increased difficulty controlling urination
Heart	Increase in atherosclerosis (heart attacks) and congestive heart failure (decrease in ability of the heart to pump blood)
Bones	Osteoporosis (fragile bones, risk of breaking bones)
Circulation	Problems with blood circulation, especially to the feet and legs
Brain	Memory loss; higher chance of stroke
Many organs	Increased chance of cancer

**CORRECTION:** In the Spring 2001 issue (Vol. 10, No. 2), there was an error in the Good Nutrition column on page 11. In the fourth bullet in column two the article reminds readers to bring an adapter for their meter. It should read "batteries" instead of "adapter."

***If you'd like to contribute to the  
National Kidney Foundation, visit our  
Web site at [www.kidney.org](http://www.kidney.org)***

***or call***

***(800) 622-9010***

***to make your donation as a***

***Family Focus reader.***

# Where There's a Will, There's a Way: Advance Directives

By Erica Perry, MSW

*William remained motionless on the hospital bed. Tubes provided nutrition and oxygen as he remained in his five-month coma. While family sat silently in the room, hoping for some sign, doctors could offer nothing more. Everybody wondered what William would want but nobody knew for sure.*

**C**ongress passed the Patient Self-Determination Act in 1990 to avoid situations like William's. This law requires personnel in certain health settings to provide information about your right to have an advance directive.

## What is an Advance Directive and Why Should I Have One?

An advance directive is a legal document, and there are two types. A living will states the type of care you would want or not want in a medical crisis if you were unable to communicate your desires. A health care durable power of attorney, sometimes called a health care proxy or agent, allows you to name someone to make decisions for you if you are unable to make them. Ideally, you would have both a living will and a proxy, as the living will would inform the proxy of your wishes. It is also very important to discuss your desires with your proxy to assure that he or she understands what you would want and would be able to carry out your instructions. Although not complicated, writing your thoughts and making plans for what you would want in this situation can be uncomfortable. If so, why do it?

Hospitals want to know patients' wishes about medical care. Even if care near the end of life offers no hope, medical personnel often feel duty-bound to do everything unless the patient directs otherwise. Spouses or other family members may feel unprepared to tell a doctor what care to provide when a loved one cannot give permission. Courts have taken months to decide whether families can refuse treatment for permanently unconscious loved ones and allow them to die without an advance directive. A written advance directive, such as a living will, can help avoid legal problems by providing families and health care professionals with information about the care you would wish to receive.

## What Do Others Say About Having an Advance Directive?

Some "veterans" with kidney failure who help others with kidney failure take control in their lives have thought about living and dying. They share why they value advance directives.



**KIM KAPRON**, a 34-year-old diabetic, peer mentor, with kidney disease for 14 years:

*Despite my age, I have been close to death's door many times and have thought long and hard about writing my advance directive. However, until recently, I had a mental block that prevented me from writing my wishes down. Although I understood the benefits of the document, I harbored a superstitious fear about writing my wishes. During my grandmother's final months, I experienced the turmoil that results from not knowing someone's wishes. Still, I denied that I would ever be in that situation. Two years ago, my life changed when my daughter, Annabelle, was born. Having a child really changed my way of thinking. I want the best for her and do not want to leave her without guidance if something were to happen to me. My husband and I are both filling out our advance directives. We certainly don't like to think about dying, but we know about uncertainties in life and want to be prepared for whatever comes our way.*

**SALLY JOY**, a National Kidney Foundation of Michigan employee and peer mentor with type 1 diabetes who has had a cadaveric transplant for 15 years:



*Having an advance directive allows me to keep some control over my health care. There are worse things than death, and I do not wish to have my life maintained, merely to prolong the dying process. If my health care advocates are drawn into the decision making process with my end-of-life care, the discussions we have had, during the good times, will make their job easier.*

**AMY LOGAN**, a peer mentor with chronic kidney disease due to lupus who had her first dialysis in 1983 and a transplant in 1999:



*I find that dealing with the reality of death increased my appreciation of life immeasurably! Writing an advance directive and discussing death do not in any way mean that I'm giving up on life. I look at the cup as half-full, not half-empty — what I can do, not what I have lost. While the doctors do what they can do and I try to do what I can, I put my trust in God.*

Below are the steps you need to take to write your advance directive.

1. Imagine yourself in a medical crisis and unable to communicate. What kind of care would you want? Would you want to be on a breathing machine — ever?

*continued on page 10*

## Where Can I Get More Information About Advance Directives?

Additional sources of information about advance directives:

- Your dialysis or transplant social worker or other team member
- The Federal government regulations about advance directive can be reviewed at the following Web site: [www.uslivingwillregistry.com/fedregs.shtm](http://www.uslivingwillregistry.com/fedregs.shtm)

You may also request the patient booklet, *Advance Directives: A Guide for Patients and Families*, from your National Kidney Foundation affiliate or the national office at (800) 622-9010 or find "advance directives" on the NKF's Web site at [www.kidney.org/general/atoz/](http://www.kidney.org/general/atoz/) to print a summary of the brochure.

# Representative Karen Thurman Champions Cause of Kidney Patients

By Dolph Chianchiano, JD, MPA

**H**on. Karen Thurman was first elected to the United States Congress in 1992. A Democrat, Congresswoman Thurman represents the 5th Congressional District of Florida. She is the sixth woman to serve on the Ways and Means Committee of the House of Representatives in its 200 year history. (The Ways and Means Committee has authority in legislative matters involving Medicare.) Before coming to Washington, Representative Thurman served in the Florida State Senate and taught mathematics in a Florida middle school. She graciously agreed to be interviewed for this issue of *Family Focus*, and we are pleased to publish the transcript of that interview, which took place on July 25, 2001.

**Could you tell us how your personal experience with kidney disease has influenced your priorities for health care legislation?**

Back in the early 1990's my husband was diagnosed with polycystic kidney disease. Even though this is a hereditary disease, we didn't know that it was in the family because his father had died at a very early age. We learned that my husband would eventually end up on dialysis and he underwent dialysis treatments for three years before he received a transplant.

My husband joined a kidney patient support group in Gainesville, and meeting with members of that support group was what got me interested in the problem of reimbursement for immunosuppressive medications. We met individuals who could not afford these drugs and actually lost their transplants for that reason. Some had to choose between putting food on the table or a roof over their family's head and paying for their prescriptions.

**One of your priority issues as a member of Congress has been legislation to eliminate the 36-month Medicare time limitation on immunosuppressive medications for transplant recipients who received a Medicare-covered transplant. Could you comment on the advances that you've made in this effort?**

In the last session of Congress we passed the Medicare, Medicaid, SCHIP Benefits Improvement and Protection Act of 2000 (BIPA). This Act included a provision that I worked to put in place,

which provides lifetime coverage of immunosuppressive drugs for Medicare beneficiaries. I found out later that there is a loophole that does not extend lifetime coverage of these medicines to people who became eligible for Medicare primarily because of their ESRD. That is why I have introduced H.R. 1839, which would extend coverage to everyone who had a kidney transplant covered by Medicare.

Passage of BIPA was made possible because so many groups and individuals came together to work for the extension of coverage. Each was able to touch another member of Congress. I can't emphasize enough how much members of Congress relate



**Representative Karen Thurman**

to the personal experiences of constituents. Constituents can make a dramatic difference by making their senators and representatives aware of their problems. The Congressional recess provides an opportunity to do this while elected officials are in their home districts. We also got lots of help here in Washington from individual Representatives, especially Rep. Tom Bliley, who was chairman of the Commerce Committee in the House of Representatives, as well as Rep. Vic Snyder.

**What legislation have you sponsored in the 107<sup>th</sup> Congress to benefit dialysis patients?**

I have joined Representative Dave Camp in sponsoring H.R. 2220, which would increase the level of Medicare reimbursement for dialysis treatments and authorize payment for four dialysis treatments a week for children and for patients who weigh more than 165 pounds. Based upon my

husband's experience I understand the value of a fourth dialysis treatment for those who need it.

**If enacted, will the Patient Bill of Rights and Medicare Prescription Drug Coverage improve the care of kidney patients?**

The Patient Bill of Rights will ensure that individuals with kidney disease can have access to specialists. There are many kidney patients who are covered under an employer's health plan rather than Medicare. These people would benefit greatly from unfettered access to nephrologists and other specialists that this legislation would guarantee.

Being able to see a nephrologist may help preserve kidney function for a longer period of time in those who are approaching the need for dialysis. It can also help with the other kinds of complications that can accompany kidney disease. In my husband's case, we learned that aneurysms are common in individuals with polycystic kidney disease. Because of that information we consulted a neurosurgeon who located not one but two aneurysms. My husband could have died had he not had access to that neurosurgeon.

Similarly a Medicare prescription drug benefit will help beneficiaries pay for medications that control high blood pressure and lipids, both of which are common among kidney patients.

**The Secretary of the Department of Health and Human Services and the Administrator of the Centers for Medicare and Medicaid Services have a goal to substantially increase the number of Medicare beneficiaries in managed care plans. There is a statute that prevents individuals with End Stage Renal Disease from joining health maintenance organizations. Should that legislation be repealed?**

I think it should be repealed. Patients should not be locked out from any form of insurance because they have a certain medical condition. While kidney patients should not be forced into managed care, they should have the option if they want to exercise it.

*continued on page 7*

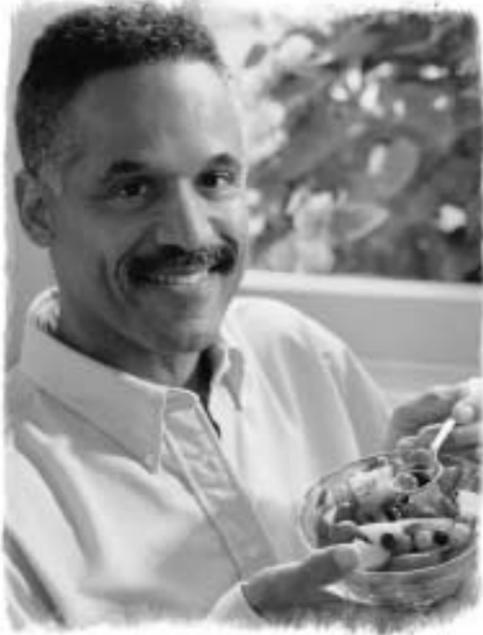


# Good Nutrition

## Nutrition Through the Life Cycle

By Mary Ellen Brabec, MHS, RD, LD

**A**s people on dialysis age, their nutrition needs and their ability to get adequate nutrition change. Following are some recommendations for how to meet the challenge of good nutrition.



As you move from one decade to another, the first change may be in the size of your meal. Typically appetite decreases and people feel full faster as they age. You may find you can only eat part of a sandwich at lunch or half of your usual portion. A solution may be to save the other half and eat it an hour or two later. If decreased appetite continues for more than a few days, you should tell your health care team. It may be due to a problem, such as inadequate dialysis or infection, which needs medical follow-up. The dietitian also may be able to help you plan your meals to assure you get adequate nutrition. He or she may provide supplements, suggest you eat more often or concentrate the calories in your food.

Another major change with age can be in body weight. Some people's weight will increase while others' will decrease. As the body internally slows down, it needs fewer calories to work. Many people, including those on dialysis, become less active as they get older and they will burn fewer calories as a result.

Increased body weight is known to contribute to the development of diabetes in adults or to make diabetes

more difficult to control. Being overweight can also lead to high blood pressure, high cholesterol and triglycerides and heart disease. Heart disease is a problem for many Americans but especially for people on dialysis. (See table below for ideas to decrease calories.)

Some solutions for controlling these potential medical complications include exercise, diet and medications. We all need to stay active. Be sure to include daily exercise in your life. Walk for 15-20 minutes, ride a bike, take an exercise class, play tennis, swim, play with your children or grandchildren; do something active. Better food choices, less sugar and fat, and an active lifestyle can help control your cholesterol level and manage the risk of heart disease. Taking these steps will help.

Dental problems can also impinge on good nutrition. Many people have chewing problems due to bad or missing teeth or poorly fitting dentures. Many times this can be corrected by seeing a dentist. It may also help to eat soft foods like eggs or egg substitutes, cottage cheese, rinsed canned tuna, thinly sliced meat or

casseroles with ground meat. If you are missing teeth or cannot wear dentures, it may be necessary to blend food in a blender. High protein drinks may help improve intake. Talk to the dietitian at the unit for more ideas.

Some people experience taste changes. This can be due to aging, medications, infections, dentures, inadequate dialysis or inability to smell food. Be sure to stay for your full dialysis treatment since inadequate dialysis is the most common cause of taste change. If you are adequately dialyzed and still have problems with taste, talk to your dietitian for help.

The ability to prepare food may be limited at any point in the life cycle. For example, a broken arm or leg can limit mobility. A stroke or a long period in the hospital may leave you too weak to fix meals. Talk to the dietitian or social worker about home delivered meal programs, someone to help with household tasks short-term or special equipment to make food preparation easier. 

*Mary Ellen Brabec, MHS, RD, LD, is a dietitian with Renal Care Group, Inc., in Olympia Fields, Illinois.*



*By following these few tips and keeping your health care team informed about any changes in your diet and in your life, you can maintain your nutritional status.*

To decrease calories:

**Have This:**

5 Vanilla Wafers  
Thin slice angelfood cake  
Graham crackers  
Light popcorn or unsalted pretzels  
1 Frozen fruit bar  
English muffin  
Sliced turkey or roast beef  
Dinner roll

**Instead of This:**

2 Chocolate Chip Cookies  
Poundcake  
Brownies  
Potato chips or corn chips  
Ice cream bar  
Donut or sweet roll  
Bologna, salami, corned beef  
Croissant



# PATIENT AND FAMILY CORNER

## When Saying Hello Seems Tougher Than Goodbye... And Other Things I've Learned

By Bruce Schultz

I was 13 years old in 1971 when I first walked into the Kidney Dialysis Center in Miami, Florida. The first thing I noticed was the smell of dialysate solution. To me, the smell was neither pleasant nor unpleasant, it just "was."

Now, after all these years, I can't remember the names and barely the faces of the first nurses who helped me with dialysis. My dad was with me to learn the machine because he was going to dialyze me at home for what turned out to be the next 15 years. I remember not liking the experience. The treatments were between six and seven hours long, and I had a hard time moving after each treatment ended.

Over time, the dialysis machines and kidney filters improved with technology. Treatment times became shorter. I understood my diet and fluid intake, began a sensible exercise program and started taking my medications as prescribed. I hope to pass on these well-learned lessons so that you, too, can survive long-term on dialysis.

An important thing to remember if you're going to have any kind of life on dialysis is "don't keep secrets!" What I mean is that your body is like a barometer: it can tell when you are in a "high" or "low" state of wellness. Learn to listen to what your body is telling you and report any new aches, pains, swellings, cuts, bruises, side-effects from medications, dizziness, falls, fainting, problems with your access, diet problems and changes in energy level. In other words, when things seem different or out of your normal experience with yourself physically, tell the dialysis nurse or nephrologist about it immediately. The staff can't read your mind, so talk to these people. They are there for your benefit and well-being.

Dealing with chronic kidney failure and dialysis long-term is like many things in life: you have choices. You can choose to make it the most difficult and depressing of experiences or make it another challenge on your life's journey, to be handled and eventually conquered. Education about the ins and outs of kidney failure and choices of dialysis were key in helping me move

beyond the self-pity and rebellion against everything the doctors, nurses, dietitians and my parents were telling me about how to live as a person who happened to need dialysis. Now, dialysis and all it entails have become a very small part of my life. I like the smell of dialysate. It just is.

I've been extremely fortunate to have known some very special people who work at the dialysis centers where I've received treatment. When someone who has become a "friend" leaves the center it's like any other loss in life — it's sad. But I look at it as an opportunity for that person to broaden his or her life, to take on new challenges and to make a better place in the world. What I usually do with these staff friends is make sure I say "goodbye," wish them good luck and fortune in the new life they have chosen and let them know they will be missed by me.

Saying "hello" to a new staff person is often tougher than saying "goodbye" to a long-time staff person. I always try to make the new person comfortable with me and make him or her feel welcome at the dialysis center. I must

learn to trust the skills of the new technician or nurse. I do this by talking to the new person. Talking to people in a conversation is the most effective way for them to begin to know you and for you to know them. Ask about their training, education and experiences. When you get to know them better, ask about their family or their life outside of the dialysis job. Tell them about your life, but make sure you have one first! Dialysis does not have to be the focus of your life. Be open in talking about your family, friends and relatives. Talk about your job and its ups and downs.

Hobbies, vacations and pastimes are also good ways to let new people know a little about you as a person and allow them not to just see you as another dialysis patient. Let the new staff member know exactly how much you do for yourself before, during and after your treatment. I've found that most dialysis technicians and nurses are happy to let you do as much self-care as possible once they are sure you are able to handle things.

I've learned that these ways of handling dialysis are successful for me. I know that these tips can help others on dialysis too! **FF**

*Bruce Schultz has been on hemodialysis for 30 years, with 15 of those years spent on home hemodialysis. He has not had a transplant or been on any other type of dialysis. He has a master's degree in Counseling Psychology and is currently employed part-time at Crisis Services of Brevard as a telephone information and referral and crisis intervention counselor.*

## Representative Karen Thurman...

*continued from page 5*

**You have been a tireless champion of the needs of Americans with kidney disease. Can you suggest how kidney patients might motivate other members of Congress who have not been personally affected by kidney disease?**

I hope that this article will inspire more kidney patients to become involved. Recent progress has come about because of those who have taken the time to draw the human picture of kidney disease. We can build upon that experience. When I testify before the Appropriations Committee about kidney disease, I can talk passionately about it. Members of Congress respond when they are faced with a real person with real problems.

**Over 275 Representatives have joined the Congressional Diabetes Caucus with a goal of increasing awareness in Congress about diabetes and promoting expanded federal support of research into**

**diabetes and diabetes-related complications. Would a Congressional Kidney Caucus help to advance the cause of kidney patients on Capitol Hill?**

A Congressional Kidney Caucus would bring attention to kidney disease on Capitol Hill and could provide a forum. However, there are many Caucuses, and, as I have said before, it is participation from individual members of the American public that will ultimately make the difference.

**Do you have any final words for the readers of Family Focus?**

Don't give up on Congress. We've already made strides and we're trying to make lives better for kidney patients. Your letters and expressions of concern have really made a difference and can do so in the future. **FF**

*Dolph Chianchiano, JD, MPA, is NKF's Director of Scientific and Public Policy.*

# Experience Breeds Success:

*Tips for Success From Patients Who Have Been on Dialysis or Have Been Transplanted for 25 Years or Longer*



**Carolyn Taylor**  
Hemodialysis since 1975 (TN)

My tips for success for long-term dialysis are a strong faith, positive attitude and remembering that life continues on, even with dialysis!



**Alexis B Southworth, MSW, LSCSW-C**  
Kidney failure since 1976 (MD)

As a renal consumer, success is a positive attitude! A positive attitude=education. Education to empower you. As knowledge is power, and the more you know, the better informed decisions you can make. K/DOQI is an important tool for US renal consumers!



**Lee Deuell**  
Dialysis since 1974 (IA)

The fork is a wonderful invention that you can use to eat some of the things you normally use a spoon for. (From *When Your Thirst Is At Its Worst*)



**Bruce Lublin**  
Kidney failure since 1970 (WI)

Understand your disease and how it affects you then take control of it.

**Val England**  
Kidney failure since 1975 (UK)

Stay positive and optimistic, look forward to something (like a holiday), keep yourself occupied (like a college course), and don't worry about the little things. Learn all you can about the dialysis machine and its settings and stay informed about new developments and discuss them with your doctors and nurses.

**Editor's note:** The staff and editorial board regretfully acknowledge the passing of Val England on July 9, 2001.

**Gary Drazewski**  
Dialysis 1972-1982, transplant 1982-1985, dialysis 1985-2001 (IL)

Instead of crying, you have to learn to laugh. Humor will take you much further than tears.

**Lois Hanavan**  
Home dialysis (hemo and CAPD) since 1974 (NJ)

Keep a list of all past surgeries and dates, a list of all medications you're allergic to or have had reactions to, and a list of medications you currently take. If you have a computer, start a list and update it regularly. If you don't have a computer, keep a running list in a notebook. It's great to have this information when you see a new doctor, visit a different dialysis unit or go to the emergency room. The "current medications list" is a handy reference when you're packing your pills for a trip.



**Robin Driedger (left)**  
Kidney failure for 31 years (CA)

Tell yourself... "I can do it," whatever "IT" may be. Over the past 31 years this has helped me through a lot of trials. It's not always easy but you must focus on your diet/fluids, eat right, take your food binders, and no matter what is going on, always have a smile on your face!



**Helen Jacobs**  
Kidney failure for 27 years (MS)

Watch your fluids.



**Frank Germinaro**  
Transplant for 31 years (WI)

Live each day as if it is your last, but plan your life as if you were to live forever...You never know how long you have. I'm living the full life!!!

# Experience Breeds Success



## Lynn Correll

*Dialysis 27 years (PA)*

Dialyze as much as you can, follow the doctor's prescription and do not ever shorten your treatment time.



## Martha Patrick

*Kidney failure since 1972 (MS)*

I have learned that when I eat well on a daily basis I feel well. If you are going through a bad time it will not last forever. Always live for the positive and good in life.

## Sheldon Mielke

*Dialysis since 1967, kidney transplants, 1968, 1975 and 1977 and still going great (WI)*

Surround yourself with "Angels." Family, friends, neighbors, doctors, nurses and many others helped me along the way. I call them my Angels. My wife and daughter are my special Angels. Everyone has people around them who want to help; the secret is to let them be your Angels. They will give you the will to go on. In addition, laughter is the great healer. Maintain a sense of humor when times are bleak. It can be difficult at times, but it will help you heal.

## Rich Salick

*Kidney failure since 1973 (FL)*

I have 3 tips: Stay Fit! Keep your humor because everyone has their own problems, too....and, finally, have three brothers like I have!!!

## Reginald Matthews

*Kidney failure since 1976, transplant 1979-93, on dialysis (MS)*



Take charge of your situation, following all of the instructions given to you by your doctor, dietitian and other health care professionals that are caring for you.

## Donna Trala

*Kidney failure 29 years, two transplants, last one for 15 years (NY)*

I must say that I only have one suggestion that all transplant patients should keep in mind and live by. You have heard the saying "don't drink and drive." Well, this definitely holds true for transplant patients. "Don't Drink and Live." That would be a great slogan, don't you think?



## Lori Hartwell

*Kidney disease since the age of two, dialysis 12 years, following two failed transplants, now transplanted since 1990 (CA)*

Living with renal disease can leave you with (at times) a lot of down time. I have always loved being creative and would often bring art and craft projects with me to my doctor's visits, dialysis treatments or hospital stays. I didn't realize it then but what I was doing was developing a vital survival skill. First, colors make you happy. Second, it helped me get my mind off my problems and (sometimes) pain. Third, it helped me feel like I was being productive, which is critical to your self-esteem.



## David Axtmann

*Dialysis 32+ years (MN)*

I have written a book about living a full life in spite of the need of a machine to survive. It is called "Dialysis—An Unanticipated Journey". My book includes love, trust and belief and may bring laughter and tears. My tip is that dreams do not have to be over after a chronic illness, only changed. Attitude can affect much of our outcome. Living with a chronic illness is never a chosen journey, rather a learned one. In any life, the better we form it, the better it will be.



## Darell D. Fairchild

*Kidney failure over 25 years (OK)*

Gift of Life: The kidney machine. It's not the real thing, but it's not the end, if you keep things in order. You have to live life to the fullest, every day, one day at a time. Keep the Good Lord at the top of your list. Stay on your diet. Exercise. Get lots of sunshine. Stay active, even when you don't feel so good. Get interested in something good. My wife and I love to go watch our grandchildren, who are active in sports. They make you feel young at heart. Thanks to my doctors, nurses, dietitian, and most of all to my darling wife of 41 years. Thank God for all.



## Nancy Spaeth

*Kidney disease since 1966, now transplanted (WA)*

In order to keep doing the active things you love to do, keep doing them and never give up.

## Why Should I Exercise?

By Tiffany Shubert, MS, PT

*Remember to check with your physician before embarking on a new exercise regimen.*

**Y**ou hear it all of the time. "Start an exercise program. It will be good for you!" You may be wondering just how good it could be. Exercising seems like so much work, and what do you really get in return?

Everyone knows that exercise helps with managing weight. Did you also know that when you get your heart rate up for 20 minutes or more you are helping your heart and lungs work better, keeping your blood pressure low and your hematocrit high, helping your mood to be happy and keeping your muscles and bones strong? Hopefully this sounds like a good return for your time and energy, but let's explore this further.



We will be talking about two different types of exercise, aerobic and strength training. When you participate in aerobic exercise, such as walking, bicycling, swimming or dancing, you are mainly exercising your heart muscle. When you are strength training, that includes weight lifting, sit-ups, push-ups or squats, you are exercising the big muscles in your arms, legs and body.

Aerobic exercise will strengthen your heart and lungs. People who exercise regularly experience a drop in their resting heart rate. If you do not exercise, your heart rate at rest will be between 75-85 beats per minute, which is 4,800 beats per hour or 115,200 beats per day. Someone who exercises will have a resting heart rate of 60-70 beats per minute, which translates to 3,900 beats per hour or 93,600 beats per day. The exerciser will save his or her heart an average of 21,600 beats per day! Besides a decrease in heart rate, people who exercise have lower blood pressures. Regular exercisers have more efficient

circulation of their blood and more vessels to carry blood to the muscles, resulting in a drop in blood pressure.

Many people use exercise to manage stress, which also lowers blood pressure. When you exercise, your body releases hormones called endorphins. Endorphins give you that "runner's high," which is a general feeling of well-being and happiness that exercisers experience. Often this feeling is what motivates people to exercise, because they feel so good afterwards.

Another benefit from regular aerobic exercise is an increase in hematocrit (the number of red blood cells in your system). Your heart pumps faster when you exercise to circulate your blood through your lungs, where the red blood cells pick up oxygen. The red blood cells then carry oxygen to your muscles. When you exercise regularly, the body realizes more red blood cells are needed to keep up with your muscles. When this happens, a signal is sent and the body makes more red blood cells. This is especially important for people with chronic kidney disease and kidney failure, who tend to have low hematocrits.

Both aerobic exercise and strength training will help your muscles stay strong. When you participate in strength training, you are using your muscles to push or pull against

resistance. The more you use your muscles to push or pull, the stronger they will become, allowing you to move more weight.

The final benefit is that your bones will become stronger. When you use your muscles for walking or resistance training, your muscles push and pull on your bones. These stresses are a signal for the body to lay down more bone. This results in the bones getting stronger and being less likely to break. That is why your doctor will tell you that exercise is one of the best ways to prevent osteoporosis, or weakening of the bones.

For investing only 20 minutes of your day, you are getting lifelong benefits for your heart, muscles, bones and spirit. You are also helping your body cope with the challenge of chronic kidney disease. Not a bad investment for your time! **FF**

*Tiffany E. Shubert, MS, PT, is a practicing physical therapist in San Francisco. For the past two years she has been coordinating the Nandrolone and Exercise Trial in several San Francisco dialysis units. The purpose of the study is determine the mechanisms of muscle wasting in dialysis patients and to investigate the effects of anabolic steroids and strength training on hemodialysis patients.*

## Where There's A Will, There's A Way...

*continued from page 4*

- Temporarily? Remember you can change your advance directive at any time. It may also help to speak with your doctor or nurse about the various treatments that might be needed if a medical crisis occurred.
- Decide who you would trust to carry out your wishes. After you have discussed your wishes, this person should sign your living will or durable power of attorney for health care showing agreement to follow your wishes.
- Have your advance directive form(s) notarized or have two witnesses sign it to make it official.

Witnesses typically cannot be family members or your medical staff.

- Give copies of your advance directive to your family members, doctor, hospital and dialysis or transplant clinic. You should also discuss your wishes with these individuals to ensure they would be willing to follow them. **FF**

*Erica Perry, MSW, is a nephrology social worker at the University of Michigan Medical Center and a Peer Mentor Program Consultant at the National Kidney Foundation of Michigan in Ann Arbor.*



## NKF Takes Action for Those At Risk



While developing the Clinical Practice Guidelines for Chronic Kidney Disease, medical experts confirmed what the National Kidney Foundation (NKF) had long suggested — that the scope of the problem is much, much greater than previously reported. The new guidelines on Chronic Kidney Disease (CKD), funded by Amgen, founding and principal sponsor of NKF's Kidney Disease Outcomes Quality Initiative (K/DOQI), will be published in early 2002. With the CKD guidelines as the scientific evidence, the NKF has developed a four-part plan to attack chronic kidney disease:

**Phase 1.** The launch of the CKD guidelines identifying and defining the problem and what can be done about it.

**Phase 2.** A targeted awareness campaign reaching those at risk of developing chronic kidney disease and encouraging them to be routinely tested.

**Phase 3.** Early detection through KEEP (Kidney Early Evaluation Program) screenings identifying (through simple tests) those with

chronic kidney disease or at high risk of developing the disease.

**Phase 4.** Establishment of the Kidney Learning System™ (KLS™) educating health care professionals, patients and those at high risk and providing resources and tools for treatment.

In this issue of *Family Focus*, we will highlight part three of the plan. Look for more information about the plan in a future issue.

### What Families Need To Know

If you are currently on dialysis, **your family members may be at risk for kidney disease.** People with diabetes, high blood pressure or first-degree relatives of those with diabetes, high blood pressure or kidney disease are at increased risk of developing kidney disease.

KEEP, a free health screening program coordinated by the NKF, offers blood and urine testing, on-site consultation by a physician, referrals to health care facilities and follow-up for those whose tests results are outside normal ranges. To date, nearly 4,500 people have participated in more than 80 KEEP screenings offered

through the NKF's affiliate offices across the country. You must be 18 years or older to participate in a KEEP screening. If you attend a KEEP screening you will receive the following:

- Blood pressure check
- Glucose check (blood sugar check)
- Hemoglobin level (anemia blood count)
- Urine dipstick test for hematuria (red blood cells in the urine)
- Urine dipstick test for microalbumin (protein in the urine)
- Urine dipstick test for pyuria (white blood cells in the urine)
- Blood test for creatinine (measures how well the kidneys are filtering blood)
- Calculated creatinine clearance (measurement for kidney function).

Ortho Biotech Products, L.P., is the primary sponsor of the KEEP program. Additional sponsors include Bayer Diagnostics and Satellite Healthcare.

To find out where KEEP screenings are held, call your local NKF affiliate or look up our KEEP screening schedule online at [www.kidney.org](http://www.kidney.org). 

## Heart and Kidney Disease: Silent Killers in Women

By Peter A. McCullough, MD, MPH, FACC, FACP, FCCP

Most women think the single greatest threat to their health is breast cancer. Many do not realize that heart disease is the single greatest cause of death among women, far out-pacing breast cancer. The problem with both heart and kidney disease in women is the fact that, for the most part, the symptoms of heart and kidney disease are often silent or very slight. Studies show that up to one-third of heart attacks in women are completely silent. Sometimes they may be felt as a period of weakness, sweatiness, mild shortness of breath or upset stomach. Heart failure is somewhat different, in that the most common symptom is excessive weariness, then shortness of breath and swelling of the feet and legs.

Kidney disease is often the most silent disease of all, with only feet and leg swelling, mild tiredness and, sometimes, foamy urine being early signs. When kidney failure sets in, the symptoms often turn to weight loss, itchiness, nausea, loss of appetite and worsened swelling.

What is behind these silent killers? In our society today it is largely the presence of diabetes. Recent studies indicate that if you are overweight and over age 55 the chance of developing diabetes during your lifetime is 20 percent. In addition, high blood pressure, smoking, high cholesterol, lack of exercise and a family history of diabetes, kidney disease or heart disease can increase the risk of diabetes.

What can women do to learn about these silent, but deadly problems? The answer is just like with breast cancer, early screening. It is recommended that all adult women have blood pressure, cholesterol, blood sugar and blood chemistries measured to check on kidney function. Even some of the seemingly minor symptoms mentioned above should be checked out thoroughly by your doctor with tests of the heart and kidneys. Most tests today are simple and low-risk and can provide useful information to you and your family. Finally, to keep yourself in

good shape, it is recommended that you stay trim by eating fewer calories, having lots of fresh fruits and vegetables and avoiding extra salt and foods with high cholesterol, such as eggs and liver, and foods with high saturated fat, like red meat and fried foods. It has been clearly shown that eating this way along with regular exercise, such as brisk walking for 30 minutes, at least three times a week can prevent diabetes and the heart and kidney problems that diabetes can cause. This can help keep you healthy and allow you to spend your time on the most important things in your life. 

*Peter A. McCullough, MD, MPH, FACC, FACP, FCCP, is an Associate Professor of Medicine and the Cardiology Section Chief at the University of Missouri – Kansas City School of Medicine and Truman Medical Center.*



# HOSPICE: A Compassionate Choice for End of Life Care

By Bobbie Knotek, RN, BSN

## What is hospice?

Hospice is a special way of caring for someone who is close to the end of life. Hospice, which focuses on caring, not curing, is based on the belief that every person has the right to die pain free and with dignity.

## How does hospice work?

Specially trained hospice team members work together to develop a plan of care that includes the specific hospice services, medical equipment, tests, procedures, pain medicines and treatments needed to keep the patient as comfortable as possible.

Life partners, relatives or friends are the primary care givers in hospice. Hospice staff teach them how to work with the hospice team to care for their loved one. The hospice team is available to the person and the care givers 24 hours a day, seven days a week.

Hospice care is usually provided in the individual's home. If the patient needs more care than is possible at home, hospice care can be provided in a hospice facility (if one is available in the community) or a hospital or nursing home.

Hospice programs include specially trained professionals and volunteers who provide medical, nursing, emotional and spiritual support for the patient and his or her care givers. These team members include:<sup>1</sup>

- ♣ The individual with the terminal illness and his or her care givers - Hospice staff depend on the patient and care givers to keep them informed of needs and concerns that arise.

- ♣ The patient's own doctor and/or the hospice doctor - The doctors are responsible for the individual's medical care, including the ordering of needed medicines and treatments

- ♣ Nurses - Hospice nurses make regular home visits to assess, treat and prevent physical symptoms that can cause discomfort.

- ♣ Home health aides and homemakers - These team members help care givers with personal services, such as dressing and bathing.

- ♣ Social workers and counselors - Social workers/counselors help the patient and care givers talk about difficult issues like advance directives (documents that can clarify the type of care you want if you become unable to communicate your desires), the patient's last hours and funeral

arrangements. They also, with the help of clergy, provide bereavement (grief and loss) counseling for the individual and loved ones. Hospice offers bereavement counseling for families for up to one year following the death of a loved one.

- ♣ Clergy - If desired, clergy are available to the individual and loved ones for spiritual support.

- ♣ Dietitians - Dietitians, available for dietary counseling, help the care givers choose foods and fluids that are best for a loved one during this time.

- ♣ Trained volunteers - Volunteers, specially trained in hospice care, assist family members as needed (grocery shopping, making phone calls, etc.)

- ♣ Speech, physical and occupational therapists - If special therapy is needed, these professionals work with the patient and care givers.

## When would someone with kidney failure need hospice services?

An individual with kidney failure can have other illnesses like cancer, heart disease or diabetes. Also, some people simply may not do well on dialysis. If a patient's health and quality of life get so bad that dialysis is perceived as prolonging death rather than prolonging life, the individual may choose to stop dialysis. A similar situation may arise when a patient with poor health and quality of life is told he or she has kidney failure and needs dialysis. The individual may decide not to start dialysis.

The decision not to start or to stop dialysis is life-threatening and should not be made lightly. The decision should be carefully discussed with family members and the health care team. However, when an individual makes the choice not to start or to stop dialysis, hospice or hospice-like care is the recommended treatment.<sup>2</sup>

## Can a patient who stops dialysis and chooses hospice care have a change of mind and re-start dialysis?

Yes. At that time, hospice care is discontinued, with the option of re-starting it in the future.

## Who pays for hospice care?

Hospice care is a benefit of Medicare Part A. Everyone who qualifies for Medicare because of kidney failure is eligible for hospice. Medicare pays for 100 percent of most covered hospice services. The only cost may be a small co-pay (approximately 5 percent) for

medications and respite care.

Medicaid programs in 43 states and the District of Columbia, as well as an increasing number of private insurance companies and HMO's, also pay hospice benefits.

## What's the best way to choose a hospice program?

First — find out about hospice care in your community. Sources of information are doctors, nurses, social workers, clergy, counselors, friends with personal hospice experience, the local or state office on aging, senior centers, state health department, state hospice association, Medicare and health related Internet Web sites and the National Hospice and Palliative Care Organization. (See resource sidebar).

Next — call or visit hospice programs. Ask questions about the services they offer, such as:

- ✓ Have they worked with someone who has kidney failure?

- ✓ Do they make pre-hospice referral visits (consultations prior to the onset of insurance eligibility) to patients who are thinking about stopping dialysis?

For a list of other questions to ask hospice programs, read *Hospice Care: A Consumer's Guide to Selecting a Hospice Program*. (See resource sidebar)

## How can someone get a referral for hospice services?

Hospice services require a doctor's referral. The referral must certify the individual has six months or less to live. For a patient with kidney failure, the referring doctor could be his or her nephrologist. An individual who doesn't have a regular doctor can contact a local hospice program for help in getting a referral.

If you or someone in your family is interested in pursuing hospice care, you don't need to wait for the health care team to bring up the subject. Tell the doctor, social worker or nurse you want to discuss hospice as an option for care.

## References:

1. National Hospice Foundation (2001). *Hospice Care: A Consumer's Guide to Selecting a Hospice Program* [Brochure]. [www.hospiceinfo.org](http://www.hospiceinfo.org).
2. Renal Physicians Association and American Society of Nephrology (2000). *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*. Recommendation No. 9: Palliative Care.

*continued on page 13*

HOSPICE continued from page 12

### Resources for Hospice Information

■ Medicare Resources – To view, print or order online, go to the Medicare Web site at [www.medicare.gov](http://www.medicare.gov) and click on the publications section located in the left column of the home page. Pamphlets can also be ordered by calling 1-800-Medicare (1-800-633-4227). Refer to the publication number beside each pamphlet.

*Medicare Hospice Benefits*  
English Version (Publication #02154)

Large Print English Version  
(Publication #02154 - LE)

Spanish Version (Publication  
#02154 - S)

Large Print Spanish Version  
(Publication #02154 - LS)

■ National Hospice Foundation Resources – To view or print the online version, go to [www.hospiceinfo.org](http://www.hospiceinfo.org) and click on the publication name. Pamphlets can also be ordered by calling 1-800-338-8619.

*Hospice Care: A Consumer's Guide to Selecting a Hospice Program*

*Communicate Your End-of-Life Wishes*

*Hospice Care and the Medicare Hospice Benefit*

■ National Hospice and Palliative Care Organization — This organization provides educational materials and a searchable database for locating resources in your area. You can view the organization's Web site at [www.nhpco.org](http://www.nhpco.org).

■ National Kidney Foundation Resources — To order copies of these brochures, call your local National Kidney Foundation affiliate or contact the National office at 1-800-622-9010

*Advance Directives: A Guide For Patients and Families* (Publication #08-03)

*If You Choose Not to Start Dialysis*  
(Publication #03-130)

*When Stopping Dialysis Treatment is Your Choice* (Publication #03-131)

The above topics can also be viewed and printed by going to the National Kidney Foundation Web site at [www.kidney.org](http://www.kidney.org):

- Click on Information (on the NKF home page)
- Click on A to Z Guide
- Select letter from alphabet drop-down box that matches the first letter of the topic you desire
- Advance Directives
- Dialysis: Choosing Not to Start
- Dialysis: Deciding to Stop

■ To find a hospice that is a member of the National Hospice and Palliative Care Organization (NHPKO), call the NHPKO HelpLine at 1-800-658-8898 or log on to their Web site at [www.nhpco.org](http://www.nhpco.org).

# The Parent Connection

## Making a Successful Transition from Supervised Living to Independent Living

By Arlene C. Gerson, PhD, and Alicia Neu, MD

Many young people hope and dream of the day when they will be able to successfully live on their own. Many parents also share this expectation for their children. For young people with kidney disease, it takes hard work and careful planning to make independent living a reality. Making a safe transition from home to independent living requires advance preparation for both expected and unexpected challenges. This article will provide some recommendations that parents can use to help their child prepare for independent living.

One of the most important preparations involves teaching your child how to monitor his or her health status. Taking on the responsibility for monitoring one's health should be done gradually by the child with chronic kidney disease. Some parents are very comfortable giving their child increasing independence in managing health while other parents are very uncomfortable giving up control. There are a variety of self-care tasks that need to be mastered by your child. These include:

- Filling prescriptions
- Taking medications independently
- Knowing the names of medications and what each medication does (or why each medication is prescribed)
- Following dietary or fluid restrictions
- Taking a temperature
- Checking blood pressure
- Monitoring for changes in urine output
- Making doctors' appointments
- Talking to insurance companies
- Arranging transportation to get to the doctor or dialysis facility.

These self-care tasks should be taught gradually so that your child does not feel overwhelmed by the responsibilities. In addition, by gradually introducing greater expectations for independent self-care, parents can monitor closely and step in if help is needed.

Another important preparation involves teaching your child to develop a plan for what to do if a health problem arises. One of the most difficult aspects of independent medical self-care is noticing early on that there is a problem. Parents need to teach their child how to become an expert in recognizing signs and symptoms of

infection, high or low blood pressure, fluid build-up or dehydration and possible side effects of medications. Parents can teach children the importance of paying attention to changes in the way the child feels and what can be done to make sure that the problem is not a serious one.

Unfortunately, because of the nature of kidney problems, there may be times when a serious health problem occurs suddenly. Parents can help their child prepare for such an event by identifying someone the child could call for help. Parents and their child should also plan for how to get to the doctor's office or to the hospital emergency room.

Perhaps the most important preparation for successful independent living involves learning how to communicate with health care providers. It is impossible for them to give good recommendations without patients providing information about their health, lifestyle and adjustment to living with kidney disease. It takes practice to feel comfortable talking to doctors, nurses, dietitians and social workers.

Parents can encourage good communication skills by letting their child talk to health care team members at clinic visits and during phone consultations. Parents can also support independence by allowing their child some private time with health care providers during clinic visits. Finally, they can suggest that their child jot down problems and questions and bring them to each clinic visit.

In summary, there are many ways to make your child's transition from living in a supervised home to living independently successful. These include your child making a commitment to close monitoring of his or her health status, developing an emergency action plan and your child learning how to talk directly with health care team members. Early on parents should start teaching the necessary skills that will enable the child to move toward independent living. **FF**

*Arlene Gerson, PhD, is a pediatric psychologist at the Johns Hopkins Hospital in Baltimore, Maryland. Alicia Neu, MD, is a pediatric nephrologist also at the Johns Hopkins Hospital.*

# Meet Joe Brush: Almost 100 Years Old and on Dialysis

By Jean Albertson, MSW, and Joanne Lewandoski, RD

*The dialysis population is aging. The average age at our center in New Jersey is 72 years old, with 71 percent of our patients over the age of 65. Four of our patients are in their 90's.*

*In the fall of 2000, we welcomed Joseph Brush, a patient who transferred from a New York facility. On September 10, 2001, Joe celebrated his 100th birthday. Meeting him and his family prompted this article, an interview with Joe and his daughter, Peggy-Ann Mendler, about their thoughts on what happened in their lives this past year.*

## THOUGHTS FROM JOE

**Jean:** *How do you feel about approaching your 100th birthday?*

**Joe:** I'm thinking...how the heck did I do it? I'm puzzled. I'm the oldest of seven children. All my brothers and sisters have died. How come they missed me? Something must be wrong with the bookkeeping up there...

**Jean:** *Can you identify things that you believe influenced your longevity?*

**Joe:** First, my sense of humor has helped me a great deal. I see humor in almost everything. I have been through some tough times in my life, but I always try to see the lighter side of things. A wise man once said about difficult moments in your life, "And this too shall pass."

**Jean:** *You began dialysis in July 2000. Did you ever consider not starting dialysis at your age?*

**Joe:** Right from the beginning. I thought: Why should I bother with dialysis at this age? This is ridiculous!

However, one day my granddaughter came to visit me in my home. I was so sick and weak; I had fallen on the floor. I did not want my family to see me this way. I thought: I can't go out this way, on my knees. I decided to go ahead with dialysis.

**Jean:** *Are you pleased with your decision?*

**Joe:** Yes, I have a new lease on life now. I have 10 grandchildren and five great-grandchildren, who I enjoy and would like to see grow up. The only time that was difficult was when I had my graft surgery. The anticipation of the surgery was difficult for me to deal with. But I handled it. This was something that I could handle!

**Jean:** *What advice would you give to others on dialysis?*

**Joe:** Do it! You can do it! I give up

four hours, three times a week—that's a bargain because it gave me back my life!

## THOUGHTS FROM PEGGY-ANN MENDLER

**Joanne:** *When were you told that your dad needed dialysis and how did you handle the situation?*

**Peggy:** "Pop Pop" has been living on his own, in his own home, since our mother died in 1995. That was when our worries started. If he didn't answer our phone calls fast enough we'd panic and call the neighbor to check. My sister Lynne and I were both stressed, but he was fine. The two of us made at least four phone calls a day and went over at least once or twice a week. He promised to "stay vertical" and give us two days notice if he planned to leave this world.



**Christmas 2000:** *Joe continues his 60+ year holiday tradition of reading *The Night Before Christmas* here, to his five great grandchildren. Without glasses!*

He was seeing his doctor regularly and we were watching "the numbers" go up slowly. Pop Pop was slowing down and taking lots of naps—just getting old, we thought. In the spring of 2000 his doctor said we should start getting ready for dialysis by the fall. We made an appointment with the nephrologist, but everything went sour very quickly. My sister and I struggled with whether or not dialysis was the right thing. In June I visited Lillian Booth Dialysis and spoke at length with Rosmary Leva, the director, about my dad and what dialysis entailed. Her words "age doesn't matter" made me realize that it would take time and effort, but I felt he could do this. I went over and told him and it helped ease his fears. He started dialysis in July. Lynne and I had the summer to get him organized and we ran back and forth trying to keep him in his own home—one he loved. We hired a housekeeper, but that only lasted four days. Early in September we decided it would be much better for dad to come and live with my husband Jim and me.

**Joanne:** *How have Joe's dialysis treatments affected you and your family life?*

**Peggy:** Dad has a positive influence on our family. His personality is a magnet that draws people toward him. It's a pleasure having him with us on a daily basis and I would not give up this time for anything.

Before September I only saw him a few hours a week. With his wit and humor, Dad keeps us all on our toes. The weekends he spends with my sister makes our home a very quiet place...a vital spark is missing.

Our only conflict comes in the evenings when Jim and I are collapsing at 10 or 11 and dad is full of life and ready to party. The Dad of last spring who was getting old and tired is so energetic now that dialysis is cleansing the toxins from his system. It's as if the clock has turned back 10 years.

Our biggest change as a family is eating later on dialysis days. Watching Dad's diet is beneficial for the whole family. Of course, pizza and Chinese take-out are things of the past and inventive, tasty cooking is a challenge to this reluctant chef.

**Joanne:** *What advice would you give adults with older parents who are in need of dialysis?*

**Peggy:** Life is such a fragile and precious gift that those of us who are lucky enough to have parents who can benefit from dialysis need to move past that first stage of panic when you hear the words End Stage Renal Failure. Dialysis is a "do-able" procedure that makes the difference between life and death. The choice is so simple. My dad made the decision to live. It's definitely the decision our family wanted. Because of that he has attended our daughter's wedding, enjoyed the holidays and watched the great-grandchildren grow and scramble into his lap. He now awaits the arrival of his sixth great-grandchild.

Recently, he came to the grammar school where I teach to share with 250 children what life was like 100 years ago. Someone told him he was "cool." Not a bad description at any age.

For Dad, each day is an affirmation of the sweetness of life...a life he owes to dialysis. We are truly blessed. **FF**

# T R A N S P L A N T

## R A N S P L A N T

### A Little Help From My Friends

By Roy Moxfield

I want to share with you the continuing saga concerning my loss of kidney function and the subsequent coping process. I cannot begin to tell you of my experience without first expressing enthusiasm and appreciation for those who took care of me when I could not do it on my own.

I first knew that I had kidney failure when I was 30 years old. I had had no complaints and felt "fit as a fiddle," but I had not seen a doctor in a few years. A physician with whom I consulted examined me and gave me a clean bill of health, with the exception of some red blood cells in my urine. He asked that I do a 24-hour urine test, and of course, the cells were still present. He sat me down and explained that my kidneys were damaged and might fail sometime in the future.

I continued to see the physician every three months for the next 20 years, as my kidneys deteriorated. I felt healthy enough to do whatever I wanted. Early in 1992, I began exercising, losing weight and getting muscle strength. During my quarterly visit that fall, my physician stated that the weight loss was not due to exercise but rather to the loss of kidney function. I was beginning to feel apathetic about things around me. He said that it was time to think about the options, dialysis and transplantation. I made an appointment with another physician to see if I could be placed on the transplant list, and I went to a dialysis unit to talk to the nurses about dialysis. After an explanation of the types of dialysis, I chose continuous ambulatory peritoneal dialysis, or CAPD, as it seemed to fit my lifestyle better than hemodialysis.

My wife and I also discussed the types of dialysis and I had her support. I soon found out that family support is important for kidney failure patients. The special diets, the depressions and the weakness that can come and go can surely try the support network. I was fortunate that I had this support.

Some of you may not know about CAPD. You can do this type of dialysis in your home, at work or wherever you happen to be that has a clean environment. I have been known to dialyze at weddings, funerals, dinners or work meetings! One of the drawbacks to CAPD is that you may develop a tunnel infection where the peritoneal catheter fits through the skin. This, as well as other things, such as not using sterile technique during your CAPD exchanges can lead to peritonitis. This is a serious infection, which is nothing to sneeze at. In fact, I dare say that you cannot sneeze or cough while your abdomen is inflamed without intense pain! After several episodes of peritonitis I was also told that if I had an infection and was called to receive a transplant, I would be bypassed. I then made a decision to switch to hemodialysis.

You may wonder why I did not check with my family for someone who might be a compatible kidney donor for me. I knew that there was only one person who could possibly match me because of my blood type. It was my son. He was 17 years old and I was 52. I could not ask for his kidney. He offered, but I could not accept it. I love my son and knowing that he was willing to sacrifice his kidney was enough for me. I was willing to wait, maybe not with patience, but wait I had to do.

Those of you who have been accepted to the transplant list remember the day you got your beeper and the expectancy that brings. It could go off at any time and it would mean that I had that long-sought-after kidney. I was accepted on the list. One day led to another and nothing happened. I was patient yet impatient and frustrated. I hope that those who have had a transplant remember the longing, and those waiting for a transplant do not get impatient. A year went by, and only incorrectly dialed numbers came through on the beeper. Another year and nothing. A third year and nothing. I can still remember the nurses, who seemed like family, gathered around me during my hemodialysis sessions. It seemed as if everything that could go wrong with my treatments did. Everyday I would tell the staff that my kidney was coming. I was living for that day.

June 17, 1996, was a momentous day for me. I had dialyzed on Saturday and I had not yet dialyzed that Tuesday. I received a call from my physician asking if I had had a good lunch and if I felt fine. I asked if the laboratory tests drawn on Saturday were the reason for his call. When he answered no, I began to understand the nature of his call. The more he talked, the more excited I became. By the time I got off of the phone, I could not put the receiver in the cradle. I had to have a co-worker dial the number for my wife. We met at the hospital, and it seemed that as soon as I got there, everyone wanted a piece of me. By the time they were done, I wished I had skipped lunch!

Everything went well during the surgery and the recovery period. I attempted to write a letter to the donor's family, and that was the hardest thing I ever wrote. I spent three days writing the letter with countless starts and stops. I can still remember the words I finally wrote. "No words can ever express the thankfulness in my heart for what your family gave to me. I thank you and value your gift." What a humbling thought that someone would give you the gift of a new start.

It has now been four and a half years since I received my kidney. I have not had any setbacks. I have been able to travel and do those things that I want to do. One of the things I have been trying to do is repay the debt that I incurred from that donor's family. They deserve for me to do the best that I can with my life.

We must not forget those who have helped us get where we are today. In my case each nurse, doctor, phlebotomist and the donor's family have provided me with the ability to live normally again. 

*Roy Moxfield is an engineer and works for the Illinois Department of Public Health. He is 55 years old, married for 32 years and has two children and a grandchild. He believes that his transplant has allowed him to see his children graduate from college.*



**Three generations: Roy Moxfield with his son, Don, and grandson, Roy.**



# POETRY

## CORNER

### Dry Humors

By Arthur Gordon

When I first checked the loathsome scale  
I saw a weight that made me pale,  
You hooked me up and took my blood,  
I weighed again, I'd lost much crud.

The nurses checked. The techs kept joking.  
At last I saw they were not joking.  
My weight dropped down, approaching "dry."  
From tree trunk legs to old skinny guy!

And I feel good. My cheeks are pink.  
Who needs bean soup, spaghetti, drink?  
I found I liked the way I looked.  
Dialysis, I think I'm hooked!

Kathy, Touron, Vicci, Sue  
New mobility I owe to you.  
Bobbie, Julie, Chris, Marjo,  
The swelling's left my big right toe!

Percy, Mary-Anne and Chay.  
My hypertension's gone away!  
Gayle and Kevin, Andrea, Sherri.  
Kilogrammatic thanks. Christmas merry!

Sheila, Marilyn, Emily, Arlene,  
Joy, Margaret, Anna Jean,  
You all helped to make me lean!  
My mind gets fuzzy, but my blood is clean!

So I look upon our clinic fair  
With upcast eyes so debonair.  
I'm one who's had top renal care,  
Sanguine treatment and solace rare.

Your job is tense and you are few;  
So thanks for your good humor, too!  
Enjoy your party, food and brew,  
Skoal! 888-88-1852.

P.S.

Now if I've left out anyone,  
Well tweedle dum and tweedle dee.  
I'll say right here in shameless pun:  
You have the right to needle me. 

### The Night Before Dialysis

By Lee Duell

'Twas the night before dialysis,  
And all through the house  
Not a person was drinking:  
No one was a souse.

The glasses were stacked  
In the cupboard with care:  
No one tonight would be  
Caught in drinking's snare.

The children were nestled  
All snug in their beds,  
While visions of bananas  
Danced in their heads.  
And Mama in her kerchief,  
And I in my T-shirt,  
Were lying in bed, dreaming of  
Candy bars for dessert.

When out on the lawn  
There arose such an uproar;  
I sprang from my bed,  
And I flew to the door:  
I opened it cautiously  
Knowing not what I'd find,  
And what I saw there  
Put my senses in a bind.

It was there!  
A dialysis machine:  
Small enough to wear,  
But big enough to get the blood clean!  
It had instructions,  
So I tied it in 'round my middle.  
And in just two minutes  
I felt fit as a fiddle!

I wore it inside, and  
Showed it to Susie, my wife.  
She said, "Darling,  
We've got a new lease on life!  
No more counting of proteins,  
Potassium, salt;  
This watching of fluid intake  
Will come to a halt!"

"You'll be a new person;  
Not weak, as you're now;

You'll have strength to do  
Anything you want to do! Wow!

"Susie," I said,  
"Here's a unit for you,  
And there is one for Sally  
And Johnny and Stu."

They each tried theirs on,  
And soon were like me:  
Laughing and dancing  
And singing with glee.  
We'd found the solution  
To our blood's pollution;  
We'd found the cure  
To make it clean and pure.

And then I awoke:  
It was all a dream!  
When I realized what had happened,  
I wanted to scream!  
For a moment I was happy,  
And cheerful, and well.  
The joy I felt in my heart  
Words cannot tell.

"Someday," I said,  
"They'll make a machine  
That a person can wear  
To make his blood clean.  
No more time wasted  
With needles in his arm  
Or leg; or a shunt with  
Infection causing harm.

"They will find something  
To take away our plight,  
And make each of our  
Blood chemistries right.  
But for now, it's just a dream:  
Something to search for, to strive;  
Something to make us 'well,'  
Not just keep us alive."

Then I rolled over in bed,  
And pulled the covers up tight,  
And said, "Happy dialysis to all,  
And to all a good-night!" 

### Cycle of Life

By Tammy Keeler

Attached to a machine that cleans the blood of wastes.  
I wonder if others feel the way I do.  
Feeling despair at times and peace of mind the other times.

Knowing that any day could be a good day or a bad one.  
Realizing that there is a chance I might get a new kidney.  
I'm thankful for this cycle of life that keeps me in this world.



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