Transplant Digest

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ST. MICHAEL'S
UNITY HEALTH TORONTO

My Kidney Journey: From Diagnosis to Transplant and Beyond

Bob Sanders

Every kidney patient journey is unique. Mine began in 2010 with a viral infection that damaged my kidneys. As my kidney function declined over the next eight years, I educated myself about dialysis and transplants - that ultimately led to a life-changing kidney transplant nearly two years ago, at age 72.

Before Dialysis: A Hopeful Start

I initially hoped to avoid dialysis through a pre-emptive transplant, and my sister generously offered her kidney. We were a perfect match, but her kidney function narrowly missed St. Mike's criteria. Although disappointed, the silver lining was that my transplant workup was already complete - saving valuable time down the road.

Dialysis: A Steady Routine

By 2019, I began peritoneal dialysis (PD), which I could do at home with minimal disruption to my daily life. For someone with blood Type O, I faced a 4 to 6 year wait for a transplant, but PD served me well for 4 years, 7 months, and 3 days.

A New Option: Kidney Paired Donation

The Kidney Paired Donation (KPD) program connects willing but incompatible donor-recipient pairs, allowing them to "swap" kidneys anonymously within a group. Dr. Prasad told me about a unique situation - a donor in one chain remained unmatched, and I was the compatible recipient near the top of the waitlist. I joined the chain, receiving a kidney from a living donor - an option known for lower rejection rates and longer survival.

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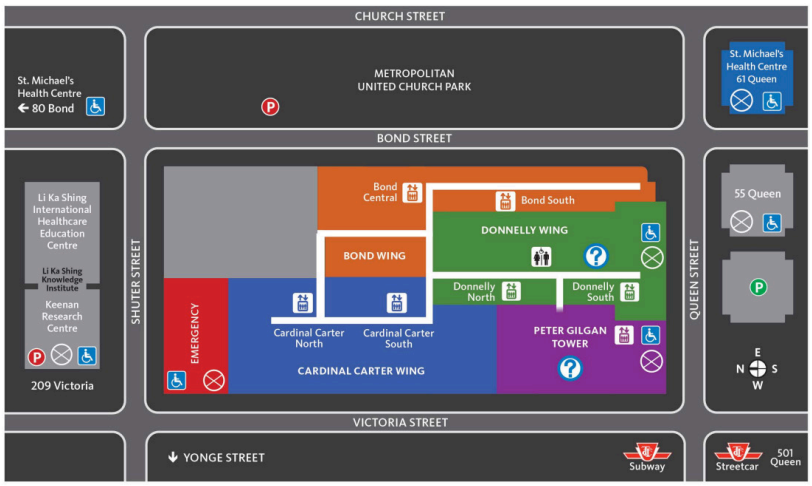
In this issue...

From the Editor's Desk

Dr. Ramesh Prasad

Welcome to the Fall 2025 edition of Transplant Digest. I hope you had a pleasant and enjoyable spring and summer. The weather this year was indeed exceptional. There were many sunny days, and there was also just enough rain to keep everything green and looking fresh. There was little humidity, so not much sweating either. It doesn't get better than this, anywhere in the world. It does not even seem as if summer is over yet! But we are officially in the autumn, the leaves have started to change color, and it is only a matter of time before they fall and winter is upon us. I hope you have been able to do all the things you wanted to do, things that your kidney transplant has now made possible. I wish for you to enjoy every minute of these golden years of your life.

In this issue, we cover diverse topics such as generic medications, education needs, personal hygiene, treatment of abnormal cholesterol, healthy eating, urgent care, and serious complications of kidney transplantation such as avascular necrosis and post-transplant lymphoproliferative disorder. We have a detailed account of the experiences of one of our recent transplant recipients. As always, please do not hesitate to ask questions about these articles or anything else about kidney transplantation in general, or contribute an article to Transplant Digest yourself. It will almost certainly be published.



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Please send your comments or suggestions of topics for future publications to:

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Disclaimer Note:
Views presented in this newsletter are those of the writers and do not necessarily reflect those of St. Michael's Hospital or the University of Toronto. Subject matter should not be construed as specific medical advice and may not be relevant. For all questions related to your health please contact your health provider.

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Transplant Surgery and Recovery

In early 2024, Dr. Ordon and his team performed my transplant. My hospital recovery lasted six days. I was walking with assistance by Day 2, managing my medications with a visual checklist by Day 3, and walking the halls by Day 4. Post-discharge, my creatinine levels dropped below what they were 15 years ago. I'm deeply grateful to the nurses and doctors who supported me every step of the way. I'll never know who my donor was, but I wrote an anonymous letter of gratitude.

Life After Transplant

Initially, I visited the Post-Transplant Clinic frequently, meeting with a nurse, doctor, dietician, and social worker. After six weeks the stent placed in my new ureter to allow its connection to my bladder to heal was removed. Clinic visits gradually tapered. After six months, blood work was needed every two weeks, and clinic visits every three months. After two years, I will get blood work every three months and see the clinic annually. I'll be on three anti-rejection drugs for life, suppressing my immune system and making me more susceptible to infections and skin cancer from sun exposure. To stay safe, I wear a mask in crowded places, use sunscreen and a hat outdoors, and keep up with my COVID and flu vaccines. Live-virus vaccines are off-limits, so I always consult my family physician first. I did lose muscle mass after surgery, but with effort, I regained my strength and stamina.

Giving Back

Today, I'm thriving - free from dialysis and enjoying dinners with family, theatre outings with my wife, swimming with grandkids, and doing cottage chores.

I've also joined the volunteer Nephrology PFAC (Patient-Family Advisory Council) at my local hospital and the Transplant Ambassador Program (TAP), a peer support group of kidney transplant recipients or living donors. You can find TAP volunteers at transplantambassadors.ca, or reach me directly at bobs@transplantambassadors.ca and I would be pleased to share more details of my journey.

Stay strong, and stay positive!

Congratulations to Dr. Ramesh Prasad, Director of Transplantation for receiving the 2024-2025 Mitch Halperin Faculty Award for Excellence in Teaching from the University of Toronto. Dr. Prasad is seen here with Dr. Ron Wald, Director of Dialysis, who received the Excellence in Mentorship Award. Dr. Prasad said this is his first ever professional award since starting medical school in 1985.

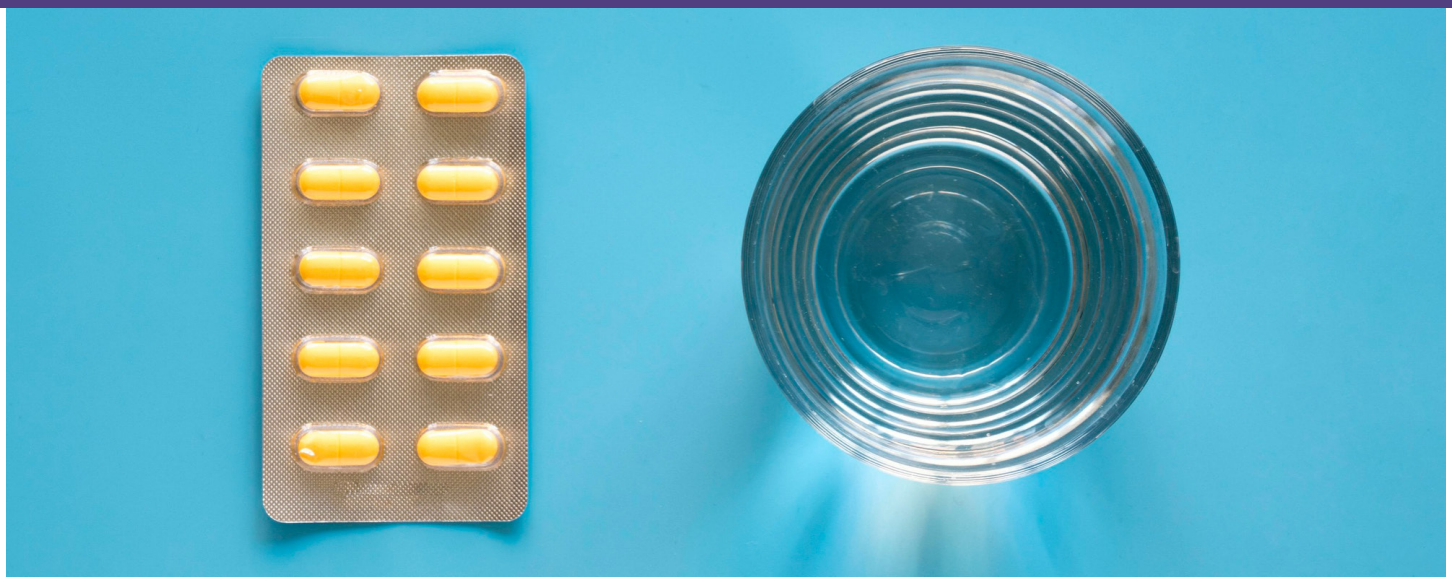
Avascular Necrosis

Dr. Ramesh Prasad

Avascular necrosis (AVN), otherwise called osteonecrosis, is a disease that results from loss of the bone's blood supply. When blood supply drops, bone tissue dies and the bone then collapses. If AVN happens near a joint, the joint surface can collapse as well. The hip, ankle, jaw, shoulder, and knee are common places to get AVN, although the head of the thigh bone is the most common. Kidney transplant recipients are at higher risk, especially if they take prednisone as an immunosuppressive medication. Other risk factors include osteoporosis, diabetes, lupus, sickle cell disease, smoking, alcohol use, and radiation therapy. Fortunately, your risk of AVN is under 1 percent unless the process began before your transplant. If you had AVN already, there is a 50 percent chance of it also affecting another part of your body.

Common symptoms of avascular necrosis include pain, especially with weight bearing or pressure, stiffness, and limited movement around the joint. In severe cases, limping and difficulty walking are common. Cold and hot treatment, as well as physical therapy can help relieve some symptoms. Unfortunately, avascular necrosis can progress. You should avoid non-steroidal drugs NSAIDs because of your kidney transplant. One treatment is to make small surgical cuts into the bone to increase its blood supply. Your orthopedic surgeon might also suggest a bone graft or joint replacement.

You might develop bone pain that is not related to AVN. Drugs like cyclosporine and tacrolimus can sometimes constrict the blood vessels to your bone, especially if you also have high blood pressure. An MRI scan will show bone edema. The condition can be treated with calcium channel blocker antihypertensive medications.



Generic Medications

You have probably heard of the term “generic” medication at some point, even before you received your kidney transplant. All medications are known by two names: a generic name and a brand name. It can be confusing when medical staff use these names interchangeably, but since we won’t change, you must learn both names!

Whenever a company develops a new drug after research and rigorous testing, it holds exclusive rights to make and sell that drug for a certain number of years. When that protected time ends, other companies are allowed to start making and selling generic versions of the medicine. Generics are usually cheaper than the brand name drug. In this case, the cheaper price doesn’t mean a cheaper quality. Health authorities set strict requirements for generic medicines before they can be sold in pharmacies. First, the generic medicine must contain the exact same active ingredient in the exact same dosage as the original. Second, the generic medicine must reach similar levels (such as between 80 and 120 percent) within the bloodstream or tissues as the original. Generic medicines are cheaper because manufacturers do not invest money in researching and inventing new medicines, but can employ established methods.

However, there are some important differences as well. Generics do not always contain the same filler ingredients as the original. If you are sensitive to a particular filler ingredient, you may not tolerate some generic medications. Generic medications also usually look different from the original brand name product. This can seem alarming when you are suddenly dispensed a generic at your pharmacy.

Although generic medicines reach similar levels within the body as the original, even small differences can have a big impact when it comes to antirejection medications. This is especially true for medicines that require you to get the levels checked in your blood. Your jurisdiction may or may not permit generics for these medications, but you need to know the policy of your specific transplant. You should not go back and forth between branded and generic formulations. If you take a generic medicine, it is best to stick with the same one, if possible. Unfortunately, companies that make generic medications may suddenly decide to stop manufacturing a particular medication if it is no longer profitable for them.

Healthy Eating: Fats in the Diet

Katie Poolman, RD CDE

Part of eating well after kidney transplant includes eating a heart-healthy diet. This includes eating a balance of the right types of fats. You may have heard the terms “good fats” and “bad fats.” Let’s have a look at the different kinds of fat in your diet, and how to fit them into a healthy eating pattern.

Saturated fats:

Saturated fats should be limited in your diet. Most people should aim for about 12-15 g per day. Eating too much saturated fat can raise your LDL (“bad”) cholesterol, which increases the risk of heart disease. Saturated fats are found in high-fat meat, high-fat dairy like butter, ghee, and cheese, baked goods, and coconut oil.

Trans fats:

Trans fats should be avoided as much as possible. These fats are found in packaged baked goods, fried foods, hard stick margarine, and some processed snacks. Trans fats raise LDL cholesterol and lower HDL (or “good”) cholesterol.

Unsaturated fats:

Unsaturated fats should be the majority of fats you eat in your diet. These types of fats are found in olive oil, canola oil, fish, nuts, seeds, and avocado. Unsaturated fats help lower the risk of heart disease.

Omega-3 fats:

Most people don’t get enough omega-3 fats. These essential fats support heart and brain health. The best sources are oily fish like salmon, trout, mackerel, sardines, and haddock. You can get smaller amounts of omega-3 fats from some plant foods, like walnuts, flax seed, canola oil, and soy products.

Tips for getting more healthy fats in your diet:

- Cook with olive or canola oil instead of butter.
- Choose lower-fat dairy options like 0%, 1%, or 2% milk and yogurt. Look for cheese with less than 20% milk fat (labeled as M.F. on the front of the package).
- Eat a serving of oily fish twice a week.
- Have a handful of nuts as a daily snack.
- Check your food labels. Look for foods with less saturated fat and 0 grams trans fat.

Personal Hygiene

Washing hands is a crucial part of your personal hygiene. You should always wash your hands:

- before preparing or eating food, or touching your mouth, nose, or eyes
- after touching or cleaning up after animals, handling soil, changing diapers, or touching your body fluids and genitals

Always keep some hand sanitizer within easy access.

Many people are wearing masks these days. The COVID-19 pandemic taught us how easily infections can spread from one person to another. Masks help prevent spread of fluid droplets from person to person. During the pandemic, many kidney transplant recipients were infected with COVID-19, and unfortunately some died. Although the pandemic has declined, many people still worry about getting an infection when they are in public. Some kidney transplant recipients choose to continue wearing masks, and that's perfectly fine. Hospitals may have different policies about using masks. If you feel comfortable wearing a mask at all times in public, please continue to do so. However, also keep in mind that you are not immunosuppressed to the point where you are going to catch every infection that is going around. In other words, wearing a mask in public is not absolutely necessary. Be careful, of course, and stay away from people who are obviously sick. At public gatherings such as resections, weddings, and other big parties, you are actually more likely to get an infection at the buffet table. Be aware of fresh waves of existing or new pandemics, and be especially cautious during those times. You can certainly take public transit if it is convenient for getting to your medical appointments.

When it comes to fluids, you can drink bottled water if it makes you feel more comfortable. Boiled water is the safest to drink, but it is not always practical. However, if the tap water is safe in your area, there is no reason not to drink it regularly, use it for cooking and washing, and any other purpose.

Post-Transplant Lymphoproliferative Disorder

Dr. Ramesh Prasad

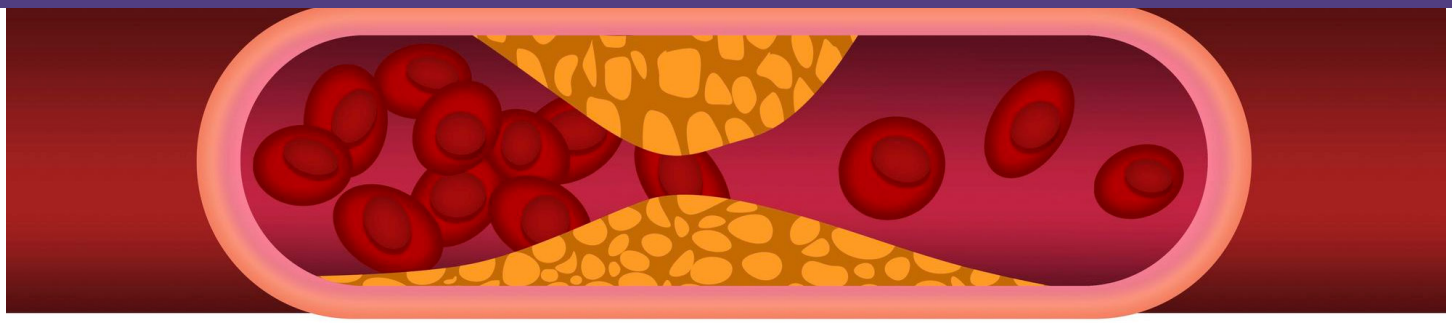
Epstein-Barr virus (EBV) is a DNA herpesvirus like cytomegaolovirus, or CMV. The virus spreads by intimate contact. The spreader usually does not have any symptoms. EBV causes "mono" or infectious mononucleosis (IM) in teenagers and young adults when saliva is exchanged. Once acquired, the virus remains dormant in the body for life. About 98 percent of people are positive for EBV antibodies. EBV is a trickier virus than CMV. When EBV reactivates, it can cause a variety of cancers, including lymphomas and carcinomas. EBV is commonly transmitted among teenagers, through exchange of saliva. EBV antibodies, like CMV antibodies, stay in your body for life. Although only 50 percent of people develop any kind of symptoms, more than 90 percent of all adults have EBV antibodies.

Since most adults are EBV antibody positive, it is rare to have a mismatch situation after a kidney transplant where the kidney donor is positive but the recipient is negative. However, a transplant candidate who is EBV antibody negative is very likely to receive their transplant from a donor who is EBV antibody positive. With a mismatch, the recipient may get this virus soon after the transplant. Because of having a suppressed immune system, EBV might spread quickly in your body. This can cause B lymphocytes to spread without being slowed down by your T lymphocytes. Unless the spread is slowed down, this can lead to post-transplant lymphoproliferative disease, or PTLD for short. PTLD is one of the most feared complications of kidney transplantation. However, because there are so many benefits from receiving a kidney transplant, it is rare for transplant candidates to decline a kidney transplant from a donor who is an EBV mismatch.

Just like with CMV, the amount of EBV in the blood can be measured through a PCR test. If the level in your blood is rising, then your transplant centre might recommend reducing your antirejection medication, or giving a medication called rituximab. The goal is to find the right balance: to prevent the virus from spreading too much and also prevent sudden rejection of your kidney. The risk for developing PTLD is highest in the first year after transplant. The risk over a lifetime is between 1 and 10%. The risk is higher if you have more intense immunosuppression, if you have had a cancer before, or if your transplant is an EBV mismatch situation.

What are the symptoms of PTLD? Fever, fatigue, and weight loss are common. Your lymph nodes will probably enlarge, and there may be masses outside the lymph nodes as well, such as in the stomach, bowels, lungs, brain, or in the transplant itself. PTLD might be limited to the kidney transplant and picked up on routine ultrasound. The blood concentration of calcium or uric acid might rise. Of course there are many other conditions that called these that caused the symptoms. Before starting therapy, you would need a tissue biopsy, and possibly a bone marrow biopsy. The majority of PTLD cases turn out to be B cell lymphomas.

Therapy will be supervised by an oncologist, while your transplant nephrologist will adjust your antirejection medication. Surgical removal of masses is sometimes needed. Cyclophosphamide and other chemotherapy might be given along with rituximab, and your antimetabolite (mycophenolate or azathioprine) will likely be stopped. Even your tacrolimus or cyclosporine might be stopped. PTLD can be cured, and another drug like sirolimus may be used along with prednisone. Unfortunately, about a third of patients will succumb to PTLD especially if it is of the "monomorphic" or "T cell" variety. Most patients, however, are reluctant to stop their antirejection medications entirely and lose their kidney transplant, even if that means not being able to cure the cancer. Even if you are cured of PTLD, it can recur. This means, it's important to continue to be vigilant.



Treatment of dyslipidemia

Dr. Ramesh Prasad

Medication treatment for abnormal cholesterol, or dyslipidemia, depends on your specific overall heart disease risk. The Framingham risk calculator is a common tool to measure the risk in the general population of having a cardiac event for the first time in the next ten years. Although it is not validated for kidney transplant recipients, it can still be very useful. You can also find other risk calculators online, which ask you to enter your age (probably the most important risk factor), smoking history, diabetes history, and your various lipid levels. If your risk comes out as "low", then you might be able to postpone treating dyslipidemia with medication until a later time. Your doctor will advise you on this. However, CKD is often associated with heart disease, and you may have already been diagnosed with heart disease. A high serum cholesterol concentration, although painless, cannot just be wished away.

HMG-CoA reductase inhibitors, or statins, are the most commonly used class of drugs for dyslipidemia. Common examples of statins are atorvastatin and rosuvastatin. In some countries, they combine a statin with an antihypertensive medication as a "heart protection" pill. Statins are safe to use when properly monitored. Kidney transplant recipients usually take lower doses because of interaction with CNIs. Statin concentrations in the bloodstream can lead to tissue damage, especially in the liver and skeletal muscles. It's common to have aches and pains in your body when taking these medications, but this is rarely serious. Your serum liver enzyme and muscle enzyme concentrations will be monitored to ensure that any tissue damage is not serious. If these test results come back normal, then a medication like coenzyme-Q10 might help relieve the muscle aches so that you can continue taking your statin.

If taking a statin isn't enough to control your lipids, then a drug like ezetimibe can be added. This also involves the same monitoring precautions with liver and muscle. Another drug called fenofibrate might be added especially if your serum triglyceride concentration is particularly high. It is a good idea to consult with a specialist in lipid metabolism if you have a genetic predisposition to heart disease or lipid abnormalities.

While following a healthy diet and lifestyle is an integral part of controlling your lipids, please stay away from herbal medications marketed for this purpose. Preparations such as red yeast rice, which might be appealing because they are "natural", contain statin-like substances. Since the amount of these substances is neither accurately known nor standardized in type and amount, side effects can be both unpredictable and dangerous to your liver and muscles.

A well-controlled serum lipid profile will assist in lowering your cardiac risk and contribute in its own way to enable you to live a long and healthy life with your kidney transplant.

Understanding the Education Needs of Kidney Transplant Patients

Emily Campbell, RD CDE MScFN
Care and Transitions Facilitator

We recently published a study to learn more about what patients want to know after a kidney transplant and how their learning needs change with time.

Thank you to all the patients who took part in this study between **September 2019 and March 2021**. We really appreciate the time and effort you contributed to this important study.

The study is called: **"Lessons Learned About the Education Needs of Kidney Transplant Recipients: A Mixed-Method Study."** The study is unique in that is was designed by a multidisciplinary group that included a nurse (Michelle Gabriel), pharmacist (Lucy Chen), social worker (Sharon Lee) and dietitian (Jenny Acceutura).

We included **20 patients** who were **3 to 6 months** post-transplant in 2019. These patients filled out a **survey and had an interview** at two times:

- Once at **3–6 months after transplant**
- Again at **12–18 months after transplant**

Based on our participants' feedback, we learned that the following **3 factors** had an impact on their education after kidney transplant:

1. **Having a trusted healthcare team** helps patients feel more confident and supported in their learning.
2. **Having support from family, friends, and others** makes it easier for patients to stay positive and take care of their health.
3. **Patients face different challenges** after transplant, and these affect what kind of information they need and when they need it.

Patients told us that:

- Their learning needs changed over time, and getting **personalized education** was important.
- **A team approach** works best — including not just doctors and nurses, but also **pharmacists, dietitians, and social workers**. We continue to offer these supports in the clinic or by referral.
- Having a **strong support system** (family, friends, coworkers, social media, or community groups) helped them feel more confident and ready to manage life after transplant.
- Views on some topics, like **alcohol use and dental care**, changed over time. For example, dental care became more important after one year (P = .031).

You can read the full study here: https://journals.sagepub.com/doi/10.1177/20543581251338462

The study was conducted and reported in collaboration with the Kidney Research Team (Michelle Nash, Lindita Rapi, Niki Dacouris, Weiqiu Yuan, Tiffany Thai) and the Kidney and Metabolism Program Care and Transitions Facilitator (Emily Campbell) and the Interprofessional Practice-Based Research Team (Melanie Dissanayake, Teresa J. Valenzano-Hacker).

Want to Be Part of Research?

Feel free to reach out to the Kidney Research Team if you are interested in or have questions about research. Your input helps us give better, evidence-based care.

If you are interested, please let your healthcare team know at your next clinic visit, or contact our Kidney Research Team at: kidney.research@unityhealth.to

Help outside of transplant clinic

For patients with a kidney transplant

If the transplant clinic is closed, here is what to do to get medical help:

Make the first-available appointment with a family doctor, visit a walk-in clinic or urgent care:

- Low-grade fever (up to 37.9°C)
- Cough, cold, flu symptoms
- Sore throat
- Urinary tract infection
- Stomach pain or diarrhea
- Eye, nose or ear complaints
- Minor head injuries
- Minor cuts, rashes, or skin infections
- Minor sprains and strains
- Minor burns
- Muscle aches and pains
- Allergies
- Changes to your mental health

This is not a full list. There are many conditions that can be serious and that may not be included here. If you are concerned, seek medical attention as soon as possible.

Go to the Emergency or call 911:

- Chest pain or pressure, or feeling like your heart is racing
- Trouble breathing
- Any fever in the first 6 months after transplant
- Fever 38°C and above
- Blood pressure more than 180/110 mmHg or less than 90/60 mmHg
- Severe bleeding or bleeding that won't stop
- Sudden facial swelling or difficulty breathing after taking a medication or an insect bite
- New confusion
- Trouble staying awake or lost consciousness
- Numbness, weakness or other signs or symptoms of stroke
- Seizures
- Severe headache
- Dizziness or fainting
- New vision changes
- Cannot pee, peeing very little or blood in pee
- Vomiting or diarrhea that won't stop
- Blood in vomit or stool (poop)
- Severe pain in your belly
- Pregnancy complications
- Serious injuries
- Thoughts of harm to self or others
- New change in blood sugars, higher or lower than your normal values

What to bring

Bring the following items when seeking health care:

- Your current medicines and supplements in their original packages
- Name of your usual drug store along with the address and phone number
- Names of your healthcare team members
- A notepad and pen to take notes (this can help you remember everything your health care team tells you when you go home)
- OHIP card, drug insurance card or any other method of payment in case you get a prescription.

Still not sure who to call?

For urgent transplant-related issues:

Hours: 8 a.m.to 3:30 p.m.

Phone: 416-867-3665 option #2

To speak with the nephrologist on call on weekends or holidays

Hours: 8 a.m. to 4 p.m.

Phone: 416-864-5431

Outside of these hours, go to the nearest Emergency Department if unwell, or contact the transplant clinic the next day.

Kidney Transplant Resources

Scan the code to learn about kidney transplants and patient resources

Visit **www.kidney.to** for more information.

This newsletter is sponsored through an unrestricted educational grant from Astellas Canada.

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