

ESRD NETWORK 13

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KIDNEY CONCERNS

SPRING/APRIL 2003

ISSUE 43

How Does a Family Cope With the Challenge of a Chronic Illness Such as ESRD? - Part II By Gordon Lore

[Editor's note: Both Part I and Part II of this article, along with an INCITE Interview, are included in this issue of Nephrology INCITE. Part I covers such topics as changing roles, how a chronic illness can take "unexpected and unpredictable turns," a marital dyads study, responsibilities and stress, Twelve Steps for Caregivers, and sexual dysfunction.]

(Kidney Concerns will publish the articles in four parts)

Roles, Responsibilities, and Stress

There is little doubt that chronic, long-time dialysis patients and their families "are constantly vulnerable to medical, social, and emotional crises, including frequent trips to emergency rooms, hospitals, and specialists. Most areas of living are affected, including work or school schedule and leisure activities, and regular employment may be precluded. The roles and responsibilities of the patient and family are frequently changed, and many families need help with the cost of treatments, medications, special diets, and transportation.

Stress can also be a major problem. Causes of stress include sexual problems, changed appearance (access placement, needle marks, etc.), renal osteodystrophy, co-morbid physical problems, "and, ultimately, the threat of death." The marital relationship between a patient and his/her spouse can be at risk because of the disease, and many advocate home dialysis only if patients can assume major responsibility for their care.

"Managing Your Stress"

At a patient and caregivers' conference sponsored by the Northwest Kidney Centers, there were tips on "Managing Your Stress as a Caregiver," which included:

- Patient caregivers should ask questions, read, and request from the patient the physical and emotional effects of the illness.
- Discover what community resources (adult day care, in-home assistance, Meals-on-Wheels, etc.) are available to help.
- Get others to help when necessary to avoid exhaustion.
- Take time off. Go to a movie, take a walk, or visit friends.

- Know your limits. Note physical or emotional changes in yourself. Utilize relaxation techniques. Discuss any changes with your doctor.
- Go with the flow. Accept changes.
- Look after financial or legal planning needs. What about a will or trust? Many dialysis facilities have forms and information about a Living Will, a Durable Power of Attorney for Health Care, etc.
- Be realistic and realize that many chronic illnesses get worse over time. You have every right to grieve for the losses you experience and to enjoy the positive moments and your good memories.

“Twelve Steps for Caregivers”

At the same conference, Carol J. Farran, DNSc, RN, and Eleanora Keane-Hagerty, MA, outlined “Twelve Steps for Caregivers”:

- (1) “Although I cannot control the disease process, I need to remember I can control many aspects of how it affects my relative and me.”
- (2) “I need to take care of myself so I can continue doing the things that are most important.”
- (3) “I need to simplify my lifestyle so my time and energy are available for things that are really important at this time.”
- (4) “I need to cultivate the gift of allowing others to help me...”
- (5) “I need to take one day at a time rather than worry about what may or may not happen in the future.”
- (6) “I need to structure my day” to maintain a consistent schedule.
- (7) “I need to have a sense of humor because laughter helps to put things in a more positive perspective.”
- (8) “I need to remember my relative is not being ‘difficult’ on purpose; rather that his/her behavior and emotions are distorted by the illness.”
- (9) “I need to focus on and enjoy what my relative can still do rather than constantly lament over what is gone.”
- (10) “I need to increasingly depend upon other relationships for love and support.”
- (11) “I need to constantly remind myself that I am doing the best that I can at this very moment.”
- (12) “I need to draw upon the Higher Power...”

There are certain “phases of adjustment” many kidney patients and their families face. These include optimism, even euphoria, in those patients who experience an improvement in their physical condition when they first start renal replacement therapy. Then, when the long-term reality of the illness and treatment sets in, such emotions as discouragement, disillusionment, and depression may become a part of a family’s life. As a result, counseling for depression and other behavior problems may be in order from renal social workers, psychologists, or psychiatrists.

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Taking a Look at Vascular Access

The issue of types of hemodialysis vascular access in hemodialysis patients is a hot topic in the world of dialysis today. Vascular access are fistulas, grafts, subcutaneous devices (such as Lifesites®), and catheters. I hope by now all of you have heard the term KDOQI, which stands for Kidney Disease Outcome Quality Initiative developed by the National Kidney Foundation. It is a guide used to measure quality of care issues for dialysis patients to ensure that they are getting the best quality of care possible. The newest initiative, as you may have guessed, is on vascular access.

You are most likely familiar with the type of vascular access you have. What you may not know is that KDOQI recommends fistulas as the primary vascular access for patients. Studies have determined that fistulas usually provide better clearance for dialyzing patients and are less costly in the long run than other accesses. The Centers for Medicare & Medicaid Services (CMS) and the ESRD Networks are focusing on vascular access performance targets to measure the number of patients using fistulas and grafts and help clinicians move patients from catheters to fistulas where possible. The goal is to reduce the use of catheters and increase the placement of fistulas to improve patients' dialysis and thus their quality of life.

Let's take a look at why they say fistulas are the preferred access and discuss what that means for you as a patient. The focus is on increasing fistula use and decreasing catheter use. First, let's look at the pros of having a fistula. It is reported that:

- Fistulas have a lower risk of infection, lower incidence of thrombosis (blood clot) and a lower rate of stenosis (narrowing of the vessels)
- Fistulas get better blood flow rates which equals better dialysis. This can be seen in lab work with Kt/V and URR results
- Patients with fistulas typically spend less time in the hospital and have fewer interventions to fix access problems
- Fistulas usually last longer than any other vascular access
- Fistulas are all you and require no foreign material in the body (there is nothing outside the body) therefore there are less restrictions on the patient's activities.
- Using a fistula to dialyze can require less time on the machine

As you can see, there are many good reasons that fistulas are a preferred choice. Fistulas provide better dialysis and fewer hospitalizations, which is something every patient desires. As for the cons of fistulas, there are very few. You may, however, have some concerns about having a fistula. Here are some of the reasons that you may not have a fistula:

- unsuitable blood vessels
- takes time to mature, catheter was quickest way to begin dialysis
- began with catheter and don't want to change
- fistulas require needle sticks

The first reason is something that you cannot change and a subcutaneous device may be a better alternative for you. If a catheter was placed just to get you started on dialysis,

now is the time to begin planning for a more permanent access. You need to discuss vascular access with your physician. If the only thing holding you back from getting a fistula is the fear of the needle stick, again, talk to your physician. There are things such as numbing creams that can help take the sting out of the stick. You really need to think about your vascular access and get the one that is best suited for you. Whatever issues you have, discuss them with your doctor, social worker or nurse. They are there to help you choose the best treatment for you. The goal of getting the best access for you is that you will live a longer, healthier life.

Enhanced Meat

By Susan Knapp, MS RD CSR LD



Look closely at the meat that you are getting from your meat case or freezer section of your grocery store. Beware— it may be “enhanced”, therefore higher in nutrients usually needing to be limited for dialysis patients’ wellbeing. Enhanced meats appear to be fresh, but in fact they are fresh or fresh-frozen meats that have been injected with a solution. In addition to water, the solutions that are used to enhance meat products contain some combination of these: salt, sodium phosphate, sodium lactate, potassium lactate, flavoring agents, and/or flavor enhancers. The enhancing solution is used to make the meat more juicy, flavorful, and tender. It also can make the meat appear redder in color.

It may also be used to extend the shelf life of the meat, i.e., the time that the meat stays palatable and is safe to eat. The sodium content varies between manufacturers, and the amount of fluid injected, usually 8 to 20% of the original weight of the meat. Enhanced meat may have from 150 to 900 mg. of sodium per 3-ounce serving (cooked weight), compared to less than 100 mg. of sodium for truly fresh meat. Most dialysis patients need to limit their daily total sodium intake to 2000 mg. Besides the extra sodium, enhanced meats may also contain more phosphorus and potassium than those that are not enhanced. This can be an unsuspected source of phosphorus or potassium in the diet. All kinds of meat may be enhanced, including chicken, pork, and beef.

What can you do?

Before you buy:

- Read labels carefully!! In very fine print, the label will read something like “Enhanced with ___% solution containing water, salt, and sodium phosphate.” It may also be labeled “enhanced or processed with a chicken broth solution” which is also high in sodium. Look closely because enhanced meats are often found in the meat case right next to those that are not enhanced.

- Some chains carry only enhanced meats. Brands of meat may vary from store to store. If the price of enhanced meats appears to be less, keep in mind that you are paying for the weight of the additional water (8% - 20%).

Talk to the meat manager to make sure the product you are thinking of buying is not enhanced. Request that they carry meats that are not enhanced. Many people, in addition to those on dialysis, need to limit their sodium intake.

References & Resources

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www.meatpoultry.com/ — contains links for many food related Associations & Agencies

Enhanced Meats Word Find

Find the hidden words.

They can be across, down, forward or backwards.

Find the following words:

- Chicken, Beef,
- Pork, Turkey,
- Meat, Sodium,
- Potassium,
- Phosphorus,
- Juicy, Salt,
- Protein, Frozen,
- Fresh, Grocery,
- Enhanced,
- Tender, Solution,
- Moist, Label,
- Water.

(Answers on page 8)

H	S	E	R	F	B	E	E	F	F	R	O	Z	E	N	P
A	L	A	B	E	L	N	R	A	J	Y	P	K	Z	N	O
B	W	T	O	P	P	H	O	S	P	H	O	R	U	S	S
T	A	U	Q	J	L	A	V	S	O	I	T	H	R	O	Y
E	T	R	K	U	M	N	S	A	R	W	A	T	O	D	C
N	E	K	C	I	H	C	H	L	K	U	S	L	B	I	I
D	R	E	J	C	M	E	A	T	U	T	S	A	M	U	U
E	G	Y	I	K	N	D	X	E	G	V	I	M	K	M	J
R	P	R	O	T	E	I	N	S	O	L	U	T	I	O	N
C	H	Y	R	E	C	O	R	G	F	H	M	O	I	S	T

Caribbean Chicken

A one-pan meal your whole family will enjoy.

1¼ pounds of boneless chicken breasts, cut into bite-size pieces (or substitute boneless pork roast, cut into bite-size pieces, or cooked & peeled shrimp)

2 Tablespoons Olive or Canola Oil

1 cup onion, chopped (1 medium)

2 cloves garlic (1 teaspoon minced)

1 cup carrots, chopped (2 to 3 medium)

1 cup green pepper, chopped (1 medium)

1 can (14½ oz.) pineapple chunks

1 teaspoon ground ginger

2 Tablespoons barbecue sauce

2 ¼ cups water

1 ½ cups white rice, uncooked



In a large skillet, saute the chicken*, onion, and garlic in the oil until the chicken is lightly browned and the onion is transparent. Stir in the carrots, green pepper, pineapple chunks (including juice), ginger, barbecue sauce, water and rice. Bring mixture to a boil, stir, & turn the heat down. Cover and simmer on low for about 20 minutes, or until the rice is tender & the water is absorbed.

Serves 5

* Note: If shrimp is substituted for the chicken, wait to add it during the last 5 minutes of cooking time.

Per Serving: 380 Calories, 29.6 grams Protein, 46.2 grams Carbohydrate, 8.5 grams Fat, 175 mg, Sodium 521 mg, Potassium 194 mg, Phosphorus
= 3 oz. Meat, 1 ½ Starch, 1 Medium Potassium Vegetable, 1 Medium Potassium Fruit

NEW GRIEVANCE POSTER

In February Network 13 distributed the new Grievance Poster to all facilities. The facilities were instructed to place the poster in the facility in an area it can easily be viewed by patients. The facilities were informed that the Network 13 staff would verify the presence of the poster whenever they visit. The State Survey Agencies were also notified of the posters and will also verify the display anytime a facility survey is performed.

The poster outlines the complaint and grievance process that Network 13 uses when a complaint or grievance is received. The poster provides the contact information for Network 13 to file a complaint or grievance with the toll free patient phone number. All patients have a right to file a complaint or grievance with Network 13 if they feel the care they are receiving is unprofessional or not to accepted quality.

If you do not see the poster displayed at your facility ask your facility staff about it or contact Network 13.

Information on Vocational Rehabilitation Services:

If you are between the ages of 18 and 59 years old and are interested in returning to work, school or retraining, your state Vocational Rehabilitation Services office is the place you want to contact. A rehabilitation counselor will meet with you to complete an application and to do an initial assessment of your needs and eligibility for services. If you are found eligible for services, a written Individualized Plan for Employment (IPE) will be completed. You will be provided the services identified in your IPE. Upon completion of those services, you will be provided job placement assistance.

Studies have found that ESRD patients that work full- or part-time or do volunteer work have better outcomes than other patients, tend to follow their treatment recommendations better and have a focus outside of the treatment process for ESRD.

The ESRD Medicare Program was approved on the idea that if persons with ESRD received dialysis treatment, they would become well enough to return to work and would not rely on government assistant programs for support. In the year 2001 only 10% of eligible patients were referred for vocational rehabilitation services, a decrease of 3% from 2000.

Ask your social worker or vocational rehabilitation counselor about the Ticket to Work Program and the benefits to you. For more information contact Maximus toll free at 866-968-7842 or go to the link on the Social Security Web site www.ssa.gov. Your ability to continue to receive extended Medicare coverage is improved through this program.

The Institute on Rehabilitation Issues recently published a training manual for vocational rehabilitation counselor titled *Effective Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease*. Request your vocational rehabilitation counselor review this manual so they can better understand your ability to work. The manual also provides basic education of chronic kidney disease and treatment options.

If you want information on what vocational rehabilitation services may have for you please contact:

Arkansas: Andrew Jones, Program Administrator
Arkansas Kidney Disease Commission
Phone: 1-800-330-0632
Web site: www.state.ar.us/ars

Louisiana: Louisiana Rehabilitation Services
Phone: 1-800-737-2963 (inside Louisiana only)
Web site: www.dss.state.la.us/lrs

Oklahoma: David Couch, Programs Field Representative
Oklahoma Department of Rehabilitation Services
Phone: 1-800-487-4042
Web site: www.drs.state.ok.us


ESRD Network 13

ESRD Network 13 provides patient services and outreach programs for people with End Stage Renal Disease. Some of the functions of these services include resolving patient grievances and providing educational and informational materials to assist patients in improving their outcomes.

Web site: The primary focus of Network 13's (<http://www.network13.org>) Web site is to serve the Arkansas, Louisiana and Oklahoma End Stage Renal Disease (ESRD) communities. This site will provide useful information on ESRD to the public as well as professional caregivers and ESRD patients.

The Patient Advisory Committee (PAC): Through Patient Services, publishes the patient newsletter, Kidney Concerns, quarterly. The newsletter provides educational and informational materials to assist patients in improving their outcomes. At least one PAC member serves on the Network Board of Directors, Medical Review Board and Grievance Committee. The PAC adopted a mission statement to add to the goals it formulated at its inception.

MISSION STATEMENT: "The mission of the Patient Advisory Committee (PAC) is to express the opinions of the ESRD patient population of Network 13, serving the states of Arkansas, Louisiana and Oklahoma. PAC members represent the ESRD patient population by actively participating in Network duties designed to promote quality of care."



KIDNEY CONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for SUMMER/JULY. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

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Answers:

