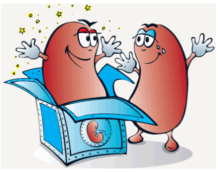
Kidney Kronicle



Fall 2015

Introduction From The Chair

On behalf of the members of the Patient and Family Advisory Council I wish to extend our hope that all our fellow renal patients and the staff of the renal program will have an opportunity to enjoy the season. Since we will soon be into a new year, let us hope that it will be a good year for all of us.

This has been a busy year for the Council and I would particularly like to thank the members of staff who have worked so closely with us.

George Goodlet

Chair, PFAC.

Dear Dr.Doctor:

I have just started hemodialysis and have to travel 3 hours to and from dialysis. I'm finding the travel really tough. I spend my off days recovering only to jump in the car to do it all over again. Can anything be done to make life easier?

Signed,

Already Tired of Driving!

Dear Tired of Driving:

Thanks for asking this question. Many people find the dialysis commute taxing. Dialysis has a huge impact on peoples' lives; so choosing a type of dialysis that fits your lifestyle and enhances your quality of life is pivotal.

Are you aware that you could possibly dialyze at home on either hemodialysis or peritoneal dialysis? People who choose to dialyze at home report having more control over their lives and feeling well. It's not unusual for people to be nervous when the prospect of dialyzing at home is presented. Please keep an open mind and not let your concerns keep you from looking at this as a possible option. Get the facts to help you make a sound decision. Ask your dialysis team for more information. Carolyn Ingram (the Nurse Case Manager for Independent Dialysis) can meet with you to provide information, clarify any misconceptions, and address any specific questions or concerns you might have. Arrangements can also be made for you to talk with people who are on home dialysis.

If you decide that home dialysis is not the route you want to go, we have eight satellite dialysis units across Southwestern Ontario.

It's important to note that dialyzing in a satellite unit is a bit different than in the UH or Victoria hospital dialysis units. An individual needs to have stable dialysis treatments; be able to dialyze in a chair (as most of the satellites do not have space for beds); and transfer in and out of the dialysis chair with minimal assistance. Also, there is not a dialysis nurse practitioner (NP) or nephrologist on site to address concerns. The nephrologists and NPs conduct clinics in the satellite units once a month.

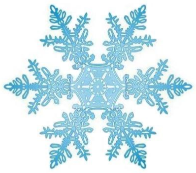
You also need to know that there is a waiting list for each of the satellite units. An individual's place on the list is based on the date of his/her first dialysis as an outpatient. The lengths of the lists vary according to the size of the satellite and the number of people waiting for a spot in that unit. Unfortunately there is no predicting how long someone will have to wait to transfer to a satellite.

If you opt to go on a satellite wait list, you might consider talking with your renal social worker. There are agencies that assist with transportation to and from dialysis. Your social worker can help you explore these resources and discuss the cost of using these supports.

Hopefully your question has been answered. Remember that your team is here to support you in whatever choice you make for yourself.

Best of luck.

Douglas Michael Smith's Story Part 2



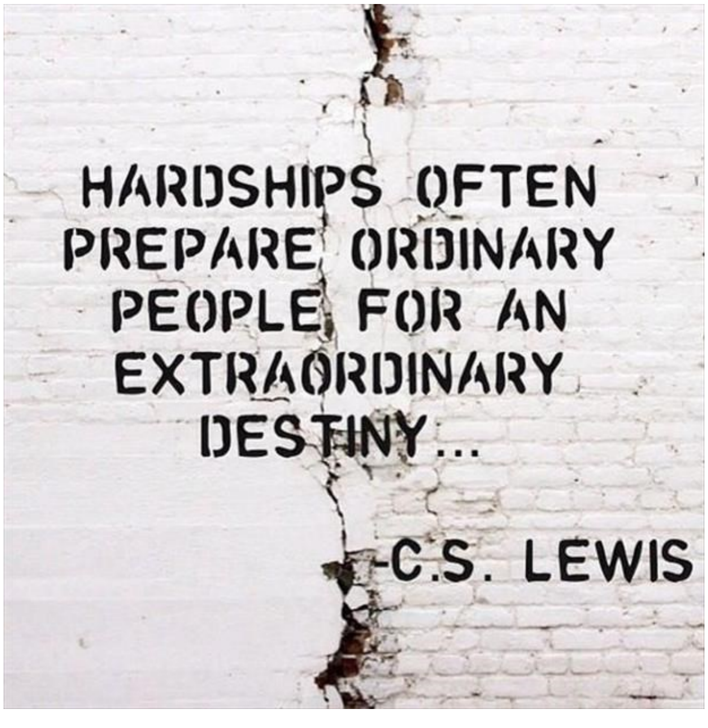
I got another transplant in 2012 and from day one there were complications. It was a huge back and forth struggle the whole time. Due to the nature of my disease, it is difficult to detect the signs that something is wrong. It was like a lottery every time I had to go for monthly blood work. Those were always the worst days, as I sat in the office alone, waiting to hear what the doctor would say. The doctors and staff were always sympathetic with me as they would explain to me what was going on. As well, they always had a plan on how to stop the rejection. I received Plasmapheresis a few times among other procedures. In the end, I lost my kidney in April 2014 and started dialysis at the LHSC. Unfortunately, because of plasma exchange through my fistula it clotted solid even when they would try to clean out the clots. I know I heard the doctors when they told me the risks of doing plasma exchange, but if I had known what I know now, I would have never undergone the plasma exchange, because now I am stuck with catheters.

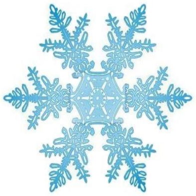
I've had so many catheters that I now have severe stenosis in my veins in my chest. Also the only place left to do a fistula is my leg. At this time I feel like a leg fistula is not an option, only because of the risks. I have other options for catheters still but am working hard to keep the line alive.

I feel that in order to give myself the best care possible I have paid attention over the years, followed my fluid restrictions closely, and my diet now is like second nature. I don't even think about it now. I just know what to stay away from and what I can eat. Staying on top of my fluid restrictions has helped my dialysis experience. I feel better and find that I am not so restricted from activities and work compared to when I first started and would go to dialysis with 4 or 5 kilos of fluid. I understand these are big changes in life but that is what dialysis is about. Trying to give people their lives back even though it takes a lot of time out of our days.

I have been on dialysis a total of 15 years, with two, three month breaks, and I can proudly say I have never missed my four hour treatment. I feel as if I am in the most control now of my health than I have ever been. I thank the doctors and nursing staff for being positive in the worst of times and my mom for showing me that I can still have a normal life, no matter what the odds. I cannot stress enough that being knowledgeable about my health has given me not only a better understanding of my illness, but has given me the confidence to ask those tough questions that need to be asked.

We all have to remember that doctors and nurses, even though they have years of school and great knowledge, are still compassionate and caring people behind it all and are here to help. There is no such thing as a wrong question; you won't know unless you ask. I don't look at my illness as something holding me back. I look at it as something I had to go through in order to show other people that it's not that bad, not to give up and to try and stay positive even in the toughest times. We are all good people under bad circumstances. I just want to make the best of what I have, don't you? Keep smiling, it will get better! We can all live normal lives. But it's our normal.





ROASTED RED PEPPER SOUP

Preparation: 20 minutes
Cooking time: 30 minutes
Makes 6 servings
Ingredients
3 whole red peppers, washed*
1 tablespoon olive oil
2 garlic cloves, minced
1/2 cup onion, chopped
1/8 teaspoon cayenne pepper
3 cups no salt added chicken broth
1 tablespoon lemon juice
1 tablespoon fresh or dried marjoram, chopped
1 tablespoon fresh or dried oregano, chopped
* To save time, you can use roasted red peppers from a jar.

PREPARATION

1. Preheat oven to 450°F or medium broil (conventional oven).
2. Place red peppers on baking sheet and broil on top shelf, turning if necessary, until the entire skin has turned black and blistery (20 minutes).
3. For removal of the skin: place roasted red peppers in a bowl and cover with plastic wrap. Once the peppers have cooled, proceed with skin removal: remove stems, cut pepper lengthwise in 4 slices, remove the seeds and peel off the skin.
4. Heat oil in saucepan over medium-high heat. Sauté garlic and onions until onions soften (5 minutes). Add roasted red peppers, cayenne pepper, and chicken broth to pan. Bring to a boil, close lid and simmer for 10 minutes.
5. Add lemon juice, marjoram, oregano and mix with a blender.

Count 1 serving (1/6 of recipe) in your meal plan as:
1 Fruits & Vegetable

Peer Support Survey

How Do You Connect ?

CCO Ontario Renal Network

The Kidney Foundation of Canada and the Ontario Renal Network are working jointly to evaluate peer support needs amongst people affected by kidney disease as well as understand the awareness, access, uptake, and sustainability of The Kidney Foundation of Canada Peer Support Program. Completed surveys will be used for the purpose of evaluating The Kidney Foundation Peer Support Program.

We need your help by completing a survey (takes up to 10 minutes to complete). Please go to: **https://cco.fluidsurveys.com/s/peer/** to complete the survey online.
If you have any questions or would like a paper copy of the survey please contact **Carolyn Ingram (519-685-8500 ext. 75606) or Daniela Marghella (519 -685-8500 ext. 75979)**

Satellite Unit Visits

The Renal PFAC has visited several of the LHSC satellite hemodialysis units, including Woodstock, Sarnia, Hanover and Chatham. We have been on a mission to meet hemodialysis, PD, and home hemodialysis patients, to promote the PFAC, and to gather feedback from patients who live outside of London. We want to know the issues patients who have treatment in their own community face that might be different from patients who live in London. We have heard from a lot from patients about problems associated with travelling for their medical care, including dialysis and clinic appointments in their own community, or in London. We have also heard about problems with the cost of parking at their local dialysis units. Some patients expressed an interest in having “virtual” clinics where they would meet their doctor for an appointment over the internet instead of travelling all the way to London. We want to hear from all renal patients at LHSC so that we can we can make recommendations to the program to improve your care. We plan to visit Tillsonburg, Owen Sound, Stratford and Goderich in early 2016. We’re looking forward to meeting you!

RENAL PATIENT FAMILY ADVISORY COUNCIL ACTIVITIES

Regular monthly meetings of Council resumed in September after a summer break.

Representatives from Baxter Canada presented "A Dialysis Snapshot," a patient education tool for dialysis patients at the November Council meeting. This reference guide is a strong complement to in house training and education and is available online at **www.kidneycampus.ca**.

Council members attended the launch of the Ontario Renal Plan II which sets out specific goals and a work plan for delivery of renal services in Ontario through 2019. Regional representation for this plan is being provided by Janice McCallum, Regional Director and Dr. Norman Muirhead, Regional Medical Lead. The plan emphasizes support for patients and family members to enable them to take a more active role in their care. The Ontario Renal Network published a pamphlet which outlines the plan and it is available online at **www.renalnetwork.on.ca**.

The Transportation Task Group will conduct a more in-depth survey of patients using transportation services to and from the clinics and satellite units. A clearer picture of conditions is needed to draw attention to transportation issues and work out solutions where possible. Patients who require transportation services are encouraged to respond to the surveys which will be circulated in the units shortly.

Home hemo-dialysis patients experience increased costs pertaining to utility services directly related to operating the home hemo-dialysis equipment. In a small number of cases the additional costs present a financial hardship to the patients and their families. Council, working with the Social Work team, is reviewing this matter and will work with senior program managers to seek relief for these increased costs where required.

The Resource Task Group recently submitted a proposal to program management for the creation of patient information kiosks at the Kidney Care Clinic and at units housed in the University and Victoria Hospital campuses. Arrangements to post the patient information in the satellite units are currently being established as an addition to facilities currently in place. The kiosk to be located at the Kidney Care Clinic will include a suggestion box for patient comments and suggestions.

Submitted by Fred McInnis, Vice Chair

Don't worry, I'll find a good site soon.

renal P.F.A.C.
PATIENT & FAMILY ADVISORY COUNCIL
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www.lhsc.on.ca/renal

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