



Winter 2016

Renal PFAC Activities

The LHSC Patient Experience Coordinating Committee (PECC) focus on initiatives to improve patient care. The Renal PFAC participates as part of the PECC. Their approach is divided into four main categories for improvement, each of which are assigned to a Continuing Task Group.

1. Management of Change and Communication: This group will seek opportunities to involve the PECC in the planning and management of health care from the perspective of patients. Efforts include a move to entrench the PECC in the Hospital Accreditation program, a move which will ensure attention to patient interests.

2. LHSC Policies and Guidelines: The group is attempting to establish a policy to allow 24 hour visitation so patients/families become part of the health care team and more involved in care.

3. Community of Practice for Patient & Family Advisory Councils (PFAC): A number of PFAC's are now established within LHSC. This group will seek opportunities to bring the individual PFAC's together to share information on activities and promote a system wide collaboration on initiatives.

4. Physician Engagement: The clear

focus of this group is to set out a plan that continually engages physicians in a manner that promotes the work of the PECC and program specific PFAC.

The aim of the volunteer PECC is to clearly represent and reinforce the interests of patients at the planning, management, and operational levels throughout LHSC.

Council heard a summary report on the Vital Behaviours Workshops which brought together all of the staff in the Renal Program to draw attention to the feelings and interests of patients and caregivers. Each workshop included at least one family patient/family member. A document which sets out the vital behaviour commitments of program staff towards patient oriented care will serve as a continuing guide to staff at all levels for their daily patient interactions. Council heard feedback pertaining to satellite visits in Woodstock, Sarnia, Hanover, and Chatham hospitals. Janice McCallum noted that council observations from those visits will be shared with the management at these hospitals. The LHSC Renal Program Website is an excellent source of information for kidney patients and their caregivers. The site includes a separate webpage for the Renal PFAC. www.lhsc.on.ca/renal



Dear Dr. Doctor

I've been on dialysis for about a year and it's gone smoothly - - until recently. I've been feeling unwell lately and have been booked for a few tests. I'm afraid that if I wind up in hospital - - or get worse -- my family will be more worried than they already are. Is there anything I can do to ease future burdens? I've been told about the importance of having a Power of Attorney, but haven't done this because lawyers are expensive and I don't want to further stress my family.

Sincerely,

Wanting to be Prepared

Dear Prepared:

Thank you for your question; you've raised an important topic. It's important for everyone - - not just people with kidney disease - - to have a Power of Attorney (POA). There are two parts to a POA: One is for personal care, the other is for property. In Health Care, we are concerned about the personal care aspect.

A POA for personal care is a written document that identifies the person you have chosen to be your "attorney for personal care". Your attorney will act as your substitute decision maker (SDM) and make decisions about your health care if you are unable to do so yourself. You can name more than one attorney; you can also change your attorney. Similarly, the attorney can opt out should he/she feel unable to manage the responsibility.

A SDM is asked to make decisions when a person may:

- Not understand the information required to make a decision
- Not understand the consequences of making a decision
- Be too sick to make a decision

The SDM can only consent to accept or refuse a treatment plan proposed by a clinician. The healthcare team will inform the SDM when decisions are needed. Personal care decisions include matters related to health care, nutrition, housing, clothing, hygiene, and safety.

You need to prepare your SDM to speak on your behalf. They must understand what you would or would not want to do or have done. This involves some personal reflection on your behalf. Consider the following questions. Do you want to:

- Start, continue, or stop dialysis?
- Have surgery no matter what?
- Have a blood transfusion or blood product?
- Be started on a feeding tube?
- Live in a retirement home or nursing home if needed?
- Die naturally if you were to stop breathing or your heart stops?
- Go to the Intensive Care Unit and be on a breathing machine?
- Have a breathing machine turned off and have a comfortable, natural death?

These are not easy things to consider. However, your SDM's decisions must be based on your known expressed wishes from when you were capable. Talking with your SDM about these things will make it easier for him/her should he/she be called upon to speak for you.

When deciding on a SDM, consider

the following questions:

- Have I asked this person if he/she is willing?
- Have I talked with this person enough so that he/she understands my preferences, values, and goals?
- Is this person willing to follow my preferences not theirs?
- Can this person make decisions under sometimes difficult situations?

If you don't have a POA, the order of people who can make decision for you and act as a SDM is:

1. Spouse, common-law spouse, or partner
2. Parents or child over 16 years of age
3. Brother or sister
4. Other relative by marriage or adoption
5. Office of the Public Guardian and Trustee

My recommendation is to be proactive and choose your attorney for personal care. You do not need a lawyer to complete a POA. However, a lawyer can help you to complete the POA document if you wish. Your Renal Social Worker can provide you with a POA kit and other resources to help you with this process.

I know this sounds like a lot of intense work. However, being proactive and having your POA arranged can be very helpful in reducing some of the stressors that families may experience should a health crisis occur.

In Ontario, there is a Website that has Free Documents that may assist you in completing this task. They can be found at:

www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.php

Best of Luck!

TUNA FARFALLE

Preparation: 20 minutes

Cooking time: 10 minutes

Makes 4 servings

Ingredients:

2 cups dry farfalle pasta

2 tablespoons olive oil

2 garlic cloves, minced

1/4 teaspoon red chili flakes

1/4 teaspoon ground black pepper

1/2 cup artichoke hearts (packed in water), drained and diced*

2 cans (170g each) tuna (packed in water, unsalted), drained

1 cup arugula

1/2 cup parsley, washed and chopped

2 tablespoons lemon juice

1 tablespoon parmesan cheese, grated

*** Artichoke is a high potassium vegetable and should be enjoyed in moderation.**

PREPARATION

1. In a large pot, bring water to boil and cook pasta according to instructions on package.

2. Heat oil in a large skillet over medium heat. Sauté garlic with chili flakes and black pepper (2 minutes). Be careful not to burn the garlic.

3. Add artichokes, tuna, arugula, parsley, and lemon juice to skillet and cook until arugula wilts.

4. Add the pasta to the sauce and toss it.

Sprinkle the pasta with parmesan cheese and serve.



Nancy's Story



My journey with kidney failure started when I was in my early twenties when I found out I had kidney disease. At that point it meant little to me as my kidneys were still functioning well.

Fast forward to my early fifties and my creatinine levels started to climb and I was faced with choosing a form of dialysis. After studying my options I chose peritoneal dialysis. The catheter was inserted and I was trained to provide my own dialysis at home. I had hoped to continue working even though I was eligible to retire. My husband and daughter accompanied me throughout the training. I was sent home and started my dialysis. Unfortunately the next morning I noticed a crackling sound in my chest when I took a breath. Upon phoning the unit they advised me to stop dialysis and get a lung x-ray. The x-ray showed I had a hole in the lining of my lungs and that it would need to be fixed before I could continue. Faced with the reality that my kidneys would continue to get larger and larger I realized that hemodialysis was my best alternative. Retirement was a necessity as 3 trips a week to University Hospital didn't work well with teaching. This was a very low point for me as I had thought I could handle dialysis as long as I kept my independence. I had watched my Father go through this 30 years before this

and now it was my turn.

The chest tube was inserted in my chest and I started hemodialysis in June 2009 at University Hospital. I was able to move to the satellite unit in Tillsonburg in early September. While I was being assessed at Baseline for the satellite unit, one of the nurses suggested that I would be a good candidate for home hemodialysis. That was the first time someone suggested home hemodialysis to me. While I was at Tillsonburg, the nephrologist commented on the recent results concerning nocturnal hemodialysis...as it was comparable to transplant survival rates. That was very encouraging news. I went for my first visit and eventual training in October of that year. Our training in the hospital was extensive and as patients we weren't sent home until we were ready.

It was nerve racking to be on my own at home and completing my own dialysis but it was well worth it. I can't give enough praise for the nurses in Home Hemo. The nurses are not only there for our support but they are like our family. They are only a phone call away and available 24/7.

Now that I was home I could dialyze at any time of day. I was in charge of my own care. In April of 2010 I had a gortex graft inserted and I started nocturnal dialysis. I couldn't believe the difference between daily and nocturnal dialysis. My energy and appetite had returned.

I hadn't felt this good since early 2008. Nocturnal home dialysis was another adjustment but it was well worth it. I would recommend it to everyone.

In summary dialysis in centre saved my life but home dialysis gave me back my life.



ANEMIA AND CHRONIC KIDNEY DISEASE

Anemia means you have a low level of red blood cells. Red blood cells contain hemoglobin which carries oxygen throughout your body.

What are the Symptoms of Anemia?

Symptoms include: weakness, fatigue, headaches, feeling cold, and not thinking clearly.

Why do People with Chronic Kidney Disease have Anemia?

The healthy kidney makes erythropoietin (EPO). EPO stimulates the production of red blood cells. Since people with chronic kidney disease make less EPO

they will have fewer red blood cells. Normal red blood cells contain hemoglobin. Sometimes they have low levels of hemoglobin. This can happen when people have low levels of iron. Injectable forms of EPO, called Aranesp and Eprex are available for people with kidney failure.

How Can Anemia be corrected?

You must have enough iron and EPO. Without adequate iron stores in your body, EPO will not work.

How Do You Get Enough Iron for EPO to Work?

PILLS: You may need iron pills. It will take at least 6 weeks for your iron level to increase once you start taking the pills. Ferrous Gluconate, Ferrous Sulphate, and Ferrous Fumarate are names of iron supplements.

Do not take your iron pill and phosphate binder at the same time. If you do, the phosphate binders will bind to the iron and, as a result, neither will work. You should take your phosphate binders with each meal, and you may take your iron pills at bedtime.

The main side effect of iron pills is constipation - if you become constipated report this to your clinic or dialysis nurse. Green or black stool is common when taking iron pills.

INTRAVENOUS (IV) IRON: Sometimes pills are not enough to increase iron stores. People on hemodialysis often receive iron IV during their treatments.

If you are in the pre-dialysis clinic or on Peritoneal Dialysis, and need IV iron, special arrangements can be made for you to receive it.

When will You Start Aranesp or Eprex (EPO Injections)?

You will start Aranesp or Eprex if you have low hemoglobin and your iron stores are adequate.

If you are a pre-dialysis, or home dialysis patient Aranesp or Eprex is given by a needle under the skin.

Hemodialysis patients receive Aranesp or Eprex intravenously through the hemodialysis machine.

How Soon after Starting Aranesp or Eprex will You Start to Feel Less Tired?

It usually takes 1 to 2 months before you will start to feel less tired.



Kidney Pie?

The LHSC Renal Program is Looking for Patient & Family Storytellers

Every patient and family has a story to tell. Your stories, opinions and impressions from your health care journey are invaluable to us as we strive to foster patient and family-centred care and improve the overall patient and family experience.

Through the sharing of your healthcare journey, you can offer valuable insight on what the Renal Program does well, and where we can make improvements. The Renal Program will offer support for you to develop your storytelling skills in a compassionate and safe environment that is open to sharing and learning.

If you have any questions or are interested in signing up please contact:

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