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COMPLEMENTARY AND ALTERNATIVE TREATMENT: FRIEND OR FOE?

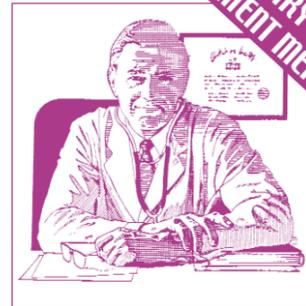
Family Focus

The Renal Community's Newspaper

VOLUME 10 NUMBER 3

SUMMER 2001

WHAT DOES
COMPLEMENTARY AND
ALTERNATIVE TREATMENT MEAN TO YOU?



Can the Mind Heal the Body?

By Beth Witten, MSW, ACSW, LCSW

Use of Complementary & Alternative Medicine

Do you take herbal supplements, do yoga or see a chiropractor? All of these treatments and many others are called *complementary or alternative medicine*. Traditional medicine considers complementary and alternative medicine (CAM) to be outside the range of "proven" treatments. People use *complementary medicine* along with what their doctor prescribes. People use *alternative medicine* instead of what their doctor prescribes.

The basis of traditional medicine is that the doctor knows best and the patient does what the doctor says. The basis of CAM is that patients and healers work together. Rather than the doctor taking full responsibility for the patient's health, both share responsibility for the patient's health and choices.^{1,2}

CAM's Use & Acceptance

One national study compared the use of CAM treatments in 1990 with those used in 1997. Thirty-three percent of those surveyed reported they used CAM treatments in 1990, while 42 percent reported they used CAM treatments in 1997. People said they used CAM for ailments like back problems, headaches, depression and anxiety.³ Eighty percent of elderly Californians insured by a Medicare HMO said CAM treatments helped them. However, 58 percent did not tell their doctors they used CAM practices.⁴ Ninety percent of family doctors said they believed exercise and diet, biofeedback, psychotherapy and behavioral medicine were reliable. Fifty percent of these doctors would refer for these services.⁵

Study of CAM Practices

Congress funded an office in the National Institutes of Health in 1992 that was charged with studying CAM practices and informing the public of its findings. This office became the National Center for Complementary and Alternative Medicine (NCCAM) in 1998. The NCCAM has found that some treatments that were once considered CAM work and are gaining acceptance in traditional medicine. Many doctors who would have considered patient education, behavioral and "talk therapy" to be CAM 20 years ago are embracing these treatments today. Doctors will also accept other treatments when research shows they are safe and effective.⁶

Mind-Body Medicine

Can the mind affect the body? Research has shown that stress can affect blood pressure, pulse and breathing. It can also affect blood clotting, blood sugar levels, sodium retention and the immune system.⁷ It makes sense that if stress can harm the body, techniques to reduce stress might help the body. Research has shown that this is indeed the case. Relaxation, yoga, biofeedback,

meditation, guided imagery and psychotherapy may reduce stress and control blood pressure,⁸ reduce pain and anxiety and shorten hospital stays following surgery.⁹

People using *meditation* and *relaxation* learn to sit comfortably with their eyes closed. They breathe regularly and repeat a sound, word, phrase or prayer while they ignore all other thoughts.

People using *yoga* do exercises ("postures") that use particular meditation and breathing techniques. Yoga focuses on physical, emotional and, especially, spiritual well-being.

People who use *guided imagery* believe the mind can create images almost as real as actual events. If they relax and think of an image that stands for a problem, they can control and overcome the problem.

People who practice *biofeedback* use a machine that detects a body function such as blood pressure, heart rate or body temperature. The machine sends a signal people can see that represents a particular body function. They learn to manipulate the signals from the machine, and as a result, control the body function in their everyday life.

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FROM THE EDITOR



Karren King

After preparing and editing this issue on complementary and alternative treatment, as well as being an occasional consumer, I still have a difficult time categorizing the treatments as either friend or foe. The main points we want to stress are that we should take all of these treatments seriously and that each of them has the potential to aid or to harm us, as well as to have no realizable impact at all. The *Family Focus* Editorial Board is by no means

attempting to influence you to use or not to use complementary and alternative treatments. We, however, do want to influence you to inform your partners on your health care team about any treatments that you are either considering trying or are currently using. We want to ensure that if you use complementary and alternative treatments, you do so without any ill effect.

There are two issues that your Editorial Board regrets we did not have the opportunity to explore for you in this issue. One of these is how our ethnic and cultural backgrounds may influence how we view and use various forms of complementary and alternative treatments. While some cultures may see certain types of these treatments as "mainstream," others will view the same treatments as anything but common! The other issue we did not delve into is the historical aspect of these treatments. As Dale Ester points out in his article, "Cautions about Using

Alternative Treatments," some forms of treatment were used by the "human race long before the present time." While we couldn't cover all aspects of this topic in one issue, we do hope that you will enjoy and be informed by the wide range of information that we have provided.

It is hard to believe that the first year of this Editorial Board will be coming to a close after our next issue, Chronic Kidney Disease and the Life Cycle. As we wrap up this year, we begin to look to future issues of *Family Focus*. With that in mind, we would love to hear from you. We invite you to share with us suggested "themes" that you believe are timely, needed and important for future issues of this newspaper. Please send your ideas to me in care of the National Kidney Foundation. After all, who knows better what is needed than people like you who live with chronic kidney disease? We can all learn from what you have to share. 

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



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Editorial Office:

National Kidney Foundation
30 E. 33rd Street,
New York, NY 10016
(800) 622-9010 • (212) 889-2210
<http://www.kidney.org>

Editorial Director:

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Can the Mind Heal the Body?

continued from page 1

People who seek *psychotherapy* (counseling) talk about their problems, feelings, behaviors, hopes and dreams with trained mental health professionals such as social workers, psychologists and psychiatrists. By talking through their problems, they "get problems off their chests" and learn new ways to cope.

Learning What You Can About A CAM Provider

Although some CAM therapies can be helpful, others are dangerous and can cause serious problems. Be on guard if you think claims sound "too good to be true." A fact sheet from the NCCAM¹⁰ recommends that you:

- ♣ Talk with others who have used the CAM provider.
- ♣ Ask the CAM provider about his or her qualifications.
- ♣ Check with your State Department of Health to find out if the CAM specialty is regulated in your state, and how to find out if your provider is licensed or certified.
- ♣ Interview the provider so you're more comfortable receiving services there.
- ♣ Learn what treatments cost and what is covered by insurance.
- ♣ Tell your kidney doctor and health

care team all the CAM treatments you are using.

Remember, you have a duty to yourself and your family to protect your health and your life. Learn all you can about all your treatment options. Choose what you do wisely using the information you learn.

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Letter to the Editor

In 1993, my medical doctor at that time informed me that proteins were "spilling" into my urine. My hematologist referred me to my renal doctor of eight years now. By June 22, 1998, a Tenckhoff catheter was placed in my abdomen. I began peritoneal dialysis on July 8, 1998. I started out with four treatments a day, but it was determined that I would need five a day after the first year.

I have suffered with sickle cell disease since the age of five years. Frankly, ESRD and sickle cell are in direct conflict in my body. Consequently, I've been having a tough time. I've been going into crisis much too often.

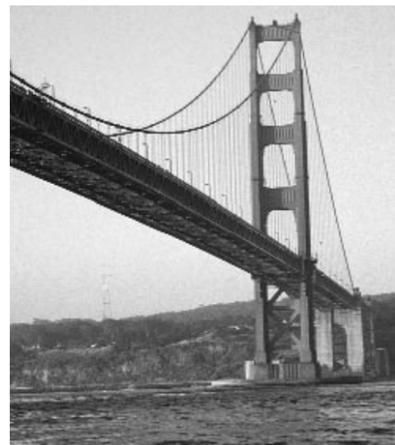
As painful as my crisis can be, I'm in even more pain now and it's constant. I also have hepatitis C, contracted from a blood transfusion in 1989. I need as much information as I can get. To be able to correspond or talk with someone dealing with the same situation might be helpful also. Thank you for any time and attention you can give to this matter.

If you would like to correspond with the above patient please send your reply to Family Focus Friends, National Kidney Foundation, 30 East 33rd Street, New York, NY 10016. 

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October 13, 2001
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Kidney Disease Caused By Chinese Herbs

By Marc E. DeBroe, MD, PhD

It is very important to be aware that “natural” herbal remedies, many of which can be purchased easily in grocery, drug or health food stores, can be harmful to the kidneys or other organs. Doctors in Belgium noted an increasing number of women who developed acute, often near end-stage kidney failure after taking Chinese herbs at a weight reduction clinic in 1991. A total of 14 women were found to have severe kidney disease over a three year period of time in Brussels, Belgium. They had kidney biopsies that showed a type of kidney disease called chronic tubulo-interstitial nephritis; nine of these women took Chinese herbs to lose weight. More than 100 women who had developed kidney disease from taking Chinese herbs were identified by early 1999. More than one-third of these patients have already had kidney transplants.

In addition to causing kidney failure, these Chinese herbs also affect cells in the kidneys and ureters, causing changes that can result in cancer of the kidneys or ureters (tubes that carry urine from the kidney to the bladder). As a precaution against developing cancer, Belgian doctors have removed native kidneys and ureters from 10 patients during or after kidney transplant. At least one of these patients had bladder cancer. Four patients had an early form of cancer. The rest of the patients had cells which looked abnormal and showed changes that might lead to cancer.

The reason that Chinese herbs cause kidney disease is not well understood. A toxin (poison), aristolochic acid, found in some Chinese plants that cause kidney damage was thought to be a possible cause of the kidney failure, but it was not part of the herbal preparations used by all the patients. In addition, this chemical has been used by thousands of patients in Germany for more than 20 years to regulate the immune system and has not caused kidney disease in any of these patients.

In addition to Chinese herbs, patients who developed kidney disease also took two medicines for weight loss. These medicines, fenfluramine and diethylpropion, cause a decrease in appetite. In

addition, they make blood vessels grow smaller, which leads to less blood flow or supply of blood to tissues and organs. Tissues are damaged when they don't receive enough blood. Cells may die. Scars form. If the affected organ is the kidney, it loses the ability to do its work. The kidney disease that happened so rapidly in these Belgian women may have been caused by a combination of exposure at the same time to the toxin and the two medicines that caused a decrease in appetite and a decrease in blood flow.



It is also not known why only some patients who took the herbs got kidney disease, and for some reason women appear to be at greater risk than men. Other possible factors include the amount of herbs that were taken, batch-to-batch differences in toxin content, individual differences in the way the body handles the toxin and an inherited tendency of a person towards kidney damage from such toxins and/or towards development of cancer.

Regardless of how it occurred, there is no question that kidney disease from Chinese herbs is associated with the development of cancer.

Presentation and Prognosis

Affected patients typically present to a medical professional with kidney failure. Their blood pressure is either normal or only slightly increased. They don't have a lot of protein in their urine, and the urine contains only a few red blood cells and white blood cells.

Kidney function may range from being slightly decreased or severely decreased when patients first see their doctor. The patients' creatinines have ranged from 1.4 to 12.7 mg/dl. Those patients with serum creatinines closer to the normal range seem to do well and do not need dialysis. However, progressive kidney failure leading to a need for dialysis or a transplant may occur in patients

with more severe disease even if they stop taking the Chinese herbs. The longer patients take the herbs, the more likely they are to have severe kidney damage. A similar problem happened to a group of patients from Taiwan who took some other traditional Chinese herbs that were not the same as the weight loss herbs. Even though the Taiwanese patients stopped taking the herbs, they had kidney failure. The important point to remember is that these herbs are not tested like prescription medications to make sure that they don't cause harm to the body. In addition, they may not be “pure” but may be mixed with other ingredients that can be harmful. It is always a good idea to ask your doctor before you take any herbs.

Treatment

There is no effective treatment for the kidney disease that the Chinese herbs cause, although it is possible that corticosteroids such as prednisone, may slow the course of disease. Because of the risk of cancer, these patients have to be examined on a regular basis to look for cancer in the kidney, ureters or bladder. Some doctors have suggested that these patients should have their kidneys and ureters surgically removed because of the high risk of cancer.

Lessons

- ☞ Not everything “natural” is healthy.
- ☞ Don't take any herbs or herbal remedies without talking to your doctor first. You can buy many “over-the-counter natural medicines” without a prescription that can harm you.
- ☞ Natural herbs may be more harmful for patients who already have kidney disease. St. John's Wort, for example, which has been used to treat depression, shouldn't be used by anyone with a transplant because it affects the blood level of medicines that help prevent transplant rejection. 

Marc E. DeBroe, MD, PhD, is with the Department of Nephrology at the University of Antwerp in Belgium.



PATIENT AND FAMILY CORNER

Cautions About Using Alternative Treatments

By Dale Ester

It may seem that herbal formulations can't be life-threatening or even the least bit dangerous because they are sold over the counter in grocery and health food stores. Buyer beware! You must be careful because herbal treatments are medications and all drugs have some effect on the human body.

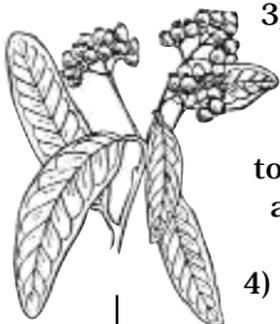
Although herbs were used largely in their raw and unprocessed form by the human race long before the present time, it does not mean they are any safer or have fewer risks or benefits today. We have simply come to know more about them. Herbs are often called complementary medicines or herbal treatments, but don't be fooled by the different names used to explain the same thing. Many of these treatments, regardless of the name used to describe them, could result in a serious and dangerous, possibly even life-threatening, crisis.

How does one know if an herbal treatment is safe? If it works well for a friend or a family member, will it be a good treatment for you? No two people are alike. This means that what works well for them may not work well for you. In fact, it may not work at all for you! They may not have had a bad reaction from taking a particular supplement but you might.

Are the risks worth it? It is important to look closely at the proposed benefits and to decide whether they outweigh the potential risks. An herbal formulation that solves a specific problem without causing other health problems would be beneficial. However, if the treatment creates problems on top of the existing condition it could be

risky. Weighing the pros and cons may be confusing, so here are some suggestions for how to approach herbal treatments:

- 1) Proceed with extreme caution.
- 2) Discuss the treatment idea with your health care team before you start the treatment.
- 3) If your doctor says it is okay to take the supplement, learn as much as possible about it to familiarize yourself with any potential side effects.
- 4) Share the responsibility about whether to use herbal treatments with your health care team by knowing the proposed benefits and the potential risks before making a personal choice. Ask yourself, "Do the potential positive effects outweigh the negative ones?"



Herbal treatments can be a friend if they solve health problems or a foe if they create more problems than expected. Since no two people are alike, the benefits of complementary medicine for one person will be different from those for another. The benefits should always outweigh the potential risks. Discussing any treatment ideas with your health care team and kidney doctor before you decide to start an herbal treatment program will always be the wisest way to achieve the best possible health outcome. Remember that safety begins by knowing that herbal treatments and complementary medicines are real drugs in a different form than what you may be used to seeing. Your life may depend on proceeding with caution and learning the facts. 

➤ To Learn More About CAM

- Alternative Medicine: www.nccam.nih.gov or call the National Center for Complementary and Alternative Medicine at 888-644-6226
- NCCAM fact sheets: <http://nccam.nih.gov/fcp/factsheets>
- Research centers working with the NCCAM: <http://nccam.nih.gov/nccam/fi/research/centers.html> or call the NCCAM Clearinghouse at (301) 589-5367 or (888) 644-6226
- National Library of Medicine database of free abstracts of journal articles on CAM: <http://www.nlm.nih.gov/nccam/camonpubmed.html#>
- The Combined Health Information Database: <http://www.chid.nih.gov>
- Acupuncture: www.medicalacupuncture.org or call the American Academy of Medical Acupuncture at 323-937-5514
- Herbal remedies: www.herbs.org or call the Herb Research Foundation at 800-748-2617

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Good Nutrition

Naturally Safe

By Kim Stevens, RD

Alternative medicine has been around for centuries and it's making a comeback. An estimated 629 million Americans sought alternative medicine practitioners and 60 million Americans were taking herbs daily in 1997.¹ One reason for this increase is that herbal supplements appeal to people's desires for a quick fix, and they allow people to participate in their own care. You must be aware though because supplements may not be safe for those suffering from kidney disease, diabetes and other diseases.

Who regulates herbal supplements?

According to the Dietary Supplements Health and Education Act (DSHEA) of 1994, dietary supplements include ingredients such as herbs, vitamins, minerals, amino acids and substances such as enzymes, organ tissues, glandulars and metabolite.² The manufacturer regulates the safety of its own product according to the Act² and is not required to notify the Federal Drug Administration (FDA) or consumers of any reported adverse effects. However, the FDA monitors the safety of these products through voluntary reports.³

How safe are herbal supplements?

The safety of the supplement depends on the consumer's medical history. Side effects have been documented about consumers who have taken "safe" herbs such as ginkgo biloba, ginseng and St. John's Wart. Ginkgo biloba may cause infrequent headaches or gastrointestinal upset and shouldn't be taken if you have a bleeding disorder.⁴ Ginseng may cause someone to suffer from headaches, inability to sleep, nervousness, diarrhea, rashes, asthma attacks, high blood pressure and arrhythmias.⁴ St. John's Wart, which is often taken to improve a person's emotional well-being, is not without its share of complications. It may hinder the effectiveness of cyclosporin and other immunosuppressants used to prevent transplant rejection and cause high blood pressure when taken with beta-blockers medication.^{4,5}

Aristolochic acid is sometimes used to stimulate the immune system. It

may also be used for treating GI and gallbladder colic that is caused by allergies, gynecological problems, wounds and ulcers and problems associated with the ears, nose and throat. Aristolochic acid and products that contain it have been found to be toxic to the kidney and to cause cancer.⁶ Approximately 100 cases of kidney disease were diagnosed in people who used a product containing aristolochic acid in Belgium, and 70 of them required dialysis or transplantation.⁷

Why may supplements be unsafe?

Complications from taking herbal supplements may arise due to unknown effects that have not yet been documented, long-term use or the kidney's inability to filter waste products. Consumers may also experience negative side effects from complications caused by their disease when taking a supplement. For instance, those on dialysis should be wary of herbs that do not list potassium and phosphorus on the label. Also, contamination of herbal supplements with such ingredients as lead, arsenic, gasoline and bleach have been well documented.^{8,9}

What can you do?

Learn about the ingredients listed on the label. It's important to be aware that manufacturers are not required to list potassium and phosphorus on the label. You may need to call the manufacturers for nutrient analysis. Most important, talk to your medical professionals about their experiences with various herbal products and their recommendations about using them. Use the Internet to gain product information. Finally, tell the medical professionals on your kidney team about any herbal supplements that you are taking and report any physical and emotional changes that you have noticed since taking them. It may be the most important piece of information that you provide to them!

Nutrition Facts	
Serving Size = Renal Serving Size	
Servings Per Container	
Amount Per Serving	
Calories	Calories from Fat
Value* % Daily	
Total Fat g	%
Saturated Fat g	%
Cholesterol mg	%
Sodium 140mg	6%
Total Carbohydrate g	%
Dietary Fiber g	%
Sugars g	
Protein g	
Vitamin A %	Vitamin C %
Calcium %	Iron %
*Percent daily values are based on a 2,000 calorie diet.	

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Kim Stevens, RD, has been a renal dietitian for four years. She currently works with Renal Care Group of Oshtemo in Michigan.

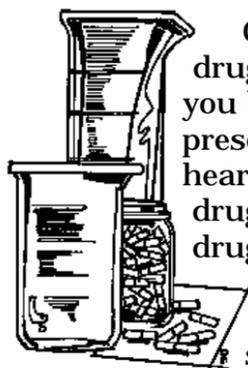
In the Winter "Quality of Care" issue of Family Focus we included a list of high potassium foods. We want to let our readers know that anytime Family Focus prints lists of foods it is recommended that you check with your own dietitian for what works for you, as every diet is individualized for that specific patient.

Questions and Answers About Over-the-Counter Drugs

By Bobbie Knotek, RN, BSN

For People With Chronic Kidney Disease and Kidney Failure

What are over-the-counter drugs?



Over-the-counter drugs are medicines that you buy without a doctor's prescription. You may also hear them called OTC drugs or non-prescription drugs. You can buy OTC

drugs from grocery stores, convenience stores, gas stations, drug stores and even from TV ads and Internet Web sites.

The most common OTC drugs are medicines for cold, cough, fever, headache, pain, constipation or diarrhea. Other products that are considered OTC drugs are herbal or natural medicines, vitamins, minerals, weight loss drugs and diet supplements. OTC drugs are very popular because you don't need a prescription, you can find them in almost any store and they're usually cheaper than prescription drugs.

If you or a family member has chronic kidney disease or kidney failure, however, you need to be very careful with all OTC drugs. Just because you can buy these medicines without a prescription doesn't mean it's safe for you to take them. OTC drugs are serious medicines and if you have kidney disease or kidney failure, they can make you sick or cause life-threatening side effects.

Should I check with my kidney doctor before I start taking an OTC drug?

YES! Many medicines act differently or build up inside your body when you have kidney failure. Ask your kidney doctor about an OTC drug before you buy the drug and start taking it. If you are already taking any OTC drugs, take time during your next treatment to tell your kidney doctor or nurse what OTC drugs you're taking. It's very important that you tell your kidney doctor if you're taking any OTC drugs because:

- Some OTC drugs can change how your prescribed medicines work. They can make prescribed medicines weaker or make them too strong. They can even stop your prescribed medicines from working.
- Chemicals or electrolytes in some OTC drugs (like potassium, sodium, phosphorus, magnesium and aluminum) can build up in your body and make you sick or even put your life in danger.

- The OTC drugs and your prescription medicines could "fight" inside your body and cause serious side effects or allergic reactions.
- Some OTC drugs can cause increased bleeding. If you have a graft or fistula, this could make your needle sites bleed longer after dialysis.

Are there common OTC drugs that I should avoid?

YES! You should not take the OTC drugs listed below unless your kidney doctor tells you to take them.

- Alka-Seltzer, baking soda or other bubbling medicines—high in sodium, cause extra fluid gains.
- Milk of Magnesia or antacids—many have magnesium or aluminum that can build up in your body and cause nervous system problems.
- Enemas or laxatives—may be high in phosphorus; can also make you dehydrated and make your body lose important chemicals.
- Aspirin—can cause increased bleeding.
- Vitamins and minerals—vitamins and minerals are also medicines and some can make you sick if you take them; take only vitamins your kidney doctor prescribes for you.
- Diet supplements—contain high levels of potassium and magnesium; check with your kidney doctor or dietitian about these products.

Do I need to tell my kidney doctor if I'm taking herbs or herbal products?

YES! You should always tell your doctor if you are taking or plan on

taking an herbal product. Many people think that because herbal products are "natural" they're safe. That is not true, especially for people with kidney disease and kidney failure. Many herbal products can be very dangerous for you. They may cause:

- Worsening of kidney disease
- Loss of a kidney transplant
- High potassium or phosphorus levels
- Increased bleeding
- Changes in how your prescribed medicines such as those for your blood pressure work.

Does my care team need to know about "home remedies" that I use?

YES! You should tell your kidney doctors and nurses about any home remedies that you use. Most of these home remedies are probably safe. However, there's always a chance that your home remedy could make you sicker. It could be full of potassium or salt, or it could change how your medicines work. Your kidney doctor will be able to tell you if your home remedy is safe for you.

Remember—every OTC, home remedy, herbal product or alternative treatment (i.e., acupuncture, chiropractic treatment) that you use has an impact on your personal health and well-being. You can help yourself by keeping your treatment team informed about the use of any of these OTC drugs or treatments! 

National Institute of Health Classification and Examples of Alternative Health Care Practices

Cook, Becvar and Pontious

<u>Manual Healing</u>	<u>Nutrition and Lifestyle Change (cont'd)</u>	<u>Herbal Medicine</u>
Therapeutic Touch Aromatherapy Massage Therapy Acupressure Chiropractic Medicine Biofield Techniques	Megavitamin Treatment Macrobotics Changes in Lifestyle Magnetoresonance Spectroscopy	Echinacea Ginseng Root Ginger Rhizome Ginkgo Biloba Extract Yellowdock
<u>Mind/Body Control</u>	<u>Pharmacological and Biological Treatments</u>	<u>Bioelectromagnetic Applications</u>
Guided Imagery Yoga Meditation Prayer Therapies Art and Music Therapy Progressive Muscle Relaxation	Chelation Therapy Use of Cartilage Products Metabolic Therapy	Electromagnetic Fields Blue Light Treatment and Artificial Lighting Electrostimulation Electroacupuncture
<u>Nutrition and Lifestyle Change</u>	<u>Alternative Systems of Medical Practice</u>	
Nutritional Supplements Diet	Traditional Oriental Medicine Acupuncture Homeopathic Medicine Ayurveda Shamanism Naturopathic Medicine	

From: Office of Alternative Medicine (1997). Alternative Therapies in Clinical Practice, March/April, 63-64.

You Can Be Whole

By Pat Donnelly

The Centers for Medicare and Medicaid Services (CMS), formerly known as the Health Care Financing Administration (HCFA), reports that more than 230,000 Americans are being treated for kidney failure. I'm one of them. Learning how to live successfully with a chronic illness has been the biggest challenge of my life.

Chronic illness is different from other maladies. Seemingly endless, its cure lies in some distant future. It can be life threatening or simply annoying. You are forced to face life rather than face death; putting the brakes on a once complacent, confident perspective and being sent forth into the unknown.

Living successfully with an illness seems like an oxymoron and almost impossible to some. I was tossed on the flip side of life instantly, seeing everything through dark, distorted glasses. I realized our society slices us into two distinct groups—the healthy and the not-so healthy, with the healthy confounded as to how to handle the not so healthy. I could see *them* but could they see me?

I was expected to at least appear whole, and quickly, thank you. Stories about “overcoming,” or even “denying,” disability lurched out at me; running the marathon with one leg, climbing Mt. Everest while blind. Surely acts of heroism, but not truly mainstream. These are the “disability superstars,” anointed to represent all the nameless rest of us who aren't quite so brave, quite so resilient.

It sometimes seems that people with disabilities have to dance just a bit better and faster than others to make other people feel good about themselves. We're made to feel guilty just sloshing through the day like everybody else instead of trying to be “more than.”

Kidney failure is deceptive. “You look terrific!” If you look well then surely you are well, regardless of how you feel. We're all products of a perfection-seeking childhood. Our

feelings about illness are rooted in our earliest memories; those worried parental whispers when something is “wrong.” We learn straight from the womb to be fearful of “different.”

Society follows a rigid set of rules for what is considered “normal.” “Be yourself,” yet we chastise the individuality out of our little ones, lest they be shunned as “unpopular.” We prize individuality but assess it within very narrow parameters, comparing ourselves incessantly to the perfect ones in magazines.



Pat Donnelly has learned to live with her illness, in part, by focusing on her present quality of life.

“Don't be a crybaby!” We chide our children to blink back tears, hide their anger or disappointment, bite their lips and avoid eye contact. *Try to be brave.* Rather than teaching them how to face and get past their fears, we teach the fine art of numbing, of self-paralysis—to not feel at all, to be alone with their boogey men. It's how we become grown-ups—to distance ourselves from ourselves. And it has a profound effect on how we handle illness later. It traps us in fear. Culturally fanatic about strength, we espouse the belief that negative emotions are weak. “Nothing ever gets you down,” or “You're tougher than you think” only tighten our vise-like sense of anxiety.

Think positive. O.K, but I was

mad as hell when I found out I was dealt a chronic illness. I couldn't think of a single positive thing about it. I felt cheated, envious of the still healthy, absolute despair for my own future and frightened as can be. I wanted to run, to hide, but there was no place to go. And always, there's a fathomless, nagging loneliness.

I began to search for the “cure,” examining every treatment that came down the pike. I bought every New Age book, studied Eastern religions, learned to meditate, visualized, changed my diet, bulked

up on seaweed and learned biofeedback. Vitamin therapy, herbs, magnets, shamans; somewhere, someone must hold the answer, the key to controlling or even obliterating my illness. I thought I could rise above it, cleanse my body of its frailties, overpower it with my will. When I couldn't, I felt defeated, worthless, inept and deserving to be sick. I was looking for a way out rather than creating a way to stay in.

I blamed God. How could He let this happen? What had I done? How could I win back His favor and perhaps, dream of dreams, maybe procure a little miracle?

How foolish I was. I truly believed I was capable of controlling every aspect of my life. Why not? That's what I'd been taught. When that miracle didn't come, somewhere deep inside, a piece of me whispered that perhaps I didn't deserve one.

Finally, a break came. Months of searching began piecing itself together into an almost crazy patchwork of ideas, bits and pieces pilfered from this belief or that opinion. I chewed up what I liked and spat out what I didn't.

Reality is I'm not a Tibetan monk. I'm a Westerner whose mind is cluttered with insignificant cultural facts and brimming with single, unrelated refrains to a thousand

continued on next page

You Can Be Whole

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songs. I am undisciplined but resolute. It takes more than will to overcome an organic illness. It happens, but truthfully, aren't we talking super mystics here, people way more advanced than the average Joe?

Face it. Chronic illness evolves. Assume it's not anything you alone did or did not do. Assume it was all part of an organic misstep that you happened to be involved in—a cosmic thing. Let's move toward dumping your guilt. Forget and forgive the "if only."

You can't reason your cure. I'm all for miracles, but I can't wait for mine. I have to find ways of living that exist for me today. It's only in this moment that I have any pretense of control, and that's because the goals for this day and this hour little influence the great scheme of things. They are goals for the now. I don't have a monopoly over myself, my own health or my potential cure.

This is my reality, and I cannot change it, despite all the good intentions of every guru I've ever met

Sometimes it seems hard to imagine our way through, to ever find a way to live with imperfect health.

or read. Our reality is the "is" of truth that we all share. You can, however, change your *reaction* to, your *perception* of your reality and devise a new set of insights and ways of living your life for yourself. You *can* redirect your energies and effect change, especially in the process and experience. That's the essence of life. Tomorrow will take care of itself. *Today is alive.*

Living with life as it really is provides the true path to healing and living successfully with a chronic illness. You'll see the landscape is not simply composed of black and white. There are nuances in nature, subtle variances that defy accepted or

normal classifications. Nature is change, truth in an inconsistent present.

Sometimes it seems hard to imagine our way through, to ever find a way to live with imperfect health. We become so identified with the illness that we lose sight of ourselves. Categorized by labels, our names are lost to our conditions. This world defines us by what we do and measures and evaluates us by our accomplishments. Illness uproots us; we must find new meaning for our self.

And, of course, there's that issue of control, or lack thereof, that so defines our culture today. Yet facing loss and pressing through anger and grief and coming out the other side whole, embracing change as the stuff of life, is to triumph. You *can* be whole again. Control and change are lousy bedmates. You either commit to control or to change, to stuffing your emotions or experiencing them. Control is stagnant; change is progress. Remember that all emotions have value. All emotions have truth.

Let's say you have kidney failure and you're feeling pretty low. Depressed. Tired. Angry. Frustrated. Scared. How can you get from point A to point B? What's the secret? How can you create new dreams and enrich your days? How can you go to sleep at night and not be afraid of the dark?

Start now. There is a distinct mind-and-body link that can be honed and used. Breathe. Fill your lungs deeply and then let go. Visualize yourself calmer and under less stress and in less pain. Systematically relax each part of your body until you are completely at ease. Imagine and go to a quiet place in your mind. Visualize changing what you can control and letting go of anger and resentment. See yourself happy.

Be aware of your pain. Its severity can be managed. Your fear of pain might actually be a bigger pink elephant than the thing itself. Pain is as much a part of life as is joy. They are opposite sides of a coin, equally valuable and equally viable. They are truly a part of the spirit of our existence.

Exercise. Move. Check with your physician first but don't not do it. You have a million choices. I'm partial to yoga. Make an appointment with yourself and do it. Exercise counters depression. Give it a shot.

Focus on the quality of your life as it exists right now. We flourish when we surrender to the way life is and not to the way life should be.

Keep a journal. Keep lists with titles like "I hate not being able to," "Things I like about myself" or a "Goal for today." I don't care if it's watering the plants or baking cookies. Walk to the kitchen and back 10 times, five times, once. Go. Start small and if you think it's too small remember all the days when you were well and you didn't do a darned thing.

Hum. Sing. Listen to music like B.B. King, Chopin or whatever. Laugh. Cry. Let your emotions roll over you. Dance. Feel silly. Be silly. Get out. Go out to the woods and scream a few times. You don't have to prove anything to anyone but yourself.

Call somebody this week. Volunteer one hour anywhere. Everybody needs help. If you can't get out, knit, cook, write notes or make calls for someone. Giving has a remarkable way of getting back. It feeds on itself. Say hello to a neighbor or a child. Open your heart.

Delay any important decisions for a bit. You're bound to have a different perspective six months or a year from now. Be kind to yourself. It's not the destination but the journey. Remember that.

Focus on the quality of your life as it exists right now. We flourish when we surrender to the way life is and not to the way life should be. Franklin Roosevelt once said, "It's common sense to take one method and try it. If it fails, admit it frankly and try another. But above all, try something." In the end, all you really need to do is to cooperate with life. It will, in short order, open itself up to you. 

The More YOU KNOW

News from the National Kidney Foundation's Patient Services Committee

The NKF's Patient Services Committee identifies and evaluates the needs of people with kidney and urinary tract disease and organ transplants and the needs of their families. Once it has taken these diagnostic steps, the committee then develops programs to address the identified concerns.

National Kidney Foundation programs are developed by obtaining the input of the 51 NKF affiliates around the country. All of the programs mentioned below may not be available in your specific location due to the size and particular focus of each affiliate. We want to keep you informed of the current programs and will highlight a few of them here.

KEEP is a health screening program offered in local communities to identify

individuals who are at an increased risk of developing kidney disease, inform them of their risk and encourage them to seek appropriate medical attention that may prevent or delay the onset or progression of kidney disease. Goals of the program are early detection and intervention and the prevention of kidney disease through treatment of risk factors such as hypertension and diabetes. Local NKF affiliates select the KEEP screening sites and work with trained volunteers to conduct the program in their communities.



Individuals with kidney disease, both those currently on dialysis or those considering treatment options, and their family members can learn about kidney disease, treatment options, nutrition, coping and other related information at a People Like Us, Live! program. Sessions provide unbiased information and the emotional support needed to make treatment

and lifestyle choices and are taught by skilled professional volunteers, as well as patients and family members.



The RISE Program was developed to encourage individuals with kidney disease to return to meaningful activity, which may include resuming daily routines, employment, continuing education and volunteering. Individuals learn decision-making skills to help them pursue the options available to them to maximize their quality of life. Sessions include information on interviewing skills, resume writing, importance of exercise, Social Security and much more!

Peers Program

The NKF Peers Program provides special training to people with chronic kidney disease and transplant recipients and their family members who have made a positive adjustment to their chronic illness with the goal of having them provide support to others who are new to treatment. Peers empower individuals with chronic illness to become active members of

their health care team and to assume responsibility for their own health care.

The Patient Services Committee has created suggested guidelines to help the NKF affiliates develop programs in addition to those listed above. Some of the guidelines that have been developed include those for emergency financial assistance programs, establishing a discount medication program, implementing a nutritional supplement program and implementing an educational scholarship program. Other programs offered by some Patient Services Committees of local NKF affiliates include medical alert jewelry, camps and camp sponsorships and educational seminars.

This information about Patient Services provides a glimpse into the activities and commitment of our hardworking national committee members and staff and the affiliates that provide these programs. The committee wants you to know that *Making Lives Better* is the true focus of all of the programs. For more information about any of these programs, please contact your local NKF affiliate office or the National Organization at (800) 622-9010.



MAIL BOX

Dear Donor's family,

Hello. My name is Kelly and I am 14 years old. First off I would like to say how sorry I am for your loss. I hope it will comfort you to know how much better I feel after receiving a kidney from your loved one. Everyone is amazed, because it was a PERFECT match. EVERYTHING matched up. I feel better than I have in YEARS. I just got out of the hospital five days ago. You have been in my prayers ever since I got that call that I was going to get the transplant. It was surprising because I have only been on the list for six months and the average is three years. It was a very unexpected thing that I am VERY grateful for.



Kelly

I hope this will help you with your loss. I am very grateful for this gift that I have been given. God bless you and your family.

What's New in Hemodialysis

By Sanford Reikes, MD

Hemodialysis therapy has come a long way since the first outpatient dialysis program was established in Seattle in the 1960s. New dialyzers and hemodialysis machines allow dialysis fluid to flow faster, resulting in better removal of toxins from the blood. Severe nausea and fatigue caused by dialysis don't occur as often as they used to due to changes in the dialysis fluid chemicals and new dialysis machines that control the amount of water removed. Measurement of the flow of the blood through dialysis grafts and fistulas allows early repair of accesses that are not working well before they become completely unusable. Current research is being done in two areas: increasing the number of dialysis treatments given to a patient each week, or increased dialysis frequency, and improvements in the design of hemodialysis catheters.

Increased Dialysis Frequency

Undergoing three hemodialysis sessions a week seems hard enough. Increasing the number of treatments hardly seems like an improvement. However, many experts point out that healthy kidneys clean the blood 24 hours each day, seven days a week, so why should we expect that three treatments a week of only three to four hours each would be enough for dialysis patients?

Carl Kjellstrand, MD, PhD, FACP, FRCPC, an expert in daily dialysis therapy, points out that after each dialysis session, waste products and fluid build up in the body until the next treatment. Since the next treatment is usually two or three days later, toxins and fluid reach high levels, only to be rapidly removed during dialysis and then the cycle is repeated all over again. It looks like this constant up and down pattern of waste products and fluid can, over time, cause damage to the heart, brain and bones. Also, many of the common side effects of hemodialysis such as cramps, sudden drops in blood pressure and the "washed-out" feeling that many experience are caused by the rapid removal of these toxins and fluid. Daily dialysis for shorter periods of time or with slower blood flow rates may do away with some of the side effects of dialysis treatments. Many people would rather

have a short dialysis treatment every day and feel well afterward than have only three treatments a week and feel sick and tired after each one.

Most people who have daily dialysis have better blood pressure control and need fewer blood pressure medicines. Phosphate levels are often lower and the red blood cell count is usually higher in those on daily dialysis. Perhaps most important, people who are on this type of dialysis tend to feel better, are more active and have a greater enjoyment of life.

Daily dialysis may be done in different ways. Some units have you come to the dialysis unit for short daily treatments. Other centers use nightly dialysis in special units where you may sleep while receiving



Teresa Hernandez receives her dialysis treatment at Mt. Sinai Hospital in New York City.

treatment. You or your partner can be taught to operate the dialysis machine in the home for short daytime or overnight dialysis sessions. Also, some centers use the Internet to connect dialysis machines in the home to the dialysis unit where the treatment is checked by trained technicians.

Daily dialysis is, in fact, more convenient than traditional dialysis in that it may take place in the home. It also allows you to take fewer medicines, have a less restrictive diet and fluid limit and feel better, while possibly reducing heart and bone disease. At present, one of the main reasons that daily dialysis isn't done more often is that Medicare and insurers don't want to pay for it.

New Hemodialysis Catheters

Many people need dialysis before a graft or fistula is ready to use, or they have problems with their graft or fistula and need to use a dialysis

catheter. Sometimes those on dialysis run out of places to put new grafts and must use catheters permanently. Unfortunately, these catheters may cause life-threatening infections. In addition, blood flow through catheters may not be good enough to clear waste products adequately from the blood.

New dialysis catheters have been made that have specially shaped tubing that improves blood flow. Some catheters are made out of plastic containing antibiotics or silver, both of which may help prevent infections by not allowing bacteria to grow. Another way to prevent infections is to have the whole catheter placed under the skin so it is harder for bacteria to enter. Special dialysis needles are placed through the skin into the catheter. It will take some time before we know if these catheters will do a better job.

Though hemodialysis is life-sustaining for hundreds of thousands of patients, significant complications are an all too common occurrence in dialysis patients. New catheter designs and increased use of daily dialysis are revolutionary changes with tremendous potential to improve your quality of life. These advances in the science and technology of dialysis may soon allow hemodialysis patients to live longer, healthier and more satisfying lives.

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The benefits of daily dialysis are well reviewed in the following references:

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Sanford Reikes, MD, is an assistant professor of internal medicine at St. Louis University School of Medicine and the associate medical director of St. Louis Renal Care, LLC. 

Fluid Removal Fiesta: How I Learned to Love to Sweat

By Monique Janelle London

This article will give you yet another good reason to adopt a regular exercise program. Remember to check with your physician before embarking on a new exercise regimen. Read on!

I thought sweat was disgusting before I developed kidney failure. After all, I'm a girl and girls don't sweat! We have make-up, hairdos and delicate clothes to protect. Sweat is not pretty; it stinks; it certainly won't attract a guy. It doesn't feel clean to sweat. How could it be clean, when you always have to wash the clothes you have worn when sweating? So I trained myself from an early age not to sweat. I had the appropriate light-weight clothing, the air conditioner and the iced tea—all ready to launch an attack at any hint of a glisten.

Then I developed kidney failure. I was told the goal was to gain less than two pounds between hemodialysis treatments. But what about those days when I was ridiculously thirsty for no apparent reason? When I took a sip, I would put the drink back in the refrigerator and try to walk away, but I would make a U-turn back and gulp that precious fluid down! What about when I would stingily pour out a tiny glass of cranberry juice over ice, then feel that cold explosion of flavor as it flowed over my parched throat, and pour myself another and another and another?

I had blown the fluid restriction on lots of days before I knew it. I could tell. My eyes were puffy. I failed my "ring test," which is when the ring I wore that fit loosely on my finger just after dialysis was too tight to remove. Whenever I failed the "ring test," I knew it was time to take action. But at first, I didn't know what action to take. I just had to try to not drink another DROP of fluid until the next dialysis session. Rarely was that plan successful. I would step sheepishly onto the scale at dialysis and realize that I had a hellish session ahead of me—one filled with plummeting blood pressure and plenty of cramps as I tried to remove too many kilos of fluid in such a short time.

Then it dawned on me one very hot day. Sweat is fluid—fluid that I could get rid of before my next dialysis treatment even if I couldn't urinate. I started changing my attitude about sweat. I tried to convince myself, "It's not disgusting; it's beautiful!" I asked my dialysis nurse what exactly is in sweat. She told me that sweat



includes sodium and a small amount of potassium. She said that skin is actually like a third kidney in that it can filter out some toxins through sweat. I thought, "Hallelujah!" Why had no one told me this before? I envisioned getting a sweat box for my living room with just my head sticking out through a hole, like I'd seen on *I Love Lucy* and in cartoons. Oh, the liberation I could get from this nugget of wisdom!

I sprang into action. I started wearing more clothes than I needed to wear. I kept the heater on in my car until I could feel myself start to sweat. I took long walks and bike rides wearing extra sweatshirts and a windbreaker. Sometimes I would come

home drenched from sweat. True, I had to do more laundry, but my ring turned easily on my finger. I was passing the "ring test" with flying colors. I was able to arrive at dialysis only a pound or two over my dry weight even though I was drinking more fluid. I felt much better. My lab results were great. Sweat was my new best friend.

I still enjoy sweating even now that I have a kidney transplant. It feels good to know that I am cleansing my body of toxins when I sweat. When I'm sweating a lot, I always keep track of my weight to make sure I'm not losing too much fluid and getting dehydrated. Usually, I'm not. Sweat is beautiful. F

Monique Janelle London lives in San Francisco, California. She was previously on dialysis and now has a transplant. She works at DaVita, a Dialysis Provider. Ms. London is an avid exerciser.

Examples of Alternative Health Care Practices

By Dale Ester

N V C T E V S R C K I T C G Q F X U O N P S M M L A M E M D
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WORDS TO SEARCH:

- | | | |
|----------------------|------------------------------|-----------------------------|
| ACUPRESSURE | ELECTROSTIMULATION | METABOLICTHERAPY |
| ACUPUNCTURE | GINGERRHIZOME | MIND |
| AROMATHERAPY | GINKGOBILOBAEXTRACT | NATUROPATHICMEDICINE |
| ARTANDMUSIC THERAPY | GINSENGROOT | NUTRITIONALSUPPLEMENTS |
| ARTIFICIALLIGHTING | GUIDEDIMAGERY | PRAYERTHERAPIES |
| AYURVEDA | HERBALMEDICINE | PROGRESSIVEMUSCLERELAXATION |
| BIOFIELDTECHNIQUES | HOMEOPATHICMEDICINE | SHAMANISM |
| BLUELIGHTTREATMENT | MAGNETORESONANCESPECTROSCOPY | THERAPEUTICTOUCH |
| BODYCONTROL | MANUALHEALING | TRADITIONALORIENTALMEDICINE |
| CHELATIONTHERAPY | MASSAGETHERAPY | USEOFCARTILAGEPRODUCTS |
| CHIROPRACTICMEDICINE | MEDITATION | YELLOWDOCK |
| ECHINACEA | MEGAVITAMINTREATMENT | YOGA |
| ELECTROACUPUNCTURE | | |

(answers can be found on page 16)

The Parent Connection

How to Increase Your Child's Adherence With Home Dialysis

By Arlene C. Gerson, PhD, and Barbara Fivush, MD

Adherence is defined by how well patients follow medical advice. Most parents know that adherence has health benefits and that non-adherence usually results in health problems. Unfortunately, children and adolescents often do not recognize the relationship between their behavior and their health. As a result, many children do not participate eagerly in their medical self-care. In fact, when home dialysis is needed, parents frequently have problems getting their child to follow the doctor's orders. This article will suggest strategies to improve your child's adherence with home dialysis.

☞ **Set realistic expectations for involvement**

It is very important to be realistic about how involved and independent your child can be in home dialysis. Your expectations should take into consideration your child's learning abilities and motivation. Awareness of your child's current abilities will help you determine which tasks your child can be successful in doing alone or with your assistance and which tasks you will need to do for your child. When skill problems are identified, the clinic nurse can often help teach your child.

It is equally important to be aware of your child's skill strengths. It is likely that your child will be interested in participating in aspects of the dialysis routine that he or she is good at doing. It is also possible that your child may be better able than you to do some of the dialysis tasks.

Being aware of your child's feelings regarding the benefits and drawbacks of independence in dialysis will allow you to use strategies to decrease unrealistic fears he or she may have about doing dialysis alone. Finally, it is important to reevaluate your expectations for your child's independence and participation as he or she grows and develops.

☞ **Organize the home environment to boost successful participation**

Home dialysis can be a complicated and time-consuming responsibility. You will be able to increase your child's motivation and success in doing dialysis independently if supplies are kept together in a consistent location, the room that is used during the hook-up is quiet and

calm and you insist that dialysis be done at approximately the same time each day. Use of these strategies gives a child a sense of comfort, control and confidence about safety and success with home dialysis.

☞ **Provide regular enthusiastic praise and occasional tangible reinforcement for adherence**



Without obtaining your child's interest in participating in home dialysis, there is no hope of increasing the child's involvement.

You can get and keep your child's interest by providing reinforcement that is rewarding a desired behavior. Since reinforcement of desired behavior leads to its continuation and improvement or increase, it is particularly important to pay attention to the kinds of reinforcement that are meaningful to your child.

It is important to praise a child's attempts at increased independence rather than waiting until he or she is fully successful. Many children have behavioral improvements when they are given reinforcement in the form of enthusiastic praise for their efforts. Other children need tangible reinforcement such as toys, food treats or privileges for behavioral improvements to occur.

Unfortunately, performing dialysis is not a very rewarding task. In other words, staying healthy is often not a strong enough reinforcement to encourage adherence to dialysis. In

fact, performing dialysis often interferes with a child's ability to participate in more enjoyable activities, and for many children, dialysis is perceived as an unpleasant or disagreeable experience. Therefore, you will need to give praise and occasional rewards. This will help your child achieve involvement and independence that is age-appropriate in home dialysis. If serious adherence problems surface, you may want to consult with the unit social worker or ask your child's health care provider to refer you to a therapist who can help you identify your child's preferred rewards.

☞ **Provide a safety net of supervision to assure that the treatment regimen is carried out**

It is important to recognize that a child's interest in participating in dialysis treatment will wax and wane throughout childhood, adolescence and early adulthood. You will need to monitor this and vary your interventions to increase participation and independence as needed. Ultimately, however, parents need to provide a safety net of supervision to assure that dialysis is being completed correctly and consistently.

In summary:

- Be realistic about your expectations.
- Organize your home environment to encourage and support your child's successful involvement.
- Give your child positive feedback about his or her involvement and independence.
- Always supervise. ●

Government Support of Medical Research Benefits Kidney Patients

By Dolph Chianchiano, JD, MPA

The National Kidney Foundation (NKF) Office of Scientific and Public Policy, in addition to its advocacy for Medicare and Medicaid programs that benefit kidney patients, is actively involved in generating support for the kidney research programs of the National Institutes of Health (NIH), an agency of the U.S. government.

The principle organization supporting kidney research at the NIH is the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). A 17-member Advisory Council decides funding priorities for the NIDDK. Judge Levan Gordon, a member of the Board of Directors of the NKF, is also a member of that Advisory Council. NIDDK is supporting many research projects that pertain to the well-being of dialysis patients.

The Hemodialysis Study, for example, is designed to investigate whether higher levels of dialysis dose and changes in dialysis flux improve how long those on dialysis live and if it reduces their hospitalization. There are 15 centers representing 900 patients that are involved in the study. The study began on June 1, 1995, and the final results should be available by November 2001.

The goal of the Vascular Access Clinical Trials Network, which was developed last year and is funded by the NIDDK, is to study ways to decrease hospitalization for those on dialysis due to vascular access problems. Problems related to vascular access account for 15 to 25 percent of the hospital admissions for people on dialysis in the United States. The Vascular Access Clinical Trials Network was begun because there have been few rigorous studies that use medications to prevent vascular access failure, and because there are new therapies on the horizon that should be thoroughly evaluated. The research on vascular access, which will soon be under way, will be conducted at six centers: University of Texas Southwest Medical Center (Dallas), Maine Medical Center, University of Iowa, Cleveland Clinic Foundation, Duke University Medical Center (Durham, North Carolina) and Boston Medical Center. Ultimately 2,000 patients will be involved in this project.

Dr. Alan Christensen at the University of Iowa has been funded by the NIDDK since 1995 to study the quality of life of those with kidney failure. His research examines whether certain psychosocial characteristics make some people better candidates for certain kinds of dialysis therapy. He is also identifying personal characteristics that are related to adjustment for those with a kidney transplant. Another NIDDK grant has been awarded to Dr. Ashwini Sehgal at Case Western Reserve University in Cleveland, Ohio, for the project, "Overcoming Barriers to Adequate Delivery of Hemodialysis." This study will explore whether patient-provider communication is a barrier to adequate delivery of hemodialysis, and it will test interventions that could improve this communication. In addition, NIDDK has provided grants to Vanderbilt University in Nashville, Tennessee, for a study of malnutrition in people on dialysis, and to the Northern California Institute of Research and Education for research on exercise for those on hemodialysis.

An additional NIDDK study is currently in the planning stage. This trial will compare the outcomes of people who are on daily hemodialysis with those who receive hemodialysis treatments three times a week. The cost of the study is being shared by the Centers for Medicare and Medicaid Services (CMS), formerly known as the Health Care Financing Administration. The trial will document the cost of daily dialysis so that a payment policy can be developed for it.

It is clear that NIH-financed research is paving the way for better treatment of kidney disease. However, funding for the study of kidney disease competes with demands for research on other important health problems, such as AIDS, arthritis and cancer. We need to continually remind members of Congress that breakthroughs in our understanding of kidney disease and its treatment are vital. If you are willing to help get that message across to decision makers in Washington, please call the National Kidney Foundation Office of Scientific and Public Policy at (800) 889-9559.

Dolph Chianchiano is NKF's director of scientific and public policy. ●

Good Luck or Good Management

By Richard Dulebohn

This article was written in response to "What is Quality Care?" which was featured in the Winter 2001 issue of Family Focus.

I feel cold dread knowing again today that I must go...to what? Will it be another day like that? Wheeled down into the icy, night-marish, dialysis dungeon where, it seemed, civilized life came to a halt. I was manacled to the rack; a beeping red-eyed monster sucked my blood and then spat it out. Masked, robed imps with blue hands crept around pinching my arm and muttering incantations. Later, I felt weary relief, not that my life was reprieved for another treatment—just that the ordeal was over.



Richard Dulebohn relaxes in front of his home in western Oregon

Yet I have felt the wonder of being in a well-run, comfortable unit in a distant city, like a dream where there is no dread of dialysis, no halted life, no stress. I have rejoiced in my good luck. In my more lucid moments, I recognize it's not luck or anything mysterious that results in this type of unit. It is good management.

Good managers can be found. They need to be told what their job involves, to stay within the budget and to follow the prescription for each patient's treatment. Additionally, they must see that the time the patient spends in their care is pleasant. The goal should be to provide a non-jarring ambience that allows the mind to drift and meditation to happen. Two types of changes, one involving the facility and the other the personnel, are needed to create this type of environment.

Architectural and mechanical

Managers should have budgeted funds to keep machines and dialysis chairs in repair and to make changes to things that jar or irritate people in the unit. The following are just a few examples of annoying deficiencies that I have observed in various clinics.

◆ The wheelchair accessibility is too difficult.

continued on next page

TRANSPLANT

TRANSPLANT

My Angel

By Donna Joy

I have been on dialysis for four years and the first two of those were awful for me. I got cramps, had a badly bruised arm and was often dizzy and nauseous. My strength, ability to work and play, financial circumstances, physical appearance, sexual drive and outlook on life were changing. I asked "why me" and felt extremely sorry for myself. I avoided family and friends, cried a lot when I was alone and I only did what I had to do for my daughter. I was in a deep depression.

My attitude began to change, however, and as a result, things became easier to handle. While it is certainly true that I would be much luckier if I had never gotten kidney disease, it could be a lot worse. If it had been my heart or another organ rather than my kidneys that failed, I would probably be dead now. Thank goodness for the inventors of dialysis machines.

I have learned to appreciate so much that I once took for granted. I used to worry about everything, but I have come to realize that worrying only wastes time. It won't change the outcome. Arguing over trivial things with loved ones also seems foolish. Who cares whose viewpoint is right? Just think of each other's feelings and drop unimportant issues. Every day we need to act as if it may be the last time we will see our loved ones and never part ways angry or with a bad word. We never know what will happen in this world and to live with regrets forever would be unbearable. I am so grateful for my loving family and friends who are there for me no matter what happens.

I am also extremely grateful for Dena, my angel, who has recently come into my life. I was at my sister's home in December 2000 at the same time that Dena was visiting. She had noticed that I was ill and called my sister the next day to ask about me. When she discovered that I needed a kidney transplant she decided to try to donate one of her kidneys to me. She wanted to see the results of being a donor in her lifetime rather than waiting until after her death. I was speechless! What do you say to someone who offers you health after 10 long years with kidney disease and four years on dialysis? I will soon be free of dialysis because of the kind-hearted selflessness of Dena, who is a 28-year-old mother of two.

Dena's response to my words is "How can people not do this...give up a few months in order to give someone so much?" It isn't just giving to one person but also to a spouse, children, parents, siblings and friends. Dena has said that her scar will be a reminder that she not only gave life to her two boys but to me as well. She is God-sent. If only more people were like Dena, my angel.

The transplant surgery was a success and both Donna and Dena are doing well. Dena was released from the hospital only four days after the surgery to remove her kidney, and she returned to work 26 days afterward. She is now interested in becoming a bone marrow donor. Donna had some initial rejection of the kidney but is now off dialysis. Dena 2, the name Donna has given her new kidney, seems to be adjusting. 

Good Luck or Good Management

continued from page 14

- ◆ There are no nurse or attendant call buttons.
- ◆ The chairs are poorly designed and constructed so that in the position furthest down, a little squirming causes the chair back to drop and the footrest to rise abruptly. Chair footrest's adjustments are faulty, as they often require the use of stools to hold them up.
- ◆ The automated blood pressure cuff works on only a few chairs.
- ◆ When chair backs are lowered, patients face dazzling ceiling lights. This strains the eyes when reading a book or watching TV.
- ◆ No diversion other than TV is offered.
- ◆ Ventilation and air-conditioning produce cold drafts.
- ◆ Patients have to carry blankets and other personal items from home each time they come to dialysis because storage space is unavailable.
- ◆ The waiting room is too small and drafty because the entrance door opens directly to the street. Waits in those rooms are long.

Things like these are easy to spot and repair. One just has to look!

Personnel selection and education

Even with low staff turnover, staff selection and training are difficult because every patient has his or her unique problems and the personnel



Mr. Dulebohn has experienced well-managed dialysis units and knows what a valuable difference they make for the patient.

have their own strengths and weaknesses. The manager must mold them into a team and pass a positive attitude on to both.

A nurse assesses the patient physically before and after each treatment. At that time, the nurse should also monitor the technician's finesse and gentleness in handling the needles and the patient's access. It is also the nurse's responsibility to assess the patient's emotional condition and morale and then advise the technician if the patient needs special attention that day or about conditions to watch

for during blood pressure checks. For example, the technician can offer a cup of ice, help arrange pillows or blankets, assist with the adjustment of the chair or provide earphones, TV remote control or a portable phone. Thus guided, a potentially good technician will learn to ask, "Is there anything else you need?" before leaving.

The manager should arrange informal staff conferences to emphasize the need to treat patients with respect and courtesy. This should include a review of the clinic's policy on noise, radio and TV. Loud personal conversations between patients and even staff can interfere with healing. The social worker, with the patient's consent, should also brief the staff on relevant patient needs or preferences that have been identified.

Good management of dialysis units can assure that all patients receive the type of stress-free care they deserve.

Mr. Dulebohn was born in 1919. He practiced architecture and engineering in Ohio, California and Idaho. He retired in 1981, married Mary C., and moved to a mountain cabin in northern Idaho. After an operation to replace a dissecting aorta in 1992, he lost kidney function and began hemodialysis. The Dulebohns moved to western Oregon in 1999. 



POETRY

CORNER

Giving

By John (Buddy) Muzzy

For the past several years her father had a routine
 Every day he had to be hooked up to a dialysis machine.
 It ached her heart to see her dad go through this each day,
 But there was nothing she could do, much to her dismay.
 The doctors ran all kinds of tests on his kidneys,
 to see what could be done,
 They concluded he could live a normal life, if
 he had a good one.
 They ran compatibility tests with the family,
 including her sister and her brother,
 The doctors decided the donor should be Debbie and no other.
 What a decision she had to make,
 Would she someday need the kidney they wanted to take?
 But this was her dad who made sacrifices for her
 throughout the years,
 When she thought about her decision it brought her to tears.
 What better way to show the love that she had,
 Than to give the "Gift of Life" to her cherished dad?
 So on April 14, 1993, this courageous young lady
 showed the ultimate meaning of love,
 Now they'll both lead productive lives with God's
 blessings from above.
 What an inspiration she has been and as long as she's living,
 She'll always be happy, because she knows the joy of giving. ^F



Compassion Sits

By Mary Lou Kennerly
 and Robert Fisher

Arms
 Hugging snug
 Water mug
 Chugging spring
 Drip drop
 Ring door bell
 Well wishers
 Healing touch
 Feeling words
 Birds passing
 Verbal concern
 One by one
 Done
 One day
 Say a cure
 For sure will be
 Found sound mind
 Find kind of
 Relief have belief ^F

Dialysis

By Jose A. Carmona

Dialysis
 Crimson runs wild through
 Plastic veins sewn to
 The appendix of an arm
 Artificial system to
 Maintain a life gone by
 Lent to a world
 Of internal suffering
 Stampede of broncos
 Inside an enclosed valley
 Of desperate hope. ^F

Answers to the Words Search Puzzle on page 12 (Over,Down,Direction)

ACUPUNCTURE(1,28,E)
 ARTANDMUSIC(THERAPY)(3,22,NE)
 ARTIFICIALLIGHTING(1,5,SE)
 BIODETECHNIQUES(29,27,N)
 BODYCONTROL(2,17,NE)
 CHIROPRACTICMEDICINE(3,1,SE)
 ELECTROACUPUNCTURE(22,5,SW)
 GINGERHIZOME(13,25,W)
 GINSENGROOT(1,11,SE)
 HERBALMEDICINE(1,7,SE)
 MAGNETORESONANCEPECTROSCOPY(28,30,W)
 MASSAGETHERAPY(8,24,E)
 MEGAVOLTAGE(TREATMENT)(23,1,S)
 MIND(18,6,NE)
 NUTRITIONALSUPPLEMENTS(1,22,NE)
 PROGRAMMEDRELEXATION(27,27,NW)
 THERAPEUTICTOUCH(16,27,W)
 YOGA(2,5,E)
 ACUPRESSURE(25,12,N)
 AROMATHERAPY(13,21,NW)
 AVURVEDA(29,9,N)
 BLUETIGHTTREATMENT(10,29,E)
 CHELATION(THERAPY)(26,28,NW)
 ECHINACEA(27,26,NW)
 ELECTROSTIMULATION(26,6,S)
 GINSENGOBLOBAEXTRACT(25,21,NW)
 GUIDEDIMAGERY(14,1,SW)
 HOMEOPATHICMEDICINE(19,26,W)
 MANUALHEALTHING(24,1,S)
 MEDITATION(27,1,S)
 METABOLICTHERAPY(30,24,N)
 NATUROPATHICMEDICINE(20,1,SW)
 PRAYER(THERAPY)(7,24,NE)
 SHAMANISM(22,25,W)
 TRADITIONALORIENTALMEDICINE(28,27,N)
 USEOFFARTTLAGEPRODUCTS(1,23,E)
 YELLOWDOCK(14,15,SW)