



Windows of Our World

Patient Advisory Committee

HOLIDAY EDITION

Winter 2011

Western Pacific Renal Network #17

My Shining Star Francisca C. Laniyo-Kapileo.



First, I would like to make a simple introduction of my family and myself. My name is *Francisca C. Laniyo-Kapileo*. I am from Saipan, a tiny island east of Japan. I am now 53 years old and married to my wonderful supportive husband Arnold Kapileo. We have two wonderful kids and one precious granddaughter who we call our “Shining Star”. I have been on in-center hemodialysis for over four years now and I am proud to share my story of what helped me accept the fact that I had to start dialysis. I encourage all patients that are now on board, and those who are candidates, to really try to look at the bright side of life.

In the middle of 2004 I was diagnosed with hypertension and diabetes. Ignorantly, I did not really take into consideration the advice my doctor gave me until one day in early December of 2006.

I went to the hospital for a foot sore and fearful for amputation. I quickly got rid of the salty snacks that I enjoyed so much. My doctor ordered that I stay in the hospital for observation. After my foot x-ray, I felt relieved because the infection was not as bad as we thought it was. Thankfully, amputation was no longer part of the discussion.

I spent a week in the hospital to heal my foot sore not knowing that another ailment was forming fast. I noticed that the nurses never touched my left hand. It was never used to check my blood pressure or for lab draws. When I inquired why no one ever touched my left hand, I was told it was being prepped for a fistula creation. I could not believe what I was hearing. I was completely shocked; “Me on dialysis? No way”. I stared up to the ceiling with my mouth wide open. I could not say a word. I could not believe what I was hearing. I was in such dismay. Two days after, I was sent home with the instruction from my doctor to come back after thirty days to do a follow-up on my fistula creation. I was told that I may not start dialysis right away but my doctor wanted me to be prepared. Yeah right, I did not want to show up thirty days later. I told myself, “I would rather die then to go on dialysis”.



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Seven months had passed and still I had not gone in for my follow-up. Then one day the dreadful incident happened; one I was avoiding for months, one that I thought would have never happened to me. I woke up early one morning and could not open my eyes. The whole world was spinning so fast which made me incredibly nauseated. I started throwing up practically every second. This was something I have never experienced. This was so foreign to me. My panicked husband called 911 and immediately the ambulance arrived. I was brought to the ER and the same doctor, who lectured me about the importance of my follow-up appointment for my fistula, was attending to me. He quickly examined me and ordered an IV because I was severely dehydrated from throwing up. He told me that he could not do much to help unless I agreed to go on dialysis. He said it was the only medicine for me. With my eyes still closed, I shook my head and said "no, no, no". By that time my family surrounded me. My dear granddaughter, my Shining Star, held my hand. Her soft voice trembled in fear as she asked me, "Grandma, what happened? Can you open your eyes?" I could not answer her. I felt a huge lump in my throat and I was about ready to choke. Tears started to flow down my cheeks uncontrollably. How could this be happening to me?



The doctor then informed me that if I agreed to go on dialysis, I would live more years to come and see my granddaughter grow. I was told that if I refused the treatment then I may not make it in two weeks. Without waiting for the last part of his sentence, I started nodding my head in agreement "Yes, yes, yes". Immediately I was rushed to the Intensive Care Unit for a catheter insertion. In less than ten minutes, I was on my way to the dialysis unit to start treatment. I started out with one hour the first two days, then my time was gradually increases to four hours. Now my time has been reduced to 3.5 hours. My Shining Star gives me a reason to keep on going and makes me feel so good.

I encourage everyone on dialysis to find his or her Shining Star. Someone or something that makes you look at the brighter side of life. My Shining Star got me through one of the toughest moments in my life. She is one of the reasons I smile!

WESTERN PACIFIC RENAL NETWORK # 17

Fistula First Achievement Project



You can become an "Essential Piece" by asking your physician about Arterio-Venous Fistula (AVF) placement to improve the quality of your dialysis treatments. Find out more about AV Fistula for dialysis at the Network #17 website at:

www.esrdnet17.org

Travels with Iris

By Iris A. B. Barnett

H2oFrontCL@aol.com



“I’m going to Disneyland” is what I’ve been fantasizing about saying and doing. It has been quite some time since I’ve been, long before my ESRD was diagnosed, but finally my chance has come. I know what you’re thinking; “a hemodialysis patient at Disneyland, who are you kidding?” I’m not, it was a little challenging but possible, I did it. I played with Mickey and the gang in Disneyland.

Disneyland opened July 17, 1955 in Anaheim, California. This fanfare was hosted by Ronald Reagan, Ark Linkletter and Bob Cummings. It opened with 18 attractions including the Jungle Cruise, Tomorrowland, Autopia, Mr. Toad’s Wild Ride and the Mark Twain. Sleeping Beauty Castle Walkthrough was added in 1957 and Tinker Bell’s first flight from the Matterhorn was in 1961.

Today there is so much including a “better than ever” Pirates of the Caribbean; and the most recently added Disney’s California Adventure. There is also Downtown Disney. Other amusement parks in the area are: Knott’s Berry Farm, Legoland, Magic Mountain, Universal Studios, Sea World, and Medieval Times. FYI there is a great antique shop across the street from Knott’s (a must see) and all those convenient beaches: Long Beach, Seal Beach, Huntington Beach, Newport and Laguna Beach.

Although Disney Resort is “where the magic began”, my fantasy was to ride only three attractions: the Jungle Cruise, the Pirates of the Caribbean and the Mark Twain (steam boat).

All three were exciting and much more enhanced from my memories. Other A+ attractions were the street parties, the flag ceremony and a fantastic fireworks extravaganza. Ok, what were the challenges; walking, standing in lines and setting up your treatment. Walking the 5 miles of the park was Ok, but standing in lines kills me so here are the keys to overcoming my challenges.

- ◆ **Use a travel service** to arrange your travel (ask your center’s social worker for their information).
- ◆ **Start planning early.** Contact your travel service as soon as you can supply the information of your staying place.
- ◆ **Eat well** before entering and after leaving the Park. Treat the kids to beverage breaks while in the park, it’s cheaper.
- ◆ **Go directly** to the main office after entering the gates, explain your disability needs. They will help with information so you do not have to stand in lines.
- ◆ **Rent a motorized chair** (motorized chairs are much less burdensome on loved ones).

That’s it! So when your family starts talking about going to Disneyland, tag along and relive your fantasies. You can do it!

“Writing is My Spice!”

HOLIDAY

RECIPES



**Renal
Diabetic
and
Guilt Free**

Sweet Dijon-Glazed Turkey Breast (*Recipe submitted by dietitian Maria from North Carolina)

Portions: 20

Serving size: 3 ounces

Ingredients:

- * one 5-pound turkey breast
- * 1/3 cup pineapple topping
- * 2 teaspoons Dijon-style mustard
- * 1 teaspoon lemon juice



Preparation :

1. Wash turkey breast and prepare for roasting.
2. Place in a roasting pan, breast side up; cover and bake at 350° F for 1 1/2 hours or until internal temperature is 170° using a meat thermometer.
3. In a small bowl, combine remaining ingredients and stir to blend.
4. Remove turkey breast from oven and brush glaze over top.
5. Return turkey to oven and cook uncovered for 30 minutes.
6. Remove from oven. Let turkey rest 15 minutes before slicing.

Nutrients per serving;	
Calories: 179	Protein: 24 g
Carbohydrate: 5 g	Fat: 7 g
Cholesterol: 63 mg	Sodium: 69 mg
Potassium: 253 mg	Phosphorus: 180 mg
Calcium: 18 mg	Fiber: 0 g



*Renal and Renal Diabetic Food Choices: **3 meat**

Helpful hints: Extra glaze can be served on the side as a dipping sauce. Glaze can also be used on chicken or pork chops. CKD non-dialysis: This higher protein recipe may be appropriate for your diet if the portion size is adjusted to reduce protein content. Adjustments should be based on your individual protein prescription. Check with your dietitian if you are unsure.

Easy Pumpkin Cheesecake

Portions: 8

Serving size: 1/8 pie

Ingredients:

- * One 9-inch Nabisco® 'Nilla® wafer crumb pie crust
- * 1 egg white
- * Two 8-ounce packages cream cheese, softened
- * 1/2 cup sugar
- * 1 teaspoon vanilla extract
- * 1/2 cup egg substitute
- * 1/2 cup pumpkin puree
- * 1 teaspoon pumpkin pie spice
- * 8 tablespoons Cool Whip® frozen nondairy topping



Preparation :

1. Preheat oven to 375° F. Brush pie crust with egg white and bake for 5 minutes. Reduce oven heat to 350° F.
2. Combine cream cheese, sugar and vanilla in a large bowl and beat with mixer at high speed until smooth.
3. Beat in egg substitute. Add pumpkin puree and pumpkin pie spice and blend until smooth.
4. Pour pumpkin mixture into pie shell and bake 40 to 50 minutes until center is set. Cool pie, then refrigerate.
5. Cut into 8 slices. Serve each slice with 1 tablespoon Cool Whip®.

Nutrients per serving:	
Calories: 365	Protein: 6 g
Carbohydrate: 29 g	Fat: 25 g
Cholesterol: 58 mg	Sodium: 245 mg
Potassium: 126 mg	Phosphorus: 66 mg
Calcium: 11 mg	Fiber: .7 g



*Renal and renal diabetic food choices: **2 starch, 1 milk, 3 fat, 1 high-calorie**



Holiday Punch

4 cups cranberry juice
2 cups 7 UP

Adjustment to ESRD and Dialysis

A Social Work Perspective

By Diane Ruddell

As a dialysis Social Worker, I see first-hand how starting dialysis can be a huge adjustment for patients. This adjustment takes time and means significant changes in different areas of a patient's life.

When patients first come to our clinic they often report feeling overwhelmed, anxious or depressed. The emotional adjustment to dialysis is significant and often has different stages; denial, anger, bargaining, depression and finally acceptance. The independence associated with home hemodialysis (HHD) or peritoneal dialysis (PD) is very positive for most of our patients, but can result in a patient feeling isolated. Talking with one of your peer mentors, attending a support group meeting, working with a therapist, or talking with your dialysis Social Worker and the rest of the team, are some of the ways patients cope with the emotional adjustment related to starting dialysis.

Physically our patients report feeling much better once they start dialysis. However, PD patients deal with the adjustment of having a catheter coming out of their belly, and weight gain from the calories in the dialysate used with PD. HHD patients deal with the placing of needles and being connected to a dialysis machine for many hours during a treatment.

All dialysis patients need to adjust to changes in diet. Again, seeking support thru peer mentors, support group attendance, and speaking with the treatment

team can greatly help with these concerns.

Socially, a patient may be relying on a caregiver, often a family member, to complete home treatment. This level of dependence is new for many patients and often adds stress to the relationship. In addition, for a patient that enjoys being spontaneous, particularly with travel plans, being on dialysis often requires advanced planning to ensure treatments can continue without interruption. Helping a patient



anticipate and cope with these changes in lifestyle and relationships is an important part of my role in the clinic.

Many of our patients continue to work full or part-time while on dialysis, but for others, ESRD results in a significant loss of income. I can refer patients to the department of vocational rehab to help with job re-training. I also assist with questions about insurance, and refer patients to available programs to assist with financial hardships that can arise.

Adjusting to dialysis is a complex process and different for each patient. By using available community resources, working closely with the treatment team, and being aware of the different areas of one's life dialysis impacts, can greatly help a patient have a positive and successful adjustment to dialysis.

Diane Ruddell, LCSW, is a Social Worker with WellBound in Santa Rosa, California

A Patient Perspective

By Sarah Ellsworth

What was your reaction when you learned you had ESRD (End Stage Renal Disease)? What about when you were advised you would have to go on dialysis? Perhaps you were like me--overwhelmed. You may have said to yourself--how can I do it all?! You are not alone. Many health professionals have assisted me in adjusting to my new reality. But I had to make up my mind that I could make those adjustments.

The act of will is essential!!!

So many things to consider: emotional reactions and feelings, financial implications, social involvement, physical reality and spiritual needs. That's a lot to consider!

Where to start? For me, the godsend was my dialysis facility network; my social worker, nurses and a dietician to guide me. The first thing to do was to meet with the social worker to discuss all the various issues. I also wanted to continue to work for a few more years. The emotional support for me from the social worker, the nurse and the dietician were key to a successful adjustment.

Once set up with the social worker, the next hurdle was to learn how to handle my own dialysis at home--peritoneal dialysis. Having decided this was the form of dialysis for me in order to keep working and remain as independent as possible. My nurse trained me how to do peritoneal dialysis. At first I was very nervous but soon learned how simple it really was and how much it was like a natural body process.

The physical adjustment was somewhat of a challenge but doable. When you do dialysis at home, you have to manage the medical supplies needed for dialysis and

sometimes in a space which is not ideal. Such was my situation. Living alone (with my cat) in a small one-bedroom apartment, my medical care supplier provides terrific support and delivers to me. The inconvenience is a small price to pay for the freedom and well being you may feel now, even on dialysis.

The issue of self image is one you may have to address. When you learned you had ESRD, you may have realized life would be very different now from what you experienced before. One may feel somehow "less than" one was. That is part of the change you have undergone. Some family, friends and employers, may be unsure of how you and they will be impacted. You will likely need to educate them and reassure them that you can continue as before. It is important to remember that "you are not your circumstances", as a wise counselor once told me. You now have a new challenge that will cause you to redefine yourself in some ways. Your body image may change but you will learn to overcome some self-consciousness.

If you face the challenges head on and use all the forms of support you have available, you can surmount them and come out stronger than before. Seek out the support that may be available from your social worker or spiritual adviser.

You are not alone!

Reach out and learn all that is there to help you succeed in your multiple adjustments. Realize how fortunate you are to have options available to you so you can continue to live and enjoy your future.

YOU CAN DO IT!

Be Aware Be Safe!

As a dialysis patient you can play an important role in your own safety. Form a safety partnership with your caregivers – it benefits you and it benefits your provider.

Ask Questions
Watch Your Treatments
Alert Staff to Problems
React Quickly and Calmly
Educate Yourself



Ways you can be aware of safety

Medications – Know what kinds of medicine you take and know about your dialysis prescription.



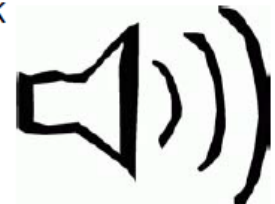
Access – Protect your arm (or where your access is).



Diet – Know what foods are good and safe for you to have. Know how much fluid is safe.



Advocacy – Speak up for yourself or ask your Social Worker to help you.



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