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## PARENTING

# Family Focus

The Renal Community's Newspaper

VOLUME 9

NUMBER 4

WHAT DOES PARENTING &  
KIDNEY DISEASE MEAN TO YOU?



## A Family Like Any Other

by Jennifer Nix Leonard

Playing in the yard, bounding through the door of my house with several neighborhood kids in tow, is the essence of many a childhood memory for me. If one of those kids was new to our home, there might be a sudden stop in the action followed by a "What's *that*?" The "that" they referred to was my father's dialysis machine. "Oh, it's just a kidney machine - it cleans my dad's blood." Then, we'd all be off again, on to the next adventure. Most of the time, life with my father's end stage renal disease was simply that normal.

If you have recently been diagnosed with kidney disease, "normal" is probably the last word you would choose to describe any facet of your life. In the initial painful phases, after diagnosis, there is that moment when you not only think your life is over, but you feel a tremendous and

time spent on dialysis—added to the normal stress of everyday life—are overwhelming at times and often weigh heavily on children.

When you're feeling better, you can focus on what every parent should strive for: healthy communication with your kids. There is no absolute right or wrong way to handle telling kids about kidney disease and dialysis. You must decide for yourself what is best for your kids. In John Newmann's experience, as in my own, openly including the reality of dialysis did far more good than harm.



Jennifer, second from right, with her dad, Wayne, mom Sharon, and sister Kathy.

**"Kidney diseases poses special challenges for families, particularly in parenting."**

overwhelming sense of guilt that your disease will ruin your family's life. While I did not have the disease myself, I am living proof that children and families can adapt well to this disease. Even with kidney disease, you can define what "normal" is by your courage and actions.

Kidney disease poses special challenges for families, particularly in parenting. The sickness and fatigue, the

"Because dialysis is so exhausting, and with all the pressures of trying to continue working full-time, my temper was short and I raised my voice with my kids when I didn't want to," says John Newmann, PhD, MPH, kidney disease health policy consultant, and long-term renal patient. "But once I got past the initial four-to-six months of depression, I was determined not to live a mediocre life. I believe this disease gave me a tremendous gift: a much-increased appreciation for life and my kids."

One of the first steps to being a good parent with kidney disease is making sure you feel as healthy as possible, so that you have the energy to give your kids what they need. That means being responsible for your treatment, working with your medical team to find your optimal dialysis level, following the diet and getting plenty of exercise.

"Communicating with children is important because they undoubtedly feel the side effects of what their parent is going through with kidney disease, and they need to be able to ask questions and deal with their fears," explains Rosa Rivera-Mizzoni, MSW, LCSW, a social worker and special projects coordinator for Renal Networks 9 and 10.

According to Rivera-Mizzoni, young children may see the dialysis machine as a kind of "blood-sucking vampire that is hurting their mommy or daddy," while older children tend to fear and resent it. Open communication about kidney disease creates a healthier foundation for children to continue talking through rough times. It is important to validate their changing feelings about the disease. If they stop

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This publication is a Family Focus Program of the National Kidney Foundation and is made possible in part through an educational grant from Amgen.

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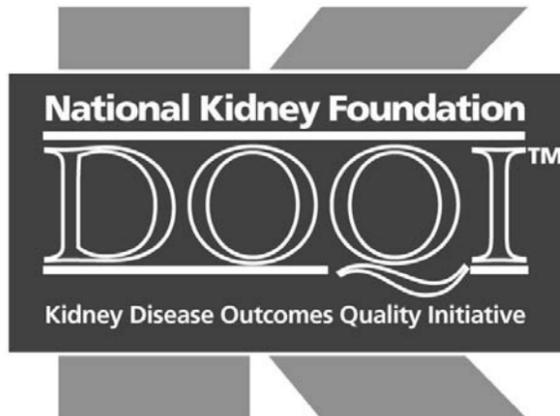
## K/DOQI and You

**M**any of you who are on dialysis are aware of the National Kidney Foundation's initial efforts to improve the standard of your dialysis care with the development of the NKF-Dialysis Outcomes Quality Initiative (NKF-DOQI). These guidelines were originally published in 1997 and are recommendations for health care providers to follow in order to meet a high quality of care that is best for you. A new set of guidelines is being developed which will encompass the original DOQI guidelines, but are expected to include patients at all stages of kidney disease, including pre-dialysis. It is called Kidney Disease Outcomes Quality Initiative or K/DOQI.

K/DOQI's goal is to establish guidelines that would include people at the earliest stage of kidney dysfunction, as well as those with overt kidney failure. It will involve the active role of all members of your health care team, paying special attention to the primary care physician. A primary care physician is important because he or

she is often the first person you see when you feel ill and is in a unique position to become involved in the preventive treatment for anyone showing early symptoms of kidney dysfunction.

Recent data from the Third National Health and Nutrition Examination Survey (NHANES III), estimates that approximately 12 million Americans



have an elevated serum creatinine, an early indicator of reduced kidney function. That means that someone

you know could be in the early stages of kidney failure and would benefit from quality care that will be recommended in upcoming K/DOQI guidelines.

The first clinical practice guideline released under the K/DOQI banner in June 2000 was the Clinical Practice Guidelines for Nutrition in Chronic Renal Failure. In addition, the original DOQI guidelines have been revisited and updated and are expected to be available to your health care providers later this year. You can expect other guidelines to follow over the next three years that will look at heart disease, bone disease, blood pressure, cholesterol and their relation to kidney disease. It is important that you play an active role in your care, and you can do that by keeping yourself informed of the changes and updates available to you and your health care team. More information on K/DOQI is available by visiting our web site at [www.kdoqi.org](http://www.kdoqi.org) or ask your health care provider for more details. 



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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## Are we missing you?

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

# COVER STORY

## A Family Like Any Other

continued from page 1

talking, look for indicators such as changes in behavior and sleeping patterns, or grades suddenly dropping.

Your social worker can help you face your kidney disease diagnosis and aid your children as well. Your kids can visit your dialysis unit, or if home hemodialysis is the best alternative for your lifestyle, home visits by your social worker are an option. The National Kidney Foundation has educational videos for children of all ages. You may choose to seek professional counseling at some particularly difficult stages as my family did. The key is knowing help is out there and seeking it out.

"What you've got to realize is that kids are tremendously resilient—they can take almost anything if they are brought into the circle," says Rivera-Mizzoni.

One important realization to reach is that the disease should not define your relationship with your kids. Kids need to have parts of their lives that aren't touched by kidney disease—everything from playtime, to help with homework, to punishment when they get out of line. Dialysis shouldn't be an excuse for you to pass the buck to a spouse or to just let things slide.

I saw my dad strive to keep kidney disease in its place in all of these ways. We traded the dinner table for dinners in the den, while Dad ran on the machine. He taught and coached football, and came to my basketball and volleyball games. He took us camping all over the country. He played goofy Dad-jokes on Saturday mornings. He rode me hard about grades and did not shy away from discipline. He also lost his temper and wasn't always "Mr. Wonderful." But, whose father is?

At the age my father was during his first year of dialysis, I can tell you that I believed his renal failure, and the way he and my mother dealt with it, showed me the meaning of strength, commitment, and love. I call that a far cry from ruining my life.

My father died this past December, but he lived with kidney failure for 27 years—17 of them on dialysis, 10 with a transplant. He outlived several of the doctors who told him back in 1973 that he probably had only six months to live. At the time, my sister, Kathy, was



Wayne Nix

three, and I was six years old. Instead, he was around to see both his daughters get married. He got to see a grandchild born into our family. He and my mother had found a beautiful island

in Lake Michigan where they liked to spend their summers. He also saw his idea for how to help improve the lives of all people with kidney disease spread across the country—the NKF Rehabilitation, Information, Support & Empowerment (RISE) program.

My father, Wayne Nix, provided a wonderful example of how to rise above adversity, and he knew he had lived his life to the fullest.

Your kidneys may have failed, but it is still *your* life to live, *your* example to set for your kids—and most important, *your* love to give and receive. Accept that you are not perfect; you will make mistakes. You do have added pressures and challenges with kidney disease. You will be exhausted, sick and overwhelmed at times. You will probably be a grump and yell quite often. But you will also be here to see your kids grow up, and you will be there for them when they need you. And, that's as normal a life as anyone can ask for. 

## NKF's Patient and Family Council Invites You To Join Us In 2001 For



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**Mark Your calendars for these exciting upcoming events!**

**For more information contact the National Kidney Foundation at (800) 622-9010 or visit us at [www.kidney.org](http://www.kidney.org)**

## Parenting

# Sex and Kidney Disease

by Wendy Weinstock Brown, MD, MPH



*Birds do it, bees do it  
Even educated fleas do it  
Let's do it, let's fall in love!<sup>1</sup>*



**C**elebrated in song and movies, love and physical intimacy are an important part of life and human relationships. Coping with chronic illness is never easy. Coping with chronic illness while trying to maintain a normal and fulfilling relationship is frustrating, particularly when the topics are sex, impotence, infertility and loss of desire. Many patients are reluctant to discuss sexual problems with their doctor or other caregiver—it is uncomfortable and embarrassing. Some caregivers are also embarrassed to talk about these sensitive topics. However, it is essential to discuss these issues with someone (kidney doctor, nurse, social worker) who is knowledgeable about kidney disease and medicines and can help you look for solutions to help you enjoy all aspects of life fully.

### ♡ DESIRE AND PHYSICAL CLOSENESS

First, remember that you are not alone. More than half of kidney patients, both men and women, have less interest in sex after diagnosis. Others are interested, but don't find sex and closeness as satisfying as they did before they had kidney disease. About half of men with chronic kidney failure have trouble having or maintaining an erection. Sometimes there is a physical cause—kidney disease can cause fatigue or nausea, depression and changes in sex hormone levels. Other causes include anemia or a shortage of certain vitamins or minerals in the body. Medicines, particularly those used to treat high blood pressure, can affect sexual function, as can certain diseases such as diabetes or hardening of the arteries. Patients who perform peritoneal dialysis may be embarrassed that they have a tube in their abdomen.

### ♡ WHAT HAS HAPPENED TO MY BODY?

There are changes in sex hormone levels in men and women with chronic kidney disease, even before they need dialysis. For example, men make less

testosterone, the "male" sex hormone. Most men with chronic kidney disease make less sperm, and most cannot father a child. They may also notice an increase in the size of their breasts.

Women with kidney disease also have changes in hormone levels. Many women stop menstruating by the time they start dialysis. Some have increased or decreased blood loss. Although most women on dialysis no longer release an egg each month and cannot become pregnant, it is still important to discuss contraception with your doctor. Pregnancy can occur in a dialysis patient, even when a patient hasn't had a period for many years. However, pregnancy while on dialysis is very rare. There are increased risks for the pregnant dialysis patient and for the baby. More premature babies, stillbirths and miscarriages occur in women with kidney disease than without. However, with increased dialysis and specialized care, healthy babies have been born to dialysis patients.

### ♡ WHAT CAN I DO?

Even before you talk to your caregiver about your worries, there are some things YOU can do that may help.

- ♥ Make sure you don't skip or shorten dialysis treatments. Inadequate dialysis is a very important cause of decreased desire and impotence
- ♥ If you smoke, stop smoking—it can cause or aggravate impotence
- ♥ Avoid alcohol—it can cause impotence
- ♥ Discuss concerns about your change in appearance with your partner—you are likely to discover that any differences bother you more than your partner
- ♥ If you have diabetes, make sure your blood sugar is well controlled
- ♥ If you have high blood pressure, make sure it is well controlled.

### ♡ WHAT CAN MY DOCTOR DO?

Your doctor will begin with a careful review of your medical history, lab

values and current medication. He or she may refer you to a specialist (a urologist for men, a gynecologist for women) who will take a sexual history and do a physical examination, and may order various tests. Treatment of sexual problems in both men and women with renal disease may include:

- ♥ A change in blood pressure medicines or other medication
- ♥ Increasing your blood count
- ♥ Vitamins or minerals
- ♥ Hormone therapy
- ♥ Evaluating and treating of depression
- ♥ Better control of calcium and phosphorous levels
- ♥ Referral to a psychologist or marriage counselor

*Depending on the cause, treatment of impotence in men with kidney disease may include:*

- Medication
- Insertion or injection of medication into the penis
- Vacuum/pump devices
- Surgery

*Treatment of women with sexual problems may include:*

- Estrogen creams
- Lubricants

### ♡ WILL THINGS CHANGE IF I GET A KIDNEY TRANSPLANT?

Most patients, both men and women, experience a significant improvement in their sex life after receiving a kidney transplant. It is also important to remember that for most patients fertility is also restored. If you don't want to have a child at this point, you need to discuss contraception with your doctor.

*(Thanks to Charles Slaughter, hemodialysis patient at St. Louis VA Medical Center, for his assistance on this article. )*

1. Cole Porter, Cole Porter Songbook, disc 2, 1928. From the show, Paris, sung by Ella Fitzgerald.

## Up & Down: Balancing Calcium, Phosphorus and Life with Kidney Disease

by Steven Sirois

**A**t the age of five, my kidneys failed.

At that point my life changed forever. Once my kidneys shut down, my life was full of hospitalizations. There were times when I'd be in the hospital for months. I was very sick and went through a lot of pain. Doctors were hesitant to treat me at that stage of my illness. They sent me to Yale New Haven Hospital. Once I arrived at Yale, I was started on hemodialysis. Back then dialysis wasn't very advanced and I had many problems dialyzing.

I was lucky enough to receive a transplant, but the kidney never worked to its full potential. Each time I started to reject it, I was pumped full of steroids. The steroids stunted my growth very early. After three and a half years, my body rejected the kidney. I thought the transplant would make my life easier, but that was not the case with me.

Through all the times of illness and the many problems I faced, my family always provided comfort and support. My mom and dad did everything in their power to make my life worth living. When I found out that I was going to have a brother, I was happy. Even though I was very sick at the time, the excitement of having a new brother made me focus less on my illness. My brother arrived in 1974.

A few years later, I received a second kidney transplant donated by my mother. I was 10 years old. Many trips to the hospital followed and after three years, that kidney rejected as well.

Today, I am a 30 years old. I have been on dialysis for almost 12 years. I've done very well on hemodialysis and hope for continued success.

One constant challenge that I've faced while on dialysis is a battle with my calcium and phosphorus levels. Many dialysis patients face this issue.

My phosphorus level has been very difficult to control. I originally started with a low calcium level that increased my parathyroid level. It required me to have a parathyroidectomy. (The parathyroid glands are responsible for regulating the calcium and phosphorus levels in the blood through the parathyroid hormone (PTH). Low blood calcium levels cause an increase in the PTH levels. A parathyroidectomy is a partial removal of the parathyroid gland to assist in lowering PTH levels). Dialysis patients must work to control these levels in their blood.

After my parathyroidectomy, I had the opposite effect than was expected. It became even more difficult to control my calcium and phosphorus levels. It was a challenge for me to deal with the dietary phosphorus restrictions. I did not always do what I was told.

It wasn't until I finally made up my mind to get this problem under control, that I began to succeed. I followed

three steps to control my levels. The first step began with my dietitian. Using her guidance and information, I got

on the right track with my diet. Dairy products and chocolate were the most difficult to limit. The next step was to take my phosphate binders. Following the diet is one thing, but if you don't take the binders, the whole process doesn't work. The third step was to increase my activity level to help with bone strength; I started a water aerobic class and a light weight training program that has been provided through my dialysis unit.

My phosphorus level has improved greatly. For all the dialysis patients out there who may be having the same challenges I did, there is hope. Just look to your resources and always keep your head up! **F**



**Steven Sirois is keeping his head up!**

**C A R T O O N**

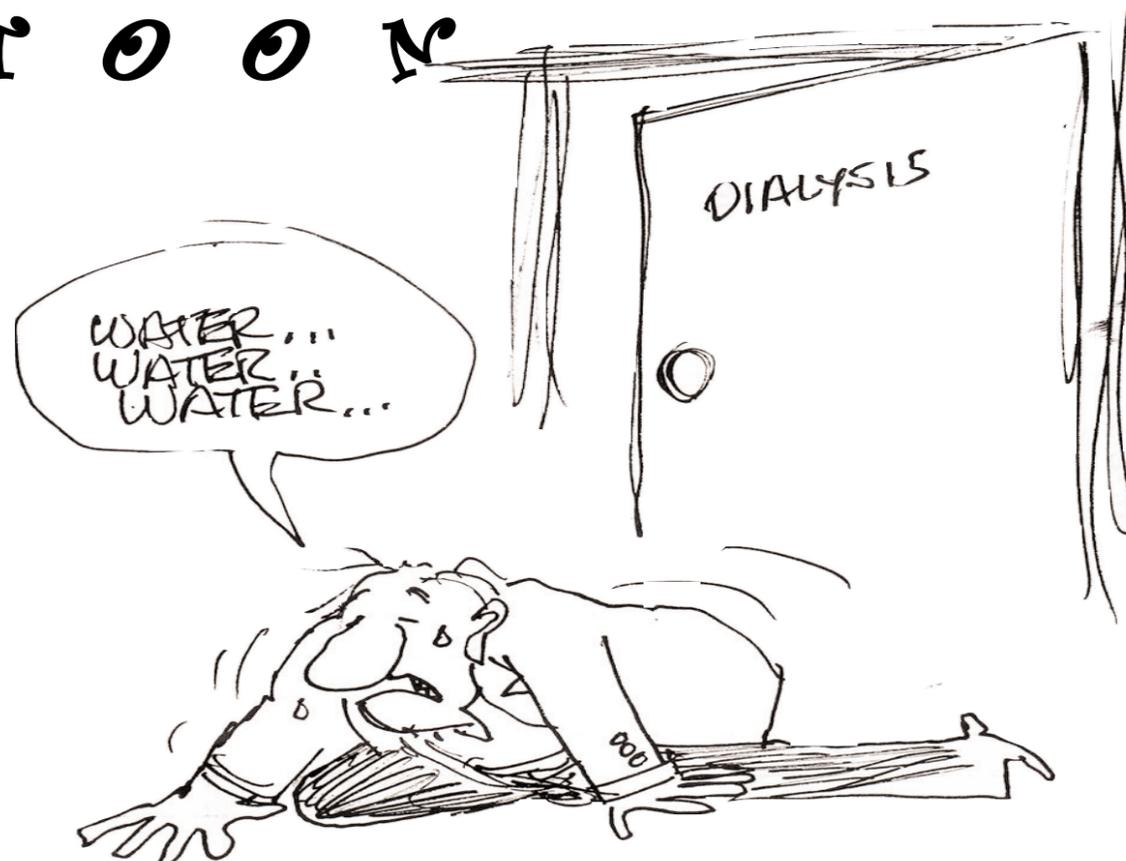
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by Ray Osrin, retired editorial cartoonist of Ohio's The Plain Dealer.



# Good Nutrition

## The Challenge of Feeding Kids with Kidney Disease

by Charlotte Stall, MA, RD

**W**hen you have a child with a chronic illness such as kidney disease you and your family are faced with increased demands and stresses. Meeting your own needs as a family and the special needs of your child often involve unplanned challenges. Frequently, one of those challenges is dealing with either diet restrictions or special diet needs. Whether your goal is to restrict potassium, limit salt, or increase calories, changing eating habits is not easy.

The first step is to learn and understand your child's specific diet needs. Your renal dietitian can be your guide. Then, depending on your child's age, include him or her in the explanation of those special diet needs. Even young children can learn basic guidelines and be motivated to cooperate. Older children can share the responsibility for following a diet, but should not be solely responsible until later teen years.

Since eating is a social and emotional behavior as well as the way to provide nourishment for our bodies, any special diet recommendations need to be a part of your regular routine and life. Cooperation and support from all family members (parents, step parents, brothers, sisters, and grandparents), as well as friends and school personnel are necessary. Not only will your child who needs the diet be more accepting of his or her situation, but it will make family life more pleasant.

Siblings might not understand the need for a diet or even the chronic illness itself. They may feel abandoned or resentful of what they see as special attention for the "sick" child. Different or extra food preparations can make them jealous. Sometimes favorite snacks or foods that aren't permitted on the special diet will need to be given up by siblings. At other times, children on the special diet will need to understand when brothers and sisters eat a food that they cannot eat. You can also include special, inexpensive non-food treats when a child is feeling left out.



As a parent, you need to let the children in your family know that they are all different, but each special in his or her own way. By involving them in the special diet process, you can teach them the importance of the diet and how to be supportive of each other. Brothers, sisters, and grandparents can help shop for foods, read labels, cook and serve meals or snacks. Siblings can even make the special diet the subject of a science project.

Another way to make a special diet more acceptable is to frequently serve foods that are allowable for everyone. Through education and the support of each other, families can happily balance the diet and nutrition needs of everyone.

The child who won't or can't eat enough for good growth poses another challenge. Many children with kidney disease have this problem. Some have poor feeding skills due to long hospitalizations or dependence on feeding tubes. Other children have swallowing difficulties or problems with reflux. Still others may just be "picky eaters." Whatever the reason, feeding problems can be a great frustration for families.

Before tackling feeding problems, be sure that the possible medical causes have been addressed. Studies on speech and swallowing, occupational therapy, and laboratory test checks for nutrient deficiencies can be helpful in identifying specific problems.

Many infants and young children, plus some older children, need tube feedings to get in enough calories to thrive and grow. While these tube feedings provide adequate calories, the issue of non-feeding remains. Families struggle trying to get children to eat. Your renal dietitian can help you choose foods that are high in calories and learn how to add calories to regular meals. By using "calorie dense" foods, you can add calories without increasing the amounts of food your child needs to eat. The behavior modification techniques which follow can also be helpful.

As parents, you need to agree with your child on some feeding and eating rules. You are responsible for providing healthy meals that are appropriate for your child's age and specific diet. Your child is responsible for eating. You cannot force eating!

You and others in your family should try to be examples for good eating and acceptable table manners. While it may be difficult to do so in our busy, fast-paced world, it is best to eat meals together at the table. Distractions such as television, toys and books during meals are not recommended.

Most of all, ignore food refusals and reinforce eating. That doesn't mean that food is a reward. You should not bribe or reward your child to eat. Don't be afraid to set limits. It is not necessary to be a short order cook, either. Offer foods that are being served to the entire family. Occasionally, when foods are too spicy or too fancy, it is okay to offer simple, easy-to-prepare substitutions.

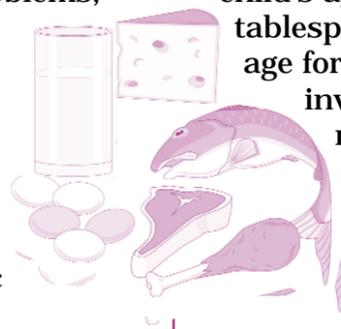
All children in your family, even toddlers, can help with food preparation and setting the table. They can also have some choice in the foods that are served. Offer new foods one at a time and with favorites. Be sure to give the right size servings for your child's age (usually about one tablespoon of each food per year of age for young children). By involving children with the meals, you can make mealtime a pleasant and positive experience.

Check with your renal dietitian for more information on special diets or for information about children who are poor eaters. You may also find the following books to be helpful:

*Why Can't I Eat That! Helping Kids Obey Medical Diets.* John F. Taylor and R. Sharon Latta; R & E Publishers, Saratoga, CA.

*Poor Eaters. Helping Children Who Refuse to Eat.* Joel Macht; Plenum Press, New York.

*How to Get Your Kid to Eat... But Not Too Much.* Elyn Satter; Bull Publishing, Palo Alto, CA. 



## When Your Child Is Diagnosed With Kidney Disease

by Jean Carosella, LCSW, ACSW

**B**eing a parent can be one of the most wonderful, yet difficult jobs in the world. From the moment of birth, parents have the awesome responsibility of decision-making, which continues until that infant reaches adulthood. Raising a physically healthy child is tough enough. But when your child suffers from kidney disease, the role of parent takes on a whole new dimension.

The age at which a child is diagnosed with kidney disease has a great impact on how parents cope with a chronic illness in the family. Parents of an infant, especially first-time parents, may feel particularly overwhelmed. Not only are they trying to become acquainted with their infant, but they must also learn about their child's illness. Often, parents may be at a loss, feeling they have nothing to offer their infant. Doctors and nurses are providing necessary medical care and there is no clear cut role for them as parents. The truth is that only Mom and Dad can provide the physical closeness, love and bonding that a child needs in the first few weeks of life.

If the child is diagnosed with kidney disease during the pre-school years, separation from parents is a major issue. Children view their parents as protectors, but illness, hospitalizations and necessary medical treatments cause some separation from parents. At this age, it is difficult for parents and children to be apart. Yet, if other children need care at home and the parents have work responsibilities, these separations are inevitable. It can be difficult to soothe and explain these

absences to a chronically ill child. But in most families, some separation occurs.

A new dimension of responsibility is added for the parents of a school age child with kidney disease. It becomes their job to educate teachers and other staff about the child's condition as well as any special educational needs. Parents become advocates to ensure that there is no disruption in the educational process, although attendance may be disrupted due to illness, hospitalizations, surgeries, etc.

Children in the pre-teen and adolescent stage of life typically become more independent from parents. They become more capable of making their own decisions. Parents struggle with their wish to keep "holding on" to their sick child or encouraging independence. Regardless of age, all parents want to protect their children. A chronic illness only reinforces their desire to shield the child from potential sadness or suffering. But adolescence is a time of testing and breaking away from parental ties. A chronic illness will make it difficult to move toward independence and result in anger from a teen with kidney disease.

Parenting never ends, even when children are adults with their own families. Older parents of adult children may still experience the same reactions as younger parents when it comes to the well-being of their child with kidney disease. A parent's desire to nurture, soothe and protect is common, even when the kidney disease patient is well into adulthood.

Being the parent of a kidney disease patient can often be a lonely and scary experience. Some parents feel ostracized by their peers who show concern, but are often unsure about how to express themselves. Kidney disease can become the focus of the whole family and result in a limited social life outside the hospital or clinic setting.

What helps parents of kidney disease patients? First, parents need to feel that they are competent. They need to feel some control over a difficult situation. Some ways to increase this feeling of competence include talking to medical staff and experts in the field of kidney disease, reading and attending parents' groups.

The social worker can be invaluable to parents, particularly in times of medical crisis. He or she can help to explain what the child is experiencing in a clear, simple way. Parents can be shown what to expect during the natural course of their child's care. Remember, the social worker can identify resources that can help the family cope.

Ask questions, seek out caregivers, and look for support. Regardless of your child's age or medical condition, remember that help is available to you as parents. The more you are able to cope with your child's illness, the more you will be able to support your child on his kidney disease journey.

(Thanks to Evelyn Corsini, MSW, for her consultation and collaboration on this article). 



## MAIL BOX

When I first started dialysis, I was only 22 years old. It's been almost 13 years. After some time on dialysis, I began reading *Family Focus*.

Before I began reading your newspaper, I would often get depressed and feel sorry for myself. Then I would read the articles in *Family Focus*. I'd gain new hope and confidence in myself when I read about other dialysis patients going through the same things. They were working and excelling in life!

Please continue to publish *Family Focus*. It has been a great inspiration to me. It motivated me to find work as a part-time secretary and volunteer as a driver for our department of human resources.

*Family Focus* and the staff at the Monroeville Dialysis Center deserve thanks for their dedication and support over the years.

Minnie Henry

Dear Editor,

I am writing this letter to express my appreciation for the article in *Family Focus* Special Edition on "How to Read and Understand Your Lab Values" by Wayne Nix. I have been on dialysis for over seven and a half years and this is the first time I have really understood the lab values. I found that the definitions of the many terms and abbreviations used in monthly lab reports will be very helpful in my review of the lab reports with my nephrologist and the dialysis center dietitian. I especially liked the sample Dialysis Report Card. The blank card furnished as an insert in the *Family Focus* newsletter will certainly assist all of us hemodialysis patients to keep a record of the lab reports and assist each of us in adjusting our schedules and diets to achieve our goals and we hope, prolong our lives. That is the ultimate goal of all kidney disease patients.

Please continue to send a copy of *Family Focus* to me. I like it and find all the material to be very informative and helpful.

Thank you,

John B. Mc Govern

## Parenting

# A Very Tough Balancing Act

by Deborah Brouwer, RN, CNN

**R**aising a family is the hardest, yet most rewarding role for any of us to fill. To balance the treatment requirements of a chronic illness and the role as an active family member must be especially difficult.

I became a nurse because I wanted to help others in the battle against chronic illness. Caregivers understand all of the stress a chronic illness places on a person and the entire family and can be a source of great assistance. This article gives suggestions to help you talk about the issues with your caregivers so you can find a way to balance the role as a parent or grandparent with the role of the dialysis patient.

Your family needs to come first, but not at the risk of your health. What does that mean? You need to select a type of dialysis and schedule that will work for you and your family.

■ Peritoneal Dialysis (PD) can allow for the maximum freedom. There are various forms of PD. The PD nurse or your nephrologist can explain the differences. PD can be an option at any time. Ask your nephrologist to make sure you do not have any medical reasons that would limit PD as one of your options.

■ Home Hemodialysis might be an option for you and your family. You need space in your home for the dialysis equipment with a proper water source. A caregiver within your home can be your dialysis partner. You can learn how to set up the dialysis machine and assist with most of the procedure, but you need a partner to help assist and supervise the dialysis treatment. This may be a good choice for working families because dialysis can be done in the evening at home.

■ In-Center Hemodialysis is the most common option for kidney disease patients. You will need to talk with your dialysis nurse, social worker and nephrologist about treatment issues that cause hardship to you and your family.

Often, the most difficult issue is the dialysis schedule. You need to explore

scheduling options. If you work, you will need to adjust a dialysis schedule that will permit you to continue working. Not all centers offer multiple shifts. You may need to transfer to another unit that offers various shifts. It is your health and you must take the primary responsibility by taking an active part in your care. Talk with your center's staff to work out details so you can receive the best care possible. If you need to change your dialysis schedule for special events, like a child or grandchild's activity, you need to talk with the dialysis staff as far in advance as possible. Many dialysis units are full, with no open dialysis chairs. Another dialysis patient may need to switch schedules to allow you to dialyze at a different time or day.



What is most important is not to skip or cut treatments short. Your dialysis is only for a few hours a week, so even 15 minutes missed is a large percent of your treatment time. Your kidneys functioned every minute of every day (about 10,080 minutes) — now dialysis tries to do the same job in 9-15 hours a week. Every minute of treatment time is important to your health. Cutting off minutes can end up cutting off days of your life and make the days you have be days on which you don't feel well.

The balancing act is to feel well, take the best care of yourself and still have time to spend with your family. It is important to your family that you're as healthy as possible so your time together can be focused on having fun and creating life-long memories. Talk to your family about the stress they feel from your illness. Sometimes it seems that everyone is being selfish, but that is often a front to hide the true concerns and fears that a chronic disease creates. We all fear the loss of health and lifestyle. When an illness occurs we need to pull together to overcome the problems. Hope is a key factor. Talk about what gives you hope and strength with your family and caregivers.

In this busy world it may seem like no one wants to hear about your

problems—so try to talk about your feelings in a way that allows people to help. Be specific about your hardships. Ask your dietitian questions. Explain, for example, that the renal diet is hard for you because your family likes to go out to eat at restaurants or fast food places to save time. Ask what you can do about it. Talk about make-ahead meals. Explain to loved ones that you're just too tired when you get home to help care for the kids.

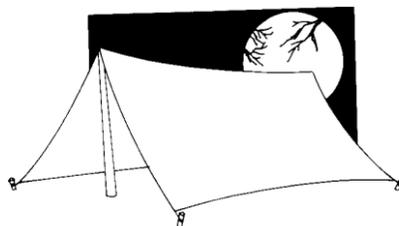
Talk with your dialysis nurse, nephrologist and social worker. You may be tired for several reasons. Your hematocrit may be low. You may have side effects from your blood pressure or heart medication. Consider changing to a different medication. If you have low blood pressure (hypotension) following treatment, your medications or dry weight might need to be adjusted. Excessive weight gains between treatments are another cause of fatigue because of the extra fluid removal that is needed during dialysis. You may need to have longer treatments to provide for better fluid removal and clearance of waste products. Often, resolving the issues of dialysis requires teamwork. You need to be part of the team.



What I have learned in my own life's experience with illness is that you cannot do it alone. You need your family and they need you. Talk openly with your health care providers and family about issues that concern you. Remember that your nurses, social workers, dietitians and doctors may have had many different reasons for becoming health care providers, but they all share the same goal now—to help kidney disease patients live as healthy and happy as possible. Help balance your life! Keep your faith and family as your strength. Most importantly, enjoy each day with your family. It is a gift that has to be treasured. 

## Explore New Opportunities at Kidney Camp

**B**eing the parent of a child with a chronic illness or being a chronically ill parent does not have to present a challenge to find activities in which you can participate. Many people with a chronic illness such as kidney disease often feel that they cannot maintain a normal life and enjoy daily activities that enhance personal growth.



Although there may be limits to the activities that a kidney patient can engage in, there are many opportunities available for patients and their families. One excellent opportunity is camps that accommodate people with kidney disease. There are camps specifically for children with kidney disease, as well as camps that provide activities for the entire family.

Kidney Camp can be a chance for people affected by the emotional, financial and physical challenges of kidney disease to develop a support system. It is a great opportunity for children, adults and families to cultivate new learning and living experiences. It is a unique way for people to explore different areas of interest while developing new skills, making new friends and having fun. There are opportunities for enhancing social, athletic, language, reading, gross motor, coping, and independent living skills, which can in turn enhance self-esteem. Not every camp offers all of these opportunities, but by understanding your needs and those of your child and family, you can equip yourself with the right information to choose the camp that is right for everyone.

Many camps take place during the summer, but there are other camps that have sessions at different times of the year. There are day and sleep-

away camps. Most camps are equipped with professional counseling and medical staff, and some provide on-site dialysis or transportation to a dialysis facility nearby. One of the many considerations in choosing a camp is cost. Many camps offer financial assistance or scholarships. Additional financial support may be obtained through some National Kidney Foundation (NKF) affiliates.

### *Here are some things to keep in mind as you begin looking for a camp:*

- Know that you have the right to ask questions.
- Know what you or the camper want out of the camp experience.
- Know the specific areas of interest the camper would like to improve.
- Know the potential camper's personality.
- Know what type of camp will best suit the camper (day or residential/sleep over).
- Involve the camper in the decision-making process.

### *Things you may want to ask about:*

- The camp's philosophy.
- The criteria for choosing campers.
- The qualifications of the director and staff.
- The make-up of the professional staff (counselors, therapists, etc.).
- The ratio of professional staff to campers.
- The availability of medical staff and facilities.
- The procedures for administering medications.



- The provisions for dietary needs.
- Safety procedures.
- The cost — funding, assistance, scholarships, payment plans.
- Camp transportation.
- Camp setting — sleeping arrangements, tents, cabins' bathroom/shower facilities, etc.
- The types of activities offered, and whether they vary by age group, abilities, interest, etc.
- How the individual needs of the campers are addressed.
- The procedure for handling behavioral/disciplinary problems.
- Anything else that will help you in choosing the right camp for you and your family.

To obtain information about a camp in your area that accommodates dialysis patients or kidney transplant recipients, you may contact the National Kidney Foundation at 800-622-9010 for a copy of its annual Kidney Camp Directory, or your local NKF affiliate. Your social worker may also have information about local camps. 



## Parenting

# Adoption: A Loving Option

by Fred M. Kouri, LMSW

**A**doption is a loving option for many couples who experience infertility or uncertainty about the likelihood of having another child with a chronic illness. Following is information on the different types of adoption, the adoption process, the impact on families and resources and steps to take if you are interested in adoption.

### WHAT IS ADOPTION?

Adoption is a legal process by which a parent and child relationship is established between individuals who are not otherwise related. There are three sets of participants in an adoption: adoptive parents who are seeking to adopt the child, the child to be adopted, and the natural parents of the child who is to be adopted (birth parents). Not only does the adoption create a new legal relationship between the adoptive parents and the child, but it also terminates any legal relationship existing between the child and the birth parents. Therefore, it is a significant legal, social, emotional and financial step for all parties involved.

### WHAT ARE "CLOSED" AND "OPEN" ADOPTIONS?

A *closed adoption* means that there is very limited information about birth parents and adoptive parents before the adoption, and no personal or written contact between the child and birth parents afterwards. It is generally felt that completely closed adoptions are not in the best interest of the child unless there are safety or specific legal concerns. Some degree of openness is seen as being positive to help children know his or her birth history and reasons for the choices made by the birth and adoptive parents.

An *open adoption* means that some personal and family information is shared between birth and adoptive parents and there may be some contact between the child and birth parent(s) after the adoption is complete. There are varying degrees of openness with adoption, and most adoptions today include some shared information before birth and limited contact through pictures and letters after the adoption is complete.



(L to R) Hannah Marie Kouri (age 16 months) and Leah Catherine Kouri (age 4 1/2 years).

### WHAT ARE THE DIFFERENT TYPES OF ADOPTIONS?

Five different types of adoption (listed below) can occur between birth parents and adoptive parents. The process, costs and philosophy can vary significantly among these types. Anyone assisting with any type of

adoption should have a state license to provide this service. Prospective parents are encouraged to talk with others and the state licensing bureau before proceeding with the adoption process.

#### ■ Relative Adoption:

A family member legally adopts another member of the family. In the most common relative adoption, a stepparent seeks to adopt a child or children of his or her current spouse (also referred to as stepparent adoption). The second most common type of relative adoption is between grandparents and grandchildren.

#### ■ Agency Adoption:

An individual or couple signs up with an agency to assist with all aspects of the adoption process. Agencies are usually private, not-for-profit, or religiously affiliated and can be found in the yellow pages or the

Internet under "adoption." An agency adoption can be either open or closed.

#### ■ Private Adoption:

Typically, involves a social worker and attorney who arrange the adoption based on a process that is agreed upon by both the birth and prospective adoptive parents. Private adoptions are generally open.

#### ■ State Adoption:

The local child protection or welfare program identifies a child in state custody who is eligible for adoption. Usually there is financial assistance available for the costs of adoption and ongoing expenses if the child has special needs.

#### ■ International Adoption:

Adoption of a child from another country requires the assistance of a skilled and respected agency with contacts and expertise in the country the prospective parents are considering adopting from. Because the political climate in some regions of the world can change abruptly, research about the agency and country before traveling abroad to adopt is imperative.

### THE PERSONAL SIDE OF ADOPTION

Choosing to pursue adoption can be an emotional process that is filled with mixed feelings. There is frequently a feeling of sadness about the inability or choice not to give birth but a joy that comes with the possibility of parenting. Within the Transplant and Dialysis Program at Children's Mercy Hospital in Kansas City, Missouri, there are a number of families who have participated in the adoption experience. While each story is unique, they have all involved caring for a child on dialysis or with a kidney transplant.



*continued on page 11*

# Parenting

## Adoption: A Loving Option

continued from page 10

### Michael's Story:

Shortly after birth, it was learned that Michael needed dialysis. His birth parents were unable to cope with that situation. Having been abandoned by his parents, Michael was adopted by a loving couple who nurtured and loved him as only parents are able to do. Michael's adoptive parents learned how to do home peritoneal dialysis. Five years ago, he received a kidney transplant at age 6. Michael's adoptive mother reflects that raising a child with end-stage renal disease (kidney disease) has been a tremendous blessing and she would not hesitate to adopt another child just like Michael.

### Megan's Story:

Megan was born with oxalosis, a congenital defect of the metabolic system that causes oxalate to deposit in the kidneys and elsewhere in the body. Oxalosis eventually leads to kidney failure. She has undergone two kidney and two liver transplants. Megan's parents pursued adoption of her sister after Megan turned 9 and they are just now adjusting to the sleepless nights of a 5-month-old daughter. Megan's dad talks about the differences in dealing with "normal baby girl problems" as opposed to Megan's early episodes of peritonitis, medications and hospitalizations. "It is an adjustment to just allow her to crawl freely on the floor, get prolonged baths and just explore her world without worrying about harming the catheter. There is plenty of love for Megan and her sister."

### Raymond's Story

Raymond was adopted by his grandparents after a kidney transplant and is now living with his siblings in southern Missouri. This adoption was a difficult process for the entire family and counseling was necessary to help everyone adjust. Being abandoned by parents as a young child can have long-term effects, making counseling essential for all parties involved.

At a recent clinic, one of our foster parents (who has two adopted special needs children and a 1-year-old foster child on peritoneal dialysis) told me that she gets very angry when people say that special needs children are "unadoptable." She said that it is no secret that it takes the commitment of the entire family and support from the medical team, but that the joys exceed the challenges of caring for a child with kidney disease.

### ARE YOU THINKING ABOUT ADOPTION?



If you are, here are some suggestions that may make the process easier.

- ☞ Meet with a counselor or social worker about your readiness to adopt.
- ☞ Do your homework about adoption by looking on the Internet (see recommended web sites) and reading adoption handbooks and articles.
- ☞ Talk with other individuals and couples who have adopted.
- ☞ Attend a meeting of parents who have adopted children.

- ☞ Contact your state licensing agency to see who is an approved provider of adoption services for your state.

- ☞ Interview agencies, social workers and attorneys before you commit to working with them.

- ☞ Stay organized. There are reams of paperwork and documentation, and you need a system to stay organized through the process.

- ☞ Set a budget. You may find it helpful to talk with a financial planner about paying for adoption expenses and your eligibility for state and federal tax credits for adoption.

- ☞ Make adoption a family decision by talking with immediate and extended family members.

- ☞ Last, seek the support of your friends. This is a process you need to share with others.

### MY FINAL THOUGHTS:

Adoption has changed the lives of my wife and me with the addition of our daughters, Leah and Hannah. We feel so blessed to have such wonderful and loving children. Although all adoptions have unique challenges, adopting a child, especially one with special needs, is sure to result in many lifelong rewards. **FF**

### WEB SITES ON ADOPTION:

[www.adopting.com](http://www.adopting.com)  
Complete adoption resource site.

[www.adopting.org](http://www.adopting.org)  
General overview of adoption and resources.

[www.adoptionguide.com](http://www.adoptionguide.com)  
Advocacy for families adopting nationally and internationally.

[www.adoptivefam.org](http://www.adoptivefam.org)  
Established in 1966, an excellent resource for getting started.

[www.wendys.com/community/adoption/foundation](http://www.wendys.com/community/adoption/foundation)  
The Dave Thomas Foundation (Thomas is the founder Wendys) supports adoption through education and employee benefit reforms to cover adoption costs.



# POETRY

## CORNER

### *Dialysis*

by Carmela DeLuca

Dialysis is a machine that keeps us alive.  
You can't miss treatments or you can die.

Arteries remove the blood from the body to be cleaned,  
Veins return blood to the body; it flows like a stream

We either have a catheter or a graft in our arm.  
It sounds pretty awful, but don't be alarmed.

Two needles with tubes connect us to the machine,  
That's how the blood gets ready to be cleaned.

Reuse Technicians wash the dialyzers to make sure  
they are safe,  
They also fix our machines when they break

Doctors come visit us, "Hello, how are you?"  
They give us a medical report and tell us what we  
should do

The Nurse Practitioner comes to see us, too  
She does the same things the doctors do.

The Secretary's job is to make sure things run smooth,  
She does this for the staff and also for you

The Administrator gets many things done,  
He solves our complaints, one by one.

If you need to talk to someone at sometime,  
See the Social Worker; He will ease your mind.

The Dietitian tells us what food we should eat,  
All of us, I'm sure, sometimes cheat.

We all get sick on the machine, at times;  
Nurses give us hypertonics  
Technicians say, "You'll be fine." 

*Carmela DeLuca is a dialysis patient.*

### *Baxter*

by Kristen Dana

*For her father, Jim Dana*

Whose machine is this? I think I know  
It saved the life of a man I also know  
It will never see how much I care  
to watch a life appear from nowhere

The big house in which it dared  
to stop the heartache and my fear  
Between his skin and frozen pain  
All the long nights and suffering remain

He tried all he could, but nothing worked  
Since he was little, it always irked.  
We all thought it was gonna be easy

Baxter would hum and then it would whirl  
It did its night's job in spite of the hurt  
It all worked and felt like clockwork  
But it took a lot of team work 



Chamberlain