Kidney  Kronicle

Fall 2014

Introduction from the Chair

Patients and medical staff are both involved in treatment but how they look at the treatment experience is completely different. Since patients know best what it is like to be patients, they must be involved in attempts to improve the treatment experience. In kidney care, this has been recognised by the London Health Sciences Centre by setting up the Renal Patient and Family Advisory Council to advise on changes which may need to be made to the Renal Program.

The Council represents all patients, and their families, at any stage of the kidney program so this is very much your Council. There are staff members on the Council who care very much about how patients experience the program and their input is essential. However, because the aim of the Council is to express the views of patients, there will always be more patients than staff on the Council.

The Council will be looking for input from patients. Please respond to any request for information. You will also be able to bring to the Council any concerns or suggestions you may have. We want to know what you like about the program and what you think could be improved.

This is the first newsletter from the Renal Patient and Family Advisory Council. It won't be the last. You will be hearing much more from the Council in the future.

George R. Goodlet

Chair, Renal Patient and Family Advisory Council

Dear Dr. Doctor:

My scheduled appointment time says one thing, but it's usually 2 hours later when I finally see him. I know that he is a very busy man, and has many patients to care for. My question for you is, what can I do, or how can I prepare for appointments so that I can be a better patient, and take up less of my time, and his at appointments?"

Signed, "A concerned patient"

Dear Concerned Patient,

This is an outstanding question. As a kidney doctor myself, I have been definitely guilty of this in the past, although I have adopted certain strategies to try and minimize wait times.

This is usually not primarily a patient issue and the following explains some of the reasons: patients are often double and triple booked into clinics in order to deal with increased patient loads; booked meetings or procedures occasionally go overtime and physicians are guilty of starting clinics later than scheduled; we rely on bloodwork results to determine the status of the patient's kidney function, and it can take 2 hours to get results. As physicians and healthcare providers, we need to do the following to try and help minimize the wait times:

1. Ask the clerical staff to audit wait times for patients. By doing these audits, we can find out why these de lays are happening and start strategies to prevent these delays.
2. Start clinics on time and establish best practice patterns with your clinic staff that ensure patients are promptly first assessed by a nurse for a brief history, and for a check of their heart rate, blood pressure and temperature. This information will help the physician do a more efficient assessment.
3. Consider allowing the patient to do the bloodwork at their own lab a week before the appointment so that they do not have to arrive early to have these tests done and then wait for the results to come back.
4. Consider opening clinics on week ends and evenings so that patients do not have to miss work.

Of course, sometimes delays are not preventable, especially if one patient becomes very unwell and needs prolonged attention but in my opinion, these delays should be very occasional and not as frequent as they are.

Can patients help with the efficiency of the process? Absolutely! My favourite patients are those that take control over their own health by doing the following:

1. Bringing a complete and up to date medication list. This helps prevent medication errors.
2. Check their blood pressures at home and bring a report of the readings.
3. Diabetic patients bring their sugar check results.
4. Bring a list of questions that they need addressed.

I am confident that nurses, doctors, clerical staff and patients can work together to do more to minimize wait times for all of our patients.

Sincerely,

Dr. Faisal "King" Rehman

Send questions for Dr. Rehman to

renaladvisor@lhsc.on.ca.

Hypertension: Blood Pressure Control

Did you know that high blood pressure (also called hypertension, HTN) and kidney disease are closely related? In fact, kidney disease caused by high blood pressure is the leading cause of kidney failure. The kidney produces a hormone called renin, which helps control blood pressure, but in a damaged kidney this hormone is not produced properly. HTN also damages the small blood vessels which deliver blood to the kidneys' filters. Over time, this decreases the flow of blood through the kidneys, causing progressive renal insufficiency. Uncontrolled HTN can cause heart attacks and strokes, which are the major causes of death in patients with kidney disease.

High blood pressure is not diagnosed with one reading, but by monitoring blood pressure readings over time. The cause of HTN is not always known, but can include diabetics, overweight individuals, those who eat a lot of salt and those with a family history, among other reasons. HTN is often called a silent disease, since many people do not experience any symptoms. If HTN has done damage, some symptoms can include headache, chest pain, shortness of breath and nose bleeds.

If you are a renal patient, it is important to monitor and record your blood pressure readings at home, and share them with your doctors. Tips for taking your blood pressure at home include using equipment that is regularly calibrated and checked for accuracy, to take your blood pressure on a bare arm, wait for at least five minutes before taking your blood pressure, and to wait at least 3 hours after strenuous activity before taking your blood pressure.

Controlling your blood pressure by altering your lifestyle and/or taking medications can reduce risk to the heart, brain and kidneys, and can slow the progression of renal failure. You can do this by eating a healthy diet, with reduced salt intake. Stop smoking, and avoid excessive alcohol intake. Exercise on a regular basis, and if you are overweight, lose weight. If you do require blood pressure medications, take them as directed, and let your doctors know.

If you are a hemodialysis patient, it is not unusual for your blood pressure to be high at the beginning of dialysis, since you have had fluid building for several days. As fluid is removed the blood pressure typically decreases but if there is a large amount of fluid to be removed your body may not tolerate it. If your fluid gains are not consistently removed, you may get fluid overloaded, which over time can strain your heart as well. To help control blood pressure, try to limit fluid gains to 1.5 to 2kg over a two day period, and no more than 3kg over a three day period. Your blood pressure medications will be assessed by your kidney doctor, and often can be decreased or stopped once you start hemodialysis. In many cases, home hemodialysis patients are able to eliminate all of their blood pressure medications, since they are being dialyzed more often, have better creatinine clearance and have better fluid control.

Your kidney care team can provide information and medication to help control your blood pressure, but it is up to you to take responsibility for managing your blood pressure.

From: Nephrology Teaching Manual. London Health Sciences Centre. 2004.

Submitted By Angela Andrews

NIKKI ANDERSON

MY RENAL STORY

PART ONE

I guess I have been sick for as long as I can remember. I was in and out of the doctor's office and put on anti-biotics every time. It wasn't until I was nine that the doctor found more wrong than just bladder infections. He referred me to a specialist, Dr. Shepard who put me through a battery of test. The drinks I had to endure back then were the worst tasting stuff I have ever had (and they do taste better now). The pain and the torment of everything I was put through and being scared of what was happening was overwhelming. I did have good family support and that helped a lot.

Finally the entire battery of tests was done and Dr. Shepard told us I had 'refluxing', requiring surgery with no guarantee that it would work or last. Refluxing is where the tubes from the kidney into the bladder are too short and some of the fluid returns to the kidneys, causing the damage to my kidneys. By the time surgery came around my kidney function was 70% and 30%.

The day before surgery I was brought to the old children's hospital in London to be prepped for the next day. To get to surgery from the children's hospital I had to travel under the street to the Old Vic. This

was a damp ride with drips of water that would land on you. I was terrified of being put to sleep and being cut open.

This surgery lasted about two years then I found out that my kidneys were done for good. Then dialysis started.

I was eleven years old when I started on dialysis at the Old Vic. Back then I had what was called a subclavian put in my shoulder on the left side. I had this in for only a very short time before it got infected. My temperature was so high that I nearly died. Once they got my temperature down they went ahead and used my fistula prematurely just so that I could have dialysis. The first time I had a needle put in I screamed, it hurt so bad. Back then they didn't use numbing agents to freeze your skin beforehand.

I was on dialysis for only about a year, before my mother gave me a kidney, I was twelve by now.

Continued in the next issue.

Council Activities to Date

Developed a mandate and terms of reference for Council.

Prepared a letter, to be issued shortly, to patients across the kidney care program which outlines Council's mandate and service intentions.

Prepared a poster, available at all patient service facilities, which illustrates the structure and purpose of the Renal Patient and Family Advisory Council.

Conducted small scale surveys of patients presently served by the Kidney Care Centre in the in-house dialysis and home hemodialysis units, seeking suggestions to improve patient experience. These surveys are ongoing and will expand to remaining areas in due course.

Participation of Council representatives in an open house at the Kidney Care Centre.

Promoted large print, name tags to be worn by all medical staff in the patient service areas. This move which is currently being implemented will ensure patients know who is serving them at all times and locations.

Listened to "stories" from patient members of council. The stories revealed issues from patient experience such as transportation wait times, and ways to break the boredom factor associated with dialysis. Council's intention is to expand story-telling opportunities to the general patient population.

Council was represented at the annual Kidney Foundation Walk in Springbank Park.

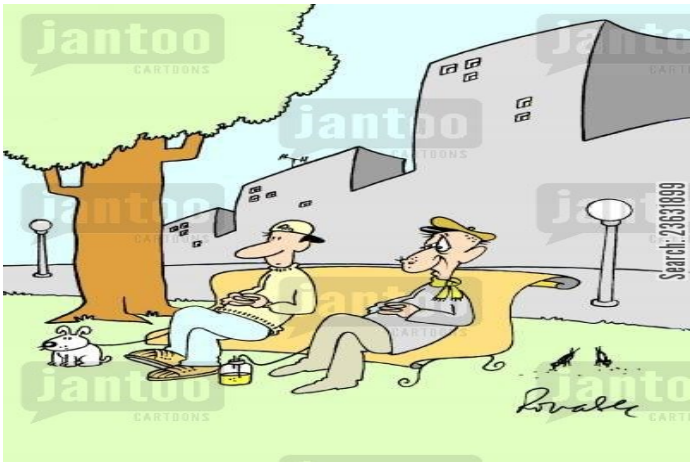
The ongoing agenda for Council will focus on ways to improve patient experience recognizing, as well, the importance of inclusion for care-givers who serve a vital role in patient care.

Submitted by Fred McInnis, Vice-chairperson of the RPFAC

A Joke for the Fall Issue

Two older men were sitting in the nephrologist office. One man turns and says, just when we get used to taking everything with a grain of salt, they put us on a salt free diet.

Submitted by Paul Dixon



Have you experienced difficulties with travel? Submitted by Michael Hermiston.

The Renal Patient and Family Advisory Council is seeking information about problems experienced with respect to transportation, especially to and from dialysis. If you have experiences we would be more than happy to hear them. We are hoping to assist with negotiating more consistent service from the service providers.

To tell your story, contact Angela Andrews at renaladvisor@lhsc.on.ca or call her at 519-685-8500, ext. 34411.

Honey-Ginger Crackles

Ingredients (21/2 Dozen Cookies)

3/4 cup shortening
1 cup granulated sugar
1 egg
1/4 cup honey
2 cups all-purpose flour
2 teaspoons baking soda
2 1/2 teaspoons ground ginger
1 1/4 teaspoons cinnamon
1 teaspoon ground cloves
granulated sugar for coating

Preparation

Preheat oven to 325° F (conventional oven).

Cream together wet ingredients in one bowl.

Prepare dry ingredients by sifting flour with soda and spices in a second bowl.

Blend dry ingredients into wet and mix thoroughly yet quickly.

Drop in heaping tablespoons into granulated sugar, roll into balls and place on greased cookie sheet or on parchment paper, 2 inches apart.

Bake 8 to 10 minutes in the middle of the oven, remove and cool on tray before transferring to rack.

renal P.F.A.C.
PATIENT & FAMILY ADVISORY COUNCIL
PATIENT | FAMILY | HEALTH TEAM

Michael Hermiston: Editor

Nikki Anderson: Newsletter Design & Production