Through Thick and Thin

STORIES OF COMPASSION, COURAGE AND LOVE TO OUR SIBLINGS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES

Written or adapted by Helen Ries for The Sibling Collaborative

The Sibling Collaborative
DEDICATION

This book is dedicated to all the people who, with the deepest compassion, courage and love, journey through life alongside their siblings with intellectual or developmental disabilities.
# CONTENT

DEDICATION ........................................... 2  
AWAKENING ............................................. 3  
FOREWORD ............................................. 5  
INTRODUCTION ........................................ 6  
KURT AND VAL ......................................... 7  
JANET AND WENDY ...................................... 10  
SHAWN AND RAWLE .................................... 13  
AUDREY AND MICHAEL ................................. 16  
BARB AND ELEANOR .................................... 19  
ALLISON AND JOHN ..................................... 22  
FRANCES AND GUS ..................................... 26  
HELEN AND PAUL ....................................... 28  
ERIC AND SARAH ....................................... 31  
ACKNOWLEDGEMENTS ................................. 34  
THE SIBLING COLLABORATIVE COMMUNITY FUND .... 35

Copyright 2019 by The Sibling Collaborative
FOREWORD

Written by Eric Goll

When we have a sibling with an intellectual or developmental disability (IDD) we can get lost in the chaotic moments of our lives and forget to tell our stories. We may feel that others will not understand our story – and sometimes we even forget that we have one. For these reasons and others, our stories go untold. While this is tragic, it is also about to change.

As children and teenagers our stories are part of the daily dialogue, but as adults we become ghosts. As young adults we don’t exactly know how our story will unfold. Our parents encourage us to live our own lives but we are left waiting. We are left waiting for the story to unfold of our future lives with our siblings.

We are the first generation of individuals living our lives alongside our siblings with an IDD in the community – and our siblings are the first generation outliving our parents. Our stories are not easy and, until now, they have lived in isolation, disconnected from other siblings. Just like we as siblings have.

The Sibling Collaborative is shining a light on our stories as siblings, bringing them out of the dark, out of isolation. Our stories are both beautiful and challenging. They bring our humanity to the surface. Though our lives have countless twists and turns unique to each of us, we are connected by a common invisible thread of love for and dedication to our brothers and sisters.

“We are connected by a common invisible thread of love for and dedication to our brothers and sisters.”
INTRODUCTION

Written by Helen Ries

This book was motivated by the desire to share real stories of the lives of individuals who have a sibling with an intellectual or developmental disability (IDD). Stories of the realities of adult siblings’ lives are often overlooked or even sugar-coated. The Sibling Collaborative believes strongly that our stories need be told. It is our hope that by telling our stories we can be included in the conversations around family, caregiving, disability, social policy and social change.

The storytellers in this e-book emerged from a call for participants in our closed Facebook group or through natural connections. I would invite the storyteller to speak with me in an informal interview and write up their story. The storytellers would review and send feedback before their story was finalized. The exception was Audrey who generously wrote her own story and let me adapt it for this e-book.

I think it was hard for some siblings to tell me their story or to see their story as text. It made me realize that sometimes we don’t even know the power of our own stories.

The goal of this e-book is not only to help others understand but to add our stories to the rich fabric of our society. I want readers to see that we, adult siblings, are not part of the shadows – we are a critical pillar in the long-term wellbeing of people with IDDs and we are, and always have been, on the frontline of the inclusion movement.

Our stories are about love in the face of incredible personal trials.

“Siblings are, and always have been, on the frontline of the inclusion movement.”
KURT AND VAL

The Gift of Compassion

When we were growing up, our family was much like any other. My parents spent evenings and weekends cheering my sister Val and me on at our respective sporting events, we ate our meals and did things together as a family, we shared jokes and much laughter. Our family was all about laughter and love. Although my parents are now in their mid-80s, we still have family dinner together on Sundays. The laughter and love are still there.

In my early 30s, I moved away from Ontario to live and work in British Columbia. My parents encouraged me to live my own life and so I did. I loved being out west – mountain biking, skiing, hiking and kayaking on the weekends with my friends. I didn’t feel that I was different from any other sibling.

My sister, like me, loves sports and has been physically active all her life. She has been an excellent swimmer and runner and these days her passion is Zumba. Physical activity gives my sister a great sense of purpose and pride.

I CALL WHAT MY PARENTS BUILT “THE FAMILY SILO” BECAUSE WHAT THEY BUILT WAS DONE SO WELL AND WILLINGLY, WITHOUT MUCH OUTSIDE SUPPORT.

My parents have been very successful in building a good life for Val. She has lived independently for many years in an apartment of her own. My parents wove together daily supports with tireless energy, love and advocacy. I call what my parents built “the family silo” because what they built was done so well and willingly, without much outside support. No one could do for Val what my parents have done – not even me.

About 10 years ago my sister went through a health crisis so I decided to come back to Ontario to be closer to my family, especially Val. I felt she needed me there, to be her big brother and to support her during this time. A lot changed for her as a result of this crisis and her suffering during this time affected me deeply. It has been difficult to see my sister face emotional and physical challenges. I struggle when she struggles. Her health crisis led me to become more involved and while my father and mother have provided the bulk of the support, I’ve stepped in as best as I can. Even if it’s just to be there to provide company, outings, dinners and support. And a good dose of (gentle) teasing and humour, which goes a long way. We like to laugh.
Four years ago, I was listening to the radio and heard an interview with another sibling of a person with a developmental disability, who was their sibling’s primary support and carer. The interview galvanized me because I had never really heard another sibling talk about their adult experience. When I heard the other sibling’s story, I felt less alone in my own journey with my sister.

After the radio show, I sought out and attended gatherings for adult siblings and tried to reach out to others. I have made friends with a few other siblings who are deeply involved in the lives of their brothers and sisters with a developmental disability. I have been listening to their stories and the more I hear, the more I am able to recognize the parallels between their lives and mine. Connecting with other siblings and hearing their experiences has helped me so much to learn how to better support and care for my own sister. I have become aware of new funding supports, the disability tax credit and the power of creating a person-centred vision with your sibling.

While I see that some other siblings are suddenly thrown into the role of primary carer without much preparation, I feel I have had time to consider what is coming. Providing care for Val is all my parents have known for over 50 years, so my transition to being Val’s carer is a gradual evolution. For my father especially, it is a big part of his purpose in life. I know that both my life and the life of my sister are going to change at some point. I am willfully and lovingly stepping up to be the one who provides the day-to-day support for my sister when the time comes.

At the same time, I have always enjoyed and valued a life of sports, travel, music and friendships. It is vital for me to continue to invest and build in my own rich life. Understanding and knowing what I need for my own self-care is what will help me to continue being my best self for Val in the days that lie ahead.

I am also a volunteer advocate for others with developmental disabilities through a local organization. Volunteering is something I have done all my life and I find that helping out is a valuable way to learn and make connections.

Over time, I have come to realize that as siblings of a person with a developmental disability we have certain superpowers that come from the gifts of the role. For one, we are able to take complex and difficult information, distil it down and communicate it in a way that can be easily understood. We have been doing that every day, our whole lives. We are also used to disruption and disorder. As children and teenagers, we became accustomed to plans not unfolding as expected and to sudden changes to our day. As a result, I believe we can deal with challenges better than most. Finally, I find that we, as siblings, are resilient and often flourish in the midst of a crisis around us.
AS SIBLINGS WE HAVE LIVED THROUGH SUFFERING IN OUR FAMILY, WE HAVE SEEN SOCIETY’S CRUELTY, WE HAVE WATCHED OUR SIBLINGS STRUGGLE TO READ OR WRITE AND WE HAVE WITNESSED THEIR FRUSTRATION. I HAVE MORE COMPASSION TOWARDS ANYONE WHO SUFFERS BECAUSE OF MY SISTER.

The greatest gift my life with my sister has given me is compassion. As siblings we have lived through suffering in our family, we have seen society’s cruelty, we have watched our sibling struggle to read or write and we have witnessed their frustration. I have more compassion towards anyone who suffers because of my sister and for that I am grateful.
JANET AND WENDY

A Sister’s Blessing

When my sister was 27 she met a guy at a party. They soon fell in love, moved in together and got married. Wendy and her beau Phil were married 33 years. It has been my privilege to have them in my life.

Phil was 27 when he escaped from a Saskatchewan institution where he, and many other people with disabilities, had been kept against his will. Phil’s experience was no less than remarkable and, with some guidance, he became a bold community advocate. Deeply invested in closing the institutions, he worked tirelessly speaking up for inclusion and a better way of life for people with disabilities. Phil is one of my heroes.

AT THE TIME I HAD NEVER HEARD THE WORD ADVOCACY AND YET I WAS ADVOCATING FOR MY SISTER.

Phil was 29 years older than my sister. Wendy somewhat lived in his shadow, given his advocacy profile and that he was the elder in their relationship. As the years passed, I began having more discussions with Wendy about the time when Phil would pass. I would explain that Phil would, one day, be so tired he would need to rest. Wendy knew what I meant. Those discussions were not easy, and she often said, “I don’t want to talk about it” or “When that happens, I am going to be upset”.

Ever since I was a young girl, I have helped Wendy when she was upset. It is sometimes difficult for me when Wendy is upset. I wondered how bad it would be when Phil died. I started to engage Phil in the discussions about him aging. It was very painful as Phil would tear up and state he did not want to go into a home. Wendy always assured him that would not happen. Over the years I watched my sister deal with Phil’s aging and illness.

I have been responsible for Wendy most of my life. I remember when I was 14, Wendy and I were at the same school and my guidance teacher asked me if I would like to explore schooling options for Wendy. At that time, she was attending an occupational class and her teacher did not feel it was an appropriate class for her.
With encouragement, I went with Wendy’s teacher to visit Donald Patterson School for the Retarded. I took the tour and vividly remember seeing a young boy standing up against a wall with his tongue hanging out. Many of students appeared non-verbal and confused. “No, that is not a place for my sister.” At that time, I had never heard the word ‘advocacy’ and yet I was advocating for my sister.

As years passed, every autumn Phil seemed to become ill with pneumonia. He would take a fall and Wendy would call the ambulance. The third year that Phil fell and Wendy called an ambulance, they checked him over at the hospital and sent him home. Within 48 hours he fell again and Wendy hesitated to call the paramedics. She covered him with a big blanket and provided a pillow. The next morning, I received a call from Wendy and dashed over to find Phil on the floor, definitely ill again. This time the visit to the hospital led to palliative care.

The family had arranged a cruise for Wendy and Phil to celebrate their 33rd wedding anniversary. We had arranged for their friend Ray, who was also a care-aide, to go on the cruise with them. After his move to palliative, Phil woke up with a spurt of energy saying, “Make sure Wendy takes Gravol before she gets on the plane.” At that moment my heart lit up. Phil knew he could not take the trip with Wendy yet wanted her to go and, even on his death bed, was thinking of her well-being. That is the kind of relationship they had.

Phil, at the age of 89, passed away on September 11, 2017. A number of us worked at preparing Wendy for the day and I am proud to say she cried out, cried and then calmed herself.

Since my brother-in-law and dear friend passed, I have to say that Wendy has matured. Sure, she complained the nights were lonely, yet she gets out there keeping busy with bowling and friends and is now making decisions based on looking after herself and being happy. Wendy has always held her schedule above all else, much to the family’s chagrin at times. Now, it was her ace in the back pocket and it was holding her together.

In April, Wendy approached me, pounding her heart to convey her pain and pleading for help to find the birth daughter she was forced to give away. Wendy was only 22 when she gave birth. Our mom said she did not want to bring up another child, so adoption was set up by the social worker. Not only did Wendy have to give her baby up but they also had her tubes tied. For many years, at the end of September, my sisters and I would get calls from Wendy grieving for the child she was allowed to hold once but never got to know.

After 20 years Wendy asked a worker to help her find her daughter. The child’s name was given to Wendy. Though we chatted about her being patient for me to be there to make the contact, Wendy had a visit from a friend and, in their excitement, they looked up the daughter’s name in the phone book. A call was made and Wendy told the young recipient on the other line, “I am your real mother.” That was a big mistake.
This time, 20 years after that call, Wendy was asking for help and understood she would need to be patient. I Googled her daughter’s name and amazingly there she was and I knew she was my niece. Like her mother, my niece also has developmental disabilities and was receiving support from a local organization.

Wendy’s daughter agreed to meet me first as she was still upset about the phone call Wendy had made 20 years earlier. We got along from the start and I loved that she offered me a bit of a hug when we said goodbye. She is so much like my sister Wendy. Her aging parents were happy for their daughter to gain an extended family.

My niece had many questions and loved all the pictures I showed her. She definitely wanted to meet the family, in particular the little ones. By our third meeting, I had to tell my niece she could not meet the rest of the family until she met her birth mother.

Wendy’s meeting with her birth daughter went very well, with some shyness and nervousness from both. When Wendy met the adoptive parents, she handled herself so well. She walked up to both, shook their hands and said, “Hi, I am Wendy.” She then said, “I have told your daughter, she can call me Wendy. I am okay with that.” Wendy also thanked them for doing such a good job bringing up her daughter. I could not have been prouder of my sister.

I grew up being Wendy’s second Mom; she was always there, just a call away. When Phil came into the picture I learned clearly about advocacy and believed if Phil could do public speaking, so could I. My life journey of supporting people with disabilities began.

Little did my family know how rich a life Wendy would live. Married 33 years to a gentle man who loved her and being re-united with the daughter she had to give up.

Wendy has a good life. I am the sister who is blessed.
SHAWN AND RAWLE

Making Changes

I have always had a strong bond and good relationship with my older brother Rawle, an individual with Autism Spectrum Disorder (ASD).

A few years ago, I had the difficult realization that his needs were changing. Around the same time, I noticed my mother wasn’t able to care for him like she once could and was struggling to balance supporting his complex needs with looking after herself.

My brother didn’t always have access to support from social services. In the 1970s and 80s, there were generally fewer government-funded supports available and gaining access to what little there was failed to acknowledge the challenges of navigating systems for racialized individuals. For these reasons, my mother took care of my brother largely on her own – with some assistance from community housing and social assistance programs. Throughout my brother’s lifetime, I have witnessed my mother facing stigma from both systems and community. I have been in awe of the resilience, strength, sacrifice and courage she has demonstrated in the face of all this adversity.

Because there has always been a lot of stress in our lives, I didn’t feel the changes in my brother and mother as a sudden crisis. It was more like the constant undercurrent of stress that became stronger and stronger.

When a crisis would arise with my mother or brother, it felt like I was trying to put out a fire by just waving my hand over it. It seemed that I could never get to the root of the issues. So, one day, I decided I needed to look for better supports.

By the time I was 38 and my brother was 42, I found I had transitioned into the role of caregiver – not only for my brother but also my mother. I hear people talking about being part of the sandwich generation because they are taking care of both their children and their parents. I am a triple decker sandwich: I have my own young family and now I have my mother and brother to care for too.

In the face of the stress and pressure of all this caregiving I began to feel my ability to manage was being tested. I wasn’t able to hold it all together like I usually could. Finding myself in this situation led to an entanglement of emotions. The increased responsibility made me more anxious and I felt shame for not having done more to avoid the difficult moments we were now facing. I also felt dread whenever my mother called me crying and I had to pull away from my own family.

One of the first things I wanted to do in my search for added supports was determine whether Rawle needed a diagnosis that included his mental health. He hadn’t been assessed in over 30 years, so I approached the Centre for Addiction and Mental Health (CAMH) for reassessment.
The process of better understanding his diagnosis and searching for new supports led me to finding and securing a place for my brother in a group home. After 45 years of living with my mother, I felt it would be good for him to be in a different setting and to develop new skills. So, after much planning and effort, Rawle transitioned to the group home. He is now doing new things in his day, enjoying his activities and become more conversational.

As brothers and sisters, we need to ensure our siblings have the correct diagnoses so they can get the right help for them to thrive.

While I know Rawle is doing well, my mother doesn’t agree. I think that caregivers of a certain generation have a hard time understanding modern approaches to caring and disability. Because they struggled so much on their own, they are used to operating in fight or flight mode. My mother is no exception. She did so much for my brother over the years; she has been his tireless caregiver, his friend and his fiercest advocate. I know that after all this time and all that she has done, her sense of identity has become tied to my brother. I thought that my brother’s move to a group home would reduce the stress I was feeling but it didn’t. Instead the stress has re-positioned itself from my brother to my mother.

My brother visits my mother once every two weeks on the weekend and my mother sees him often at other times. Whenever she sees him, she notices right away if something is not quite as she expected, such as his hair not being brushed the right way. Somehow over time I have become the conduit between the group home and my mother. My anxiety and stress levels are now directly connected to the stress my mother feels about my brother’s day-to-day living. I look at my brother and think he is fine, and then I look at my mother and I know she sees it differently.

Now that Rawle is living in the group home, I have gained a new perspective. I have a stronger understanding of his diagnosis and I realize that growing up I didn’t have a full...
appreciation for his well-being. I have taken this new perspective – along with my life experience – and channeled it into creating better systems for people like my brother with ASD.

In 2017, I completed a research study into virtual reality technology and how it can be used to better design human service systems. The human service system is complex and difficult to navigate. My research focused on capturing and sharing the lived experience of families and caregivers in virtual reality so that it could be shared with those on the other side of the system, such as human services professionals and policymakers. Using this technology will help them to better understand our experiences of navigating multiple services and supports. I hope that my research will have real implications for individuals with a disability and their supports and offer important direction for future research.

IT IS ALSO IMPORTANT TO UNDERSCORE THE CULTURAL CONTEXT IN WHICH FAMILIES EXPERIENCE DISABILITY. SIBLING AND FAMILY DYNAMICS CAN HAVE DIFFERENT CULTURAL INTERPRETATIONS.

As brothers and sisters, we need to ensure our siblings have the correct diagnoses so that we can get the right help for them to thrive. When relevant, this includes a mental health diagnosis. We need to recognize that our siblings have their own stress too and, such as in the case of Rawle, in a different context and with better supports a different person might emerge.

It is also important to underscore the cultural context in which families experience disability. Sibling and family dynamics can have different cultural interpretations. Not everyone has the strongest advocacy voice – and those people are often forgotten. This could be because they don’t have the necessary network, knowledge of services, understanding of the various roles service providers or communication skills to connect. Now that conversations are starting to take place around confronting the gaps of understanding cultural nuances within systems of care, I am emboldened to shed light on the fact that we must do better to connect with those communities.
AUDREY AND MICHAEL

If not me, then who?

Written by Audrey Deutschmann, adapted by Helen Ries

When my mother dies, I am 500 kilometres away. There's no prologue, no warning. Just a phone call and the irrevocable knowledge that she’s gone. It cuts so fast and deep that the pain is as unrecognizable as the fear that crowds it. My world is shattered.

My mother was the only person who ever just loved me, without condition, and the loss is inconceivable. She was my friend, my ally, my security.

I've lost my best friend, but my brother and father have lost their very foundation. Mom didn’t just live her own life – she was an anchor for my ailing father and my autistic brother. She made the money, she paid their bills, she filed taxes, she grocery shopped, she picked up medications and drove to appointments.

At 28 years old, being estranged from my father is an old fact; the edges have been worn down over time. I never learned to be the kind of woman he was able to tolerate and had long since given up trying. After high school, I’d left Kamloops and gone to university on the coast. Victoria was now home.

I had, in arrogance, claimed I would never go back, but with mom’s heart attack, everything that came before collapses under my feet. I am alone, and I have to go back.

I barely know my brother. I hate my father. But they’re so vulnerable and so isolated. Neither has friends. Mom had a few, but not the kind to throw themselves into the teeth of what she’d left behind. I haul a duffle bag out of the closet and begin to pack.

When I arrive in Kamloops, the house is dark and silent. Before my brother, now 25, closes the door to his room, I glimpse him lying in bed with his hands stiffened at his sides, staring at the empty space above him. I wish I had comfort to offer, but there is none to give. We are not a demonstrative family. Nothing can help him, the same way nothing can help me. If I’m drowning, he’s lost at sea.

My father looks up from the dining room table when I tentatively approach. His grey eyes are empty and he has nothing to say. I’ve seen his moments of vacancy before. His mind wanders in time. Sometimes he’s confused by what he sees because he thinks we’re still living in Toronto.

My father doesn’t want to have a funeral or ceremony for mom. But Thompson Rivers University, where she worked, hosts a memorial in her name. The memorial takes place in a rose garden on campus. There’s an impressive turn-out, but most of the people I don’t recognize. Enough students attend that I feel sheltered by their presence.
Since I returned to Kamloops, I am constantly aware of my brother, Michael. I’ve been trailing him like an anxious sheepdog, ready to interfere or herd him away from threats. No one would intend to distress him, but I worry about nosy questions disrupting the dreamy calmness in which he’s drifting.

At the memorial service, Betty-Ann, one of my mother’s friends and allies in advocating for Michael, puts herself between Michael and myself. For the first time since I arrived, I feel able to turn down the volume of worry about him. But it is still there, a feral growl of “keep him safe” that’s unfamiliar, illogical, and impossible to ignore.

When the memorial is over, my father is drifty and confused enough that it’s easy to pluck the car keys from his hand. After taking him and my brother home, I turn back onto the street and aimlessly drive.

The next day, my father is clear-headed and not happy I’m here. I’m not happy that I’m here either, but then, there’s no happiness here at all. He thinks I came here to pick his pockets, empty the bank account, and steal anything that isn’t nailed down. If he’s worried about Michael, it’s only what I might do to him. He wants me gone.

Once I’m sure my father is occupied in his den, I rummage through mom’s purse. I pocket the cash, which is just enough to cover a Greyhound ticket. I don’t know the code for her debit cards, but I borrow the credit card. With Michael’s preferences in mind, I take the car again and grocery shop for things he’ll eat.

If you know someone with autism, you probably understand how brief and precise that list is: a certain kind of pasta, a certain kind of peas, a certain brand of crackers. Numb, I fill the cart with things Michael can eat. The food won’t last forever, but then, nothing ever does.

Around two in the morning, I am on the Greyhound, sleepless, rushing down the Coquihalla so fast it feels like freefall.

It was all in the cards since I was born, but mom’s death shook me awake. It’s a familiar wait for many whose siblings have a developmental disability and are being cared for by aging parents. Most of us will spend part of our lives idling in this maddening purgatory. I can’t speak for all of us, but our communities echo with familiar refrains: when the sword hangs over your head, no joy is absolute, no victory complete, and no happiness sustainable. Fear nibbles at the edges of everything.

Years later, we’re okay. After an exhausting series of side-steps, my father moves into a care home where he eventually transitions to palliative care. We sell the Kamloops house and use the money to get my brother an apartment of his own. The building is a bit shabby, but it’s on a bus route and a block from his volunteer job at a community farm.
Yet the journey shouldn’t be this hard or this long. There should have been a will, a Representation Agreement, and a trust fund to cover my brother. There should have been another twenty years in my mother’s life. We scrambled through, but the cost was high.

The most valuable resource was money. Once I gained access to the family estate, I had the freedom to put my brother ahead of the need to earn rent. It’s a hard truth to face, but the rewards of mom’s successful career saved my life. Of near equal importance was mental health support. I limped away from my father’s house weary, battered, and flinching at shadows. All I could see were the ways in which I failed. It took immense patience for a psychiatrist to nudge me back into balance. Thirdly, it hinged on the support of friends whose roots were deep enough to withstand the hurricane my life became. For them, the words “thank you” seem wholly inadequate.

Learn from us. Don’t wait for a path to appear. Get a machete and carve a path of your own. Demand a will, a Representation Agreement, or a disability trust account. Maybe you’ll stumble onto better answers, but any path is better than no path. If you cannot protect your heart, protect whatever you can.
BARB AND ELEANOR

Caring for the Carer

My sister Eleanor has just celebrated her 70th birthday. Many people will tell you Eleanor is very charming. She was always active, capable and game for anything.

Except for ten years at the Rideau Regional Centre, Eleanor lived most of her life with our father and stepmother. She adored her father and felt he was her pal. They went bowling together, to McDonald’s for supper once a week and to church. When our father died in 1987, she wasn’t as much sad as she was overwhelmed by the question of who would take care of her. She always had surprising insight.

Our stepmother Jean was really close to Eleanor. While our dad had been the boss, our stepmother helped her with social outings, learning and street skills, like using buses on her own. Jean took over Eleanor’s care after our father died until she had a stroke and moved into long-term care 13 years later. That is when Eleanor came to live with me.

This was a very confusing time for Eleanor. Even though Jean was in long-term care, she still felt that she was Eleanor’s primary caregiver and would direct her life from the facility. Now, Eleanor had two people as primary caregivers and many times what I thought was best for Eleanor, Jean did not. Eleanor didn’t cope well in that time and frankly neither did I. I was running everywhere looking after everyone and not able to properly direct Eleanor’s care. It was a time of much confusion and stress.

When Jean first became ill, Eleanor would visit, and a social worker noticed Eleanor was having a very difficult time. I asked the social worker if she could please give Eleanor some counselling to help her adjust. She counselled her for about six months; it really helped and eventually restored some balance to our life. Jean died in 2005.

I used to lead a perfectly normal, adult, single life. I might even say it was totally self-centered and self-directed. I lived in Australia for 40 years. I had a home there and was a teacher in a local school but I still weaved Eleanor into my life. When Eleanor was living with Jean, I would come back to Canada and bring Eleanor back to Australia for me for three months at a time every two years. She had a special room in my house. They welcomed and included her when she visited. Our good friend, Cheryl, was especially supportive. She gave Eleanor a volunteer job at the school library. After Jean passed away, we would live in Canada for six months and in Australia for six months. I kept our houses going in both countries.

I have always been good at networking. I never forget who people are and what they can do. Also, I don’t feel any kind of ownership over Eleanor, meaning that if anyone
expressed an interest in getting to know Eleanor I would say, “Sure, that’s great”. As a result, Eleanor has enjoyed many friendships.

I have enjoyed being Eleanor’s caregiver. We were great travel buddies, good companions and we are very close. Eleanor is very chatty and would get wholeheartedly involved in whatever we were doing. She was self-motivated to do jobs: she would automatically sweep the kitchen and patio, fold the laundry and help cut up vegetables. I never felt that Eleanor was a burden to me or the life I was leading. I was able to adapt situations to suit our needs.

Eleanor used to complain that her back hurt and would say, “I am getting old.” I used to just treat it lightly and tell her that I was getting old too! But one day she stopped saying “I am getting old” and I realized that she had indeed become old. She was having trouble with her daily activities and needed a wheelchair to get around. Our last trip to Australia together was two years ago.

Eleanor losing ground was a shock to me. I had no vision of how this was going to play out. I had no vision of her being physically disabled. For me, it was really sad but, in a way, Eleanor loved it. Using a wheelchair was a relief for her. We finally received a lot of home support and Eleanor – someone who has always loved attention – now gets 40 hours a week of one-on-one attention from the people who support her.

Life today is actually a piece of cake compared to when Eleanor was so active and busy. I have been very tired from always thinking for two, looking for resources, supporting
her need for stimulation and independence. I am now enjoying the many hours of support she has from others.

What has made the biggest difference for me and for Eleanor’s life has been my ability to seek opportunities. I would invite friends to join us in our activities and we would all do things together. It was wonderful for me too. I just had to adapt things so she would be okay. Inclusion worked both ways for us – it gave me a busy social life and it helped Eleanor develop a large network. But there are no free lunches in this world: I would go overboard looking after the friends that were included in our life and put a lot of energy into building and maintaining relationships.

Through word of mouth, I would find a young person who, in exchange for cheap rent, would be both a companion to Eleanor while we were in Canada and a house sitter for the six months we were in Australia. All kinds of people came into our life looking for accommodation or house sitting and they gave back much than they received, often more. Some of the people who stayed with us are still part of our lives today.

WRITING TO SOCIAL SERVICES IS LIKE WRITING LETTERS TO SANTA CLAUS. YOU NEVER KNOW IF IT HAS BEEN RECEIVED.

Insistence and persistence have made a difference in how I have dealt with support services. I feel that social services were indifferent towards my requests and I had to badger them. I wrote, called, emailed, asked to speak to the supervisor. One time I even threatened the staff of the Ontario Disability Support Program with involving my lawyer. Writing letters to these people is like writing a letter to Santa Claus. You never know if it has been received. I tried for seven years to increase Eleanor’s individualized funding, so she could have money to participate in the community. Yet only when Eleanor’s health changed dramatically did we finally receive the increase we needed.

I am now a senior and, because I have so much help, I can actually stop struggling and enjoy a bit of my retirement. When I think back, I don’t know how I have managed to look after Eleanor all these years with limited financial resources and my commitment to a life of going back and forth from Australia. In some ways, it has taken a toll. We definitely had difficult times, especially in the earlier years. The saying “Care for the carer” used to make me bristly but in the end I learned that I can only do so much – and I am doing my best. You are first and you have to learn that. This took me longer than average to learn.
ALLISON AND JOHN

Baby on Board

Quinn was born in August 2018. My wife Kerry and I were thrilled to welcome our beautiful baby boy into the world.

The lead up to Quinn’s arrival was difficult for my brother John. Since my parents died, I am the only family he has left in Canada. As my own family has been forming and growing, understanding his place has been an ongoing source of stress.

Our mom died when John was 19 and I was 21. When she passed away, I was off at university living my own life and John went to live with our father. My mom and dad never agreed that John had a disability. My father denied there was anything wrong and felt that John just had to find his path; he refused my mother’s request to have him assessed as a child. Only later in life did he come around to the idea that John had a disability. I remember his acknowledging it by saying to me, “You can paddle the river, whereas your brother can’t.”

My brother was dependent and very close to my father and, just nine years after we lost our mother, our father died too. As he was dying, I asked my dad, “What am I supposed to do with him?” He didn’t have an answer for me. I was so broken and overwhelmed by the death of our parents that at first, I didn’t feel the stress of caring for John. At that time, I just dealt with what needed to be done and, given that my father didn’t leave a will, that was a lot.

WITHOUT A WILL I WASN’T THE EXECUTOR, I DIDN’T HAVE POWER OF ATTORNEY AND THERE WAS NO HENSON TRUST.

Without a will I wasn’t the executor, I didn’t have Power of Attorney and there was no Henson Trust. We dealt with his estate through the court system and without a disability diagnosis John was left with no financial support.

I had to work out a way to keep my brother from becoming homeless. My brother didn’t want to move out of my father’s house, but we couldn’t afford to keep him in it. I decided to clean it out, renovate it and find renters. I would find John an apartment and use the rental income from our father’s house to pay John’s rent.

It took about two years for the dust to settle and for John to actually move. Without a Henson Trust there was no way to direct John’s share of the inheritance so, although he is thrifty with his money, he has now burnt through almost all the money my parents
had left him. In my opinion John is housed and safe and we still own our dad’s house because of my efforts, my brother doesn’t understand what I have done. He believes I kicked him out of the house and it’s my fault he doesn’t have more money.

I find my brother and our sibling relationship difficult, especially these past few years as I’ve started my own family. When I first met my wife Kerry and as our relationship was growing, he began to see her as competition. At first Kerry tried to ease this tension by working at building a relationship with him. She knows he loves to fish so they planned an ice fishing trip together. What was supposed to be a fun and bonding day included a fair amount of chivalrous grilling about our relationship. He can be quite rude to Kerry and if she doesn’t agree with him, he can become condescending and aggressive. She tolerates him for my sake but the power dynamic between them has taken many years to work out.

John doesn’t really understand why we don’t live together. Like we used to. Like the family he had growing up. But this isn’t what I want. He is lonely and feels we don’t see enough of each other, even though I see him every week. He used to have a key to my place but when Kerry moved in, it became awkward to come home and find him on the couch using the internet. He would also drop by uninvited, or let himself in while we were at work. When it was time for him to go home, he would belabour leaving. He didn’t understand why he couldn’t stay with us. I would try to explain that I had my own family now and he was not part of our marital partnership – which made him feel pushed out and displaced. The more he persisted with attempts to include himself in our family, the more I would push back. It makes me sound like a terrible person – but my wife was right to say that she was marrying me, not me and my brother.

When I told John that we were going to try to get pregnant, it renewed his concern about his role in the family. It was confusing to him how we would even have a baby as two women. And would he be the father? No John, you are the uncle – Uncle John. My brother. It took time and patience to iron this out, but we finally got him to understand. Things became much clearer once the baby arrived.

John had been floundering for many years. Leading up to the pregnancy, I felt a lot of pressure to get John’s life and affairs properly arranged because I knew I wouldn’t have time when the baby arrived. I brought together two of his oldest friends, one of my mother’s friends and Kerry to form a sort of “board of directors” for him. We all met to let him know that we cared about him and that we were offering our time and energy to help him get his life on track, since he didn’t seem happy and hadn’t held a job in eight years. It took him awhile to agree to the concept, concerned we were trying to control him at first. But once he was confident that he was still in control of his decisions and leading the directions we’d go in, he loved the attention and being the leader of his board. After a year of meetings, I have noticed that while not much has substantively changed other than a couple of burning financial issues, he seems a lot less depressed. I have also noticed that I feel less isolated knowing that others better understand John’s challenges.
Once Quinn was born, there was a big shift in our relationship. John wholly accepted his role as uncle and actually seems more secure, not less. Kerry and I are both happy to have him over because for the first time I really need my brother. He knows he has an important job in helping me around the house or taking care of Quinn so I can rest. John loves to be genuinely wanted and needed, and he loves Quinn. We now have a weekly date for John to come over and take care of the baby. I will sometimes strap Quinn to his front and send him for a walk around the block. He is very gentle and amazingly patient with the baby.

For me it has been a great liberation. I don’t know if it is because I have a new project with the baby or I am just exhausted from being a new mom, but my boundaries feel less murky and my focus on John is less intense. I’m finally clear on how to incorporate John into my life in a way that I feel cared for too. I am over the moon that we are finally moving in a new direction in our lives.

I look forward to the days ahead when I can send Quinn over to his Uncle John’s house to play video games or they go on fishing trips together.

Looking back, one of the best strategies I employed with John was convening the “board of directors” of competent people who care about him. There were some issues that we had butted heads over for years that had started to just seem like me meddling or an outright power struggle between us. But the group gave legs and sense to some concerns and was able to inject different ways of talking about things. Also, when John heard all the people he cared about saying the same thing, there was mandate for change. I had backing.

The next strategy was getting him involved with a local disability organization. With an employment counsellor to support him, I had another route for helping him think through things. What does Josh say about that? Well, why don’t you ask Josh? This changed our relationship from one of me playing a more parental role to just being able to be a sister sometimes.

Lastly, the baby has created an opportunity for Uncle John to grow and be useful. It wasn’t right away, but after the fragility of the first few months was over things are working out very well. At first the concept of assisting with the baby by helping feed and clean for the mothers perhaps didn’t land; but now that we have Uncle John-Quinn time, things seem to feel more sibling-like.
I LOOK FORWARD TO THE DAYS AHEAD WHEN I CAN SEND QUINN OVER TO HIS UNCLE JOHN'S HOUSE TO PLAY VIDEO GAMES AND THEY GO ON FISHING TRIPS TOGETHER.
FRANCES AND GUS

Confidence through Contribution

My mother, who is now 89, has been taking care of my brother Gus his whole life.

About three years ago Gus underwent some major eye surgery. We realized post-operative that he would require a number of eye drops, several times a day. My mother was overwhelmed with the care required and suggested he stay with me for his post-operative recovery. Ever since then, Gus has stayed with us on the weekends. My brother is loveable, peaceful and very personable and we enjoy having him around.

In my mother’s home, Gus had no responsibilities and few opportunities to make his own decisions. She does everything and makes choices for him. It is the way it has always been. When he is my house with my husband and me, it is totally different. I really want him to contribute to our home, to increase his confidence and independence. I especially want him to build his own life skills. So, when he is with us we give him responsibilities and ask him to make his own choices. My husband is very patient and together we are teaching him how to do certain chores such as setting the table, doing the dishes or holding the bag open when we rake the leaves. I remind him that our home is not a hotel and he must chip in. I know he really enjoys it but unfortunately, when he would go back to my mother’s house, he would retreat back to his old self.

Because my brother has spent so much time with us, he is interacting more with other people. We go out, do stuff, see friends and family. Gus has had a chance to meet some of our friends and they have started inviting him to go places. This summer my husband’s nephew got married and we were happy that Gus also got an invitation to attend the wedding.

I have noticed that over time my husband and brother have become closer. They are giving each other more hugs, spending time together and joking around. The other day my husband took him out for a beer, just the two of them.

My husband suggested that Gus come with us on a holiday to Newfoundland. We love hiking but Gus is not a big walker so we had to modify our trip. With the right planning there is something for everyone.

Unfortunately, a few months ago our house burnt down and we had to move in with our mother and Gus while our house is being rebuilt.

Sharing the same space with them has been very eye opening. My mother is not very mobile and can’t take him places like she used to, so Gus is very isolated. They also seem to bicker quite a bit. My brother has a number of health issues and we are worried that if my brother is ill, she won’t respond to it in a way that would keep him safe. In fact, one day when we were living at our mother’s, Gus was very sick after
eating a hot dog and my mother didn’t realize he required medical attention. I noticed he was ill as soon as I got home from work.

After that incident we thought, there is no way they can keep living together just the two of them. We proposed to my mom that Gus could come and live with us after our house is rebuilt. But my mother doesn’t want to live alone, so she is going to come to live with us too. We are all going to live together.

I really want him to contribute to our home, to increase his confidence and independence. I especially want him to build his own life skills. So, when he is with us we give him responsibilities and ask him to make his own choices.

Before Gus comes to live with us, I need to figure out how he is going to get to his day program at Community Living Toronto. Since he is going to be in a new area of the city, there might be an issue with the bus service. I think figuring that out will be quite stressful. I am also worried about my mother and brother losing contact with their neighbours. Right now, all the neighbours know my mother and will help out if needed. I don’t have that kind of arrangement with my neighbours.

One strategy that I have been using has been to be creative and flexible with options for my brother. For instance, we have to take into consideration his needs and health issues if we want to go out for dinner so we look at all kinds of options so everyone can enjoy dinner out.

Being involved with my brother all his life, and especially since he has been coming to our house on the weekends, helps me to know what to expect for the future. It is not always an easy thing to care and support your brother but being involved early helps to ease anxiety – not only for me but for him too. I am still trying to figure it all out. It is a work in progress.
HELEN AND PAUL

Healing our Hearts

As I put the key in the front door I could see through the glass that my mother was lying on the floor in the hallway. I rushed in and started to perform first aid. I yelled for my husband still standing at the door to call 911. As I sat on the floor, with my mother’s head in my hands, waiting for the ambulance to come, I knew that my life as I had known it was about to drastically change.

Our lives had already changed a lot. My husband and I had moved in with my mother and brother after my father died only a few months earlier. We had decided to all live under one roof to better support each other as my mother aged. Although she did all of the support and care for my brother, I thought that at least if we lived under the same roof, I could gradually take over. I hadn’t expected the change to happen so suddenly and so soon.

Growing up we had always been a close and loving family. Our parents built a happy home with what they had, which was not much. We went camping, we took road trips and sometimes we would take a trip to visit our family overseas. My parents fought for my brother’s inclusion in school, community and eventually the workplace. They were careful to ensure I wasn’t left in the shadows and I was careful never to rock the boat.

For many years, my parents talked about their plans for my brother once they passed away, like where he was to live and who would take care of him. My father had planned that a live-in caregiver would do the work but I never really understood who that would be, where they would come from and where they would live exactly.
My parents never used outside supports to help them; they dropped out of the social services support system when they got fed up of waiting for services. They saved money as best they could, rarely afforded themselves any luxuries and made it very clear that I was to make my own way in the world, on my own dime.

I am Paul’s only living blood relative. Until my parents died, I never wanted to listen or engage in the talk about his future care. I would change the subject quickly, deflect or have an outburst that would stop the conversation in its tracks. It was too painful to comprehend – my parents not being here or that my life would be dedicated to taking care of Paul. I couldn’t imagine it. I didn’t want to imagine it.

That day in intensive care when I agreed to end my mother’s life support, I took Paul to Tim Horton’s. Over a coffee, I explained that our mom was going to die. He reacted like his favourite donut was being discontinued. That sucks but oh well. I knew it was because it was unimaginable. Every flutter of her eyelid or deep breath was a sign to him that she would wake up soon. The overwhelm of his vulnerability without his parents and in the hands of his sister was incomprehensible to him. That was understandable. It was incomprehensible to me too.

We ended life support and our mother died quietly and peacefully.

It didn’t take too long before I realized there was no way I was going to be able to have any kind of life of my own without help. A good friend who was very familiar with our family and social services called me and said, “Here is the phone number of a wonderful worker, call her and hire her right now. Take as many hours a week that she has to give you and pay her well.” I did just that. Shelagh is still an important part of our life today; she has been a lifeline and has stopped me from drowning as a caregiver. The weekends she comes, my husband and I enjoy going on day trips, our outdoor hobbies and, most importantly, each other’s company.

Realizing that we needed more help, I began to explore what was available to us from social services. I spent hours in social services offices and on the phone with them but kept hitting brick wall after brick wall. I couldn’t believe or accept that this was true: there was no support forthcoming. How was it possible that Paul, basically totally alone in the world, was left unsupported? The message was that I was to carry on as my parents had and provide care to him on my own. I ended up leaving my very good government job and staying home to support Paul.

It infuriated me that I was being forced into this life and so I began waging war on the local social services office. I generated bad press for them, demanded to work with better staff, went to my MPP with complaints and made it my full-time job to ensure they knew they messed with the wrong sister. In the end, all that effort and extreme stress amounted to very little.
I THINK I HAVE SURROUNDED MYSELF WITH PEOPLE WHO GENUINELY CARE AND WANT THE BEST FOR US. THESE PEOPLE HAVE A LOT OF INSIGHT THAT IS SOMETIMES HARD FOR ME TO HEAR BUT OFTEN THEY CAN SEE MORE CLEARLY THAN I CAN.

After almost four years and Paul going through a near-devastating health crisis, we finally did get more support at home. Now we have a team of good people in Paul’s life. This team includes Supported Independent Living workers, an Independent Facilitator and Personal Support Workers. Some are publicly funded and some we pay for out of pocket. What this means for me is that I can finally let go and reclaim my life. Only now the stranglehold of my role as caregiver is so strong that letting go requires considerable effort. I am trying. I often wonder how I got here. How is it that my life has changed to revolve around my brother?

I am working to refocus my career, to visit long-neglected friends and, most of all, to go on trips with my husband where we can be together like we used to, just the two of us.

This has been a difficult, long and life-changing journey. Along this journey, I have tried to be open to what others tell me they see. I think I have surrounded myself with people who genuinely care and want the best for us. These people have a lot of insight that is sometimes hard for me to hear but often they can see more clearly than I can.

So, I listen and try to grow from what they offer.

On the other side of that coin, I have shed, sometimes cruelly, others. I have not had time for people who hold different values around disability and family. Institutionalization is not an option for us. Proposing it slams the door on the relationship.

In retrospect, the energy spent on pushing the mountain of social services was a wasted effort. The time would have been better spent on myself, soothing my own grief and navigating my own difficulties. There is no money. There are thousands of stories harder than mine. They don’t care and they won’t help.

Finally, I have carved out some space to take care of myself. It sounds like a cliché – and I really got tired of people telling me to take a bubble bath – but there is an element of truth to that advice. Taking time to heal my own grief and to experience joy in my own life has been very important and has not been done well. Today I am endeavouring, with the help of some trusted allies and friends, to loosen my grip on my role as caregiver and refocus my attention on my own life.
ERIC AND SARAH

Unleashing Potential

One day my mother called me while I was at work. She was in tears. She said she couldn’t do it anymore. She couldn’t continue to provide the care that Sarah needed and Sarah had to move out.

The phone call made real what I knew was taking place at home but had chosen to ignore. My family was letting their lives happen by default and they had no plan for Sarah’s future.

My sister, now a 35-year-old woman, had been living in my parents’ basement with nothing to do since leaving school at 21. Over time I had separated myself from my family’s situation because I was stuck in the middle and I didn’t know how to cope or contribute.

AS A SIBLING I SEE THE INCREDIBLE CAPABILITY MY SISTER HAS THAT OTHERS DON’T SEE OR THEY HAVEN’T BEEN ABLE TO SEE. IT IS A PRIVILEGE FOR ME TO HELP MY SISTER REALIZE HER CAPABILITY.

I could understand my mother’s perspective. She and my father are aging, and the physical care they provide my sister was taking its toll. I could see how being a caregiver for 35 years would be difficult. There was also an emotional toll from ongoing conflict. My parents wanted to keep Sarah safe and so they held back from trying anything new. They feared making a bad decision. My parents still treated Sarah like a little girl but Sarah wanted to be treated like the 35-year-old woman that she was. I could also understand my sister’s perspective: she felt she wasn’t being listened to and wanted to be her own person.
I needed to decide. I could either continue on my own path of not being involved or I could take an active role in supporting my family.

After the call from my mother I spent a lot of time reflecting. I realized that my family couldn’t move forward on their own. I felt a strong pull to be with them and to help them. At the same time, there were a number of things in my own life that gave me pause to think. Until then I had been focused on a career in top-level management, financial gain and climbing the corporate ladder. But I wondered why I was so focused on accumulating wealth doing something I didn’t really care about. I thought about how I only have so much energy to give and so much time on this planet. What is the impact I want to make? I realized I wasn’t happy and I wanted more from my life. So, I left my job and moved close to home.

Despite Sarah wanting to be in a home of her own, the jump from living with my parents to living on her own was too big a leap. We agreed that my sister would come to live with me for a two-year period.

A lot of work went into preparing for her to move in with me. It didn’t take long after moving in, however, that Sarah started to experience tremendous growth. With the help of support workers, she had created a daily routine that she controlled and enjoyed. There was also enormous growth for me and I had the opportunity to grow much closer to my sister. Although living together has been incredible, it has also been incredibly challenging.

My sister, my mom and I have a long history of knowing exactly how to push one another’s buttons. There have been some challenges in terms of boundary setting and understanding personal space. My parents have done everything for Sarah and my mom’s identity has become tied to my sister. Even though Sarah had moved in with me, my mother still wants to do everything and often comes over uninvited. I have had to have some tough conversations with her about being a visitor to our place. As with any other visitor, the expectation is that you would knock on the door, wait for an invitation to open the fridge or not just start cleaning up the house. So there has been a learning curve for everyone in that respect.

I have had to focus on being mindful and controlling my emotions. I think I have learned to be calmer and maintain a peaceful presence with both my sister and mom. An important part of my agreement with Sarah about living together is that we build a team of workers to support Sarah in her day. Just getting used to people coming in and out of my home, while it seems small, has been a huge adjustment for me too.

On top of all the change at home, I have slowly shifted my career focus towards more heart-centred work. I thought about how I could use my skill set and experience to help other families in similar situations. I have built a coaching practice working one-on-one with families and, in March 2017, I launched the Empowering Ability podcast. For my podcast I interview guests from around the world who are experts on disability to share insights and practices to help families create the lives they want. I have also joined...
forces with Helen Ries and Becky Rossi to co-found The Sibling Collaborative.

As a sibling I see the incredible capability my sister has that others either don’t see or haven’t been able to see. It is a privilege for me to help my sister realize her capability. She has gone from living at mom’s four-seasons, full-service resort to becoming a contributing adult room-mate.

Nonetheless, I have found the balance of supporting her growth difficult. It has been really hard to know how much I can ask of her before she becomes overwhelmed. Just last week Sarah became overwhelmed and decided to move back in with my parents. She also cancelled all her supports. Although she realizes she has made a mistake and has asked to move back in, it is our agreement that for her to live with me she needs to have supports.

I continue to be supportive of my sister and my family. I am letting her make her own decisions and I am finding the right balance of not trying to save her from these. I approach even our difficult and challenging decisions with loving presence.

My home life is finding a new pace right now. I am still acting as a facilitator to my family while being careful to not become immersed in their challenges. I have relied on some key strategies on my journey with my family. I have built and maintained a meditation practice that has paid big dividends. It has helped me to control how I react to challenging situations, maintain a calm composure and show up with a loving presence.

Another strategy for our family has been to create a vision for the different areas of our lives. The vision, such as Sarah moving to a home of her own, acts as a map and we need that map to help us move in the direction that we want to go. The work and time we spent on the vision has been instrumental.

Over the past three years, with the assistance of a facilitator, we have built a support circle with my sister. The support circle has been there holding consistent conversations about moving forward and helping us proceed with ideas. The number of people in that support circle has shifted over time but the five to eight individuals have been helpful to gain outside perspectives. In particular, it has been helpful for my mom to hear the perspectives of people she respects.

Sometimes I hear from people that I am such an amazing brother and am doing incredible things for my sister. I understand why people say that and while I know they are trying to be kind it is still hard to take. I am not doing these things to be a good person... I do these things because Sarah is my sister and I care deeply about her. If I didn’t take this action she would be stuck in my parent’s basement. I am sure others would make the same decision about their family members. The decision is humanitarian - Sarah was being oppressed by our family (me included) and she deserved the opportunity to have choice and control in her life. She has taken the opportunity and she has started to fly.
ACKNOWLEDGEMENTS

Writing these stories was much harder than I anticipated and more rewarding than I could have ever imagined.

A heartfelt thank you to the siblings who told your stories and allowed them to be part of this e-book. It was an honour and a privilege to sit with you, hear your stories and attempt to write them in a way that would do justice to your pain, love, compassion and care. Your stories have touched me deeply and made me feel like I have great company on this journey. I am sure that others will feel the same way too. Thank you for your bravery and your willingness to share.

A special thanks to Charles Gordon for supporting me to write. Thank you for your generous feedback and encouragement, not only for this project but at other times as well. Thank you.

Also thank you to Becky Rossi for your eagle eye and your great sense of professionalism.

Visit our resources page to find out how the sibling collaborative can support you on your journey.
THE SIBLING COLLABORATIVE
COMMUNITY FUND

If you believe in the importance of connecting siblings and strengthening families, please consider supporting our work by donating to The Sibling Collaborative Community Fund.

The Sibling Collaborative Community Fund is the fundraising arm of The Sibling Collaborative. Our community fund will support new initiatives and special projects in collaboration with government, charities or non-profit organizations.

In return for your donation of more than $20, you will receive a receipt for tax purposes.

Donate online

Or if you would like to donate by cheque, please make it payable to the Ottawa Community Foundation and specify “The Sibling Collaborative Community Fund” as the beneficiary on your cheque.

Cheques can be mailed to:

Ottawa Community Foundation
301-75 Albert Street
Ottawa, ON, K1P 5E7