

HUMA: Regarding Decision-Making Abuse and its Impact on Quality of Life.

By Jen Romnes

It's my hope that sharing my family's story will help protect families from abuse in Canada.

Choice is critical with regard to powers of attorney. Powers of attorneys are supposed to be enact your life choices. But what if a power of attorney acts against your expressed wishes and best interests? Denies you of medical care? Tramples your rights? Causes a premature death?



Choice is absent with next to no protections for several populations of citizens who live with downright coercion. Those at heightened risk are the elderly, those with disability and people who have diseases like my mother.

My family's experience illustrates that Canada lacks meaningful checks and balances to prevent decision-making abuse to the point that decisions were made that were contrary to Ontario's Bill of Rights for Residents in Long-Term care.

Photo: Jen with her mother, Darlene, in 2004. Remember Darlene 1957-2012

My family has the first discovered gene mutation that causes Early Onset Alzheimer's Disease. APP is a very rare inheritable gene mutation. Researchers for Alzheimer's seek out families like mine.

Having so many family members get sick and die from this disease provides a homogenous study group for decision-making too. So far, in my mothers generation, three members have become symptomatic or died from the deadly gene directly inherited from my grandmother. In the last 10 years, four family members have succumbed to early-onset Alzheimer's. Of those, **all four of my family members were abused by their decision-makers.**

Four out of four were coerced into actions against their best interests by their decision-makers. They were:

- isolated from visits and support from their loved ones by their decision-makers
- drained of their finances by their decision-makers
- had negative health impacts caused directly by their decision-makers

The women in my family didn't start out downtrodden. My grandmother and her sisters had post-secondary educations. I came from a family where the women had professions, not just jobs. But they were made vulnerable by a disease.

Abuse is a lot like Alzheimer's. It begins slowly and builds over time. Under their abuser's influence, the smart, beautiful women in my family became conditioned over time until they were so brow beaten by their abusers, and so confused by their disease, that they—the VICTIMS—were unable to protect themselves.

This includes signing forms that weren't in their best interests - which is terrifying because now there are forms for doctor assisted death. Regarding my family, as a granddaughter, I wasn't privy to the nuts and bolts of how my grandmother's life fell apart once she had her diagnosis of Alzheimer's. But I did have an active role in what happened to one of my aunts and my mother. My aunt lived in Ottawa, and my mother's story unfolded in the GTA surrounding Brampton.

My aunt was the first person in my family to go missing in 2007. She had been isolated from her family by a live-in boyfriend. During that time, the common-law boyfriend cashed her cheques, sold her art, and kept her money for himself. The police didn't help my cousins find her. While locked away, she wrote letters to her loved ones that never got mailed. The letters expressed my aunt yearning to see us. After nine months of captivity, my aunt broke the locks on the outside of her bedroom door, and fled to a nearby church for help.

During those nine months, she had become malnourished, she'd lost nearly half her body weight, and her corpulent frame had withered to around 100 pounds. She was so malnourished she was losing her hair and her teeth had become loose. When she was reunited with my cousins, they found that my aunt's short-term memory was shot.

A year later, in 2008, I started noticing small lapses of memory with my mother. She wasn't able to work. That's also when Mom told me that my father, her common-law spouse was locking her within her bedroom. Mom had to ring a bell if she wanted the door to be unlocked to use the washroom or get something to eat or drink.

My mom and I were close, and because of what had recently happened to my aunt I was scared for my mother's safety. In a letter Mom wrote to my cousin about me, she wrote: "I love my daughter very much and I would go to the ends of the earth for her."

Sadly, my father followed my aunt's abuse template, by preventing mom from visiting with me and my young daughters. My mother's isolation was gutting for me. It took dogged planning and determination to see my mother. Although outsmarting my father so that I could visit my mother was hard, the effort was worth it because my daughters loved their grandmother, and it was critical for us to get together to create memories.

By then, most of my parents large assets including several properties boughten over their decades together, had been sold, and Mom told me that my father had kept all the money for himself.

Although Mom made less earnings than my father, he kept her broke by taking her earnings and never allowing Mom to have money of her own. Keeping her broke meant she'd never have the

means to leave him. She'd never have enough funds to support herself or to hire a lawyer to fight for her share of the assets.

My terror grew when the pattern of my aunt's abuse continued with my mom. Each contact with my mother was becoming more difficult because my father had banned her from using email. In a letter sent by post, Mom wrote to me: "If you write I'm off the internet now, so I'm writing you by snail mail."

It's a testament to Mom's character that while she lived with grinding fear, she tried to lessen the hurt from the loss of email with something adding a moderately positive passage to that letter: "This is a control thing with your father. But now he can't monitor what I'm writing to you."

As could be predicted, my father completed his isolation of my mother by banning her from the phone and post. They had moved into a gated condo, which meant I couldn't even reach my mother by knocking on their door.

It took one more year—until July 2009—for my worst fears to be realized: My mother was missing.

Just like my cousins, I couldn't find her. When I went to the police, they wouldn't help because to them, she wasn't a missing person. My father knew exactly where she was and wanted to keep her and his own secrets hidden. I'd phoned a list of institutions in the Brampton area, but Mom wasn't there. She didn't appear to be anywhere.

Although our family could scarcely afford it, I sacrificed several unpaid work days so I could travel from London, Ontario where I lived to Brampton and the GTA to search for my mother. Privacy law was a huge hurdle. I didn't expect to find my mother in another far away town in the Caledon Hills, locked in a derelict institution.

Once Mom was in long-term care, her abuse became worse, which shows the systemic problem that needs to be fixed.

I allege that my father dumped her there the first chance he got — Mom was 52 years old and still had her wits about her, and was dreadfully unhappy about the conditions in which she was expected to live. My father had enacted my mother's powers of attorney, and Mom's healthcare team refused change my father's orders to reflect my mother's wishes.

Just like at home, Mom had no access to a telephone or means to mail me through the post in this subpar facility. Even if she could get out of the locked-down ward, she wouldn't get far without her ID and money. Issues with this particular long-term care home was on the government's radar, and shortly after Mom was there, a resident leapt from a third storey window to her death. This place remains open to this day.

Ontario has passed a Bill of Rights for Residents in Long Term Care in 1987. A copy of it is supposed to be displayed within the each and every facility, and by law, staff are supposed to be educated about it. But that was not so at this facility. And many other well-run facilities that my mother was moved through during the last years of her life. The problems are systemic.

In my mother's case, nearly each and every Right was trampled, however, I will focus on six Rights that were the most egregious to her quality of life.

The first Right is NO ABUSE, including financial and emotional. "Every resident has the right to be protected from abuse."

When Mom was first moved into long-term care, she had none of her mid-upper class affluent belongings with her. No evidence of the proceeds of the sales of three properties. No access to her three decades of contributions. Even I, a person who knew the depths to which my father could sink, was shocked by how thoroughly he swindled her assets and cash. When the Ontario Public Guardian and Trustee took over Mom's finances this is what was discovered:

Mom's Ontario Public Guardian & Trustee cash balance was \$4,593.72

Her income was \$400 from Ontario Disability. Since Mom was young—only in her early 50s—she was ineligible for Old Age Security.

Her expenses for a basic room in long-term care was over \$1,800 per month. Mom couldn't afford to see the dentist. Get foot care. Purchase a walker or any "frill" above the basic life necessities provided by the long-term care facility.

My father had not and refused to pay spousal support. Instead, my father used my mother's own assets to pay for legal expertise that helped him to keep my mother's money for himself.

Mom did have a small locked in savings account — the only kind of account my father couldn't loot.

But that "bonus" was offset by a CRA income tax debt of over \$1,700. In case you're wondering, my father's taxes were paid in full.

You can see that mom's expenses to live were well outpacing her means to pay them.

I know it sounds like I'm harping on money, but financial abuse the easiest to understand and prove. I was never after my mother's money. In fact, I had many cheques, gifts from her that I never cashed because I knew how poor my father kept my mother.

This leads us to another Right: Going outside "Every resident has the right to be given access to protected outdoor areas in order to enjoy outdoor activity unless the physical setting makes this impossible."

This was a critical point for mom: Locked down dementia wards, especially the subpar one that Mom was imprisoned in, was not an appropriate place to bring children. Many wards have set age limits at 13 years and older, and my daughters were 3 and 5 at this time.

There was a nearby park that mom was denied to go to so that she could see her granddaughters. She was denied the simple pleasure of joining us at McDonalds for an ice cream. Mom was able-bodied and allowed to leave the facility with my father whenever he wanted. Mom was well enough to go to Casinos with him, so there was no safety issue. This double standard upset mom greatly.

My mother's enduring emotional abuse is linked to this next right: Participation in decisions: "Every resident has the right to have his or her participation in decision-making respected."

The fact that my father overrode my mother's wishes was documented early, in August of 2009, in writing from a government capacity assessor, but nothing was done about lessening the abuse of this right. Here's an excerpt from my mother's capacity report.

"Ms. D's nursing home reinforced the rules which her husband set up for her without any consideration about her wishes. The rules reinforced by the nursing home were related to Ms. D's access to her only daughter Jennifer and her grandchildren. With limited exposure to her daughter whom Ms. D trusts and loves she has become even more vulnerable and unwilling to ask her husband about her own money. Ms. D's stress and isolation contributed to her further cognitive decline and confusion."

Let that report sink in. Her violated rights are pretty clear, aren't they?

In August 2009, I allied myself with the Public Guardian Investigator, Jim MacKenzie. He intervened with the nursing home and somehow persuaded them into allowing my mother to go outdoors for an visit to the nearby park. I have photos showing mom frolicking with my daughters in her rightful role as grandmother. However, this triumph was short lived. The next visit, the administrator quashed Mom's rights again and forbade Mom from going outdoors. It was then that Mr. MacKenzie suggested that Mom revoke her powers of attorney in an attempt to end my father's abusive control of her.

This brings us to the next Right: Communicate and visit in private. "Every resident has the right to communicate in confidence, receive visitors of his or her choice and consult in private with any person without interference.

At that Nursing home, the administrator, "Ms. Gird" was downright hostile when Mom tried to meet with long-term friends of the family, Leo and Eric, who were supposed to meet Mom in the vacant dining room—the only private room the Nursing home had to offer.

To illustrate this right being broken, I'll read a passage from my book, ***Entangled 1: Caught between Choices***

While Mom, my daughter and I watched and waited for Leo and Eric to arrive, I explained to Mom that the first step to release her from Dan [my father's] control was to revoke her existing powers of attorney. Next, Mom required a formal capacity assessment to determine her true mental state, which wouldn't be done as long as Dan was in charge of Mom's healthcare choices.

Within a half hour, Leo and Eric arrived. While we made small talk, the forms for the revocations of the powers of attorney sat unsigned on the table before us.

Suddenly, the doors of the dining room flew open, and in barged Ms. Gird. Mom stiffened reflexively at the sight of her.

When Ms. Gird spied Leo and Eric, she bellowed, "Who are you?"

Leo knew that by law, Mom was allowed to visit with whomever she wished so she answered calmly, "We are friends of the family." While gesturing to Mom, she added, "We have known each other for decades, since Owen Sound."

Ironically, by this time, Ms. Gird had only known Dan for mere months. But it was Dan whom Ms. Gird obeyed. She looked diabolical as she charged toward the table where the unsigned papers were in view. Recognizing what they were, she turned to me and snarled, “If you don’t stop, I’m going to call the police.”

While rising to her ante, I replied, I would welcome that. Ask the police to bring their domestic abuse file as well.” The situation was spiralling out of control. Mom was supposed to be able to consult in private without interference, so I jumped to my feet and raced toward the window to access cell reception—my link to the Public Guardian, who I knew could protect my mother and me.

Eric piped up, “Why would you be so confrontational in front of Darlene and the baby? Couldn’t you just talk to someone to straighten this all out? Both he and Leo were educated people who weren’t used to such blatant thuggery.

“This doesn’t involve you,” Ms. Gird hissed. “You only know Jen’s side of the story.”

“Have you heard Jen’s side?” Leo asked. Jen’s calling the Public Guardian now. I urge you to talk with them.”

Ms. Gird declared, “Nobody here is going to take that call. Darlene is unfit to be filling out such forms.”

Flatly, I corrected Ms. Gird, “That’s for a capacity assessor to decide.”

End of passage

The end result was Mom signed both revocations for her power of attorney for assets, and power of attorney for personal care. However, the revocations were only halfway successful. The Public Guardian & Trustee took over Mom’s finances — which is what we wanted. But the revocation was unsuccessful to protect my mother from the tyranny of my father’s personal care decisions. Substitute decision-making law kicked in, and he outranked me as a common-law spouse verses biological kin.

Soon after the revocations, my father began a sick shell game. When I would make progress negotiating for mom’s rights with one institution, he would move Mom and not tell me where she was. That resulted in lost time looking for her, plus wasted time with new negotiations with a different administrator who was intent on obeying my father’s orders. Mom was moved eight times between four institutions in two years.

In December 2009, Mom was moved to Brampton Civic Hospitals’ Adult Mental Critical Care Unit. Brampton Civic banned me from taking mom out of the unit for 10 months. My father could take her anywhere he wanted, so it wasn’t a safety issue. It was another example of the healthcare team dismissing what my Mom wanted, and following my father’s perverse orders. Children under the age of 13 were not allowed in the unit. During those ten months, Mom’s mental Health and capacity deteriorated to the point that she could no longer speak. Resulting in losses that we would never recover from. Mom lost her chance to create new powers of attorney AND they robbed my mother of her last chance forming lasting good memories of with her granddaughters.

This was inexcusable. They allowed my father’s abuse to taint another generation.

At this point, I was stressed out of my mind. I was witnessing my mother deteriorate before my eyes. I negotiated hard for my kids to see her. Although I persuaded a visit, Mom’s healthcare team continued to withhold my mother’s medical information. This was particularly scary because they hinted that my mother’s condition was genetic, but were forbidden by my father to

provide me with the key information I required to seek my own healthcare: I was terrified for my health and the health of my daughters.

Just read their response to me being denied of information that my mother wanted me to have: “We are unable to share personal information about your mother unless authorized to do so by her substitute decision-maker.” Somehow they expected me—a layperson—to be able to visit with my mother and deduce this critical medical information with my naked eye.

I sensed that time was of the essence. The slow grind of court action began. I believe that my father had knowledge that my mother was drawing close to death. Her death would result in all of his legal and financial problems going away. His twofold tactic to avoid a resolution in my mother’s favour was to delay court action and continue to keep Mom in situations that negatively impacted her mental health, therefore speeding her decline.

That’s when these next two Resident Rights, and the denial of them kicked into play.

Firstly, visitors during critical illness: “Every resident has the right to have family and friends present 24 hours per day.”

Meanwhile, My father insisted that I had to prearrange short visits during a prescribed time set by him to see my mother.

And the final Right: Designated contact person. “Every resident has the right to designate a person to receive information concerning any transfer or any hospitalization of the resident and to have that person receive that information immediately.”

You already know about my father’s sick shell game. But by 2011, it had reached a critical point. Mom’s health was failing and my father was setting me up for this one last inhumane act. Which I’ll read to you from this passage in my book, ***Entangled 2, Betrayed from Within***.

By the time I read Dan’s instructions in the event of Mom’s death, I was dumbfounded. I had anticipated Mom’s organ donation forms. But the depths of Dan’s inhumane torture was in those forms: Mom’s healthcare team *could not* notify me of a change in Mom’s health or even if she died. That meant I would have shown up at their facility, blissfully unaware, only to be sent on another search for Mom, blinded by Privacy Law.

By the time I could have pieced together that Mom had in fact died, her remains would be long gone from the morgue. There would be nothing left for her loved ones to bid farewell to or get closure from. Mom’s wish to be buried in her family plot would be nearly impossible to grant. My future would be haunted by the pain of wondering if Mom suffered during her last hours. Or if she died alone. There would have been no autopsy. No DNA. Dan’s cruelty was beyond disturbing.

My anger ran so deep I could feel the tips of my ears burning. I had not doubt that these women [Mom’s healthcare team] would have followed Dan’s directions *to the word*.

End of passage.

That passage should make Canadians feel uncomfortable. As a reminder, this happened to Mom between the years of 2009-2011 in Canada, not some third-world country.

To recap, my mother's and aunt's decision-makers had kept them from their loved ones when they needed us the most, drained their finances, hurt their health, and were now in charge of their end-of-life decisions. Those spouses were motivated to be rid of my aunt and mother. It's not a stretch to say if euthanasia was available in 2009, they would have been gunning for it.

Once it was clear that my aunt and mom's rights were not going to be protected within these institutions, the route to protect them was expensive and time consuming court action.

In my aunt's case, the police refused to press charges against my aunts common-law spouse. That left my cousins no option but to get a restraining order against him. He didn't contest when my cousins filed a separation so he was no longer her common-law spouse, so that they could take over my aunt's decision-making.

I wasn't so lucky. I tried to negotiate, mediate but those avenues were shut down by my father, who refused to participate.

I had to pursue court. Since Mom had in fact revoked her powers of attorney, and my father was only her Substitute decision-maker by default. Instead of being trapped by the slow mechanisms of Ontario Supreme Court, I was able to trigger a hearing with Ontario's unique Consent and Capacity Board.

At that hearing, I was advised by my mother's own lawyer, assigned by legal aid, to cancel the hearing. He assured me that abuse was really hard to prove, and had no confidence in my ability to do so. To them, I didn't stand a chance. I was too broke from earlier lawyer fees plus time away from my work to afford to pay for counsel to protect me. However, my father had plenty of money to hire a top law firm to fight for him. The odds were against me.

The experience of the hearing was downright awful. The time, money and energy I had spent merely defending my mother's rights over the two prior years had already hurt my work and health. This hearing was my last ditch effort to protect my mother before she died. Although my mother and I were the victims, I was attacked once more as my father's lawyer ruthlessly pursued any and every unflattering event in my life.

It was surreal to be at the hearing, with my father's lawyer trying to pin the blame for this situation on me. Because my father had gotten away with so many abusive acts in the past, he believed he was entitled to treat my mother and me this way. He was so confident, that even under his lawyers strict guidance and correspondence, my father couldn't help but reveal some of his true attitudes about me and my mother.

Just read his email: "Because of you, your mother does not eat or shower. They [mom's healthcare team] tie her to the bed with the restraints and she lies there in her piss and shit, unable to speak. The next day, after seeing my lawyer because of you, I pull the balls of shit from the hairs of her ass and change her diaper. If you had not revoked my powers of attorneys, I would not have to see my lawyer and your mother would have better care."

It's almost laughable when he begrudges the Public Guardians fee when he has already stolen 98% of mom's assets. It's an accusatory email, and his derogatory tone about about my beautiful mother is shocking.

The hardest part about the hearing was my father's assertions that my testimony couldn't be trusted because I had inherited the same early-onset Alzheimer's gene that my mother had. That mind thuggery had worked so successfully for him before. If your victim is fighting back, infer that they are mentally impaired, and then your word will overpower theirs.

Now for some much needed uplift.

I won the hearing. I was finally able to reunite Mom with her beloved granddaughters. My youngest wasn't phased by Mom's illness, in part because she was too young to have memories of her when she was well. My eldest daughter did remember when Mom was healthy, and seeing the changes caused by the disease all at once—not gradually as the disease progressed—scared her. I have no doubt that my mother knew what was going on, and her actions after the hearing changed the attitudes of her healthcare team.

In closing, the worst part of my family's journey was that my mother and aunt were aware of their abuse, but powerless to stop it. Because they had a capacity-robbing disease, their claims of abuse were drowned out by their spouses assertions. These same spouses consistently made decisions for them that weren't their choices, and although my cousins and I were screaming about the mistreatment of our mothers from the sidelines, not one person in authority stopped the abuse.

The end result was that the men essentially got away with it. My cousins were successful in getting a restraining order against my aunt's spouse. But he got away with liquidating my aunts assets, so my cousins were only able to retrieve a few mementoes from their mother's apartment after her escape.

In my mother's case, she died penniless. While alive she couldn't afford the additional life-sustaining care she needed, while my father hoarded all their assets and lived like a king. She died before her date at Ontario Supreme Court to rectify her finances. And although she had nulled her powers of attorney, she hadn't attended to her will. An old will had listed my father as the executor. Although I had successfully won the right to care for her during her last year of life, this legal protection stopped with her final breath. After her death, her wish to donate organs and have her cremains added to her family plot was sabotaged by my father. The system failed her yet again.

I'm passionate about protecting vulnerable people from abuse because supposed protections of my mother's and aunt's rights failed miserably. Our system is skewed to keep the status quo, which for our family meant that it helped keep abusive men in control over my loved ones who inherited the early-onset Alzheimer's gene. It was a double tragedy they shouldn't have had to bear.

It took all the strength I could muster to ward off my father's abuse. But the systemic acceptance of my father's abuse meant that my mother remained his victim with only one year of respite during her whole adult life. More grievously, I was unable to prevent my father's abuse from negatively impacting my young daughters.

My mother and aunt didn't choose to be robbed. They didn't choose to be locked up and mistreated. They didn't choose solitary confinement, away from their families. And they wouldn't

have chosen to be euthanized. Canada desperately needs new laws and regulations to protect choice, rights, and quality of life.

My mother's and aunt's quality of lives were diminished greatly by their decision-makers. The US is a bit ahead of Canada by passing Visitation Laws that prevent decision-makers from allowing family members and loved ones from being with their dying loved one. This scenario is most common with divorced families where the newly-married spouse denies the children of prior marriages from a relationship with their parent.

Currently, Canada lacks mechanisms to protect basic rights. It's an absurd frontier, where vulnerable victims are expected to self-propel their own justice through court actions—which simply won't happen as they are weakened toward the end of life. The fact that those in authority in Canada didn't stop the abuse that happened to my mother during her last three years of life created a taxpayer burden that conservatively exceeded \$300,000. This fee includes court costs, lawyers fees, Public Guardian involvement, and languishing in Brampton Civic Hospital for 10 months. It would have been cheaper—and more humane—to have just honoured my mother's decisions.

My final point is this: Canada needs to bolster and add protections to protect the quality of life for the elderly, the disabled and people who have capacity robbing diseases, like my beloved mother.