



## **Brainwaves: A Memoir**

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To my unforgettable husband, Yurgen,

And all those who helped me come to terms with his loss

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## Introduction

I came to write this book in response to the recent pandemic. It's not just that pandemic-related isolation gave me time to write, but also that it rekindled in my mind memories related to the last great viral illness in Toronto. It wasn't quite a pandemic, but S.A.R.S. (Severe Acute Respiratory Syndrome) turned life upside down for many of us in 2003, especially those needing access to hospitals. My late husband, Yurgen, was one of those unfortunates, suffering a severe stroke at the tail end of the S.A.R.S. epidemic. Many of the events related to his death had been organized and processed in my mind in the intervening seventeen years. Some were still as fresh as yesterday. Those events re-emerged in stark relief as I reacted to a book club meeting, and as I tried to support my son through a hospital procedure during the current pandemic. These recent experiences convinced me to revisit this dark but life-altering chapter one more time. Perhaps I also had a need to finally define the story, rather than continuing to allow the story to define me. In any case, it started with a book...

This year's offering in our church book club focused on gratitude. Chapter by chapter, we asked ourselves questions related to the topic, and one in particular stuck in my mind. "Can you think of a past event that was painful at the time, but for which you are now grateful?" I thought of several, but then my mind started playing devil's advocate and pondering painful events for which I could *not* feel gratitude. I started to realize that cultivating an attitude of gratitude is great, but it's not a panacea for happiness, especially when it comes to examining the past.

Sure, we have much to be thankful for in being born into a democratic, affluent society. Sure, it helps to savor positive memories of life's joys and satisfactions, and to dwell on them more than on the negative ones (though we can't forget the negative ones entirely, or we risk repeating history). There are also painful memories we can eventually see as blessings in disguise: the awful childhood that helped me understand children's mental health and became the basis for a rewarding career in Child

Psychiatry; the humiliating traffic court date that made me realize I needed to leave a toxic work environment and take better care of myself to avoid driving distracted; the frightening accident which prompted someone to stop and hold me until help arrived and made me realize that there are angels among us.

But then, there are other painful memories that are so traumatic and overwhelming and senseless that no matter how many disguises and layers you strip away, the blessing eludes you. Moreover, whatever growth or learning you experienced as a result of the horror can never justify its occurrence. With those memories, you eventually realize that there is only one blessing: the strength to survive the events so you can do what you must for the important people in your life... and perhaps to tell the story, in the hope that others may suffer less. My late husband's death is one of those memories. Surviving it is the focus of this memoir.

Each chapter begins with an insight gleaned during or since my husband's passing. It is the sort of thing I would tell my younger self now, if I had the chance. However, the book is not intended to be a lecture on meaningful living. Rather, I hope to show how the events that unfolded changed my perspective on certain aspects of life, and how that new perspective might make a difference if you ever find yourself in a similar situation...which I truly hope you don't. I wouldn't wish these events on my worst enemy, and I know of several people who have treated me badly enough to warrant that label.

After sharing an earlier draft with a couple of close friends, I also realized that each chapter needed some concluding thoughts for two reasons. First, I wanted to avoid asking the reader to make intuitive leaps about what I learned from these events; second, I realized from my friends' comments that without a reflective pause at the end of each chapter, the manuscript was too raw and disturbing for some people to comfortably read through to the end. Of course, if you prefer a more gripping tale, feel free to skip or skim the concluding thoughts.

The story is written chronologically starting about a year before my late husband's stroke, reflecting how this tragedy affected our family at the time. However, I didn't necessarily reach these conclusions in the order presented, nor were my thoughts as organized at the time as they appear in this manuscript. Rather, I became gradually convinced that these ideas were true as I grappled with my traumatic memories, and lived a life that needed to transcend those memories. Perhaps that's why it's taken so many years to sit down and write this. Perhaps I just needed some time where my energies were not urgently needed elsewhere.

Because the events and people described are real, I faced the usual memoir-writers dilemma: to use real names and descriptors, or avoid doing so to protect people's privacy. In the end, I decided on a compromise: I have included my husband's first name only ("Mr. M."—not his real initial--instead of last name), and real descriptors but no names for the children (i.e., "my son", "my daughter"). Names and certain features of other participants in the story have been altered or left vague enough to avoid identification. Certain private details were removed with editing to avoid nasty surprises for readers within or close to our family.

In any case, I hope you find meaning in the story, and in the ideas related to it. A single story or philosophy is probably inadequate to heal a person, but if you are dealing with traumatic grief, I hope this book reduces your suffering in some small way. If you are not, be thankful. I hope it is still an interesting tale.

Blessings,

Katharina Manassis

**Part I: The Previous Year**



## 1. Children's Aid

No matter how far you climb on the ladder of success, your position is precarious. You can never know when some fly ball out of left field will knock you into the dirt, and there are often self-righteous people who want to see you there. Still, you must risk enjoying the sunshine while it lasts, even when the horizon is dark, or life seems endlessly gray.

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"Mrs. M., please come into the office for a moment" ordered the matronly day care provider, swirling away in her paisley dress. Her tone made it clear this was not a request. I nodded, breathlessly. I was pleased I had made it through rush hour traffic just in time to avoid a "late pick-up" fine.

As the door closed behind me, the echoing din of children shouting and squealing in the cavernous church basement started to ebb. She adjusted her glasses, cleared her throat, and shifted uncomfortably in her chair. "This is Ms. Fanshaw from the Durham Children's Aid," motioning to the petite twenty-something waif in the corner, "We notified her of the abrasions on your son's back."

I volunteered, "Yes, as I explained in my note, he struggled with me when I tried to get him into the tub, and accidentally scraped his back. You know he's very sensitive to the feeling of water on his skin."

"He told us 'Mommy dragged me'" she countered, glaring over her spectacles. Clearly her faith in this statement was absolute, though it came from a developmentally delayed five-year-old who had just started speaking in short sentences a few months earlier. "And as you know, we have a zero - tolerance policy...we investigate whenever a child arrives with marks on his body. Ms. Fanshaw will accompany you home."

The gravity of the situation dawned on me, and I felt my insides drop into an abyss. Here I was, a respected Child Psychiatrist and researcher working in one of the top children's hospitals in the world, and I was being accused of abusing my own child. I felt utterly humiliated. More importantly, I was scared. If the allegations were considered to be valid, I could lose my children, my position, my reputation, and potentially even my medical licence. The life my husband and I had struggled tirelessly to build, the life that allowed us to escape the soul-crushing poverty and chronic misery of our dysfunctional immigrant families, would be ruined.

The waif explained that I would drive my son home and she would follow in her car, and that all information she collected at the home visit would be shared with her supervisor. Both women stood up abruptly and escorted me to the door. I had to rise so quickly I saw spots, clearly dehydrated from the long evening commute, but there was no time for water. I was surprised they hadn't brought handcuffs.

"Trouble?" asked my sweet but worried-looking son. "No, you're not in trouble" I reassured. His little arms wrapped around me tightly, as though the earth were about to swallow me. We headed to the parking lot, the waif two paces behind, and I strapped him into his car seat.

Leaving the lot, I could see the ugly yellow Chevy tailing me in the rear-view mirror. It occurred to me that I knew the area well-enough to lose the newly minted social worker on a side-street, but then my rational mind kicked in. I had to protect my family from this socially sanctioned home-wrecker. Fleeing would only make me a fugitive. I couldn't risk her calling the police to find me, or losing my son's daycare placement that we had fought so hard to keep. He always reacted badly to noise and changes in routine, and his tantrums were cause for dismissal from the facility (another "zero-tolerance policy"), so we had to get professional help for those. No other daycare in our town would take him because of his toileting delays. Without daycare, I couldn't work and, once again, my husband and I faced the prospect of losing the life we had struggled so tirelessly to build. My only choice was to treat the pubescent social

worker with saccharine sweetness and total cooperation, in the hope that she would be reassured and eventually go away.

Once at home, the intruder asked to speak to my seven-year-old daughter in a separate room. My inquisitive, blonde Montessori maven giggled as she came out, reporting that the funny lady had asked her how often I beat her, “as if that actually happened.” Her father, mid-forties and paunchy, chuckled “I wonder in what high school they found her!” and reported that the waif had asked him about recreational drug use. His dismissive response had been “Do you honestly think I would tell you if I did that?” I hissed “You have to take this seriously! She can take the kids away!” He shook his head at my reaction. Yurgen was fearless in the face of authority.

My side of the story didn’t seem to interest the worker. Instead, she charged me with writing out a list of every professional who had ever seen my son so she could call them and determine if there were others who suspected abuse. I surprised myself with the length of the list...a general pediatrician, a speech therapist, two types of occupational therapists, a physiotherapist (for toe-walking), a psychologist (who diagnosed learning disability), a pediatrician specializing in toileting, and a psychiatrist (who concluded “anxiety with mild developmental delay”).

“Would you like their phone numbers too?” I offered. I was really laying it on thick.

“Please,” she responded, and thanked me. She told me I would hear her decision after the calls, and after she had spoken to her supervisor, but couldn’t estimate how long that would take. I mentioned a family vacation in a month, just so she wouldn’t think I was skipping town if I wasn’t available at that time. She left.

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The memory was tattooed into my brain, displaying itself repeatedly as I tried to relax on the beach. It only left me momentarily when I swam with my daughter to a trampoline-like float in the bay by the resort. She still wore water-wings, but emulated my strokes perfectly and got to the float before I did. Seeing her soar in the sunshine above the lake made me smile for the first time in weeks.

Now, my husband was helping the children change for dinner as I watched a near-perfect sunset over the water, but all I could see was a rip-tide that pulled my little ones away to the land of social workers, and I was helpless to stop it. I was too anxious to show any affection to my husband. I was too humiliated to joke with other guests at the resort. Based on the length of my list of professionals treating my son, I also knew I had to contact a colleague who specialized in autism to evaluate him. Throughout the vacation, my mind was elsewhere. It was the last vacation we would ever take as a family. I regret not being present for it.

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Perhaps my reaction to these events was greater than most people would have experienced. I have a history of social phobia which renders me super-sensitive to criticism and humiliation. I stew over minor slights for days; more significant ones often send me spiralling into depression. This was one of those significant ones, with the added stress of a threat to my family's integrity. Had it not resolved in a month, I'm sure my mental health would have markedly deteriorated.

Still, even for people without a significant mental health history, the unpredictable blows that other humans inflict upon us can be difficult to bear. This is especially true when those humans wield state-sanctioned power over us. We have no opportunity to shield ourselves from the onslaught: we are exposed and vulnerable in ways we never thought possible. When they hold our lives for ransom for prolonged periods of time, the anguish is worse. We constantly ruminate about ways of preventing the

worst outcome, while resenting the power they have to harm us and our loved ones. We think of nothing else. They hold our minds hostage.

At these times, introversion works against us, for the answers are not found within the cesspool of our minds. They are found outside ourselves in the sunbeams reflecting off pristine water, in the exhilarated squeal of a child who becomes airborne over the lake. When we are able to look out at the wonders of life, forgetting for a moment ourselves and our troubled minds, we find joy. Even in the midst of trepidation and uncertainty, we find joy. Practice this outward-looking self-forgetfulness when you can. Practice joy.

## 2. The Diagnosis

Conventional success based on competition is meaningless. We only thrive when we bring out the best in everyone's talents and abilities, allowing all to contribute. Disability is defined by how a person compares with others; when we stop comparing and just focus on the person, ability shines through.

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It was almost Christmas by the time we got the results from my son's evaluation. Like many anxious people, I tended to get to appointments early, so found myself staring at the brightly colored, cheery walls in the hospital waiting room. They were adorned with plump, dancing cartoon hippos, strategically placed at eye level for six- or seven-year-olds. Did they really think this would relax the children, or was the idea to remind parents of the carefree days of youth (if they had any of those)? I remembered reading somewhere that fat mammals like hippos or panda bears are considered cute because their proportions resemble those of newborn babies, so maybe that was the rationale. A screechy children's choir sang popular hits in the background—all in C major and irritatingly upbeat.

My husband was running late, as was his custom. When we were first dating, I used to take his tardiness personally, thinking he either wasn't very interested in me or didn't respect me enough to value my time. Eventually, I learned that he was late for all appointments, whether they involved me or not. I habitually told him to arrive fifteen minutes before I actually needed him to arrive in order to ensure punctuality. Unfortunately, in this case the doctor's assistant had communicated the appointment time to him.

I thought back to our unwelcome visitor from the Children's Aid. After returning from vacation, we had finally heard back from her.

"I'm calling to inform you that we're closing your file."

“What does that mean, exactly?” I tried to clarify.

“I called the professionals on your list, none reported additional evidence, and so my supervisor concluded that your case was an isolated incident. For isolated incidents, we close the file.”

“Will my name be on any sort of record? Is there anything else we should do?” I pressed. I didn’t want to stir up more trouble, but it was hard to believe that I wouldn’t suffer some sort of consequence, or at least have to take a remedial parenting course.

“No record, madam. My supervisor suggests you get your husband to help when you bathe your son so this doesn’t happen again. Have a nice day.” Click.

Thankfully, there was no further follow-up by the agency but I felt a bit uneasy. I guess, just like some car insurance companies forgive the first accident, they forgave the first incident of alleged child abuse. It was a relief for me, but I couldn’t help wondering if all parents were as conscientious as we were about avoiding repeat performances. My reminiscing was interrupted by my husband’s booming baritone...

“Mandy, how are you?” he warmly greeted the receptionist, “I’ll have to get my wife a bracelet like that. Gorgeous!” Yurgen had a talent for remembering the first names of all clerks, assistants, janitors, and other institutional minions, and complimenting them on a regular basis. In return, he elicited smiles wherever he went, obtained easy access to the halls of power, and was never criticized for being late.

We were ushered into the office where the doctor was waiting. She was a gentle, middle-aged woman with kind eyes. Besides the usual wall of diplomas, there were a couple of subdued Japanese prints. There were no garish cartoon animals or harsh sounds, and the furniture was neutral and soft—nothing to overwhelm the senses. A variety of games and toys were strewn about, seeming to invite

visitors to play. I could see why my son didn't mind coming here for his assessment appointments. After offering us some water, the doctor reviewed the information we had each provided and the results of her testing with our son.

"He is on the autistic spectrum, but at the milder end," she concluded, "so it's understandable that he wasn't diagnosed earlier. The speech, learning, and coordination issues are prominent, but the autistic features are more subtle." She reassured us that we had done well to pursue the interventions my son had received to date, made a few more suggestions, and provided a list of resources.

My husband asked for more details on the "subtle features." My mind went foggy after I heard "on the autistic spectrum." The appointment ended cordially.

We had come in separate cars, each from our place of work, so didn't have a chance to talk until we got home. A million thoughts cluttered my mind, so I probably shouldn't have been driving, but I got there safely somehow.

"So, it's autism," I began, stating the obvious. "I suspected it, but I didn't think it would hit me so hard." My voice was shaky and I was tearing up.

He shrugged, "Well, we always knew he had problems." Silence.

"Problems, yes, but I thought we could help him overcome those. This isn't just another problem, it's a life-long disability!" I was breaking down. More silence.

Yurgen was uncomfortable with strong expressions of emotion, probably because these were associated with violence in his childhood. I, on the other hand, behaved stoically at work but was emotionally volcanic in private. He almost left me in our first year of marriage when I threw a dish during an argument. Being half-Greek, I didn't think it was such a big deal. I soon learned I had to rein in my feelings if I was going to preserve my relationship with Yurgen.



It was hard to do in this situation though, and his response to my distress felt cold. It seemed to come from more than just discomfort with emotion. Yurgen had a life plan that included a good job, a happy, dual-income marriage, one child (not necessarily two), a paid off mortgage, an investment portfolio designed to minimize taxation, and a cottage for recreation and eventual retirement. He had just started working with a contractor to build that final item. Our son's disability didn't fit with the plan. As his developmental delays started becoming apparent, Yurgen became more distant. Perhaps it was coincidence, as his company moved across the city around the same time lengthening his commute, perhaps it was not. I couldn't be sure.

The next day, I tried to talk about the diagnosis one more time, determined to be less emotional and more practical.

"You know some of the doctor's suggestions look pretty easy to implement. I could look into these three...but this one would be difficult to fit into my schedule every week. Do you think we could alternate those visits?"

"Not unless you want me to sleep at work," he muttered. He looked away. He was ending the conversation.

Clearly, this was my issue to solve. I had rarely felt so abandoned and alone.

Yet where Yurgen saw a complication to his plans, I saw a blessing. Sure, my son's incoordination and learning problems and tantrums and sensory sensitivities cast a shadow over his young life, but I could see past all of that. I grew up with strabismus, an eye condition that prevents part of the visual cortex from developing and impairs depth perception. It's a mild disability, but results in me seeing everything as if through a dark curtain when I close my "good" eye. I've had to practice looking past the curtain literally, and now I was doing it figuratively when it came to my son.

Where others saw tantrums in response to change, I saw a toddler who was perfectly content watching the mobile over his crib for hours and smiled more than he cried. Where others saw delays in speech and reading, I saw incredible perseverance with the multiple remedial programs I tried, and an unequalled eagerness to please. Where others saw impaired social skills and inappropriateness, I saw an affectionate boy who instinctively knew when I needed a hug and was too honest to deceive or manipulate. Where others saw restricted, idiosyncratic interests, I saw the ability to recite Thomas the Tank Engine and later Monty Python scripts verbatim, and a simple, child-like faith in a loving God that never left him. My son was loyal to a fault, a dedicated student, and a better friend than most of his peers deserved. How anyone could treat him as a social outcast baffled me.

All of these abilities shone through for me when I looked at my son. I remember wondering if others suffered from disabilities so severe that this lustre became impossible to perceive, but it was a fleeting question in my mind. I didn't know then how much that question would come to haunt me.

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Many people have some degree of disability relative to the average person. The degree of one's disability matters when it comes to relationships and when it comes to the things that give life meaning. For me, lack of depth perception made surgery impossible: I cut sutures either too short or too long, never the right length, because I couldn't see them properly in the surgical cavity. It resulted in one bad grade but had no impact on my very meaningful career because I was interested in psychiatry, not surgery. It also affected my driving, as I couldn't judge the distance to the next vehicle in front of me very well. I learned to be extra-careful on the road, and my driving record isn't bad. It had no impact on my relationships...if anything, not seeing the other person's blemishes perfectly was sometimes helpful!

My son's disability was more significant because it affected both meaningful activities and relationships. He would never go to university because of his learning disabilities, which closed many

doors of meaning. He would never have an easy time finding friends or a life partner because of his autism. Some people would only see his problems, never his attributes as a person. Some people, even in his own family, would tolerate him but not welcome him. Medical complications would add to his struggles.

And yet, as he matured, he came to know more than I did: he knows not to dwell on horrible criticisms, he knows to steadfastly hope for a better tomorrow, he knows to focus on favorite comedies when down, he knows not to respond to people when upset. Did he learn these things because of his disability or in spite of it? It doesn't matter. He has found a way to persevere despite the obstacles and the doubters. He exudes more positive energy than people with twice his IQ. He never gives up, and I am certain he is finding a meaningful place in this world.

Over time, I've come to see humanity as less of a graph and more of a jigsaw puzzle. Graphs divide people into those above the curve and those below. Those with significant disabilities are invariably lumped into the latter category. Jigsaw puzzles unite: every piece has a unique shape and hue; every piece contributes to the whole picture and is missed terribly if lost. Whatever people's abilities or disabilities, try to perceive their place in the puzzle, and try to perceive yours. Everyone has a place. Life is not complete until everyone fits.

This discussion begs the question: are there disabilities which affect relationships and meaning to such a degree that life becomes intolerable for the person? This question, unfortunately, is explored later in this book.

### 3. The Self-made Shining Knight

The belief in total self-sufficiency is a dangerous myth. It hinders our participation in relationships, in self-care, and in the interdependent cosmos.

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Thump!

I turned around in the living room and saw my husband beside a snowbank just outside the window. He was lying on top of his right arm, the shovel under his leg. It was the middle of March, when the warming temperatures cause the snow to melt and then refreeze overnight. Put a fresh inch or two on top, and the black ice is imperceptible to even the most experienced homeowner.

“Are you OK?” I shouted from the door.

After finishing a string of swear words he replied, “It’s nothing. Just a bruise. Go back inside.”

The injury was painful enough to stop him from finishing the driveway though, so I knew it wasn’t so trivial. “Last time you hurt that shoulder it turned out you had a broken collarbone,” I reminded him, “Better get it checked out at the E.R. I’m worried it might be more serious.”

“You worry too much. That old bicycle injury was years ago. I’ll drive over to the walk-in clinic later.”

I knew that was as much medical follow-up as I could hope for. Yurgen hated doctors. Seeing one seemed to be an admission of vulnerability or dependence on others, and if there was one trait that he valued it was self-sufficiency.

Financially, he was determined to turn his moderate salary into a small fortune with savvy investing and tax strategies. I still remember his secrecy about his net worth when we married. In truth,

it was a bit underwhelming. It was just enough for a down payment on a semi-detached house and would be eclipsed within a few years by my earnings as a physician, but to him it was magical. It meant we didn't have to rely on anyone's charity when starting our life together, and he didn't have to cower to his abusive father.

When it came to education, he scoffed at most of his teachers. Yet he was an amazing fount of knowledge he acquired on his own, and a skilled handyman around the house, also self-taught. Emotionally, he saw himself as a defender and nurturer of the underdog, whether junior colleague or spouse. He gave great pep talks when I felt discouraged or put upon by others, and was a great shoulder to cry on when I despaired. He loved enriching my life with interesting travel destinations, new types of cuisine, and other new experiences. As long as I was a damsel in distress, he was my Lancelot.

In this unusually vulnerable state, however, he allowed me to fetch an ice pack and brew some hot coffee for comfort. Usually, we put a bit of Bailey's in it on weekends, but I reminded him he was planning to drive later so we skipped the liqueur that day. Saturday coffees where we dissected the newspaper and debated the issues of the day were one of our favorite rituals, and often the only time in the week when we shared our opinions and feelings.

We glanced at the editorials in the National Post. It's a decidedly conservative paper, so most of them focused on government mismanagement of tax dollars to benefit insiders and the indigent, unnecessary government regulation of free enterprise to benefit "tree huggers" and companies that could not compete, and examples of countries flourishing despite privatizing health care, education, or other sectors considered sacred government property in Canada. For the most part, our views at the time aligned with those of the columnists, though I detected a note of misogyny in some, and the paper's tendency to vilify the poor seemed a bit mean-spirited. Still, just like Yurgen, I was a goal-

oriented, intensely competitive social climber eager to escape my impoverished past. I admired independence and self-reliance as much as he did, perhaps more.

After we tired of the paper, he inquired “How’s that project coming along?”

“The pilot on school-based therapy? It’s getting there. We’re having a hard time convincing some of the principals that we won’t inconvenience their janitors too much after school, but they like the idea of the program overall, especially in the underserved neighborhoods.”

He commended me. “You’re making those kids more resilient than their welfare-loving parents could ever imagine. That’s decent. Hope you get some credit for that at the hospital.”

“I will if I can get funding for a bigger trial. That’s really what they value: research dollars, and the publications that follow. Helps them brag about the department.”

His mouth tilted into a wry grin. “Isn’t it ironic how you guys are supposed to be mental health experts, yet your department is run by selfish bastards. And I thought working in banking was bad!”

I couldn’t help but agree, and we laughed. He showed me pictures of his latest project: the cottage he was building for the family in Wasaga Beach. The exterior walls were up, and soon we would be making decisions about the interior design. Yurgen was looking forward to that. We were both project-focused, and happiest when planning the future.

Consistent with the knight persona, he described the cottage as something built for me. Whenever we discussed details though, it became clear that he was building it as a retirement home for both of us, and primarily for himself. He imagined himself rebuilding antique cars in the basement, and relaxing by the beach in a Muskoka chair while I pattered in the kitchen. He even had a dream like that, though in the dream he left the chair, floating out of his body into the light. In hindsight, I wonder if it was a premonition.

There was only one chink in the shining knight's armour: his damsel grew up. When we met, I was twenty-six and younger than that developmentally, having moved out of my parents' home just a year earlier. I was starting a residency in Psychiatry, struggling to impress my superiors, doubting my every clinical decision, barely affording my bachelor apartment, and had traveled outside the country only once independently. I was drawn to Yurgen as much by our mutual commiseration about our controlling and impossible-to-please European parents as by his confidence, humour, and chivalrous manner. He supported me in my struggles, and I was happy to let him take the lead on most personal decisions.

By the time we parted, I was forty-two, developer and head of a major internationally known research program in childhood anxiety disorders, an Associate Professor with more than double my husband's salary, a mother of two young children, and no longer nearly as preoccupied with my family of origin as before. Meantime, his parents had died and seemed to become more hallowed figures in his mind every year. He supported me less, not just because of late hours at work but because I seemed to need less support as time went on. I challenged his decisions more, and tried to develop a more reciprocal relationship where each gave to the other and each was able to receive.

The knight was not amused. One year I prepared an overflowing basket of his favorite goodies for his birthday, accompanied by a couple of rare books about World War II aviation that I knew he would like. He acknowledged the gift briefly, but was not nearly as happy as I had hoped. The following week he announced that he was buying himself a scroll saw for one of his projects around the house. "You can cover the cost, and that can be my birthday present," he concluded.

I was dumbfounded. It was as though my gesture the previous week had never happened. Had he forgotten it? Or could he simply not accept the "damsel" giving him a meaningful gift? I was deeply hurt, and didn't make that sort of effort again. Whether he needed to treat me the way he thought his

abused mother should have been treated by her husband, whether he needed to always be the “giver” to prop up his self-esteem, or whether there was some other reason for the pattern didn’t matter. It was a pattern he was not ready to give up.

Despite the changes in the relationship, we still enjoyed our Saturday coffees and he could still make me laugh. Despite the changes in me, I still worried more than he did and was more proactive when it came to health. That Saturday evening, I grilled him about what advice he received at the walk-in clinic.

“Like I thought, nothing was broken. He just told me to keep icing it. For that I waited two hours!” he complained.

“Anything else he suggested?” I pressed.

“Said my blood pressure was high and I should come back in two weeks to re-check it. He says lots of people are nervous around doctors and that might account for it.”

My husband was rarely nervous and never intimidated by a doctor or any other authority figure. “Sounds like a good idea, honey. If you take care of it now maybe you’ll be healthier in the long run,” I responded. His mother had died of a stroke in her sixties.

“It’ll be fine,” he grumbled. He didn’t keep the follow-up appointment.

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My husband and I were both fiercely independent but for different reasons. I needed to be self-sufficient because I feared the alternative: being helplessly vulnerable to the whims of a depressed and often denigrating parent as long as I was unable to support myself away from her. He needed to be self-sufficient because it was part of his identity as a man, because his father would not respect him if he wasn’t that way, and because he needed to see himself as my protector and provider. The latter may



have come from an unfulfilled wish to protect me the way he could never protect his mother from her abusive husband, or not. In whatever way one analyzes the facts, he had a lot more reasons to cling to the myth of total self-sufficiency than I did.

I've already alluded to how this affected our relationship: it became stagnant. Our respective roles could change neither in response to our development as human beings, nor in response to our changing circumstances. Any attempt to challenge the knight/damsel dynamic was ignored or quashed. Changing it would have meant venturing into a frightening unknown, so we carried on with what was familiar. I often wonder what would have happened if we had pursued marriage counseling.

And yet, if I am honest with myself, I must admit that part of me enjoyed perpetuating the myth. Who wouldn't want a spouse who was attentive to her needs, listened to her many complaints, and defended her against all detractors? My husband's ease at navigating large social functions, where I was a life-long shrinking violet, was a nice bonus. I even recall "dumbing down" my contribution to our conversations sometimes, so he could continue to be the teacher and protector. The companionship and emotional support I found in our relationship was unparalleled, even if I couldn't quite be myself.

The myth also resulted on some rather unkind attitudes toward others and the planet. We lived in an imaginary meritocracy: the world was divided into the slothful poor and the successful or upwardly mobile strivers. We were definitely in the latter category. Social disadvantages were dismissed as the excuses of the indigent. Environmental concerns were seen as exaggerated, and an unnecessary hindrance to prosperity. Our focus was on the lives we would enjoy in the ever-progressing society of the future. Our work would help build that future, even if we had to use a few people along the way to ensure our projects got done.

Finally, there was the destructive effect on my husband's health. Physical invincibility was part of the self-sufficiency myth, so symptoms were ignored. Doctors, who were liable to challenge that

invincibility, were avoided. When vulnerability was acknowledged, it was only for a brief time and only after a critical event. Long-term issues were swept under the rug. Unfortunately, neither of us saw how massive the bulge under the rug had become.

My concluding suggestion is this: be willing to receive as well as to give, and to recognize the realistic limits of your independence. Do it for the sake of your health, your relationships, and your effects on others and the world. Moreover, learn to accept your place in the interdependent cosmos, where you are neither self-sufficient nor helplessly dependent on others. Think of yourself as the nidus from which the effects of your deeds emanate like ocean waves. Then, imagine those waves intersecting with the wave-like effects of others' deeds, forming complex interference patterns that amplify or attenuate your impact on the world. Recognize how little is driven by individual goals; how much by the connections between us.

#### 4. Gathering Clouds

We must strive for a good quality of life, for the quantity is not up to us. We must look for opportunities to love today, for tomorrow they may be gone.

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“We should probably get started if we want to go to the park. They’re saying it might rain later,” I urged my family on a sleepy weekend morning. We weren’t church goers, so taking the kids out for a stroll was our Sunday morning routine.

Strapped into our sedan, we listened to a song by Neil Young on the ten-minute drive. It was one of Yurgen’s favorites. He insisted that this was the music playing in the background on our first official date, and that made it “our song”. I didn’t remember that, but I knew we met on a harbor cruise where we danced to Whitney Houston. For me, “I Wanna Dance with Somebody (Who Loves Me)”<sup>1</sup> was the theme song for the early, happy years of our relationship.

The past few months had not been so danceable. I was too busy to notice winter turning to spring. Given my success at the hospital, I had been granted the rare privilege of working from home one day a week to pursue my research. Since my son’s diagnosis though, my “research day” was taken up with appointments focused on his development. The actual research happened at night or on weekends. These times were not guaranteed though, as I was often “on call” on weekends which meant spending much of the day at the hospital and being woken by a pager several times during the night. The S.A.R.S. epidemic (Severe Acute Respiratory Syndrome) which limited patients’ access to our clinic was further complicating my work that spring. I was also looking into private schools for my son’s upcoming transition to Grade 1. I was also trying not to neglect my daughter’s special events, and her Montessori organized a number of these annually. Many of the other mothers did not work outside the

home, so looked at me askance when I didn't sew costumes for the play and chose to buy my contribution to the bake sale at the supermarket.

Yurgen hired a part-time nanny to mind the children after school following the infamous Children's Aid incident, "to help you with the children." I appreciated the help, but resented the implication that the children were entirely my responsibility. I shouldn't have bothered with the resentment...I knew Yurgen had to convince himself that he was rescuing me, whatever the occasion.

The nanny was an experienced, older British woman with a knack for arts and crafts. She provided better, more individualized care than my son experienced in the endless din of his "daycare for the masses". My daughter benefitted too...she now spent more time at home than at Montessori school, so was no longer inclined to confuse the two. Best of all, I got to avoid parading in front of the watchful daycare staff who still regarded me as a criminal despite my Children's Aid file being closed. Unfortunately, the nanny developed an allergy to our cat and had quit rather suddenly a few weeks earlier. I was back to stressful rush hour driving to avoid late pick-up fines, as well as my walk of shame at the daycare. Yurgen did the morning drop-offs, and didn't return till the late evening. We passed like ships in the night apart from the occasional "free weekend" like this one.

Bright sunshine greeted us on this particular Sunday. Normally, Yurgen would have laughed at my insistence on bringing an umbrella but he was silent that morning. We had argued the previous day at the Home Depot, and things had not ended well.

Yurgen's focus on the cottage had become obsessive, so we skipped our usual Saturday coffee to drag the family through the enormous orange warehouse-like store so we could decide together on various interior features. Yurgen would narrow the range of choices to a few that were acceptable to him and affordable, but then I was expected to make the final decision. We decided on the bathroom fixture style, the doors' design, the wood for the ceiling panels, the floor tiles, the backsplash, and so

on...just about everything including (literally) the kitchen sink. Then, we got to the window blinds. There were several very similar designs, I was tired, and I couldn't tell them apart.

"Can you decide this one, honey? I'm beat," I complained.

"Oh no! I won't have you making me choose, and then blaming me if you don't like the result," he countered.

My son tugged at my sleeve and pointed to the hot dog vendor just outside the door. "The children are hungry. Let's get them some lunch first" I suggested.

"And come back with the crowds in the afternoon? We'll never finish, and I still have to mow the lawn and fix the swing set before dark. WHICH OF THOSE BLINDS DO YOU WANT?" It was more of an order than a question.

"Stop shouting at me. I really can't tell the difference. Let's come back with fresh eyes another day," I pleaded.

"Mommy, where's the bathroom?" my daughter asked shyly, wiggling and crossing her legs.

"Oh, for Pete's sake! Go look after the children already...here I thought you cared about this, but obviously it's all on me." He walked away in a huff.

When the children and I joined him in the car, we were met with stony silence.

I tried a more conciliatory tone. "I'm sorry we didn't finish today. I know you're angry but..."

"I AM NOT ANGRY!" he seethed.

I shook my head, "If you say so."

We drove home. He didn't say a word the rest of the day. The next morning, he suggested the park and I agreed. Outdoor fun usually helped everyone decompress.

We found ourselves in a broad, tree-lined glacial valley cupping a small stream. The wide gravel path beside the creek allowed for walking and biking side by side, which worked well for our young family. Fallen trees were regularly cleared away. It was a well-maintained city park that created the illusion of immersing oneself in the wild.

Our daughter took the lead on her two-wheeler with training wheels, while I helped our son with his trike. Yurgen narrated the walk by explaining various natural wonders, identifying bird species, and pointing out the buildings and river embankments his father had constructed when he worked for the Parks Department. Sharing his encyclopedic knowledge always brightened his mood.

After a half hour or so, we found a bench next to a gnarled apple tree with thick branches which scooped towards the ground. I knew from my childhood that this was a perfect climbing tree. My daughter obviously agreed, and both children were soon scrambling upward.

Yurgen and I sat on the bench, warmed by the sun. For the first time in a long time, we didn't talk about plans. Instead, Yurgen shared some interesting ideas from a book he had started to read, "Guns, Germs, and Steel"<sup>2</sup>. It was a nonfiction bestseller which illustrated how geography, as opposed to race or nationality, dictated the progress of civilizations. Regardless of our conservative leanings, we both enjoyed thought-provoking non-fiction. He drew me in with his animated description of the book. I loved the creases around his eyes when he smiled. I reminisced about a picnic at the beach on Victoria Day. He teased me, remembering how I had worried that he would blow himself up with the fireworks he shot over the lake. The arguments and strain of the past year were forgotten. The drives in the country together and warm nights by the fireplace were remembered. Maybe "us" didn't always need to take third place behind careers and child-rearing. We kissed briefly, but long enough to elicit an "ooh, yukky!" from the children.

Then, he played Marco Polo with them, a version of hide and seek. Seeing him running around the park after my daughter and son, he looked the picture of vitality despite a few extra pounds.

In hindsight, it seemed really unfair. I have known many people who were more obese and looked less healthy than Yurgen but lived well into their eighties. Maybe that's why I didn't push him more to eat healthy and follow up with the doctor. Maybe it was my lifelong tendency to avoid confrontation. Maybe if I'd emphasized how much better he would feel, rather than the risks of dying young, he would have responded. Regardless, genetics can be a bitch. He had a mother and maternal grandfather who both died from blood pressure complications in their sixties. He was only forty-seven, so I thought we had time. I was wrong.

As we started back toward the car, short bursts of wind rattled the trees. The sun started to dim as heavy cumulonimbus clouds pushed towards us from the west. When the first drops of rain started, my umbrella was useless in the windy conditions. My daughter accelerated on her bike, and Yurgen ran with the trike in one hand while my son and I brought up the rear. He started the car remotely. We jumped in, turned the heater to maximum, and were quickly warm again.

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I was once shown a set of pictures of happy couples and asked which most resembled my relationship with Yurgen. The choice was easy. It was the couple who were both looking forward towards their next goal or adventure. That was us. We were both happiest when looking and working towards the future. That moment on the bench in the park sticks in my memory because it was so rare for us to actually look into each other's eyes.

We weren't good at attending to the present, as it often interfered with our future plans. The part-time nanny, needed to reduce my risk of stress-related illness and traffic accidents in rush hour as well as benefitting the children, was seen as a luxury. The cost of hiring her cut into our budget for the

cottage and other future plans. The children's immediate needs for food and bathroom breaks were seen as a nuisance for similar reasons. They interfered with future plans. Working in a hospital, I should have found the S.A.R.S. crisis a frightening threat to my health. Instead, I grumbled about how we couldn't do group-based treatment research because of all the epidemic-related restrictions. The future success of the project was my biggest concern.

This style of thinking was ingrained in both of us from a very young age, and not just in our upwardly mobile immigrant families. Society generally values those who can delay gratification. There is even a famous psychology experiment where children are given the option of eating one marshmallow immediately or waiting a while to get more. Those who can wait have been found to be more successful in the long run<sup>3</sup>. No wonder so many of us learn to focus on the future prize rather than seeing what's happening around us!

And yet, we only live in the now. Our influence on future events is uncertain. What is certain is that hungry children appreciate being fed, mothers are kinder and more attentive when they haven't been racing across town, and couples need to take time to really look at each other in order to feel connected. Love happens in the present, nowhere else. If it matters to you, don't put it off.



## Part II: The Catastrophe

## 5. The Telephone Rings

It's the things you never thought to worry about that bite. All you can count on is your own ability to respond, come what may.

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Cardiovascular events are more likely to occur on Mondays than any other day of the week<sup>4</sup>. I wasn't thinking about that fact this particular Monday. Instead, I was rushing around trying to get Yurgen and the children out the door so I could start my day working from home. I grabbed the cat (who was supposed to be an indoor cat, but didn't believe it), pressed the button to lower the garage door, and waved good-bye as it droned shut. I don't think I even remembered to say "I love you."

I looked forward to a quiet day at home. My daughter had a play date after school (the Montessori had a summer program so she was still "in school"). She would be occupied for most of the day. I would pick up my son from daycare in the afternoon to drive him to an appointment, but I had at least six hours of uninterrupted time before that. At last, I could catch up on my grant-writing!

I sipped my second cup of coffee and resolved to let the phone go to voicemail. I've always hated telephone communication anyways. It's not just the fact that it usually interrupts important work, the annoying need for "telephone tagging" when calls are missed, or the preponderance of telemarketers among the callers. Telephone calls are a form of social interaction which arrives with no prior warning and with no nonverbal cues as to the speaker's intention apart from tone of voice. For a recovering social phobic like me, who contains social anxiety by carefully scripting most interactions, that's horrible. I often misunderstand the gist of the conversation, and fumble for words like a bad actor who hasn't rehearsed their lines. Invariably, I remember the most important idea I wanted to communicate just after I hang up. I was glad I could spare myself this experience today.

After a productive morning, I ate a light lunch and picked up my son from daycare. We took the highway to the older section of Whitby. It's a small, quaint town with wrought iron street lamps which seems to be a Mecca for various developmental therapists.

My son had left his teddy bear in his father's car that morning, and worried "When will Mr. Snoozer come home?"

"He'll come home with your Dad this evening," I reassured. I had inadvertently lied.

The appointment went well, and we stopped at a playground on the way home. The occupational therapist had recommended doing this more often, as the climbing equipment could improve confidence and coordination. That afternoon, I was impressed with how my son talked to another boy as he waited for the slide. This was a rarity for my shy, autistic preschooler. I exchanged phone numbers with the boy's mother, hoping to encourage a friendship. The slip with the number on it would be lost in the chaos of the next few days.

Just as we arrived at home, the telephone rang. I had forgotten my prior resolution about voicemail and picked it up.

"Hello. Trillium Hospital. Dr. Manassis? Our neurologist wants to speak to you." I had kept my maiden name professionally, though socially I was often called by my husband's surname. As a psychiatrist, I often saw cases where the mental health problem might be caused by a brain problem, so I assumed the neurologist wanted to discuss such a patient.

"Dr. Manassis, we have your husband here. He was brought in by ambulance from his place of work. A colleague accompanying him told us he started to slur his speech at a meeting and reported his arm was numb. We've sent him for a CAT scan, but I'm afraid it doesn't look good. Based on my clinical examination, he has suffered a severe stroke. I suggest you get here as soon as you can."

The gravity of the situation dawned on me, and I felt my insides drop into an abyss. Only it was a much deeper abyss than that caused by the Children's Aid incident, because this was not just about a threat to reputation and livelihood, but a threat to life itself.

"Can I talk to him?" I asked desperately.

"He's away at the CAT scan. If you get here quickly, you can talk to him when he's back" came the strained reply, "But only one visitor is allowed due to S.A.R.S., so come alone."

"I need to find childcare, so it will take me quite a while to get there, but I'm on my way. Thank you, doctor," I gasped. I felt dizzy and had to sit down for a moment.

How could this happen? He was chasing around after the children and joking with me just the previous day. A 'severe stroke' sounded like he was barely alive. I had to get to him, but alone. How would I do that? How was I going to get the children looked after during the hours I would be spending at the hospital? My daughter might be OK with the family hosting her playdate, but they were unlikely to feel comfortable taking on an autistic boy overnight. I kept hearing the word "quickly" in the doctor's speech and started to panic. The hospital was in Mississauga west of Toronto and we lived in Pickering east of Toronto. Crossing that vast expanse would take hours unless I took the toll highway Yurgen typically drove across for work, but that would take me to the north end of Mississauga and the hospital was in the south end. It was impossible...

I took a deep breath. My thoughts became laser-focused on dealing with the crisis. I strapped my son into the car, called the family where my daughter was staying, explained the situation, and picked her up early. I called my elderly parents who lived closer to downtown, and drove the quickest route I knew to get there and drop off the children. Thankfully, they agreed to keep them overnight. I hoped to find an equally fast route from the city west to Mississauga. I tried to reassure myself that if a lifesaving procedure was needed and Yurgen couldn't consent, they wouldn't wait for my consent (as

substitute decision maker) as I had indicated it would take time for me to get there. They would go ahead, as the law allowed for this in emergencies. I wound through several side streets toward the expressway next to the lake which would take me further west. The expressway was clogged with traffic leaving Toronto in the late afternoon. It took over two hours from phone call to hospital arrival.

After parking, I had to join a massive queue to complete S.A.R.S. screening before entering the hospital. I tried to explain it was an emergency, but nobody was willing to make an exception. It was obviously another “zero-tolerance policy” despite the fact that it had been over a month since the last case of the illness had been diagnosed in the Toronto area. I became beet red with rage, but belligerence would have resulted in being barred from the hospital altogether, so I waited.

While waiting, I left a message for my secretary at work, telling her I wouldn't be in the next day and asking her to cancel my appointments. Then I left two more: one for the Montessori school and one for the daycare. Then I realized Yurgen was transported by ambulance, so his car must still be in the company lot and might be towed if it was left there overnight. I left a message at his workplace asking them to please not do that. I tried unsuccessfully to get an update from the Emergency Department. As the only telephone number on record was our land-line, they didn't recognize my cellphone and I had no way of proving I was actually my husband's spouse. I was quoted confidentiality legislation and told to show official identification when I entered the hospital. At the three-hour mark, I was finally allowed onsite, only to be told my husband was no longer in the E.R., but had been taken to surgery. No other information was available.

I curled into a chair in the surgical waiting room and cried. There was nothing else to do. My pulse was racing, and probably had been for the previous three hours. I leafed through stupid waiting room magazines. Who would think that people whose relatives are dying would be interested in fashion trends or in the latest celebrity fling? Oh well. At least it wasn't as bad as when I found a magazine on

“Waterfalls of Hamilton” while waiting for a pregnancy ultrasound a few years earlier. After a while, a kind nurse came by and told me the surgery would be a couple of hours yet. She pointed me to some vending machines as the cafeteria had just closed. I had enough change for some cookies, and felt a bit better as my blood sugar rose. My pulse slowed down, my face was no longer flushed, and I started feeling cold in the drafty, air-conditioned space. I shivered. I hadn’t thought to bring a blanket.

One stretcher after another rolled out of surgery past the waiting room, each bearing an unconscious body with intravenous bag and cardiac monitor attached. At first, I looked closely to see if any were Yurgen. Eventually, I realized my vigilance made no difference. The appropriate relative was always summoned about two minutes after each stretcher, so I just had to be patient. The sequential stretchers rolled on. They had a hypnotic effect, like one sheep after another on a giant medical conveyor belt. I dozed off.

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You prepare for rain and the wind inverts your umbrella; you anticipate someone getting blown up by firecrackers and instead the ‘blow-up’ happens in their own body. No matter how carefully you try to avoid trouble, trouble finds you and it’s usually in a form you never expected.

Worries are futile, it’s true, but not because the things you worry about are unlikely to happen. Rather, worries are futile because they never capture the thousands of random events that could potentially befall your life. Even the best meteorologists can barely predict the weather from one day to the next. How arrogant to think we can predict the future vicissitudes of our individual lives!

Live long enough, and unexpected tragedy will strike you at some point. On the other hand, live long enough and unexpected joy will find you too. It’s all part of an uncontrollable, crazy ride.

So how do you stay balanced in the middle of the maelstrom? First, let go of the idea that you can predict or control what's ahead. At best, you might be able to follow your plans for a day. Even that is not guaranteed.

Second, learn to trust yourself and whatever gives you strength. You will persevere and do what is necessary. If you have beliefs or favorite affirmations that reassure you, use those too. It may be that, for a while, you need to rely on the fight or flight reactions that get us through crises. That's OK. Your heart might be racing but your thinking will be laser-sharp to help you get around whatever obstacles are in your way. You can't live this way forever, but in the short term it will help you get by.

Lastly, learn from these difficult experiences to face those yet to come with grace. There will always be regrets, so figure out what to do better next time. What else could you have done? Who might have been able to help? What values do you not want to compromise? The more you learn, the more you can trust that you will be increasingly competent in the face of adversity and increasingly true to yourself over time.

All of this may sound a bit glib when you are in the midst of disaster. It may not be till years later that some of it rings true. At least, that's what I found.

## 6. Urgent Care

A few years before these events, an injury to the brain stem would have meant immediate death. A few years after these events, researchers found clotting agents which minimize the damage following hemorrhagic strokes. If only...but we have no control over timing.

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I awoke to the sound of my name being called. A lithe woman in scrubs and surgical cap summoned me with a hint of an Australian accent. The surgeon had moved on to the next case, but she had been the anesthetist during Yurgen's surgery and was at the end of her shift, so was free to talk.

"What have you been told?" she began gingerly. Her face looked wan and tired but she sat beside me patiently, obviously willing to engage in conversation. I was thankful she wasn't in a hurry.

"Only that my husband was brought to the Emergency Room after suffering a stroke at work. By the time I arrived here, he was in surgery. I haven't heard any details."

"Actually, he had what we call a hemorrhagic stroke. Some strokes happen when a blood vessel is blocked, but in a hemorrhagic stroke a blood vessel breaks and there's bleeding into the brain."

I nodded, "I'm a physician myself...psychiatrist but I remember some neurology from my training."

"Oh." She paused, undoubtedly to ratchet up the level of her explanation. "His CT (CAT scan) showed a large cerebellar hemorrhage (bleeding at the base of the skull). Smaller ones are often managed expectantly (wait and see, hoping things resolve on their own), but given its size surgical drainage was recommended. Unfortunately, he suffered a respiratory arrest (stopped breathing) in the



E.R. (emergency room). Our neurosurgeon was already on site, so he was moved into the O.R. (operating room) immediately. He was resuscitated there and is stable now.”

“Respiratory arrest? Do they know what caused that?” I asked anxiously. A stroke in the cerebellum doesn’t usually stop people from breathing unless there is another complication.

“The bleeding caused raised intracranial pressure (there was not enough room in the skull for his brain and the blood, causing pressure to build), and his brainstem herniated through the base of the skull (the bottom of the brain, which controls breathing and other vital functions, was crushed as the pressure pushed it down through the hole for the spinal column at the base of the skull).”

“He coned,” I summarized, the colour draining from my face. I had learned in medical school that this was a catastrophic complication which was generally not survivable. Times had changed though, as had medical science, as Yurgen was obviously still alive. Still, the outlook after this type of injury was probably grim. Would he ever breathe without assistance? Would the damage result in paralysis? I wasn’t sure what to expect.

“What is the prognosis?” I tried to clarify. I dreaded the answer, but the more I knew the more I could prepare for the situation.

“I’ll be frank,” she continued sympathetically, “It’s guarded. The degree of recovery is uncertain. Some of us weren’t sure about resuscitating at all with this type of damage, but the surgeon felt he had to be given a chance. He’s so young for something like this! Your husband is in the ICU (intensive care unit) now. They may be able to tell you more.”

I appreciated her honesty, grim as it was. I felt helpless though, and had the urge to do something. “Do you suggest I stay overnight? I can, but I’d have to make arrangements for someone to look after the children for another day.”

“No, you should go home and get some rest. If he regains consciousness, it wouldn’t be till tomorrow afternoon at the earliest. How old are your children?” she inquired warmly.

“They’re turning eight and six this summer, girl and boy,” I responded. She was likeable enough that I was about to show her the family photo from my wallet.

I wasn’t prepared for her reaction. Tears began streaming down her face as she wrapped her arms around me in a genuine hug. “I’m so sorry,” was all she could manage.

I hugged back. The words “If he regains consciousness, IF he regains consciousness, IF, IF, IF” echoed in my mind. I hadn’t even considered the possibility he might be left in a coma.

My brain told me I had to look up everything known about this type of hemorrhagic stroke on reputable websites. The Mayo Clinic site was always a good resource for patient information, and the latest research papers would be on PubMed. Maybe I could also call in a favor at the hospital where I worked and get a consultation from one of our neurologists.

My gut was not listening to my brain though. My gut reacted to the anesthetist’s sorrow at hearing the ages of my children. My gut produced this gnawing feeling that is difficult to put into words. The closest translation is “This can’t end well.”

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I stopped by the ICU briefly before leaving the hospital. At minimum, I had to make sure they had my contact information in case there were new developments overnight.

It was the one area of the hospital where staff routinely outnumbered patients: a whirling dance of white lab coats, green scrubs, and the blue garb assigned to orderlies, all choreographed to a symphony of ear-piercing beeps, whooshing ventilators, and alarms. Despite the frenetic environment, Yurgen looked peaceful. I had expected the plethora of tubes and monitors, and could see past them to

the body in the bed. There was no blood or bruising or other outward sign of the aggressive surgery he had recently survived. It made sense: the location of the bleeding had resulted in an incision at the back of the head which was invisible in the position he lay. He looked like he was just taking a nap.

As I talked to his nurse, we were interrupted by the physician in charge of his care. He was tall and sported wild, curly hair. His athletic build belied an age in the fifties. He seemed overly jovial for someone whose patients were all on death's door.

"So, does he have a history of diabetes?" he started, "I know he reported the high blood pressure that caused all this when they questioned him in the E.R., but his sugars are sky high too."

"Not that I know of," I replied. "Are they sure this was caused by high blood pressure? Could it have been an aneurysm?" This was the first time anyone had talked about a possible cause for the stroke.

"Surgeon's notes show he didn't see any abnormal blood vessels, so untreated hypertension is the most likely culprit," he clarified, "Monday morning work stress probably pushed it even higher than usual. Now about the diabetes, any history of recent changes in appetite, frequent urination, weight loss..." He rattled off a list of the most common symptoms of diabetes.

I stopped him. "Wait, I remember Yurgen telling me a couple of weeks ago that he had lost a few pounds without even dieting. He was really pleased about that."

The physician nodded, knowingly. "That's a common presentation. No worries. We'll get that under control. The blood pressure's already coming down nicely with medication. Any questions?"

I was a bit overwhelmed by all the diseases now attributed to my apparently healthy husband, so couldn't think clearly. "When should I come back tomorrow?" was all I could blurt out.

“Whenever you like,” came the cheery response, “We’ll have a better idea how he’s doing in twenty-four hours,” and he was gone.

I walked in the moonlight to the dimly lit parking garage. The attendant told me the highways to follow to speed my trip to Pickering. It was considerably faster than earlier in the day, as the midnight traffic was light. “Dance with My Father”<sup>5</sup> was a popular song playing on the radio. It made me wonder if my children would ever dance with their father again. I felt tears welling up and shut it off. I had to stay in a logical frame of mind to deal with all this.

The children were with their grandparents until morning, so I headed home. As I pulled into the garage, it seemed empty. The absence of the second car was conspicuous. I sipped some milky chai tea to steady my nerves. I couldn’t sleep. After a night of online information-gathering, I drifted off for a couple of hours.

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I started donating regularly to cardiovascular research about two years after these events. My donations were prompted by a piece on the evening news. I recognized the speaker’s voice immediately: he was the neurologist who had treated Yurgen in the E.R. He was reporting some exciting findings from his research into hemorrhagic strokes. His team discovered that clotting agents, administered soon after bleeding started, could reduce the size of the bleed and the risk of brain damage from bleeding-related pressure effects. Outcomes were significantly better for those who received these clotting agents than for those who did not.

Research takes time to complete and publish, so I knew immediately that Yurgen had missed the opportunity to benefit from this research by mere months. Leading edge surgical and resuscitation techniques, on the other hand, did improve his chances of survival relative to those in similar

predicaments years earlier. It's unfortunate that funding medical research is not always a priority for governments, leaving individual citizens to make up the shortfall.

As a researcher myself, I've found that there is a certain amount of faith involved: you have to believe that your work will make a positive difference in the future, though you may not be able to tell if it will at the time. Nobel prizes are usually awarded decades after the relevant scientific work, and many of the winners are surprised that their efforts actually mattered.

On the other hand, clinical work requires less faith but more empathy. I read an interesting study once in which people rated their quality of medical care. One of the strongest positive predictors was whether or not the doctor sat down when talking to them<sup>6</sup>. This simple change in posture made them feel heard and cared for. The anesthetist in my story did more than sit down: she took the time to explain the situation in language I understood, mirrored my emotional turmoil, and offered comfort. Some of those behaviors can't be taught. They are simply genuine expressions of one's humanity.

In the healing professions we need both research and clinical care: both faith and empathy. It distresses me that there has been a recent tendency to divide the two. Young graduates with research aptitude are too quickly funneled into "wet lab" positions where they splice genes or analyze data all day, often losing their understanding of the clinical world in the process. Clinicians are relegated to providing subjects for research, often with little understanding of the potential benefit and without getting credit for their specialized skills and bedside manner.

Trying to do both clinical work and research as I did in my career is taxing, to say the least. But where do great research hypotheses come from if not from careful observation of patients? Where does great clinical care come from if it is not informed by science? The clinician-scientist is becoming a rare breed, but when I look at what happened to Yurgen and what's happened in medicine since, I definitely don't want to see that breed to become extinct.

Sometimes the research findings do make a difference sooner rather than later, as shown by the example of Yurgen's neurologist. With sufficient funding, that work might have been accelerated, resulting in a more positive outcome for my husband. Unfortunately, elected officials direct most funds to causes that help them get elected, and medical research is rarely on that list. That's why I donate to it regularly. Maybe it will make a difference to someone else's husband.

## 7. S.A.R.S.

There is no greater cruelty than to apply the rules indiscriminately to hurt your neighbour.

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Early the next morning, the phone calls started. Not the earth-shattering, punch-in-the-gut disaster calls, but the calls from friends and colleagues, from the curious and the confused, coated in saccharine sympathy to create the illusion of caring. All wanted to know what had happened to Yurgen, and when they could visit him in the hospital. Voyeurism is a common human trait. We were the medical equivalent of the wreckage from a traffic accident which everyone slows down to see. Many also wanted to know how to “cover” the various responsibilities Yurgen and I would have to abdicate at work. To be fair, we each had far too many work responsibilities, so delegating various aspects of our jobs would not be easy. Only one call was a genuine offer of help: a colleague who offered to drive Yurgen’s car home if I could get the keys from his personal effects. I gladly agreed.

Despite the admonition to “come alone” the previous night, I decided to bring the children with me to the next hospital visit. What were the staff going to do? Send my children into the street? They had a right to be there and know how their father was doing, and I didn’t want them to face the same barrage of questions from their school or day-care providers as I was facing that day. We would prepare some simple answers after the visit, which they could share without too much discomfort the next day.

I picked them up from their sleepover and was thankful they had already been fed breakfast. Given my philosophy of self-reliance, being grateful was foreign to me, but I really learned to appreciate the family, neighbors, and friends in my community who went out of their way for us repeatedly in this trying time. I had no appetite, but forced down a sandwich with my coffee so I wouldn’t feel faint on the

drive. I made a mental note that I had to find out about the visiting rules so I could get back to the various morning callers.

We drove mid-day to minimize traffic woes, and found the S.A.R.S. screening queue was unusually short when we arrived.

The surly, hunched-over screener frowned when she saw the children. "Only one visitor allowed," she growled, parroting the hospital rules. She reminded me of the daycare provider who had introduced me to Ms. Fanshaw.

"We live in Pickering, so where do you suggest I have the children stay?" I asked pointedly, putting the ball back in her court.

"Well, they can't go to the ICU," she insisted, folding her arms across her ample chest as she glared at me over her reading glasses. "Didn't you think about that before you brought them?" Some people have a talent for making your feel like a criminal.

I ignored the rhetorical question. "It's raining. Would you really force them to get soaked to the bone out here?" I countered, appealing to whatever sense of decency she possessed.

"Well, I guess they could stay in the lobby if you have someone to watch them," she relented.

"My someone is in the ICU," I replied icily, "but the older one is pretty responsible, so thank you for letting them wait in the lobby." We walked past her and she did not stop us.

It was a traditional dreary, two-story lobby with echoing loudspeakers and vomit-colored walls, not like the neon-lit modified strip malls that pass for lobbies in newer hospitals. I found a bench by the wall for the children, instructing them not to leave it under any circumstances. After explaining that I would not be far away and providing a travel game to pass the time, I left them there. Despite being just



shy of age eight, I knew my daughter would keep an eye on her brother and ask someone for help if needed. I took the elevator to the ICU.

“Where is he?” I asked anxiously, as I didn’t see Yurgen in the bed where he lay the previous night.

“Had to move him to another bed,” a world-weary nurse replied laconically, “another patient wanted to watch the T.V., and your hubby’s not watching anything just yet.” It was the first of many moves. It seemed the hospital played “musical beds” routinely whenever someone complained or it suited the staff. The damage done by repeated moves when people are in a fragile or disoriented state was never considered. Yurgen couldn’t speak for himself, so the television addict was given priority. I fumed silently.

Yurgen looked no different than the night before. He seemed to be sleeping peacefully to the rhythmic whoosh of his ventilator. I tracked down the doctor to get an update.

“Easy patient from my point of view,” was how the curly-haired ‘Dr. Cheerful’ described him, “Blood pressure and sugars are nicely controlled, and his vitals are strong. He’s not gonna give out from heart failure like my older gents, that’s for sure.”

“What about regaining consciousness. When do you anticipate that?” I queried.

He shrugged. “No telling in these cases. I’ve seen some of them walk out the door and others end up in a permanent coma. Just have to wait and see.”

“How soon will you know?” I pressed.

“Usually pretty clear in a month or so,” he explained, “but once he’s breathing on his own for a day he’ll be back in a regular surgical unit. I don’t always see the end result.”

Up to a month without answers...Wow! I didn't think we would be in limbo that long. The doctor turned to move on to another patient.

"One more question," I stopped him. "He has a number friends, colleagues, and family who would like to see him. Is that possible?"

"That's up to the nurse administrator." He pointed to an impeccably groomed brunette with short, fashionably styled hair sitting at the desk. "She who must be obeyed," he whispered jokingly. I waited my turn to speak to her.

S.A.R.S. was an unusual epidemic, in that it was hospital-centric. It spared most people in the community but targeted those in hospital, front-line hospital workers, and hospital visitors. Hospital administrators, on the other hand, rarely became ill but became unusually influential almost overnight. They could now impose whatever rules and restrictions made their lives easier in the name of safety, and anyone who challenged them was considered a social pariah. In short, if power is an aphrodisiac these people were having multiple daily orgasms.

The ICU nurse administrator was no exception. When I tried to explain my situation hoping she would sympathize, she did not respond. She merely gestured to the rules recently posted on her wall. They read roughly as follows:

1. All medical communication must occur via one family member.
2. The communicating family member must inform all other friends and relatives of the patient's condition.
3. Only visitors age 18 and above are permitted.
4. A maximum of two visitors per day are permitted, one at a time.
5. It is the responsibility of the communicating family member to ensure that the maximum is not exceeded and that visiting times do not overlap.

6. Visiting hours are strictly limited to the following...
7. All visitors must undergo S.A.R.S. screening at every visit.
8. Only visitors on a list approved by the nurse administrator will be permitted entry. It is the responsibility of the communicating family member to provide this list as well as contact information for all people on the list for vetting by the nurse administrator.
9. Visitors who behave rudely towards any staff member can be barred from the hospital at any time, at the discretion of the nurse administrator.

As the “communicating family member” it looked like I had my work cut out for me. I would start contacting people, obtaining their details, and creating a visiting roster that evening. The rule about rudeness obviously applied only to visitors, as several colleagues of my husband complained about how they were treated by hospital staff. In one case, a colleague was barred entry despite being on the visitor’s list, and then subjected to a racial slur. Later on, our visitor’s list including contact information was posted prominently in a waiting area, with no consideration of confidentiality. Apparently, this was felt to be justified as it was longer than most visitors’ lists so the nurses couldn’t remember everyone and needed a visual reminder. Meanwhile, I had to petition for an exemption to rule #3 if the children were ever going to be able to see their father. Three weeks later, they were finally granted access.

All of these restrictions persisted for the entire hospital stay, even though there were never any S.A.R.S. cases in the hospital, and the last case in the Toronto area was diagnosed more than a month prior to Yurgen’s hospitalization. The administrators clearly saw visitors as a nuisance, and S.A.R.S. gave them free reign to act accordingly. They seemed oblivious to how their actions exacerbated suffering among families.

When I returned to the lobby, the children were playing quietly. They were overjoyed to see me, one hugging me tightly and the other clinging to my leg and refusing to let go. They asked about seeing their father. I explained that “Daddy is still sleeping from his operation, but is looking well,” and that I would try to get permission for them to see him another day. We all took an overdue bathroom break, then left the institution.

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After supper, we planned for school and daycare return the next day, got ready for bed, and read a story. Once everyone was settled, I communicated with various callers and started to create a visitor's roster. Thankfully, one of Yurgen's colleagues suggested dividing the task by having a list for colleagues, which he would create, and a list for family or friends which I would create. As two visitors were allowed per day, it seemed fair and would work as long as I agreed to visit (or have family/friends visit) at a consistent time which colleagues would be told to avoid. As many in my family were traveling in Europe and Yurgen's were deceased, I would be able to visit most days and squeeze in the occasional friend. I also drafted the first of several letters asking that the children be allowed to see their father.

Then, I tried to sleep. It did not go well. There was a disturbing thought I had been pushing to the back of my mind since the previous day which began to surface now. Actually, it was a memory of a thought I had immediately after the painful exchanges with Yurgen around our son's diagnosis. I had felt so abandoned by him and so deeply hurt by his reaction that I thought at the time (though I didn't say it) “Why don't you just drop dead.”

Now, that thought seemed to be becoming a reality. Had I inadvertently made this disaster happen? Had he sensed my hatred and somehow reacted to it physically? I found myself mumbling “I didn't mean it, I didn't mean it, ...” repetitively sixteen times to neutralize the thought. Why sixteen? Because two squared is four and four squared is sixteen. As the square of a square, sixteen is a special

number. It had always been my special number when my Obsessive Compulsive Disorder (O.C.D.) flared up, as it was evidently doing now. As a psychiatrist, I knew that magical thinking was a common symptom of this disorder which I was intermittently plagued by when stressed. Nevertheless, there was a part of me that wasn't entirely sure. Maybe there was a grain of truth to the idea that my thought had somehow caused this calamity. I continued to fret and mumble throughout the night.

The predisposition to O.C.D. is hard-wired in the brain, but its focus often relates to one's experience. In my case, obsessions about inadvertently destroying someone else's life predominated, perhaps because I had grown up believing that my illegitimate birth destroyed my mother's life. O.C.D. took that fear to an extreme though, to the point that I sometimes had nightmares about maiming or killing people I cared about, or not being able to stop others from maiming or killing them. On the other hand, perhaps my fear of doing harm contributed to my motivation to join a profession whose prime directive (in the Hippocratic Oath) is "First, do no harm"<sup>7</sup>. Working as a physician had many rewards, but I also may have needed to become a healer to disprove my greatest fear.

The alarm clock shocked me into the next day.

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There is an old saying that rules are made for people, not the other way around. And yet, human beings crave power and those with little power often resort to rules to increase their influence. This seems to be especially true of those with limited specialized skills, whose only way of asserting their dominance is to resort to the legitimized abuse known as "enforcing the rules". It's often true of traffic officers, members of the Department of Motor Vehicles, administrators of various types, clerks who punch a timeclock in a department store, and many more. Anyone who can make life miserable for another human being and defend their actions with a regulation will do so if they're having a bad day, or just need to boost their flagging self-esteem. The humanity of the person in front of them doesn't register in

their myopic view. Only the self-righteous enforcement of “the rules” matters, because it makes them feel important.

In medical circumstances, this insistence on unbending rules can be especially cruel. Common sense dictates that once safety concerns are no longer pre-eminent, the wellbeing of the patient and the family should come to the forefront. Unfortunately, common sense is not rewarded in the same way as towing the line on hospital policy is, and it doesn't provide the same rush as grinding someone else's hopes into the dirt.

This reflection is certainly an angry little diatribe, but it is not without justification. What happened to my late husband, to me, and to our children in the name of preventing an infectious disease that no longer existed was deplorable. I often wonder if I would have handled the whole situation better if I had not needed to expend so much mental energy on adapting to the hospital's various S.A.R.S.-related policies. I certainly would have been calmer and more focused on what really mattered.

If you ever wield the power to enforce arbitrary rules, look into the eyes of the person in front of you before you exert it. Then, look into the eyes of their children. Ask yourself: is it really worth destroying their lives for the thrill of a small, self-righteous ego boost?

## 8. The Illusion of Control

Many events in life are not within our control. If we try to make them so we only become foolish and aggressive. Courage lies in the ability to accept the chaos and respond with compassion toward ourselves and others, moment by moment.

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I hate the term “new normal”. It implies that somehow a resumption of usual routines, adapted to whatever the crisis, can protect us from chaos and its associated maelstrom of emotions. In reality, chaos follows us and any equilibrium we achieve is destroyed by the next untoward event. Yet my response to this situation was indeed to try to create a “new normal.”

Sending the children back to school and daycare respectively would create predictability which usually reduces anxiety, and would occupy their minds for much of the day which would distract from the disaster at home. Returning to work promptly would have similar mental health benefits for me, at least in theory. Its tiring effect might also force me into a bit of much-needed sleep at night.

So, I created a routine of dropping off the children in the morning, driving in to work late, attending to only the most essential appointments, and then driving to the hospital mid-afternoon to be with my husband for an hour (the maximum visiting time allowed) before picking up the children again. Evenings were spent feeding ourselves, attending to homework, responding to calls, researching hemorrhagic stroke treatments and prognosis, paying bills, and planning the upcoming birthday party for my children. They were both summer babies, so we usually combined the festivities.

When I couldn't sleep, I got back to my hospital projects. I would later joke that I wrote my most successful grant application ever while my husband was in a coma, but it was true. Over half a million dollars was awarded to our team by a national health research fund so we could study the effects of

school-based therapy. It's amazing how focused you can be when you need to take your mind off messy life events. Crossword puzzles on the train to work had a similar effect. The great thing with puzzles and grant-writing is that there is a single, clear solution. That's so much more reassuring than navigating the uncertain, unpredictable vicissitudes of a medical catastrophe. In short, solving things made me feel back in control.

Unfortunately, my adrenaline-fueled attempts to regain control left me, for the most part, feeling like an automaton going through the motions of living. I was dead inside.

The only exception to this state was my one daily hour at Yurgen's bedside. Here I sometimes found peace. I had read somewhere that people in comas can sometimes still hear what is happening in their surroundings and find comfort in familiar voices. Rather than questioning the evidence for this idea, I chose to believe it and provide my husband a familiar voice (mine) reading a familiar book (*Guns, Germs, and Steel*). Judging by the placement of his bookmark, Yurgen had only read about 20 pages on his own and it's a tome of almost five hundred pages. I started where he left off, and read aloud accompanied by the familiar rhythm of the ventilator. The text was factual and a bit dry unless you listened for the underlying theme: the generous embrace of all humanity as each group's development was understood in the context of its environment. It was anathema to the "us versus them" mentality of the *National Post*. There were no winners who pulled themselves up by their bootstraps, nor any losers who were vilified as lazy or unintelligent. There were just people doing their best with what they were given, just as we were now doing our best with what we were given. We could only hope that with time our efforts would bear fruit, knowing there were no guarantees. Our choices were limited to deciding how to spend a few moments each day. Even though he was unresponsive and his eyes remained closed, there seemed to be an intuitive connection between us in those moments.



My new equilibrium lasted about a week. At that point, I faced the first of several “mini-crises” within the overall ordeal, some medical and some due to events outside the hospital. This mini-crisis started with a consent form, presented to me by a newly employed intern with bad acne. It was July, the start of the academic year, so the medical staff were all new. For this reason, it’s important to avoid hospitals in July if you can help it.

The intern casually explained “You need to sign this. Your husband needs a procedure called a tracheostomy. That’s where they make a small cut in the windpipe so he can be ventilated more easily.”

“So, then you are anticipating prolonged ventilation?” I speculated.

He shrugged, “It’s already been a week. You can take a day to read the fine print if you like.”

“What I would like to do is speak to his surgeon,” I demanded, going up the chain of command.

“He usually does rounds at six on his ICU patients,” the pimply-faced boy replied, “Or you could try calling his office.”

If I stayed till six, I risked conflicting with another visitor, who was probably already on their way to the hospital. I called the office. His administrative assistant said I could have an appointment in three months. I wasn’t surprised. Part of her job was to be a gatekeeper, protecting her boss from unexpected intrusions. I often gave similar instructions to my own administrative assistant. I made child care arrangements and waited till six, only to find out that the rounds were cancelled as the surgeon had to leave early that day.

What infuriated me was the impersonal nature of the consent request. I had never met the doctor who performed the aggressive surgery that heroically resuscitated my nearly-dead husband, only to leave him in a coma. Now, I was being asked by his subordinate to consent to another aggressive surgery by the same doctor with no idea what the results might be. Was I consenting to them putting

my husband on a ventilator permanently? Would they do another heroic resuscitation if there were surgical complications? Could he be left even worse off (if that was possible)? Finally, and most ominously, at what point did it make sense to stop the dramatic interventions and let nature take its course?

As I couldn't talk to the surgeon in charge of my husband's case, I did the next best thing: I talked to a neurosurgeon at the hospital where I worked. Granted, his expertise was in pediatric neurosurgery but he had trained in adult neurosurgery first and was well-acquainted with the field. I was very thankful he agreed to take my call the next morning. He felt strongly that the tracheostomy should proceed, as being ventilated without it could damage the lungs in the long term. He didn't feel the operation implied anything about prognosis one way or another, and that too little time had passed since the stroke to make any decisions about "nature taking its course." I felt reassured, but still wanted to hear the information from the doctor who was actually in charge of my husband's case.

I communicated with Yurgen's colleague who was helping me manage the visitors' list to make sure that nobody would arrive at the hospital at six o'clock. I assumed (correctly) that rounds would not be cancelled two days in a row. I made child-care arrangements again and waited.

The maverick surgeon was older than I had expected. He was silver-haired but with lively, darting eyes which took in each patient scenario quickly and accurately. He then asked his subordinates a few relevant questions before striding briskly to the next bed.

I interrupted his stride with a pointed question. "Excuse me doctor, but I need to know the potential risks and benefits of the surgery you are proposing before I sign this consent form."

He gaped at the intern who had not prevented my ambush. "She's a physician, sir," the boy meekly confessed.

“No kidding” the elder surgeon grumbled. He then politely reiterated the same information I received in the morning from the pediatric neurosurgeon.

“What are the chances of a serious adverse event like a cardiac or respiratory arrest?” I pressed him.

“Your husband’s a young man,” the surgeon reassured, “His vital organs are strong. As long as there’s no further hemorrhage, he should be fine.”

“I don’t think he’s fine right now,” I countered darkly. “I want a DNR (do not resuscitate order)”.

He looked dismayed. “It’s too early for that.”

“He’s in a coma. If he has a serious adverse event and you resuscitate, he’s going to be in a deeper coma. That’s not living, especially for someone whom you consider a young man. I want a DNR before I sign this consent” I reiterated.

In truth, I was hoping the DNR would never be needed, that Yurgen would eventually recover and come home, but I wasn’t going to be pushed into signing a form that gave the surgeon carte blanche. If he wanted my cooperation, he had to take me seriously. If I couldn’t control the situation, at least I would insist on being heard. He grudgingly relented, and I signed both the consent form and the DNR form in his presence.

Having asserted myself with the surgeon, I felt pretty good about how I was managing the crisis as I drove home that night. I saw Yurgen’s car in the driveway. His colleague must have driven it to our home that day. I was relieved to find my son’s long-lost teddy bear in the back seat.

I unlocked our front door and entered the two-story foyer, just as my son was running down the stairs to greet me. I waved the treasured toy. “Look. Mr. Snoozer’s back!”

My son was not nearly as thrilled as I had anticipated. “Where’s Daddy?” he asked. He looked at me sternly. “You said he would come home with Daddy!” His eyes were beginning to water.

He was right. That was precisely what I had said. I apologized and gave him a hug. We both cried.

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How does one adapt to chaos? Everyone has their own favorite strategies but mine involve carving out small pockets of my life where I can still feel in charge. As I am writing this, I realize that even this memoir is one of those “pockets”. My son is currently enrolled in an overwhelming pre-employment program where his mistakes are repeatedly misinterpreted as deliberate rudeness or irresponsibility, where he is expected to do dozens of job applications weekly resulting in phone calls at all hours from prospective employers and sudden schedule changes to drive him to interviews, and where his existing credentials are ignored, forcing him to obtain them again. My attempts to communicate with staff are deliberately ignored in the name of promoting his independence, and quitting the program would result in loss of support for a potential job he was offered a week after the program started. We have no choice but to persevere for eight weeks in this unnecessarily aggravating and tumultuous whirlpool, or risk starting his quest for employment all over again.

My response is to take some time each day to write, as this is one of the few activities the program people cannot touch. My grant-writing and puzzles seventeen years ago were a similar coping strategy. They were self-compassionate activities, even as my daily reading at Yurgen’s bedside was an attempt to extend some compassion to him and maintain some sort of relationship. These are sane, healthy ways of finding some peace within the storm.

What is different from seventeen years ago is the degree to which I try to control external events. Insisting on a “Do Not Resuscitate” order even though I wasn’t sure I wanted it came out of that

irrational need for control. I needed to feel that the doctors were including me in their deliberations, and this was a dramatic way of guaranteeing that inclusion, regardless of whether or not it was in my husband's best interest.

In my son's situation, I am trying not to let that happen. I am stepping back to avoid ruining his chances of accessing a potentially great opportunity in eight weeks. I'm not so insistent on being a lead actress in the play: I'm OK with working behind the scenes with some advice and support from my friends (more about those in the next chapter). Admittedly, it's not nearly as difficult a situation because we are not talking about potential loss of life, merely potential loss of a young man's self-esteem and future employment, and because there is a definite time limit.

Still, I'd like to think I've learned something in the intervening years about where true influence lies. In complex situations, it's not always about confronting people head-on until they take you seriously. It's often more of a martial art: a dance where you redirect your opponent's energy while trying to support your allies. The outcome is not entirely within your control, but sometimes you can deftly shift things in your favor.

## 9. Accepting Help

It takes a village...to survive a trauma.

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It took a few days to schedule the tracheostomy so I returned to my newly found routine, looking forward to those serene moments reading to Yurgen in the late afternoon. They were my respite from the turmoil.

Bracketing those moments were chance encounters with his colleagues coming and going, often either just before or just after my visits. The size and dedication of this group surprised me. All considered Yurgen a trusted friend or admired mentor. He was known for being one of the few managers who was always forthright and did not “play politics,” as well as being a very sharp systems analyst. He had rarely shared this part of his life with me.

I had a longer conversation with the colleague who had accompanied him in the ambulance. He was a soft-spoken, Hispanic man of about thirty who was new to the country. He described gratefully how Yurgen had taken him under his wing at work.

“He give me so much,” he explained in broken English, “I have to take him to hospital. Now, I pray every day he get better.”

“Thank you,” I replied sincerely. “How was he when he first came to the hospital? Was he able to say anything?” I was particularly interested if he had tried to communicate anything meant for me, but would take whatever information I could get.

“He talk and joke in the ambulance. He think everyone overreacting. Then nurse in ER put in his chart he was forty-nine years old, and he keep correcting people “forty-seven”. Then, he have headache,

more and more strong, and they take him to CAT scan. When he come back, right away go to operation. They tell me he admitted and go home,” he sadly concluded.

The description was reassuring in that it sounded like there had not been any delays in treatment, whether related to my late arrival or otherwise. It was also quintessentially Yurgen: joking and minimizing his distress, and insisting on accuracy.

The young man continued, trying to be encouraging. “I know looks bad, but we pray, all my church pray, and God listen. You see. Miracles happen!”

Though I’d always been fascinated with religion, I had long ago given up on the idea of the “vending-machine god” who pops out a miracle when fed the requisite number of prayers. I didn’t completely dismiss the idea of a creative Force for compassion in the universe, nor the idea that appealing to that Force might be helpful in troubled times. I just didn’t have a consistent, personal relationship with God in the way this young man seemed to believe he did, and if there was such a God, I didn’t believe He or She intervened in human affairs directly in response to requests. I didn’t question the young man’s faith though. It couldn’t hurt to have some extra prayers said for Yurgen, even if I wasn’t sure it would help.

As I learned more about Yurgen’s colleagues, I was pleasantly surprised by my own. They went out of their way to help, offering to take on some of my usual duties in addition to their own. Even though I knew some things would not be done to my usual standard and had to resist the urge to micro-manage, I thanked them and accepted their help. Even though it meant relinquishing some control over the outcome, I learned to delegate.

My children’s friends and their parents were equally helpful. One of my daughter’s little friends even promised to build her a time machine some day so she could go back to before her father became ill. If something came up with Yurgen, there was always a parent willing to provide childcare on short

notice. The neighbors pitched in too, as there were many chores around the house and property that Yurgen had done and I could not attend to at the time. Even the holier-than-thou daycare providers were nicer to me than before.

I had not realized we were part of such a caring community, probably because we rarely asked for help and I had never looked like I needed it. When people assume you are highly competent and self-sufficient, they are less likely to offer their services. When you feel in control of your life, you want to bolster that feeling rather than compromising it by accepting help. In short, sometimes kindness and interdependence can emerge when we dare to let our guard down.

Nowhere was this more evident than at the children's birthday party, which became a true community effort. I had rented a large public pool for the occasion so we could include all of their friends and classmates. These themed mega-parties were a suburban tradition in our area. An impressive venue, enough food to cause some youngsters to throw up, and overflowing "loot bags" to take home were expected. It was not unusual to rent a public pool, large gym, bowling alley, multiple rows in a theatre, or an entire restaurant for such an occasion. Pizza, pop, and a giant themed cake were always provided. Loot bags consistent with the theme had to be personally designed, as store-bought ones were frowned upon. Depending on the number of guests, they sometimes cost more than the venue rental.

That year, I had paid for the rental but done nothing else to prepare. I was determined not to cancel the event though, as it would be one of the few bright spots in the children's summer and I couldn't stand the idea of adding a huge disappointment to the tragedy they were already facing. After they informed their friends that the party was going ahead, offers of help started pouring in from other parents. From ordering the pizza and cake to designing the loot bags to finding out the rules for the



change rooms (an important issue at a pool party for young children), they took care of everything. One even negotiated a reduced life guard fee. My only response was a humble “thank you” in each case.

When the big day arrived, it happened to coincide with Yurgen’s tracheostomy. The procedure had been scheduled on short notice for that afternoon. Going to the party not knowing the surgery’s outcome was nerve-wracking, but I couldn’t back out of the event at that late stage. I made sure the ICU staff had my cellphone number in case anything unexpected happened, and hoped for the best.

I splashed around at the noisy pool party, trying to look happy for my children. Like many of the parents, I kept them at arms’ length rather than relying on the rather distracted-looking lifeguard. They still seemed to have fun with the slides, sprinklers, and other amusements the recreation complex provided for these occasions. Just as I was changing my son back into dry clothes while another parent was setting up food, my phone rang. The number indicated it was from the hospital.

I froze. This was the call I had been dreading. Something had obviously gone wrong. My hands shook. I doubted my decision about the DNR. If he was dead now, it was on me. Once again, my insides dropped into an abyss.

“Hello,” I responded, my voice quavering, and identified myself.

It was ‘Dr. Cheerful’, the intensivist. “Hi there, how are you? Just thought you’d like to know your husband came back from surgery a while back. Everything went well, and guess what? When the anesthetic wore off, he opened his eyes. No other movement, but it’s a really good sign.”

“Wow! Thank you!” I gasped, “When I saw your number, I thought the worst.”

He chuckled, “No disaster...good news for a change. Come down and see him whenever you like.”

I enjoyed the rest of the party, arranged for the children to sleep over with friends, and visited the hospital that evening. It had been eleven days since Yurgen's stroke.

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The story of the pool party and the dozens of other helpful gestures provided by friends and acquaintances during this difficult time beg the question: Why didn't I rely on this supportive community sooner? Even prior to Yurgen's stroke, life had been difficult and probably more stressful than it needed to be because of my rugged self-reliance. Why didn't I ask for assistance?

Over time, I've come to realize that the answer involved more than just relishing the feeling of self-sufficiency. It had to do with whether or not I could trust people enough to let my guard down and tell them I needed help. In my family of origin, such requests usually resulted in the other person either feeling overwhelmed by yet another demand, or making me feel that the problem was somehow my fault, or making me feel I was imposing, or all three.

In my childhood peer group, letting my guard down could have even more dire consequences. I recall giving a "friend" my telephone number, only to be shamed by a group of girls calling my house and chanting "brown noser" and "teacher's pet" in unison, then laughing at me. I was rarely chosen to attend parties, so was thrilled when I was finally invited to one in Junior High. When I arrived, I found out that the theme was doing makeovers on the three "ugly ducklings" of the class, including me. It was humiliating. I preferred being dry humped on the way home from school by Dougie, the local pervert, or beaten up by the boys whose grandfathers fought in World War II and considered my family Nazis because of our German roots. Those things happened too, but they were not as personally wounding as the crank phone calls or the pity party.

When I entered the professional world, my peers were more civil but also more competitive. Some were experts at ingratiating themselves to the higher-ups while quietly undermining people they

saw as rivals. The fact that this reduced productivity and increased divisions within the department didn't seem to matter to them. The fact that it was wrong seemed to matter even less. No wonder I guarded my privacy and cultivated an air of invincibility!

And yet, I have come to believe that for every back-stabber there is at least one other person who doesn't twist the knife and may even use it to help you feed your child. It's not always obvious who these people are, but over time one gets better at recognizing them and welcoming them in. Some people learn to do this gradually as they figure out signs of trustworthiness and experience genuine friendship. Other people learn this suddenly and of necessity, as I did that fateful summer. I often relied on my "village" of helpers in subsequent years.

## 10. Relationship and Isolation

What is the value of a life in isolation? We are inherently creatures of relationship.

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I had really looked forward to seeing Yurgen awake that evening, yet was not prepared for what I found. Lack of movement or speech was expected. What I didn't appreciate was how much we humans communicate with our facial expressions. When a face has no expression, it doesn't look like the same person. It's like looking at a badly done portrait, where the painter's creation is accurate but wooden and devoid of the person's essence. You have to use your imagination, projecting onto the image what might be going on emotionally. If you're anxious by nature as I am, those projections can be negative or even frightening.

Moreover, what do you say to someone who just stares at you wide-eyed but blankly like a deer caught in the headlights of your car? What do they need to hear? What have they already been told by others? Do they remember your previous encounters?

I decided to assume nothing and start from the beginning, orienting Yurgen to where he was and, briefly, what had happened in the previous eleven days. I decided to hold his hand as I did this, even though I had no idea if he had any feeling in his limbs. I tried to be encouraging about how the children and I were coping and how we were looking forward to him recovering and coming home.

He blinked only once during the whole speech, apparently at random.

I wondered if he would enjoy hearing more of the book that I had been reading to him.

There was no perceptible reaction.

I was feeling awkward and a bit guilty about not knowing how to be supportive. I decided to return to our previous routine and started to read.

It seemed to help. His wide-eyed stare changed to a less dire look as his eyes were now half-closed. Maybe he enjoyed the book. Maybe he was just getting sleepy. Regardless, the book continued to be an anchor point in my attempts to relate to him. After about twenty minutes, his eyes closed completely and he seemed to sleep.

As the cheerful intensivist was not on duty, I read Yurgen's chart. I knew it was against the rules for family members to do so but my curiosity got the best of me. Besides, I told myself, unlike other family members I actually understood the medical jargon, so I wouldn't misinterpret anything. I've always been good at rationalizing my misbehaviour.

Most of the chart consisted of boring daily records of vital signs. There was also a record of "Glasgow Coma Scale"<sup>8</sup> scores which had gradually increased over the previous few days, indicating a greater level of consciousness. That was not unexpected. Notes from the consulting neurologist were more interesting. The deficits already present in the emergency department were documented, together with the diagnostic impression that this was probably a hemorrhagic stroke. The CAT scan confirmed it. The note after the emergency surgery indicated "reduced level of consciousness and control of vital functions, likely related to brainstem herniation." It was exactly what the anesthetist had told me.

The final note from earlier that day indicated "clinical examination consistent with locked in syndrome." That was a new diagnosis. I knew it meant the person was conscious yet unable to move, but had no idea what the treatments were or what the prognosis was for recovery. I made a mental note to research it further.

"That's only for the doctors!" exclaimed a strident young nurse, pulling the chart away roughly.

I apologized, feigning ignorance of the rules. “I was looking for what I could do to help, now that he’s conscious,” I added, hoping she would see me as a misguided but well-intentioned family member. It wasn’t a complete lie.

She softened. “Bring a calendar to keep him oriented, and some family pictures or mementos. That will help. Right now, you need to go home. Visiting hours are over.”

I thanked her and drove into the night, racking my brain for facts about locked in syndrome I had learned in medical school.

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In the coming days, an extensive gallery of snapshots came to grace the wall across from Yurgen’s bed. They included family and friends on various memorable occasions, some including Yurgen and some where he had been the photographer. I also found a large-print calendar that I imagined he could see from a distance.

I questioned the perpetual, twenty-four-hour twilight of his surroundings, created by the bright neon from the nurses’ station fading gradually into the dark area where patients lay. It gave people no indication of day or night. That was bound to mess up the body’s normal biological rhythms. It also meant that I could never predict if Yurgen would be awake or asleep when I came by. It was difficult enough to maintain a sense of connection given his disability, but this made it worse.

Responding to my concerns, the stern, impeccably coiffed administrator replied sharply “This is a short stay unit for the severely ill. It is designed for intensive medical care, not a pleasant lifestyle.”

Circadian rhythms impact human physiology in multiple ways, and so are definitely more than a lifestyle issue. Her claim that the unit was “short stay” was also not entirely accurate as Yurgen spent several weeks there. However, I thought it unwise to correct her. I brought a flashlight so I could

continue reading at the bedside without eye strain. I was learning to accept that I was a pawn in this medical chess game.

The weirdness of one-way communication continued. I could never be sure if he enjoyed my visits or if they were depressing reminders of all he had lost. I became self-conscious about discussing food, as his was limited to a milky white solution in a tube. I became self-conscious about discussing physical activities, as he could do none of those. Even reporting good weather was awkward, as he had not seen sunshine in weeks. I explained that I was working on getting the children access to him, but wasn't sure if he appreciated that or didn't want them seeing him in his debilitated state. I had to guess at his wishes, and I'm sure there were times when I guessed wrong. That must have been horribly frustrating for him.

I was starting to run out of material for my monologues too. Yurgen had always been more of a talker than me. Explaining historical trivia was one of his favorite pastimes, and he was a born teacher. I tried the well-known "blink once for no and twice for yes" approach, but it didn't work very well. His blinking was infrequent and I wasn't sure if it was entirely within his control. It seemed random. The whites of his eyes were getting pink too, though the nurses assured me they were giving him artificial tears to keep them moist and prevent infection.

Still, I persevered. Yurgen and I had come through some very difficult times before, and I had the faint hope that this recent disaster might turn out to be just a "wake-up call" alerting us to the need for better self-care once he recovered. We'd weathered many storms before. There had been his grief from losing his parents, years of weekend visits in his father's final days (while I looked after two infants at home), two disappointing miscarriages, a cervical cancer scare during the pregnancy with my daughter (the pre-cancerous growth was lasered away shortly after her birth), a premature infant with a dislocated hip, jaundice, feeding problems, and seemingly permanent sleeplessness, and now the child

that had appeared to be the “easy baby” turned out to be autistic. Nothing was ever easy in our family. Nevertheless, we continued respecting each other and liking each other’s company most of the time. True, our bond had been stretched to the limit in the past year, but it was still strong.

Judging by the number of “Get Well” cards, there was still some connection with Yurgen’s friends and colleagues too. Anecdotes from his place of work were undoubtedly supplementing my daily family updates and readings. How long would these connections continue though? Most of his friendships grew from his perceptive mind and acerbic wit. Now, that brilliance could no longer be communicated. Even his role as helpful teacher and mentor was gone. Would they continue clamoring to see him if things didn’t improve further in a week or a month or longer?

So much of what was meaningful to Yurgen derived from relationships, as it probably does for most people. Would he ever be able to re-engage in those relationships in a meaningful way? Only time would tell.

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We are a naturally gregarious species. In the most recent pandemic, some people have chosen to risk death rather than endure continued isolation. Solitary confinement is considered one of the worst punishments inflicted upon prisoners. Only the most ascetic of saints spend prolonged periods alone in the wilderness. Most of us cherish each other’s company too much to manage more than a few days at a retreat. In the movie “Castaway”, the main character copes with being stranded on a desert island by personifying his volleyball<sup>9</sup>. So strong is the human need for companionship.

I can only imagine how being stranded in one’s own body must be even more devastating. What hides behind the eerie stare of someone who is completely unable to move or to express themselves? There’s an old German saying that shared sorrow is halved and shared joy is doubled. It rings true. Who



wouldn't become despondent at the prospect of never being able to share either emotion?

Communicating feelings, perceptions, and thoughts is such a vital aspect of being human.

Then, there is the joy of movement. Yurgen may not have been a graceful dancer, but the sense of personal agency that came from walking, driving, cycling, and completing the myriad tasks he performed at work and around the house was an indispensable part of his being. Doing things gives life a sense of purpose. Movement is also relational: the ability to reach out and touch another person is invaluable, and a horrible ability to lose.

Finally, there is the satisfaction of seeing others respond to one's words and actions. That response reminds us that what we are saying and doing has an impact. When we have an impact, we feel we are a part of things and we belong. We also learn from this impact what we might want to do more or do differently next time, and so we grow.

Some philosophers claim that when a tree falls alone in the forest, it makes no sound because sound only exists when someone perceives it. I wonder, when a person has a thought alone in their mind and nobody else can perceive it, does the thought exist? If it happens continually, does the person exist? Connection with others may be more than a human need. It may define who we are.

## 11. The Missing Spouse

Even when we accuse our spouses of not doing their share, they do more than we realize. Sometimes that doesn't become obvious until they're gone.

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"We just delivered the furniture. How will you be paying for that?" a perky voice inquired at the other end of the line. I was caught off guard in the middle of sorting through some correspondence.

"Excuse me, but I don't think I ordered any furniture, and we haven't received any deliveries here in Pickering," I replied, "Is this something to do with the cottage in Wasaga Beach?" If this was a legitimate caller, that was the only logical explanation.

"Mr. M. indicated that you would be paying upon receipt, and we just delivered to this address...and yes, it is Wasaga Beach."

"I see. So, what do we owe you?" I wondered. It was just shy of ten thousand dollars.

"I need a day to confer with our bank," I explained, "Can I get your number and call you right back tomorrow? My husband has been in hospital the past two weeks."

The caller willingly provided her number, website, and other contact information confirming that this was a legitimate transaction. She even expressed some sympathy for my husband's ill health. It was the first of several unexpected bills that I struggled to pay.

Unfortunately, I made the mistake of informing the bank of Yurgen's condition. Rather than helping, they responded by immediately freezing all accounts in his name. Most of our bills were paid by automatic deductions from those accounts. Now, I had creditors calling me at all hours of the day and night because those bills "bounced" and I had to make other payment arrangements.

The only way I could access Yurgen's accounts was via a Power of Attorney. I thought there might be one, but couldn't find it in the room full of filing cabinets that Yurgen had used to catalogue every official document, every receipt, and every bill we had ever paid since we got married, as well as his parents' financial affairs. It was like seeking the proverbial needle in a haystack. I knew there was a safety deposit box though, and was able to find the key.

I stood patiently in a long line-up of people waiting for the bank to open on a hot, humid day to see if that box might contain a Power of Attorney. Summers in Toronto are known for their stifling humidity. Several women's dresses were clinging to their thighs, freshly applied mascara was running, and an older man with a cane looked like he was about to faint. At last, the bank doors opened and we all tumbled into air-conditioned bliss.

My interaction with the short, taciturn teller went something like this:

"Hello. My husband has a safety deposit box at this bank and I need to see it to determine if he has done a Power of Attorney so I can access his account. Here is the key."

"We cannot grant access to safety deposit boxes to relatives without a Power of Attorney."

"Here's some identification and a marriage licence confirming I'm his wife. Please let me see the box, as a large bill has come due."

"We cannot grant access to safety deposit boxes to relatives without a Power of Attorney."

"I don't think you understand: if there is a Power of Attorney it is inside the safety deposit box, so I can't show it to you until you open the box."

"I cannot open the box without a Power of Attorney. Your husband needs to sign one." She was adamant.

My patience was dwindling, “Look, I’m dizzy and dehydrated from lining up out there in the heat, my husband is comatose and can’t sign anything, and I’m not leaving until I get some help!” I insisted. “I need to speak to your supervisor.” I had learned in an assertiveness course that the “I need” phrasing is generally more effective than “I want,” and that one should go up the chain of command.

She left briefly, returning a few minutes later. “My supervisor says we can’t open the box without a Power of Attorney. She also says you need to leave or we will call security.”

I was livid. “My husband worked for this bank for over twenty years, and your supervisor doesn’t even have the decency to come out of her cubicle and talk to me in person?”

My outburst resulted in a second threat to call security.

I left. As soon as I was able to do so, I transferred all of our money, every last cent, from that bank to another one.

Fortunately, I was able to scrounge together enough money from my personal accounts to pay for the furniture. However, I knew I could not cover another large bill. I wondered why we had never created joint accounts. Were we each that determined to be independent, or did we just never get around to it? It didn’t matter. For now, I had to rely on my own resources.

Sure enough, the final construction costs for the cottage came due to the tune of ninety thousand dollars, and that was too much to “scrounge”. I was thankful that the contractor gave me some time to arrange a loan, and helped me tie up loose ends on the building. The final one of those ends was picking the blinds: the same blinds Yurgen and I had argued about two days before his stroke.

As I admired the finished product in Wasaga Beach, a small group of locals came by and talked about how they wished they could afford such a splendid second home by the lake. They had no idea what our family was enduring. Envy is a truly stupid emotion.

And yet, it wasn't just the money troubles that reminded me of everything Yurgen used to do. He was also a consummate handyman. His home improvement projects were originally spurred on by a desire to disprove his father's accusation that he was a "useless paper pusher" because of his university education and career at the bank. His father was an uneducated but clever laborer with many home repair skills. With time, Yurgen seemed to find genuine satisfaction in working on upgrades to the house, as well as taking care of any needed repairs.

I knew that further upgrades were out of the question in our predicament, but was determined to avoid having the house fall apart. Even this modest goal was often difficult to achieve. I quickly learned that tradesmen only provide a "window" of four or five hours for their appointments, and someone must be at home for that entire window. This was impossible to manage with my schedule at the time.

Instead, I had to categorize problems by their level of difficulty. Ripping down the vines that were destroying the mortar between the house bricks was a no-brainer. Learning the mechanics of a broken flush toilet was not too difficult with a bit of guidance from an older salesman at Canadian Tire. Installing a new screen door or replacing a broken washing machine without creating a flood was more difficult. I called on handy friends and neighbours for those.

Finally, there were things that could not be done without professional help. The clogged tubing in the fountain that fed our backyard pond was one of those. The landscaper who installed it was booked for three months, and the pond was a slimy mess full of disgusting water worms. It attracted mosquitoes, so posed a risk for West Nile virus, as well as emitting a putrid stench. Moreover, the rubber pond liner ran beneath piles of immovable heavy rocks at the edges. I had to find my own solution for this one. I had no idea what to do with the fountain, but was able to bail most of the water out of the pond with a bucket. Then, using a carpet-cutting tool I found in the basement, I cut through

the rubber liner at the edge of the rocks. This allowed me to remove it, bail its wormy contents into a composter, and roll it up for the trash. I then made multiple trips to the garden store to purchase large bags of cheap soil so I could fill the giant hole where the pond had been. There was no time to plant anything to make it look pretty. I had safely removed a hazard, and that was enough.

Meanwhile, I was still trying to find a replacement for our allergic part-time nanny. The agency was having some difficulty, as we needed a candidate who had a car to do school and daycare pick-ups and had experience minding children with special needs. Such candidates were rare in our area. It needed to be done though, as my late-day rush across the city from hospital to daycare was becoming increasingly exhausting, the “late pick-up” fees were mounting, and friends were getting burned out with my frequent short-notice requests for childcare whenever something changed in Yurgen’s condition. I really missed having a partner in raising the children.

Of course, being a father means so much more than being a helper with child-minding. The children were reacting to Yurgen’s absence, each in their own way. My son alerted me regularly to situations where he expected his father’s presence. The most poignant was an evening ritual he had developed when his father came home, often when I was already asleep. He routinely had a bowl of cereal with his Dad before bed. My son tugged at my sleeve at the same time every evening, stating the brand name of that cereal. I provided it, knowing he missed his father’s company more than the meal.

The bath issue resurfaced as well. After the infamous incident with Children’s Aid, Yurgen and I had always carried our son to the bath tub together, often kicking and screaming, in order to avoid any further injuries. With Yurgen unavailable, I did not dare to try this on my own as I would risk another child abuse allegation. Therefore, I did what many parents do when stuck: nothing. I had enough other problems to solve, and thought that a few days without bathing wouldn’t harm the boy. Before I knew it, days turned into weeks.

One weekend, my son pointed to his bottom and said “Hurts!” Removing his pants revealed the worst diaper rash I had ever seen. He was still using pull-ups at the time, and without his baths the urine had eaten away at his skin. Alarmed, I told him “Honey we really need to wash you in the bath and then put cream on that. It’s not going to get better otherwise!” Perhaps it was the fear in my voice, perhaps it was wanting relief from the pain, but my son cooperated. He walked to the tub himself and never objected to bathing again.

My daughter seemed to be coping better but, like her father, she didn’t readily express vulnerable feelings so I couldn’t be sure. She seemed to have fun with her friends and their families in her spare time, but how did she feel in her room at night? She had been so close to her father, especially as I became more focused on her brother’s lagging development. Even earlier in life, her father had been the only one who could reliably comfort her. I would try every trick in the book to calm my dysregulated, inconsolable premature baby without success. Her father would make one unique, indescribably funny face and she was laughing for the rest of the day. I often regretted not talking more to my daughter about losing her Dad, but then again maybe it wasn’t her style to talk her way through grief.

In hindsight, I wonder if my first-born was a bit like me: looking after the emotional needs of everyone else in the family and suppressing personal feelings the way I had as a child. I did it because of the need to tell my depressed mother whatever she needed to hear to avoid her going off the deep end, even when it blurred the psychological boundaries between us, and to achieve the outward success which my father needed to experience vicariously. Similarly, my daughter needed to be “OK” despite her father’s grave illness because I couldn’t handle one more problem or one more distressing emotion on my plate. Later, she sought freedom from the family as soon as opportunities presented themselves, much as I had. I often wonder how different her life would have been if her father had survived.

Some aspects of a person are truly irreplaceable.

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We naturally tend to divide up chores in marriages, sometimes according to gender roles, sometimes according to areas of expertise or ability, and sometimes a bit of both. Over the years, we come to rely on those divisions of labour, to the point where our skills in the 'spouse's areas' diminish and increase in our own domain. Unfortunately, this can leave our families quite vulnerable if one spouse is suddenly gone. Compensating for the loss in areas we know how to manage is tiring enough without the added burden of having to learn new skills overnight.

My advice: retain some familiarity with your spouse's fields of expertise to avoid facing a steep learning curve if they are incapacitated at some point. Besides home maintenance, one of the most important of these fields is finances. You don't necessarily have to be an expert in investments or accounting, but you need to know who to ask about these matters. You should also know what you own, what your spouse owns, and what you own jointly. Make sure you have some assets in the last category just in case your spouse's assets are frozen at some point. Similarly, know what you and your spouse owe and how you typically pay your debts and bills. As the chapter illustrates, keep important legal documents like Wills and Powers of Attorney in places that are safe but readily accessible: a copy at home and a copy at work (in case of disaster striking your home) are prudent. NEVER use bank-controlled safety deposit boxes for these documents.

More important than a spouse's practical contributions to the household, however, are their relationships with other family members. Census forms would have you believe that families are just a certain number of people of certain ages cohabiting in one dwelling. Therefore, losing one member of a family of four merely means living in a household that is twenty-five percent smaller. Nothing could be further from the truth!



Families are complex systems which vary in a multitude of ways<sup>10</sup>. For example, they vary in the degree of closeness or distance in different relationships, in what power people hold relative to each other, in communication styles (including, in many cases, covert “unwritten rules” specific to that family), in openness to outside influences, and in the degree of autonomy granted to family members. Furthermore, these family characteristics often result in circular, self-reinforcing patterns of interaction among members which eventually become entrenched. By the time these patterns are discovered by a family therapist or other professional, it is impossible to tell how they started. They are both everyone’s fault and nobody’s fault. Therefore, it doesn’t make sense to assign blame, only to seek ways of changing the patterns. Making changes to family systems is difficult enough to have spawned an entire field of therapy!

Life events, however, can have a dramatic impact on family patterns. Even normative changes like a move of house from a big city to a smaller town or having children leave for college can really upset the apple cart. In the first case, expectations of what family members share or don’t share with neighbors may change; in the second case, parents may need to re-evaluate their relationship in light of the “empty nest.”

Changes in family patterns are heightened in the face of extraordinary events like the ones our family faced seventeen years ago. A metaphor for families is that each is an interwoven fabric of relationships. When one member is ripped out of the fabric, many frayed threads of emotion become exposed among those who remain. Such events cannot be prepared for. The remaining members have no choice but to huddle together for comfort and try to tie up the emotional threads amongst themselves if possible until (hopefully) the missing member returns. Sadly, that repair is not always possible, and sometimes the missing one does not come back.

In summary, losing a member of one's immediate family can have a multitude of logistical and emotional consequences. Many are painful and complex. A few are obvious immediately; others don't emerge until years later. Sadly, some unique ways in which a person contributes to our lives may not become clear until they are gone.

## 12. The Neurosurgery Unit

Life is harder after you graduate, because nobody knows you.

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“Where is he?” I asked anxiously as I didn’t see Yurgen in the bed where he lay the previous night. There had been several bed-moves around the ICU, but this time I didn’t see him anywhere on the unit. I feared the worst. I had been trying to avoid the nasty nurse administrator, but she was the only one who could help in this situation.

“Transferred to the neurosurgical unit,” was her curt reply.

I breathed a sigh of relief. Moving to the neurosurgical unit was a good sign. It meant his doctors were confident Yurgen could handle less intensive care now. Still, I was irritated that nobody had informed me about this change before it happened.

Arriving in his new room, I noticed he was no longer hooked up to a ventilator. His breathing was shallow and raspy, but he was clearly doing it on his own. This was probably the reason he had “graduated” to the new unit.

The room was quieter than the ICU, given the lack of life-sustaining machinery, and shared with only one other patient. A translucent curtain could easily be drawn to separate the two occupants for privacy. I was pleased to find that someone had collected our pictures from the ICU and left them at the bedside. I quickly reassembled them into the familiar wall gallery Yurgen was used to seeing, so the new room resembled the old one more closely. Then, I proceeded with my usual routine of updating him on events of the day and reading from our lengthy nonfiction book. His eyes went to half-closed, as they usually did when he relaxed.

We were interrupted by a chipper voice. "Would he like the chicken or the fish for dinner? They're both OK with his diabetic diet." The uniform suggested she was a nurses' aide, but I didn't bother reading her nametag. There were so many caregivers that they all started to blend together after a while.

"I don't know if you've noticed," I replied haltingly, "but he's tube-fed."

"Oh." Long pause, "Sorry."

I was irritated, but continued to read.

A timid knock on the door interrupted us again. "Mr. M.?" came a gentle voice with a distinct Filipino accent.

"Yes, this is Mr. M.," I confirmed.

"Oh, hello. I am his physiotherapist" the petite young woman replied, "Sorry, but I need to do assessment. Just few minutes."

"No problem," I replied and gave her some room to work.

"Mr. M., squeeze my fingers," she instructed, placing them in his right hand. Predictably, nothing happened.

She increased the volume, "Mr. M., try to squeeze my fingers," Again, nothing happened. She repeated the exercise on the left side, increasing her volume each time.

I interrupted. "Excuse me, but he hasn't moved a muscle in three weeks, so he can't squeeze your fingers." I added, "By the way, his hearing is fine so you don't need to shout."

"Sorry. I need to do assessment. You maybe please wait outside?" she suggested.

Very few people in this hospital said “please,” so I didn’t mind stepping out. She really was well-intentioned despite her naivete.

Fifteen minutes later, she came out into the hallway and stated the obvious. “I assess him. There is no movement, but he sometimes blink his eyes. That is a good sign.”

“Thank you for that insight,” I replied with a hint of sarcasm in my voice. I wondered how many years of post-secondary education were spent developing those assessment skills.

“You’re welcome!” she cheerfully responded. She clearly hadn’t taken the hint.

Inane people make me anxious, especially when they are responsible for a family member’s care. In this case, anxiety about the clueless physiotherapist heightened my previous irritation. I was becoming enraged.

Based on my two interactions with people on this unit, I concluded that my husband was being treated by morons. It was time to have a conversation with the head of the morons, and this time I wouldn’t take an appointment in three months’ time. I couldn’t risk my husband being mistreated that long. I would not rest until I had some say in his care, no matter how much of a pain in the butt I became for the surgeon.

I greeted the neurosurgeon’s young administrative assistant and informed her I would be camping out in front of his office until he spoke to me. She looked flustered and made multiple attempts to convince me of the inappropriateness of this behavior. I held my ground. I made myself comfortable, ate the first of several granola bars I had brought along for the occasion, and waited. I got chilly after a couple of hours and huddled under my coat for warmth. I was determined. I would sleep in this waiting room if I had to.

The silver-haired surgeon looked tired by the time he emerged from his office that evening. I could tell he wasn't thrilled to see me, but he waved me in. He had a life-size plastic model of the brain on his desk, no doubt for educational purposes, and several scholarly books he had co-edited. His diploma-wall contained multiple academic awards.

"To what do I owe the pleasure, Dr. Manassis?" he started. "Your husband is doing better. We were able to wean him from the ventilator and transfer him out of ICU. That's good news. What are you concerned about now?" The eminent neurosurgeon and scholar sounded like a little boy, disappointed that he cannot get parental approval despite his best efforts.

"The people on the neurosurgical unit today didn't seem to realize he's tube fed and the physiotherapist didn't seem to realize he's paralyzed," I countered, "Hasn't there been any communication about his condition?"

"It takes time for them to get used to new patients," he explained, "but they're good people...and I know the physiotherapist you're talking about." He sighed, "Please understand that with the bed shortage the hospital administration is requiring all of us to show how we are reducing length of stay. In our unit, that means showing we are making rehabilitative efforts by ensuring physiotherapy for all our patients. I agree, in some cases there's limited benefit, but that's the way it is. Sometimes the physio comes up with passive exercises to reduce contractures. Those aren't bad. Give her time."

I nodded, "OK, I'll be patient...but can you tell me what comes next? What are the goals for Yurgen on your unit?"

"Talk to Jerry, the respiratory therapist. He's experienced with this population and has a good head on his shoulders," the surgeon suggested.

“I will,” I replied, “But I’d also like to communicate with you more regularly so I’m up to date on new developments. I don’t want to take over your waiting room again. I just want to schedule a few minutes’ conversation once a week.”

“Surgeries don’t always follow a schedule,” he admitted sheepishly, “But come by Monday afternoons and we can talk if I’m not in the O.R.”

I agreed, and thanked him sincerely.

The following day I spoke to Jerry, the amiable respiratory therapist. Tanned and muscular, he looked more like a surfer dude than a medical professional but, as promised, he was experienced and had a good head on his shoulders. He explained that Yurgen’s airways would be suctioned regularly and he would perform various additional manoeuvres to help keep the lungs clear. The tracheostomy also needed regular care. His rather modest goal was to have Yurgen re-learn how to cough in the coming weeks so that he could clear phlegm on his own, reducing the need for frequent suctioning and reducing the risk of pneumonia.

He concluded “Yep. My buddy Yurgen and I are gonna be working together for quite a while, but he’ll get there.” It was one of the most realistically hopeful statements I had heard in a long time. He was also one of the few people at the hospital who used Yurgen’s first name. It was nice...he seemed to relate to Yurgen as a fellow human being.

I felt reassured after talking to Jerry that day, Yurgen’s second day out of the ICU. I also believed the surgeon’s claim that with time, the rest of the staff would also get to know my husband and know how to best care for him. I’d had similar experiences as a child graduating from one school to another: adapting to new people was always more challenging than learning whatever new tasks were expected, but they came around eventually. Overall, I thought that transition to the neurosurgical unit might have started out bumpy, but would be positive in the long run.

The next day, everything changed.

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As this chapter shows, the difference between the patient experience in an intensive care environment and a general hospital ward is immense. The analogy that springs to mind is the difference between a student's experience in a small, graduating high school class and their experience in a university lecture hall of hundreds. Like teachers in a small, graduating high school class, staff in the ICU serve a limited number of patients. Therefore, they understand each person's unique needs and tailor care accordingly. As in a lecture hall, there is little individualized attention in a general surgical ward. Staff assume that everyone benefits from the same type of care unless proven otherwise. Moreover, there are so many staff popping in and out of the patient's life that nobody knows them really well. It's scary how much can go wrong with this "one size fits all" approach. The situation is often exacerbated by thoughtless administrative rules like (in Yurgen's case) mandating rehabilitative services, whether beneficial or not, in the hope of shortening hospital stays.

Family members advocating for better, more individualized care for their loved ones are often dismissed as being overprotective or unreasonably demanding. "We have other patients to look after besides him/her," is a common refrain. Rather than giving up on good care, it may be helpful to identify which person or people are actually critical to your family member's progress (as Jerry was in Yurgen's case), and which are not. Then, nurture relationships with those critical people, even if it means going out of your way.

Still, the need for transitional support as people move from one environment to another is often neglected based on the assumption that they are ready for the move. Evaluating that readiness may, however, be based on fairly arbitrary criteria. In the case of the student, readiness for college is determined largely by examination scores. Those scores have little to do with the complexities of



learning in large lecture halls and living away from home on campus. Some manage these additional challenges, others don't.

Similarly, in my son's current employment program, readiness for the workforce is determined based on resume-writing and interviewing abilities with no attention to, for example, the need for a driver's licence in suburbs without reliable public transit. He can get that licence, but not overnight as those who deliver the program seem to expect. He also needs regular feedback about how he is doing once he starts a job, and he doesn't automatically think to ask for it. With no one supporting his communication with the employer (and social communication deficits are a hallmark of autism), things easily go awry. Normally, I would offer that support, but in his current program my involvement is strictly prohibited. As I'm writing this, he has just been unexpectedly fired from yet another program-related job trial.

In Yurgen's case, readiness for the general surgical ward was determined based solely on the ability to breathe without a ventilator with no regard for his many other medical needs. Those needs could have been addressed appropriately with a tailored care plan for staff to follow. Unfortunately, that didn't seem to exist. Instead, they were expected to learn what he needed based on the results of *not* providing it. Those results proved to be disastrous.

### 13. Back in the I.C.U.

Some questions cannot be answered.

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I was on the highway, driving to the hospital, when I heard my cellphone buzz. I always put it on 'vibrate' when driving to reduce the temptation to answer it on the road. I was less than half an hour from my destination, so decided to respond to the call when I arrived there.

In the hospital parking lot, I looked at the number and recognized it as the neurosurgical unit. I called right back but nobody picked up the phone. They were probably busy with patients or doing a shift changeover. I tried again a few minutes later in the S.A.R.S. screening line-up, with the same result.

"Where is he?" It was a familiar refrain by now. Once again, Yurgen was not in the bed where he lay the previous day.

"Who are you looking for, madam?" asked the calm, bearded gentleman at the nursing station. He was the administrator for this unit, and considerably more diplomatic than 'she who must be obeyed' in the ICU. I had forgotten that it was too soon for people to recognize me on this unit.

"Mr. M. I'm his wife," I clarified.

"Oh. We were trying to get a hold of you earlier," he explained. "Your husband had a respiratory arrest, and we were told there was a DNR but couldn't locate it, so wanted to confirm with you. When we couldn't reach you, we resuscitated. It was successful, but he's back in the ICU."

Stunned, I stammered meekly "I...I was on the road so I couldn't pick up the phone." I added, "Thank you for the information," and left.

My legs were wobbly and my thoughts were racing as I stepped onto the elevator. I had to calm down. Maybe this wasn't so bad. Staff in the ICU knew Yurgen well and were experienced. He was going back to more expert care than that he received in the neurosurgical unit. Sometimes it's not so bad to repeat a grade if you're not quite ready to graduate. Maybe the misplaced DNR was a blessing in disguise too. If I was honest with myself, I wasn't sure I was ready to let him go yet. This was a setback, sure, but maybe a necessary one on the road to recovery.

Back in the ICU, things were worse than I had been told. Even the usually cheerful intensivist looked glum. They were still working on Yurgen behind a drape.

"I heard he had another respiratory arrest," I started.

"Yeah, I guess he did need the ventilator a bit longer, but that infection didn't help." He looked away and shook his curly locks.

"What infection?" I asked, as this was news to me.

"Oh, I guess they didn't tell you. When they lifted him up for the transfer to ICU, there was a gush of fluid from the back of his head. He's got a nasty wound infection in that surgical incision. We've got him on broad spectrum antibiotics though, and his vitals are stabilizing." He couldn't resist ending on an optimistic note.

"So, to be clear," I asked rhetorically, "He had an abscess growing on the back of his head, and nobody noticed until now?"

He shrugged. "They're supposed to check incisions on rounds, but post-surgical care isn't always ideal. Regardless, infection and poor wound healing are pretty common in diabetics."

When things go wrong in medicine, people often resort to blaming the patient. I suppressed the urge to challenge his final comment. I knew I would need to maintain a good relationship with him in the coming days. I merely nodded.

“By the way, our social worker wanted to have a word with you,” he added, clearly uncomfortable with our conversation.

Not everyone was assigned a social worker, but I was not surprised she had been called. With the recent deterioration in my husband’s condition, it was appropriate to involve someone who could assess how our family was coping and engage supports if needed. It was more likely though that she was summoned because I had been pushier than the typical family member. Her job would be to keep me out of the doctors’ hair.

Despite my cynicism about the reasons for her involvement, I welcomed the opportunity to talk to someone who didn’t have an M.D. behind their name. There were always nurses to talk to, and some were truly wonderful people, but they changed all the time. It was rarely the same person on the same shift for more than a couple of days. That made it hard to develop more than superficial relationships. I simply didn’t feel comfortable sharing my more serious thoughts and feelings with someone who I might not see again for weeks, if at all.

I recognized the social worker by her street clothes. She was the only professional on the unit not dressed in a uniform or in surgical scrubs. Her attire was consistently neat but drab, as though she had always just come from a funeral. She was soft-spoken and an excellent listener. I immediately felt comfortable providing a summary of what Yurgen and our family had gone through in the previous three weeks or so, and my concerns related to these events. I can’t recall exact bits of dialogue with her, probably because nothing she said irritated or surprised me.

For the most part, she just listened and validated my concerns. She supported my proactive approach to my husband's care, and was impressed with how I had kept my career and family going through this difficult time. She encouraged me to page her rather than the doctors if there were additional concerns about my husband's care, which I appreciated even though it confirmed my suspicions as to why she was involved. When she made the occasional suggestion, it was sensible. For example, she suggested checking with my husband's workplace about applying for long term disability. The short-term disability payments were already being deposited regularly into his frozen accounts (and I had not found the time to figure out how to legally access those), but making a long-term disability claim was more complicated. I would need considerable medical documentation for the application. She offered to help obtain this. She also supported my letter-writing campaign to allow the children to see their father. Within a day of her involvement, access was granted. Overall, I felt I finally had someone in my corner.

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The children seemed excited to go to the hospital and see their father, and I was thrilled the hospital was finally bending the rules to allow it.

"Lobby?" my son wondered anxiously. He had regressed to uttering single words since his father's hospitalization.

"No, you won't have to stay in the lobby this time," I reassured him, "We're going up to the ICU where Daddy is."

I tried to prepare the children that their father wouldn't be able to move or talk, but encouraged them to talk to him as he could still listen and understand. I also mentioned the "breathing machine" (the ventilator) connected to a hole in his throat (the tracheostomy) and the family pictures on the wall across from his bed "to help him remember home."

Still, I guess no amount of preparation would have been enough. Yurgen was awake when they arrived, and met them with his usual wide-eyed stare. My daughter stammered a few words, then turned to look at the pictures on the wall. My son said nothing and joined his sister. I stood between Yurgen's bed and the children, not knowing which way to turn. I tried to tell Yurgen about some recent events at school and daycare, hoping these might resonate with one or both children. He stared motionless. They stared at the pictures. I stood in the middle, unable to bring my family together. The children later described the experience as "really creepy."

They could tell I was upset as we drove home, and my daughter started to apologize. I told her there was no need, as it was a very tough situation.

"Will he ever get better?" she asked innocently.

I was honest. "I don't know."

Some questions can never be answered. Would the man in the pictures ever come back, or was their father destined to be the haunting figure in the bed? Would they ever be able to relate to that figure, or would they only remember the father shown in the gallery? Would he have wanted me to turn away and focus on the children, or go to his bedside and reassure him that they would come around? What would the family look like in a month, a year, a decade?

Moreover, what was his real potential for recovery? We were approaching the one-month mark where this trajectory was supposed to be clearer. So far, the only concrete goals had been independent breathing and coughing. Was that enough to go on? Would he ever come home, or would he be forever dependent on an institution? Would any communication or movement ever return? Computer-neural interfaces were just starting to give people with locked in syndrome some means of communication, but would that be positive or just an opportunity for him to tell me that he didn't want to live this way?

Could he ever adapt to such a limited life, or would he hate me for prolonging it? Even with the most up to date information, the answers were mere guesses.

The children didn't ask to go back for another visit, and I didn't urge them to.

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Questions that cannot be answered often have to do with the future or with other people's wishes.

Would Yurgen ever move, communicate, or come home? How would we carry on if he didn't? Would he ever reconnect with his family or his friends in a meaningful way? How would he carry on if he couldn't? Nobody had a crystal ball or even an educated guess to predict what was going to happen.

The most disturbing unanswerable questions had to do with his wishes: Did he want to live this way? How long could he bear it? Did he love or hate the people who kept him alive and encouraged him to persevere? Did he love or hate those of us who were starting to contemplate the alternative? Nobody can read another's mind. I came to regret the fact that end of life care was not one of the topics Yurgen and I had discussed over Saturday coffee.

Questions that can be answered often relate to present experience or to one's own wishes. The social worker and the children helped anchor me in that present experience. It was productive to follow the social worker's suggestions about long term disability. It was helpful to talk to her before approaching doctors, not only because that was her assigned job, but also because it put me in a calmer frame of mind if I did proceed up the chain of command. The children showed me that they were not going to readily connect with their father when he was a shell of his former self. At the same time, they seemed to find comfort in good memories of the father they used to have as he appeared in the gallery.

Similarly, the present experience with my son's unexpected job loss made it clear that what matters is not having my son please the program leaders and meet their ridiculously high expectations,

but for him to recover from this shocking experience without having his self-esteem shredded. When the leaders contributed to that shredding by blaming only him for the problem, I knew it was time to withdraw him from their toxic influence and try something else. I hadn't been allowed to salvage his job, but I was determined to salvage his mental health afterwards. The result was a new employment direction that he finds satisfying, honourable, and far less stressful. Trusting what you observe in the present is the basis of much common sense.

When it came to my wishes in 2003, I clearly knew what I wanted: to reconstitute my family, for Yurgen to have a more predictable and less chaotic hospital course, to get some semblance of order back in my life, and to have reasons for realistic hope. Knowing that's what I wished for didn't make it so, but at least it wasn't in question. His wishes, on the other hand, continued to be a mystery.

In the end, we must focus on what's currently answerable, make an educated guess at the rest, and do what is needed day to day despite the uncertainty. We must trust that the answers will emerge eventually. However, if we strive to behave kindly and honorably in the meantime, we will know we have given it our best effort. Giving one's best effort is somewhat comforting, whatever the outcome.



## 14. Brainwaves

When neither of two options is acceptable, wait. A third may yet emerge.

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My next appointment with the silver-haired surgeon was near the four-week mark. I brought a small box of chocolates for his assistant: a peace offering after our last encounter. He was a few minutes late, but fortunately didn't get called away to the O.R. so we had time to talk. He beckoned me into the office.

"So, what's on your mind today, Dr. Manassis...or should you be asking that?" he smirked. He knew I was a psychiatrist, and had jokingly reversed our roles.

I smiled. We all get a bit giddy when we're tired. I began. "Well, the infection and the respiratory arrest last week were quite a shock. His eyes are also looking worse. He seems to be getting good care in the ICU though, and the social worker on the unit has been helpful. I'm worried about his neurological progress though, or rather the lack of it. What can you tell me about that?"

His beady eyes fixed on mine, and I could tell the wheels were turning. "You're right," he started slowly, "There's been no evidence of movement beyond the eye-blinking, and he's developed some conjunctivitis because it's not that frequent. We've started antibiotic drops for that. Remember though, he's just bounced back from a major setback. I'm anticipating some further progress in the next week or two. In fact, we did an EEG two days ago because he's gone through a couple of resuscitations now, and it looked surprisingly good. His brainwaves are normal. He can't communicate with us, but his mind's all there!" He was clinging to hope.

"That's great. But his mind's trapped in a body that's non-functional and ventilator-dependent. What sort of life is that? How much better do you expect he can get?" I needed that answer desperately.

He sighed, "It's hard to say. I've seen some similar cases where the person was eventually able to re-learn to talk, breathe with very limited ventilation, and even gain enough mobility to travel independently in a wheelchair. Granted, those were traumatic brain injuries in twenty-somethings, not forty-somethings with strokes, but you never know."

"How long would that take? From what I've read, most progress happens in the first month, and it's pretty incremental after that."

He conceded, "It is a long road. For dramatic improvement...probably a year or more, and no guarantees. It's possible his condition might not change that much."

I hesitated to ask the next question. "If things are not changing for the better soon, is there a point where we reduce medical intervention? If so, what would that entail?"

His expression was grave. "We sometimes limit the treatment of complications in these cases. He already has a DNR, which is now flagged on the chart. We could also start reducing medications. I do want to treat his conjunctivitis since it's really uncomfortable, but if he developed something like pneumonia..." His voice trailed off and a disturbed look came over his face.

He regained his composure. "Let's see how things go this week."

I agreed, thanked him, and left.

I had to think about this. He had normal brainwaves, so he was sentient. But being fully human was so much more than brainwaves. People who were epileptic had scrambled brainwaves and yet could live very meaningful lives. People like Yurgen had normal brainwaves and yet their "living" was hardly detectable. What is the value of a disembodied mind, particularly one that cannot communicate with the rest of humanity? Can mind and body be neatly separated, as some would claim, or is that Idea just an artifact of our Cartesian past? How would an epicurean bon vivant like my husband ever find

meaning in a life devoid of food, sex, and any other sensual pleasure? How would a born teacher find meaning in a life that prevented the communication of ideas? Relating to his children was already impossible. How many more relationships would wither and die as a result of his disability? If there is an individual soul, an essential quality to a person, I am convinced it is more than brainwaves.

Philosophical musings aside, I realized I was approaching a difficult choice. To withdraw care would mean an inexorable progression towards death. My insistence on a DNR had stemmed partly from a need to assert my wishes in this medical maelstrom, but also partly from a hidden wish. Part of me wished that God or the universe would make the choice. If there was a disaster from which Yurgen was not resuscitated, his death would be considered natural, rather than being a result of anyone's intention. I did not want to be responsible for that intention. If it was going to happen, I wanted it to just happen. I thought of the biblical verse "Father...let this cup pass from me."<sup>11</sup> Jesus says it in the Garden of Gethsemane when he cannot face his own crucifixion. I'm no Jesus, but I really didn't want to face the possibility of killing my husband.

If it had been a matter of killing his father, it would have been easier. My father-in-law had often said "If I can't take care of myself, shoot me! Don't let me live till I can't wipe my own ass." Yurgen and I had never had that conversation. I knew he valued self-sufficiency, but he wasn't as extreme as his father. What would he want, I wondered? How much dependency could he tolerate?

There was also the logistical issue of how to withdraw care without triggering a major legal or ethical challenge. After all, as he had normal brainwaves any attempt to "pull the plug" could be seen as murder. It would not be easy to argue for that option. More importantly, the last thing my children needed was a prominent media story about how their mother was advocating killing their father.

But what was the alternative? If I did nothing, the medical system would take over and gradually move him from the ICU back to the surgical unit and then on to a chronic "rehabilitative" hospital where

nobody ever got rehabilitated. Instead, people there were warehoused indefinitely as they could no longer function anywhere else. We even had a derogatory name for such places when I was an intern filling out the transfer forms to them: the vegetable patch. More than once, I sent a severely debilitated patient “to the vegetable patch,” never to be seen or heard from again. Now, I was contemplating allowing some other intern to send my husband there.

Moreover, I would be paying for the privilege. The social worker didn’t know how much such places cost, so I researched it online. Even if I succeeded in the long-term disability application for Yurgen, it wasn’t nearly enough to cover the fees. To pay them, I would be decimating family savings set aside for the children’s education and my own retirement. Would Yurgen, the consummate provider and giver, want that for us? Could I allow that progression to his warehousing and our impoverishment to happen? And what of my own life-long fear of being stuck in poverty and despair? Was I dooming my children to a similar childhood to the one I had experienced; myself to a fate similar to that my mother had endured? I had fought so hard to escape that sort of life.

We seemed to be trapped between an option that was disastrous and one that was unconscionable. There was no good or right decision.

I thought back to similar scenarios in my life where I appeared to be in a “no-win” situation. A number of traumatic events came to mind. There was a childhood incident where my mother locked herself in her room, said her life was over, and became unresponsive. I wasn’t sure whether to keep talking in the silence, knowing she might harm herself, or risk humiliating her by calling a neighbour for help. After a moment, I realized slipping a caring note under the door might cause her to re-engage with me, and it did. The crisis passed. Then there was the time in my teens when I went jogging and got trapped in a ravine with a knife-wielding sexual predator. He was too big to fight off and I wasn’t sure I could outrun him, but I had to survive. I feigned ignorance of his proposition, kept jogging, and bided my

time until I saw an escape route. Another time I was suicidally depressed and got fired from a job that I needed to pay for university tuition. I stood on a tall bridge ready to jump, as I could not go home and face my parents. I hesitated, and realized there was another option. I went to the library daily, pretending I was still working, until I was offered a scholarship. Finally, there was the day I swam too far from shore and started to drown. I fought the waves, desperately trying to get back without success and was ready to give up. Then, I realized I could tread water for a minute, just long enough to feel a current that pushed me towards shore. In each case, there were no good choices except to wait until another option presented itself.

Similarly, in this situation, the only choice was to wait for that third option. The surgeon was right. I just had to see how things went the following week.

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When we are caught between two untenable alternatives, third options can come in several forms. Sometimes an obstacle that can neither be accepted nor overcome needs to be circumvented, like climbing over or around a boulder in your path. When facing powerful human foes that will not budge sometimes, like Ghandi, you need to pursue passive resistance. Sometimes you need to accept a situation without surrendering to it. This means developing ways of surviving which are consistent with your values in the face of uncontrollable events. Sometimes, as in this story, you just have to wait for a new option to emerge.

None of these approaches is easy, and all can be elusive. To perceive them, we need to loosen the narrow, goal-oriented thinking which occurs with the “fight or flight” reaction<sup>12</sup> and allow for some creative, tangential thoughts to surface. The physiological stress reactions we experience in a crisis often make this impossible.

Sages tell us that we need to center ourselves in a peaceful place within where we can observe thoughts and feelings, and let them come and go. That mindful centering reduces stress, allowing the “big picture” to emerge. In mildly stressful situations, there seems to be some truth to this idea. The ability to access one’s “peaceful place” is also known to improve with regular practice, so mindfulness exercises are definitely worthwhile.

Trauma is different though. Think of your mind as an old merry-go-round of rising and falling horses at the fair. Thoughts and emotions come to the foreground and then fade into the background repeatedly, some resembling passionate stallions, others gentle ponies; some lively, energetic thoroughbreds, others tired old plow horses. When mildly stressed, we can get off the ride and stand back, observing the progression, moment by moment. When traumatized, we cannot. The ride is spinning too fast for us to be able to get off and observe it, so all we can do is hang on. Therefore, don’t be ashamed if you’re just hanging on. That’s all that is possible in the midst of traumatic events. Your carousel will slow down eventually.

## 15. The Following Week

Sometimes the worst thing you can do is nothing.

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I soon learned the reason for the surgeon's giddiness during our last talk: he was heading out on vacation. He hadn't bothered to mention this fact, but he would be gone for the next ten days. In his absence, everything continued as before. Ventilation continued with the goal of eventual weaning and return to the neurosurgical unit. The wound infection and the conjunctivitis were treated, as were newly arising infections in the sinuses and at the tracheostomy site. The infectious disease expert visited daily, though never when I was around, and added another antibiotic almost every time. When I questioned the ever-expanding medication cocktail in view of my conversation with the surgeon, I was told that no details of that discussion were in the chart. He had merely noted its time, presumably for billing purposes.

When I raised my concerns with the dourly-dressed social worker, she asked whether or not I was sure about withdrawing care. I had to admit I still had doubts. "I want to give him every reasonable opportunity to recover," I explained, "But I'm wondering if we're getting beyond the point of what's reasonable." We agreed to defer a definite decision until the surgeon got back.

As we reviewed the financial situation, she advised I continue borrowing money rather than starting court proceedings to access Yurgen's accounts. She informed me that without a Power of Attorney, such court cases typically took at least six months of intensive effort, "and you have enough on your plate." In the back of my mind, I wondered if she also anticipated that it might be easier to access the money from Yurgen's estate if he passed away. She also began bringing brochures from various long-term care facilities to our meetings, "just in case we go in that direction." Nevertheless, she

was still an excellent listener and consistently sympathetic about our family's situation. She also congratulated me heartily when my efforts to find a new part-time nanny finally paid off. It would still be a few weeks before the nanny could start, but the end was in sight for my frantic rush-hour drives across the city to the daycare.

For my part, I continued the pattern of reviewing daily events and then reading from a book at Yurgen's bedside. I finished "Guns, Germs, and Steel" that week, and moved on to a more meditative text. Paradoxically, based on his eyes remaining wide open, Yurgen seemed to find it less relaxing than the previous book. I realized he was a man of ideas and sometimes considered spirituality a bit "airy-fairy". I would have to find something more suitable.

My late-night excursions into the medical literature continued too, but with increasingly less informative results. Large-scale studies of hemorrhagic strokes were few and far between. There was even less information about locked in syndrome, and what existed pertained mostly to brainstem strokes rather than brain hemorrhages that resulted in coning (Yurgen's situation). Even though reading anecdotal reports is usually frowned upon in medicine as "poor quality evidence", it seemed justified because so few cases similar to Yurgen's existed. I began looking outside medical databases to find analogous situations.

The most famous seemed to be a case of locked in syndrome in France described in a memoir called "The Diving Bell and the Butterfly"<sup>13</sup>. Bauby, the author, had painstakingly dictated it using a system of eye-blinks. He devoted a couple of years to writing it as he learned to adapt to his condition, mostly in hospital, only to eventually die of an infected bedsore.

I surveyed the ICU nurses about similar cases. Only a very experienced senior nurse had ever seen one, which confirmed the rarity of this situation. "An Asian gentleman of about fifty, I recall. He



was locked in after resuscitation in the O.R. and they ventilated him here for a couple of months. His family hardly spoke English though, so they didn't consult the doctors regularly like you do."

"Was there anything that was particularly helpful for him?" I wondered if there might be something that they hadn't tried yet to help Yurgen.

"No. Sad situation. They brought in some traditional herbs at one point, but that did nothing except annoy his surgeon."

"What happened to him?" I asked.

"Don't know. They transferred him to a rehab hospital."

As I suspected: sent to the so-called vegetable patch. That's inevitably what happened to these people when nobody advocated on their behalf. I thanked her for sharing the story.

It reminded me of an old adage in medicine: sometimes the worst thing you can do is nothing. In my own specialty, this was evident when parents feared medicating their children because of a small risk of side effects. Without medication, some of the children deteriorated in their ability to cope outside the home and showed marked regression in their development. Thus, the risk of doing nothing exceeded the risk of intervention. In Yurgen's case, the risk of doing nothing would lead to a miserable life in a rehab hospital and, most likely, eventual death by bedsore.

Moreover, the possibility of that bleak outcome seemed to be drawing closer. The conjunctivitis was not improving despite antibiotic drops. One eye was horribly inflamed and oozing pus. It was patched shut to allow for healing. Yurgen's world had shrunk further. If the second eye followed suit, he would be blind. My furtive glances at his chart revealed another troubling trend: his Glasgow Coma Scores were going in the wrong direction again. This made sense to me: he had been asleep more than

awake during the last few visits. Still, it worried me. Was he just over-medicated or would he eventually lose consciousness completely?

I made the mistake of sharing these concerns, including my doubts about continuing intervention, with people who had not seen Yurgen but were within our circle of friends. They just didn't get it.

"You should get a second opinion!" ...as if I wasn't already consulting with multiple doctors and combing the medical literature for other opinions.

In relation to withholding intervention: "Don't you think that's pretty drastic?" spoken in a guilt-inducing tone; "You have to give him till at least Thanksgiving" with no explanation of the reason for that arbitrary date; and the ever-popular "Have faith. Miracles happen!"

At first, I was annoyed. Eventually, I realized that their comments were based on the assumption that the old Yurgen, the articulate, vivacious, funny force-of-nature they used to know, could return to them. They had not seen him as the children and I had seen him: the wide-eyed silent spectre wedded to a machine for ventilation. I had to forgive them. They were not malicious, merely clueless.

That week, the traveling relatives returned too and immediately demanded "When are the visiting hours so we can see him?" I patiently explained the ongoing S.A.R.S.-related restrictions (even though it was now two months since the last local case had been diagnosed), the roster I had been forced to create, and the fact that I couldn't put them at the front of the queue right away. Once they saw Yurgen, they didn't demand a second visit.

People with a bit more medical training were often kinder in their approach. I talked to a helpful mentor who commended my dedication to Yurgen's well-being, which she knew to be difficult while juggling my many family and career responsibilities. I felt supported and understood. I talked to a

wise colleague who advised, “Don’t drive yourself crazy with this. It’s not entirely in your control.” She was right. I tended to become controlling to cope with anxiety, but in a situation like this one where my control was limited, that could backfire. For my own mental health, I needed to continue doing what was within my power for Yurgen’s sake, but to accept that the outcome was not in my hands.

I refused to pray for miracles though. It was fine for others to do so, but I believed more in a God who inspired human action rather than one who intervened directly. My prayer was for an end to the uncertainty: for a sign that would indicate either definite improvement or definite progression toward his demise, and the strength to act accordingly.

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In the past, people often talked about hastening death by “passive” or “active” means. Passive involves allowing a disease process to complete itself without interfering. Pneumonia, for example, used to be called “the old man’s friend” because its ravages ended suffering for many old people before the advent of antibiotics. Not medicating pneumonia is a passive way of hastening death. Actively hastening death, by contrast, usually involves administering some noxious substance that affects the heart, the lungs, or both. Morphine, for example, is a common pain-killer which will stop breathing when given in high doses. It’s not unusual for doctors to adjust the dosage upward in the final stages of terminal cancer. Nevertheless, most people are more comfortable ethically with passive rather than active approaches.

In modern medicine, however, the distinction between the two approaches has become blurred. Doctors rarely sit idly by when someone has pneumonia and is not responding to medication: they intubate rather than waiting for the final gasp. Once the patient is intubated, removing the tube is a lethal act, though one could argue that it is also passively allowing the disease process to complete itself. Removing intravenous fluids, removing tube feeding, and withdrawing life-sustaining medication are similar lethal acts which allow disease progression toward death. Withdrawing medication is often a

first step, as it is entirely within the purview of the medical team. Other eliminations of life-sustaining procedures usually trigger the involvement of ethics committees and sometimes the legal system.

In all of these situations though, letting nature takes its course means eliminating life-sustaining measures. That action involves a conscious decision. Such decisions can be agonizing when they cannot be made by the patient themselves, because the person making them is assuming responsibility for life and death. It is a daunting prospect, even when the decision is shared with the medical team. For someone like me, who tends to assume more than my share of responsibility for any outcome, it can be overwhelming.

Doing nothing, on the other hand, results in abdicating responsibility to the medical system. When it is not challenged, that system provides whatever is needed to prolong life: any life, no matter how miserable. Medical procedures are designed to increase our number of days on earth, not their quality. The patient is shifted between different levels of care (intensive, acute hospital, chronic hospital, etc.) depending on what is needed to sustain life, but the experience of living is often lost in the shuffle. This is the reason for the chapter's introductory quote, "Sometimes the worst thing you can do is nothing."

As the chapter illustrates, however, there is an exception to this rule. It is sometimes helpful to do nothing, or at least say nothing, when it comes to supporting family members grappling with end-of-life decisions. Like Job's comforters, many people I encountered offered unsolicited advice or self-serving explanations. Those who were helpful acknowledged my difficulties and then simply listened.

## 16. Darkness and Disconnection

Certainty, even if depressing, can be appealing because it causes the uncertainty to end.

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On Thursday August 14, just after 4 p.m., a software bug at an energy company in Ohio triggered a cascade of events that resulted in the Northeast Blackout of 2003, one of the largest power disruptions in the continent's history<sup>14</sup>. The electrical outage extended throughout parts of the Northeastern and Midwestern United States, and the Canadian province of Ontario, plunging this vast area into darkness. Public transportation ceased, internet and cable service vanished, and large areas were without telephone service as well. Power was not fully restored in the Toronto area until August 16.

It happened to start on a day when I was not visiting the hospital, as others were taking their turn. Instead, I was on the road home from work when I noticed the traffic lights failing: all of them. Every intersection had to be treated like a four-way stop. Some drivers handled that well, others did not. It was a harrowing drive out of the city. There was no phone service, so I didn't know what was happening at my children's daycare and school until I got there. I was relieved that everyone was alright. I parked outside on my driveway as the garage doors were non-functional. We ate cold leftovers, found using a battery-operated flashlight to illuminate the dark refrigerator. I knew our food would soon spoil from the heat, so transferred what was salvageable to a couple of picnic coolers placed in the coolest room in our basement.

Once the children were fed and we had some candles lit for reading, I started to think about the hospital. There was no way of reaching the ICU to find out what was happening there. Did they have backup generators to keep the ventilators going? Were other aspects of medical care compromised? I realized to my horror that I didn't know if Yurgen was dead or alive. The phone had no dial tone, and the neighbors confirmed that theirs didn't either. Computers, televisions, and other potential communication devices were useless. Nobody knew how long this would last, so despite my anxiety I decided to wait it out.

The next morning, we were still without power. I knew I wouldn't be expected at work, so I connected with some of the neighbors. People pulled together, checking to make sure everyone had food, water, and a cool place to get away from the sweltering heat. Some even played board games together to help pass the time.

One neighbor mentioned that phone service had been restored in parts of Scarborough, a neighboring area. Despite my trepidation about the traffic lights, I gathered a handful of coins and ventured out, hoping to find a functioning payphone. I had to know what was going on at the hospital. I tried about five phones in various locations before finally finding one that worked. The hospital operator, predictably, indicated she could not provide any patient information as I could not prove my identity to her. However, after a few minutes of arguing, she did disclose that the hospital had sufficient back-up generators for all essential patient care. I was thankful to her for that small mercy. Half an hour later, I finished navigating the terrifying traffic lights and arrived back at home.

We somehow got through Thursday, Friday, and Saturday as a neighborhood before rejoicing when the lights came back on Saturday night. Most of us went grocery shopping the next morning, not just out of necessity but because we wanted to support the local grocers who had lost a fortune in spoiled frozen food. The shared ordeal seemed to bring out the best in people.

Nevertheless, I was still in the dark about what was happening with Yurgen, so headed to the hospital as soon as I was able to do so on Sunday.

Anticipating my question, the stern administrator volunteered, "He's back on the neurosurgical unit," as I passed her desk.

"Thank you." I headed to the elevator. I wasn't sure if I should be laughing or crying. They must have weaned him off the ventilator again, which was a good sign. On the other hand, he was back to being treated by people who didn't know him and weren't always the brightest bulbs on the Christmas tree.

Yurgen was being seen by the respiratory therapist when I arrived, so I waited at the nurses' station. It was a good opportunity to re-introduce myself, highlight key aspects of Yurgen's care, and make sure they had accurate contact information for me. I emphasized calling my cellphone or work phone during the day, as I only checked the home phone in the evenings.

When heads were turned, I sneaked a peek at the chart. An occupational therapist had seen him that morning, no doubt to meet the hospital requirement for rehabilitative efforts which might shorten length of stay. Her final conclusion was "Questionable neurological rehabilitation potential." It wasn't surprising, as it was consistent with everything that I had observed in the last five weeks, but still felt like a punch in the gut. Seeing the truth spelled out in black and white was different than thinking it.

Jerry the respiratory therapist looked even more tanned than usual as he came out of Yurgen's room. I was glad to see a familiar face, and we chatted briefly.

"How's he doing?" I started.

"Well, the breathing's getting stronger and his lungs sound clear. We've got our work cut out for us, but I think this time we'll get there."

I clarified, "You mean keeping him going without the ventilator?"

"Exactly."

"What happens if he doesn't improve, and has another respiratory arrest?" I worried.

"It's possible, but I'm monitoring him pretty often, so we'd get Yurgen back to the ICU before that happened," he reassured. "You can go in and see him now."

Yurgen looked bloated and tired as I entered the room. No wonder...he had endured a transfer from ICU, an occupational therapy assessment, and a session with Jerry all in one morning. I didn't want to stress him further, so I reassembled the picture gallery on the wall before talking. It was rare for me to go several

days between visits, so I explained to him how the power-out had prevented me from coming and described how the family had coped during the previous three days.

He just stared at me with his one unpatched eye. It had been a long time since we had made eye contact. I noticed the previously pink sclera was now an angry red. A small bead of pus had formed at the inner canthus. They would probably patch that eye shut soon, leaving him in darkness. I couldn't help thinking of the contrast between this Yurgen and the one who held me tenderly on the park bench five weeks earlier. It was a different reality, a reality which seemed eons ago.

I also remembered how methodically Yurgen made decisions. I would spot some shoes I liked in a store window, try them on, and buy them if they fit. Yurgen would visit at least five shoe stores before coming back to a pair he liked, sometimes after someone else had already bought them. He deliberated about every choice, fearful of choosing an option he would regret. That style resulted in our pet cat being the runt of the litter...all the other cats were gone by the time he decided which pet store to buy from. The same dithering nearly cost us our second house...I insisted on putting in a bid at the eleventh hour so we had a chance of competing with other buyers. Unlike Yurgen, I feared missing out on opportunity more than I feared regret.

In this situation though, our styles seemed to converge. I saw the window of opportunity that led away from life in a chronic care facility starting to close; he had undoubtedly evaluated his repeated experiences in the ICU and in the neurosurgical ward carefully, and concluded that neither option was one he could bear to continue. At least, that's what I sensed.

As I stared back at him, the world seemed to revolve around the concentric circles of his remaining tortured eye, like a galaxy swirling around the black hole at its core. This was probably the last time I could really look into his soul. The violent crimson orb seemed to call out, "Stop this!"



I startled. I couldn't be sure if it was just my imagination, but it disturbed me. I would have recurring nightmares about it later. I squeezed his hand and said, "I'm talking to the doctor tomorrow. I'll see what I can do. I love you. Try to get some rest."

I had to sit down for a few minutes after leaving his room. The eye contact and Jerry's comments started to fuse together, forming the shape of a new thought: what if I could convince his surgeon to *not* transfer him back to the ICU the next time his breathing failed? He would suffer a third respiratory arrest. The DNR was flagged prominently on the chart now. His life would end quietly, without the need for a legal circus.

It seemed so cold and calculating. The compulsive chanting started "I didn't mean it, I didn't mean it..." Then I stopped. I was lying to myself. I did mean it this time. This was the third option which would avoid both a public "pull the plug" ethics fiasco and permanent life in the vegetable patch. This would end the uncertainty and the suffering.

I needed air. I needed to get away from the antiseptic hospital smell. I rolled down the windows in the car and drove. The wind tousled my hair. The radio blasted some carefree summer ditty. The late-afternoon sun was still bright, and beat down on my outstretched left arm as I steered with my right. I would have a mild sunburn by the time I got home, but I didn't care. This was freedom. This was living. This was what Yurgen could not do, and could never do again. I would have to do it for both of us now.

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In a prolonged blackout, the usual rules of civilization are suspended. This can bring out the best or the worst in people. In our neighborhood, people stepped up and helped each other and local businesses. In a different neighborhood, they might have taken advantage of each other in the chaos or looted local stores. I was grateful we lived where we did.

Because the usual rules don't apply, a blackout can create a surreal, almost post-apocalyptic view of one's environment. It's like living in a weird, dystopian novel. When added to the weirdness of living for months in an epidemic and all of the emotional extremes of Yurgen's medical situation, this added event "out of left field" made it seem like the world was crazy. I felt like I was living in a kind of parallel universe which was not part of the real world. In this other dimension, the complex ideas and ideals that normally governed my life didn't exist. Instead, there were merely instinctive responses to guide me through this foreign land.

As the blackout ended, my instinctive response to seeing a pained, near-blind, defenceless body was to recognize unimaginable suffering. Like any primate seeing a fellow creature suffering, my instincts told me to end it. Were those instincts to be trusted though? Can you make sound decisions when you feel so disconnected from any sort of normative existence? Can choices made in the "parallel universe" be applied in real life? These questions would haunt me.

Perhaps the question that would haunt me most though was whether I was really aiming to end Yurgen's suffering or my own. Chronic anxiety is not physically painful, but the insomnia and mental anguish it produces cannot be borne indefinitely. As long as the outcome of Yurgen's illness was uncertain, that anxiety persisted. I needed the uncertainty to end in whatever way was possible, whether by signing the forms for long term care or talking the surgeon into ending things with a minimum of fuss. My gut said the latter was the more humane option. Nevertheless, part of me wondered whether I was just trying to end my own mental torture.

In the end, all difficult decisions involve mixed motivations. If one's motives were clear and pure, they would not be difficult to follow. If it is possible though, aim for a calm and thoughtful frame of mind when making difficult decisions. That way, you can be confident that the best parts of your character have spoken. If that is not possible, talk to someone you trust about the options.

## 17. The Final Conversation

Wisdom is elusive when we are desperate.

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Despite my joyride the previous evening, I had not slept. I had played out the upcoming discussion with the surgeon over and over again in my mind. How was I going to word my request in a way that sounded compassionate and reasonable? What responses did I need to anticipate? Would he even have time to see me or would he get stuck in the O.R.? There was also a part of me that still wondered if I'd stopped my compulsive chant too soon, if maybe there was still some doubt about what to do.

The next day, exhaustion was catching up with me. I had often gone a night without sleep when working on call at the hospital, but this wasn't just one night. This was a night that followed thirty-five other nights where I had barely closed my eyes. I shivered despite the heat. My body wasn't regulating its temperature anymore. My thought process had become almost reptilian from sleep deprivation: narrowly focused on the necessities of life. I rarely reflected on the big picture. Even my upcoming conversation would be goal-oriented rather than reflective.

The rest of life wasn't faring much better. My clothes didn't fit. I was thinner than I had been since before puberty. I was often dizzy from dehydration. My career was not sustainable. I couldn't delegate away all of my leadership responsibilities, and my salary depended in large part on patient billings. I couldn't generate those billings working less than half-time as I struggled to maintain my home and family and fit in daily hospital visits. I would have to renegotiate my contract soon and take a substantial cut in pay. That raised another issue: my finances weren't working. With only one income and most of our savings frozen, I was living paycheck to paycheck for the first time since my early twenties.

Looking at the cost of long-term care, the meager benefits of long-term disability (if they were ever granted), and Yurgen's substantial life insurance policy, a chilling thought crossed my mind. He was worth more dead than alive. Maybe my fear of poverty was driving this decision. The chanting started again. "Cut it out!" I told myself, "You have to focus!"

However, I was clearly not focused. As I pulled into the hospital parking lot, I realized I didn't know how I got there. I must have driven myself there but had no memory of doing so. Repeatedly practiced skills like driving can be done automatically, even when we are barely conscious. It's not safe. Yet, with extreme fatigue, it happens.

Then another disturbing thought: was I really acting out of love, or just self-preservation? Did his suffering need to end, or did mine? To be truly empathic to others, we need to be able to look beyond our own needs. I wasn't sure I was capable of doing that anymore.

Yurgen was asleep when I arrived. I provided my daily report, but his eye didn't open or move. At least they hadn't patched it shut yet. His breathing was regular but shallow. I wished him well, and headed to my appointment with the surgeon.

The eminent doctor was dusting off his brain model when I walked into his office. He looked refreshed and youthful after his holiday. I looked dishevelled and grim.

"Hi. What would you like to know today?" was his friendly opening gambit. We were clearly not on the same page.

Rather than asking questions, I made statements. "His eye looks worse."

"Yes, we're switching the drops for that. Hopefully we can get some healing and avoid patching it. You know, just this morning I thought he was blinking with intention when I asked some yes/no questions."

I challenged his observation. "Has anyone else on the unit seen that?"

“Well, no, but maybe in time.” He was seeing what he wanted to see.

“There’s no sign of any other movement,” I stated.

He sighed. “No, it would come back very slowly at this point. You can’t expect change day to day...there may be something in a few months.”

“Will he ever come home?” I had to express my last little shred of wishful thinking.

“Maybe for some short visits once he’s stabilized in a rehab hospital.”

“But will he ever live outside a hospital?” I needed to know if we would ever be a family again.

“Unlikely.”

My heart sank hearing this one word which summarized a devastating truth.

“Anything else?” The surgeon was starting to look less refreshed.

“One more thing. His breathing seems shallow.”

“Jerry’s been working with him on that. We’ll monitor it. This is the second time he’s been weaned, yes?” His memory was obviously foggy from vacation-brain. “We do see some cases that need intermittent ventilation long-term. Unfortunately, that may mean some more back and forth between here and the ICU.”

I saw my opening, “What happens if his breathing fails and we don’t transfer him back to the ICU?”

He looked at me skeptically. “Do you know what you’re asking?”

“Yes,” I said with steely resolve. “I know he would have another respiratory arrest, and that would be the end.”

“Are you sure?” He was very serious now.

“Yes. I know my husband, and without a marked improvement, this isn’t a way he can live...and I haven’t seen a marked improvement. Am I being unreasonable?” Given my exhaustion and mental health history, it was a distinct possibility.

He conceded. “No. It’s not unreasonable. I might have given him another week, but it’s not unreasonable.”

“Will you document it in the chart please?” I remembered the lack of records regarding our previous conversation, which resulted in an ever-expanding melange of medications.

“Sure.” Silence.

“How long do think he has?” I needed to make a plan.

“A couple of days. Organize your family and your job, and I’ll see to it that you can stay overnight tomorrow.”

I thanked him and he turned away grimly. I had certainly put a damper on his vacation mood.

I had a cup of coffee before leaving to give me a better chance of paying attention during the drive. “Wow,” I thought to myself, “He actually supported my idea.” I had expected a tougher argument, but it obviously wasn’t the first time the surgeon had heard such a plan. Maybe in his line of work it wasn’t that unusual.

Still, I wished I had been in a better frame of mind when I presented it. My own needs for certainty, sleep, and financial stability were such a big part of the motivation. It reeked of desperation more than compassionate care.

And yet, how could I *not* set Yurgen free? The pathetic semblance of a life that was left to him really couldn’t continue. Maybe I had waited too long already. A friend of mine who is very intuitive saw him earlier that day to do some therapeutic touch (not curative, I know, but it couldn’t hurt). When I told her that

evening of my conversation with the surgeon, she was relieved. She had been deliberating whether or not to tell me that she sensed anger in Yurgen during her visit: anger at being kept alive. Whether or not that was accurate at the time, I knew it would become accurate eventually. He would resent me if I allowed the agony to continue much longer. I thanked her, and tried to get some rest.

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I've often looked back at these final days in my husband's life, trying to make peace with my actions. Over time, hindsight has not changed my view that they were necessary but I've often wished they had been driven less by desperation.

In addition to the need for certainty, relief from anxiety, and sleep, this chapter identifies another unsavory source of that desperation: financial considerations. I am reminded of posters in the Old West identifying fugitives. They typically read "Wanted: Dead or Alive." In other words, it didn't matter if the outlaw was killed or captured, as the value of the bounty was the same. Given the complications of catching and transporting the law-breaker to the local jail, there was a definite incentive to shoot them.

In Yurgen's case, and in many cases where there is a choice between death and severe disability, there is an even greater financial incentive to opt for death. Regardless of whether or not there is life insurance, the staggering costs of looking after a severely disabled family member for years tip the balance toward their demise. Round the clock nursing care, ongoing life-sustaining equipment, and ongoing life-sustaining treatment are almost never fully covered by private or public health insurance plans, or by long term disability benefits from the person's employer.

Moreover, these costs do not just apply to those nearing the end of life. Families of children with severe developmental disabilities often incur similar expenses. I recall spending many thousands of dollars on occupational therapists, physiotherapists, psychologists, and specialized educators in raising

my autistic son. In some cases, services were available in publicly funded settings but only after enduring lengthy waitlists. Often, the waitlist was long enough to extend beyond the critical developmental period when the intervention in question could actually make a difference. Thus, pursuing and paying for private therapists became essential.

The reasons for this lack of funding for chronic medical care have to do with history as well as cost. Modern, evidence-based medicine has developed an emphasis on curing rather than caring. Doctors are paid mainly to remedy diseases with the goal of quickly restoring the person's previous level of health. Preventing disease is lauded as well, but often consists merely of scolding patients whose lifestyle habits are poor and doing a few annual screening tests. Caring for those with chronic conditions is even less dramatic, and therefore considered less prestigious than curing acute illness. Over time, most of this chronic work has therefore been delegated to a small army of para-medical professionals: physiotherapists, occupational therapists, psychologists (in the case of chronic mental health issues), and a variety of other "ists" as well as specialized nurses and personal support workers.

When compensating health care costs, this division of labor has created a simple formula for many insurers: cover the services provided by those with the initials "M.D." behind their names and have families pay for the rest. Many jurisdictions, including my own, follow this formula. Thus, as long as your relative's illness is considered acute and treatable, your financial worries are minimal. As soon as the illness is considered chronic or untreatable, watch out!

Undoubtedly, there were many complex reasons which factored into the decision not to prolong my husband's life. Many of these reasons had nothing to do with money. There is no denying, however, that when looming health care costs place families in a position of financial insecurity, this position can affect their choices. Dollars and cents definitely contribute to desperation.



## 18. The Discovery

Some things are impossible to prepare for.

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I had done as I was told: organized my family and my job. I had friends picking up the children after school, and had prepared them for a sleepover. I had told my administrative assistant that I would have to “tie up loose ends” at work and then be away for several days. I had created “out of office” messages for my email and voicemail. I had cleaned up essential paperwork.

Still, there were a few appointments I couldn’t avoid. We were interviewing potential candidates for a new research assistant position that morning. I was the principal investigator on the project, so I had to participate in the decision. My administrative assistant had rescheduled one family twice already, and they were due to be seen that day. She didn’t want to reschedule them a third time. I was annoyed, but kept their appointment at 1 p.m. It turned out to be yet another useless attempt to teach parents how to set behavioral limits with their children without arguing. Even when I demonstrated effective time-out techniques with the children in my office, the parents didn’t get it. I ended the appointment promptly at 1:45pm. I answered two more last-minute questions from my administrative assistant, then left for the hospital to be with Yurgen.

Toronto roads are plagued by perpetual construction delays during the summer. That day was no different. I tried several alternate routes, but it still took over an hour to get from downtown to the hospital just west of the city. I shouldered my overnight bag as I left the car, completed my S.A.R.S. screening, and headed to the now-familiar surgical unit.

Arriving at Yurgen’s room, I noticed it was empty. Another move, no doubt. I asked my usual question at the nursing station, and was told he had been moved to a private room at the other end of

the unit. It was secluded, at the very end of a long hallway next to a janitor's closet. I would later learn that this was how the neurosurgical staff envisioned palliative care: relegating the patient to a distant corner to die.

The first thing I noticed when I walked in was that his face was unshaven. For someone as meticulous with his grooming as Yurgen was, it seemed particularly neglectful to not bother shaving him. As I came closer, he looked paler than usual. His eye was staring ahead, but his chest wasn't rising or falling. His forehead felt warm though. I felt for a pulse. There was none. This was a corpse.

I was horrified by the unexpected discovery. I screamed at the top of my lungs. A young male nurse with a pronounced lisp came running down the hall.

He seemed more concerned with covering his butt than consoling me. "We checked on him just ten minutes ago," he started, catching his breath. He was documenting it in the chart as he was talking, no doubt anticipating a complaint on my part.

He continued, "We tried to call you, but got your answering machine." He had called only the home phone, despite my multiple requests to use the work or cellphone numbers during the day.

Finally, "The respiratory therapist said he should go back to the ICU this morning, but the doctor told us not to send him." Of course, that was what we had agreed upon.

I didn't have the strength to argue with any of his statements, but his attitude caused me to utter a loud profanity. "I want to see my social worker," was all I could say coherently.

"The one assigned to this unit is busy," the bearded administrator responded, having heard the commotion and come down the hall to join us.

"I don't want the one from your unit, I want you to page the ICU social worker who knows what the hell we've been going through!" I wailed.

He took a moment to confirm the absent pulse and close Yurgen's eye, then paged her as requested. He suggested I wait for her at the bedside. He and the unhelpful nurse returned to their posts.

I was reeling. I had lost patients in my career, but I had never walked in on a corpse, let alone one that was my spouse. Moreover, I had nobody but myself to blame. This was the logical result of my actions. The surgeon might have overestimated the time left, but I couldn't blame him as it wasn't an exact science. All the chanting in the world wasn't going to remove my culpability. I had made happen what I feared most. I had caused his death. I had killed my beloved.

I was also angry at myself for agreeing to that final clinical appointment with the argumentative family. If only I had left the hospital an hour sooner, at least he wouldn't have died alone. But then, perhaps he sensed I was coming and didn't want me to see him struggling for that last breath. Perhaps he didn't want to be seen until the process was finished. I was probably rationalizing again.

I found myself touching his forehead repeatedly with my left hand, as I couldn't believe he was gone. It went from warm to the touch, to cool, and finally to cold by the time I left. I didn't wash that hand for weeks afterwards. It was more magical thinking based on some vain hope of undoing what I had done. Lady Macbeth washed incessantly saying "Out damned spot,"<sup>15</sup> and I couldn't wash at all. Looking at his body, I thought there was a final gasp but I couldn't be sure. Corpses release air sometimes. Maybe I just couldn't bear to say good-bye to him.

"Who do I need to call?" was my distraught greeting to the social worker. Her funereal attire was certainly appropriate now.

"I'm so sorry about this," she answered genuinely. She gave me a hug. "Let's take this one step at a time." I didn't feel like talking though. Looking after the practical stuff seemed to be more calming.

We got to work. First, I needed someone to drive me home from the hospital, as I was in no condition to drive. I called Yurgen's best friend who readily agreed. I asked the social worker to make sure my car didn't get towed, as it would obviously remain in the hospital lot for a day or two. She agreed. Next, I needed to make sure Yurgen's body was looked after. I called the funeral home near our house where arrangements had been made for Yurgen's parents several years earlier. I was glad they were willing to look after all the details of obtaining his body from the hospital and transferring it across town. Finally, I called the friends who were looking after the children. I told them what had happened, but asked that they let me break the bad news in person. They were very sympathetic, and agreed.

The social worker's visit was interrupted by a phone call received at the nursing station. Yurgen's surgeon had been informed of his death. I took the call. He expressed his sympathy, and added, "His last chest x-ray suggested he was developing pneumonia anyways." I wasn't sure if it was true, or if it was his way of comforting me, but appreciated the comment.

Afterwards, I made a couple of additional calls: one to Yurgen's place of work and one to mine, informing them of what had happened and, in my case, of the time off required.

The social worker stayed until Yurgen's friend arrived to take me home. I thanked her sincerely, took a final look at the lifeless body, and walked away.

Yurgen died on August 19<sup>th</sup>. It was his thirty-seventh day in the hospital.

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Yurgen died under deplorable circumstances. He was alone in a distant room at the far end of the surgical unit, unkempt and unshaven, and had probably not been looked after for several hours, despite whatever creative fiction the young male nurse penned in his chart. He slowly suffocated with nobody present to offer comfort or even to witness his last breath. It was inhumane.

If I had known that this was the standard of care in this surgical unit once medical interventions ceased, I would have requested he be transferred to a palliative care unit. I didn't know, and I didn't think of this option at the time.

I was furious with what happened, and not just because it was so shocking and because it exacerbated my guilt feelings about his death. I was furious because nobody had warned me that this was how the end would come, because nobody had taken the time to call my daytime telephone numbers, and because almost everyone seemed more interested in covering their own butts than in offering comfort or care to me or to Yurgen.

Over time, I've become a bit more forgiving. General medical or surgical units are not designed to provide palliative care. They have no guidelines or procedures for handling the end of someone's life. Therefore, overworked staff do what is expeditious: they focus their care on the living rather than the dying, and hope that by isolating the dying they can avoid causing distress to other patients. Communication with families is often at the bottom of their long priority list.

Even the creative charting done by the young nurse is not unique. Entries in medical charts are often written after the fact, and in light of subsequent events, to reduce the appearance of culpability. He needn't have worried about being sued. I've always accepted responsibility when I've had a hand in bad outcomes, and I also knew from clinical experience that traumatized people generally shouldn't file lawsuits. They only prolong the agony. Moreover, as a young psychiatric resident, I recall doing such an "after the fact" entry myself when a patient committed suicide while out on a pass I had permitted. I didn't alter the timeline (as the nurse probably did), but I did embellish the assessment of suicidal ideation done before the patient's departure from the hospital. In medicine, there are always times when things turn out badly and you get scared. When you get scared, one of the most natural and most common reactions is to cover your ass.

Unfortunately, this reaction adds insult to injury for surviving family members. Survivors need comfort, not contrived justifications for what happened. Survivors need “I’m so sorry about this,” not “We just checked on him a few minutes ago.” Maybe that level of care and maturity is too much to expect from most hospital staff. Nevertheless, in the worst moments, explanations don’t help. In the worst moments, you just need someone to hold your hand and someone to drive you home.

**Part III: The Recovery**

## 19. One Foot in Front of the Other

Work and rituals are a good distraction, but children give you a reason to go on.

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As we drove quietly across town, I was thankful that Yurgen's friend was not one to pry information out of people. I outlined the events of the day briefly. Then, we both sat in stunned silence. My thoughts were swirling, but I tried to formulate what I was going to tell the children.

When I arrived, I made sure they were sitting down and kept it simple. "There's something sad I have to tell you. You know how your father wasn't connected to the breathing machine the last couple of days? Well, this afternoon he stopped breathing and passed away."

They didn't say much, but clung to me tightly. They hadn't really interacted with their father in over five weeks, and seemed more focused on how I was doing than their own grief. It made sense. When a young child loses a parent, their biggest fear is losing the other one too. They would each grieve in their own way later.

The strength of their reaction made me think. Whatever confused, angry, horrified, self-loathing feelings I might have had, I had to stuff them. The children needed me to go on. I was their only parent now. If I fell apart, there was nobody to look after them. If I became suicidally depressed as I had in my youth, they would be orphaned. I even mumbled the idea to myself as we rolled into the driveway, "Suck it up, and do what's necessary."

The events of the last few hours, including my gruesome discovery in that distant, secluded room, needed to be set aside. I locked them in a distant recess of my mind. I vowed to only access them at times when I could afford to fall apart. For now, I just had to put one foot in front of the other.



Despite my exhaustion, I couldn't sleep. I focused on what I could do...write a notice for the paper, start writing a eulogy for the funeral, follow up with the funeral director in the morning, leave messages at the children's school and daycare saying they would be away for a few days.

-----

The funeral home was surprisingly prompt. They retrieved the body the next morning and met with me that afternoon. I walked into a large complex with a spacious, two-story chapel and several grand visitation rooms lined with super-plush furniture. The latter looked like living rooms on steroids. The offices were more modest and business-like, and there was an ominous door marked "caskets".

Even during the day, funeral homes can be eerie places. This one seemed even eerier because it felt like I had been dropped into it out of *The Twilight Zone*<sup>16</sup>. Nothing felt real. I wasn't even sure I was real. I expected to wake up from a nightmare at any moment. I had a strange urge to giggle.

A petite, animated French-Canadian woman greeted me, "Hello bonjour! Our director is on vacation, so sorry, but I am familiar with all procedure. Come in, come in!" She wore a dark fitted skirt-suit, smart and just long enough to not look slutty.

"May I get you some water, some tea?" she offered kindly.

"Water please."

"It is your husband, Mr. M., yes?" she confirmed.

I nodded. She began writing notes into a template which had obviously been designed for these occasions. As I sipped, I noticed a large box of tissues on her desk.

I couldn't suppress my giggles anymore and burst out laughing. She looked alarmed. I pointed at the box, "I'm sorry, but I'm a psychiatrist and it just occurred to me that you must have the only profession that goes through more of those than I do!"

She smiled obligingly, probably wondering if she would need to call the local mental health line soon. "It is strange when a loved one passes away," she normalized, "We see all the different emotions."

I pulled myself together and thanked her for understanding. We talked about the size of the venue in relation to the expected number of attendees, the decorations, the visitation times, the background music, and other details. She dutifully recorded each option in her template. She informed me the casket choice was usually done last. She gave me a checklist for the financial procedures that typically occur after a death: applying for survivor pension, claiming life insurance, starting to execute the will, working on the final tax return, etc. Then, we started planning the service.

"So, we do the celebration of life or the religious service?" she asked.

"Well, I think for the family religious would be nice," I answered.

"What denomination?" she tried to clarify.

"What have you got?" I chuckled. "My parents are Greek Orthodox and German Evangelical, his were Lutheran, my colleagues are mostly Jewish, his colleagues are mostly Asian, and Yurgen himself was pretty much agnostic. So, I guess we need something generically spiritual."

"Ah! You want United Church then. We have a very nice minister on call from them. You will meet with him tomorrow."

I trusted her judgment, and agreed. Pleased to have settled the issue, she ticked the second-last box in her template and moved me along to the casket room.

When describing how they came to faith, some people talk about growing up in a particular tradition, others speak of being swept up in the spirit of a revival meeting, others of awe-inspiring conversion experiences. For me, it started with a template.

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Arranging the appointment with the minister was not as easy as the junior funeral director had led me to believe, but he was an immediately calming presence when we did finally meet. He was a bit older than me, probably about Yurgen's age, gentle and thoughtful. Similar to my experience with the ICU social worker, I don't recall detailed dialogues because little he said was upsetting or unexpected. I do recall a comforting thought he shared: he described my ordeal as "allowing a natural process to complete itself." In other words, my actions had allowed the inevitable result of a severe brain hemorrhage to finally occur. Nothing more.

He was obviously experienced in planning funerals and, according to my efficient French-Canadian funeral host, "makes excellent services." It sounded like a bit of a sales pitch (they obviously didn't have many on-call ministers to choose from), but turned out to be accurate. He gave me an outline of what scriptures and sentiments might be appropriate in our situation, and all were spot-on. He even thought about how to make it a helpful experience for the children. He had them sit in the front row with their friends and addressed them at one point in the service, encouraging mutual support within their little group.

He only disagreed with me once: when I showed him a draft of the eulogy I was planning. He felt it was too upbeat, and people needed to "stay with their grief" at a time like this. He was probably right, but I was trying to put one foot in front of the other and carry on. I wasn't ready to go into any dark places yet. I would send him several emotional, convoluted emails a few months later when I was.

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The picture gallery from Yurgen's hospital wall was easy to turn into a collage for the visitation. The background music included some of his favorite folk artists. The number of visitors was larger than I expected. The efficient young funeral director had obviously publicized the event well.

After consulting with my family, we decided on a closed casket to spare the children the shock of seeing their father's body. I didn't want a repetition of their "creepy" hospital experience. In truth, Yurgen was made to look very nice—unlike the hospital, the funeral home obviously valued a close shave. Still, it meant I had only one final opportunity to look at him before he disappeared under the casket lid.

In the chaos of that final day in the neurosurgical unit, I hadn't really said good-bye. This seemed an appropriate moment to do so. The hospital horror-show was locked in its mental cage. I savored a few more positive memories. I thought of our first meeting on a sailing cruise around Toronto harbour. It might never have happened if I hadn't been keen on the bargain being offered by the sponsoring singles club: free cruise if you paid to join. I couldn't resist a good deal. The tall, self-assured gentleman who easily made everyone laugh stood out immediately. He later told me he knew we would eventually marry even before we left the boat. I thought of our first trip together: a Caribbean holiday in Barbados. We dined at an upscale restaurant jutting out over the water. After that, fine dining always brought back the sound of crashing waves and steel drums. I remembered our skiing honeymoon in Banff, the hot springs there, and the gondolas ascending the mountains. I remembered the small, semi-detached house we struggled to buy during my residency training, and the early, happy years we spent there. And of course, I remembered our blissful moment together on the park bench just a few weeks earlier.

What came to mind was not the word "good-bye", but the expression "thank you." It had always been a conflicted expression for me, because gratitude was obligatory in my family at Christmas time to avoid my mother having a breakdown. We always needed to express profuse thanks for whatever gifts

she gave, or rather the “Christ Child brought”, whether we liked them or not. To not do so meant profoundly hurting both our mother and the Christ Child, and was therefore sacrilegious.

For the first time in my life, the expression did not have these messy, deceptive connotations. It was genuine. It was pure. It was what you said to someone who had devoted sixteen years of his life to you and was the father of your children. Someone you had never told all the ways he made your life better. It meant so much more than “good-bye.”

I said a heartfelt “thank you”, shed a tear, and shut the lid.

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The funeral chapel was overflowing. Between all of his colleagues, all of my colleagues, family, and friends it was standing room only. Despite the crowd, it was difficult to find people who wanted to speak. Yurgen was one of those people who was liked and admired by many, but close to few. In the end, his best friend and I did the honours. I had spent sixteen years with Yurgen, but was glad to have someone who could speak to the other thirty-one.

As promised, the service was excellent. I was focused on my speech, and bit my lip to avoid becoming overly emotional. I shook many hands afterwards, and accepted many sympathy cards. I had to comfort my mother, who was weeping non-stop. She had often told me how lucky I was to have found a man like Yurgen, and how she would have loved to find someone similar, if the eligible German men of her generation hadn't all been killed or maimed in the war.

Afterwards, the whole family went to a large Chinese buffet. It was the first full meal I had been able to eat in six weeks. Lots more food followed. Neighbours brought casseroles, colleagues sent baskets of nutritious treats, and I received multiple gift cards for home meal delivery services. One colleague even bought me a new microwave oven.

It seems to be the circle of life: soon after birth, we start feeding babies. Soon after death, we start feeding the survivors. My clothes fit properly again in no time.

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There's a famous song by Queen called "The Show Must Go On" which describes how your heart can be breaking but you continue smiling in order to complete a show you are committed to doing<sup>17</sup>. It speaks poignantly of the difference between our private and our public selves. Coincidentally, their lead singer died in his mid-forties as Yurgen did.

Yurgen's funeral reminded me of that song. My private torment needed to be set aside, at least for a while, in order to put on a good show. Funerals are big, public spectacles. Even the best ones are not always conducive to mourning the deceased. Visitation rituals allow for more individual interactions among friends and family, but those too are well-rehearsed and time-limited to ensure access for large numbers. There was that one authentic moment of gratitude before I closed Yurgen's coffin lid, but the rest was choreography.

Part of me welcomed the chance to plan and choreograph things. The young funeral director's pragmatic, organized style was not unlike my own, and it offered some relief from my inner turmoil. It also provided the illusion of at least some control over overwhelming life circumstances. I much preferred feeling in control over wallowing. I wasn't ready to delve into melancholy, as the minister had suggested, at least not yet. Feeling back in charge and catching up on food and sleep had to come first. I appreciated the friends and family who understood those needs. Grief could come later, once I was stronger.

Still, the children needed more than just a show or a ritual. They needed friendly faces and the support of a community, as the minister recognized and tried to foster. They also needed their one remaining parent, me. I had to not only survive but survive well enough to continue looking after them

and raising them, all the while sensitive to the grief they were experiencing themselves. It was a huge responsibility for a newly single parent. Nevertheless, it grounded me and banished any thought of letting myself fall apart. Whatever my mental health symptoms, whatever my life's other sources of meaning, the children were my best reason for going on.

**20. Channeling Yurgen**  
**(a.k.a. The Missing Spouse, Part 2)**

When we lose someone close to us, sometimes we inherit aspects of their being.

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The widow was dressed in black from head to toe as she walked into the bank. She carried an ebony, leather handbag. Oversized sunglasses completed her look, reminiscent of the Widow Kennedy in 1963<sup>18</sup>.

“How may I help you?” was the teller’s routine question as she straightened up her counter without looking up.

The widow pushed three documents across the counter. “Here is my late husband’s death certificate. Here is the document confirming I am the executrix of his will. Here is his account information and the key to his safety deposit box. You may help me with two things: first, kindly open his safety deposit box and provide me with its contents; second, kindly issue a bank draft in the amount of all of his remaining assets with this institution.”

“Uh...I, I can’t do that madam. I need to speak to my supervisor,” the teller stammered, shocked at the request.

“Please do so,” the widow instructed.

Moments later, a middle-aged woman in a business suit emerged from her office and asked the widow to come in. She clasped her hand warmly and offered, “I am so sorry to hear about your husband’s passing. I noticed he was a long-time employee of our bank. Can I get you a coffee or a tea? Here, have an Arrowroot too if you like and some lollipops to take home for the children.”



“Thank you,” the sunglasses nodded. Silence.

“I understand you want to access your husband’s accounts, is that correct?”

“No, actually I want to close them,” the widow clarified.

“May I ask why?” The bank manager was clearly concerned.

“Last summer, when I explained to your teller that I needed your help, you couldn’t even be bothered to come out of your office. Now that I don’t need your help, you express sympathy and ply me with refreshments. Do you see what’s wrong with this picture?”

Copious apologies and promises to do better in the future followed, but to no avail. The widow left the bank with a rather large draft tucked into her wallet. The remainder of her black purse was filled with assorted jewelry and documents from her late husband’s safety deposit box. She never returned.

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I know my response to the bank manager was not very nice, but vengeance is sometimes just too sweet to pass up. It was a bit out of character for me too. I tended to be polite and deferential when dealing with officials, sometimes to a fault. It was almost as if they were doing me a favor by tolerating my intrusion into their lives. The incident above was more consistent with Yurgen’s style: demanding to be treated like an intelligent, competent adult deserving of respect.

Assertiveness courses can teach you the demanding part, but believing you deserve respect comes from within. My childhood left me without that belief; the fact that I had it now was definitely Yurgen’s influence. More than once during our Saturday coffees he had asked me the same rhetorical question when I complained about people at work treating me like a doormat: “Why do you put up with them?” In other words, “You don’t have to put up with disrespectful people. You deserve better.” Over time, I had started to believe it. Years later, it would prompt me to leave the relative stability of my

hospital position where I had to “put up with them” for the less secure but more independent field of private practice. It was a very gratifying career change.

Over time, I found myself emulating other aspects of Yurgen’s personality too. Sometimes, it happened out of necessity. When we were married, he was scrupulously neat and I was slovenly, usually because I was preoccupied with some important project at work. Now that his constant straightening and organizing was no longer happening, our dwelling was beginning to resemble a house out of a reality show on hoarding. I had to become tidier.

As parents, we had followed stereotypical gender roles: I was usually nurturing and he was usually the disciplinarian. Ironically, I had professional training in limit-setting. It just didn’t come naturally to me at home. Now that Yurgen was gone, I had to start implementing some of that training. I also learned that it’s not always enough to say “I love you” to a child. Sometimes it’s equally important to say “I’m proud of you.” The latter had usually been Yurgen’s comment. Now, I had to say both.

The finances were another necessity which he used to handle. As I was working full-time and parenting 24/7, they were easy to neglect, especially in the first year after his passing. For example, my approach to bills was like a kneejerk reaction: receive bill, pay immediately, toss it away and repeat. Thus, I didn’t realize that I had not received any bills from the gas company supplying the cottage until they shut the gas off, resulting in frozen pipes and water damage. The bills had been sent to the wrong address. The incident taught me to keep track of bills better. Similarly, I knew little about taxes because Yurgen always paid those, and I knew nothing about estate taxes. I ended up with a hefty bill due to an error in the estate taxes detected during an audit by the Canada Revenue Agency. There were repeated audits for several years afterwards, which is a common practice once they find a tax error. I learned the value of a good accountant. Fortunately, Yurgen had already engaged an investment advisor, who I gladly inherited and continued to utilize.

Other traits were not necessities but seemed nice to develop because I always found them admirable in Yurgen. For example, taking the time to learn the names of subordinates and bringing them special treats on birthdays and holidays was a nice practice, and smart too. They often repaid the favours later. Yurgen's irreverent humour, which often poked fun at authority, was another real gem. I was never quite as good at it as he was, but the children and I sought out movies and books that exemplified it. My son can still quote several Monty Python movies verbatim.

Then there was the uncanny tendency to copy some of his mannerisms or phrases without even thinking about it. "Please do so," is a short instruction that avoids repeating what the speaker has just suggested. I found myself using it regularly after Yurgen passed away. "So, as I understand it, you are saying..." is a clear way of indicating that you are about to summarize what you have gleaned from the other person's communication. Again, it's a turn of phrase that Yurgen often used and I came to use more. Allowing for silence in a conversation, rather than jumping in to avoid awkwardness, was another common Yurgen behaviour which I emulated without realizing it. Even the pitch of my voice changed after his passing, dropping from a mezzo-soprano to a low alto. None of these changes were deliberate.

Of course, there were traits which were so unique to Yurgen that I wouldn't even try to recreate them. His favorite poster, for example, was of a herd of cartoon sheep. They are mindlessly wandering off a cliff. A single sheep pushes through the herd in the opposite direction, avoiding the cliff. Politely but firmly it says "Excusez-moi, Excusez-moi!" That sensible, rugged individualism which often goes against the grain was pure Yurgen. I would have probably tried to debate with my foolish sheep companions before they fell, but that wasn't Yurgen's style.

His insatiable curiosity was another unparalleled trait. Starting in high school when he competed on a popular quiz show, he loved acquiring facts from a diverse range of fields: from the history of the ladies' high heeled shoe to the latest breakthrough in quantum mechanics, it was all fair game. Yet, he

didn't use his encyclopedic knowledge to intimidate or show off. Instead, he treated facts and ideas like treats in a candy store: exciting to behold and savor. He enjoyed sharing them even more, especially with his children. I could teach them things too, but never with the same delight.

I cherish those unique aspects of his character in my memories, but they're not me. Nevertheless, as described, I did adopt a number of his traits. Whether by necessity, by admiration, or by some intuitive connection, parts of Yurgen seemed to live on through me.

Although this is an interesting and somewhat comforting observation, one person can never truly replace what is lost when another dies. I could modify my parenting to include some of Yurgen's strengths in this area, but I could not be two parents. I could be kinder to subordinates, more insistent on respect from officials, neater, and financially smarter but learning those behaviours in my forties was different from always being that way. It was like learning a new language as an adult to which you are not exposed in childhood: you always speak it with an accent. I couldn't do it all, and many things I couldn't do half as well as he did. I could only do as much as was needed to keep our little family going.

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I suspect my tendency to emulate my late spouse was not unique. I've heard of other widows and widowers doing the same, often without even thinking about it. When we review old home movies which capture the spouse's mannerisms, or listen to old voice messages which include certain words or phrases they favored, the tendency may increase. Even though these reminders of the departed can be jarring, they are also familiar. When we are not quite ready to let go, that familiarity offers some comfort.

The tendency to emulate is only one aspect of widowhood which distinguishes it from other forms of relationship loss. Given my age when Yurgen died, I had more friends who were experiencing separation or divorce than widowhood. Like them, I struggled with a wide range of emotions, but the

predominant ones differed. After the initial shock subsided and my anxiety about coping alone started to subside, I was left mostly with guilt and sadness. My divorcing friends were initially anxious too, but then they were left mostly with anger. Moreover, recurrent contact with their “ex” resurrected that anger again and again long after they thought they had overcome it. I didn’t have that experience. Sure, I sometimes wished Yurgen had looked after himself better, and resented him “abandoning” the family at such a young age. These thoughts were fleeting though. The more predominant theme was missing him, and regretting the missed opportunities in our relationship.

Parenting after a spouse dies is also different from parenting after divorce. In separation or divorce, custody is often joint and if it is not there is usually some continued involvement by the non-custodial parent. It is rare for one parent to be responsible for the children all day every day throughout the weeks, months, and years it takes to raise them.

Yet this is precisely the experience of a widowed parent. Nannies, daycares, after-school programs, friends, and relatives can all be engaged to assist with childcare, but if anything goes wrong the buck always stops with only one person: the surviving parent. It’s a tremendous responsibility. It’s often difficult for non-widowed adults to understand why, for example, the widowed parent cannot easily make weekend or dinner plans on short notice. Colleagues may not understand the number of child-related absences from work. The surviving parent themselves may not realize how much self-care is needed to maintain health when raising children this way, especially when also working full-time. If you are a widowed parent, take time for that self-care and forgive yourself if you cannot be an ideal parent “24/7”. Nobody can.

Despite the stresses faced by widowed parents, research suggests that their children don’t do badly in the long run<sup>19</sup>. Their occupational outcomes are actually a bit better than those found in children of divorce, and their delinquency rates are lower. Internal forms of distress like anxiety and

depression are common though. Perhaps like their parents, children coping with loss tend to be sad rather than mad. It's important to be aware of those risks if you ever find yourself parenting a child who has experienced the death of a parent. The symptoms may not be obvious immediately, but every new stage of development can bring reminders of the missing, irreplaceable parent.

Similarly, every new stage of child development can rekindle memories of loss in the surviving parent. Whether due to genetics or some distant early memory, children may come to look and act like the parent who is gone. A youth may smile or walk a certain way, and you could swear that your spouse is present. The similarities can be haunting.

We often think of someone's legacy in terms of their accomplishments or their impact on those who admire them. That's only part of the story though. People also live on through their loved ones, often in untold mysterious ways.

## 21. Crazy Grief

Many odd experiences can be part of normal grief. Unless you're sure they are something else, don't let anyone diagnose you with another mental health condition.

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The walkie-talkie crackled as I looked up from Yurgen's bed.

"All set?" asked a husky male voice.

"Ready to go," I confirmed, hoisting an oxygen tank onto the bed and removing the intravenous bag from its pole. "What time?"

"On the roof in ten minutes," the voice answered.

I was wearing my lab coat and stethoscope as I pushed the bed through the halls, so the security people let me pass assuming we were doctor and patient.

"Where to?" asked a muscular orderly on the elevator.

"Radiology," I lied, knowing it was just below roof level. He left the elevator a couple of floors earlier, and there were no further obstacles on the way to my destination.

Arriving on the roof, the wind was blowing fiercely. Barbed wire surrounded us, as I tried to find a shadowy corner where we wouldn't be spotted from the guard tower. The building resembled a maximum-security prison more than a hospital.

I was relieved to hear the repetitive "Thwack, thwack, thwack" of the chopper blades. The roof served as a helicopter pad for the local air ambulance.

Yurgen's best friend was piloting the chopper and yelled at me to hurry aboard. We somehow got Yurgen's stretcher and oxygen tank strapped in as bullets from the guard tower whizzed past.

The bird lifted us into a sunny, azure sky. The bullets stopped coming. We were free! We had broken Yurgen out of the hospital!

I heard the repetitive banging of the garden door I had obviously left unlatched. It wasn't a chopper. We weren't free. I was alone in bed and Yurgen's ashes were in the closet.

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It started with a dream, this uncaging of the summer's experiences. More dreams followed. In some, he was a ghostly apparition. In others, he was alive and back in perfect health. Sometimes they were so vivid I awoke believing Yurgen was still alive, until a few minutes of reality proved otherwise.

There seemed to be a recurrent theme to many of the dreams. They often started with very pleasant or even sexual experiences and then turned into nightmares. In the nightmares, we were running from the law because we had been found guilty of insurance fraud.

In real life, I had found it surprisingly easy to claim Yurgen's life insurance. Given the substantial amount of the policy, I expected a drawn-out battle. Instead, I faxed in a death certificate and voided check, had a ten-minute telephone conversation with the claims' adjuster, and two days later I was four hundred thousand dollars richer. Given my mixed motivations around allowing Yurgen to die, I really didn't feel I deserved it. My subconscious mind obviously didn't think so either, explaining the nightmares.

My sleep was regularly disturbed by these experiences to the point where I felt perpetually jetlagged. Nevertheless, I continued to push the summer's events to the back of my mind during the day. I allowed only three weeks from Yurgen's passing to my return to work. It was just enough time to



help the children transition into their new school years and allow me to start chipping away at the mountain of death-related paperwork.

My daughter was starting Grade 3 in her Montessori school. The school engaged in the questionable practice of running their students a year ahead in mathematics, which was not my daughter's favorite subject, so I discussed with her teacher the possibility of paying for extra tutoring if needed. I was glad I did, as there was soon a line-up for this service. My son was starting at a private school in a neighboring town which I had identified the previous spring. It was one of the few schools in the area equipped to teach children with developmental or behavioral problems in addition to learning disabilities, and had a small student-teacher ratio. They were patient and somewhat nurturing too, especially when they learned of my son's recent bereavement.

The date of my return to work was suggested by my administrative assistant. She was an older British woman who, coincidentally, had been widowed at a young age too. She assured me that the sooner the children and I resumed our normal routines, the better we would deal with what had happened. In truth, I probably would have returned to work quickly regardless of her advice. I was eager to lose myself in my projects and my patients again to avoid having time to ruminate.

For the most part, immersing myself in work stabilized my emotions. There were exceptions though. Most of my work was in a large outpatient department which was separate from the hospital inpatient units. It was a suite of offices that could have been found in any downtown building, and contained few reminders that this was a medical setting. When I was on call on weekends though, I was expected to do rounds on the psychiatry inpatients, who were clearly being treated in a hospital.

Stepping onto the elevator to the psychiatry unit my first weekend on call, my heart started to race. The buttons on the elevator wall started to swim before my eyes. My ears were ringing. I had trouble catching my breath. When I got off at my floor, I feared passing out so I sat down with my head

between my knees. I knew this position would minimize the risk of fainting. Early on Saturdays there were few people around and I was thankful to be alone. It took a good fifteen minutes to regulate my breathing to the point where I could get up and proceed to work. I claimed my tardiness was due to traffic problems, and carried on. I would have a panic attack every weekend morning on call for almost a year.

I also noticed a change in my clinical work. Previously, I had enjoyed psychotherapy more than medication treatment, to the point that I had focused most of my research on evaluating child therapies. Now, the reverse seemed to be true. I had not developed a sudden fascination with pharmacology, but rather I felt uneasy with the therapy I was doing, cognitive behavioral therapy (CBT). The basic premise of this therapy is that changing negative or anxious thoughts and behaviours to more adaptive ones reduces depressive and anxious symptoms<sup>20</sup>. At the time, however, CBT with children still tended to emphasize realistic or probabilistic (rather than adaptive) thinking. We would have children say things like “the chances of my worries coming true are like the chances of winning the lottery”. Statements like this were realistic, but not always helpful as my own recent experience had taught me. My worries on the Victoria Day weekend prior to Yurgen’s stroke had focused on the remote chance of my husband being blown up by fireworks. Sure enough, it didn’t happen. The problem was, something I had never thought to worry about, a brain hemorrhage, did happen and was just as lethal. I realized I was conning my patients when I minimized their worries without telling them that other awful things could happen, and that didn’t feel good. For the first time since becoming a doctor, I felt I was just “working for a paycheck” with no belief that I was making a positive difference.

For the most part, my home was a relaxing place, but with some exceptions. We lived in a beautiful, wooded suburban area with hiking trails, bicycle paths, and a beach nearby so I was in no hurry to move. At the same time, I was surrounded by constant reminders of Yurgen. When I found out it was illegal to scatter his ashes where I had hoped to, I kept the urn in the bedroom closet. I couldn’t

sleep until the closet door was shut, and sometimes had the irrational belief that his ghost was in the closet. I tried removing his clothes from the closet and giving most of them away, but it didn't help. When I turned around quickly, I thought I saw him out of the corner of my eye. In the transition between sleeping and waking, I hallucinated his presence. I couldn't answer the phone. It brought back the feeling of my insides dropping into an abyss. I got an answering machine and lowered the volume on the ring tone. It didn't help. I still jumped to the ceiling whenever it rang.

One day, I was late for my commuter train after dropping off my son at school. I thought I could make it if I ran, but somehow tripped and fell forward onto my hands and knees. I asked for band aids at the ticket counter to cover the scrapes. The woman at the counter provided them, but I had to fill out a detailed incident report and accompany her back to where it happened. Strangely, there was no uneven ground, nothing to trip over, and my shoelaces had been firmly tied. There was no reason for my fall. Then, I looked across the station platform and saw some graffiti on the highway barrier beyond the tracks. It said, "I love you." It seemed to be a message from Yurgen, perhaps a warning. He seemed to be saying "Don't make my mistakes! Slow down your life, or worse will happen to you than a few scrapes. I love you." I knew the person who spray-painted those words had nothing to do with Yurgen, yet the message seemed directed at me. In psychiatry, messages like that are called "ideas of reference" and are considered psychotic. In my case, they were just part of grieving.

If there was a still point in my whirlwind of psychological symptoms, it was that I didn't seem to be alone in my craziness. A sudden death affects those outside the immediate family too. Many mourn losing a good friend. Many vow to take better care of their health or "stop to smell the flowers more." But there are also those who interpret the death as a sign that "life is too short to waste time" and embark on major life changes in response. I heard several stories of people who reacted to Yurgen's death that way: leaving an unhappy marriage, having another child, or even moving across the country because "life's too short". Was it sensible to make these drastic changes in response to a friend's

passing? Or was Yurgen's passing merely a catalyst for something that was destined to happen anyways? I don't know. I always urged them to think about these decisions carefully though, even as I was trying to avoid doing too much thinking myself.

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When evaluating someone's mental state as a psychiatrist, I would examine five main areas: appearance and behavior, mood, thought process and thought content, perceptions, and insight. With the possible exception of insight, all were affected during my grieving process. Insight merely meant I retained some ability to distinguish between my symptoms and what was realistic or reasonable.

Many of the symptoms were also transient, coming and going over time, sometimes flaring up with holidays or anniversaries, but eventually abating. In other words, my craziness did not persist. Most importantly, despite my distorted, distressed view of life, I could continue doing what I needed to do. That lack of functional impairment meant I did not necessarily need to consider myself a mental patient<sup>21</sup>.

I later found out that many of my experiences were not unique. Talking to other bereaved adults, I learned that the death of an immediate family member can trigger everything I experienced and more. The usual rules of what constitutes a psychiatric disorder cannot be applied to people who have suffered recent bereavement.

When there is a traumatic element to the loss, as there certainly was in the last few weeks of Yurgen's life, the mental health effects tend to be even worse. Constant edginess or insomnia, re-experiencing aspects of the events in flashbacks or dreams, avoiding or overreacting to traumatic reminders (in my case, the telephone and the inpatient unit), and depressive mood are all hallmarks of Post-Traumatic Stress Disorder<sup>22</sup>. When these are added to the "usual" symptoms of bereavement, if there is such a thing, the result can be overwhelming.

I present these ideas for two reasons. First, because it is important to recognize that the psychological effects of bereavement can be extreme and vary tremendously from person to person. There is no “typical” way of mourning a significant loss. It is important, therefore, to not allow others, especially medical practitioners, to convince the grieving person that they are mentally ill. Grief is a process, not a pathology. Second, because there is no need to suffer in silence. Even though grief is not a disease, talking about its distressing effects with others can be helpful. Knowing we are not alone and that others have emerged “out the other end” of the dark tunnel we are experiencing can reassure and strengthen us. Consider a support group if you are grieving. I also hope that sharing some of my mental health symptoms here may help you, the bereaved reader, feel less alone.

## 22. The Muskoka Chair

Nothing stays hidden forever.

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We all drove to the cottage Thanksgiving weekend: me, the children, and the urn. I had decided the ashes belonged in the cottage, as it represented the fulfillment of Yurgen's final dream. Perhaps I was also secretly hoping to feel less haunted by the bedroom closet, with the ashes moved elsewhere.

The cottage was a beautiful, windowed A-frame building with a two-story great room, three spacious bedrooms, and a loft. It hardly seemed appropriate to call it a cottage, as it was more like a second home. I planned to keep the urn on the mantle of the fireplace.

After dropping off our overnight bags, some games, and assorted sports gear we drove to a local attraction. It was a farm that had been converted into a kind of rural amusement park. There was a large corn maze, a scavenger hunt through a smaller maze made of hay bales, a pumpkin patch, wagon rides, and a petting zoo. There was even a miniature catapult for launching pumpkins across a field at several targets, with prizes for accurate shots. We were busy and happy for several hours.

Returning to the cottage, we picked up some groceries for supper and rented a couple of videos in town. To get away from civilization a bit, I had deliberately avoided getting cable or internet service at the cottage but had bought a VCR and small television set so we could watch videos in the evenings. With the children engrossed in cartoons and popcorn, I went for a sunset walk on the beach.

The long sunbeams bouncing off the water reminded me of skimming stones across the lake as a child. The flat ones always worked best, so I picked up a few to see if I remembered how. Sure enough, I could catch the top of the waves once, twice, three times...and that was my limit. I used to be better at this game.

Hearing the rhythm of the waves put me in a calm, meditative state of mind. Ever since my near-drowning experience in my twenties where the waves pushed me to shore, I had an affinity for this sound. I even sometimes thought about human life as wave-like: we arise from the ocean of time, manifest our energy in this world briefly, then dissipate or break up on the shore to return to time's ocean again.

Then memories of waves started to emerge. I remembered hearing their sound as Yurgen and I dined in Barbados. I remembered being drawn to this particular cottage property because it was so close to the waves. I remembered Yurgen's dream a year earlier about sitting on the beach watching the waves and floating away...

Then I saw it. It was a big, red, empty Muskoka chair which someone had placed near the water. This was no dream. The emptiness was real. I averted my gaze from the beach, hoping to find comfort in the waves. They blurred before my eyes and became brainwaves in an electro-encephalogram.

I sobbed uncontrollably. Everything that had happened in the summer saturated my mind like my own private horror movie. Every regretful thought I had experienced skewered my brain. Why had I continued to let him abuse his body with fatty, salty foods even when I had started eating healthier? Why had I not taken the emotional risk of confronting him about his lifestyle more urgently? Why hadn't I hugged him tighter while I could? When he was in the hospital, why was I so focused on my own anxieties that I couldn't really be there for my best friend? Why did I make the most important decision about his life in the worst possible frame of mind? Why didn't I sense he was about to go and make sure I was there? Did he think I had abandoned him at the very end? There were no answers to these questions, only wretched tears.

When I stumbled back into the cottage, my daughter was alarmed. "What's wrong, Mom? Are you hurt?"

I shook my head. "It's OK, honey. I just got really sad thinking about your Dad. I'll be alright. I just need a little rest."

The children willingly went to bed even though it was an hour early for their bedtime. I tucked them in as best I could and retreated to my room. After another hour or two of sobbing, I fell asleep. I didn't dream. I didn't wake during the night. I spent the next fourteen hours in a deep, deep slumber.

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I was wakened by the acrid smell of smoke. When I recognized it, I burst out of my room like a heat-seeking missile, zeroing in on my children. I found them in the kitchen, safe but contrite. When I slept through their usual breakfast time, my daughter had decided they needed to fend for themselves. There were several oddly shaped, charred objects on a plate which I soon recognized as burned pancakes. They were black on the outside with raw dough on the inside, but I drowned them in maple syrup and said they were delicious. I made a mental note to teach both children a bit about using the stove, and to put fresh batteries in the cottage smoke detectors as these had clearly not worked.

It was raining, so we had a low-key cottage day playing board games and fixing smoke detectors before heading home. I blew a kiss to the urn and whispered "Till next time" as we left.

In the car, the summer hit "White Flag" came on the radio<sup>23</sup>. It was a catchy tune about regret, the pain of lost love, and not surrendering. It spoke to me, and got me thinking about how I was going to carry on. My attempts to "cage" the summer's events in a small, secluded compartment of my mind had obviously failed. At the same time, I couldn't surrender. The children needed me, and I needed to recover from this tragedy somehow.

I had always enjoyed writing, so keeping a journal about my thoughts and feelings seemed a logical place to start. I would fill several journals over the next few years as the grieving process



continued. Yurgen had been more visually oriented than me, and always enjoyed photography. There were a couple of undeveloped rolls of film from his final few months before the stroke. I decided I would develop them and also revisit some of our old home movies. That way, I would have “grist for the mill” as I tried to process what had happened. I had to limit these activities to non-work hours though, as I couldn’t afford another sobbing fit if I was dealing with the public.

I debated about whether or not to seek psychotherapy, either for myself or the children. I told myself I had no time for therapy, given the overwhelming family, work, and estate responsibilities I now faced. In truth, I think it was more a matter of control than time. If I journaled and occasionally looked at old photographs or videos, I could control the process and go at my own pace. If it was a particularly stressful time, I could avoid it entirely for a few weeks. I didn’t think I would have that flexibility in therapy. I didn’t trust that a therapist would not push me too much or too little. I just didn’t want to be that vulnerable to the whims of another human being, even a professionally trained one.

The children seemed reluctant to talk to anyone but me. My colleagues recommended several books for bereaved children, but they were quickly pushed aside in favor of SpongeBob. My son was too young to have many memories of his father, and was sometimes confused about what had happened. At one point, he even claimed that his father had died in the 9-11 attacks, merging the two scariest events he had experienced in his young life. He often asked me questions to clarify his history, and to confirm the few vaguely positive memories he still had of Yurgen. My daughter seemed to prefer focusing on her school and her friends. She started rolling her eyes when I mentioned her father. I could never be sure if that was her way of coping or if, as the cottage experience suggested, she was trying to protect me. I offered to find her “someone to talk to about things” several times, but she rejected the idea.

Another form of support started to appeal to me. I thought about joining a church. My experience with the United Church minister had been more positive than I expected, based on

childhood experiences with religion. I was hoping that developing a better understanding of faith might help anchor some of my tumultuous emotions, and a good Sunday school program for the children couldn't hurt either. I decided to look up the minister online. His church was only a twenty-minute drive from our house, so getting there for weekly services seemed feasible.

I had to proceed with caution though: the minister was still linked to Yurgen's funeral in the children's minds. I needed to allow some time to pass so that seeing him at church would not be re-traumatizing. I decided to present the idea to the children over the Christmas holidays as a kind of New Year's resolution to "explore something new." Thankfully, they agreed to give it a try.

I can't claim that my choices for recovery were the best or the wisest, and other options might work better for other grieving people. Nevertheless, as I started to process things in this way, the nightmares started to decrease.

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Nothing stays hidden forever. I first learned that lesson when I was about four years old and my favorite doll's leg came off in my hand. I was horrified, thinking I had killed her. I hid her under the couch and tried not to think about what had happened. I prayed repeatedly that she would be okay. It's the first time I remember doing a ritual to try to undo something awful. After two weeks of ritualized prayer, my mother found her while cleaning one day and took her to the "dolly doctor" to fix her leg. She came back in one piece, but I never touched her again, fearing what I might do to her. Was this the start of my interest in becoming a healer, the start of my OCD, or both? It doesn't matter. What remained was the conviction that no matter how well-hidden, everything eventually sees the light of day. I knew that after Yurgen's passing, even as I tried to push the memories of his hospital stay to the back of my mind.

Which is wiser: to compartmentalize grief and risk being overwhelmed by it later, or to allow grief to wash over you right away and risk becoming non-functional? It's not an easy choice, and it may

not be entirely within one's control, but given my life circumstances I feared becoming non-functional more than I feared a weekend or so of overwhelming emotion. Rightly or wrongly, I initially chose to compartmentalize. Eventually, when that was no longer possible, I sought different ways of processing my raw emotions. Journaling, reviewing positive family events through photographs and videos (even if they contained an annoying number of Easter egg hunts), and seeking a supportive community of faith were all helpful.

Interestingly, both "distraction" (my first strategy) and "social sharing/reconstruction" (my strategy after the Muskoka chair experience) have been associated with healthy mourning and eventual acceptance of loss<sup>24</sup>. Only "continuing bonds", in other words denying the loss, has not. Each of those approaches can manifest in many different strategies, so your ways of coping may not resemble mine. No two bereavement processes are the same. Also, the old rule of allowing one year for mourning doesn't always apply. This memoir, for example, extends to the five-year mark, because that was about how long it took before I felt at peace with most of what had happened.

In summary, however you manage, try not to judge yourself or others. We each have our own struggles and our own way of healing. You can't predict how that healing will occur or how long it will take, only that you will eventually face the full reality of the loss. When that happens, you may feel sucked into an emotional whirlpool. In whirlpools, even the strongest swimmers will reach out for a lifeline. There is no shame in needing one.

### 23. Faith

When something is incomprehensible, leave it with God.

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I had hoped to anonymously sneak into the church with my children at the last minute that cold January morning. Having done a bit of church-shopping in the past, I was prepared to smile and shake hands with whoever was passing out the order of service, then slip into the back row. By leaving a couple of minutes before the service concluded, we would avoid getting caught in a barrage of questions from nosy parishioners at the end. Then, once at home, the children and I could share impressions and rate the proceedings (thumbs up or thumbs down) to decide if we wanted to return.

No such luck. This had to be the most gregarious congregation on the planet, and even last-minute arrivals were welcomed effusively and ushered into the only spot in the church where three adjacent seats remained, which happened to be the front row. The people sitting next to us were not only friendly, but had elicited most of my life story before the service began.

I needn't have worried about the children's reaction to the minister though, as I was informed that the minister was always on holiday for the first service of the New Year. He asked lay people in the congregation to lead worship when he was away, and there were many articulate members to choose from. On this particular Sunday, a well-appointed woman of about my age was in charge. My son, whose senses were a bit overwhelmed by the volume of the music, immediately found comfort in her enormous fur coat.

We soon learned when to stand and when to sit, when to keep silent and when to speak in unison, and we mouthed the words to the hymns which were projected on the wall. The New Year's message was short and hopeful. Before leaving, we were asked to sign the guest book, given

information about the Sunday school, provided with leftover refreshments (the coffee hour had been before the service), and introduced to many more people. Within a couple of weeks, I was asked to join a committee and take a turn serving coffee and refreshments. It seemed that food and committees formed the foundation of this faith. I didn't mind contributing though, as serving others a bit was helping my flagging self-esteem.

I felt like an imposter given my lack of roots in this denomination, but it didn't last long. I was soon connected with a number of new friends, my children were welcomed in the Sunday school regardless of my son's autism, and we started to feel like part of the community. Inviting my new female friends (who became known as "the church ladies") up to my cottage for a week became an annual tradition. Some of my best vacation memories are from those cottage weeks, though we made a pact that "what happens at the cottage, stays at the cottage." It was nothing too wild, but some of them did have remarkable bartending skills.

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Although this congregation may have been friendlier and more welcoming than most, it was not unique. One of the best things about our denomination, the United Church of Canada, is that it is so inclusive of many different approaches to faith and questions about faith. All kinds of people can feel welcome there. On the other hand, one of the worst things about our denomination is that it is so inclusive of many different approaches to faith and questions about faith. Its theology is distinctly muddy, often leaving people to define it for themselves.

To explain why this troubled me, I need to recount some of my early history in relation to faith. I've already alluded to my difficulty believing in the "vending machine God" who intervenes directly in response to a certain quantity of prayers, rather than influencing the course of events indirectly by inspiring human action.

More important, however, was the strange mix of religion and family dynamics I experienced in childhood. Despite their different denominations (Greek Orthodox and German Evangelical), my parents shared a fundamentalist belief in a final judgment that would vindicate them in the eyes of all who had wronged them and condemn all non-believers. In my mother's case, disagreeing with her on any matter she considered important was not only considered hurtful and disrespectful, but also resulted in one being considered in the non-believer's camp.

As I started to assert my independence in adolescence, I was therefore regularly warned about the consequences for my immortal soul. God obviously hated teenagers. I also had a number of friends who were not Christians, and the idea of enjoying heavenly delights while they endured eternal torture seemed rather inhumane. Yet at the same time, I felt I owed my mother a debt, having ruined her life by unexpectedly arriving in her world, and I knew that too much disagreement could trigger one of her depressive meltdowns. So, I ended up rejecting her version of God...but not quite. I still felt I had to earn my place in the world by following the rules as my mother had defined them, and I still felt less anxious about eternal damnation when I did so.

It has been said that when you reject something (or Something) you still assume, on some level, that this something exists. Thus, I continued to have a fascination with theology, even though I claimed to not believe in God. There is a huge bookstore near the largest concentration of hospitals in Toronto, and I frequented its religion section on my lunch breaks. I read about all versions of God and faith I could find, but drew few conclusions.

I found some resolution to my quest in my late twenties, not at the book store but at an outdoor art show. There was a calligraphy artist who had created ornate versions of the *Desiderata*<sup>25</sup>. They caught my eye, and I purchased one. At home, I read through the words and got stuck on one line. "You are a child of the universe. No less than the trees and the stars, you have a right to be here." For an

unwanted child to think about existence as a right was breathtaking. I wanted to believe in that universe, or Universe, that could love so unconditionally. The idea didn't seem to fit any organized religion, but I started taking nature walks more regularly, prayed and meditated for inspiration, and had a sense of my life being aligned with a benevolent Spirit.

Unfortunately, that alignment was nowhere to be found during the traumatic events of the previous summer. Truthfully, I had also gotten too busy with work and childrearing and other concerns to pay regular attention to it. When my OCD fears of harming others got thrown into the mix, the old, punitive ideas about God re-emerged. In ending Yurgen's life, I didn't just feel I had killed my best friend. I felt I had blown any chance of a pleasant afterlife. I tried to live in the moment, knowing the future was uncertain and eternal peace was not assured. Yet the moments were devoid of any inspiration or solace. I found support in my community of faith, but apart from acknowledging that "He" might be a "She", my church did not offer a clear alternative to the judgmental, parental God of my youth.

I also continued to struggle with questions about Yurgen's death: Did I make the wrong choice? Did I make the right choice for the wrong reasons? Was there no right choice? Was the whole idea that I had a choice a delusion?

One winter day I was walking the dozen or so blocks from the train station up to my place of work. Given my many personal and professional responsibilities, it was my only way of incorporating healthy physical activity into my life. On this day, I was sniffing and running a low-grade fever. I didn't think I could risk taking a day off though, as I needed to save days off for when the children were ill. My feet were getting wet as I trudged along the slushy sidewalks.

Suddenly, fresh snow started to fall. I looked up and there was barely a cloud in the sky, but somehow the cool, gentle flakes found my burning forehead. They felt so good. They were exactly what

I needed. I felt blessed by the universe. Tears started to run as I realized that the universe, or Universe, and I had reconciled. I could stop worrying about eternal damnation. I could leave my impossible questions with God. I felt like the returning prodigal son<sup>26</sup>: worn out from my folly, but welcomed unconditionally at home.

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Faith was an important part of my recovery from traumatic grief. There are many roads to recovery though, and not all include spirituality or religion. We all find our own path.

When people do come to rely on faith, it happens for a variety of reasons. Some people need faith and faith-related deeds to feel they're making a positive difference. Personally, I've always found that feeling at work. Some people need faith to give them ideals or a moral code. I've always felt the difference between humane and inhumane behaviour in my bones. I don't need a code to explain it. Some people need faith to connect with a caring community. I have found that community at my church, but I have also found it in friends and colleagues who have stayed in touch over the years, and in neighbors and families of my children's school friends in our local area. Some people need faith to celebrate the wonder of life. I experience that wonder in each new sunrise, in the mighty rush of the surf, in the smell of cedar, and in the softness of the forest floor beneath my feet. No church is needed for that. Some people need faith to let go of their cares and quiet their turbulent minds. Faith can lead to that inner peace, but so can many other practices.

And then there are people like me: people who need faith to heal the wounds of the past in a way that nothing else quite can. For even when nothing makes sense, even when nobody values you, and even when you don't value yourself, faith says "You belong here, and you always have a home with God." I return to that home again and again, no matter from how far away. There are many ideas about God, but to me God will always be the unconditionally loving Mother I never had as a child.



## 24. Life Continues

Life is what happens between the memorable moments.

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I was grateful for my wondrous experience in the snow, but it was only one step on a very long journey. I continued journaling, emailing my minister with questions, and at one point asked to see Yurgen's medical record as there were gaps in my recollection of the summer's events. I had to revisit the hospital where he died to do this, prompting extreme anxiety, but was able to wade through most of the record in about two hours. It helped to see the events in order with a clear beginning, middle, and end. It later allowed me to reconstruct my corresponding thoughts and feelings so that the whole terrible tale started to make some sense.

My ponderings about the nature of God also continued. I started writing spiritual poetry on the train to work each morning as I reflected on different aspects of the Sacred. I was a bit frustrated by my own inconsistency, as my intellect favored more universal, spiritual versions of the Sacred but I needed a benevolent, Holy Parent when suffering. Ultimately, I came to the same conclusion as recent writers in my denomination: God is Holy Mystery who is Wholly Love<sup>27</sup>. We cannot fully grasp the Infinite, but that's alright as long as it inspires us to love. I still pray to both a benevolent Parent and something like a Cosmic Force that moves an interdependent humanity toward a destiny of love. It all depends on what I need to believe that day.

I also did some reading about traumatic grief. There, I found the distinction between regret and guilt particularly helpful. Regret is the wish that things had happened differently, sometimes including a wish that one had acted differently in certain situations. Guilt is assuming complete personal responsibility for a bad outcome, whether it was entirely within one's control or not. Regrets are and

inevitable part of life experience; being mired in guilt is not. Until I let go of my guilty feelings about Yurgen's death, I could not mourn his loss. Regret freed me to do so. No longer focused on my own culpability, I started to feel the hole in my heart left by missing him. It would always be there. I cried more, but they were healthy tears.

Most of the time, however, was spent taking care of the business of living. Beyond attending to the myriad details of Yurgen's estate, I had to raise my children, work full-time, and manage a household. Juggling those was not easy, and I probably didn't always prioritize them in that order.

Parenting took on a new urgency almost exactly one year after Yurgen died: my son developed a seizure disorder. Despite our modern, publicly funded health care system, I struggled for months to get him the expert care he needed. Waitlists don't work well for people who have life-threatening conditions. Eventually, I revisited one of the strategies I had learned during Yurgen's hospitalization: I camped out in the Emergency Department of our local children's hospital and refused to leave until I had obtained a prescription for an antiepileptic medication. A few weeks later, we were connected with a pediatric neurologist who not only treated my son expertly for a decade but also took the time to advise me on how to best support his health and overall development. She offered exceptionally helpful guidance, and was a wonderful calming influence on us both.

My son's challenges went well beyond his seizures though. The first private school he attended was supportive but more focused on children who misbehaved (which he didn't) than those who needed help with learning (which he did). They praised my son's self-control and diligence, but taught him almost nothing. The children were better behaved at the second private school, but he still learned very little there so we switched to the public system. There, he received almost no support and was left to wander around a tree every recess as there was no encouragement to socialize. A special program within the public system seemed to be the best fit, but he still didn't read until fifth grade when I

purchased a computerized phonics program. He finally developed some rudimentary reading skills after we spent a year and a half doing daily, hour-long phonics drills on the computer. In high school, things became even more difficult. Psychological assessments, numerous rounds of occupational therapy, and ongoing tutoring became a way of life. I had to admire his perseverance with it all.

His sister often disappeared in the process. She was more vocal than my son though, so still managed to involve me in major school projects and made sure I drove her to the numerous friends and activities she enjoyed. We also had some wonderful conversations over the years. Still, I fear I sometimes neglected my daughter's needs and certainly missed some opportunities to connect with her. Before I knew it, she was an independent young woman whom I admired but couldn't always understand.

I was also painfully aware that I would never replace certain aspects of Yurgen's parenting. Given my multiple responsibilities, most of my interactions with the children were either task oriented or serious. There was little opportunity for play or curiosity, and even if there had been that opportunity these areas were never my strong suit. Yurgen was a much more "fun" parent. I was also better at comforting distress than celebrating joyous occasions. The latter had always been Yurgen's forte. Thus, although the children were well looked after, their childhood may have been a bit grim.

My career was my favorite distraction from personal problems. I rose through the professorial ranks, pursued my research, and ran a large multidisciplinary team. Teaching some of my research and clinical skills to residents and graduate students was gratifying too. Presentations at conferences took me around the world, though I had to keep trips short for the sake of the children. My son once regressed for a month after I spent a week in Norway. I did have to contend with frequent interpersonal problems on the team as well as some truly stupid hospital rules and requirements, but I agreed overall

with my administrative assistant: quick return to normal routines, including normal work routines, was helpful.

We also continued to be regular churchgoers. For the most part, I found comfort, inspiration, and support in my community of faith. I eventually took on some leadership roles there as well. The children each responded in their own way: both attended the obligatory Sunday School and subsequent Confirmation, but my son showed a more persistent interest in God and the bible, while my daughter valued contact with her peers at church more, some of whom attended the same Montessori school she did. Whatever their spiritual leanings, I'm glad the children were exposed to a consistent, benevolent version of faith and a welcoming community. Wherever life takes them, they will always have a church home.

I struggled, however, with one group of people at church: the severely disabled. I often encountered people in electric wheelchairs at coffee time, and they haunted me. When they looked at me with blank or neutral expressions, I sensed anger. I felt like they were accusing me of killing a member of their tribe. I knew my mind was projecting my own issues onto them, but I couldn't shake the feeling. Like many irrational feelings, it couldn't be avoided. I just had to desensitize to it over time.

Ironically, even as I struggled in relation to those with special needs, I allowed myself to become more needy. As a working single parent, I could no longer pretend to be totally self-sufficient. I needed a "village" of friends and helpers to get by and, in my son's case, some government assistance too. I became less shy about saying "please" and "thank you." My political views shifted left accordingly.

Romantic relationships were the one area of my life that did not develop very far. As I was newly single, my friends encouraged me to date. I had to admit that adult companionship and someone to share my rather complicated life might be nice. I also felt physically attracted to men, though that waned later with menopause (which came early, as it does in many widows<sup>18</sup>). Despite various attempts

at dating, both online and via social connections, it never seemed to work out. Nobody got past the second date. The divorced or widowed were often still looking to replace their former spouse, and I wasn't willing to fit into someone else's mold. The lifelong bachelors either had autistic traits or serious personality disorders. The latter were quickly revealed in how they treated, or rather mistreated, the waitstaff at restaurants. There were also rather obvious gold-diggers or philanderers.

Nevertheless, I realized I had a tendency to dismiss my suitors quite quickly. Observing the pattern, I noticed they were dismissed even more quickly if they had health problems or were somewhat overweight. Whether I was aware of it or not, every encounter ended with the same mental arithmetic: adding up all the positive traits of this person, were they enough for me to risk going through what I went through with Yurgen again? The answer was always 'no'. Once I recognized the pattern, I was no longer ashamed to tell my friends I was single by choice.

A recent science fiction movie called "Arrival"<sup>28</sup> reminded me of this dilemma again. In it, the main character is a female linguist who communicates with an alien species for whom time is circular. Thus, she can seamlessly perceive her past, present, and future. Her timeline includes saving the world, but also experiencing terrible personal tragedy. She still chooses to fulfill that timeline. It brought to mind my own choice to marry Yurgen and made me wonder: would I do it again if I knew what was to come? In truth, there were some hints to the future. There was a history of early death by cardiovascular disease on his mother's side of the family. Yurgen himself was fit when I met him but often made comments like "Let's hold onto this moment. Whatever happens, remember this moment," almost as if he knew that his life might not be long. I even had a tarot card reading which suggested my "king of hearts" might die. Yet he was so sweet and funny and attractive, and the parallels in our histories, character traits, and values were so strong that I couldn't help but love him. Moreover, without him I wouldn't have my two wonderful children. Watching the movie, I tearfully realized I would

have chosen to marry Yurgen again, even knowing how painful his loss would be. I just couldn't imagine making the same choice with anyone else.

Despite raising the children alone, I still had a full, rich life. I missed adult conversation and sometimes a shoulder to cry on, but then that's what friends and therapists are for. I turned to both when needed. When not, I continued to juggle.

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It's curious what we find memorable and what not. As a psychiatrist, I often encountered patients who recalled times when I was really helpful to them, even though I had no recollection of saying the wise things they reported I had said. Conversely, my daughter sometimes remembers times in her youth when I inadvertently embarrassed her, and I have no memory of doing so.

Perhaps what's memorable is what stirs up our own emotions, rather than others' emotions. When we are not in one of those memorable, personally gripping situations, it's easy to be unaware of the consequences of our words and deeds for others. For them, the consequences, whether positive or negative, may be etched in memory forever.

This observation is what makes it so important to be a decent human being throughout the day, including and perhaps especially during the ordinary times. You may not recall those times next week, next month, and certainly not next year. Yet for others, their impact may be profound. Therefore, no matter how busy life gets, we need to juggle but never treat other people as juggling pins, nor be distracted by looking ahead to when the performance is over.

This opportunity to connect with another human being may not come again. Pay attention to that person, and how they react to you. Sometimes we only have the look in their eyes right now to tell us that this is one of their memorable moments, even if it feels like nothing at all.

## 25. Sulphur Mountain

We are all eventually erased from history, but live on in the hearts of those we touched.

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The bus was humming with anticipation as we cleared the Calgary city limits and headed toward the foothills of the Rockies. My coach-mates were mostly Asian tourists laden with cameras, cellphones, and selfie sticks. As my knowledge of European languages was irrelevant, I just sat back and enjoyed the scenery and the rhythm of the excited, incomprehensible conversations.

I had been invited to speak at a conference in Banff, Alberta. Yurgen and I had honeymooned there two decades earlier. I wondered if I would recognize the place, though confident that the grandeur of the mountains would remain. I remembered skiing on a sunny, crisp cross-country trail and accidentally ending up on a downhill ski slope. Somehow, I found my way down the mountain on my narrow cross-country skis, only to be scolded by my new husband for scaring him half to death. I chuckled. It was a wonderful memory.

There had been more positive memories recently, now that almost five years had elapsed since his passing. I had cultivated those memories too, not just with home movies and photo albums but also with annual efforts to commemorate Yurgen's life.

The first anniversary of his death, I organized a planting at church in his honour. It was a red oak sapling which would become a sturdy, shade-giving tree in time. I crafted a poem for the small ceremony:

We found a tree that's strong and true

Whose shade will shelter from the sun

As timeless as all the tales you knew  
Of history's lesser-known heroes and bums;  
Its supple branches will hold birds and nests  
As you held your daughter, weighing mere ounces;  
Your quirky humour wouldn't rest  
As playful as an acorn bounces;  
You spoke your mind, you laughed out loud  
Straight as the trunk grows from its stem  
We feared the critics and the proud  
But you asked "Why put up with them?"  
And when you had no more words or deeds  
We set you free, to where God leads.

The second anniversary, I bought a niche to give his ashes a permanent resting place. It was in the most beautiful part of the cemetery, overlooking a pond with a waterfall and swans. Again, I organized a small ceremony with family and a few close friends to honor his memory. The inscription on the plaque read "Forever in Our Hearts." For a symbol on the plaque, I chose a bird in flight. Yurgen didn't have any particular fondness for birds, but the idea that he could soar freely away from that wretched hospital bed appealed to me.

The third year, I wrote a short letter to the editor of a prominent medical journal about the abysmal care received by those who died in hospital in non-palliative units. It was ironic: after decades



of trying to publish painstaking, rigorous research in my field in high-impact journals, this paper in a field I knew only from limited personal experience ended up in the highest impact journal of all.

The fourth year, I spent some money on an endowment at Yurgen's Alma Mater. It generated enough income for a modest annual scholarship in Economics that bore his name. I meet the winners every year, and it does seem to be making a positive difference. The award has also ensured that his name continues to appear on Google, despite being removed from professional and other websites almost immediately upon his passing.

Heading into the Rockies, I wondered how I would commemorate Yurgen that fifth year. Nothing brilliant occurred to me, so I looked out the window again. The bus seemed smaller than before as it pattered between the looming crags on either side. My fellow travelers started shouting "Ooh!" and "Ah!" as a new splendored vista appeared around every corner.

Finally, we reached the gate of the Banff National Park, signalling that we had arrived. A few people at a time, we were deposited at our respective hotels.

Mine was near Sulphur Mountain, named after the sulphurous hot springs at its base<sup>29</sup>. The mountain was known for its breathtaking views from the top, accessible only by gondola. I wasn't due to speak until the next morning, and was pleased to find the gondola still running even though it was almost sunset. After dropping my bags at the hotel, I stepped aboard.

Dark, rocky slopes hugged the tiny craft as it slowly ascended towards the sky. Minutes passed, and the darkness continued. It seemed we would never reach the summit. Suddenly, we burst into the light and there was a panorama of snow-covered peaks on all sides. The doors slid open, and we were set free to explore.

To my delight, a trail had been built connecting the two main peaks of Sulphur Mountain. It offered even more expansive views. I followed it across and back again, enjoying the sights, the cool mountain air, and the descriptions of local flora and fauna on signs along the route.

Then, I stopped. I breathed deeply. A cloud in the distance cracked, allowing the last rays of the sun to shine through. My eyes were drawn to the sunbeam and followed it. It found a lake, which now glowed turquoise. I followed the beam back to its source, partially hidden behind the torn cloud but definitely there. A line from an old Leonard Cohen song came to mind, "There is a crack in everything. That's how the light gets in."<sup>30</sup>

I felt cracked and broken, yet blessed at the same time. I experienced an overwhelming feeling of peace. Without a word or an explanation, I knew for certain: Yurgen was with God, and he was well. And from that vantage point, he was looking down on me kindly and always would. I wept. I didn't need to design any more public memorials. He was well, and he would live on in my heart.

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We all have our mountaintop moments. They often happen at the culmination of a long, frustrating struggle that has left us tired and baffled. Like Archimedes soaking in the tub in ancient Greece, we sometimes need an unfocused, relaxed frame of mind before inspiration strikes. In his case, he discovered how to calculate volumes of objects by measuring how much bathtub water they displaced<sup>31</sup>. The struggle with a difficult problem has to come first though. Without it, a relaxed break becomes merely a mindless escape. With it, a sudden revelation during downtime can be both moving and memorable, as mine was. The low-oxygen states we enter at high altitude can add to the euphoria.

Yet this moment was more than just an alpine high. It was magical. There was a sense of connection with another realm: a realm of infinite peace where all was well. Yurgen was watching gently from that realm, even as he lived on in my heart. I had no idea what it looked like there, but felt no need

to know. I took comfort in knowing he was well and I would be too one day. I felt forever connected to him and to that sacred realm. I no longer doubted that death is a transition to something wonderful.

## Epilogue

As you may have guessed, my mountaintop moment wasn't quite the end of the story. Grief continued in many forms, sometimes dormant for long periods of time, sometimes re-awakened by various life events. I felt that moment on Sulphur Mountain was the end of the most interesting part of the story though, so decided to end the memoir here.

In the course of writing it, I've drawn a few further conclusions I thought I would share. First, I've learned that not everyone remembers life in vivid, emotional episodes as I do. Some people's memories are much more subdued and factual. Episodes that sear the brain make interesting stories, but for those of us with vivid recall it's important to be aware of something: grand moments and momentous decisions make up less than one percent of life. The other ninety-nine percent consists of ordinary events we experience and ordinary choices we make each day. Yet the ripple effects of the ordinary can be extraordinary. One smile, one reassuring word, one kind act can change the world when we send it out into the interconnected, interdependent fabric of life. We may never see it happen, but it does. Therefore, worry more about how you treat the cashier at the store and less about achieving some sort of great legacy.

Second, uncertainty and unanswerable questions are an ongoing part of life. For example, although my son came through his recent hospitalization during COVID fine, I'm still not sure if he will be consistently, gainfully employed. Just as I was sadly resigning myself to the idea that he wouldn't be, he was accepted to a paid pre-employment program. Just as I thought this would be the answer to his employment problems, he was fired from a job trial and raked over the coals by the program leaders. Now, he's emerged from that despair and started in a new direction, but will that be the final outcome? Nobody knows. As in most situations where one's control is limited (and there are SO many of those),

just when you think you have it figured out, the course of life changes. Maybe that's okay though, because not every change is as catastrophic as what our family experienced in 2003.

Finally, I must revisit the gratitude question from the introduction: can a series of events that are as devastating as what you have just read about ever inspire gratitude? I'm still not sure. This pandemic year has been difficult for everyone in my family, and yet writing this memoir has made much of that suffering seem modest by comparison to the past. There have been great moments and jaw-droppingly awful moments this year, but there has not been the prolonged, relentless encounter with chaos and mortality we experienced in the summer of 2003. There have been bumps in the road, figuratively and literally—one recent bump even sliced open the bottom of my car like a can-opener, but they have only been bumps. They don't compare to the life-altering mountain I faced with Yurgen's hospitalization and death. I learned from that mountain, I gained a new perspective from that mountain, and it changed me in many ways that enriched life. Objectively, that's something to be grateful for. Subjectively, I don't feel it. On the other hand, maybe gratitude is more than a feeling. Maybe it's something to cultivate over time.

It seems too simple to summarize things this way: accept uncertainty, cultivate gratitude, and behave like a decent human being towards others. Life is so much more complex, and each of your experiences of loss will differ from mine in a myriad of ways. Therefore, perhaps I'll conclude with a hope rather than a summary: I hope you have found something useful or something comforting in these pages. May your catastrophes be few and your wisdom grow as you find and follow your life's path.

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