

ESRD NETWORK 13

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KIDNEY CONCERNS

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How Does a Family Cope With the Challenge of a Chronic Illness Such as ESRD?- Part I

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)

Introduction

Living with a chronic illness such as End-Stage Renal Disease (ESRD) is a real challenge, and it may take both the patient and his/her caregiver(s) a while to realize it.

"It takes time to understand your illness, the treatment options available, and how living with illness will affect your life and the lives of your partner and family," according to Pauline Salvucci, MA, founder and president of Self Care Connection, LLC, an Internet-based coaching company offering family caregiver and other services for men and women at mid-life.

Changing Roles

Patricia Katherine Novick, PhD, a therapist in private practice, says that, at some point in their lives, most people will become caregivers for aging parents or other loved ones, and "often this role comes on without warning or preparation." It is difficult for anyone to sustain the "difficult and draining role" of caring for a chronically ill patient. It can be an "extremely stressful" role fraught with adverse health effects.

Family roles also change. The caregiver often has to take over the household and other chores of the partner. This includes maintaining medication schedules, doctors' visits, insurance forms, etc. Most caregivers are not trained or prepared for caring for a chronically ill person. This is unfortunate since, according to one report, the number of caregivers increases an incredible 10-fold daily. (cont. page 2)

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“A Roller Coaster...”

As any long-time dialysis patient knows, having a chronic illness “is like being on a roller coaster-you can be up and hopeful one minute and down and doubtful the next.” The illness can also take “unexpected and unpredictable turns... This can be frightening as well as exasperating.” It affects every part of a patient’s life and every significant relationship that patient may have.

Kidney disease, certainly, “is a major life change that can cause a great deal of stress and can give rise to a range of emotional reactions.” These include depression, anxiety, and “feelings of frustration or anger about the illness.” While there is disagreement about its prevalence, one report says that as many as one-third of all dialysis patients suffer from depression. Clues to depression include “feeling hopeless and helpless for a few weeks as well as “sleeping or eating more or less than usual” and missing dialysis treatments. When a patient discovers that his/her kidneys no longer work, “it is normal to feel angry, fearful, and sad.”

A Marital Dyads Study (DYAD - Two Persons)

Researchers at George Washington University, Washington, DC, and the National Institutes of Health, Bethesda, MD, reported that “little research has been performed assessing patients with ESRD as parts of marital dyads or within family structures. Recent findings suggest patient interactions within such systems are associated with patient outcomes.” They studied the “relationship between level of patient depression and spouse psychosocial status” in 55 couples, with one partner undergoing chronic hemodialysis therapy.

“Spouses reported significantly lower functional status for patients than did nephrologists,” the researchers said. “Spouse and patient levels of depression are related... These findings suggest that the patient with ESRD functions in a psychosocial dyad. Spouse psychosocial status could impact on the level of patient depression, and the spouse might be amenable to interventions that could improve patient outcome.”

(continued next edition)

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Partner’s Corner

As the partner of an ESRD patient I was always worried about being adequately prepared to meet emergencies and unforeseen situations that would require quick responses. One of the most helpful things that I came up with to calm my anxiety was to keep a small pocket-sized notebook filled with critical information about my partner’s medical condition and needs with me at all times.

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I included such things as:

- Patient's full name
- Date of birth
- Social Security Number
- Name of insurance companies and patient identification numbers (as well as copies of the actual cards)
- Exact diagnosis of the medical condition
- Treatment mode, frequency, duration of treatment
- Site of the implant (if applicable)
- Doctors' names and phone numbers and that of treatment centers
- List of all medications and dosages (including all over-the-counter preparations)
- List of all prior surgeries
- Allergies and any condition that might affect treatment or effect of medication
- Name, address, phone number of another contact person beside myself

Armed with this extensive information in my little notebook, I then had confidence that in an emergency I could provide the necessary information to ensure that my partner would receive the correct treatment with the least amount of delay. I updated the information as medications or conditions changed. My notebook served me well over the years and saved time in filling out hospital forms.

I also set up a notebook for my elderly parents so they would be better prepared for hospital stays or for seeing new doctors. The elderly frequently forget to bring or mention all the medications they take.

By Sandi Morant, Patient Advisory Committee, Network 13

JUST IN TIME FOR CHRISTMAS

Book is Now Available!

Chronically Happy - Joyful Living in Spite of Chronic Illness

By Lori Hartwell

\$12.95

There are several ways to order Chronically Happy.

1. Order online at www.chronicallyhappy.com
2. Order online at www.amazon.com
3. Complete and fax back the form (PDF File) available at www.ChronicallyHappy.com.
4. Call Poetic Media Press (415-447-4800 ext. 4) and they will take the order over the telephone.
5. Go to your local bookstore and ask them to special order it (ISBN No. 0972278303, Poetic Media Press).

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RENAL HOLIDAY RECIPES

Submitted by Susan Knapp, RD, Network 13 Board Member

ROAST CHICKEN

- 1 whole chicken
- ½ tsp. garlic powder
- ½ tsp. onion powder
- ½ tsp. thyme

Mix together the spices and rub the chicken inside and out with them. Place on a rack in baking dish. Place in 350 degree oven for approximately 1 hour, or until juices run clear when meat is pricked with a fork.

Renal Exchanges: Each cooked ounce = 1 oz. Meat

ROASTED ONIONS

- 4 large onions, halved and peeled
- 1 Tbsp. margarine
- 1 Tbsp. olive oil
- ¼ tsp. Pepper
- ½ tsp. dried Thyme or Oregano (or 1 ½ tsp. fresh)
- 1/2 cup dry white wine

In a skillet, melt the margarine and oil over medium heat and then add onions, placing them cut-side down. Brown for about 10 minutes on both sides — starting with the cut side down. Place in a baking dish and sprinkle with pepper, thyme, and wine. Cover and bake at 375 degrees about 1 hour, or until tender.

Yield 8 servings.

Each serving contains: 63 calories; 0.7 g protein; 5 g carbohydrate;
 109 mg potassium; 14 mg sodium; 20 mg phosphorus

Renal Exchanges = 1 Medium Potassium Vegetable

BREADED NOODLES

- 8 oz. Package of wide egg noodles
- 2 Tbsp. margarine
- 5 Tbsp. Italian dry bread crumbs
- Chopped fresh parsley

Prepare and drain egg noodles as directed on the package (except leave salt out of the cooking water). In saucepan, melt the margarine. Add breadcrumbs to margarine and saute until browned. Toss with egg noodles. Toss in parsley.

Yield: 8 servings.

Each serving contains: 153 calories; 4.7 g protein; 23 g carbohydrate; 55 mg potassium; 106 mg sodium; 54 mg phosphorus

Renal Exchanges = 1 ½ Starch

HOLIDAY COLESLAW

3 cups of green cabbage, shredded

2 cups of red cabbage, shredded

1 cup of dried cranberries

1/4 cup thinly sliced red onion

Dressing:

1/3 cup red wine vinegar

1/4 cup canola oil

1/3 cup sugar (or sugar substitute)

3/4 teaspoon celery seed

Mix together the slaw ingredients. Toss with the dressing. Cover and refrigerate at least 2 hours. Drain off liquid prior to serving.

Yield: 10 servings.

Each serving contains: 125 calories; 0 g protein; 110 mg potassium; 6 mg sodium; 15 mg phosphorus

Renal Exchanges = 1 Low Potassium Vegetable; 1 Low Potassium Fruit; 1 Fat

RICE PUDDING

4 cups rice beverage (not enriched)

½ cup long grain rice

½ cup sugar

2 large eggs, beaten

1 ½ tsp. vanilla extract

Heat the rice beverage in a saucepan over medium-high heat and bring to a boil. Add the rice to the boiling liquid. Lower the heat, and cook, stirring occasionally, for 25 to 30 minutes, until rice is tender. Mix together eggs, sugar and vanilla in a small bowl. Stir a small amount of the hot rice mixture into the egg mixture and mix well. Now stir the egg mixture into the pan, stirring well. Cook over medium heat for another 2 minutes, until thickened. Stir in vanilla.

Yield: 6 (½ cup) servings

Each serving contains: 219 calories; 4 g protein; 46 g carbohydrate; 3 g fat; 130 mg potassium; 92 mg sodium; 102 mg phosphorus

Renal Exchanges = 2 Starch; 1 High Calorie Choice

Patients Can Ask Five Simple Questions to Help Avoid Medication Errors

Health-System Pharmacists Offer Medication Safety Advice in Support of National Pharmacy Week

“Drug interactions are a real concern for many patients, as well as for pharmacists,” said ASHP President Debra Devereaux, MBA, FASHP. “It is extremely important that patients tell their health-care providers about all of the medications they take. Pharmacists in hospitals and health systems are a great resource for patients who have questions or concerns about their medications.”

Health-system pharmacists recommend that patients in the healthcare setting ask their caregivers the following five questions about their medications:

1. What is the name of my medication?
2. What is it used for?
3. How will this drug interact with other medications I am taking?
4. Should I expect any side effects? And what should I do if I experience a side effect?
5. What should I do if I miss a dose either in the hospital or at home?



ENID MAN'S POSITIVE OUTLOOK EARNS HIM NORMAL LIFE, AWARD.

Co-workers and acquaintances describe Andrew Ritz as quiet, friendly and unassuming. But the 36-year-old electronics technician at Enid Dialysis Center has had his share of setbacks. Ritz became a double transplant recipient and amputee in 1998 - all within two months. His attitude about his illness before the transplants and amputation and his willingness to get back to a normal life is just part of the reason a co-worker nominated him for the 2002 Governor's Disability Employment Award. Ritz accepted the award at Governor's Mansion in Oklahoma City. Ritz attributes his fast recovery and ability to overcome his disability to staying positive throughout his experience.

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"I didn't get down about it," Ritz said. "It's kinda hard to explain. I put it all to being a Christian and believing in Jesus." Nancy Holden, vocational rehabilitation counselor with Oklahoma Department of Rehabilitation Services, worked with Ritz during his recovery. She describes him as friendly, intelligent and a go-getter. "That's just Andrew. That's his outlook on life," Holden said. "(He was) able to hang in there until he got what he wanted in spite of setbacks." Ritz first became ill as a child when he was diagnosed with diabetes. By 1996, he was suffering from end stage renal disease. Doctors told him he'd need a transplant, and he began dialysis once a week at Enid Dialysis Center. He was on dialysis for the next two years.

Ritz's life changed in the summer of 1998. One evening at dusk, Ritz turned his motorcycle into a car he didn't see. The wreck crushed his right foot, and doctors amputated the leg just below the knee. He spent the next month in the hospital recovering from the amputation.

A month later, he was back in a hospital bed - but this time he was getting a new kidney and pancreas. Ten days after the transplant, he was at his home in Hennessey, thinking about a future without renal disease or diabetes. Ritz attended Autry Technology Center and Northern Oklahoma College-Enid, studying electronics and computers. Now he spends his days working on dialysis machines at the clinic where he spent so much time. Some of the same patients who were receiving dialysis when he was awaiting his transplant still are being treated today. "It's nice to talk to them," Ritz said. "Some of them I know from before, and some don't know anything about me." Ritz believes there's an explanation for why he seems to recover so easily from setbacks that others would find debilitating. "I feel like there's gotta be a reason," Ritz said. "I feel like I was put in this place for a reason, not really for me, but maybe for the dialysis patients.

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Condolences

The Network expresses condolences to the family of Wayne "Terry" Earley, of Poteau OK, who recently passed away. Terry had just begun work with the Network Patient Advisory Committee. His contributions were beneficial for the patients he represented in Network 13.

The Network expresses condolences to the family of Mohammed "Sonny" Rahaman of Tulsa OK. Sonny was killed in a convenience store robbery where he was a clerk. His dialysis facility staff remember him fondly and will miss the positive attitude he brought with him to his treatments.

New Material to Train VR Counselors About ESRD

The Rehabilitation Services Administration (RSA) recently released new training material to educate vocational rehabilitation counselors on the employment potential of people with end-stage renal disease (ESRD). The 27th Institute on Rehabilitation Issues released Effective **Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease**. This training material will assist the vocational rehabilitation counselor to have a better understanding of kidney disease.

The material will assist the vocational rehabilitation counselor and patient to emphasize the rehabilitative potential of people with kidney failure. The materials include a toolkit for the vocational rehabilitation counselor to utilize in assisting their client. The toolkit includes a Kidney Disease Dictionary, Medicare coverage and payments information, flow charts to assist in vocational rehabilitation planning, rehabilitative program information and exercise information. Ask your vocational rehabilitation counselor if they have material so they can provide you with their best services.

Robert Woods Johnson Foundation releases Promoting Excellence in End-of-Life Care for End Stage Renal Disease

A multidisciplinary ESRD workgroup spent 18 months to release a report on steps needed to improve palliative care for ESRD patients. The recommendations are directed towards the Centers for Medicare & Medicaid Services, dialysis corporations, individual dialysis facilities, nephrology professionals and organizations that advocate for dialysis patients. The released report contains a final report summary and the final report. These materials are recommended to be utilized to address and assist dialysis professionals in assisting patients plan and prepare for end-of-life. The report addresses advanced directives, palliative care, Do-Not-Resuscitate order and quality in dying. The report provides tools and model policy and procedures for dialysis professionals to utilize in planning for end-of-life care with patients. The full report can be accessed at www.promotingexcellence.org. (Palliative= Hospice)



KIDNEY CONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for SPRING/APRIL. 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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