

American Association of Kidney Patients (AAKP) Information

AWARDS

AAKP seeks nominations for Chronic Kidney Disease (CKD) Awards. The AAKP is seeking nominations for two CKD awards; AAKP Spirit of Service Award and the AAKP Visionary Award. The awards are designed to recognize and honor a patient and physician who have performed extraordinary service on behalf of those with CKD.

The awards will be held in conjunction with the AAKP Annual Convention to be held in New Orleans, Louisiana. The awards will be presented during the Welcoming Ceremonies.

Any kidney patient who has performed outstanding public service on behalf of those with CKD is eligible for the AAKP Spirit of Service Award.

Any physician who has achieved outstanding success in caring for CKD patients is eligible for the AAKP Visionary Award.

The deadline for nominations is July 18, 2003. You can request a nomination form from the AAKP national office by calling 800-749-2257 or via e-mail at info@aakp.org.


CONVENTION

The AAKP 30th Annual Convention will be held August 28-31, 2003 in New Orleans, Louisiana. The convention will be held at the Sheraton New Orleans on 500 Canal Street. For a registration packet contact the AAKP national office by calling 800-749-2257 or on the web site www.aakp.org. The conference is in our Network and is accessible to many patients. Let's support the AAKP and the work they do on patients' behalf by attending this conference. The AAKP will sponsor free admission to a limited number of local patients unable to afford the registration. If you are interested in attending and live in the New Orleans area contact your social worker so your name can be submitted to Network 13 for consideration. Network 13 staff will see you there.

Answers:

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

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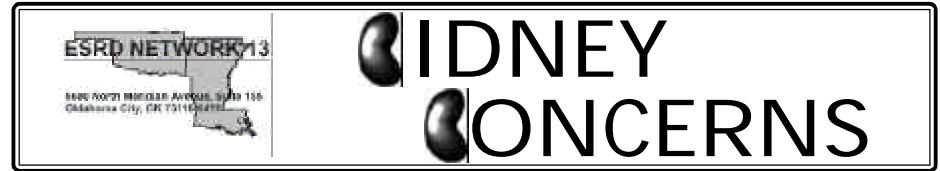


KIDNEY CONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for FALL/OCTOBER. 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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A Challenging Dilemma

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

By Gordon Lore

“Sexual Dysfunction”

Decrying the fact that “few controlled studies have evaluated the independent effects of hypertension and antihypertensive medications on sexual function” in both men and women, Jean L. Holley, MD, a nephrologist, said that most studies that have been done “have shown that age, cigarette smoking, hypertension, and chronic kidney disease all contribute to sexual dysfunction. Reduced sexual interest and activity has repeatedly been observed in studies of men and women on dialysis.”

Do antihypertensive medications contribute to sexual dysfunction in men? That question remains a controversial one. Studies have apparently shown that “erectile dysfunction in men was associated with age, systolic blood pressure, and previous antihypertensive use.” Another study indicated that losartan, an angiotensin II blocker, “improved erectile function as well as satisfaction and frequency of sexual activity.”

“Sildenafil [brand name: Viagra] has been shown to be an effective and well-tolerated treatment for erectile dysfunction in men with hypertension and [ESRD],” Hollee remarked. “Future research studies will elucidate the factors and mechanisms involved in sexual dysfunction in men and women with hypertension and chronic kidney disease and will thus allow improved understanding and therapeutic interventions in this important area affecting patients’ quality of life.”

“Many Hurdles”

David L. Axtmann knows what it’s like to be a chronic dialysis patient. He’s been at it for 33 years and has even written a book about the journey with his wife, Marlene, of more than 40 years. Both were only 27 when Axtmann began dialysis treatments.

“There were many hurdles along our journey that we could never have imagined,” Axtmann wrote. “We learned to use these hurdles to strengthen our love and relationship rather than let them get the best of us. Our love is stronger today because of it all.”

One of the major hurdles was sex. Dialysis treatments began “when the masculine desire is usually strong,” but both husband and wife found “some good and necessary help,” and they were able to discuss any problem. While much of the problem was psychological, there were also parathyroid problems that affected the sex drive. After a second parathyroid surgery, however, “my desire was greatly improved.” Both husband and wife also had to develop other strengths to keep their relationship intact.

“The Adjustment Period”

Wendy Funk Schrag, LMSW, ACSW, has been helping dialysis patients with adjustment problems for the past decade. She is the Patient Services Manager for Renal Care Group, and is current chair of the National Kidney Foundation's (NKF) Council of Nephrology Social Workers. She also serves on the Life Options Rehabilitation Advisory Council.

“The adjustment period varies widely,” Schrag said in an interview with INCITE. “For some, it may depend on whether they had gradual kidney failure and received good pre-dialysis intervention, education, and support. Those patients who have acute kidney failure that then leads to a chronic condition may have more trouble in the beginning and go through more shock than those whose kidney disease was gradual. Throughout life with kidney disease, there may be times of setback when patients and families may feel they have to go through the adjustment process all over again. The mark of a patient and family who are coping well is their ability to be resilient and bounce back from occasional setbacks.”

Schrag believes that the healthcare professional “should ask questions about what type of outside activities the patient and family are involved in and also what type of emotional support they are receiving.” Patients and family members will adjust better if they continue on with their normal daily activities. Also, “it is important that patients and families understand what they need to do to take care of the patient, but not spend all the time dwelling on the illness itself.”

“Difficult Issues”

This may be difficult to do, however, since ESRD affects patients both medically and psychologically.

“Depression, loss of self esteem and loss of regular roles in the home or at work have a great impact on the patient and family,” Schrag told INCITE. “Physical effects such as hair loss and the way the access looks may keep patients from being as free to participate in social activities as they use to. This then affects the whole family and friends, not just the patient. Problems with sexual function due to kidney disease also have an impact on the intimate relationship patients have with their spouses. These may be very difficult issues for patients to talk about with their loved ones.”

Schrag also believes that “the most important thing” for healthcare professionals “is to address the issues openly and not wait for patients to bring up difficult topics. Having general patient educational information on these topics that is given to everyone gives the message that these are not taboo subjects. Patients will feel more free to discuss difficult issues if they feel the staff are willing and expecting to deal with them.”

“Humor is Very Important”

“Caregivers need to take frequent breaks and time away from the patient, if possible,” Schrag believes. “They need to not give up the activities they enjoy and continue to do fun activities with the patient they have done in the past as well as find new activities. Humor is very important. Those caregivers and patients that can continue to enjoy themselves and find things to laugh about do much better than those who focus so much on the illness that it takes over their lives.”

I am certainly pleased with the reasonable diet that I follow and the medications necessary to ensure a healthy existence. Progress is slow but is being made and deserves notice and occasional celebration. Presently I weigh 263 pounds. I only have five more pounds to lose to meet my weight goal. I'm nearing the goal to get listed for a transplant. I have waited for this time since I set my goal and took the action necessary to accomplish it. I know that getting placed on the transplant list does not guarantee a transplant will occur. Nothing is promised and there is no guarantee that a match will be found. As dialysis continues, one must learn the art of waiting.

The key may be explained in the word patience. My faith provides assistance with this. It is anchored in hope and I must keep this faith. This is assisted by the support, love and compassion of those around me. It certainly calls for diligence and perseverance. It takes knowledge and self-control to sustain my quality of life. I am thankful for the brotherly kindness shown by family, friends and the staff at my dialysis center. I have been in treatment a year now. My treatments are three days per week and last for four hours and forty-five minutes each. I am learning patience and the art of waiting. Hopefully, I will be fortunate enough to get on the transplant list. Then I will wait for the call that a match has been found and I am transplanted.

This article was sent to Network 13 by a dialysis patient from Northwest Arkansas. All views and opinions are that of the author and do not necessarily reflect those of ESRD Network 13.

NOMINATION FOR NKF of OKLAHOMA ANGEL OF THE YEAR AWARD

By Staff of RCG-Lawton Dialysis

Maria Matthews has been nominated for the NKF of Oklahoma Angel of the Year award for her tireless efforts assisting dialysis patients in her community. Mrs. Matthews is 80 years old. She became involved in assisting dialysis patients in 1992 when her son required dialysis. Her son received a kidney transplant in 1993 but Mrs. Matthew stayed involved with the dialysis center and the other patients.

Once a year Mrs. Matthews fixes the dialysis patients at the facility a sack lunch with homemade cookies. The social worker passes the lunches to the patients to enjoy. These lunches are warmly received and anticipated by the patients. Mrs. Matthews cooks a Thanksgiving meal for the facility staff and brings it to the unit for each shift the week before Thanksgiving Day. It is not uncommon to find bake goods in the staff break room throughout the year for all to enjoy.

An example of Mrs. Matthews's kindness and concern occurred this year when a patient moved to Lawton and was in need of furniture. Mrs. Matthews located a couch and other needed furniture and the staff helped move the furniture into the patient's home.

Mrs. Matthews is the administrator of the Lawton Kidney Support Group Fund. The fund is utilized to assist indigent patients with financial needs. Her projects to raise finances include a yearly bake sale in which Mrs. Matthew does all the baking. She uses the recipes passed down from her German heritage so all her baked goods have that special German touch. Once a year she takes orders for a dinner of either schnitzel or cabbage rolls that she hosts. This past year she held a garage sale and took donations to raise money for the fund.

A number of patients have benefited from this fund to assist with gasoline, taxi fares, medicine, utility bills and other miscellaneous expenditures. If it were not for Mrs. Matthews, some of these patients would experience greater hardship than they already do. Mrs. Matthews is a jewel who can be called on at any time for assistance. We appreciate Mrs. Matthews and believe she is worthy of the NKF of Oklahoma Angel of the Year award.

Word Search

Answers on last page.

Words to find:

Fluid
water
ice
popsicle
grapes
lemon
salt
sodium
spray
mouthwash
rinse
small cup
gum
coffee
tea
soup
jello

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

DIALYSIS AND THE ART OF WAITING

By David F. Vierck

I am grateful for dialysis, a thankfulness that is truly heartfelt.

End Stage Renal Disease (ESRD) involves the accumulation of waste and fluid in the blood. Dialysis involves the removal of this waste and excess fluid. The dialysis machine is fantastic. The artificial kidney works! The machine functions like a cell pulling waste and fluid from the body. At a set pressure, over a period of time, the process quietly happens.

Before I had the need for dialysis, other problems had occurred. My medical condition deteriorated. Warnings to be heeded echo in my mind. "David, you are overweight. Do you want a heart attack or stroke?" "You better calm down, the hypertension will kill you." "Type II diabetes did not happen overnight, it's been a long time coming." I did not heed the warnings or take the time to listen. I did not have the time to wait.

There are goals to celebrate while on dialysis, yet there are goals still to be accomplished. My journey began years ago at 320 pounds. Hypertension was diagnosed when I had reached 312 pounds. My body could not hold up to this condition and my kidneys failed. I began dialysis. Shortly after starting dialysis I become interested in a kidney transplant. The desire for a transplant led to setting a weight goal of 258 pounds from my then weight of 291 pounds. This is when a surgeon gave me a "fat" lecture "Too much fat makes surgery difficult" he said. My only option was to lose the weight if I truly wanted a transplant. I wanted to heed this advice.

Partner's Corner By: Sandi Morant, PAC member.

Living with kidney disease requires adjustments in everyone's life, the patient, of course, but the whole family as well. Adjusting to change is not easy for anyone concerned but facing the problem with honesty and openness goes a long way towards coping successfully with this or any other disease.

A big first step is admitting that adjustments have to be made. Life is not going to continue just the way it was before ESRD. Time in treatment, financial demands, physical discomfort, dietary restrictions, and the accompanying emotional reaction to these constraints are some of the changes that need to be recognized and dealt with.

When these issues are discussed and handled by the family or support system as a whole, it is more likely that treatment will be successful since everyone is ultimately impacted by the situation, either directly or indirectly.

Sometimes people prefer to escape the reality of the situation through denial of the problem or by trying to ignore the complications it causes. Many partners and/or family members are afraid to face the situation directly. They may even avoid visiting the hospital or treatment center. Some may refuse to educate themselves about kidney disease, treatment modes, and dietary guidelines. Others may be hesitant to discuss the disease with others, especially their children.

While in the beginning avoidance may appear the easiest approach, in the long run it's not. Nothing is solved, the situation does not resolve itself or simply go away. It is very difficult to be up-front about your feelings, fears and doubts. It is part of the human condition to be apprehensive of change. However, not all change is bad. While honestly admitting your fears and frustrations, you and your partner have an opportunity to grow closer as a couple and as a family. Working together in dealing with these complex issues builds a strong bond that can comfort and support you throughout your life.

My partner, Walter, was already in treatment when I met him so I knew in advance that we would have to face some complications that other couples may not have to encounter. However, we prepared ourselves to deal with the problems we knew would pop up from time to time. We vowed never to take each other or our time together for granted. It was a promise we diligently kept. When Walter died (after almost 32 years on dialysis) while I was devastated by my loss, I could comfort myself with the fact we had made the most of our time together (27 years). Instead of pulling us apart, kidney disease helped bind us more strongly together because we faced everything together.

**Fluid Tips**

Summertime can be an especially difficult time to control fluids. The amount of fluid that you should drink depends upon how much urine output you have. If you make very little urine, then your body can only handle a little fluid. Here are a few tips to help out.

1. Fill a small spray bottle with your favorite beverage & keep it in the refrigerator. Spray some into your mouth when you are thirsty.
2. To decrease thirst, avoid salt and salty foods.
3. If you are diabetic, controlling your blood sugars will decrease your thirst.
4. Chew gum, or suck on hard candy to moisten a dry mouth.
5. Rinse your mouth out with chilled mouthwash.
6. Anything that melts at room temperature counts as fluid (even Jello). Think about it — soup doesn't do anything to quench your thirst.
7. Use a small cup, rather than a small amount in a large cup.
8. Measure your fluid allowance out in the morning & subtract from it whenever you drink anything. Stop when your allowance is gone.
9. Use applesauce to swallow your pills so you don't have to use some of your fluid allowance for pill swallowing.

(Cont. on page 4)

(Cont. from page 3)

10. Try some frozen grapes to moisten your mouth.
11. Suck on ice—but remember ice melts to become water. Generally a cup of ice is equal to ½ cup of water.
12. Cut a lemon into wedges & freeze it. When your mouth is dry, suck on a frozen lemon wedge.
13. A little lemon juice added to the water of the ice cube tray makes it more refreshing.
14. Remember that your dialysis will be less troublesome (less blood pressure drops & cramping) and you will feel better after dialysis when you don't have excessive fluid gains.

30 Year Milestone

Mr. Joseph Arceneaux of New Orleans, Louisiana is celebrating 30 years of dialysis. He has been a patient of Dr. Tom Oelsner and Dottie Forley, RN for the whole 30 years at Uptown Dialysis. Dr. Oelsner credits Mr. Arceneaux's longevity to his consistent involvement in his treatment process. Congratulations and continued success with your management of ESRD.

Summertime Food Safety

By Susan Knapp, MS RD CSR LD

Summer is a great time of year for friends and family to get together for picnics & cookouts. However, you can become sick if food is not handled correctly. This is true anytime, but especially in warm weather. People with kidney disease tend to be more likely to get sick from contaminated food. Sometimes you may not even be aware that your illness has been caused from food. There are many different food-borne diseases and the symptoms can vary but most often include diarrhea and vomiting. Other symptoms may include nausea, stomach cramps, fever and chills. Food safety is in your hands. Make sure that no one gets sick from the food by handling it correctly.

**Food Safety Tips:**

- Wash your hands—thoroughly and often. Always wash hands after handling raw meat, poultry or seafood and before cutting up raw vegetables or fruit.
- Keep hot foods hot and cold foods cold. Have plenty of ice chests and ice and keep the cold foods on ice. Bacteria can grow quickly at room temperature and even quicker outside on a hot day.
- Refrigerate leftover foods from a meal within 2 hours, 1 hour in hot weather.
- Refrigerate fresh produce within 2 hours of peeling or cutting.
- **Do not eat raw or undercooked meat, seafood, or eggs.**
- Keep surfaces clean. Wash cutting boards, countertops, appliances and utensils in hot, soapy water. Wash knives, utensils and cutting boards often and well.
- Use a different cutting board for the meat & vegetables / fruits.
- Use a different plate for cooked meat and raw meat.
- Wash fruits and vegetables right before you eat them. Scrub firm vegetables and fruits with a clean vegetable brush.
- Thaw meat in the refrigerator or microwave—not at room temperature on the counter.
- Use or freeze fresh meats within 3 to 5 days of purchase.
- Use or freeze poultry, fish, and ground meat within 1 to 2 days.

Renal-Friendly Foods for a Picnic or Cookout:

Meats:

Hamburgers, Grilled Chicken Breasts on buns, Chicken Quarters, Smoked Ribs – pork or beef (go easy on the sauce), Smoked Brisket (go easy on the sauce), Grilled Steak, Grilled Fish, Deviled Eggs.

Salads/Fruits/Vegetables:

Macaroni Salad, Pasta Salad, Potato Salad (with potatoes "leached" first), Marinated Cucumbers & Onions, Tossed Salad, Fruit Salad (using lower potassium fruits such as canned pineapple, mandarin oranges, grapes, & apples), Green & Red Grapes, half-ears of corn (wrap in foil & grill), Grilled Vegetable Kabobs with onion, green pepper, zucchini, White or French Bread.

Desserts:

Apple, Blackberry, or Cherry Cobbler, Cookies (Without nuts or chocolate), Lemon Bars, Angel Food Cake with Strawberries and whipped topping, Toasted Marshmallows, and Rice Crispy treats.

Drinks:

Lemonade, Crystal Light or KoolAid, Iced Tea, Carbonated beverages (without phosphorus)

SUMMER TREATS

Dilled Cucumbers: Serves 6, Serving size:
¾ cup

Ingredients:

3 cups sliced cucumbers
1 cup sliced onion
1 cup white vinegar
¼ cup water
2 Tablespoons sugar
2 teaspoons dillweed

Directions:

Boil vinegar, water and sugar until sugar is dissolved. Add dillweed and pour over cucumbers and onion. Cool and refrigerate several hours.

Renal Exchanges:

1 Medium Potassium Vegetable

Renal Diabetic Exchanges:

1 Medium Potassium Vegetable [Substitute 3 packets of artificial sweetener instead of sugar for lower carbohydrate (5 g carbohydrate)].

Will keep in refrigerator for 3 or 4 days.

Recipe from "Cooking For David: A Culinary Dialysis Cookbook", www.culinarykidneycooks.com

Bow-Tie Pasta Salad: Serves 8, 1/3 cup per serving

Ingredients:

2 cups cooked bow-tie pasta
¼ cup chopped celery
2 Tablespoons chopped green pepper
2 Tablespoons shredded carrot
2 Tablespoons minced onion
1/8 teaspoon pepper
2/3 cup mayonnaise
½ teaspoon sugar
1 Tablespoon lemon juice

Directions:

Mix pasta, celery, green pepper, carrot and onion in a bowl. In separate small bowl blend pepper, mayonnaise, sugar and lemon juice till smooth. Pour over pasta and vegetables and mix until well coated. Chill.

Renal and Renal Diabetic Exchanges:

1 Starch, 2 Fat, Calories – 189, Carbohydrates – 12 g, Protein – 2 g., Protein – 2 g., Fat – 15 g., Sodium – 111 mg, Potassium – 61 mg, Phosphorus – 31 mg.

Recipe from "Living Well on Dialysis" cookbook.