

# KIDNEY

# Living

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## Living Donation:

## When One Choice Changes Everything



**kidney**  
FOUNDATION



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# Editor's Message

In this issue of *Kidney Living*, we explore the power of organ donation through a series of articles that highlight the impact of living donation. From personal stories that reveal the profound experience of giving and receiving this life-changing gift, to practical guidance on how to start conversations about finding a living donor, and information on the financial supports available to patients and donors—this issue is filled with inspiration and insight.

Our cover story introduces Lucas and Debbie, two strangers whose lives are now forever connected through an extraordinary act of generosity. What makes Debbie's decision to donate especially compelling are the deeply personal reasons behind it. Turn to pages 4–5 to read their remarkable story.

Maureen shares her journey of staying positive while waiting for a kidney transplant, offering hope and resilience drawn from her lived experience. Transplant Coordinator Natalie Witton provides practical tips for maintaining positivity while on the transplant wait list.

On a national level, The Kidney Foundation has been leading efforts to raise awareness and drive government action to transform kidney health care for all Canadians. The National Strategic Framework for Chronic Kidney Disease was released on World Kidney Day on Parliament Hill. Now, we need your voice. Learn more about the Framework on page 16 and take action by writing to your Member of Parliament and signing the petition at [ActforCKD.ca](http://ActforCKD.ca).

We also take a closer look at relationships and how kidney disease affects not just individuals, but their entire circle of support. Be sure to read “Intimacy Reshaped” by Dr. Gavril Hercz (page 14) and “Taking Care of Care Partners,” where Irwin shares his perspective as a caregiver (page 12).

Finally, don't miss “Cooking with Care: When AI Gets Kidney Diets Wrong,” a thought-provoking piece exploring the role—and risks—of AI in dietary guidance for kidney health.

Yours truly,



Trish Reynolds, Editor  
The Kidney Foundation of Canada  
Ontario Branch

# A Transplant for Lucas

By Heidi Westfield



Debbie Timpson

## Debbie's Story

**H**ow did an Ontario doctor come to donate a kidney to a teenager she had never met? The story begins more than fifteen years ago, when Debbie Timpson learned what a powerful difference organ donation can make.

Debbie remembers the moment they got the call. It was 2011. She and her husband Rob were in the car,

going to a friend's place, when they learned there was a match. An extensive search had come to an end: Rob's cousin Ian had the green light to donate a kidney. After spending three years on dialysis, Rob had new hope for a better life.

*"I was overwhelmed with gratitude,"* Debbie recalls. *"The transplant was going to happen and change Rob's life. And as an extension, my life too."*

Rob was in good health before he developed Focal Segmental Glomerulosclerosis (FSGS). The autoimmune condition damages the kidneys' filters and for Rob, that led to kidney failure. He began dialysis in 2008, eventually opting to dialyze at home five days a week.

*"We were grateful for the dialysis team, but it was very challenging,"* Debbie says. *"Rob did not feel well on dialysis. He was tired all the time with no appetite."*

During that time, they hoped for a kidney transplant. Debbie was not a match, but joined the Kidney Paired Donation Program to increase Rob's chances of finding a compatible donor.

There was a breakthrough when a young cousin volunteered to be tested. He was a match, and the transplant was scheduled. Debbie remembers how Rob went from looking grey and sick to having pink cheeks right away after surgery.

*"Initially we had to take precautions with crowds, and he had some issues with the anti-rejection medications, but we were free,"* she recalls. *"We were able to travel and went to Europe many times. We were able to resume our lives that were on hold for three years. He basically got his life back."*

Rob lived with his new kidney for 12 years, before passing away from heart disease. After his death, Debbie remained grateful to Ian for providing a kidney to her husband. She decided to honour both her late husband and Ian by offering to be a kidney donor herself.

It was soon after that, that she saw a "Share Your Spare" Facebook post with Lucas's story. She did not know him but learned he lived in a rural community near Ottawa, just 45 minutes from her home.

*"I saw that he was 17 years old and the same blood type as me,"* Debbie says. *"I know how dialysis took over our lives and couldn't bear the thought of a teenager having to do that."*

Debbie reached out to his hospital, and Lucas's family was contacted. After some additional tests, she was approved to be a donor. The surgery happened in February 2026 and was a success.

*"To be able to help a teenager just made me really happy,"* Debbie says. *"I was thrilled!"*

Debbie's choice to be a living kidney donor has given Lucas and his family an incredible gift. Lucas is now enjoying good health and looking ahead to a better future.

Rob & Ian



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## Lucas Finds a Donor

Lucas was born with just one working kidney in a rural area outside of Ottawa. For many years, his health condition did not slow him down. Lucas went to school, helped his family around the house, and spent time with friends. Doctors kept an eye on his health with regular bloodwork and ultrasounds.

When Lucas was about fifteen, his kidney started showing signs of damage. He was prescribed medication to regulate his blood pressure. Then, a couple of years later after a growth spurt, his family got the difficult news that he was close to kidney failure. Without a donor, he would need to go on dialysis to stay alive.

*"It was a rude awakening for all of us in the family,"* his mother, Angela Gillan, recalls. The family quickly shifted gears to prepare Lucas for dialysis while looking – and hoping for – a kidney donor. Polycystic kidney disease (PKD) runs in her husband's family, ruling them out as donors. Other relatives were assessed, but age and medical conditions got in the way.

Angela's cousin, Michelle Beauchamp, reached out to help. Six years before, her brother needed a liver transplant. She had organized a successful social media campaign to find him a donor, and suggested doing something similar for Lucas.

*"I knew how far a reach we could have if we went on social media,"* Michelle says. She approached the family and, with their permission, moved forward with Facebook posts about Lucas and his need for a living donor kidney. Her online campaign was called, "Share Your Spare".

*"We had great feedback immediately. Our very first post was shared over 1,300 times. We are so fortunate that people shared, liked and commented [on the posts],"* says Michelle, noting that the campaign also provided broader information on living organ donation. *"We have met people through this who were strangers and who are now friends. It is incredible to have so much support."*

The online call for a kidney generated responses from Ontario, Quebec, New Brunswick – even Western Canada. That led to a series of potential donors, but none

panned out at first. Then, a woman living in a nearby town saw the Facebook post. Debbie Timpson had recently decided to become a living kidney donor, and she and Lucas shared the same blood type.

*"I was at work when I got the call and I started crying,"* Angela says, on the moment doctors told her at the end of January 2026 that they had a particularly good match for a donor. Debbie would provide a kidney to Lucas. The surgery was scheduled for the following month.

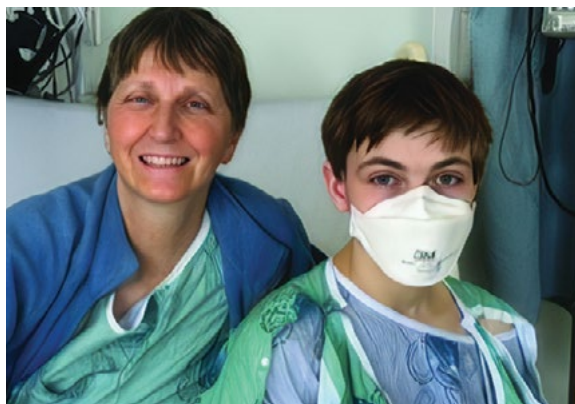
For Lucas, the surgery brought him new hope and freedom from dialysis: *"I felt relieved that I did not have to go on dialysis, that is for sure. I was glad I did not have to be hooked up to a machine and stuck at home every night."*

Now, after a successful surgery, Lucas is doing well: *"Day by day, I am getting better, getting stronger. I have the colour back in my face,"* he says. He is looking forward to going to college, seeing his friends, and returning to his part-time job.

*"I was absolutely thrilled,"* recalls Michelle. *"Then, to hear Debbie's story and her connection to organ donation and why she was doing it – it was meant to be. I truly think it was meant to be her, and we have a new family member."*

The Gillan family is incredibly grateful that Debbie happened to be on social media that day and chose to help.

*"She changed Lucas's life,"* Angela says. *"We are so thankful this has happened."*



Debbie & Lucas

Debbie & Lucas with Lucas Parents



# Raising Awareness and Funds at The Kidney Walk

**T**he Gillan family is a big supporter of The Kidney Foundation and the Kidney Walk. In 2025, the family raised more than \$9,000.00 for the Foundation with the help of friends and their community.

The family is gearing up for this year's Kidney Walk and have increased their fundraising goal even higher. They are hoping to raise more than \$10,000 to ease the burden of kidney disease on Canadians.



Angela & Lucas Gillan

*“Just knowing that the dollars you raise for The Kidney Foundation go to support research for kidney disease and treatments was important to both of us and still remains important to me,” Debbie says.*

Money raised through Kidney Walks across Canada fund programs and services for those affected by kidney disease. This includes world-class kidney research, patient support programs, and awareness campaigns.

Beatrice Nayduk, Debbie Timpson & Isabelle Boisvert



Michelle Beauchamp, Lucas's Cousin, & Penny Tough, Lucas's Great Aunt

*“Kidney disease has touched my family and my husband's family,” Angela Gillan says. “We have been helped by kidney donation, so why not raise money for a good cause?”*

Last year Debbie Timpson took part in the Kidney Walk and raised \$5,000. This year, she is joining the Gillan family on their Walk. She remembers how The Kidney Foundation helped her late husband Rob with transportation and food costs when he needed to travel outside his community for weeks of dialysis training. The couple also spent time at Camp Dorset when he was on dialysis.



# 5 Tips for Talking about Living Organ Donation

By Trish Reynolds

**L**iving organ donation is considered the gold standard of kidney transplantation, producing better outcomes for Canadians living with kidney disease. With an average wait time of 4 years for a deceased donor kidney in Canada, living donations can reduce wait times substantially.

Today, about twenty-five percent of all kidney transplants are a result of living donations, most coming from a family member or friend. Paired exchanges and anonymous living donations have helped increase living donation rates over the last several years.

But how does one go about seeking out potential donors? It's not as simple as asking someone to share their secret chocolate cake recipe or asking them to borrow a ladder. It involves asking someone to go through a surgery that they don't personally need but is entirely for the benefit of someone else.

kidney.ca

Donating a kidney is one of the most generous and beautiful gifts that someone can contemplate.

The idea of asking for such a gift can be daunting. Here are a few tips to help start the conversation:

- 1 Be Informed and Educated**

Take time to learn about living kidney donation so you're well prepared to answer any immediate questions. Sometimes sharing facts and information can serve as a conversation starter. Be ready to answer questions such as "Can I live with only one kidney?" or "Is there a cost for me to donate?"
- 2 See Yourself as an Advocate**

When you take steps to find a living donor, you're advocating for your health and well-being. Share your experience living with kidney disease, tell others what it is like to live on dialysis, how your quality of life is impacted, and how a transplant can change your life. Simply sharing your experience can help not only yourself but raise important awareness of kidney health and its treatments.
- 3 Make it Personal**

Be as open as possible. People may know you haven't been well, but they might not understand what that means. Be honest about the challenges you have faced and share your story with as many people as you can. It may be easiest to start with those closest to you, your family, and closest friends. Emails, text messages, and social media are a few of the ways to spread the word. You might also want to consider sharing your story in your place of worship, community group, or workplace.
- 4 Find Champions**

Your friends and family are your greatest champions and can also help amplify your story by sharing with their networks as well. The more people who learn about your need for a kidney, the greater the chance you will find a living donor.
- 5 Take Care of Yourself**

The process of finding a living donor takes time and perseverance. Seek the support of your health care team or connect with others who understand your experience through The Kidney Foundation's Peer Support program. It is important to take care of your own mental health and stay positive.

# “Tears of joy” as Esa Receives a New Kidney From His Sister

By Heidi Westfield

**T**he day he learned his sister was a match, Esa’s world changed. At age 25, he had new hope that a better life was around the corner. Now he could have a kidney transplant and, maybe one day, stop the hemodialysis treatments that had taken over his life.

*“I felt a light from heaven come down on me,”* he remembers, after hearing that his older sister Aliya was cleared to be a donor.

*“I had goosebumps rushing through my system. I had tears of joy that my sister would be relieving me from my pain and discomforts.”*

Esa was born with kidney disease and has lived with the condition all his life. By grade 10 he had moderate kidney damage and, by the time he was in college, the damage was severe. He faced kidney failure at age 24, when most young people are just getting started with adult life.

Esa was working for a local school board, helping students with special needs. In his spare time, he loved to mountain bike and ski. It was difficult to take a step back as he faced extreme fatigue with fluid build-up in his body, and brain fog. He had to adjust to a new reality; he needed dialysis to stay alive.

*“Spending 12 hours a week in-clinic on hemodialysis was the scariest process I endured during my kidney journey,”*



Esa says. *"I was anxious, sad at times seeing friends move on with their lives while I was hooked to a dialysis machine."*

His sister began testing to be a donor in December 2024 and had most of the work completed by the following April. When she received final approval to donate a kidney that summer, Aliya did not hesitate. The surgery took place in August 2025 and was a success.

*"It is a true honour to be his donor," Aliya reflects. "Esa is my hero and he inspires me. He is the bravest person I have ever met. He went through so much and I am so proud of him."*

Aliya has recovered from the surgery and is now training to run a half-marathon. She encourages Canadians in good health to consider living donation, or register their wishes to be an organ donor to help others in the future.

Esa is also bouncing back from the surgery. Soon after his transplant he joined a Peer Support Group for

young adults. The meetings have put him in touch with a community of people around his age living with kidney disease. They exchange stories and share their experiences.

*"Peer Support is a safe space that helps liberate me from my fears and vulnerabilities," he says. "I feel like I am not alone."*

Now Esa is no longer tied to a machine and is back to an active life. He plans to continue working in healthcare and helping teenagers with developmental disabilities.

Three months after surgery, his doctor gave him another gift: Permission to take out his mountain bike and ride again. After so many years of challenges, Esa is seeing new doors open. He plans to continue "paying it forward", by spreading awareness of the value of organ donation and working to help others.

## LIVING DONOR CIRCLE OF EXCELLENCE



**Support life-saving moments.  
Support employees when they need it most.**  
*When companies support living donors, employees notice.*

The **Living Donor Circle of Excellence** program recognizes employers who remove financial barriers to living donation by adopting a work leave policy that covers wage loss for a full-time employee who chooses to be a living donor.

Across Canada, organizations are stepping up to support the tremendous sacrifice of living organ donors.

**No upfront cost & low-cost commitment!**  
**Invite your employer to learn more.**



Learn more: [kidney.ca/Living-Donor-Circle-ontario@kidney.ca](https://kidney.ca/Living-Donor-Circle-ontario@kidney.ca) | 1.800.387.4474



# Improving Living Donor Evaluation through the One-Day Donor Clinic

**E**stablished in 2022 with the Canadian Society of Nephrology and Otsuka Canada, the Vicky Karoutas Memorial Award is granted to any applicant of The Kidney Foundation of Canada’s Kidney Health Grant that demonstrates exceptional patient-centered research.

In 2023, the Vicky Karoutas Memorial Award winner was Dr. Seychelle Yohanna, a transplant nephrologist with St. Joseph’s Healthcare Hamilton. Dr. Yohanna epitomizes the legacy of Vicky Karoutas through her passion for bettering the living donor evaluation process.

Living donation is the gold standard treatment for people living with kidney failure. For this reason, Dr. Yohanna, like many in her field, honour and celebrate the altruism of living donors. Yet, the current process of living donor evaluation can be burdensome and disenfranchising for many potential living donors which limits the number of living donations. “How are we going to increase the living donor rate if we don’t focus on the experience?”, Dr. Yohanna explains.

This is what led Dr. Yohanna and her team at St. Joseph’s to develop a one-day donor assessment clinic in 2019. This clinic streamlines the current living organ donor evaluation process from 9-12 months into a single day, providing donors and recipients the answers they need much faster.

For potential living donors, this reduces many of the barriers that may disincentivize someone from donating, including time spent travelling, time off from work or away from family, numerous incurred expenses, and more.

For potential recipients, it means faster access to a life-saving transplant. Dialysis is life-sustaining, but it can be hard on the body. Rather, the goal is to receive a kidney transplant prior to or as soon as possible after starting dialysis. Yet with the standard model of care, it can take months or even years to find a donor and go through the evaluation process. This time frame is reduced significantly with a one-day living donor

assessment clinic, leading to better health outcomes and improved quality of life for kidney patients.

*“I’ve always been super passionate about making it easier for living donors, because I look at them in awe... I just can’t believe they’re trying to give an organ to save someone’s life. I respect them so much. They’re not patients to me, they’re heroes.”*

While the value of this model is prevalent, convincing evidence is needed to develop and implement such programs nation-wide. This is exactly what Dr. Yohanna and her team aim to do with support from The Kidney Foundation of Canada and the Vicky Karoutas Memorial Award, by measuring the impact of the one-day assessment clinic on both donors and recipients and comparing it to the standard model of assessment.

With the additional funds from the award, Dr. Yohanna hopes to also develop a toolkit or blueprint to help other centres execute an expedited assessment model. Regardless of the unique differences between healthcare centres, “the idea is that you want to create an efficient, patient-centred process”, she explains.

Dr. Yohanna has already helped to implement such programs in two other centres in Ontario, but she hopes she will be able to guide the implementation of fast and efficient living donor assessment clinics across the country.



# Financial Supports for Living Organ Donors: What You Need to Know

By Candice Coghlan

One of the most common questions people ask when considering living organ donation is practical: What will this cost me? The good news is that in Ontario — and across Canada — programs exist to reduce or remove the financial burden for people who choose to become living kidney or liver donors.

Living donation offers the best outcomes for many transplant recipients, including shorter wait times and better long-term results. Still, living donors may face expenses related to travel, accommodation, and time away from work. Financial support programs are designed so that generosity is not limited by personal cost.

In Ontario, the Program for Reimbursing Expenses of Living Organ Donors (PRELOD), administered by Trillium Gift of Life Network, reimburses many out-of-pocket expenses connected to donation. Both approved donors and people undergoing donor testing may be eligible. Covered expenses can include travel, parking, accommodations, meals, and certain medical costs related to assessment visits, surgery, and follow-up appointments for up to one year after donation.

PRELOD also includes limited income replacement after surgery for donors who must take unpaid time off work to recover. This support is benchmarked to Employment Insurance rates and may be available for up to eight weeks, depending on individual circumstances and other benefits available. Some companion or caregiver expenses are also eligible, recognizing that donors often need support during surgery and early recovery.

Additional programs help close remaining gaps. The GiveLifeUHN Travel & Accommodation Program, delivered with Hope Air, assists eligible living donors and caregivers with flights, ground transportation, and hotel stays when traveling long distances for care. Some employers provide organ donor leave, and certain expenses may also qualify under the Canada Revenue Agency medical expense tax credit.

Because navigating supports can feel complex, education is built into the process. The Centre for Living Organ Donation at UHN offers regular public webinars, including sessions dedicated to financial supports, where donors and families can learn what is available and how to apply.



The Centre's education and navigation services have helped expand access to living donation by removing common informational and logistical barriers.

Living donation is an extraordinary act. Today, financial support programs help ensure it is also a realistic and supported choice for those willing to give the gift of life. Learn more at [livingorgandonation.ca](http://livingorgandonation.ca) or by contacting the Centre at [livingorgandonation@uhn.ca](mailto:livingorgandonation@uhn.ca)



# I May be Retired, But I Still Have a Job. I'm a Caregiver.

By Irwin Schweitzer

Kathi & Irwin

I am sitting in our family room, watching TV. The landline rings. It's the middle of the afternoon, my day off. Who could possibly be calling? What's worse than a telemarketer? A call from your wife's doctor.

Kathi's doctor was retiring. He'd made an error and now wanted to fix his mistake. The doctor had forgotten to discuss some bloodwork results with my wife. I wrote down the numbers. They meant nothing to me. I figured Kathi would understand her kidney function results.

Kathi returned from work. I innocently shared the news and the numbers. Watching my wife explode into tears was devastating, for both of us. There was anger too. Why hadn't her doctor shared the lab results immediately? How could he make an error so large that our entire lives were changed?

My wife ranted, *"I know there isn't anything I can do to stop the disease, but I could have started earlier, on a management program, to delay the inevitable!"* The "inevitable" was either going on dialysis or getting a kidney transplant. We never thought we'd have to deal with so much or make these kinds of life-altering decisions. We sat down, stared at each other for a few moments, and began planning what to do.

We resolved to run the disease rather than have the disease run us. We jumped into the kidney game and committed to doing everything we could to maintain the quality – and the joy – of our lives.

Kathi and I have been blessed with great careers and wonderful family. We have a daughter, a son-in-law and our three grandchildren. Kathi and I are determined to watch the grandkids grow up. Until Kathi started dialysis, she was a textbook case of low energy. Now, two-and-a-half years into peritoneal dialysis, her energy is back. She continues to work full-time.

I may be retired, but I still have a job. I am Kathi's caregiver and I experience kidney disease from an invested observer's perspective. I can tell whether the overnight dialysis session was efficient or not. Every morning we play "What Do the Scale and Blood Pressure Say?" Always a fun game. If the numbers are not optimal, we discuss the results and plan how to dialyze next time. Once we're done our strategizing, Kathi gets ready for work and I drive her in.

In my mind, dialysis marks Phase 2 of our kidney journey. Dialysis is incorporated into our day-to-day life. The only big change is that we must travel with Kathi's dialysis machine. My brother once asked if the machine had a nickname. A goofy question deserves a goofy response, so I said, "Clyde the Cyclor". A silly play on words intended to lighten the load of living with kidney disease.

While Phase 2 revolves around Kathi's dialysis and all the "health perks" it brings, we realize there is potentially a Phase 3 waiting for us. Phase 3 might be a kidney transplant. But right now, as long as dialysis is working for us, why change things?



If I had to give one piece of advice to someone like me – someone in love with a person with kidney disease – I'd say never succumb to kidney disease being the boss. You don't control what happens. But you can control how you respond. Never let kidney disease run your life. Build your support network and your second-string team. The kidney journey is not a solo trip. Everyone you love and who cares about you makes the trip.

As a couple and as a family, we've cultivated a defiant attitude. Yes, my wife has kidney disease. And together we say, *"So what!"* Life goes on. We continue to enjoy life, getting together with friends and family, sharing meals and hanging out.

Before kidney disease, Kathi and I were living life to the fullest. Today, our lives are still full. I became a volunteer with The Kidney Foundation's Peer Support program. Through peer support, I found people whose journeys were much the same as the one that Kathi and I were on, and it was good to be able to share a mutual understanding of kidney disease and know that life goes on. Every day my wife shows me what it is to live with grit and grace. We've kept our promise as a couple and as a family: we run kidney disease. Kidney disease doesn't run us.

# Taking Care of Care Partners

By meghan gorosh, RSW, SEP

It is crucial to remember that behind most care recipients, a dedicated care partner—someone fundamental in supporting and ensuring the well-being of those for whom they care—is silently working in the background. Whether tending to physical needs, providing emotional support, or managing administrative tasks, care partners shoulder immense responsibility. Often experiencing physical, mental, and emotional stress, the risk of fatigue is all too real when care partner concerns, needs, and well-being are not supported.

Caregiving brings a wide range of emotions, from joy, connection, and satisfaction to guilt, anger, and grief. Respite care is essential, as is community care. Temporary relief provided by professional services or other family members can allow care partners to take regular breaks, helping to mitigate fatigue and injury, and maintain overall well-being.

To ensure care partners receive the support they deserve, it's essential to implement multifaceted measures. Awareness campaigns can shed light on the challenges they face, reducing stigma and encouraging open conversations. Accessible mental health services tailored to their needs can provide a safe space to express their emotions and seek guidance. Respite care is a vital component, allowing care partners to take breaks and recharge. This could involve temporary relief provided by trained volunteers or professionals, offering care partners the chance to tend to their own needs without guilt.

According to Statistics Canada, more than one in four Canadians are caregivers, providing care for family members or friends with long-term conditions. Financial support mechanisms, including subsidies for caregiving expenses, tax breaks and caregiver employment insurance benefits, may assist with financial strain. In addition, education and training opportunities empower care partners with necessary skills and knowledge on available resources, tools and community health services.

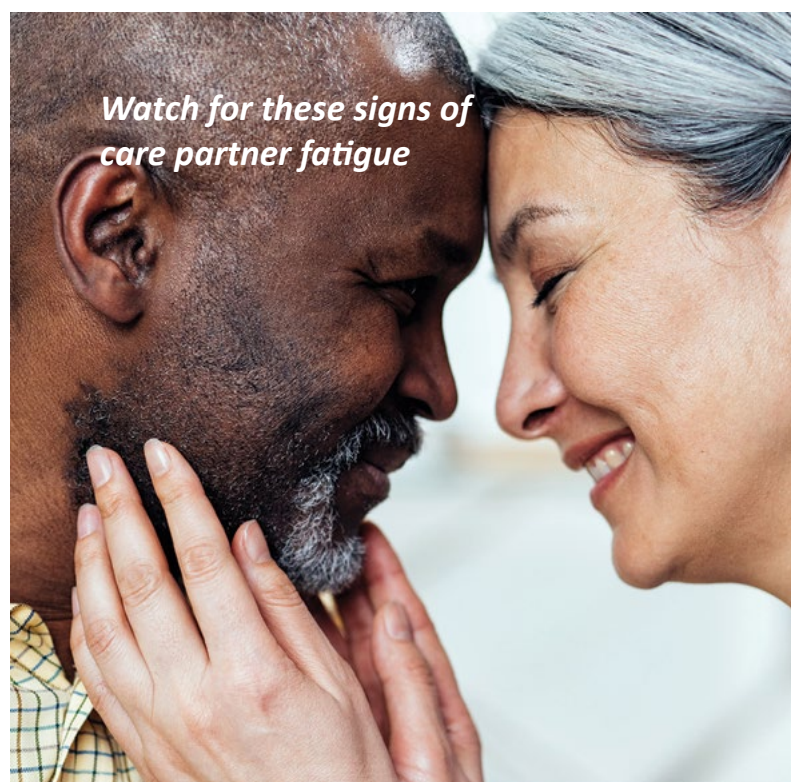
Open and honest communication between care partners, care recipients, and healthcare professionals is vital for effective caregiving. Regular discussions about expectations, concerns, and the overall care plan can foster a collaborative approach, reducing stress and improving the quality of care. To help reduce stress, it's

important to take time, as care partner Sharon Recalma knows.

*“Being a care partner to my husband who was on dialysis during COVID was an especially difficult period, and it led me to look for ways to help deal with the added stress,” says Sharon.*

*“I had been belly dancing for a few years when COVID hit and our close community had to find new and inventive ways to continue to connect and support each other. Although belly dancing is something I do just for me, I love it and am constantly amazed by the difference it makes to my physical and mental state. Not only have I met a new community of friends, after each class I feel more energized and now dance is a part of my weekly routine. Dancing helps me to be more focused and engaged to support my husband and look after our day-to-day needs.”*

Talking to other care partners who have shared lived experiences can also help. Ultimately, a society that cares for its care partners nurtures compassion. By fostering a culture that values their contributions, we ensure the well-being of those who tirelessly care for others, promoting a healthier and more empathetic community as a whole.



*Watch for these signs of care partner fatigue*

# Intimacy Reshaped

By Dr. Gavril Hercz

Living with chronic kidney disease reshapes many areas of life, often in ways that patients and their partners never anticipated. Among the most sensitive of these changes are the shifts in intimacy, sexuality, and emotional closeness. These topics are rarely discussed openly, yet they matter deeply. They influence identity, self-worth, relationships, and the sense of being fully alive. When illness enters the picture, many people find themselves unsure of how to talk about these concerns or even where to begin.

Kidney disease can introduce physical changes that feel intrusive and difficult to integrate into one's sense of self. Hemodialysis may involve a fistula or graft in the arm, while peritoneal dialysis requires a catheter in the abdomen. These medical devices are essential for life, yet they can create tension between the need to survive and the desire to feel whole, attractive, or spontaneous. Many individuals wonder if it is safe to be intimate, whether their partners will view them differently, or how to navigate closeness when their body no longer feels like the one they once knew.

The physical symptoms associated with kidney disease add another layer. Fatigue is reported by the vast majority of dialysis patients, and this alone can dramatically influence sexual desire. Pain, itching, muscle cramps, or sleep disturbance may also interfere with a person's ability to feel relaxed and receptive. Hormonal changes related to kidney dysfunction can reduce libido in both men and women, and erectile dysfunction is highly prevalent. Vascular changes, nerve involvement, medication effects, and anemia can all contribute to these challenges. From a psychophysiological perspective, the body's chronic stress, discomfort, and energy depletion make it understandable that sexual functioning can be affected.

Yet the physical story is only part of the picture. Emotionally, chronic illness often stirs feelings that are harder to articulate: a sense of grief over the loss of a former self, anxiety about burdening others, or fear of being seen as "less" in the eyes of a partner. Many people struggle with changes in body image. The presence of tubes, scars, or swelling can lead to self-consciousness and withdrawal. Some individuals begin to protect themselves emotionally by avoiding touch or closeness, even though they long for it.

Partners, too, may feel unsure—worried about causing harm or misunderstanding what the patient needs.

Communication can become strained, not because love is absent, but because uncertainty grows silently between two people who care deeply for one another. The partner may misinterpret withdrawal as rejection, while the patient may interpret hesitation as loss of interest. When left unspoken, these misunderstandings can erode emotional connection at the very time both people would benefit from greater openness and support.

This is why conversation matters so much. A gentle, honest exchange between partners can relieve unspoken fears and pave the way toward new forms of closeness. Intimate connection does not have to look the same as before illness. It can evolve, becoming slower, more intentional, more emotionally grounded. Patients who feel safe expressing their worries often discover that their partner's love and desire remain intact. Similarly, partners who express their own fears may find relief when the patient reassures them that affection is welcome.

Speaking with the healthcare team can also be a powerful part of healing. Many individuals with kidney disease assume that sexual concerns are "out of bounds" or inappropriate to bring up in a medical setting. In reality, these issues are common, valid, and deeply connected to quality of life. Clinicians can offer reassurance, treatment options, and referrals to specialists who address sexual functioning. Counseling, psychosexual therapy, and couples therapy can all provide supportive spaces to address the emotional and interpersonal effects of chronic illness. What often helps most is simply knowing that one is not alone and that these challenges are both recognized and treatable.

Another important step is broadening the understanding of intimacy. Touch, affection, shared experiences, emotional vulnerability, and companionship are all

vital forms of connection. Sexuality is one expression of closeness—not the only one. When couples free themselves from the pressure to perform in a certain way, they often find greater ease, creativity, and joy in being together. Exploring new forms of closeness can create unexpected depth and tenderness in the relationship.

Living with kidney disease will naturally bring periods of adjustment, frustration, and mourning. However, it can also bring resilience, compassion, and renewed appreciation for emotional connection. Many individuals and couples find that once they begin speaking openly—whether with each other, with their care team, or with a therapist—feelings of shame and fear diminish. What replaces them is understanding, collaboration, and a pathway to rediscovering intimacy in ways that feel safe, meaningful, and fulfilling.

The journey is not about returning to the past, but about discovering what intimacy can look like now. Patients and partners are not defined by illness; they are still capable of closeness, desire, tenderness, and love. By inviting conversation, seeking support, and allowing space for emotional honesty, it becomes possible to reclaim connection and build a new sense of togetherness—one that honours both the challenges and the strength that come with living with kidney disease.

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# New Resources on Itching and CKD

Itching affects thousands of people living with chronic kidney disease (CKD) yet remains one of the most overlooked and least discussed symptoms. It is more than a minor irritation. For many, itch is unbearable as it disrupts sleep, affects mental health, and lowers quality of life.

To help raise awareness and encourage conversation about CKD-related itching, The Kidney Foundation of Canada has some new resources available.

Often referred to as CKD-associated pruritus, itching can occur at any stage of kidney disease and presents differently for each person. It ranges from mild and intermittent to severe and persistent, with or without a rash. For this reason, many people do not report itching to their care team and often don't realize that itching may be connected to kidney disease. This leads to significant delays in recognition and management.

An awareness video highlights the lived experience of a hemodialysis patient with CKD-related itching. Alongside that, a downloadable fact sheet provides a short and easy-to-read overview of itching in CKD. These resources are part of the Foundation's ongoing efforts to improve education and awareness about symptoms of CKD to empower patients to seek the care they need.

**Learn more:**  
[kidney.ca/resources](https://www.kidney.ca/resources)  
 Click on the resource library and search itch



# Act for CKD

## ***Kidney Foundation Launches Framework to Address Chronic Kidney Disease***

**O**n World Kidney Day, thanks to the dedication of our volunteers, patients, supporters and staff, The Kidney Foundation of Canada released its National Strategic Framework for Chronic Kidney Disease. The Framework is Canada's first step toward a unified roadmap to transform the health care system from reactive and fragmented to proactive and resilient – a system that prioritizes prevention, early diagnosis and treatment, and equity for Canadians living with kidney disease.

Chronic Kidney Disease (CKD) is the 11th leading cause of death in Canada and one of its costliest chronic conditions, yet it is not formally recognized as a distinct chronic disease.

Through this strategic framework, The Kidney Foundation aims to help government leaders close the gap between the rising burden of kidney disease and the coordinated national action needed to address it, ensuring that people living with or at risk of kidney disease receive the support they need at every stage.

The goal of the Framework is to transform kidney health for all Canadians through prevention, equitable access,

and evidence-informed policymaking. It will help to ensure that every Canadian, regardless of where they live or what resources they have, can access timely, quality kidney care.

To drive this change, The Kidney Foundation of Canada hosted a roundtable on Parliament Hill, bringing together Parliamentarians, key civil servants, and people with lived experience to discuss the Framework's strategic

priorities and underscore the urgent need to move from planning to implementing coordinated national action on chronic kidney disease.

### ***We Need Your Help.***

Your support will help us build the foundation for a more accessible and equitable kidney care system focused on

prevention and early detection, with the potential to save thousands of lives at a time when kidney disease is rising nationwide.

Use the online tool at [ActForCKD.ca](https://actforckd.ca) to send a personalized letter to your MP and MPP and sign the official House of Commons e-petition. Tell them that kidney health can't wait.



## ***The Framework has Identified Three Distinct Priorities:***

**1** Prioritize Prevention, Early Detection, and Timely Intervention: Move beyond treating kidney failure to actively mitigating risk factors like diabetes and hypertension, and implementing systematic screening so at-risk Canadians are diagnosed early when serious kidney damage can still be delayed or prevented.

**2** Ensure Equitable Access to Kidney Care for All Canadians: Address systemic barriers by expanding culturally competent, multidisciplinary care, including increasing access to new treatments and medicines, especially in the early stages of the disease.

**3** Advance Research & Data for Better Kidney Health: Invest in innovative research and leverage existing data infrastructure to strengthen evidence-based decision-making, and ensure that new discoveries are rapidly translated into practice.

## Meet Francine

Francine Girard-Griffith is one of many volunteers who shared their lived experience to help guide the Framework's development. We asked her to reflect on that experience—and on why it matters to have her voice heard.

### 1 What has inspired you to volunteer with The Kidney Foundation?

*Kidney disease hits close to home. My husband was diagnosed quite suddenly with no warning with end-stage kidney disease 11 years ago. It was a shock to both of us. After dialysis and a successful transplant surgery in 2018 when I gave him a kidney, we both decided to join the Foundation's peer support program to help others navigate through their kidney journey by sharing our stories and our lived experiences.*

### 2 What sparked your interest in joining the advisory group of people with lived experience helping to guide the development of the framework?

*Having worked in the federal government my entire career, close to the decision-making process and public policy initiatives, I felt I could contribute and help The*

*Kidney Foundation advocate on Parliament Hill and in federal departments to help change the future of kidney disease.*

*Being a kidney donor, I am very passionate about helping to promote the need for more living and deceased kidney donors and to also help those living with the disease.*

### 3 Why do you think the launch of the National Strategic Framework for Chronic Kidney Disease is so important?

*There are already over 4 million Canadians suffering from kidney disease and it is continuing to rise; it's critical that the federal government recognize it as a 'chronic' disease which it doesn't at the moment; when it does the Foundation will have access to better data and other initiatives to help advance the cause. Kidney failure can be prevented if the right decisions and actions are taken by both levels of government. A national strategy will help accelerate that work.*

### 4 What is the most rewarding part about your volunteer work?

*When I think about friends and acquaintances we've met along this journey who have passed away from kidney disease, when I see what my husband goes through on a daily basis to help maintain and prolong his kidney health, when I think about all the people we've met who have become friends that are on dialysis, or waiting for a transplant, it motivates me to keep doing what I can to help advance the work needed to be done. I do it for all of them! I feel good about helping, contributing, and playing a role in moving the needle forward.*

### 5 Are there any specific moments, interactions, or events that have been memorable for you? Why does this memory stand out?

*There were many moments and interactions with Members on Parliament Hill and at Queen's Park that are memorable and unexpected. Almost all of the Members we met had a personal story about a relative, a close friend, or an acquaintance that had kidney disease or had passed away from it. I know the disease is prevalent, but I thought I'd have to convince them of the urgency of the matter. In addition to mine, they also had stories to share, and it helped to establish a connection very quickly upon which we could talk about the need for a National Framework. Those interactions were so encouraging!*



Francine Girard-Griffith

# How to Stay Positive While Waiting for a Transplant

By Heidi Westfield

**M**aureen tried to keep her spirits up while waiting for a kidney transplant. Sometimes, staying positive was a challenge. The hardest part was not knowing when – or even if – she would find a match. As an older woman on dialysis, she felt time was not on her side.



Maureen Rush

*asking you, ‘when are you going to get your transplant?’ and you don’t know.”*

That sense of uncertainty Maureen experienced is common among patients waiting for a kidney transplant, notes Natalie Witton, Recipient Transplant Coordinator at the Kingston Health Sciences Centre (KHSC). The waiting period, she says, can be both physically and emotionally demanding.

*“The uncertainty can lead to anxiety, frustration, or a sense of loss of control,”* she says, noting that many patients are balancing hope for a transplant with the challenges of their current health.

Natalie encourages patients to focus on what they can control. Try to eat kidney-friendly meals, attend scheduled hospital appointments, and take medications as prescribed. It is also helpful to get as much exercise as you can.

Maureen’s husband volunteered to be a living donor, but his blood type was not compatible. They joined the Kidney Paired Donation Program in the hopes of locating a living donor. Weeks of waiting turned into months. Then a year – and still no match.

*“There was about a year and a half of anxiety not knowing what comes next,”* Maureen recalls. *“Waiting for a transplant can take a toll on you because everybody is*

Waiting for a transplant can feel isolating, but Natalie stresses that patients are not alone in their journey. Family and friends can provide vital emotional and practical support. The hospital’s transplant team is there if you have questions or feel overwhelmed. There are also peer support groups available to share your experience and learn from others.

Patients can also opt to look at living kidney donation. Jennifer Berry, Living Donor Transplant Coordinator at KHSC, notes this option provides more control and helps you better plan for surgery. It still takes time, though, to screen potential candidates.

She adds that sharing your health situation with family and friends - instead of a direct ask for a donation – is the best approach in this case.

*“Framing it as a conversation helps take the pressure off both the patient and the listener,”* Jennifer says. *“It also allows others to process the information and come forward on their own if they feel moved to help.”*

Maureen did everything she could within her control during the waiting process. She ate healthy meals, exercised, did her work-up efficiently, and had a strong support network. When she was feeling down, she talked herself out of a bad mood.

*“I never gave up hope that I was going to get a transplant,”* Maureen says. *“I stayed hopeful and positive.”*

In the end, the wait for a match within the paired donation program became too long for Maureen. Instead, her medical team organized a list exchange. Her husband provided a kidney to someone on the deceased donor waiting list, and she received a deceased donor kidney in return. After surgery, her health has improved and she has a lot more energy.

The wait was challenging, but her self-care and positive attitude got her through a difficult time.

# Tips to Stay Positive on the Waiting List

From Natalie Witton, Recipient Transplant Coordinator, Kingston Health Sciences Centre

**1** Focus on what you can control; eat kidney-friendly meals, exercise, and take your medications as prescribed.



**2** Speak with your transplant team about any concerns you have.



**3** Accept help from friends and family.



**4** Connect with a peer support group to share your experience and learn from others.



**5** Acknowledge difficult days, while finding time for activities you enjoy. This can include going for a walk, painting, music, reading, or watching a favourite film.



# Inspired by Love to Leave a Lasting Legacy

By Imshaan Manji, Edited by Andrea Rennie

**W**e are honoured to share the story of our beloved grandmother and mother, Mrs. Roshankhanu Shamshudin Jetha, a pillar of love, care, and kindness in our lives. She was an extraordinary woman who dedicated her life to her family, always putting others first. As a devoted mother to two beautiful children and a loving grandmother to many, she touched the lives of everyone around her. Her selflessness and generosity inspired us all, and she is deeply missed.

During her courageous fight against kidney disease, Mrs. Roshankhanu Shamshudin Jetha received exceptional care at Sunnybrook Hospital's Kidney Care Clinic. The kindness, compassion and dedication of the doctors, nurses, dietitians and staff made a profound difference in her journey.

*Imshaan's Grandmother*



*Nizar G. Manji & Family*

Throughout this time, we saw first-hand the daily challenges faced by those who live with kidney disease. The medical care that kidney patients receive in renal programs at hospitals coupled with the patient support offered through The Kidney Foundation of Canada inspired us to give back. We are honoured to leave a legacy gift in her memory and support the vital work of The Kidney Foundation of Canada so that other patients can receive the support that is so vitally necessary.

Thank you for being there for our family during a challenging time. We hope that her legacy will live on through the countless lives touched by The Kidney Foundation of Canada.

Learn more about how you can leave a legacy by visiting [kidney.ca/planned-giving](https://www.kidney.ca/planned-giving)

# Apple Cranberry Mini Muffins

By chef Anna Olson, reviewed and adapted to the kidney diet by Registered Dietitian June Martin

## Directions

**A**pple butter is simply apples cooked down past the applesauce state until they have a natural, concentrated sweetness, and means that additional sugar is not needed here to make these muffins sweet.

- Preheat the oven to 350 °F and grease a mini muffin tin or line the tin with paper liners.
- In a large bowl, whisk the apple butter, apple or orange juice and egg. Stir in the grated apple.
- In a separate bowl, stir the flour, baking soda, cream of tartar, cinnamon, allspice, and salt. Add this to the apple butter mixture and stir just until evenly blended. Stir in the dried cranberries and scoop the batter into the prepared muffin tin.
- Bake the mini muffins for 15-18 minutes or until a tester inserted in the center of a muffin comes out clean. Cool the muffins in the tin for 20 minutes, then lift them out to cool completely.

**Note:** The mini muffins will keep for up to 4 days in an airtight container, or can be frozen for up to 3 months.

**Preparation time:** 10 minutes

**Cooking time:** 15 minutes

## Food Safety Tips:

- Wash your hands with soap and warm water for at least 20 seconds.
- Clean all countertops and equipment used for food preparation.
- Gently rinse all produce under cool running water.
- Use separate equipment for handling raw food and cooked food.
- Do not eat raw dough or batter as it may contain bacteria that could cause you to become sick.

*These mini muffins satisfy your sweet cravings with soft, tender bites of apple and tart cranberry in every mouthful.*

## Ingredients

1/2 cup pure apple butter  
 1 cup wheat flour  
 3/4 tsp baking soda  
 1/4 tsp cream of tartar  
 1/2 tsp ground cinnamon  
 1/4 tsp ground allspice  
 1/4 tsp salt  
 1/2 cup dried cranberries  
 1 egg  
 1/4 cup apple or orange juice  
 (please note the nutritional analysis of this recipe includes orange juice)  
 1 cup coarsely grated, peeled apple  
 (any variety)



# Cooking with Care – When AI Gets Kidney Diets Wrong

Contributors: Andrea Rudy and John Vardalos, J5 Design

**A**rtificial intelligence (AI) is changing the way people look for information, including recipes for special diets like those needed in kidney disease. While AI can generate quick ideas, there are important limitations and risks that patients and care partners should be aware of before relying on it for guidance.



## ***Inaccurate or Generic Nutrition Information***

AI-generated recipes may not always reflect the dietary requirements of people with kidney disease, and suggestions may not consider specific or unique nutritional needs. Because AI tools pull from broad sources, they can produce recipes that sound healthy in general but aren't always kidney-safe in practice.



## ***Lack of Personalization***

Kidney diets are highly individualized. A person on dialysis may have different restrictions than someone with early-stage chronic kidney disease. AI cannot take into account a patient's lab values, stage of disease, or fluid restrictions. This "one-size-fits-all" approach can give a false sense of security.



## ***Limited Context and Oversight***

AI doesn't know your full health picture, medications, or comorbidities. It may not take drug–nutrient interactions into account, which can lead to inaccurate guidance and potential health risks. Without professional oversight, AI-generated meal ideas may unintentionally cause harm.



## ***Overconfidence in Technology***

Because AI provides information in a confident, natural-sounding tone, people may assume the recommendations are safe or medically approved. This can lead to misplaced trust and fewer conversations with registered dietitians trained to provide evidence-based and individualized advice.



## ***Missed Opportunities for Education***

Working with a dietitian provides more than just recipes. Patients learn skills like reading food labels, balancing portion sizes, and finding practical substitutes—all essential for long-term success. AI lacks the human touch and teaching component that helps patients truly understand their diet.

*“AI can transform healthcare, but only when it’s grounded in the lived experience and realities of technicians, patients, and family caregivers. The most responsible systems are designed with people at the centre and validated with the same rigor and evidence expected of any other care-related intervention.”*

John Vadalos, CEO [jfive.com](http://jfive.com)

Using AI can be a fun way to spark ideas in the kitchen, but it should never replace professional dietary guidance. For kidney patients, certain dietary changes can have an impact on health. The safest approach is to use AI recipes only as inspiration, then review them with a registered dietitian or healthcare provider before adding them to your meal plan.

You can also use a trusted resource for every stage of kidney disease like [kidneycommunitykitchen.ca](http://kidneycommunitykitchen.ca), where you will find reliable, stage-specific diet guidance, detailed recipes, and practical meal-planning tools.

### **Did You Know?**

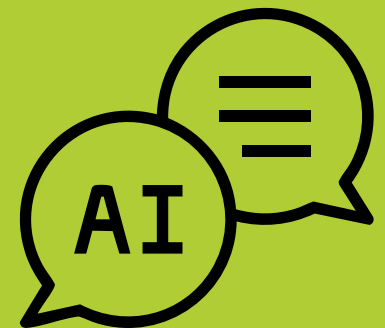
AI’s accuracy depends on the quality and reliability of its training data, which can often be flawed or unverified on the internet.

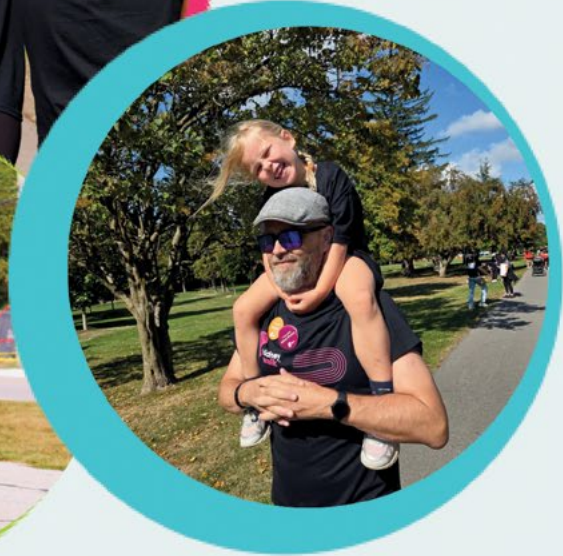
### **Pro Tip**

Recognize oversimplification. Complicated issues like kidney disease rarely have simple one-size-fits-all answers. If the explanation feels too elementary, it may be leaving out important nuances.

### **How to Safely Use AI for Recipe Inspiration**

- Use AI for ideas, not instructions. Think of recipes as a starting point to spark creativity.
- Check ingredients carefully. Look out for high-potassium, high-phosphorus, or high sodium foods.
- Watch portion sizes. Even safe foods can become unsafe in large amounts.
- Cross-check with reliable sources. Compare recipes to trusted kidney diet resources.
- Talk to your dietitian. Bring new recipe ideas to your healthcare team for review.





Together, we're stronger than kidney disease

Register at [kidneywalk.ca](http://kidneywalk.ca)



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