

My Totally awesome Kidney Adventure

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A huge thank you to.....

Somewhere in North Bay early August 10 2018 some unfortunate fellow died from a Brain tumour. He had the foresight, and his family had the resolve to see that his organs were harvested and used to end the suffering of someone he and they did not know and would never meet. I am that unknown recipient.

My wife who I jokingly call my weary deary has demonstrated endless love. There are no ifs, no ands nor any ors about it, without her by my side I would have given up a long time ago. She has answered the question “If it all fell to pieces tomorrow would you still be mine?”

Few are as lucky as I am to have friends who make a difference. Laurie is one of those friends. I always seemed to get a call from him when I was the most depressed and usually ended up laughing. So thank you Laurie.

Sometimes people surprise you with their lack of selfishness. Half a dozen people offered me their kidneys. For various reasons they did not work out. To Steve, Rob, Eleanor, John, James and Judy; thank you.

Allot of Doctors and Nurses worked to keep me alive. For an old toolmaker who spent his life in a cold uncaring world of making metal and plastic parts it was a shock to meet so many strangers willing to care for you, It was a side of life I never really knew.

The Nephrology Department at the General Hospital

Dr. Mohan Biyani,
Dr. Kevin Burns,
Dr. Todd Fairhead,
Dr. Swapnil Hiremath,
Dr. Stephanie Hoar,
Dr. Peter Wagner,
Dr. Brendan McCormick,
Dr. Deborah Zimmerman,

The surgeon who headed the transplant team:

Dr Brian Blew, thank you

The nurses

Dana, the very patient vascular Access Nurse
Dialysis Nurse Marie Jose and countless others, I wish I kept a list of every nurse who was kind to me; every one has earned a place in my heart by holding my hand when needed and keeping me alive for years on end. Give them a raise.
Michael who sweeps the dialysis room and made a point of talking to me, he was always smiling and the techs who kept my home dialysis machines working they were always competent and friendly.

Polycystic Kidney Definition

Polycystic kidney disease (PKD) is a genetic disorder that causes many fluid-filled cysts to grow in your kidneys. PKD cysts can change the shape of your kidneys, including making them much larger. PKD is a form of chronic kidney disease (CKD) that reduces kidney function and leads to kidney failure. PKD also can cause other complications, or problems, such as high blood pressure, cysts in the liver, and problems with blood vessels in your brain and heart.¹

Family History Grandmother Clare, Grant, Murray and Beverly

In the spring of 1923 George's wife, Maria Alice (my great-grandmother) had surgery to remove one of her kidneys. The reason for its removal is surmised to be PKD. The family was not at all happy with the way the operation was conducted, and seemed to blame Maria's death on the surgery. Following the surgery, Maria suffered 9 weeks and died on July 25, 1923 at Holy Cross Hospital, in Calgary. The cause of death listed on her death certificate was "uremia." She was 68.²

It is reasonable to surmise that Grant, her son (my grandfather) who died at 58 suffering from High Blood pressure and eventually a heart attack also suffered from PKD because "The majority of patients with chronic Kidney Disease will die from Cardio Vascular causes before reaching End Stage Renal Disease".³ His cause of death is however speculation.

His Daughter, Beverly (my mother) and his Son, Murray (my uncle) both suffered from PKD. As you would expect Beverly's progress was much slower than Murray's which is consistent with medical research. "Male patients with autosomal dominant polycystic kidney disease (ADPKD) begin Hemodialysis earlier than female patients. The rate of progression of many other renal diseases is also faster in men than women."⁴

Beverly lived to be 87 and died when complications developed between her renal medications and Heart medications, they became impossible to stabilize. She was fastidious with her weight, blood pressure, exercise and diet and lived a long healthy life with no dialysis. Murray chose no intervention; he passed away at the age of 64.

Blood Pressure, Dr Posen and the HK prophecy

Murray was diagnosed with PKD after a car accident lead to bleeding in his urine, this was investigated and PKD was discovered. My mother Bev was then examined in 1980 as was I and she was treated by Dr Posen at the General Hospital.

When I went to Dr Posen he said "This will kill you when your 80, don't worry about this now, live a happy life. I have sick patients to take care of, so thank-you, good day to you sir!" So I did not worry about it. My blood pressure was never really under particularly good control, I did not control my weight or salt intake. It turns out the purpose of my life is to be a warning to others.⁵

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When my family doctor retired only the last 10 years of records were given to the new doctor. In the preceding 10 years I had received no treatment for PKD so my new doctor was unaware I was afflicted. When I started to complain of PKD type symptoms it was not the center of my focus or of my doctors. Around the age of 57 the PKD disease progressed to the point where I was always very tired. I did frequently reflect that my grandfather died at 58 and my symptoms were starting at 57. In hindsight it's all very obvious.

While in HK on a business trip in 1995 I found myself in the Temple Street market in Central Hong Kong. At the end of a dark alley which opened up into a big courtyard filled with 20 or 25 palm readers. My reading included the following predictions

- I had a kidney problem
- It would cause me great turmoil for 5 years
- My brothers and sisters would be unable to help me
- Once thru the turmoil I would have a trouble free time until my death at 74

Time will tell if the last prediction comes true, the first 3 were correct. My brothers and sisters were unable to help me due to their own PKD prognosis, it was 5 years of turmoil and I did have a kidney problem. Generally I don't believe in Palm reading, Ouija boards or horoscopes, but this certainly causes me to ponder.

Diagnosis and Dialysis (you have 3 great options)

Exhaustion and Blood Work

Around the time I was diagnosed we had a small farm out in the country and a 5th floor condo in the city. For exercise I worked a 2 acre garden and at the condo I would jog up 5 flights of stairs rather than use the elevator. I had endless energy from the early morning until the late evening going from my fulltime job, my farm, to my condo, working on one project or another.

I started to notice my capacity for high levels of exertion becoming less and less. It started on a trip to New Zealand a few years earlier where hiking up Mount Egmont⁶ was beyond me, I could have done it a few years earlier but now, I was old beyond my years. At the farm I frequently hired people to help with tasks over a two year period I went from working along side the helpers to watching the helpers wondering why I was so tired.

Over a period of about 6 months I went from a normal level of activity, to having to go to bed at 8 in the evening and sleeping until 8 the next morning, then I could not make it up the stairs, then I found myself sitting on chair in the garden wondering why I did not have the energy to walk 100 yards.

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Normally I loved spicy food and my tolerance for any sort of spicy food or alcohol went to zero; I developed constant and intense GERD¹ and started foaming at the mouth. It was the foaming at the mouth that finally got my attention and sent me to my family doctor for blood work. Over a period of 6 months I visited the doctor 3 times, and each time the doctor gave me a requisition for blood work and each time I found something better to do other than spending 30 minutes going to a clinic to have a sample taken.

When I finally did get blood work done and the results came back my creatinine level was over 1,000 mL/min normal creatinine clearance for a healthy man is 100 mL/min. in males.⁷ When my family Dr could not get in touch with me, she called my wife who came to get me at work, I was then driven directly to the hospital, they were waiting for me, I was admitted. It was explained to me that with a creatinine level of over 1,000 mL/min I was about to have a heart attack, if not today, in the next few days, but I would not survive the next few weeks without immediate intervention.

The 3 great options that everyone who has kidney failure gets are:

1. Hemodialysis: filtering of your blood on a machine in the hospital 3 times a week for between 4 and 5 hours at a time. This involved a temporary catheter being installed in your chest near your heart. No more showers and the worry of infections are high so keep clean. After 3 months of training you can do dialysis at home, if you can insert the 2 one and a half inch long needles into your arm yourself. What was that? What is this thing you call a fistula?
2. Peritoneal Dialysis (PD), this involves the installation of a catheter in your belly. The PD you can do at home, but you'll have about 3 liters of sugar water in the lining of your stomach, it's a bit uncomfortable, it slops around, but you get used to it. But not an option for me right now, because I was a "drop in"² there was no time. You need dialysis today.
3. Or of course you can do nothing and you will die. It's a nice death, you just get sleepy, palliative care workers hope for a kidney death as it's the most peaceful. You're really quite lucky. At this point I did not feel lucky.

The Algonquin Plan or life is worth living as long as you're holding my hand

I was a little pissed at first. I told anyone who would listen³ to leave me alone. My plan was to paddle into Algonquin Park and not come back. I liked Algonquin Park but on

¹ Gastroesophageal reflux disease (GERD) occurs when stomach acid frequently flows back into the tube connecting your mouth and stomach (esophagus). This backwash (acid reflux) can irritate the lining of your esophagus. Many people experience acid reflux from time to time. GERD is mild acid reflux that occurs at least twice a week, or moderate to severe acid reflux that occurs at least once a week. As the kidneys go from fist sized to fully infected by PKD they grow to football sized, this expansion pushes your insides around and leads to GERD.

² A "drop in" is a patient so out of touch that they do not do anything about their kidney failure until the very last minute. Some people with PKD get a transplant before they need dialysis because they have been under a doctor's care for years and have been on a waiting list for years before the final decline of their renal function. I was one of those out of touch patients.

³ For a few days about the only thing that came out of my mouth was a string of choice expletives.

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reflection while we all die alone, I don't really want to die *that* alone. That and the practical reality of not having the strength to drive for 5 hours, paddling into the wilderness, setting up a camp and waiting for the grim reaper was lost on me. I was not really thinking that clearly. There is a phenomenon called the Uremic Brain or Uremic Encephalopathy⁸ that was clouding my judgment.

Despite telling everyone to leave me alone my sweetheart Judy did not and she sat patiently at my bedside holding my hand for hours on end. At one point my anger and hostility cleared and I realized she was there and I decided "Life was worth living as long as you are holding my hand". I have not looked back from that decision and started to look at my whole situation as "**That makes me the lucky one**". I started noticing the blessings in my life rather than my misfortune. It was still a drag, but at least now the strings of obscenities returned to a normal level and I could at least smile and say thank you. The elapsed time to that transition was a miserable 4 days.

First Dialysis and learning to shut up and do what you are told.

My dialysis adventure started at the General Hospital main campus. This is where you start and end your dialysis journey. First timers and difficult cases get the attention of this unit. Once you stabilize you can go to the Riverside dialysis unit or the Baseline clinic or you graduate to Home Hemo Dialysis or Home Peritoneal Dialysis. Some people are on dialysis for 10 or 20 years or more years and complications eventually kill you. Those who are high risk are in this unit.

Before this first treatment I had a Central Venous Catheter (CVC)⁹ installed. A CVC is a flexible, long, plastic, y-shaped tube that is threaded through your skin into a central vein in your chest or neck. A CVC is not usually intended to be permanent but in my case it was a bit of an emergency and there was no time to create an AV fistula. The nurse who did my dialysis for the first time was an old hand, a short feisty nurse about 60 years of age who had a good sense of humor a definite limp and who had seen it all before. She got me through the procedure with flying colours and then I was alone for the first time in a dialysis unit with 4 hours ahead of me with nothing but my thoughts.

To my left was an older gentleman being hooked up, after the nurse was done, a few pleasantries were said and off she went. Only a few brief moments went by and I said hello to my dialysis neighbour and as he nodded, he literally nodded off, passed out, lost consciousness, gone! Surprised, no sooner had the words "Nurse" come out of my mouth, that an alarm on the dialysis machine went off and she was back at his side, the chair flipped up his legs, his head dropped,⁴ and she started emergency procedures.

Within 30 seconds there were 3 nurses, within a minute there were 10 nurses, doctors, pharmacists surrounding the patients and within 2 minutes there were a pharmaceutical

⁴ Dialysis chairs are built so that in the event of a sudden blood pressure drop in the patient the nurse can activate a feature of the chair and the feet come up and the head drops down, this assists in the patient regaining consciousness.

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and coronary crash cart and perhaps 20 medical staff surrounding the patient. It was crowded and I had a ring side seat. For your first dialysis treatment the social worker is to visit to make sure you are all right and on this visit Judy had met her outside the dialysis room seconds before this incident.

After things stabilized she told Judy to just put her hand on her back and follow her through the emergency response. When they arrived they were both very concerned as to how I would have responded to this calamity. With a big smile I said “This is the safest place in the world, this is where I want to have a heart attack” As it turned out I never found out what happened to that poor gentleman I was told in general terms he spend a few days in the ICU and he survived his heart attack.

I was lucky in that I stabilized very quickly and was transferred to the Riverside outpatient clinic within a couple of weeks of being admitted to the General Hospital. Once at the Riverside, the main concern became my diet. The Dialysis diet is fairly restrictive it goes like this.

- Restricted fluid intake. No more than one liter of all fluids per day.
- Restricted Salt intake. No food with more than 6% RDI on the label
- Restrict Potassium, no bananas, milk, cheese, pizza, Melons or raisins
- Eat lots of meat 4 large portions a day
- Grains are okay, but not whole, white is better.
- Avoid potatoes, tomatoes avocados, asparagus and beets

One day feeling particularly angry at my situation but being well enough to be out on my own and not having Judy there to keep me in line I went to Red Lobster for lunch. Having been on a restrictive diet for a few months at this point I was a bit fed up. Up to this point I had been on a short lead and had obeyed all the rules laid out for me. But this day I decided to exert some control over my situation and went to Red Lobster¹⁰ for lunch by myself and ordered something they called the Ultimate Feast®.

It was a delicious assortment of 2 lobster tails, with melted salted butter, a side of wild-caught North American snow crab legs, garlic shrimp scampi along with crispy shrimp all on a bed of rice with an endless stream of the godliest biscuits with, I could not believe my good fortune, salted butter to boot. I ate and I ate well. After a \$50.00 spread for one I proceeded to the Baseline Dialysis clinic. I was hooked up and then promptly passed out on the dialysis machine.

Waking up a few minutes later with an oxygen mask on my face and my legs up and my head down⁵, feeling somewhat worse for wear the nurse scowled at me angrily asking me what I had eaten? Hmmm, maybe these guidelines made a difference. When I explained my Lobster Feast she explained in no uncertain terms that I was two pieces of pizza and a

⁵ Yes they had those good chairs. I experienced a sudden drop in blood pressure that can occur when the patient has been a stubborn idiot who decides to eat a huge plate of salty sea food dipped in salty butter while scoffing down salty biscuits lathered with salty butter. Apparently dialysis units are equipped for those of use who are also cognitively impaired as well as kidney impaired.

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beer away from death and if I wanted to kill myself fine, but please don't do it on a Tuesday because that was the day she worked. Her sincerity had an effect on me. I had a few hours to reflect on my eating habits and my course of action moving forward.

Over the preceding months I had also been advised that crystals, a séance, a vegan diet, micro nutrients or a quick trip to China where transplants were available for only 10,000 dollars could all solve my problems. I had to compare and contrast this with what my team of nephrologists, cardiologists, pharmacists, general practitioners, nurses and assorted technologists had to say with the “alternative voices” that were rattling around in my head. Having already been a victim of vegetarianism, and not particularly enamored with the thought of some poor Falun Gong ¹¹ member being executed so I could have a kidney I decided to go with what I thought was my best chance at survival. I coined this phrase to describe my strategy:

I would shut up and do what I was told.

In hindsight this uncharacteristic move was a stroke of genius.

Clinic Visits with Dr Zimmerman and other exceptional Doctors

Clinic visits were monthly visits with a nurse, a dietician, a social worker, a pretend doctor they called Fellows and the real doctors who were nephrologists. I say the fellows are pretend doctors because after a few months of experience with dialysis what they said started to contradict what the nephrologists had planned for me. The contradictions were glaring and a patient had to be careful with what the fellows said. Fortunately they were watched closely and it was a team that reviewed your blood work to ensure that the dialysis treatment, medications and your diet were appropriate.

There was also an educational component to this as they encouraged you to be active, to evaluate your treatment PD vs HD, Home Dialysis vs In Center and overall they wanted to make sure you were not depressed to the point of wanting to jump off a bridge.

Unfortunately for my doctors I am a mechanical engineering technologist and like to know how things work. Invariably before each meeting with a doctor, I had type written statements and questions that I wanted corrected and answered. The response from the doctors varied with the personality of the doctors

- A few doctors got mad and were insulted by my apparent lack of trust and unquestioning faith in their knowledge. Encounters with these doctors made you feel like a block of meat and created frustration, fear, and when you're very sick created desperation that leads to suicidal thoughts. Fortunately I only met a couple of these twats and not until I was post transplant.
- Most doctors answered your questions and in some cases brought copies of studies that related to your “research” They were much appreciated, showing a level of respect and acknowledgement of you as a sentient human being that sometimes would carry you along for days on end. This was the vast majority of doctors, almost all with only a few exceptions.

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- Some doctors read your questions, think about them and then lead a discussion with you explaining the underlying science, other research you should consider and, although they made it clear they were busy and on a schedule ensured that you understood your situation and helped you make an informed decision about the next step in your treatment. One of those doctors, and I met a few, but one of those doctors was Dr Zimmerman of the Dialysis Clinic in the Nephrology Department at the Riverside Hospital. I really enjoyed talking and learning with Dr Zimmerman.

Dr Zimmerman always took the time to explain my situation, addressed my concerns and when I asked gave me a clear direction in regards to the choices I should make that related to my specific situation. Another Doctor who took the time and made it clear that she cared about me as a person was Dr Hoar in the post transplant clinic. They say your attitude can carry you a long way in your recovery. This is true, but also true is that your doctor's attitude could make or break you as a patient.

Hemodialysis in the Riverside Hospital and Baseline Clinic

I spent about half a year in dialysis at the Riverside and then half a year at the Baseline Dialysis clinic. The big difference for me was that the Baseline Dialysis clinic was only a 5 minute drive from our condo. The care in both facilities was comparable, there were more doctors at the hospital, but all the doctors rotated between the clinic and the hospital. The machines at the clinic were newer but that did not make a big difference to me as a patient. In both places the people were supportive, the units clean, and you were stuck on a machine for 4 and half hours 3 times a week.

In hindsight I think I liked the hospital more simply because there was a place for Judy to sit and more people for her to talk to, but there was no big difference other than you had to have no complications to be at the clinic.

Peritoneal Dialysis (PD) at home and Drain Pain

Peritoneal Dialysis is a process where you pump about 3 liters of a special cleansing fluid flows through a surgically installed tube into your belly. It goes into the lining of your abdomen (peritoneum) and the peritoneum⁶ acts as a filter and removes waste products from your blood. After about 4 hours the fluid with the filtered waste products is pumped out of your abdomen and is discarded.¹²

There are a couple of very good reasons to be on PD as opposed to being a Hemodialysis patient.

1. You are only tied to a machine while you fill up and drain. For me this meant more time at my farm, not chained to a hospital.

⁶ per-i-to-ne-um (per'i-tō-nē'ūm, -ă) The serous membrane, consisting of mesothelium and connective tissue, that lines the abdominal cavity and covers most of the viscera contained therein; it forms two sacs: the peritoneal (or greater) sac and the omental bursa (lesser sac), connected by the epiploic foramen. from Medical Dictionary for the Health Professions and Nursing © Farlex 2012

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2. You can do this overnight, it completely destroys your sleep as the machine cycles through a number of fills and drains, but it looks good on paper and they encourage this. For me this was a six month long swing and painful miss.
3. You are half as likely to be hospitalized over the first 12 months (hazard ratio, 2.17; 95% confidence interval, 1.34-3.51; P <.01) on Peritoneal Dialysis when compared to a Hemodialysis patient
4. The healthcare costs over the 12-month follow-up period is about \$43,000 higher (\$173,507 vs \$129,997 for Hemo Dialysis patients)¹³

There are a few downsides to Peritoneal Dialysis as well;

1. You have 3 or 4 liters of fluid in your peritoneum, its not painful or uncomfortable but you feel it.
2. Drain pain is a miserable and for me unavoidable feeling as the last of the fluid is sucked from you belly. The pain is not in the belly however but an excruciating sucking on the genital area, from the inside. Make no mistake this sucking in the genital area is not in any way desirable.
3. The initial approach when confronted with drain pain is **aggressive laxative administration**. This strategy can help by forcing peristalsis and forcing movement of the tip of the catheter.¹⁴ In other words we are going to move you're bowels so violently that your insides become realigned. It's not the way they explain it to you but it's what it amounts to.

So what is drain pain? Not allot written about it but I did find this:

“Contemporary cyclers use hydraulic suction rather than gravity to drain dialysate and drain pain is thought by some to be caused by the consequent application of negative pressure to the very sensitive parietal peritoneum toward the end of each drain cycle. This leads to referred pain, often quite unpleasant and felt in the genital areas. Others speculate that the pain is related to negative suction on the external bowel wall.

However, hydraulic suction cannot be the only factor as there is a marked ‘center effect’⁷ in the prevalence of drain pain. ... Suggests a relationship to how peritoneal catheters are placed. Crabtree has speculated that drain pain is more likely to occur if the intra peritoneal portion of the catheter is too long, due to the insertion site being too low in the abdomen relative to the patient’s pelvic anatomy

4. Drain pain alone would have been a “lets stop this show now” type of event but to add insult to genital injury the Peritoneal Dialysis was not working. It was not cleaning my blood enough. It simply does not work on some people, after the fact it was explained to me;

⁷ Yah about that center effect, its right in the center of your manhood, I would literally rather very slowly thread 2 long needles into my arm every second day for the rest of my life than have the inside of my penis be sucked back into my body cavity. To this day I am sure it's shorter. My advice would be “do not try this at home” but please keep in mind not everyone on PD is subjected to the pleasures of drain pain, your results may vary.

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- a. I had had surgery for an obstructed bowel and my peritoneum had been cut and healed, I was told after that this made it almost a sure fire failure. I wish they had said that to me earlier.
- b. I weigh over 100kg and I was told afterwards it works better on small and thin people. Large men not so much. I wish they had said that to me earlier.
- c. PD vs HD, PD is cheaper for the system and safer for the patient, these are good and valid reasons. That gets lost on you however when you are sitting on the edge of your bed every morning as the last of your night cycle is being completed and you are feeling this sucking from the inside that is in no way pleasant.

Sadly there is not much research into drain pain. From the limited literature on the subject it seems to be a mechanical problem, an error in installation. The really sad part of that experience was that no one ever mentioned drain pain and seemed “surprised” when I reported it, saying things like, oh that’s odd. But you know when you are being lied to, and this is one of those things, they run up the flag pole, if you’re in pain, oh well, you’re odd, that usually does not happen. But for this cohort of one it affected me negatively 100% of the time.

Combination Hemo-dialysis (HD) and Peritoneal dialysis (PD).

With the failure of PD I was started back on HD in center, this brought me back to the Riverside hospital. It was decided to create a fistula for HD, the objective of the fistula was to get rid of the Central Venous Catheter that was still stuck in my neck / Chest.

While on PD I had a surgically installed catheter permanently stuck in my belly and a surgically installed catheter permanently stuck in my upper chest/ neck area. If you can’t picture that, consider yourself lucky.

While a belly catheter was a long term part of PD, the central Venous catheter (CVC) was a temporary fix that lasted a year and half. They try to replace the CVC with a fistula because the CVC is prone to infection. The fistula is really the only practical long-term access for HD. A surgeon connects an artery to a vein in your arm, to create a fistula. An artery is a blood vessel that carries blood away from your heart. A vein is a blood vessel that carries blood back toward your heart. When the surgeon connects an artery to a vein, the vein matures and grows wider and thicker, making it easier to place the needles for dialysis. The AV fistula also has a large diameter that allows your blood to flow out and back into your body quickly. The goal is to allow high blood flow so that the largest amount of blood can pass through the dialyzer.¹⁵

The first fistula in my left arm did not work; the second one in my right did. It takes a while for the fistula to “mature” Which means swell up and become an easy target for the nurses. Until then the poor nurses are trying and missing the vein, when a .090 diameter needle that is about an inch and a half long has to be threaded into a .250 diameter vein there is a chance it will puncture the wall of the vein. It hurts and you become jumpy, the

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nurses, most of whom do not like inflicting pain also become a bit jumpy; it's a sort of cruel and painful circle. Eventually everyone calms down but if you combine an inexperienced nurse adverse with inflicting pain with an inexperienced, frightened, pain adverse patient, its sometime not a friendly 30 minutes as attempts are made and failures happen.

The failure is a big welt on your fistula that makes the fistula not usable for a few days. If you have a CVC then you go back to that. For me this went on for a few months. I commented to hospital administrators that perhaps more training was in order. I meant for the nurses, but they interpreted my helpful suggestion as a request to learn how to needle myself. It was a bit of a surprise to me when I was introduced to my new best friend Dana the vascular access nurse.

Home Dialysis: Smile with the rising sun, three little birds...

There are 5 essential steps to home dialysis

1. Having a well developed fistula; the best way to develop the fistula is to use the fistula, having one nurse, Dana, do all the needling during the month of training got my fistula established.
2. Being ready, willing and able to needle yourself; I became ready after multiple painful attempts with multiple nurses. The nurses had 2 failures to each successful needling. Once trained I did not have a single vein puncture. Not one in over 700 needlings. Its not that I was good, it's just that I could feel what was going on they could not.
3. Being ready, willing and able to learning the process of home dialysis; I am a machinist and tool and die maker experienced programming CNC machining centers, I actually like machines and enjoyed the process of working with the dialysis machine and RO filters.
4. Having the physical space for the machines, bed and storage of supplies; we sold our condo and bought a house to make home dialysis possible. We had the option to use our farm but I wanted to be closer to emergency care if needed.
5. Having a support person to help with needling and monitoring of your progress; I am the luckiest man alive in that my sweetheart was endlessly supportive and willing to give me 100% of her attention. I could not have dealt with the needling or the odd combination of terror and monotony that home dialysis is without her help.

The training for the needling took about a month. It was a very incremental process of being taught the 30 various steps and mastering one new one each day. Eventually the only step left was sticking those 2 needles in your arm. By that time Dana had walked you through everything 20 or 30 times, held your hand right up to the last step and eventually you are just ready to do it. Dana described me as perhaps her most needle adverse patient ever. I never wanted to do it, and I never wanted to give up on it.

The training for the machine took another 2 months and involved doing your dialysis in the training center where they had half a dozen rooms where people are trained on PD

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and HD. Same idea, a new step each day and eventually you are on your own. Its all hands on training with allot of hand holding

Our setup at home completely occupied a 12 x 12 bedroom. The hospital installed a dedicated hydro line for the machine and water service to the room. The dialysis machine is the size of a small refrigerator and the Reverse Osmosis water filter is the size of a small oven with 2 large water tanks the size of acetylene tanks used in welding. Water use is quite high and we got a provincial rebate on our water bill. This was another reason we did not do this at our farm, hydro was erratic and water was from a well, we did not know if the well would support the hundreds of gallons required each day.

The supplies were another issue, the road to our farm was long and very rural, our driveway almost a kilometer long, we have two 4 wheel drive trucks for a reason and the transport truck deliveries which came monthly would not be practical in a remote farm location. The supplies amounted to 5 cabinets and 10 drawers on 2 walls all filled to overflowing with an additional pallet sized area piled with boxes of supplies. In the middle of the room was a bed with the machines to the left of it. A small hospital table on wheels held all the needling supplies.

Every second day I started Willie Nelsons Evergreens and in the hour and half it took to play that CD I got the machine setup. If you're a music snob and have negative thoughts about my buddy Willy Nelson you can screw off. That CD got me through this. The songs were varied and spoke to me, especially Take it to the limit¹⁶ by the Eagles. At the time I was on a bit of an emotional rollercoaster and the downside was pretty well articulated by take it to the limit. You are in a dark place when you don't just completely relate to the following lyrics but are actually living the following lyrics.....

But the dreams I've seen lately
Keep on turning out and burning out and turning out the same

And when you're looking for your freedom (Nobody seems to care)
And you can't find the door (Can't find it anywhere)
When there's nothing to believe in
Still you're coming back, you're running back
You're coming back for more

So put me on a highway
And show me a sign
And take it to the limit one more time

Every day of home dialysis was pushing me to the limit. The music was a routine that kept me focused and on track. Judy's kindness kept me moving along that track.

The other song that became indispensable was Bob Marley & The Wailers "Three Little Birds"¹⁷ After everything was setup, cleaned, the water tested, the hoses strung in sequence, the filters in place, the system purged of air, the chemical baths stabilized, the

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error codes resolved and the needling table set up, the last thing I would do is go the bathroom, wash my hands for the tenth time during the setup, call Judy and put on my buddy Bob Marley.

The first needle was the easy needle because there was an adrenaline rush that got you through it, but the second needle was the really hard one, because the adrenaline was gone, you are tired. And sometimes the pain killer you put on your arm was starting to wear off, just enough that you felt a bit more than the first time, not painful, just a bit more awareness. It took about 20 minutes to prepare the sites and thread the 2 needles into my arm. Getting connected to the machine and getting all the air bubbles out of the lines took another 10 minutes, it was singing along with Bob Marley and Judy holding my hand that got me through it.

I usually sang along.

Rise up this mornin'
Smile with the risin' sun
Three little birds
Pitch by my doorstep
Singin' sweet songs
Of melodies pure and true
Sayin', ("This is my message to you-ou-ou")

Singin': "Don't worry 'bout a thing
'Cause every little thing gonna be all right"
Singin': "Don't worry (don't worry) 'bout a thing
'Cause every little thing gonna be all right!"

Singin': "Don't worry about a thing
'Cause every little thing gonna be all right" - I won't worry!
Singin': "Don't worry about a thing
'Cause every little thing gonna be all right"

Once a month I had to go into the dialysis clinic and I would get on their machine for a few hours and they would check my fistula for function, take blood and the Doctor would review your case. This one time the nurse came by to assist with the needling and I told her I forgot my CD of Bob Marley and I always listened to 3 three little birds. She started singing the song in a clear voice,
Singin': "Don't worry about a thing, oh no!
'Cause every little thing gonna be all right!" and I sang along.

As we sang I put in the needles and the noisy room of about 40 people on dialysis, the dozen or so nurses, technicians and general noise of a big hall just got quieter and quieter as we sang our melodies pure and true. Eventually you could hear a pin drop but for our singing. I got the needles in to **No** applause, my singing is never appreciated, but it was a neat moment anyway.

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While on home dialysis it was very much of an emotional roller coaster. While it was nice to be free of the hospital, it was also very stressful. The first few minutes of dialysis were frequently filled with alarms on the machine going off, and often a frantic call to the on call dialysis nurse. The alarms if not addressed could lead to your passing out, or getting an air embolism, they became routine but for the first few months stopped your heart. That was the upside; on the downside I was becoming depressed and anxious due to the endless monotony of dialysis. It was not painful, it was stressful and it was a combination of terrifying and boring. There were doctors to help, nurses on call 7 days a week and Judy was always by my side, but I felt alone and was becoming depressed.

Also around this time there started to be talk of a transplant, my placement on the list and doctors started talking about a 6 month window. Rather than making me happy it stirred up a lot of fears and anxiety from previous surgeries and I started seeing a psychiatrist at the General Hospital, who referred me to a psychotherapist to work through the anxiety which I did.

I am told that inevitably my new kidney will fail; 92 percent of kidneys work after one year after the transplantation success rate is still 84 percent after five years. The life of kidneys is getting longer; some are projecting 10 and 20 year transplants. I am told the biggest cause of failure at that point is that patients forget to take their medication.

Unfortunately at that point I would probably be too old for another transplant and would have to make a choice of treatment or not. Treatment would be dialysis again, if able I would prefer to do home HD dialysis rather than other alternatives.

7 surgeries for practice and countless tests for fun

Before the transplant of a new kidney I had a number of surgeries and tests

Vascular Access #1, #2 and #3

As mentioned earlier I had a Central Venous Catheter (CVC) installed. CVCs are polyurethane assemblies that contain a subcutaneous Dacron cuff for tissue in-growth; this grommet will immobilize the catheter below the skin surface. My CVC was placed into my jugular. CVC afford the luxury of speed, which was important for drop in cases like mine, but these devices are plagued by infection, thrombosis, inadequate blood flow, damage to large central veins and increased mortality risk which make their use problematic. A better solution is to develop an arterial venous fistula (AVF).¹⁸

I had 2 fistulas installed, one worked and one did not. The one that did work matured under the supervision of Dana my vascular nurse and worked without problems for over a year. A healthy fistula has a “thrill”; a rumbling that can be felt on the overlying skin as a vibration. Because large amounts of blood move through the fistulas from high-pressure arteries into low-pressure veins it creates a constant murmur that you can hear and if you put your hand over the fistula you can feel. It’s quite weird.

Fistula Gram 1 and 2:

A fistulogram is a procedure to look for blocked veins or abnormal narrowing of the fistula. You are given some local anesthesia and then a contrast liquid is injected into a catheter that has been put into the fistula in your arm, then several x-rays are taken. The contrast feeling is a warm feeling and then you feel sick to your stomach. After you calm down the blood flow and pressure in your fistula is measured. In my case they never found any serious clots so serious work was not required. For some the expansion of the fistula and or the insertion a stent is painful. The catheter was then removed and the procedure is complete. Your arm is left sore, swollen, and bruised after the procedure but this all fades in a few days. It's just another annoying, unpleasant experience.

Installing and removing a Peritoneal Catheter

The Peritoneal Catheter is surgically installed under a general anesthetic. I don't actually remember much about the surgery going in. In a short time there were allot of tests and allot of surgeries, this one is part of the blur. I remember it coming out because it was taken out with only a local anesthetic in the dialysis clinic. It was not painful just a bit disconcerting and it felt good to be finally rid of it.

With the Peritoneal Catheter in, you cannot have a shower, only a sponge bath. I also had a Central Venous Catheter in my chest and you can't have a shower with that either. The CVC was put in during my first week in the hospital. The strange thing is one of my strongest memories of this whole affair was the last shower I had on the day before I was admitted to the hospital. I did not know that morning that that afternoon I would be admitted to a hospital and essentially be tied to the hospital for 5 years with no shower for almost 2 years. But to this day I can remember standing in the shower that morning thinking how incredibly good it felt to be having a shower. It is a blindingly clear memory and almost feels like a premonition.

For me the installation and removal was a painless experience, it just did not work. For a neighbour of mine who also had a Peritoneal Catheter installed in the Kingston General Hospital it was a horrific experience, his bowel was perforated and he required a second emergency surgery. My scar is a tiny little circle beside my belly button; his scar is a foot long gash across the middle of his stomach. He almost died from his ordeal; once again I was the lucky one.

Complications: Butchers and Gropers

“Horror stories of medical incompetence, arrogance, and libidinousness have filled newspapers; broadsheets and tabloids have been united in their condemnation of a profession unable to regulate itself except when it's too late.”¹⁹ I had numerous complications⁸ and continue to have many complications⁹. There are numerous examples

⁸ Complications: Numerous bad reactions to anti rejection drugs, this went on for 4 months, almost complete hearing loss from lasix, extremely slow physical recovery due to acidosis.

⁹ Ongoing complications: Neurosis, excessive nightmares, fatigue, mental confusion, edema, acidosis

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of mistakes cause by ignorance by the medical staff¹⁰ and things I had to discover for myself only after months of suffering, things that should have been resolved by the physician.¹¹ In all cases you have to be well informed of your own situation.

Sadly that is really hard to do when you are very sick, for that reason you need an advocate. You are the only person who makes any decision about what is going to happen to you. In all cases you need an advocate by your side at **all** times ensuring you are safe from the staff. You need someone who is taking notes and writing down everything that is being said and the name of every Doctor, Nurse and Technician you have the good fortune to encounter.

Having said that, overall I think I received exemplary care. I think 99.5% of the people I had contact with were professionals who genuinely care about the care they give and want to help you live a long and healthy life. That 0.5% however your advocate has to be watching out for because they will rape or kill you.

It's a credit to the professionals in the system when you consider what they are doing, that they are doing the best they can in an environment of idiot politicians and vulture corporations circling around a public health care system.

Clostridium Difficile: And look at me, I'm in tatters

At different times different songs best articulated how I felt at any given time. The rolling stones "Shattered" best describes my experience with C. Difficile.

Shattered²⁰ Rolling Stones

Uh huh shattered, uh huh shattered, Love and hope and sex and dreams
Are still surviving on the street, Look at me, I'm in **tatters!**

C. Diff sometimes happens after a course of antibiotics. It can spread easily, and is unpleasant. I experienced diarrhea several times a day, a loss of appetite, and a fever. I became very dehydrated.²¹ To make matters worse this all happened while I was starting Peritoneal Dialysis and that lead to another complication that confused the issue and numerous visits to the Emergency room that went unresolved.

Crashing Blood Pressure and Smirking doctors

When I changed from HD to PD a change was required to my blood pressure medication. PD tends to moderate or normalize your blood pressure, if you're normally treated for high blood pressure as I was then the blood pressure medications may be no longer required or they will need to be adjusted. If you continue to take them your blood pressure will crash.

¹⁰ Mistakes caused by ignorance: EBV + kidney given to EBV - patient leading to PTLD, and the mistaken claim the incidence of PTLD is 1% when it is 15% in EBV- patients receiving a EBV+ Kidney

¹¹ Things that should have been caught by physicians: changes to B.P. meds with change from HD to PD

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No one told me this and no doctor was paying enough attention to change the prescriptions. My Blood Pressure crashed. Before my blood pressure was under poor control and was around 180/90, a normal pressure would be 120/80. On PD with my regular medication it dropped to 90/60. I was finding it hard to lift my head off the pillow and I repeatedly ended up in Emergency. Once there doctors were baffled by my combination of C. Diff symptoms and low blood pressure.

Eventually the C. Diff was identified but the low blood pressure continued. There did not seem to be any resolution even after infusion with saline to reduce my dehydration caused by the diarrhea and they just wanted to send me home. Judy refused to let them send me home; remember I was confused, nauseated and slipping in and out of sleep all the time, and so weak I could not lift my head off the pillow. So I languished in Emergency for multiple hours. Eventually Judy left for half an hour to get some dinner. I was left alone.

Sexual assault by Doctors' is probably not that common but it does happen. I remember a friend of mine, Paul had the following experience. When Paul was in his late teens he had a girlfriend also in her late teens. She was very pretty young woman endowed with ample breasts. Unfortunately she sprained her ankle and upon arrival at the examination rooms in the hospital the doctor started his examination by requesting she remove her blouse and brassiere. Fortunately she had an advocate in Paul who was aggressive in defending his girlfriend. As Paul retold the story he assertively corrected the young doctor's behavior and the ankle examination continued with her top and modesty intact. As I stated earlier it is dangerous to go to a hospital without an advocate.

Once alone, I drifted off to a low blood pressure sleep and was awoken by a young woman of an ethnic group that is obsessed with toilet culture. You can Google toilet culture and see what I mean. I had never seen her before; she identified herself as a resident doctor but I don't really know. She told me I needed an anal exam. I could not make a connection between low blood pressure and my anus but she insisted and alone without a nurse attendant this woman stuck as much of her hand as she could up my ass. This was uncomfortable and as she walked away without so much as how do you do she had a unusual smirk on her face as if to say, and I'm not sure, it could have been "boy that guy has a tight ass" or it could have been "Superior me! I humbled him and got away with it". In any event at that moment I thought to myself sexual assault **IS** about domination and that exam was not necessary.

Judy returned from dinner a few minutes later and when I described what had happened she wanted to follow up on it, but I just asked her to let it go and that's what I wanted to do, just go, let's leave. It's not a nice feeling to think of this event. Its not a big deal really if this is how this strange women gets her kicks so be it, in the current political culture there is little a white man can do about a "person of colour" sticking their hand up their ass, its just that this should be a warning to others in a vulnerable situation in a hospital, don't leave your loved ones alone, your parents, siblings, husbands, wives, or children in the presence of strangers even for 20 minutes. Sexual predators are out there waiting for

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the vulnerable, the perpetrator can be well dressed, men, women, priests, doctors, porters anyone. You need an advocate.

My underlying low blood pressure continued but this event prompted me to research the issue myself where I discovered in a manual provided by the hospital on PD that made the connection between low blood pressure and PD. The problem was quickly rectified when pointed out to the doctors.

Sores, Scabs and Sunshine

On to happier things, part of kidney failure is problems with your skin. You are going to have high levels of serum phosphorus. This is because dialysis can only take so much phosphorous out of your body. You are on a phosphorous restricted diet but some slips through. You may also react to the PVC in the blood tubing on the dialysis machine or to the dialyzer and the dialysis solutions. When you compound all this with the oil glands in your skin that cannot secrete enough oil to keep water in skin because you are on a water restricted diet²² and are hooked up to a machine for 12 hours a week that sucks the water out of your blood, it all makes for a dermatological perfect storm.

All of this to say I had itchy dry skin, so I scratched. Eventually my body was covered in hundreds of little scabs. The advice from the doctors and nurses is to stay clean, but I had not had a shower in a year and could only have sponge baths. Other helpful comments were things like, don't scratch. Yes I know but I would wake up scratching. Also don't eat foods high in phosphorus. Yes I know but there is phosphorous in a lot of non restricted foods.

Eventually I was referred to a dermatologist and started a Phototherapy²³ routine. This involved standing naked in a chamber of Ultraviolet lights (UVB and / or UVA) 3 times per week to dry out and heal my scabs. As well they prescribed powerful topical creams to prevent itching and speed healing.

Dermatologists usually advise against sun exposure but I was told to get naked in the noon day sun for at least 30 minutes a day. Yes officer I am just following doctors orders. At least that conversation never came to pass at our remote farm. All this did have a positive effect on my skin, not to mention the most bad ass line free tan I have ever had.

Exhaustion and the Uremic Brain

I worked for a few months while on dialysis, but the decline is slow and deliberate. There is no turning back. Eventually I became confused and extremely tired, the work of an engineering technologist in a plastics factory requires a working brain and I had to stop working. Uremic Brain or encephalopathy is an organic brain disorder. It develops in patients with renal failure, usually when the estimated glomerular filtration rate (eGFR) falls and remains below 15 mL/min. Symptoms vary from mild symptoms (eg, lassitude, fatigue) to severe signs (eg, seizures, coma). Severity and progression depend on the rate

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of decline in renal function; thus, symptoms are usually worse in patients with acute kidney injury²⁴

After dialysis the fatigue was quite intense, I would be out like a light after; no matter what time of day I had it. On dialysis I had one good day and one bad day, by good day I could walk, but not more than a hundred yards, I could do the basics in terms of hygiene and driving but that was about all. The confusion I experienced lead to an inability to deal with any sort of stress, having an email to read and answer was difficult. Any form of social media became an unbearable stress. Eventually each connection dropped off as the slightest hurdle went up. Most upsetting I could no longer envision a future. I was always a man with a plan, for the garden, my farm, my business, constantly planning. Now I could only react and only to very low levels of stress. I was agitated, uncomfortable and depressed.

Pre Transplant

The process of getting on the transplant list was strait forward enough. They want to qualify people for a transplant. Life is better after transplant. A transplant is a close to a cure as an End Stage Renal Patient can get. First they want to know if you can call a friend and get a live kidney. If the answer is yes it's a matter of qualifying and scheduling the surgery. You could be transplanted in 3 months.

If you are depending on the goodwill of others than there is waiting involved. In either case there are interviews, lots of blood work, ultrasounds, treadmills, and pre surgery conferences, mis starts and warnings. I was told in no uncertain terms that the outcome would be a new kidney that could last for 5 to 15 years and I was guaranteed to get skin cancer and diabetes. If I can accept that fact then I can move forward. Do you still want to wait for 5 to 7 years for the transplant? I said yes, but not everyone does.

Because I live in Canada there was one aspect I did not have to worry about and that is the cost. The biggest complaint would be the cost of hospital parking, but guess what. They give you a special card so its only \$40.00 every three months for parking so that is not evens a complaint worth making.

For an American dialysis is less than one-third of the medical cost. Looking at the 1995 yearly expenses for one patient

- \$24,000 on hospitalization,
- \$18,000 on medications and physicians care.
- \$27,000 for dialysis treatments, lab supplies and lab work
- \$10,000 administrative and insurance costs
- \$79,0000 total medical costs 1995

Medicare pays up to 80 percent, Medicare benefits do not start until four months from application date. Commercial health insurance and HMO's coverage varies from company to company. Private insurance is the primary insurer for the first 30 months and will coordinate benefits with Medicare. After that, Medicare becomes the primary insurer

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and the private insurance will be secondary if it still is in effect. Coverage varies with the person's social and economic caste. ”²⁵ It sounds like a living hell to me and I don't know if I would risk financial ruin for my family. I would probably as Wendell Berry states

Pass without haste or regret toward what will be,
my life a patient willing descent into the grass

As well as being more expensive and inaccessible full of complexities and rip offs the American system has the added benefit of having inferior outcomes for patients. An American study shows that the American dialysis patients fare worse than a similar Canadian patient with end-stage renal disease.²⁷

I was shocked but not surprised when I discovered that a disposable dialysis filter in Canada was a reusable filter in the US. The filter was reused up to 50 times between different patients. I believe that for profit should not be in the health care system. Again, being a Canadian makes me the lucky one.

Qualifying for a transplant

Hospitals in Canada follow the Canadian Society of Transplantation²⁸ consensus guidelines on eligibility for kidney transplantation

The basic checklist goes like this:

1. No cancers, infections, or uncorrectable heart disease.
2. No history of chronic noncompliance, hence my new found interest in shutting up and doing what I was told. Care after transplantation is important, it was explained to me that they care as much about respecting the donor as they care for you so they don't want to give a kidney to an irresponsible fool who will not respect the gift.
3. You are vaccinated, have a chest x-ray, screened for mycobacterium¹², and purified protein derivative skin testing¹³, a Serostatus for cytomegalovirus¹⁴ and Epstein-Barr virus¹⁵ and Screened for HIV¹⁶ infection.
4. No chronic drug abuse including alcohol. You have to keep in mind that some of the anti rejection drugs will mess up your head and mixing and matching with illicit drugs and alcohol is sure to backfire.
5. No Psychiatric problems that would be considered a high risk for increased severity of the disorder after transplantation. “Tacrolimus, a commonly used immunosuppressive drug can lead to Tacrolimus-induced psychosis. If quickly identified and substituting with another immunosuppressant the Tacrolimus-associated neurotoxicity may be reversed by discontinuing these drugs.”²⁹ The drugs they give you mess up your head.

¹² Mycobacterium is a genus of that includes tuberculosis, leprosy and 150 other diseases

¹³ Tuberculin, known as purified protein derivative, is used to diagnosis tuberculosis.

¹⁴ Pneumonia, I don't why they don't just number diseases rather than giving them multiple names.

¹⁵ Epstein-Barr virus, or Human gammaherpesvirus 4, is one of the nine known human herpesvirus types and is one of the most common viruses in humans. The cause of infectious mononucleosis

¹⁶ Human Immunodeficiency Viruses cause acquired immunodeficiency syndrome, leads to failure of the immune system leading to infections and cancers.

Waiting lists and the Antibody count

As soon as you start dialysis you are on the waiting list. If you're on top of things and seeing your doctor for a yearly check-up and they discover your diminished kidney function a few years in advance of End Stage Renal failure then you can start on the waiting list years before you need a transplant. "Preemptive kidney transplantation should not proceed unless the measured or calculated glomerular filtration rate is less than 20 mL/min and there is evidence of progressive and irreversible deterioration in renal function over the previous 6–12 months"³⁰ Which means that if your glomerular filtration drops to 20mL/min which means you are still walking about, you could be eligible for a transplant. Long before dialysis starts. A preemptive transplant is such a good idea. I was weakened by my diminished kidney function, 3 years of dialysis, the recovery from surgery, and the side effects of the drugs, it all would have been allot less painful if I had been proactive.

You met allot of people in the dialysis center that cannot get a transplant for medical reasons, they simply don't qualify, you also meet people who do qualify but are a 1/10,000 kidney match. These people wait 10+ years or never get a transplant. I matched 1 in 3 people who were rolled thru deaths door and were willing to donate a kidney. Why was I so lucky?

When I went on the list there were 70 blood type "o+" on the waiting list ahead of me. After a little over a year and I was number 60 on the list in terms of days waiting, yet I matched every third kidney that was available. Some of the other people on the list ahead of me could only match 1/10,000 or more. After a little under 2 years I was offered my first of three kidneys. I was assured I would receive a new kidney within a year of that date. When they match a kidney they match on a number of things

1. Age / size, they give a child a child's kidney and an old man an old mans kidney.
2. Blood typing (ABO compatibility) Blood typing measures blood antibodies. The Rh factor (+ or -) of blood does not matter. The following is by donor:
 - a. blood type A can donate to recipients with A and AB
 - b. blood type B can donate to recipients with blood types B and AB
 - c. blood type AB can donate to recipients with blood type AB only
 - d. blood type O can donate to A, B, AB and O (O is universal)

The following applies by recipient

- e. blood type O can receive a kidney from blood type O only
- f. blood type A can receive a kidney from blood types A and O
- g. blood type B can receive a kidney from blood types B and O
- h. blood type AB can receive a kidney from blood types A, B, AB and O

I was O, blood group O is a disadvantage in the allocation of deceased donor organs as it is the most common and as A, AB and B, can all match with O but O does not match with A, AB and B³¹ so there is a big demand for O kidneys.

3. HLA Tissue Typing Each person's tissues, except for identical twins, are different from everyone else's. The better the HLA match, the more successful the transplant will be over a longer period of time. a parent and child would have at least a 50 percent chance of matching, siblings could have a zero to 100 percent

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match, and unrelated donors are less likely to match at all. The best match for the recipient is to have 12 out of 12 antigen matches. (This is known as a zero mismatch.) It is possible for all 12 markers to match, even with an unrelated deceased donor organ, if the patient has a very common HLA type.

4. Antibodies to HLA Tissue typing this test is done for the patient only and is repeated monthly. HLA antibodies can be harmful to the transplanted organ and they can increase or decrease over time so they must be measured while waiting for a transplant. HLA antibody levels can change following events such as blood transfusions, miscarriages, minor surgeries (including dental work or fistula replacement) or severe infections
5. Percent Reactive Antibody (PRA) When you are exposed to foreign tissues, through a blood transfusion, exchange of body fluids, pregnancy or previous transplant; you develop antibodies to different HLA proteins. If you have a high level of HLA antibodies, it is more difficult to find a compatible kidney.
6. Serum Cross match Cells from the donor are mixed with your serum. If the antibodies show up under a special light, its positive and the transplanted kidney would be immediately rejected.

So why was I such an easy match, why was eligible for 1/3 kidneys when others were 1/10,000 allowing me to jump to the front of the line? I was O; I had no blood transfusions, no previous transplants, and low HLA and PLA counts. Having married my college sweetheart my rate of “protein exchange” was low so was my PRA count,¹⁷ PRA attaches to protein, now think of all the ways we share proteins away from the dinner table.

Turning down a kidney #1

My doctor turned down the first kidney that was offered without even talking to me. The reason she explained was because it was 75 plus year old person, I was in early 60's and had no co morbidities so I should get a kidney from a 50 or 55 year old it could carry me through for 10 or 20 years³² if I was lucky. It might only last 3 or 4 but better to try for a better one and that is when I learned about my 1/3 chance. I met the transplant coordinator after that and she explained I would be transplanted in 6 month to a year.

Cemetery Road Exit; waiting on death in the General Hospital #2

A few months later I got a call while I was driving my winter tires to be stored at my farm. I got a cell call and was asked to pull over by the caller from the General Hospital. At 5:00 pm on the side of the road on the Queensway at Moodie it was explained to me that another kidney was available and I was to go the General Hospital at 10:00 am the next day. The patient was dying, but not brain dead and I needed to be at the hospital when the donor died. I agreed to be there in the morning and continued on my drive to the farm to get rid of tires. I called Judy with the good news and she said I was nuts and

¹⁷ It's not a good thing to have had alot of sexual partners, you take a little bit of protein and antibodies from each partner and that makes matching tough. The other side of that sword is I never got “Kissing disease” also known as Epstein Barr virus and that lead to problems I will outline later.

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should turn around, in fact I was in shock. So I got off the next expressway off ramp and turned around. Hoping it was not an omen the name of the exit was the cemetery road exit on highway 7. A restless night ensued and we were at the hospital the next day. I was admitted and we waited.

We waited for 4 days, sadly the death of the donor took a long time and in the process the kidney was damaged and we were sent home with no transplant. At least at that point I knew I was at the “top” of the list and I was assured it would only be a short time.

Decisions on the side of the road; Kidney from North Bay #3 a charm

Judy and I have very vivid memories of the third call we received. It was also on the Queensway at the moodie exit this time. It was pouring rain and we pulled over to the side of the Queensway. After about a half hour discussion the 5 o'clock traffic cleared briefly and I started to move and pulled off onto an overpass to continue listening to the doctor and transplant coordinator outline the situation.

It was explained that none of the “problems” with the kidney were a big deal. They were portrayed as just a formality they were required to inform us about. All in good fun just to follow the rules in Canada. One little problem was AIDS. The partner of the donor had had unprotected sex in Africa 20 years earlier. They assured us that there was no AIDS in the donor but it must be reported. I was tested for aids for 6 months after the surgery.

The donor died of an abscess on his brain. He had received massive doses of antibiotics and the infection was dead in his body, it just ate his brain, so not to worry. I could not get sick the way the donor did.

And lastly was something called the Epstein Barr virus. I had no idea what this was and I was told it was a virus that 95% of the adult population had, it's just that I did not. When an Epstein Barr positive kidney (the donor) goes into an Epstein Barr negative patient (me) the patient gets EBV. **This is only a problem 1% of the time and can easily be treated with a slight change in the meds.** Remember that comment.

This is why we pulled off the Queensway onto an off ramp for some peace and quiet to reflect on all this new information. As the discussion went on and our questions got more and more specific it was explained to us that a surgical crew was at the airport with a Lear jet on standby, they were ready to fly to North Bay, get the kidney and come back and do the surgery tonight. Do you want the kidney, if not we need to go to the next name on the list.

Judy's response was guarded and cautious; my attitude was let us get this over with. I was fed up with dialysis; a bit depressed, overwhelmed by the decision and said F it lets go. And we did.

It turns out EBV is a bigger problem then they let on....

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It turns out Epstein Barr is just mononucleosis unless you are on immune suppressants. About 1% of EBV+ people who have a transplant get a flare up of EBV. The problem is if you are EBV- and then become EBV+ from a transplant (me) then you can graduate to something called Post Transplant Lymph proliferative Disease (PTLP). It's important to note that I never progressed to PTLT, That's not what makes it an interesting story. It's that when you go from – to + and they track the progress of the EBV at some point they have a conversation with you that goes like this

Team of Doctors: *“Uhhh sorry, its was not a mistake, but sorry you have EBV that seems to be Uhhh out of control, could lead to PTLT Uhhh, if we don't cut your immunosuppressant's you could Uhhh require chemotherapy, but its not cancer.*

Me: *Oh jeez, won't cutting the anti rejection drugs lead to me rejecting my kidney? And what is PTLT? Oh jeez was this all a mistake?*

Team of Doctors: *Uhhh, sorry but that PTLT, it's not happening. It was not a mistake; it's just your situation this happens about 1% of the time. And yes you could lose your kidney. But hey would you rather die from PTLT, which you don't have, lets me clear.*

Me: *Yah, sure I guess that make me the lucky one I guess. I mean thank you.*

So my situation was every week I do blood work and watch my EBV level go up. The count goes 1,000, then 3,000, then 5,000 and when it goes to 20,000 and 30,000 you have PTLT. According to the literature it happens fast and well, you die.

The number they kept quoting was 1% but the literature was pretty clear, it was up to 16% of the time and progressed to PTLT most often in my situation, EBV – before transplant. In pediatric kidney transplants where there is a high incidence of EBV-transplants it progresses to PTLT up to 10%³³ of the time.

The good news is there is a treatment, always worse without one, it just that “the cornerstone of the treatment of patients with (EBV and) PTLT is restoring the host's immunity by reduction of immunosuppressive drug therapy”³⁴

A couple of fun EBV facts:

1. A major driver of the increased risk for children was pre-transplant EBV negativity, which occurred in half of children, compared with <5% of adults. Negative recipient EBV serology was associated with a 3-fold increased risk of developing PTLT.
2. PTLT is not uncommon and appears to first year post-transplant. Being EBV negative at the time of transplant confer an increased risk, but the overall risk of PTLT has decreased over the last 15 years.³⁵

This was to become a major stress after the transplant, for me and between myself and the doctors. All of these problems are in a paragraph in a book they give you at the

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beginning of this ordeal, when they tell you about it, they also say you could wait for 8 or 12 years for a transplant and until you live it, you really don't understand it.

Transplant Surgery

My last memory going in was the Surgeon explaining the catheter strategy, I was in pre-op at the time and I remember watching him like I was looking through a long tunnel. My memory of that event was "oh a friend is here to talk to me, how nice" I was floating on a very soft "cloud" of some sort of drug. I have no memory of going into the surgery, or coming out of surgery. I have no real memories of the recovery room my first memory is waking up the next day in my room. I also have no real memories of any pain. I remember the discomfort of trying to move but not any real pain. I was on a wide range of pain killer including some narcotics.

While I have no memory that is not to say it did not affect me. I can remember taking picture of the process of my vasectomy, nothing graphic, just the whole process and I could laugh about that with my friends. After my obstructed bowel surgery in Hong Kong I left Hong Kong with a big insurance package with all my x-rays and a full colour 11x14 of a mid surgery snap shot showing where my bowel was obstructed. That I could study and look at and it had no effect. But this surgery was different. I could not look in the mirror at the scar for a year, I found myself waking up in the middle of the night moaning not in pain but discomfort over the surgery and it's very difficult for me to watch a TV show about medical issues let alone look at a picture of my insides if one were available.

My thanks to my surgeon Dr Blew who had an excellent bedside manner and did everything he could to ease my concerns and discomfort. Dr Blew was very kind and in every way I am grateful for his skill and kindness. If I was ever going to have a man-crush it would be on someone with his level of talent and intelligence.

Post Transplant week in Hospital

The first week in the hospital was difficult and uncomfortable. It was uncomfortable because of a foot long opening in my belly recently stitched up, a general re organization of my insides, and of course a catheter, which in a way was a bit of a blessing because I did not have to get up to pee and also because of a catheter in my neck used for the blood work they were taking 4 times a day.

Beyond the short term discomfort, the real difficulty was the anticipation of the workings of my new kidney. The kidney did not just start up. It was heart stopping that for 3 days it did not work. At least twice a day someone would be in talking to me about how it could start tomorrow or in a month. There were discussions about and schedules for dialysis again, Dana the vascular access nurse came to mark my arm for insertion locations and I was hyper concerned. It was shocking, terrifying and heartbreaking all at once.

The initial dose of all the anti rejection drugs are many times the maintenance dose and my body reacted by vomiting, diarrhea, dehydration, weakness and high blood sugar

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briefly requiring insulin once but not again. It was all par for the course, but yah I was hyper concerned, stressed, unhappy, anxious and holding Judy's hand when available.

Its working! On the third day my blood tests were indicating that the kidney was starting to work and about 8 people came by to tell me the good news. Everyone wanted to tell me from the nurse to the doctors to the surgeons. The next day even the tech that came in every morning to take my weight had a smile on his face when he told me my kidney was working. Later the next day my first post transplant dialysis was cancelled as it was determined the kidney was up and running. Once again I was the lucky one.

All things considered my hospital stay was very good. Judy was my constant companion, even the food was not half bad, Judy brought be meals from outside and my mood was improving, I was terrified and in pain but you tend to forget the pain and remember the outcome. Looking back on this whole ordeal the transplant was not the most difficult part. The most difficult part was the psychological toll of loosing my old life and coming to terms with the new normal.

The week moved along, I was up and walking, my bowels became regular and before I knew it I was out of the hospital. It's a bit surreal even now to think about it. Through out it all I kept thinking about the gentleman from North Bay who had just died and his family who honored his last wishes. As I was being wheeled out of the hospital in a wheelchair and going home, he was coming along with me. Once again; thank you.

Home after Transplant, Deciding on a goal

To give you an idea of my condition upon arrival at home I just wanted to have a shower and get to bed. With help I undressed, walked into the shower, turned around once without using soap, left the shower, fell on the bed where Judy had prepared towels, she dried me off, she dressed me and I fell into a drug induced sleep. There was nothing more I could do. Once home I was useless, but I decided on a goal. In high school I ran in the 400 meter event at a track and field meet and that became my goal to run 400 meters in the transplant Olympics. It's still my goal a year and a half later and the best I can do is to walk the 400 meters. To get to that level has been a struggle and I keep working at it.

My transplant was mid august and it was late September before I could start walking outside. Our address number is 80 and I would count off, first try to make it to 60 then 50 then 20 and so it went until snowfall when I could walk halfway down the street and back, a remarkable 200 feet total. That winter I could not shovel snow. By the spring sweeping the driveway was a 2 hour ordeal with 4 or 5 15 minute breaks.

With the ice I was afraid of falling, I would walk the Loblaws store. My first trip was at Christmas, I drove to the store, got out of the truck and collapsed on a skid of canned coke in the front hall, long enough that a clerk came and asked if I needed someone to call an ambulance. It was a long time and many trips before I could walk the whole store.

Fear and Loathing in Barrhaven, drug reactions and withdrawal

I was on a narcotic for pain for a week in the hospital and about a week at home. I wanted to get off it as I had some unusual experiences in Hong Kong with my obstructed bowel and the drugs I received after surgery there. The hallucinations were quite impressive.

The drugs in Canada were not nearly as good, but after only 2 weeks I decided to get off and the withdrawal was possibly the most uncomfortable part of the whole ordeal. It was a few days of Insomnia, body aches, Sweating, combined with the already prevalent vomiting and diarrhea from the high doses of anti rejection drugs and an overwhelming sense of anxiety leading to rapid breathing. The worst part is that you knew if you just took one little pill it would all go away.

A few weeks later there was a family wedding, I was unable to attend and friends came over to babysit me. I could sit up and converse, go to the bathroom myself but I was just lying around unable to really do anything. No stamina, generally uncomfortable and not all of fun to be around.

My transplant was Aug 12 2018 on Aug 29 2018 I was babysat, by Sept 20 2019 I was able to speak at my sons wedding but I was always protected, tired and I had to be driven home at 7:30pm and fell right asleep. I did manage to dance with my grandson but only for a minute. In hindsight my recovery was very slow for over a year after surgery.

3 month milestones, Nightmares, Psychosis and just let me sleep

Although I was walking and active I was also regressing in many ways. The anti rejection drugs were taking a toll on me. The whole drug regime was pretty tough. I was unable to drive due to exhaustion; my eating was off as I threw up most of what I ate. I developed intolerance to dairy products; I would only sleep for a few hours at a time, but did it around the clock. Over 3 months I lost 15 kilograms.

Judy drove me to all my clinic visits and at times I could not walk and required the assistance of a wheel chair, if I walked it was a dozen steps. It was all very depressing, it started with clinic visit twice a week at first and by 3 months it was down to once every 2 weeks as different drugs were tried to try to reduce my symptoms.

Those first 3 months were possibly the most difficult, my activity level started at zero and by the end of the month I was able to shower and dress myself, but for the next 2 months not all of progress was made except I kept the kidney! I did little other than see doctors, watch TV and take about 20 different pills every day..

Exhaustion / Drug changes / How will I find you in my next life?

The drugs flow freely after a transplant. I was off the opiates; I turned down Lipitor in the hospital, which lower cholesterol. Lipitor also raise blood sugar levels and lead to type 2 diabetes.³⁶ Cognitive impairment, memory loss, confusion, and forgetfulness³⁷ were

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other problems that the FDA warns of. I was told post transplant diabetes was a given, so I decided not to encourage it, confusion and forgetfulness were my super powers so when I asked the doctors about the diabetes and forgetfulness they nodded and said “no need then, but it’s a good drug” and there was no further discussion.

I had a problem with GERD, it only got worse post transplant. I had been prescribed Pantoloc and while on dialysis it became policy in the dialysis clinic to get everyone off Pantoloc because it also caused dementia. I was struggling with this drug; it was difficult to get off, mostly because it allowed you to eat the foods that caused the GERD so when you stop the Pantoloc the GERD is severe. You need to change your diet when on Pantoloc.

I started with oats to settle my stomach and added different foods finding out what was causing the stomach upset. Through a trial and error process over a few months and in consultation with Marie José the pharmacist and nephrologists I/we found a combination of foods / meds that did not upset my tummy. I was then able to stop taking the Pantoloc and possibly avoid drug induced dementia.

Looking for that combination of foods and meds that would not cause turmoil in my body lead to me keeping a chart I still keep where I record my pills, BP, temp, the food I eat, my sleep patterns and activity daily. It has become a habit. It was born of necessity trying to find patterns and because one missed anti rejection pill could lead to failure of my new kidney it also has become very comforting.

Blood Pressure Medications have been a constant source of problems and side effects. I suggest you write down the advice doctors give you and then compare that with the documented sided effects and then compare that with what actually happens to you. What I found is that doctors have favorite drugs. The next doctor may have a different favorite that sometimes contradict the previous doctor’s opinion. You would think science would prevail, but we are all human I suppose.

If you are ever in a nephrology clinic every doctor will try to prescribe you Lasix, in my case it lead to severe low blood pressure and permanent hearing loss. It was mistakenly prescribed to me when I started Peritoneal Dialysis by a fellow who apparently was trying to earn Lasix points for his next free trip to Barbados, no matter how much I complained they continued to insist all patients were on it. I often wonder why? When you Google Lasix you find it’s been on Shark Tank and a miracle drug, but for me it was always a nightmare.

The Drugs I was / am on for Blood Pressure, the dosages have changed

Med	Dose	Method	Comment
Bisoprolol	5mg	Beta Blocker	Fatigue inducing?
Amlodopine	10mg	calcium channel blocker	
Coversyl	2mg	angiotensin converting enzyme (ACE) inhibitors	At 4mg caused Edema, one doctor says this is not possible,
Lasix	Ended	strong diuretic	Caused permanent hearing loss

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A motivation to experiment with different combinations of blood pressure drugs is my constant fatigue. The transplant induced EBV causes fatigue but it is at a low level now and the fatigue was mostly alleviated by an adjustment to my blood Ph using an over the counter pill containing baking soda. My blood pressure was at 110 over 70 with a pulse of 60 with Bisoprolol, Amlodopine and Coversyl. If the Coversyl goes above 2mg it causes Edema and a rise in my Creatine levels.

The good news is my kidney is intact due to the anti rejection drugs I received. The challenge was to find a combination that did not kill me in the process.

Round 1 from Transplant August 12 2018 to September 16th 2018

Med	Dose	Method	Comment
Hydro Morphine	1mg per day	Pain	
Extra Strength Tylenol	6 per day		
Tacrolimus (Adagraf)	10 mg	Anti rejection	Skin cancer and lymphoma
Mycophenolate	1000 mg		
Prednisone	20mg		
Valgancyclovir	450 mg	Anti viral	
Pantoloc reinstated	Due to my constant stomach upset Pantoloc a known cause of adult dementia was reinstated. This started my logging of food and medicine to try to see patterns. My protests were noted.		
Aspirin, Sodium Bicarbonate, Vitamin D twice a day 1000 mg			

This first month was very difficult as I was trying to get off the Hydro Morphine, on high doses of the anti rejection drugs and Tylenol for pain. I was vomiting and had diarrhea pretty well constantly as well I developed very severe bleeding hemorrhoids. My sleep patterns were up ended due to the constant diarrhea and discomfort from ever decreasing doses of pain killers.

Round 2 started September 16

Off the Hydro morphine for a week, on Tylenol on demand and stopped the Mycophenolate.

Med	doses	Method	Comment
Tacrolimus (Adagraf)	10mg	Anti rejection	
Mycophenolate	1000 mg	reduced in morning then stopped completely September 24 2018	
Pregnosone	15 to 12 mg over a few weeks	Anti rejection	
Valgancyclovir	450 mg	Anti viral	
Magnesium Experiment	This was a complete failure, with all the new drugs I was taking it was decided a low magnesium level was my problem, not the stew of anti rejection drugs, the Magnesium changed my diarrhea from		

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	chronic to explosive and violent. 2 types were tried with various levels of volatility.
Sodium Bicarbonate	The Sodium Bicarbonate was stopped and not restarted for almost a year when it was noted my blood pH was off and then quickly corrected by reinstating the Sodium Bicarbonate
Aspirin, Vitamin D, and Tylenol on demand down to a few a day	

Friday Sept 28 2018

Med	Dose	Purpose	Comment
Azathioprine	75 mg	Anti rejection	New drug added
Mycophenolate	1000 mg	Anti rejection	Stopped completely was morn and afternoon

At this time the pharmacist was getting involved and she made sure I was taking my meds with and without foods and without contradictions in taking different drugs at the same time.

Oct 5 Adjusting Blood pressure meds

Med	Dose	Method	Comment
Amlodopine	2.5mg	Blood Pressure	Causes fatigue
TEVA furosemide	40 Mg	Blood Pressure	Type of Lasix

Side effects from about 3 months in were the worst as the drug regime changes and the doctors are trying new strategies. At one point laying on my chair watching TV I tried to get up and could not. I had become completely paralyzed. I could not speak or move. I remember trying to telepathically call for help. It did not work; Thanks allot Depak Chopra so much for telepathy, immaterial minds, and our collective memory.

Eventually after an hour or so this paralysis passed and I slowly started to come out of it. The odd thing was no one noticed. That's the level of activity I was operating on. Around this time I became obsessed with the notion of how was I going to find Judy in my next life. This was much more than a passing thought. Around this time my drugs were not quite in alignment, the effects of the anti rejection drugs include all sorts of psychosis, and unusual thinking patterns and I was descending into despair.

Oct 14

Prednisone	10mg to 7.5mg		
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Oct 25 2018

Tacrolimus	7 mg	immunosuppressant	
Prednisone	7.5 mg to 5 mg	immunosuppressant	
Azathioprine	75 mg	immunosuppressant	
Valgancyclovire	450 mg	Anti viral	
Apo Sulfatrim Septra	1 tablet	Anti bacterial	
Pantoloc, Aspirin, Iron, Vitamin D and Bisoprolol for BP			

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From October 2018 to January 2019 my condition was stable and improving. I was walking in the malls, I was starting to go out and shop bringing back a few items each night as I walked increasing numbers of aisles at the big box stores. At this time I could **not** walk one end to the other of a large Loblaws or Costco. But I could suit up, get there shop for an item, get home and collapse from exhaustion. Things were improving.

January 25 2019 Reduction of Immunosuppressant's

Tacrolimus	7 mg to 4 mg	immunosuppressant reduced due to EBV	To 3.5 mid april
Prednisone	7.5 mg to 5 mg		
Azathioprine	75 mg to 50 mg		
Valgancyclovire	450 mg	Anti viral	Stopped Nov 2018
Apo Sulfatrim Septra	1 tablet	Anti bacterial	
Aspirin, Iron, Vitamin D continued as normal,			
B12 added 1000mg once daily Feb 25 2020			
Pantoloc discontinued after June 22 2019			
Bisoprolol	5.0 mg	Blood Pressure	
Amlodopine added	-2.5 mg Jan 25 -5.0 mg Mar 14 -10 mg June 18	Blood Pressure	Started January 25 2020
Coversyl	2 mg	Blood Pressure	Started Feb 1 2020

As the drugs were winding up, being changed and stabilizing in my system the transplant induced Epstein Barr Virus was just starting to take hold. This was the reason that on the 25th my anti rejection drugs were reduced with the hope that it would allow my own immune system to fight the transplant introduced EBV

My current drug regime is as follows since May 2020

Tacrolimus	4.0 mg	immunosuppressant reduced due to EBV	To 3.5 mid april
Prednisone	5 mg		
Azathioprine	50 mg		
Apo Sulfatrim Septra	1 tablet	Anti bacterial	
Aspirin, Iron, Vitamin D 2x daily continued as normal,			
B12 added 1000mg once daily Feb 25 2020			
Sodium Bicarbonate 1 pill 4 times a day = ¼ teaspoon daily			
Bisoprolol	5.0 mg	Blood Pressure	
Amlodopine added	-10 mg June 18	Blood Pressure	
Coversyl	2 mg	Blood Pressure	Started Feb 1 2020
Coversyl above 2mg at 4mg caused intense swelling, Adema and my Creatine to go up 20 or 30 points.			

Epstein Barr Virus

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The good news is that the immune suppressants that prevent rejection of my kidney are working wonderfully. The bad news is the same immune suppressants are preventing my body from fighting off the Transplant acquired Epstein Barr Virus (EBV). The Epstein Barr virus is one of 8 Herpes virus that affect people.¹⁸ It is one of the most common viruses affecting 90% of humans. Only about 5-10% of the population has no EBV. You are positive or negative.

My status before the transplant was EBV Sero-negative, i.e. no EBV, however my donor was EBV Sero-positive, i.e. my donor had the virus. What I know now is that EBV – patients should not receive an EBV + kidney. It has the potential to make the recipient (me) very sick. This is not some Columbus level discovery; it is well documented in the literature. I was told that EBV- kidney would never come along so the doctors proceeded.

With no Immune system to keep it in check the EBV can progress to Post Transplant lymphoma proliferative disease; a sometimes terminal condition. So to prevent the spread of the EBV and give my immune system a chance to knock out the EBV, immune suppression is reduced. Fortunately this did NOT lead to a rejection incident. You can tell when doctors gather in groups of more than 4 you have a problem, there were 5 there the day they told me this.

DNA from EBV	Symptoms and outcomes
1000	The tolerance of the test, positive or negative
2,000-3,000	Heavy fatigue, hallucinations, this is how far I got
5,000-	Possible spleen and liver damage, symptomatic of PTLT
50,000-	Oncology is your new home 80% survive

I never really got beyond a state of fatigue, another name for Epstein Barr is mononucleosis and another is chronic fatigue. “Mono” or “kissing disease” is a month long annoyance in your teens if you have a healthy immune system. If you are suppressing your immune system to help you keep your kidney intact, then that’s another story all together.

Napping often does not capture how you feel.¹⁹ When referring to a nap or sleep, this is not just “oh I feel like a nice nap”, this is a time of mental and physical breakdown, I am unable to think, talk, drive, become agitated if I don’t lie down and cover my eyes. Overwhelmed by any sensory input, would be a better description, then falling into a deep sleep lasting 4 hours. It is not a normal response at 10 in the morning and then again at 4 in the afternoon after you have had 6 hours sleep overnight.

About 4 months after my transplant²⁰ the EBV DNA became present in my blood. It went from 1000 to 2000 to 3000 units of residual DNA of the EBV present, going up at a rate

¹⁸ Wikipedia Epstein Barr virus

¹⁹ Dr Todd Fairhead Medical Director Glomerulonephritis clinic and Assistant Professor of Medicine at the University of Ottawa has stated after examination that the EBV in the levels I have would explain my fatigue

²⁰ Refer to Appendixes titled “test result”

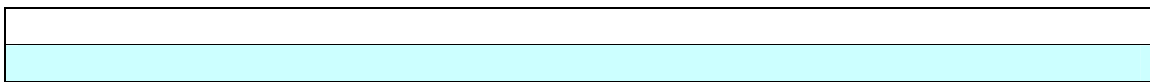
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of about 1000 points a week. There is a corresponding chronic fatigue that correlates to those numbers.

A remission occurred in In August as my EBV results returned to zero

One year Creatine Levels; Stable

At one year my Creatine levels were stable, they had been at 170 to 190 for a year. The doctor in attendance stated this was a good sign of long term survivability of the kidney. Other good news was that my condition has not yet progressed to PTLN due to a reduction in my immunosuppressant.



Improving Endurance and Working Part time

With the diminishing of the EBV and the threat of PTLN, at least for now, off the table and the continued operation of my kidney it was just a matter of increasing my endurance, little by little things got better, my nightly walks got longer, I am able to do more around the house.

I started to work a couple of days a week for a couple of hours at a time after consulting with my long term disability provider. There was no contradictions so long as I did not accept any money. It was great to be back at work. I started doing one small part of my previous job and that was hiring and managing a web site developer and working with that company to rebuild a website for the company.

I was fortunate in that the owner of L-D Tool and Die, Laurie Dickson had been very supportive during my multi year absence. He called me regularly and helped me when I was most depressed. Having a sense of being needed in the real world was invaluable.

Because of my immune suppressed state I was a non hugger, cold season was difficult and shaking hands was a chance to get an infection, with the coming of the Corona virus I had to retreat into deep isolation and along with the rest of the planet I was unable to return to work, when people started to work after 2 months my isolation continued. Judy kept me behind lock and key, if you are reading this, please help me to escape. I am being held hostage by a 64 year old retired school principal.

The New Normal 18 months in

My clinic visits are now every 3 months, due to the corona virus they are by phone. After reviewing my blood work the doctor noticed my blood pH was off and she prescribed Sodium Bicarbonate, 4 tablets daily. This non prescription over the counter remedy

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brought my pH back into line and had a profound effect on my endurance. This is perhaps the biggest single improvement in my health in last 6 months.

I am left with much anxiety. I am constantly fearful of my new kidney failing. The slightest change in my Creatine or pain in my kidney has me worrying. The isolation of the Corona virus is a big change for me; and yet it's sort of the way I have been for a while, but just more of it.

My family doctor says I am left traumatized by the whole ordeal and doctors have diagnosed me with Post Traumatic Stress Disorder (PTSD). Personally I think that is nonsense, no one gets to 63 without some PTSD, it's so common as to not be worth a label. Yes I am anxious but so what; my new kidney, that's my complaint? Good Grief. Before anxiety was about sudden death from dialysis, or infection, or anxiety over needles, so anxiety is not new and sometimes you just have to shut up and power through.

I have become something of a record keeper. Records are important. I keep track of

- Daily Drugs, Blood pressure, temperature
- Interaction records with doctors
- Records of eating, calories and activities. It all helps to see patterns and notice any trends in my health.

The good news is that most of this is fading into my memory and I am starting to have a sense of urgency in getting things done and having plans. I remain very obedient to the instructions of the doctors, for all the faults of the medical system and at least a few of the doctors in it, I am grateful for the 900 others that are there for me.

I will continue to shut up and do what I am told.

Your lucky that's the good skin cancer

A small spot developed on my forehead, my nephrologists and family doctor referred me a dermatologist and after a month of waits and a couple of telephone consultations due to corona virus I finally ended up at a Skin cancer surgeon who did a nitrogen treatment to burn off the offending "growth"

It turns out its may not be skin cancer, the surgeon thought it was just an age spot, so it all ended in a very non dramatic zap of cold nitrogen. Once again here I am; Lucky me.

GERD, Exhaustion Swelling, Metabolic acidosis, can't complain

The slightest amount of spicy foods or fried foods and the GERD returns, the slightest amount of salt and I get swelling in my legs, Metabolic acidosis went undiagnosed for a long time but not that its resolved with Bicarbonate my endurance is much higher. All is generally well except the creeping up of my Creatine levels which indicates a failing

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kidney as does the acidosis and swelling. No one has given me that diagnosis but the blood work continues, we will see what the update is at 24 months.

It's a slow climb if you're fat and deaf; what I can and can not do

Like most of the world I am trying to loose weight, I count the calories, exercise not that much and am as diligent as I can be. As I write this in June of 2020 I am having problems with water retention due to the combination of my blood pressure pills, need to keep my legs up for a few hours at a time and sitting and typing really aggravates the swelling in the legs. I am also mostly deaf in one ear and have 50% hearing in the other mostly due to a brief bout of Lasik medication. Hearing loss is a documented problem with Lasik.

I have something of a normal life, with limited endurance, I don't know if I will ever run a 400 meter race in the transplant Olympics but I can dream, and that is an improvement over where I was 18 months ago.

Bruce Coburn Fascist Architecture³⁸

I like this song because one of the side effects of this whole ordeal is “Too long been keeping my love confined” at least I lived long enough to realize it and correct it.

As well bloody nose and burning eyes, Raised in laughter to the skies; pretty well describes me and my ordeal as well...

I've been in trouble but I'm okay
Been through the wringer but I'm okay
Walls are falling and I'm okay
Under the mercy and I'm okay

So I am okay.....

This song is worth a download.

Bruce Coburn's Fascist Architecture lyrics

Fascist architecture of my own design
Too long been keeping my love confined
You tore me out of myself alive

Those fingers drawing out blood like sweat
While the magnificent facades crumble and burn
The billion facets of brilliant love
The billion facets of freedom turning in the light

Bloody nose and burning eyes
Raised in laughter to the skies
I've been in trouble but I'm okay

Been through the wringer but I'm okay
Walls are falling and I'm okay
Under the mercy and I'm okay

Gonna tell my old lady, gonna tell my little girl
There isn't anything in the world
That can lock up my love again

Reflections on Gratitude: That makes me the lucky one!

That makes me the lucky one became my mantra. As I looked around the hospital I saw that most people were in worse conditions than I was. In an early discussion with my family doctor she pointed out that I had a rough road ahead but it was possible to get through it, she also pointed out that earlier that day she had to tell a long time patient that he had cancer and would not live 6 months. So....that made me the lucky one.

During my 5 year ordeal, I had 2 friends die of brain stem strokes, another friend and two cousins died of cancer, my father in law died, you get the point. Every day about 15,000 people shed this mortal coil³⁹, and every day I was *not* one of those 15,000 made me the lucky one.

Of the roughly 55,000,000 people who die every year, about 1.5 million die of kidney failure, about the same as traffic deaths. Of those million and half people sick with kidney failure only about 40,000 a year get transplants, and that number is at a record high for the last 6 years. Only about 00.25% of those who would die of kidney failure every year get a chance at a kidney transplant. Guess what, that makes me the lucky one just became a huge understatement. I won the lottery.

So that was **lesson one**, I am one lucky bastard.

Lesson 2 was how much I depend on others for my existence, I guess this is just a variation on how lucky I am, but this hokey storey resonates more with me now than it did a few years ago. There is a Jewish folk tale that tells the story of a man who wanted to understand Heaven and Hell.⁴⁰

First, he travelled to Hell. Here, row after row of table was piled high with platters of food yet the people seated around the tables were starving to death. Each person held a full spoon but both arms were splinted with wooden slats so they couldn't bend either elbow to bring the food to their mouths.

Next he went to Heaven. The setting was the same here as in Hell – row after row of long tables laden with food and all the people had their arms splinted so that they couldn't bend their elbows. But the people in Heaven were happy and well fed.

He couldn't work out why things were so different so he watched for a while. As he watched, a man picked up his spoon and dug into the dish before him. Then he stretched across the table and fed the person across from him. The recipient thanked him and returned the favor by leaning across the table to feed his neighbour.

The man ran back to Hell to tell the poor souls trapped there what he had discovered. He whispered the solution in the ear of a starving man – “You don't have to be hungry,” he said. “Use your spoon to feed your neighbour and then he will return the favour and feed

My Totally awesome Kidney Adventure

you.” But instead of being grateful, the starving man became angry. “What are you talking about?” he shouted. “You expect me to feed that man? I hate him! I would rather starve than give him the pleasure of eating.”

Then the man understood – both Heaven and Hell offer the same circumstances and conditions. The critical difference is in the way we treat each other. I was treated extremely well, by my donor, my wife, my doctors, my employer, my friends and family. Yup, that makes me the lucky one. It was not a hell I went through, I experienced heaven.

The third lesson I learned was perhaps the hardest. I learned I really have very little control over anything. When I was in my late teens I loved to run, I did not do it because of some inbred drive to excel, I just ran because I could.

Later in life I became a machinist, then a tool and die maker, then a tool designer, then an engineering technologist, and a business owner travelling around the world 20 times. Sure there was a drive, but mostly, it was just what I did because I could.

My marriage of 40 years, there were temptations and hardships but I was faithful, we endured, but not because of me, I was raised to be faithful, surrounded by love, and I married a wonderful person, the marriage did not last because of me, but rather because of the kindness and intelligence of my wife and the kindness and caring of my upbringing.

In fact nothing I have done, and everything that has happened to me I can trace to random events or things I had no control over. You think you’re different. Just wait. Earnest Hemmingway said it best in farewell to arms: “The world breaks everyone and afterwards many are strong at the broken places. But those that will not break it kills. It kills the very good and the very gentle and the very brave impartially, if you are none of these you can be sure it will kill you too but there will be no special hurry”

So I am lucky, I was broken, not killed, not yet anyway. I now realize I was always dependent on others, I have had almost no control over this life other than to choose how I react to any given situation and it is even debatable if I had even that control. Perhaps the most important lesson was that the last 5 years was not hell, but rather I experienced a bit of heaven in every kindness I received and that I recognize the fact makes me the lucky one.

Finally thank you to one particular nurse in Nephrology I am sorry I told you multiple times in a very rude way that you should leave. I was a particularly ignorant asshole for a while, but I think I am getting better.

KT June 2020

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Update November 5 2020

I continue to have problems outlined in the table below

Issue	Cause
Creatine stable at 200	Kidney function
Acidosis	Kidney function
Low Albumin	
Edema; swelling in legs	Salt intake / inactivity
Blood Pressure	Salt intake
Anemia (MCHC 320 out of range at 315)	Kidney function / diet
Hearing deteriorating	Lasik
Vision deterioration	verify
EBV virus fluctuations	Virus from Kidney
Frustration with EBV discussions	1%; 4%, 20%, or 50%
Fatigue endurance / pain in legs	Unable to walk more than 1km
Fatigue tiredness / mental confusion	Sleepy in afternoon
Swelling in lower belly at scar area	Testing scheduled
Anxiety Stress	Perception of lack of concern by staff
Patient mentality	I need to shake this off but its hard when you are sick
Covid isolation	“insert screaming here”
“Graduation”	I lived and so I am moved along the nephrology treadmill. The ongoing support is not even close to dialysis type support

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