

# visions

Vol. 15 No. 1 2019

## supporting adult children

helping them find their way

got boundaries? why, how  
and when to use them



## visions

Published quarterly, *Visions* is a national award-winning journal that provides a forum for the voices of people experiencing a mental health or substance use problem, their family and friends, and service providers in BC. It creates a place where many perspectives on mental health and substance use issues can be heard. *Visions* is produced by the BC Partners for Mental Health and Substance Use Information and funded by BC Mental Health and Substance Use Services, a program of the Provincial Health Services Authority.

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In *Visions Journal*, 2017, 13 (1), p. 4, Sarah Hamid-Balma declared, “I’m sick of stigma.” I am too. I am sick of not just the stigma people who self-identify as having substance-related troubles face from others, but also the stigma people can face within their own “Recovery” communities. I proudly do work for three different abstinence-based Recovery programs. I am not, however, writing about how amazing sobriety is, or how “Recovery works!” I am instead writing about stigmatizing abstinence-based subcultures.

I frequently encounter people being treated with medications like suboxone who are pressured to discontinue it. People in long-term recovery have tremendously valuable lived experience—but sponsors are not doctors. I know people taking these medicines who have careers, families, and who would be otherwise happy if not arbitrarily told they are “still using.”

People looking to re-negotiate their relationship with a substance should be able to meet honest, non-judgmental information brokers that will guide them through a diverse menu of recovery options. Unfortunately, it is more common to encounter dogmatic and stigmatizing individuals who feel their path usurps other “easier, softer ways.” It is important that all of us respect the autonomy, rights, and humanity of all others and their paths. “Recovery” and “abstinence” are up to each individual to define for themselves.

—James Fraser, Victoria

## editor’s message

A few years ago, *Visions* devoted a family-themed issue to “Couples.” It was an incredibly popular issue because it focused on an often-overlooked area where mental health and substance use intersect with family life. I have no doubt this issue on “Supporting Adult Children” will be similarly popular. I even had a waitlist of potential contributors. The contributors I could squeeze in, you’ll see, are pretty diverse: you will meet single parents, step-parents, rural and urban parents, mothers and fathers, parents of young adults and others approaching middle age, those who welcomed help and those who refused. And you’ll hear from families living through a range of challenges from psychosis and anxiety to addiction and anorexia.

Even when mental ill-health and substance use are not at play, parenting is hard. And it’s not over when your child reaches some magical legal age that defines adulthood. What really struck me when I read all the submissions is how invariably the stories started—and, of course, really *must* start—when the adult child is, well, not an adult. I know first-hand that the vast majority of adults with mental health and substance use problems don’t develop these conditions as adults and, yet, the cumulative impact of reading these trajectories and transitions is still pretty stunning. You will see how the stories take shape over years and how things like information-sharing, boundaries, help-seeking and communication change—sometimes in healthy ways, sometimes in frustrating ways, sometimes in both ways at the same time. And if anyone has any doubts about the power of early intervention (or the power of family support, for that matter), this issue will put those doubts to rest.

Families worry. That’s another theme that hit me. They love, care and show concern. They try to fight and plan for what might help, they advocate and coordinate. They trust and hope, but they also fret and fear, too. They hold on. They try to alleviate suffering. They learn to accept and to let go (a bit). They make mistakes. But above all, they hope for good things. As Rebecca from Planned Lifetime Advocacy Network puts it so simply, parents want their children to have a “good life.” Yet parents of adult children are also exhausted: emotionally, physically and financially. They carry a large burden of support and need support from service systems and society, in turn. And, every now and then, they need our most sincere thanks.

Sarah Hamid-Balma

*Sarah is Visions Editor and Director of Mental Health Promotion at the Canadian Mental Health Association’s BC Division*

# Such a Long Journey

## WHEN OUR ADULT KIDS STILL NEED US

Holly Horwood

After years of our daughter's increasingly bizarre thought patterns, deteriorating cognitive abilities and mounting aggression, the news that our (then 16-year-old) child was likely suffering the symptoms of schizophrenia was almost a relief. At least we had a diagnosis and a medication plan. Our daughter is now 36, and the intervening years have taken an emotional, social and financial toll on the entire family.



*Holly volunteers with the BC Schizophrenia Society's Partnership Presentation team. As a family speaker, she gives educational talks to nursing and high-school students, police and community groups. Holly is also a member of the Family Advisory Committee (FAC) for Vancouver Coastal Health (Mental Health/Substance Use). She and her husband have two adult children; her eldest child has coped with schizophrenia from a very early age. Holly is a retired Vancouver news reporter*

Our marriage remained intact, but only due to my husband's keen sense of humour. I retired early in order to devote more time to our daughter, who suffered numerous repeated relapses, due primarily to her lack of insight into her own illness (a condition that has its own name—anosognosia, from the Greek, roughly translated as “without awareness of disease”). Over the years, we have used retirement funds to help pay for her apartment. Our son left home as quickly as he could after high school to escape the chaos and confusion.

Through it all, our family has stayed strong. Our resilience is a testimony to the age-old family instinct to protect, love and support even our most vulnerable members. It's a resilience built at great personal cost as family members search together for information and practical tools to help their loved one.

### Different supports for different needs

When a child requires acute care, finding support is crucial. The support needed depends on the illness or

disability, the kind of care required and the age of the child.

When our daughter was 19, I attended my first family support meeting with a mental health team in the Vancouver Coastal Health Region. By this point, our daughter had already been hospitalized three times with severe psychotic symptoms. Patients with schizophrenia occupy more hospital beds in Canada than those with any other single illness other than heart disease.<sup>1</sup> Schizophrenia affects one in 100 individuals worldwide.<sup>2</sup>

I will never forget the silver-haired couple in the support meeting, whose 50-year-old son also had schizophrenia. They listened while I unloaded years of parental stress. Every once in a while, they would murmur, “Yes, we’ve been through that. Yes, we know what you mean.” For the first time, I realized our family was not alone.

That was the start of my gradual acceptance of our daughter’s illness. Over the years, our empathy, tolerance and sense of connection with people living with all sorts of disabilities—not just severe mental illness—have grown. In unexpected ways, our daughter’s illness has increased our capacity to understand and respond to the pain of others.

There is a great thirst for this kind of support and education. In October 2017, a conference organized by mental health advocate and parent Susan Inman, titled “Bringing Cognitive Remediation to BC,” filled an auditorium at Vancouver General Hospital. In April 2019, nearly 200 people attended the 12th annual full-day family education conference sponsored by Vancouver Coastal Health’s Family Advisory Committee

(Mental Health/Substance Use) (FAC). The conference offered support and tools for families coping with addiction and serious mental illness.

### Confidentiality, information-sharing and your adult child

One of the challenges of caring for an adult child with a mental illness involves confidentiality and information-sharing. When our daughter was first hospitalized for psychotic symptoms at the age of 16, she was considered by the health care system to be a child. As her parents, we were asked for our opinions and a history of her symptoms. We were consulted on plans for her treatment.

All that changed when she turned 17. In BC, once a patient reaches 17, parents are not automatically included in health care plans—even if the individual is clearly ill and not able to make wise decisions for themselves. After she turned 17, each time our daughter relapsed, she became alienated from us (a common symptom of psychotic illnesses) and declined to allow medical teams to speak with us.

Over time, we’ve experienced five hospital systems and three community mental health teams within the Vancouver Coastal Health regional authority. Each has its own culture when it comes to information-sharing. The approach can vary from unit to unit, even from physician to physician.

Here are some guidelines for navigating the BC health care system’s information-sharing rules:

- Some health authorities (such as Vancouver Coastal Health) have a family involvement policy for

mental health and substance use that sets out standards for inclusion, information-sharing and support. Find out if your health authority has such a policy and become familiar with it. Don’t be afraid to bring it up with your loved one’s health team

- Under the BC Freedom of Information and Protection of Privacy Act, families can always give information. This can be valuable to clinicians, particularly in times of crisis. Your insight can help the health care team make the best care decisions possible
- The concept of continuity of care (in which families or someone acting as family plays an important role in the life of the patient) is important to clinical mental health practice in BC. Continuity of care permits an exchange of information between clinicians and families if health or safety is at risk, or if the exchange is perceived by the clinician to be in the client’s best interests. Consider how your involvement in continuity of care for your loved one might ensure an honest exchange of information

### Boundaries, responsibilities and independence over time

One of the trickiest challenges when we care for a loved one with a severe mental illness is determining how much to assist the individual in their personal struggle. Can we afford to keep giving—financially, emotionally, practically—as we (and they) get older? How do we modify boundaries as the individual’s needs and capabilities evolve over time? In the 23 years since our daughter became ill, I’ve learned that the answers to these questions are never clear or consistent.

At the 2019 FAC-sponsored family education conference in Vancouver, Frances Kenny, founder of Parents Forever, a support group for families coping with addiction, shared an excellent tool for setting and reviewing boundaries. With your loved one and other family members, make two lists that everyone can agree on: on the first list, record the things your loved one is responsible for and can control; on the second list, record the things that other family members are responsible for. Review this list on a regular basis.

In our case, our daughter has agreed that she can control how much she speaks to her “voices” when she is at our home for dinner, she can help with gardening at her condo, she can keep the cat odour in her unit to a minimum and she can maintain friendly relations with her neighbours. As her family, we can agree on how much to assist her financially and how much (often unwanted!) “advice” we give her. We can agree to regular, supportive contact through walks, healthy food delivery and phone chats.

### What do families need?

My husband and I will be forever grateful for the caring and knowledgeable case managers who took care of our profoundly ill daughter when she was in crisis, providing sound advice about caring for an adult child. I remember the wise words of one case manager, who made sure that I always asked hospital physicians for mandatory “extended-leave” treatment provisions on discharge.

Extended leave provisions under BC’s Mental Health Act allow for mandating medication and regular

I have accepted that our daughter will never be truly independent, but our role as parents is to support her so she can live as independent a life as possible and recognize when she may require more support than she usually does.

visits with a community psychiatrist. This is not always welcomed by the client, but these provisions have saved our daughter’s life. Because of her lack of insight into her own mental illness, our daughter has always relapsed when she was no longer on extended leave. This has led to her losing her job, starving herself and suffering psychotic delusions. Freedom to become psychotic is not real freedom in my opinion. Extended leave legislation gives our daughter the freedom to return to her life in the community with the provision of mandatory medication. She knows that if she does not take her medication, she faces the prospect of being returned to hospital.

Drawing on our experience, this is what I feel the health care system must offer BC families:

- the ability to empathize, listen and validate us as families that play a vital role in the care of our adult child
- the ability to balance the need for client confidentiality with the needs of the family to be included in diagnosis, treatment and discharge plans
- prompt, caring, effective action during a crisis. Obtaining effective medical help and diagnosis for an adult child in a timely manner is still very difficult, even though

the risks (to the well-being of the individual and the individual’s family) can be extreme

- access to evidence-based medical and psychosocial education. Families need guidance on available medical and social services, resources and peer and community support
- access to evidence-based rehabilitation services so that individuals can begin repairing any cognitive damage the illness has caused
- recognition that in some cases of profound psychosis, mandatory treatment—including medication—is required
- the inclusion of families and clients in policy and program planning

### Suggestions for caregivers across BC

I have accepted that our daughter will never be truly independent, but our role as parents is to support her so she can live as independent a life as possible and recognize when she may require more support than she usually does. It’s a challenging role, but there are several options available. If you are a caregiver, or if you would like more information, here are a few suggestions:

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# No Matter How Much We Love Them, We Can't Always Save Them

## BUT AS PARENTS, WE NEVER STOP TRYING

A mother

Like many parents in BC, I have a child who struggles with substance abuse. This means he could overdose and die anytime he relapses or uses drugs.

*The author is a member of From Grief to Action (FGTA), a provincial advocacy and support network for families affected by addiction*



Photo credit: Highwaystarz-Photography at ©iStockphoto.com

My son grew up in a loving home, ate healthy food, had a dog, took music lessons and played sports. He had good grades, a part-time job and a circle of friends. Overall, he was an average teen, with no abuse or trauma in his childhood.

Following a sports-related injury, he was prescribed Oxycodone. By 17, he was using heroin. By 19, he was living in Vancouver's Downtown Eastside, in trouble with the police for drug-related incidents. Now, at the age of 24 and after countless stints in detox, four recovery centres, a diagnosis of depression and social anxiety, years of counselling and family love and

support, he is back in treatment after a year-long relapse that almost killed him — and, frankly, me.

### The sobering facts of addiction in BC

In 2017, over 1,400 people died from drug overdose in BC. This number rose to 1,500 in 2018, three times higher than it was in 2015, the year my son started shooting heroin.<sup>1</sup> Many of the people he knew from that time have since died by overdose.

There are few publicly funded spaces in residential treatment centres; most of these are in the Lower Mainland. The wait for one of these spaces often



takes up to three months. Many parents (me included) have used all our savings to pay for non-publicly-funded treatment for our sons and daughters.

Since going into treatment at the age of 18, my son has been in programs with men much older than him, usually in their 30s to 50s. The only youth treatment centre in BC closed down before he aged out of it. He has been in treatment so many times from such a young age that he is losing his ability to socialize normally as a young adult. In many ways, the only similarities between my son and the other program participants is their addiction.

The youth residential treatment centre (still the only one in BC) has now re-opened in Keremeos, as Ashnola at The Crossing. We still desperately need more youth and young-adult publicly funded residential treatment programs that allow integration of the sexes and incorporate schooling and life and social skills. We need long-term treatment programs—from six months to a year—and we need treatment programs that address the unique needs of youth and young adults who identify as First Nations and as LGBTQ2S.

### When they reach out

If a youth or young adult asks for help, the window to respond is extremely small. Most residential treatment programs require a period of detoxification (or detox, during which the person abstains from substances for several days) before the program considers a person for treatment. Detox is extraordinarily difficult and can be very painful.

There are not enough detox beds available, however. Most people can't get a bed when they are ready for one. By the time a bed is available, if they have been off drugs for more than three days, they don't qualify for detox treatment. Or, if they are using stabilization drugs (like Suboxone) under a physician's care, they don't qualify for detox. Someone who requests detox may wait so long that they start to use again, or return to the streets.

Countless parents have detoxed our children at home—sometimes many times over—trying to keep them sober and alive long enough to be accepted for treatment. Residential treatment policies need to be more flexible, supporting people to enter treatment as soon as possible. Detox programs need to allow longer stays if no residential treatment beds are available. Discharging someone from a one-week detox program back onto the streets is a recipe for overdose.

### Challenges faced by parents and family

When I speak with other parents about their experiences, I hear about common challenges that prevented them from getting adequate care for their child early on.

#### 1. Treatment for substance use is currently voluntary

Under BC's Mental Health Act, if someone's mental health poses a potential danger to themselves or others, there are legal mechanisms to ensure the person receives treatment. We don't have the equivalent legislation for substance addiction. All substance-use treatment facilities in BC are voluntary.

This means that when you know that your teen or pre-teen is exhibiting the early stages of substance abuse and addiction, you cannot make them go to treatment. They have to want to go. In the case of my son, this meant that for the first two years, when opioid agonist therapies (OATs) such as Suboxone could have helped, I had no power to ensure he went into residential treatment, or got other supports to stabilize him enough to attend outpatient treatment, or to at least finish high school.

#### 2. Confidentiality and the rights of the child

In our current health care system, a 17-year-old's right to confidentiality trumps our right to know the details of our child's condition and treatment. In the case of my son, this meant that even though my son's counsellor and social worker both knew he was smoking heroin, no one told me because he didn't want me to know. I did not learn the truth for almost two years, when my son told me himself. By this time, he had graduated to shooting heroin. Had I known earlier, I could have found him appropriate supports.

#### 3. Confidentiality and the rights of the drug user

On many occasions, my son was MIA for weeks at a time ("missing in action," living on the streets and using drugs for days, sometimes weeks). I would search Vancouver's Downtown Eastside, leaving notes at injection sites and detox centres. Unfortunately, the confidentiality rules prevented youth drop-in centres, detox and treatment centres and prisons from telling me even if my son was not there. As a parent, I had no idea if

he was on the street or in a morgue. When my son is using, he frequently loses or sells his ID. If he had died in this state, there is a good chance that no one would have been able to identify his body or contact me as next of kin. We need to know if our kids are somewhere safe, or if people have seen them.

#### 4. The role of concurrent disorders

Our health care system has known for years of the link between mental health and addiction. People might self-medicate with drugs, or use drugs recreationally and trigger an underlying mental illness or create a new mental health condition. We need more supports for early detection and treatment of mental health conditions in young people. At the very least, an early assessment should happen as soon as a person is detoxed or accepted into a residential treatment program.

In the case of my son, chronic, debilitating depression and social anxiety resulted in off-the-rail relapses. Yet none of the recovery centres addressed this. In some cases, the treatment program even took him off his antidepressants. At no time has anyone crafted a plan to address the underlying mental health issues that are quite possibly the root cause of his addiction.

#### Supports for families

Some supports are available for families with a youth or young adult struggling with addiction in BC, through volunteer-led family groups such as Parents Forever (in Vancouver and Surrey) and SMART Recovery Family & Friends, NAR-Anon and Discovery.

The Foundry offers integrated health and wellness services to young people at seven locations in BC, including physical and mental health care and addiction counselling and support—sometimes family counselling. But we still need a Foundry-type program for adults over 24, including physical and mental health services, counselling support and dental options.

#### What other types of support are needed?

Many necessary supports for families caring for loved ones with addiction simply don't exist in BC. Drawing on my own experiences, I describe a few supports that could have been—and still would be—game-changers for me.

##### 1. Family inclusion policies

To ensure that services address the needs of diverse families, all levels of addiction treatment need personalized family integration programs. After all, we are the ones our kids call, we are the ones in anguish as they detox at home or use our house as a safe-injection site, we are the ones who pay for programming not covered by our social services system. We know our youth's medical history, challenges and patterns. We need to be consulted and included because we are the ones there when treatment is completed or fails.

##### 2. Free counselling for primary support providers

Many primary support providers suffer with depression, anxiety and post-traumatic stress disorder (PTSD) due to their child's addiction. The constant upheaval has a devastating effect on the physical and mental well-being of the caregiver and on the caregiver's career and finances. Part of the solution includes free, personal

counselling for parents of children with addiction, as well as family counselling when the child is ready and when it can be a positive experience for all family members.

##### 3. Free respite support for parents

As primary caregivers, particularly when our kids are trying to get clean enough to enter treatment, we often can't leave them alone because their behaviour can be unpredictable and dangerous. We can't leave the house, go to work, run errands; we never know what state our child (or our house) will be in when we return, or if they will leave the house and start using drugs again. We are trapped in our home for weeks or months at a time, in a state of panic. We burn out quickly.

Parents of young people with addictions need respite support so we can continue to provide care. Respite could be in the form of an experienced caregiver who comes to our home, or a place for our child to stay for a few days, or hours, giving us the opportunity to undertake the self-care we need.

For information on dealing with addiction in your family, visit From Grief to Action at [www.fromgriefftoaction.com](http://www.fromgriefftoaction.com). To find out about services and support groups available in your area, go to [bc211.ca](http://bc211.ca) or [heretohelp.bc.ca](http://heretohelp.bc.ca). The FGTA coping kit for families with children using substances can be found at [www.heretohelp.bc.ca/workbook/fgta-coping-kit](http://www.heretohelp.bc.ca/workbook/fgta-coping-kit). ▽

# When Hope Springs Eternal for Those with an Anxiety Disorder

Janet Peralta Laguio

*“Mom, why can’t I be happy?”*



*Janet currently works in a Catholic elementary school in Vancouver. Not only does her son describe her as naturally funny, warm and kind-hearted but he also sees her as a person who truly loves God and is true to her faith*

Janet Peralta Laguio

This was the question my 22-year-old son asked me in January 2014. These were painful words for a mother to hear—from the child she loves with all her heart and might, from the young man she thinks the world of.

The question lay at the heart of a larger conversation. He was asking me why he couldn’t be like other people. Why did he have to be anxious about everything all the time—about his performance in school and at work? Why couldn’t he live in the present moment peacefully, not worrying about what had happened and what might have been, or what will be in the future? Why did he feel compelled to do something

every moment? And why did he feel guilty whenever he did something he enjoyed?

My son has been diagnosed with generalized anxiety disorder (GAD). This illness robs him of happiness at every level.

Growing up, my son was always a good boy. He never asked for the latest games or toys or clothes. When we did buy him something new, it was always a generation behind the latest model. He never complained. He was always grateful. His wants were simple: toy cars and a big, plastic two-dimensional map of a town where he could pretend to run the cars from street to street.

Each of us approaches life and its challenges in our own way. When my son asked me why he couldn't be happy, although it hurt, I considered it a good sign that he would be seeking the kind of happiness that truly lasts.

In elementary school and high school, my son was consistently the top student in his class. He was recognized for his achievements in math, physics, chemistry and music. He received the Governor General's bronze award for topping three provincial exams in high school. He was on the Dean's List at the University of British Columbia, where he graduated with a degree in applied science in computer engineering. He has a great musical voice.

And all this time, we did not know how he was suffering inside.

Today, five years after that January morning in 2014, my son is a happier person than he was, now better able to manage his fears and anxiety and finding life's meaning in helping other people, especially youth, overcome their own monsters and fears.

This change did not happen overnight, and it did not happen on its own. We tried various counsellors, group therapy sessions and medications. When one solution didn't work, we continued to search for others. For my son and for other people with GAD, to not be anxious is a daily conscious act of the will. To face and conquer his debilitating fears, my son had to harness all the resources and

skills he has acquired during the past five years.

#### A parent's role

As parents, we can help our children overcome their anxiety. Here are a few guidelines:

#### **1. Make sure that your child has a set of committed friends whose main concern is your son or daughter's welfare.**

My son was with one of his best friends when he finally told us about his panic attacks and his sleepless nights. Although we were not the first people he turned to for help, we were very thankful that he had felt close enough to his friends to share his concerns.

#### **2. Don't play the blame game.**

There are no parenting schools; most of us are trial-and-error parents. We all have good parenting days and bad parenting days, and how we parent depends on our personality and our own experiences. Blaming yourself or your partner for something you did or didn't do as a parent—or for something you did or didn't see—is only counter-productive.

#### **3. Don't give up on finding the right therapist for your child.**

When I learned about my son's anxiety, I went online to look for a psychologist.

This proved to be a daunting task: how could I entrust the care of my son to somebody I knew nothing about? Then one day, a co-worker recommended a psychologist to me. When I contacted the psychologist, her waitlist was so long that she had to recommend a colleague. But after more than a year of waiting, my son and the psychologist my co-worker recommended finally met each other, and they proved to be a good fit.

#### **4. Cognitive-behavioural therapy (CBT) can be an amazing tool for GAD.**

After every visit with his therapist, I would always ask my son how the appointment went. He would excitedly tell me what happened in his sessions (he has generally always been open with me). I noticed a marked improvement in my son's moods. The CBT approach encourages him to be aware of his thoughts and feelings and to manage them in a way that evokes a more positive emotional response. Before he began CBT, for example, he dreaded driving; now he has a regular driver's licence. He used to not care about his health and appearance; now he regularly goes to the gym and chooses and purchases his own clothing. He never cooked before; now he makes meals and washes his own clothes. With CBT, my son started experiencing small victories and big victories, both of which improved his confidence and sense of self-worth.

#### **5. Never underestimate the value of open communication.**

In high school, my son became quieter and less communicative. We attributed this change to adolescence; we let him be, although we kept a watchful eye on his school performance and the kinds of

friends he kept. As my son grew older and family schedules changed, we spent less time together. We didn't keep our lines of communication as open as they could have been.

### Working together for positive change

When my son was diagnosed, our family agreed to make some simple changes that made a big difference. To avoid feeling like he is cooped up in his room and alone, my son now brings his laptop into the living room and stays with us. We might all be doing different things with our evening, but there is that feeling of togetherness.

We also started having family meetings, which can be called anytime by any of us. This started as a way for my son to update us on what's happening with him or for us to say what we wanted to say. At first, these meetings were difficult for us because we were so honest that they sometimes ended on a bad note. Sometimes I would end up in tears or we would finish the meeting resenting each other. But we never gave up. We continued to believe those meetings were important. They have been a good exercise in practising and improving our listening skills and thinking about the other people in the family. Now we can joke about those early, painful meetings because we have become the better for them.

Between school and teaching and his music, at one point my son was juggling four or five schedules at a time. To spend quality family time with us, my son suggested that we start a tradition of going out for Sunday breakfast. Now, every Sunday

at around 9:00 am, we head out to a nearby restaurant that serves breakfast.

### Hope for the future

There is no doubt that all these things—the support of family and friends, a good psychologist, CBT, medication (to a certain extent) and an open line of communication with his family—contributed to my son's recovery. But there is one thing that enables all these factors to work in the person's recovery process. This is the hope on the part of the person that things will get better and recovery is possible. Medical researchers Tanvi Acharya and Mark Agius point out that the "central tenet in recovery is hope—it is the catalyst for change, and the enabler of the other factors involved in recovery." According to Acharya and Agius, "mental illnesses are not part of one's nature, but are states of mind which can be changed in many instances ... hope offers the means by which a better future can be perceived; and therefore, achieved."<sup>1</sup>

Each of us approaches life and its challenges in our own way. When my son asked me in January 2014 why he couldn't be happy, although it hurt, I considered it a good sign that he would be seeking the kind of happiness that truly lasts.

In the meantime, I answered him, "There is a reason for everything, including suffering. The greater your suffering, the greater meaning you will get out of it." It was an answer borne out of faith experience and trust in the Divine Providence. My son might not have fully understood it at the time, but in our talks recently, he acknowledged that what I told him was indeed true.

Today, he is happy when he works with others who struggle with anxiety disorders. And he knows he is good at what he does because he has experienced some of the same suffering and felt some of the same pain. What gives him joy now is the fact that he is able to help keep alive that hope in people with mental illness.

It was—and still is—painful to watch my son suffer. But when I see how he has used his suffering to help others, I know that my answer was the right one. There is a reason for everything, and because of this, there is always a reason to hope for the future. In the words of Alexander Pope (from his iconic "An Essay on Man: Epistle I"): "Hope springs eternal in the human breast: / Man never is, but always to be blest." ▼

# Helping Them Find Their Way

## THOUGHTS ON PARENTING ADULT CHILDREN

Julie\*

By the time our children become young adults, many of our big parenting lessons and much of our parenting learning are behind us. Yet parenting adult children is an unfamiliar new stage—more like coaching and calling from the sidelines, “I’m over here if you need me!”

*Julie is a FamilySmart Parent in Residence (PiR) in a rural community in BC. She looks forward to opportunities to spend time visiting her adult sons and is planning to do some hiking and boating with them over the summer*

*\*pseudonym*



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I’ve been working towards this point my entire parenting life; I just wasn’t aware of how long it would take—or how fast the journey would seem once I’d arrived.

It was no easy task raising two little boys as a single parent. Our eldest son was two years old and I was seven months pregnant with our second when I left their biological father, who was later diagnosed with bipolar disorder and died by suicide when the boys were still little. After holding on for dear life in the boys’ early years and getting continual emotional

support for myself and my sons throughout their elementary school years, things were looking up. I finally felt some relief in their pre-teens. I was filled with thoughts of “We made it!” Things seemed to have settled and I had hopes that we were headed for normalcy.

But in the teen years, things got more complicated.

The challenges with my eldest son worsened. By the time he was 13, he wasn’t sleeping very much, he was impulsive, argumentative and

angry. After a mental health crisis that included an event that psychiatrists thought was a manic episode, he received a diagnosis of bipolar disorder. We spent many years trying different medications for him and attending many counselling sessions.

My younger son was the quiet one. At 14, he began to withdraw even more than usual. Most days, it felt impossible to support him to stop procrastinating and avoiding anything he didn't seem interested in. The daily routine would begin hopefully, but we would quickly get bogged down in ruts we had made for ourselves: I would end up stressed, yelling from the bottom of the stairs to not miss the school bus. He wouldn't move, and most days there wasn't a darn thing I could do about it.

I found it difficult to learn the parenting lessons of that period—like the fact that my sons could choose to connect with the world around them, or they could choose not to, and there wasn't much I could do to influence them. And the fact that it's their choice what to share with me and whether or not to divulge—and their choice depends to a large extent on how I reacted the last time they chose to open up with me.

At first, stepping back and allowing them to make more choices for themselves felt foreign, scary. When they were younger, the rule was that I needed to know where they were and who they were with. As they got older, I had to learn to let go of things that got too difficult to “police.” As the years passed, the stakes became higher: they were spending nights away, driving, going to parties. I spent many sleepless nights worrying. I tried to remind

myself that this experience as a parent was normal, but everything felt far from normal. I was having difficulty trusting and letting go. I had to learn to go to bed “okay” when they didn't follow through and communicate.

It was necessary for me to reach out and find a counsellor and supportive friends to talk to, and to practise self-care; I walked and journalled almost daily.

I learned through my mistakes. I didn't always say and do the right thing. I struggled with my own fears—which sometimes led me to react in ways that weren't helpful. I caved to the pressures that society puts on most of us, like pushing the “need” to graduate on time. Now that we are on the other side of that timeframe, it seems like a lot of wasted time, stress and frustration that affected my relationship with my sons in negative ways but didn't change the decisions they ultimately made for themselves.

Sometimes, I compared myself (and my sons) unfavourably to others who looked to me like they had it all together. I recall running into the mother of my son's friend—her son had graduated, had a great job and was doing so well. I shyly said she must be so proud, and I shared that my son hadn't graduated and that he was struggling to figure things out. I was surprised when she said, “Well, he's a wonderful person, that's what matters. He will figure it out in his own time.” I felt ashamed when I realized that she had offered me a better view of my son than I had shared with her. I wanted to change my thinking.

I found it really helpful when I started to focus more on my sons' strengths

and on my positive connection with them. I focused on finding things to celebrate about each of them. This was especially helpful when we were going through periods of conflict.

Other little things helped, too. For example, in times of crisis, I held on to the mantra “This too shall pass.” And it always did—we would have bad days, and then things shifted and changed, and we would have good days, too.

### Parenting adult children and planning for transition

As parents, one of our tasks is to assess what our children need from us at different ages and stages—whatever struggles they are facing at the time. It can be difficult to gauge what kind of support our children need, as challenges can look different for each individual. As parents, we also have to learn how to modify the support we provide as our children grow and change.

As my sons grew up, I wanted to continue to offer my support, but I wasn't sure exactly what to do or how my offer of help would be received. I realized that it was important to ask them to share what they wanted support from me to look like. When I offered support, I began to follow it with, “Would that be helpful?”

Over time, the objective of preparing them to enter the adult world became more apparent. When my eldest was getting ready to go to college in a distant city, I tried not to say things that might reinforce what he already felt anxious about. Instead, I would ask him how his rental search was going. I would share my own experiences—telling him how I had put down a

deposit to secure an apartment, how I put the bills in my own name. I offered support for those practical issues instead of sharing my worries.

Sharing my experiences as a young person landed differently. I was planting seeds, not giving advice. When I offered it in this way, my support was much better received. The adult version of support looked more like sharing vulnerabilities and finding our common humanity.

Getting good support for mental health—particularly when we are going through significant life transitions—is critical. In my son’s last medical appointment before the big move, the psychiatrist wrote up academic accommodation recommendations for his college, and the Child and Youth Mental Health clinician sent his file to the walk-in youth clinic in his new city. When my son arrived at the new clinic, they were ready for him.

My son really valued the support he received from his mental health team, and the ease with which he made new connections, as he already had so much to navigate in this big transition.

### Reframing my feelings as a parent

When my sons first left home, I was flooded with memories and felt a little lost. I felt so much pride and so much loss.

When we text or talk, I always let them know I miss them, but I don’t harp on it. Instead, I express excitement to hear what they have been up to. I want them to know that I believe they can accomplish their dreams and that I’m excited for them. Of course, I’m not perfect—I’ve said things that come out wrong, or I’ve shared my worries. But I try to learn from my mistakes, and from my reactions and theirs. I acknowledge when I haven’t listened as well or as non-judgementally as I would have liked to. I use self-

compassion. I know I’m learning how to do this transitioning, too.

When my youngest son got to the point where he needed to come home, it was hard for him. In all honesty, it was a let-down for both of us. We had both hoped he would succeed in finding a new job and a place to rent in the city he had chosen to live. But I didn’t want to view it as a failure. I purposely reframed my thinking.

I had heard the term “failure to launch,” but I preferred the phrase “false start,” which felt more positive to me. I was reminded of Ross Greene’s description of “lagging skills”—skills that would help someone cope in certain situations but that haven’t fully developed. I found this lens very helpful.<sup>1</sup> Together, my son and I brainstormed the things he needed support with in order to be successful the next time.

During this long journey, all three of us have shared unfiltered moments that tested us, but we continued to love and support one another. This is what I had strived for from the outset (even though I hadn’t always known it). My heart soars when I see them out there living their lives, and if things get hard, they know they can ask for my help.

In all this reflection, my biggest hope is that my children always know I believe in them, that they are seen and valued, even from a distance. That it’s okay that they need me differently now that they are young adults, and that our family is a firm foundation from which they can grow. Our family will always be a positive place in which they are held in unconditional love. ▾



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# Just When You Think You've Hit Bottom, You Find There Is Another Trap Door

June Ariano-Jakes

A month before his 14th birthday, my second-eldest child, Nathan, was hit by a truck while he was getting off a bus. He broke his legs, a kneecap and an ankle. He smashed his rib cage, ruptured his spleen, damaged his left kidney and left lung, bruised his heart and went into congestive heart failure. He developed a sepsis and had nerve damage to the left side of his body. He spent a long time in hospital and then spent a year and a half in physiotherapy, five days a week.



*June is the mother of five and the author of *Addiction: A Mother's Story*. She works in Whalley (Surrey), BC, with those struggling with addiction, mental illness, poverty and homelessness. She has given over 180 presentations on addiction, homelessness and gang violence throughout BC*

June Ariano-Jakes

During his time in hospital, Nathan was given morphine, Demerol and Tylenol 3. These medications were necessary—his injuries were extensive, his pain unfathomable.

Years later, my son told me he loved the feeling he got from those opioids.

In my life, I've experienced kidney stones. I've had surgeries. While morphine was necessary for pain

management at the time, I hated the way the opioids made me feel and wanted off them quickly.

But I was not predisposed to drug addiction. Clearly, my son was.

By his late teens, Nathan was battling cocaine addiction. Within a couple of years after that, he was also addicted to heroin. Drug addiction is an unforgiving disease. A horrific

One of the other things I have learned as a parent of an adult child living with addiction is that my son's addiction is not about me.

disease. A devastating disease for the person battling it and for those who love him.

Nathan tried to walk away from his addiction many times over the years. He entered treatment programs, recovery houses, treatment centres. He went to Alcoholics Anonymous and Narcotics Anonymous meetings. He knew he was in trouble. He knew that he needed help. When he said he needed help, I knew he meant it in the moment. An hour later, he may have changed his mind. But I never doubted his intent. He did not want the life that he had spiralled into.

For 23 years, my son's addiction to heroin, cocaine, crack cocaine and crystal meth took him to some dark places. As a family, we've seen darkness we could never have imagined as we've been swept along on this dangerous journey with him.

Our lives have been punctuated with addiction, homelessness and gang violence. Although he was never a gang member himself, Nathan often owed money for drugs. He has been beaten with baseball bats and metal pipes by dealers and enforcers. He has been kicked and stomped on, he has been stabbed numerous times, he has been shot at, he has been burned. He has been held against his will and he has been tortured. He has overdosed on multiple occasions.

He has also been incarcerated in municipal, provincial and federal penitentiaries for drug-related offences. The longest stretch of time in jail was two years—for a series of bank robberies. He needed the money to fund his addictions.

Sometimes my son lived with us and at times he was homeless and living on the street. Sometimes his behaviours were so dangerous that—despite the pain and guilt it caused us—we had to ask him to leave the family home. It wasn't about choosing the needs of one child over another. It was always about protecting the younger children from harm.

Regardless of where he was, Nathan and I always stayed in touch. We spoke at least four times a week on the phone and went for walks or a bite to eat. Clearly the relationship we shared—and the sort of non-judgemental support I offered—was as important to him as it was to me.

At one point, when he was struggling severely, he said to me, "You can't understand me, Mom. Just love me."

The love I have for my son, whether he was deep in his addiction or during a period of health, remains unchanged. Essentially, my son is two very different people. There is my son, and there is my son-on-drugs. I was acutely aware of who my son was, and I saw the dramatic difference when his brain

was altered by substances. Through it all, I never questioned my son's love for me. The love I have for my son is unconditional and I told him so.

And then he said to me, "I used to have hope, Mom, but I don't anymore. I used to believe things would change, but I don't believe they will. I accept this is my life. I want it to be different, I just don't know how to do that anymore."

### Understanding what lies beneath the addiction

During the many years of my son's addiction and my years of work in a mission and shelter providing support to others struggling with addiction and mental illness, poverty and homelessness, I have come to my own realization. There are only two reasons people start using a substance: curiosity and pain.

Curiosity is something we can all understand. Physical pain, too, is something most of us can relate to—to varying degrees. But the pain that is much more complex—and much more difficult to understand and relate to—is emotional pain.

Emotional pain may be the result of living in a home with domestic violence, perhaps sexual abuse. One might be a victim of a sexual assault. Or bullying. One might have feelings of abandonment or neglect.

Emotional pain often leads to depression, anxiety, panic attacks, PTSD. Feelings of low self-esteem, and of not being "good enough" or "worthy." There is always a reason for emotional pain, and often that emotional pain has been augmented and perpetuated by someone else when the victim is

vulnerable. While there are various reasons as to why people are suffering emotionally and find themselves addicted and often homeless, in my experience, the most common denominator is unacknowledged and untreated emotional pain.

### Finding a way to help your adult child

As a mother, I did everything I could possibly think of to help my son. I read everything I could find. I discovered that men make up 80% of all overdose deaths.<sup>1,2</sup> Men make up 75% of suicides.<sup>3</sup>

As parents (and as family and friends), we have to encourage the men in our lives to talk. To open up about their pain. Secrets keep us trapped and keep us feeling powerless. That old adage “Big boys don’t cry” has got us to this terrible place. Keeping secrets and carrying emotional pain is toxic. Too many people are dying because they are trying to “quiet” their unacknowledged pain in isolation, and using drugs to do so.

One of the other things I have learned as a parent of an adult child living with addiction is that my son’s addiction is not about me. My son was being held hostage by his addiction; as his family, we were held hostage by his behaviour. This is a painful realization, a painful place to be—both for the person struggling with addiction and for those of us who love them.

Is there a right way or a wrong way to help our addicted loved ones? I don’t think so. Whatever decision you make, whatever direction you decide to take, you have to be able to live with it. What is right for you may not be

right for me. Although we may be on a similar journey, we all walk in our own shoes.

Over the years, I have tried “letting go,” practising “tough love.” But for me, this kind of approach just didn’t work. I felt like I was abandoning my son. The guilt I still feel for having asked Nathan to leave the family home—even though I know I was protecting the younger children—will haunt me for the rest of my life. Instead, I held on, tried to access help, remained ready and willing to sell my home and help in any way possible to show my son how much he was loved.

Another truth I have learned is that not everyone has a rock bottom. All too often, just when you think the person you love has hit rock bottom, or that you have hit your rock bottom, another trap door opens and you fall further. But you know what? You find a way to deal with it because you have no choice. Giving up on someone we love is not an option.

When my adult son told me that he had lost hope, I knew that I had to carry hope for him. When our loved ones are struggling so incredibly and have lost all hope, it is our job to never, ever give up hope.

### Harm reduction

Today, as a mom, I believe whole-heartedly in harm reduction. Harm reduction begins with accepting the fact that we can’t control what someone does; we can only offer them the support to act in a way that causes less harm. When it comes to addiction, we can’t force someone to stop using substances. They have to make that choice for themselves. But we can offer supports so that they

cause less harm to themselves when they are using. Of course, ultimately, the hope is that someone who is addicted will come to realize on their own that they don’t want to be living a life consumed by their addiction. Providing the supports they need to arrive at this conclusion themselves is what harm reduction is all about.

My opinion of harm reduction has changed dramatically over the years. I used to think harm reduction was a way to enable someone to continue using. But someone who is struggling with addiction is in pain. They are using drugs to get through the day in the only way they know. They already feel shamed and blamed. They are being controlled by the drugs. They don’t need to be controlled by us.

We must embrace harm reduction if we are to keep the people we love from dying.

Harm reduction saved my son’s life. For the past five years, he has been on the Methadose program and his life has stabilized. Being on Methadose means he can avoid using the substances he was using before. He has maintained an apartment for five years, something that would have been unfathomable years ago. He is living a healthy, peaceful life—his best life—because of harm reduction. I think of everything he has done, and everything he has been through, to get where he is today. He is a wise and strong adult. He is deeply loved.

We do not know how strong we are until we walk the journey of addiction with someone we love. ▾

## Us vs. ED

### A MOTHER'S STORY OF EATING DISORDER AND RECOVERY

Terri McKinlay, BEd

Years after we had weathered the storm of our daughter's eating disorder, Rylee would tell us that the mental illness she fought as a teenager demanded that she do *anything* but listen to her parents. The eating disorder (ED, or "Ed", as we came to call it) insisted that she die rather than let people dissuade her from severely restricting her food and fiercely over-exercising.

*Terri is the mother of two adult daughters. She left her career as a special education teacher due to a medical condition, and for the past five years has advocated for increased education about eating disorders and improved mental health care for youth. She works part-time in family peer support at Foundry Penticton*



Photo credit: Mark Brett/Penticton Western News

Terri (left) and Rylee (right) McKinlay

Early on in her fight, Rylee said to me, "Mom, you have to understand that Ed hates you because he knows you're trying to fight him." That was the beginning of my understanding of how an eating disorder can hijack the brain—and the life—of its victim, leaving the person feeling that they are unable to choose any other way of being. Typically, when a child becomes sick, we give them the medicine necessary to heal them. With anorexia, the medicine is food—the most fearful

thing in that child's world—and they will do anything to avoid it.

Increasingly, we noticed Rylee's growing anxiety and agitation around mealtimes and a rigidity about exercise routines. And, of course, we noticed her weight loss. Concerned, I took Rylee to our family doctor and an eating disorders nurse. She also saw a dietician, a mental health clinician and a pediatrician. She waited four months to see a psychiatrist.

Initially, we tried to help Rylee without hospitalization. At home, we implemented the few strategies we had learned, not realizing that we needed much more explicit instructions on caring for someone with an eating disorder. Over time, the number of appointments with medical practitioners increased. Often, they were in another town because our hometown had few resources. While each of her providers was excellent, they gave us conflicting information and opinions, adding to our state of confusion and helplessness.

### Finding support

When a severe illness strikes one of your children, it can be overwhelming. But then, within weeks of Rylee's diagnosis, I was diagnosed with thoracic outlet syndrome, which required me to have four upper ribs removed. Concurrently, my father was diagnosed with dementia, which would ultimately take his life two years later. When we were told that anorexia nervosa often means an average of seven years of recovery, we felt like we were drowning.

Throughout this period, Rylee was angry, depressed and suffering with suicidal ideation. When she was admitted to the specialized eating disorders unit at BC Children's Hospital, both my husband, Mark, and I were oddly relieved—sad, yet thankful—that we were able to get her medically certified. This meant that Rylee would receive treatment involuntarily.

Navigating the health care system when your teenager has a severe mental illness can be tricky. As a youth approaches adulthood, they have more rights in our care system to choose

whether their family is involved in their treatment. Although at 16 Rylee was still legally a child, a 16-year-old patient who isn't certified—a patient who is in the hospital voluntarily rather than involuntarily—is able to make certain choices on their own. If she hadn't been certified, Rylee would have been able to choose to leave the hospital. We knew, however, that the eating disorder had disabled Rylee so deeply that constant supervision and care from highly trained clinicians was likely her only chance for recovery.

The willingness of Rylee's care teams to keep us closely informed of Rylee's care plan, while still respecting her wishes for confidentiality, was, I believe, one of the reasons for her successful recovery. Her care teams

were also able to empower us as parents by affirming to Rylee the importance of her family's efforts, despite Ed's constant "voice" telling her not to listen to us.

By this point, I was on medical leave as I tried to manage my chronic pain and awaited surgery. I moved to Vancouver to be closer to Rylee, leaving our home in southeast BC. Mark and our other daughter, Sydney, would come to Vancouver whenever they could, but Mark needed to work and Sydney had sports team commitments. I felt like I was in another world: suddenly living in Vancouver, missing Sydney and Mark terribly when they weren't there. But I was relieved that Rylee was in the best (and only) residential eating disorders program for youth in BC.



Photo credit: SDI Productions at ©Stockphoto.com

My husband and I also attended a caregiver's support group. This was invaluable to our own self-care.

Now that Rylee is an adult, we have found it most helpful to encourage our daughter to build supports ahead of time, so that they are available when needed.

### Learning how to be a care team

Throughout the 10 weeks that Rylee was in BC Children’s Hospital, we received training in the specialized skill-set that primary caregivers need in order to continue the recovery process at home. We found this education extraordinarily helpful. The guilt and shame that parents often feel when their child lives with a mental illness can be debilitating, hindering efforts to help. We were empowered by practitioners’ reassurance that parents don’t cause eating disorders. We were further empowered by our learning the specific skills we would need to continue battling Ed after Rylee’s discharge.

It was during this time that our family made the bold decision to relocate to Penticton, which would enable us to access outpatient support from the Kelowna Specialized Eating Disorders Program. We would be leaving behind family and friends, but we felt we needed the support that the Kelowna program could provide.

After Rylee was discharged, we became Rylee’s new local care team. We learned that even after her time in hospital, Rylee’s mind would continue to be dominated by Ed for at least a year, maybe more. She needed intensive support, and we had to consistently emulate the hospital’s program—but without a team of

highly trained professionals on-hand. We planned each meal a week in advance, using strategies to prepare Rylee, coach her and provide post-meal support. Rylee fought hard to manage depression, anxiety and, once again, suicidal ideation as she tried to do the opposite of what Ed continued to tell her.

Sydney tried her best to provide normalcy as she and her sister shared a new home and a new school. Like many siblings of youth living with mental illness, Sydney was quiet, not wanting to demand more of us than we were already giving to Rylee. We talk about this often now, as we understand it is so heartbreakingly common in families struggling with mental illness.

My husband and I also attended a caregiver’s support group. This was invaluable to our own self-care. The cross-section of parents from different socioeconomic, ethnic and cultural backgrounds reminded us that Ed doesn’t discriminate.

As Rylee continued to recover, she and I became involved in advocacy for youth mental health. We felt that our story might help other youth and families living with mental illness. Rylee has spoken at several events focused on eating disorders and youth mental health; occasionally, we have shared our story together.

### Living with mental illness as a young adult

When she was 21, Rylee moved to Kelowna to attend university. Since her diagnosis, she had been slowly but consistently recovering, gaining skills to manage the disorder. Despite keeping Ed in check, the depression and anxiety that often go along with an eating disorder (and with recovery from an eating disorder) were challenging.

Twice, she became severely depressed and was unable to reach out for professional help for herself. When I tried to do so on her behalf, I discovered that navigating the health care system for an adult is very different from navigating the system for a child. Some of the service providers required that Rylee make phone calls and appointments for herself, and we found out that she had “aged out” of some of the programs on which we had relied heavily before.

It was a scary realization for us, that we could no longer just book the services Rylee needed when she needed them. We found ourselves feeling strangely grateful that the most acute part of Rylee’s illness had happened when she was still legally under our care.

Thankfully, Rylee welcomed my help. We began with walks outside, as nature has always been a grounding source for Rylee. She attended counseling sessions through the university. She found a new doctor and, once again, drew on her incredible strength and will. In time, she was able to work through her depression.

I have learned that I can rely on Rylee to let me know when she is in trouble.

As long as she is able to do that, I know that we can figure out the rest. I trust her to make good choices for herself, and to let me know if she's struggling; she trusts me to avoid micromanaging her life, but to be there unconditionally when she reaches out.

### Helpful advice

We are often asked what helped us the most. This is an interesting question, because the answer differs depending on Rylee's age. When she was a child dealing with an eating disorder, and was legally under our care, we found that it was most helpful

- to be reassured that our child's mental illness was not a choice she was making
- to be reassured that nothing we did or didn't do had caused our daughter to develop an eating disorder
- to receive practical education and support as primary caregivers
- to learn Emotion Focused Family Therapy (EFFT)—a family-based model for support and recovery from mental illness
- to be treated with dignity and respect by Rylee's practitioners and to be involved and consulted in developing a consistent care plan
- to advocate for communication and integration between service providers
- to receive the unconditional love and support of family and friends

Now that Rylee is an adult, we have found it most helpful

- to help and encourage our daughter to build supports ahead of time, so that they are available when needed

- to check in often, in a respectful and empowering way (always giving the message that we believe in her to make the right choices), including offering help and advocacy when needed
- to continue to use EFFT skills (useful for all relationships!)
- to accept the unconditional love and support of family and friends

to lead our family in advocating for others, sharing our story and, along with her sister, helping peers who are living with "Eds" of their own. As a family, we have found a resilience we didn't know we had. We enjoy a closeness and a sense of peace that has evolved out of our experiencing something unthinkably difficult together and knowing we've survived. ▾

It has been seven years since Rylee's anorexia diagnosis, and she continues



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## Us vs. ED

### A DAUGHTER'S STORY OF EATING DISORDER AND RECOVERY

Rylee McKinlay, BHK

It's difficult to say when my mental health struggles began. I remember being exceptionally nervous as a young child—imagining nightmare scenarios like losing both my parents or getting publicly chastised in front of my primary-school classmates—and sometimes getting so worked up that my stomach would burn and my head would ache and my mom would have to pick me up from school mid-morning.

*Rylee is a young adult navigating life after her battle with anorexia nervosa as a teenager. She has a bachelor's degree in human kinetics and is a certified Ashtanga Yoga instructor. Rylee is a passionate advocate for youth with mental illness and hopes that sharing her story will help others*



Photo credit: Mark Brett/Pentiction Western News

Terri (left) and Rylee (right) McKinlay

This undiagnosed anxiety was deemed a normal characteristic of my “type A” personality, and it only grew stronger as I approached puberty. My middle-school years saw countless mornings spent in crisis as I bawled to my mom about how much I hated the way I looked, and how I couldn't possibly go to school looking the way I did. Again, this was assumed to be relatively

normal in terms of pre-teen angst, and my mom, dad, younger sister and I hoped that my mood would stabilize eventually.

As puberty took hold, I started becoming aware of my body and comparing myself unfavourably to others. Cosmopolitan magazines and less physically developed peers



had me believing that my body was somehow wrong. This dissatisfaction soon turned to absolute self-hatred, and I began experiencing suicidal ideation. I felt overwhelmed with emotion all the time, like I had no control over my body or my mind. So I began taking action: a million diets and countless hours on the elliptical trainer in the basement. The endorphins gave me a rush of temporary happiness, and the dieting provided a sense of control. When my parents tried to intervene, I was furious. I wanted nothing to do with them or their opinions on my strange new habits.

By the time I was 15, the diets had morphed into strict dietary rules, and the exercise sessions had become obsessive rituals that dictated my schedule. I constantly felt that I wasn't good enough and needed to repent for my inadequacy by punishing myself with brutal workouts and depriving myself of food. Watching me self-destruct had my parents paralyzed with fear; their daughter had become someone they didn't know. My mood was horrifically unstable, fluctuating between depressive episodes and manic bursts. I knew something was deeply wrong with me, but it didn't matter; the sense of control I got from steadily shrinking my body was the only thing that kept me going. I didn't know it at the time, but I was in the grips of a volatile eating disorder: anorexia nervosa.

Unaware of the eating disorder's monopolization of my mind, I regarded my parents as my worst enemies as they tried to derail my efforts. Despite my (sometimes violent) resistance, they diligently

took me to multiple appointments every week, hoping that someone could tell them what was wrong with their daughter. For a long time, there were no concrete answers, as eating disorders are an obscure corner of the medical world that most health professionals receive no training on. In our small, remote town of Kimberley, the resources just weren't developed to treat such a multifaceted illness. And so I was admitted into the eating disorder ward at BC Children's Hospital in Vancouver, in the summer of my 16th year.

### Finding clarity in recovery

I was furious at my parents. I refused to speak to them for the first few days of my stay. All of my painstaking work to establish control was ripped away from me by the doctors and nurses who enforced strict feeding regimens and therapy sessions. No more obsessive exercising. In fact, I was in a wheelchair for the first week because my heart rate was so low it was susceptible to failure. I went through the motions in a haze until, a few weeks in, I woke up with a feeling of freedom. I noticed, for the first time in months, the absence of that little voice telling me I wasn't good enough—that voice of the eating disorder (ED, or "Ed", as we started to call it). That moment of clarity was the first time I felt motivated

to recover, and I began to actively engage in my treatment plan.

While I was in the hospital, my parents made the bold decision to uproot us from the town they themselves were born and raised in, in order to relocate to a bigger centre, where resources were available to continue my recovery after discharge. Penticton became our new home, an hour away from Kelowna, where an eating disorder outpatient clinic exists. After almost three months on the eating disorder ward in Vancouver, I reached a level of medical stability that qualified me for discharge. By this time, I had become friends with my caretakers and fellow patients, so I was somewhat sad to leave.

Starting Grade 11 at my new school, Princess Margaret, was scary at first, especially because I didn't want anyone to know about the eating disorder. I attended multiple appointments in Kelowna each week and lied about why I was missing those afternoon classes. My parents, now equipped with vital knowledge and skills that they had learned from the team at BC Children's, became my devoted caretakers, making each meal and supporting me through them. Although we experienced minor setbacks, like a drop in my weight or a particularly depressive episode, our

If I had to summarize how my parents were most helpful through the illness, I would have to say that their continuous reminders that I was sick and that it wasn't my fault were one of the keys to my recovery.



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Now, as a young adult, what is most helpful is knowing that my parents have my back when I need them, but also that they trust and believe in me to overcome challenges.

family worked as a team to build an environment where the eating disorder was no longer welcome. Body positivity and anti-diet-culture rhetoric reigned supreme, while self-deprecation and body comparisons were eradicated.

In my Grade 12 year, I started sharing the story of my journey with mental illness, with hopes of making people more aware of eating disorders and encouraging those who are struggling to seek help. My mom and I became more involved in advocacy work for youth mental health, participating in projects aimed to improve the health care system in BC for youth with mental illness. This advocacy work was extremely beneficial to my recovery: it made me feel accountable for my own mental health.

### Becoming a healthy adult

Eventually, I aged out of youth care and had to transition into adult services. At this time, I was starting post-secondary at Okanagan College in Penticton while still living at home. I was grateful to have my parents' help in navigating this health care transition. The ups and downs of recovery continued, but with each passing year I found myself growing stronger and feeling more capable of resisting self-harming urges. The depressive episodes grew increasingly rare and the little voice in my head quieted. As the eating disorder's hold on me gradually weakened, my relationship with my parents strengthened. We worked hard to establish boundaries that would allow for transition into a more "normal" teenager-parent dynamic—a dynamic

that is challenging enough, without the presence of an abusive eating disorder!

In the fall of 2017, at age 21, I moved to Kelowna to continue my education at the University of British Columbia's Okanagan campus. It was the first time I had lived on my own and I was excited. By this time, I was almost free of eating disorder-related thoughts and impulses, but I continued to feel the dull ache of depression every now and then. My parents were nervous to see me leave the nest, but they were also excited about this new chapter. I was more confident in seeking health care providers on my own, and found a counsellor who helped me through a brief bout of school-related depression. My mom still checked in almost every day, but I found this to be comforting rather than suffocating, as I had in the past.

The team at BC Children's Hospital told us that it takes seven years to recover from an eating disorder; I remember thinking that the number seemed rather arbitrary. Today, I am 23 years old, it has been seven years since I was diagnosed, and I can proudly say that I am 100% recovered from anorexia nervosa! I still need to be wary of my mood when it dips, but I can honestly say that I am really, truly happy. For the first time in my life, I can say that I love myself.

My mom and I maintain an open channel of communication regarding our mental health, and my entire family now jokes about our horrendous experience as a way to continue healing. Then-me hated how involved and controlling my parents and my health care practitioners were during

the height of my illness; now-me recognizes that it is necessary for someone with an eating disorder to be relieved of all controls. The ill person cannot see that they are being manipulated by a ferocious disease and that they cannot make wise and healthy decisions for themselves. They might feel like they are in control, and fight desperately to maintain that control, but the fact is that the illness is controlling them. The only way to fight the illness is to remove control from the ill person entirely.

If I had to summarize how my parents were most helpful through the illness, I would have to say that their continuous reminders that I was sick and that it wasn't my fault were one of the keys to my recovery. It was also integral that they continued to paint a picture of a life beyond anorexia, giving me hope that I was capable of recovery and it was worth fighting for. Since the eating disorder was in my brain and always trying to convince me that everything was my idea, having my parents actively oppose it was necessary. Now, as a young adult, what is most helpful is knowing that my parents have my back when I need them, but also that they trust and believe in me to overcome challenges. This trust requires that we all communicate with one another and use our newly formed emotional awareness to assess where we are at.

Recovery wasn't easy by any means, but it was worth it. Our family is now bound closer than ever, and we all take pride in the fact that we faced anorexia nervosa, the most deadly of eating disorders, and lived to tell the tale. ▾

## SUCH A LONG JOURNEY—CONTINUED FROM PAGE 7

- Join the BC Schizophrenia Society's monthly support meetings (for anyone with a loved one showing signs of severe and persistent mental illness) and register for the BC Schizophrenia Society's excellent 10-week Strengthening Families Together series. Details of both can be found at [www.bcscs.org](http://www.bcscs.org)
- Ask questions of the Vancouver Coastal Health's Family Support and Involvement (FSI) team (or the equivalent team for your health authority)
- Visit [bcpsychosis.org/resources-for-families/](http://bcpsychosis.org/resources-for-families/) to learn more about resources for families dealing with severe mental illness ▾

### related resource

See Vancouver Coastal Health's valuable Family Involvement Policy and privacy guideline at [bcscs.org/family-advocacy](http://bcscs.org/family-advocacy).

Psychosocial Rehabilitation BC has sponsored an excellent webinar on family caregiver needs, available at [psyrehab.ca/resources/show/a9652](http://psyrehab.ca/resources/show/a9652).

Sign up for Spotlight on Mental Health's comprehensive newsletter: [spotlightonmentalhealth.com](http://spotlightonmentalhealth.com)

# visions

## we want to hear your story

The next issue we will be soliciting articles for is about **vulnerable youth and young adults**.

If you have a personal story about mental health and substance use challenges faced by young people facing more barriers, please contact us with your story idea at [visions@heretohelp.bc.ca](mailto:visions@heretohelp.bc.ca) by October 5, 2019.



# Between a Rock and a Hard Place

## A FATHER'S STORY OF FRUSTRATION

Gord M.

*As told to Sarah Hamid-Balma*

My stepson Marty\* is 33 and hides in the basement. This has been going on for years. He needs help but has no desire to change.

*Gord and his family live in Duncan, BC*

### Editor's note:

*When Gord and Amy\* decided to blend their two families, they knew things might get complicated. Most of the six siblings and step-siblings got along fairly well. But Amy's son Marty\* had feelings of jealousy and felt abandoned by his biological father. Now an adult, Marty is unemployed and rarely leaves Gord and Amy's basement. Gord and Amy have tried everything they can think of, short of kicking Marty out on his own. Gord is caught in the middle—wanting to help his stepson take on adult responsibilities, but not wanting to jeopardize the loving relationship he has with Marty's mother and the rest of the family. This is Gord's story.*

*\*pseudonym*



Photo credit: tirc83 at ©iStockphoto.com

Marty was 11 when we met. He was never a social kid and loved the computer and computer games. He did have friends as he grew up but they were always quiet computer kids.

He's smart as a whip. Around Grade 10, he failed Science, so we said he'd have to go to summer school. The summer school teacher let him out early because he got straight As. It was more that someone was watching him so he had to sit there and do it. Otherwise, his grades were okay. He

is one credit away from graduating Grade 12 but just won't go back and get the credit.

The first signs that something was off was probably around Grade 8. From Grade 8 on, he wasn't interested in going out with his friends. He'd call up his buddies and a bunch of boys would show up with their home computers and be playing video games all weekend. You almost wouldn't see him. He kind of became antisocial, though up until Grade 12

he still had one or two really good buddies.

When he was around 19, his friend's parents rented a place, so he and four boys were roommates together in this townhouse. He got a job at a grocery store—everything seemed pretty normal for about six months. Then he quit going to work, probably played games all day. The other guys didn't even know if he was in the house because he'd be barricaded in his room. He hid in the house until he was evicted.

Then I bought a condo for him and set him up with a plumbing apprenticeship. After about four months he stopped showing up for work and lived for two years in the condo without paying rent. We had to give him money for food.

After a while, Marty came back to live with us [his mother and me] and I got him another job—in construction. Marty worked his own hours and rarely full days. He was a good employee: he didn't talk to anyone, he just did his work. But he became increasingly undependable and was fired. He hasn't worked since and it's been over two years now.

He rarely talks to people and avoids eye contact. During family events like birthdays or holidays, he will grab his dinner and hide in his room. Although he lives in our basement, sometimes I won't see him for months. I assume he eats at night. I say it's like having a mouse in the house: I don't hear anything and the only thing I see is crumbs on the counter. He rarely leaves the house, rarely speaks. He doesn't seem passionate about anything.

## Gaming, pornography and social interaction

Maybe a year ago I unplugged [the Internet connection]. I thought if I unplugged the Internet, he's going to have to come upstairs and then we can have a discussion. It took about three days. It was almost like he was having a nervous breakdown, trembling. He's probably 6'2" but only 110 pounds, so very tall and very thin. I think he was going through withdrawal. But I don't do it anymore because I think that's his whole outside-world interaction. What little life he does have, I was taking it away from him. He actually denies that he plays games. He'll say something else is going on, but we can hear him talking on the headset, obviously playing a game. But whenever we confront him about gaming, we get, "Oh no, I read the news online."

There was a lot of pornography at one time. This is going back to when he was about 16. We had a family room with our shared family computer. I'm not incredibly computer savvy but I said to my brother, "If he's downloaded porn on the computer, how would I find it?" And my brother showed me how.

When I found it, I remember saying to my brother, "Wow, I think I'm the porn king of Duncan."

Near Christmas last year, Marty said, "Oh, I met a girl online and she wants me to move in with her." But she's in Montreal. He asked if he could borrow money and I said, "Well, I'll pay for one way to get you out there and then you're on your own." So that's what happened. Then we didn't hear anything so his mom got hold of him. He seemed okay at first but at the end of January, his mom started getting weird text messages from him because they [Marty and his girlfriend] weren't getting along and she wanted him out. We ended up wiring him the money to come back home. He was gone about six weeks.

This wasn't the first time. The first girl was about three years earlier when Marty was around 28. He comes up out of the basement one day and says to me and his mom, "Can a friend come over for a couple days?" He says she's from San Francisco. She stayed for two weeks. Then he went down there six months, the maximum he could stay in the US legally. But that [relationship] also fell apart.

My brother-in-law knew someone at the Duncan Mental Health office. I phoned them and got passed along and they said they can't really help because Marty is the person who has to come in and ask for help. I said, "Well that's never going to happen. He just won't leave the basement."



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How do you get help for someone who doesn't want to admit they need it? We don't seem to have any rights. Do we kick him out and let him live on the streets? There is no help because he is an "adult," and therefore we have no say.

### How do you help someone who doesn't think they need help?

We've tried to make deals. After a job fell apart, I said I'd pay for three months of car insurance, but I expected him to be looking for work. I listed about 20 or 30 jobs he should be going out and applying for. Nothing happened.

He started saying that he couldn't work because of health issues: his back. So we sent him to the doctor. Who knows what he told the doctor. I think the doctor could read between the lines and see that things aren't quite right, so Marty stopped going to the doctor.

Most people think he suffers from depression. When he was maybe 18, he had a medical scare related to his heart. He was in the ICU. It was a big ordeal. I took him to Victoria for a follow-up meeting six months later and I remember the doctor just looked at him and asked, "Are you depressed?" Marty always had one-word answers; it was always just "nope." He just wanted to get the hell out of there.

His temper goes from zero to 110. He's otherwise a mild person, and then all of a sudden, he's like the Incredible Hulk. Even when he was a kid, I remember telling him, "Look

you've been on the computer long enough. Go outside and enjoy some sunshine." He got into a big rage and raised his computer above his head, threatening to smash it and I went, "Go ahead, makes no difference to me." Then he carefully set it back down because he didn't get the reaction he wanted out of me.

Last year, he threatened suicide. I was just trying to get something happening, trying to have a conversation with him. "You gotta get a job, you gotta get on with your life, you're wasting away." His response was, "I don't want to be alive, I'm just going to kill myself." That's when I phoned the police. The RCMP did an assessment. A mental health nurse came to the house. But because he's an adult [and entitled to confidentiality], we don't know what the health nurse said to him, or what he said to the health nurse. He wouldn't call her back.

How do you get help for someone who doesn't want to admit they need it? We don't seem to have any rights. Do we kick him out and let him live on the streets? There is no help because he is an "adult," and therefore we have no say.

It's even become somewhat of a joke among the family. When there was a case in the States where some parents sued their son to force him to move out of the house, my brother sent me the article with the words: "Does this sound like anyone you know?"

### When is it our time?

I don't know how we can get help because you can't force him to do

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# Advocacy as a Coping Strategy

Susan Inman, MA

Just before our younger daughter received the right dose of the right anti-psychotic that ended two years of psychosis, I came across an essential book. Dr. E. Fuller Torrey's *Surviving Schizophrenia* not only provided crucial information about our daughter's illness, but by urging families to advocate for the policies and services that they and their family members need, Fuller Torrey illuminated a path for me to follow.



Photo credit: Portraits by Anita

Susan Inman

*Susan is a retired secondary school teacher. She is the author of *After Her Brain Broke, Helping My Daughter Recover Her Sanity* and writes about mental illness policies for Huffington Post Canada and The Tyee. Susan is a member of the board of the BC Schizophrenia Society*

## Advocating for better education

I began to try to identify the government and health care policies and social systems that had negatively impacted our daughter. The first issue I grappled with was the poor state of public mental-illness literacy. Awareness campaigns have avoided teaching the public basic information about schizophrenia and bipolar disorder. These are illnesses impacting 3% of the population.<sup>1,2</sup> The public needs to understand the early signs of these brain disorders. Although these illnesses can't be prevented, better services would lead to better outcomes.

I had been especially ignorant because my undergraduate and

graduate education had left me with a comforting but erroneous notion about mental illnesses.<sup>3</sup> I believed that as long as parents were loving, attentive and supportive of their children's individuality, then mental illnesses were not going to be a concern.

This ignorance had led us to choose a therapist for our daughter when she began to flounder in early adolescence. Only much later did we learn that our daughter's puzzling cognitive losses, her strange new physical gait and her increased withdrawal from the world around her were early warning signs of her schizoaffective disorder. This is an illness that combines elements of both schizophrenia and bipolar disorder.

The therapist, who had a master’s degree in counselling psychology, knew even less about psychotic brain disorders than we did. (During this time, we had begun doing quite a bit of research.) We eventually learned from our daughter that throughout her years of therapy the focus was on trying to uncover a “family secret” that would “explain” her growing problems. Our daughter’s therapist’s lack of knowledge led to a series of events that undermined our daughter’s relationship with a psychiatrist whom she briefly saw as she became psychotic.

In addition to my other advocacy efforts, I wrote a memoir about our family’s experiences. I was surprised to learn from many other families who read it how common ignorance about serious mental illness is, and how dangerous it can be to connect to clinicians who lack adequate knowledge of science-based ways of understanding schizophrenia and bipolar disorder.

As a teacher, I felt strongly that it made sense to promote the kinds of education that families like mine need. After attending a conference in the US put on by the National Alliance on Mental Illness (NAMI), I believed that families in Vancouver coping with psychotic illnesses would attend a conference that was designed to meet their needs. Having recently joined Vancouver Coastal Health’s Family Advisory Committee, I proposed that we put on a family conference.

That became the first of 11 family conferences that I worked on to provide families, consumers of mental health services and clinicians a chance to hear about evidence-based medical and psychosocial treatments.

It also provided a chance to hear from family members themselves, on panels designed to get their input on important issues.

As I began to better understand competing beliefs that inform the delivery of mental health care, I started publishing about mental illness policies for a broader audience in *Huffington Post Canada* and *The Tyee*, among other publications. These articles have given me a chance to add the family caregiver voice to discussions that have too often excluded our perspectives.

### Advocating for cognitive remediation

Because an enormous problem for our daughter has been significant cognitive losses, I began to focus on this issue. It took me years to understand these losses, which had begun long before she had her first psychotic break or started taking any medications. Such cognitive losses (which can include difficulties with concentration and short-term and working memory, reasoning, and problem-solving, judgement and social skills) are considered to be a major factor in the widespread disability of people with schizophrenia and other psychotic disorders. This has been well researched by the US National Institute of Mental Health, the world’s largest government-funded agency researching mental illnesses.

I also became aware of the growing implementation of evidence-based cognitive remediation programs in the US. I began attending the annual Cognitive Remediation in Psychiatry conferences, established more than 22 years ago by Dr. Alice Medalia, the director of Columbia University’s

Lieber Center. Dr. Medalia has established evidence-based programs not only in the US but also in numerous other countries.

When I returned to Vancouver, I began to write about the cognitive rehabilitation programs that Canada needs.<sup>4</sup> I heard from many other families who, like me, had taken the existing psychoeducation courses but had never learned about cognitive losses being a well-established symptom of schizophrenia. Unfortunately, I also began hearing from psychiatric survivors who believed that my articles were creating stigma against them and that my articles implied they weren’t intelligent. I realized in new ways that there are very different kinds of consumers of mental health services with very different needs. People like my daughter won’t have their needs acknowledged and addressed unless families are understood to be their legitimate advocates.

Having seen how valuable conferences can be, I partnered with longtime advocate Dr. John Gray and the BC Schizophrenia Society (BCSS) in a two-year planning process to create the Bringing Cognitive Remediation to British Columbia conference. We were joined in this planning by representatives from the BC Psychosis Program, the BC Early Psychosis Intervention program and BC Psychosocial Rehabilitation. The 2017 conference at Vancouver General Hospital was sold out.<sup>5</sup> Videos of the conference presentations and other related resources are available on the BCSS website.<sup>6</sup> This group is continuing efforts to implement cognitive remediation programs in BC; unfortunately, so far, proposals



to secure provincial funding to bring these relatively inexpensive programs to BC have not been successful.

### Advocating for a better understanding of human rights and mental illness

Most recently, I have focused on alarming new efforts to undermine access to the involuntary treatment that people with psychotic disorders sometimes need.<sup>7,8</sup> A challenge to BC's Mental Health Act by a national disability rights organization is still unresolved. If it is successful, very ill people will no longer have access to involuntary inpatient or outpatient treatment.<sup>7,8</sup> Without this access, people will remain trapped in psychosis. My daughter and her friends who live with schizophrenia had access to involuntary treatment when they needed it and don't want to be left untreated in the future.

People like my daughter and her friends aren't taken into account when human rights advocates tell us that they represent the views of people living with these illnesses. As I have learned, human rights advocates promoting the misguided notion that people must always choose what, if any, treatment they want are not acknowledging anosognosia, a brain-based condition that makes it impossible for many in psychosis to understand that they are ill.<sup>9</sup> People with untreated psychosis end up homeless, victimized, addicted to substances and, increasingly, incarcerated.

During her two-year psychotic episode, our daughter was assessed by the local refractory psychosis team. Refractory teams look at patients whose symptoms aren't responding

to treatment. We learned that they understood our daughter to be one of the most profoundly psychotic teens they had ever seen, and their prognosis for her was grim. However, once she was given the right dose of the right antipsychotic medication, she emerged from this devastating experience. We have been fortunate that in recent years we have had access to a very knowledgeable and collaborative psychiatrist. Our daughter welcomes our involvement with her psychiatrist. This collaboration has been key in helping her maintain years of stability.

As is the case with many people with schizophrenia, the severe cognitive losses our daughter has suffered make many of the basic tasks of daily living very difficult. My husband and I and the people we hire try to help her work on these tasks.

Our daughter's illness is compounded by severe obsessive-compulsive disorder (OCD), which causes her great distress. Although we have tried the best evidence-based medications and cognitive behavioural therapy (CBT) sessions (which we pay for privately), her OCD persists. Informed clinicians agree that she needs much more extensive help for her OCD, but it isn't available. British Columbia doesn't have the sort of intensive OCD day program or inpatient program that our daughter and people like her need, even though programs like this exist elsewhere.

Despite her very serious illnesses, our daughter enjoys her life. We long ago purchased an apartment near us for her. She lives in the neighbourhood she grew up in and where she feels comfortable; she sees many people who greet her warmly and who understand her illness. The staff at the local community centre welcome her when she arrives for almost daily workouts in their gym.

The BC government has recently announced significant new funding for mental health services. Families like mine can only hope that these services don't ignore the many unmet needs of people with the most severe mental illnesses.

For too long, the voices of family caregivers have been absent from discussions that shape mental health services. This has recently been changing, and families have new opportunities to advocate for our family members who aren't in a position to advocate for themselves.<sup>10</sup> More families can start to see that advocacy provides a meaningful way for us to cope with circumstances in which we often feel helpless.

It's unclear how effective our efforts will be. However, I do know that my daughter's chance of having a safe future when her parents are no longer alive depends on the mental health system improving its ability to respond to severe mental illnesses like hers. ▽

More families can start to see that advocacy provides a meaningful way for us to cope with circumstances in which we often feel helpless.

# The Caregiver Identity Crisis

## FAMILY CAREGIVERS OF BC IS READY TO HELP

Janet McLean, MBA

A client at Family Caregivers of BC (FCBC)—let's call her Julia\*—once shared with me a reflection on her role as “caregiver” for her son. I have put the term in quotation marks because—as you will see from her statement below—the word is charged with multiple subtle and often problematic meanings.

*Janet has worked for 18 years in the health care field. As Education Lead at Family Caregivers of BC, she focuses on ensuring that caregivers across the province can access support and services to help them balance caregiving with the other aspects of their lives*

*\*Julia's reflection is a composite drawn from various statements expressed by caregivers who call into our Caregiver Support Line*



Photo credit: skynesher at ©iStockphoto.com

*“You are not my caregiver,” my son said to me one evening.*

*“I am not your caregiver,” I said in return, hoping to relay my understanding. However, packed within his simple statement and my response were, for me, many uncertainties. I am still seeking to understand. We have been in this dance for many years, as I have watched and supported him through some serious challenges with his mental health. Am I caregiver? What does it mean to care? To give care?*

*I care for him. Through my relationship with him, I catch myself wanting to help and extending myself to help when perhaps*

*it would be better to hold back. When he was younger, I needed to help a lot more. I catch myself worrying about him—fearing for his health. And yet my concern for him is causing me distress. If I am not a caregiver, what am I?*

*Over a period of caregiving (okay, let's just use this term for now), pieces of myself seem to have slipped away as energies and focus extend outward. Not losing myself as I am caring for others, including my son, who is living with a diagnosis of schizophrenia, is an interesting challenge. More and more I recognize the need to nourish and care for my own needs. I am still seeking, and I need help to explore just how I might do this.*

Julia's reflection is not unusual. Over the 30 years that FCBC has been supporting family and friend caregivers of aging, ailing or disabled adults, we have seen over and over again how vital a role caregivers play in our society. As they care for others, caregivers need care and support themselves. Providing this support starts with what we call "caregiver self-identification."

### Caregiver self-identification

Caregivers are people who have social, personal and intimate relationships (as friends, family members or partners) with individuals who have disabling physical health conditions, are frail due to aging or disability or have mental health challenges (or all of these). People who provide care may use different labels—"caregiver," "care partner," "care provider"—or they may prefer to not label their care work at all.

No matter what they call themselves, caregivers take on a role that is separate and distinct from their primary relationship with the person for whom they are providing care. It is an important distinction because the role of caregiver is emotionally, psychologically and physically taxing. If someone doesn't recognize they are caregiving, they are likely to miss out on available supports, which can in turn lead to burnout and their inability to continue caregiving. A recent Ontario report found that only 42% of caregivers self-identified as caregivers, 35% didn't understand they were caregivers until the role was explained to them and 24% (even after the role was defined) still didn't see themselves as caregivers.<sup>1</sup>

### The impact of the caregiving role on the caregiver

While many caregivers feel deeply satisfied with the care and support they provide to others,<sup>2</sup> they struggle to maintain their own well-being in the process.<sup>3</sup> And the evidence is very clear: caregivers who identify themselves as caregivers and reach out for support early in their caregiving journey are much more likely to sustain their caregiving role over an extended period of time.<sup>4</sup>

We also know that family and friend caregivers supporting an individual with a mental health challenge are among the most stressed in the province. In 2018-19, roughly 6% of calls to our toll-free Caregiver Support Line were from caregivers caring for an adult with a mental illness. Very often, these caregivers have been caring for extended periods of time, have experienced periods of significant turbulence in their relationships and approach to caring and have become quite isolated in their roles. The mental and physical health of the caregiver is also on the line.

For example, Julia, the caregiver who shared her reflections at the beginning of this article, has been caring for her adult son since he was in his early 20s. He is now in his late 30s. Over the years, he has been in and out of direct care in the community, overseen by health care practitioners. He has been in facility-based care twice, the last period six years ago. Although he is somewhat stable, he still goes through periods where he can't manage or maintain a part-time job, which leads to financial distress. Julia is approaching 60 and has her own health issues. She worries about who

is going to look after her son when she is no longer able to, and she is also concerned about her own financial situation in retirement. When Julia called our Caregiver Support Line, she was juggling another crisis in her son's life. She had no current contacts in the health authority and didn't know who to talk to about her situation.

In conversation with caregivers like Julia on our Caregiver Support Line, we often ask, "How are you doing?" On many occasions, this question is met by the caregiver's silence. Alternatively, caregivers may say they are "fine"—or, frequently, "I am fine, I am fine, I am fine," until they fall into silence or break down over the phone.

The caregiver tends to focus on the issues of the care recipient, often singling out a recent episode that reflects a long history of relationship dynamics. When we shift the focus of the conversation to the caregiver's needs, it becomes clear that the caregiver is not fine. In caring for the recipient, caregivers often neglect to care for themselves, risking their own well-being.

Ultimately, many caregivers exceed the limit of their capacity to care, joining a growing number of caregivers who are experiencing distress and burnout. In so many of the telephone calls we receive, people have called in a moment of desperation. They have been coping up until that point, but then there is a particular episode or incident, the pressure builds, and suddenly they feel overwhelmed and exhausted and don't know where to turn.



## family caregivers of bc is ready to help

British Columbia is a large and diverse province, but no matter where caregivers live, FCBC is working hard to ensure that caregivers have access to support. There are a number of ways that FCBC offers support, and all of our services and resources are free of charge across BC.

### Caregiver Support Line

Family, partner and friend caregivers are welcome to call our toll-free Caregiver Support Line, Monday to Friday, from 8:30 am to 4:00 pm, at 1-877-520-3267. We understand that reaching out for help can be difficult, but we are always grateful when a caregiver takes that step and trusts us enough to call.

When a caregiver calls our Caregiver Support Line, we respond by

- listening to understand the caregiver’s unique situation and to provide emotional support
- providing information and referrals to resources— often through Here to Help and its partner organizations. We also encourage caregivers to seek support from their local community services wherever possible (e.g., BC Schizophrenia Society’s Strengthening Families Together program, support groups and other community organizations)
- helping to navigate BC’s medical and social services systems
- providing one-on-one caregiver consultation sessions for complex caregiving situations, a service that includes problem-solving and developing action plans for follow-up

### Online resources

Over the years, we have learned that while caregivers experience unique caregiving situations, there are common concerns. Our website ([familycaregiversbc.ca](http://familycaregiversbc.ca)) has links to handouts, webinars and learning modules that explore the common themes of caregiving. A “top

tips and tools” link encourages caregivers to explore topics such as caregiver well-being, communication skills and financial assistance ([familycaregiversbc.ca/for-family-caregivers/welcome-to-top-tips-and-tools-caregivers/](http://familycaregiversbc.ca/for-family-caregivers/welcome-to-top-tips-and-tools-caregivers/)).

We often refer caregivers to our self-assessment tool ([familycaregiversbc.ca/caregiver-self-assessment/](http://familycaregiversbc.ca/caregiver-self-assessment/)) and to one of our most popular webinars, “Where to Draw the Line: Boundary setting for caregivers.” By exploring their own boundaries, caregivers can be supported to identify their needs and set limits on the care they provide to others so they don’t lose themselves in the process.

### Caregiver support groups

Coming together to speak with other caregivers can be helpful and can reduce the feeling of isolation that many caregivers experience. As one facilitator frames it, a caregiver support group “is where a caregiver can come to remember themselves.” In this community support space, caregivers have the opportunity to reflect on and express their own inner experience and their needs. FCBC works with communities across the province to increase caregiver support through our free caregiver support group facilitator training. Across BC there are close to 50 non-illness-specific caregiver support groups that run on a peer-led model. Formats vary depending on what the groups want. For example, Salt Spring Island has been running a group since the early 90s. This group meets once a week, showing FCBC webinars on topics of interest and hosting guest speakers, carefully reserving time for caregiver sharing.

More than anything, FCBC is committed to showing caregivers that they are not alone. To learn more about our support services and resources, visit our website at [www.familycaregiversbc.ca](http://www.familycaregiversbc.ca). To stay informed about new developments in caregiving, sign up for our Caregiver Connection newsletter and our monthly eBulletin, Caregiver News You Need, at [familycaregiversbc.ca/caregiver-connection](http://familycaregiversbc.ca/caregiver-connection). ▼

# Got Boundaries?

## WHY, HOW AND WHEN TO USE THEM

Gail Rutledge, BA, CPS (F)

Boundaries in a relationship are an important part of the relationship's foundation. This is true not just in our romantic relationships but in all of our relationships. When we fail to set clear boundaries with those around us, we can end up resentful and with the feeling that we are being treated unfairly or being taken advantage of.



*Gail is Regional Educator for the British Columbia Schizophrenia Society in Quesnel. Gail holds a bachelor's degree in psychology and a diploma as a Drug and Alcohol Treatment Specialist. She is a member of the first team in Canada to gain national certification as a Peer Specialist for Families*

In my role as Regional Educator with the British Columbia Schizophrenia Society, I teach a two-part, four-hour Healthy Boundaries workshop, using materials in the SMART Recovery Friends & Family Handbook. The handbook defines "boundaries" as "the guidelines that we identify to define what we feel are reasonable, safe and permissible ways for other people to behave around us and to treat us."<sup>1</sup>

In the first part of the Healthy Boundaries workshop, we learn what

healthy boundaries are and how we can establish them. We learn how to identify our boundaries and the boundaries of others, and we discuss what to expect when we communicate with other people about our boundaries. In the second part of the workshop, we learn how to protect the boundaries we have set with our loved ones and others, we practise how to effectively communicate a boundary request and we learn the consequences when our boundary requests are not met.

## Physical and emotional boundaries and what happens when we cross them

Often when we think about the concept of a boundary, we think of the visible demarcations that separate one place from another—the border crossing between two countries, for example, the fence between two pieces of property or the wall between two rooms. We don't usually think about the invisible lines that we draw around ourselves and in our lives. These personal boundaries protect us from being hurt emotionally and physically—by ourselves and by those who are close to us. In this article, I talk about these types of boundaries, the invisible lines that we establish around ourselves for our own protection.

All healthy relationships have boundaries. Knowing our own boundaries helps us to communicate effectively if we are dissatisfied with the actions of someone else, and to request alternative behaviours from them. Knowing the boundaries of others encourages us to be respectful of other people's choices and values. When our boundaries are crossed, or when we cross the boundaries of others, this can lead to communication breakdown, discomfort and even anger.

Some types of boundaries are easier to recognize and respect than others. Physical boundaries can be crossed if someone stands too close to us or goes through our desk without permission. It is easy to see when our physical boundaries have been crossed. Emotional boundaries (for example, when someone makes a joke at our expense or uses sarcasm as communication, when a partner cheats on us or when a loved one criti-

cizes the way we look) can be harder to see. Sometimes it can be difficult to recognize when our emotional boundaries have been crossed. Often, when our emotional boundaries have been crossed, we can see clues: we might make excuses for (or try to justify) the bad behaviours of others, we might blame ourselves when things go wrong or when someone treats us poorly. We might feel shame for no reason, or we might second-guess our own decisions if someone else questions them. We might sense that something is "off" or wrong, or that we have given away our power to choose.<sup>2</sup>

Sometimes people intentionally cross our boundaries in the interest of their own personal gain. At other times, a person may not be aware that they have crossed our boundaries at all. In my workshops, I have everyone fill out a true-or-false questionnaire to see where their boundaries are being crossed—even if they are crossing their own boundaries. Most people are surprised to see how often they cross their own boundaries in their relationships.

Whether someone intends to cross a boundary or not, whenever a boundary is crossed, the result is the same. A trust is broken, and often people feel violated or uncared for.

### Five steps to healthy boundaries

Establishing clear boundaries can decrease opportunities for miscommunication and can enable us to improve the health of our relationships with others. Healthy boundaries can help us maintain and enjoy our relationships more while enabling us to remain true to our own values.

In the Healthy Boundaries workshop, I teach participants five steps to establishing clear and healthy boundaries in their relationships.

1. Identify the symptoms of your boundaries being violated or ignored. For example, identify when you feel uncomfortable about something that a loved one has said, or if you feel uncomfortable or upset about something you have heard that someone else has said.
2. Take responsibility for your own upset. Sometimes we simply react to a situation or words said, rather than taking the time to acknowledge what is being said and how it contributes to us being upset. No one can make another person upset; we choose to feel this emotion.
3. Identify new, more rational, healthy thinking and beliefs. In the Healthy Boundaries workshop, we use examples for how to do this from cognitive-behavioural therapy.
4. Identify and practise new communication skills. In the workshop, we practise these skills by learning how to use "I" statements in various situations in order to increase participants' comfort levels.
5. Implement new healthy boundary-building beliefs and behaviours.<sup>3</sup> We practise this in the workshop by using real-life examples and then working out our responses with others. Generally, we work these out on paper first so that people become comfortable setting the boundary.

## How to talk to others about your boundaries

If you feel that one of your boundaries has been crossed, it's important to communicate this fact honestly with the person who has crossed your boundary. In the Healthy Boundaries workshop, I teach participants how to respond when they feel their boundaries have been crossed. We use role-playing to practise communicating effectively about our boundaries.

Boundaries are about ourselves, not about the person who has crossed our boundary. For this reason, when we are telling someone that our boundary has been crossed, it is important to communicate using "I" statements (rather than accusing them with "you" statements).

The Healthy Boundaries workshop teaches a three-step process for communicating a boundary request:

1. State our feelings. First, we tell the person how their action (or actions) made us feel. For example, we might say, "John, when you said that my dress made me look fat, I felt angry and hurt."
2. Request a change. Second, we request that the person who crossed our boundary change or stop the action that made us feel that way.
3. Inform the person of consequences. If the person does not stop or change their actions, we tell the person what the consequence will be if they continue the actions that cause us to feel that way. Again, it is important to frame the consequence using an "I" statement ("I will do X," as opposed to "You will experience X").

## Some helpful boundary tips

Boundaries can be hard to establish and maintain. Setting firm boundaries and maintaining them takes practice.

Here are some helpful tips:

- Remember why you are making boundary requests
- Start small. Begin by addressing the sort of boundaries that are not obviously going to cause significant emotional stress. This helps us build confidence in the skills we need to set and maintain our boundaries
- Consider delivery and timing. Keep in mind that if the individual you are speaking with is emotionally distressed, physically busy or using substances, it may not be the right time to set a boundary. Discussions about boundaries should happen when both parties are feeling calm and safe
- Prepare to be challenged. When we start to set boundaries with people, they may push back harder to get what they want
- Plan to protect the boundary we are setting by reinforcing it with the person
- Lead by example. Show others that we respect their boundaries as well as our own by not crossing them. Remember that respect is a two-way street; if we want others to respect our boundaries, we must also respect theirs

For more information on the Healthy Boundaries workshop and the British Columbia Schizophrenia Society, visit [www.bcssp.org](http://www.bcssp.org) or call 250-925-4145 or email [quesnel@bcss.org](mailto:quesnel@bcss.org). ▼

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## SUCH A LONG JOURNEY— CONTINUED FROM PAGE 30

anything. My brother-in-law knew someone at the Duncan Mental Health office. I phoned them and got passed along and they said they can't really help because Marty is the person who has to come in and ask for help. I said, "Well that's never going to happen. He just won't leave the basement."

Then they told me about some program for caregivers and they could have us in for three counselling sessions and discuss this. I thought it was pointless. My wife, Amy,\* is at her wits' end. I don't think she has any idea what to do either.

Once I said to Amy that I'm almost tempted to sell the house, but that would leave Marty homeless. I had a health scare a couple of years ago—kidney cancer. That's when I thought, "If I die, his mom will be stuck with him for her whole life." He's definitely closer to her than me. If I'm not home, he will come up and see her, not talk, maybe make a meal. Lately, since I've been pushing him to get a job, he makes sure he doesn't see me. I don't think he dislikes me, but I'll call him out on stuff—and then it turns into a confrontation.

Amy and I have raised six kids, and it should be our time now. I wish we had taken more action while he was younger, when parents have a say. ▼

# Good Lives Now and Peace of Mind for the Future

## THE CRITICAL ROLE OF PERSONAL SUPPORT NETWORKS FOR OUR LOVED ONES LIVING WITH DISABILITY

Rebecca Pauls

For the past 30 years, Planned Lifetime Advocacy Network (PLAN) has worked with people with disabilities and their families to help them create fulfilling lives in their communities. Founded in 1989, this family-led non-profit organization has helped to bring families together for mutual support, learning and community leadership.

*Rebecca is the Executive Director of PLAN, a Vancouver-based social enterprise that partners with people and families facing social isolation. She regularly consults with organizations about how PLAN's network-building approach can be applied to other population groups. Rebecca lives in Vancouver's Gastown, a neighbourhood known for its immense diversity*



Photo credit: MangoStar\_Studio at ©iStockphoto.com

As every family knows, planning with people who have disabilities takes effort and intention. From planning for the future to school transitions, community involvement, financial objectives and more, very little happens without a network of caring relationships. For this reason, fostering relationships is the foundation of all the work that PLAN is involved in. PLAN supports people with disabilities to build personal networks of unpaid, caring

relationships, ensuring that there is a continuity of care even after parents have passed on or are no longer able to be as involved as they once were.

### **PLANning for a good life**

For all of us, the feeling of being connected to others gives our life meaning and offers us the opportunity to experience joy and fulfillment. Meaningful connection with others also provides space for sharing life's



passions, challenges and triumphs. Caring relationships are what fosters love and a sense of belonging; they also provide us with the support and assistance we need to make and implement life goals and plans.

PLAN's personal support networks are small groups of family members and friends who work together to establish these opportunities to benefit loved ones living with a disability, providing natural care and support to individuals who might otherwise experience isolation. These networks are the foundation for a loved one's good life in the present, and the best guarantee of their safety and security in the future.

The work that PLAN does in collaboration with networks of families and friends to address the challenge of providing long-term care begins by asking the question "What is a good life?"

Exploring the answer to this question unifies parents, caregivers and facilitators alike. It opens hearts, minds and imaginations, regardless of circumstance, age, beliefs or life experience. Discussions about a good life get to the core of every family's hopes, dreams, worries and fears for their relative with a disability. The question invites us to think beyond reliance on professional services and challenges us to reflect on the most important elements of our existence. What do we have to put in place to ensure that our loved one has a good life?

To PLAN, a good life means that each person

- knows the loving support of nearby family and friends

The work that PLAN does in collaboration with networks of families and friends to address the challenge of providing long-term care begins by asking the question "What is a good life?"

- contributes to, and actively participates in, a caring and inclusive community
- is respected and empowered to make choices
- lives in a place they call home
- enjoys a meaningful and financially secure life
- has a well-planned future, providing them and their family with peace of mind

### Every PLAN is unique

One of the core beliefs at PLAN is that every person has a unique contribution to make to the community, and the significance of that contribution is magnified when it is recognized. PLAN values each individual's unique strengths and knows that, with the support of friends, family and other members of their personal support network, a person living with disability can find opportunities to work, volunteer, create, inspire and contribute in ways that celebrate their unique qualities. Identifying an individual's gifts and determining how they can contribute leads to the growth of meaningful relationships—the foundation for a good life.

A good life also includes personal choice. PLAN believes in nurturing and honouring an individual's inherent decision-making abilities

rather than encouraging someone else to make decisions about the person's life. Honouring personal choice means taking the time to learn and recognize each person's tastes, preferences and values. It also means acknowledging their ability to discriminate—to select and choose wisely for themselves and their life.

Personal choice includes finding a true home—a home where one chooses to be. PLAN defines "home" as a place that provides continuity and security, a place that ensures privacy and reflects the personalities of those who live there. Creating a true home for a person living with disability means making sure their personal choices are reflected in their home environment, everything from the décor of their living space to whom they live with and how they plan their daily life.

There are many options today for families and personal support networks that are helping to establish a home for a loved one living with disability. In addition to home ownership and the traditional group home model, there are housing cooperatives and land trusts, which have advantages similar to those of home ownership. Home sharing offers the option of living with a loving family,

and various rental alternatives can provide flexibility and an opportunity to experience different living arrangements, which can be particularly valuable if an individual is living on their own for the first time.

Finally, PLAN acknowledges the important role that financial security plays in our well-being. Financial security allows us to plan with confidence for a future in which we can live comfortably—but also in which we can manage emergencies and other unforeseen events. We need to save money, but we also want to be able to enjoy ourselves in the present.

Many people with disabilities live on low incomes and have limited assets. PLAN encourages using a mix of financial options to help secure the future financial security of our loved ones. This typically includes ensuring that all provincial and federally available government benefits are being accessed to receive direct financial support, and help with medical, dental, optical and pharmaceutical costs, as well as help with other costs directly related to disability. People who have disabilities can also set up a Registered Disability Savings Plan (RDSP). The RDSP is a long-term savings plan to help Canadians with disabilities and their families save for the future. Many people with an RDSP are also eligible for substantial grants and bonds to increase the value of long-term savings. Building financial security also involves will and estate planning and discretionary trusts.

### PLANning for the future

For the first time in history, there are now more seniors than young people

living in Canada. According to the latest census data released by Statistics Canada, people aged 65 and older now make up 16.9% of Canada's population. People under 15 years old account for 16.6%.<sup>1</sup>

These statistics have a big impact on the future of PLAN. Currently, the median age of lifetime members of PLAN is 51, although there are some members as old as 90 who are still acting as primary caregivers for their adult children. As our medical and health care systems improve, and as our communities become more inclusive, people with disabilities—those with physical or developmental disabilities as well as those with mental health and substances use issues—are living longer and healthier lives. This means that people who need full-time or significant care are more and more likely to outlive their parents, who are most often their primary caregivers as well as the ones to grow, foster and maintain the support networks with PLAN.

These realities pose challenges for PLAN and for personal support networks everywhere. But they also suggest an opportunity for change. We have the chance to mobilize our personal support networks to create strong succession plans that ensure that the important and specific roles that parents play in the lives of our adult children can be taken up by alternative caregivers.

To learn more about PLAN, or to access information on personal support networks, health care and community advocacy, and legal and financial planning for families and individuals living with disability,

please visit [www.plan.ca](http://www.plan.ca). For information about the RDSP and upcoming wills, trusts and estates workshops, please visit [www.planinstitute.ca](http://www.planinstitute.ca). ▽



## microboards:™ creating a healthy and supported, independent lifestyle for people with disabilities

Alexi McGreer, Vela Canada

Vela Canada is a non-profit organization that works with individuals with disabilities at no cost to create customized support systems through the development of Microboards™. A Microboard™ is a unique model of care in which a small (micro) group of committed family and friends (a minimum of five people) joins with an individual with a disability to create a non-profit society (a board). With direction from the individual with the disability, the Microboard™ helps the individual plan their life, advocates for what they need, monitors their services, manages their funding and ensures they are safe. Ultimately, a Microboard™ provides the individual with the opportunity to live a self-directed, independent lifestyle.

Historically, once a child with a disability became an adult, the individual would either continue to live at home with parents or family or move into a group home with support staff managed by an agency. For some, these are desirable options. But many people living with a disability would prefer to create their own home and direct their own lives. A Microboard™ can help an individual to do just this. Because the Microboard™ manages the individual's funding, the individual can hire their own support staff and determine staff schedules. The Microboard™ also supports and empowers the person to participate fully in society, by working, volunteering, going to school or taking part in extracurricular activities—anything the individual chooses.

It is not uncommon for someone with a disability to struggle with mental health issues, because of isolation, social constraints or minimal community involvement and friendships. If an individual feels they have no choice—as if their life is controlled by a complex social system—this can increase their mental health struggles. The development of a Microboard™ can have a positive impact on not only the mental, emotional and physical well-being of the individual with a disability but also the health of the individual's parents.

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*"I was living in a group home with five other completely different people. I felt like I was merely surviving. In*

*hindsight I was very unhappy and there was very little joy in my life, but I did the best I could. I was not in control of any area of my life. One day I learned about Microboards and after setting up my Microboard it completely changed the path of my life. I learned how to live my own life and be my own person. I do whatever I want to do. I hire the people I want. I do the activities I want. I live life like everyone else. I went from a life of surviving to a life of thriving and becoming the person I am today."*

— Microboard™ user

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Many parents of children with disabilities are not aware of the supports available for their children after high school. When a Microboard™ is created, the parental obligation to care for an adult child with a disability is lifted. The responsibility of care transfers to the Microboard,™ which typically consists of family members and close friends of the individual with the disability. A Microboard™ also provides aging parents with the comfort of knowing that there will be organized support for their adult child once the parents pass on.

For more information on Vela Canada and Microboards,™ please visit our website, [www.velacanada.org](http://www.velacanada.org).

## BC Schizophrenia Society

[www.bcscs.org](http://www.bcscs.org)

The BC Schizophrenia Society supports families and loved ones who care for people who experience schizophrenia or other serious mental illnesses. Find information and tools, support groups and education events, and learn more about family advocacy. Two programs in particular include:

- **Strengthening Families Together:** A ten-session course for family and loved ones of people who experience a serious mental illness. Strengthening Families Together – First Nations was adapted in partnership with the Stó:lō Nation for First Nations communities. Visit [www.bcscs.org/support/bcscs-programs/strengthening-families-together](http://www.bcscs.org/support/bcscs-programs/strengthening-families-together).
- **Family Support Calendar:** Find family support groups and other events around BC. Visit [www.bcscs.org/events](http://www.bcscs.org/events).

## Family Caregivers of British Columbia

[www.familycaregiversbc.ca](http://www.familycaregiversbc.ca)

Family Caregivers of British Columbia offers support, education, system navigation, and resources for caregivers of adults in BC. You can also call the Caregiver Support Line for advice and information at 1-877-520-3267 Monday to Friday from 8:30am to 4:00pm.

## From Grief to Action

[www.fromgriefftoaction.com](http://www.fromgriefftoaction.com)

From Grief to Action supports loved ones of adults who use substances. Learn about substance use and find support networks and resources in BC. The Coping Kit helps families work through difficult feelings around a loved one's substance use, build communication skills, reduce some harms of substance use, take care of their own well-being, and navigate substance use treatments.

## Spotlight on Mental Health: Family Involvement

[www.spotlightonmentalhealth.com/family-involvement](http://www.spotlightonmentalhealth.com/family-involvement)

Spotlight on Mental Health offers support to families and loved

ones through Vancouver Coastal Health's Family Support and Involvement Team. Find resources on VCH systems and family policies, and learn more about the Family Connections Support group and other support groups.

## Disability Alliance BC: Help with the RDSP and DTC

[www.disabilityalliancebc.org/direct-service/help-with-the-rdsp-and-dtc](http://www.disabilityalliancebc.org/direct-service/help-with-the-rdsp-and-dtc)

A registered disability savings plan (RDSP) and disability tax credit (DTC) are tools to help families manage savings for a loved one who experiences a disability, including a mental illness. You can also call 604-872-1278 or 1-800-663-1278 (toll-free) to make an appointment with an RDSP/DTC advocate at Disability Alliance BC.


## Planned Lifetime Advocacy Network

[www.plan.ca](http://www.plan.ca)

PLAN helps families build Personal Support Networks to better support a loved one who experiences a disability. These networks ensure that a loved one's needs, preferences, and goals are fully supported while connecting family members with the right information, help, and support.

## HeretoHelp resources

- **Family Toolkit:** A workbook with information and resources to help families support a loved one. Visit [www.heretohelp.bc.ca/workbook/family-toolkit](http://www.heretohelp.bc.ca/workbook/family-toolkit).
- **Family Self-Care and Recovery from Mental Illness:** A workbook to help families take care of themselves and work well together. Visit [www.heretohelp.bc.ca/workbook/family-self-care-and-recovery-from-mental-illness](http://www.heretohelp.bc.ca/workbook/family-self-care-and-recovery-from-mental-illness).

 This list is not comprehensive and does not necessarily imply endorsement of all the content available in these resources.



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