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Family Connections

EDITED BY JUSTUN MILLER

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NEVER GIVE UP ON SOMEONE WITH A MENTAL ILLNESS. WHEN 'I' IS REPLACED BY 'WE', ILLNESS BECOMES WELLNESS. - SHANNON L. ALDER



Family Day is on February 8th here in British Columbia. As such, in this edition of the Family Connections newsletter we are going to honour families by sharing some of their courageous, inspiring stories, and hear about how they are working towards using their lived experiences to improve services and make the experiences of other families entering the mental health and substance use system less challenging.

There are over 500,000 Canadians providing care to loved ones with mental illness. Family caregivers provide care for a wide range of reasons. For some, it may be out of love and caring, a sense of duty, obligation, guilt or because there doesn't seem to be anyone else available. The support provided by family can take infinite forms including, but not limited to: financial support, driving a loved one to appointments, helping with daily activities, and advocating on their loved ones behalf to access services.

Being able to identify yourself as a family caregiver is a very important step towards recognizing the significant demands and responsibilities the role entails. Asking for help and accessing services can help alleviate the burden. It is essential to ask for support as soon as possible to avoid burnout, it is also important to practice self-care.

The Family Support Involvement team have the honour and privilege of working with family members in many different roles, and at many different stages in their journey of supporting a loved one with mental health and or substance use challenges. Please do not hesitate to contact us for support using the contact information on the bottom left hand side of this page.



Sometimes providing the appropriate care for your loved one requires you to acknowledge that you are not able and/or capable of providing them with what they need.

Please remember that if your loved one is at risk to themselves or others the best resources are your local Emergency Department, and 911.

Other resources available to you are:

Mental Health Emergency Services (MHES): 604-874-7307

Vancouver Adult Mental Health Intake (VAMHI): 604-675-3997

Children and Youth Mental Health: 604-675-3895

Older Adult Mental Health Intake: 604-709-6785

Access Central (Addictions Services): 1-866-658-1221





The *Family Connections* newsletter is available electronically, direct to your email inbox each month. If you don't already receive *Family Connections* via email and would like to stay up-to-date about programs and services supporting families with a loved one with mental illness and/or addiction, sign up for our Consumer & Family e-distribution list. Visit

www.spotlightonmentalhealth.com



Then, scroll down to the bottom of the page, enter your email address and choose the type of information you would like to receive. You will receive an email confirming you have been added to the list.



"During these years I've come to believe that much needed improvements can only come to mental health services if family caregivers work together to let others know our perspectives."

Our first piece was submitted by Susan Inman. Susan is the author of, After Her Brain Broke, Helping My Daughter Recover Her Sanity (Bridgeross, 2010), which has been recommended both by NAMI and by EUFAMI, which are the world's largest organizations advocating for families coping with mental illnesses. In Canada, it has also been recommended by the Mental Health Commission of Canada, the Mood Disorders Society of Canada, and the BC Schizophrenia Society. As well, it has received very positive reviews in numerous professional journals, including the Canadian Medical Association Journal. Susan's articles about mental illness have appeared in a variety of publications including the National Post, the Globe and Mail, the Province, The Tyee, the BC Teacher Newsmagazine, and CMHA-BC's Visions magazine. Susan is a past president of the British Columbia Schizophrenia Society's Vancouver/Richmond branch and a past vice-chair of Vancouver Coastal Health's Family Advisory Committee (FAC).

(The Huffington Post 2016)

My husband and I did not understand severe mental illnesses. Our ignorance led us to make poor choices in trying to help our daughter when the first puzzling signs emerged of what we now know was a schizoaffective disorder. We later understood that the therapist we took our daughter to, with a MA in Counseling Psychology, had trained in a program that doesn't offer science based curriculum on schizophrenia or bipolar disorder. Her inappropriate interventions led to unnecessary chaos and a two year-long profound psychosis.

Once we received appropriate help our daughter recovered from the psychotic component of her illness. Comprehensive psycho-education, that should be widely available, helped her and her friends to understand, accept and learn to manage their illnesses. A very collaborative relationship with her psychiatrist has meant that we are all working together to help our daughter with ongoing symptoms of her illness.

During these years I've come to believe that much needed improvements can only come to mental health services if family caregivers work together to let others know our perspectives. My advocacy efforts are focused on several key issues:

- Improving public mental illness literacy so people can receive basic information about severe mental illnesses and how best to respond to them
- Improving psycho-education programs so that people can develop a solid understanding of their own illnesses
- Ensuring that clinicians receive science based curriculum on psychotic illnesses and curriculum on working collaboratively with families
- Promoting cognitive remediation programs that help with the common cognitive losses associated with schizophrenia
- Strengthening the family voice so that family caregivers, as the Mental Health Commission of Canada suggests, can be involved in planning and evaluating services

My articles on mental illness policy can be found at: www.huffingtonpost.ca/susan-inman/

Nicole's involvement currently is as a member of the Stakeholder Committee for the planning of the Joseph and Rosalie Segal Family Health Center, the new mental health and addiction hospital currently being built on the Vancouver General Hospital grounds, scheduled to be opened August 2017. The Stakeholder Committee meets once a month and is instrumental in making decisions about both the physical design as well as the running of the building and the psychiatric units to be housed there. Nicole had shown an interest in the building since 2014 and has been a member of the Stakeholders Committee since September of 2015. She is also on the planning committee for the 2016 Family Conference.

Here are some of the things Nicole said about her involvement:

I finally feel I have a voice, whether it gets heard or not. I feel that I have the most involvement in the little group [of patients and family members and the patient and family coordinators]. I have also been to a family education group with Justun Miller and noticed that families have concerns that are similar. For example the lack of communication with the doctors. I was often not included, and neither was the family doctor – but what about allergies and other medical problems? Many people have medical problems, not just mental health problems. I was not the only one who talked about this lack of communication, there were other family members with similar problems. The group was really good and I learned things, for example when the pharmacist gave a presentation, talking about medication and symptoms and suggesting the use of a small pharmacy because you can build a relationship with a pharmacist there.

Why did I become involved? One of the biggest reasons I got involved was my hopes for integrated health. The mind-body-spirit connection is really important to me. I saw how well that worked when my loved one was at Early Psychosis Intervention (http://www.earlypsychosis.ca/). I found out through Justun's group that this is one of the best psychosis treatment centers in North America. They paid attention to things like diet, sleep, etc. I hope one day all of psychiatry will be like that. In particular, I'd like to see hospital food improve, it's low quality right now. Food should be healthy and not devoid of vitamins and nutrients. Also, to have the ability for patients to use alternative medicine in the hospital when that's shown to work for them, like Rescue Remedy. Of course I understand these changes are not easy – for example for the food, we have to look at the cost, too. The lack of programs is a problem, too. I noticed other patients bored with nothing to do but pace the floor. Maybe I can help with that one day as a volunteer.

I also talk to my friends and family about this. Recently, I got married, and instead of gifts, attendees generously gave monetary contributions to the cause of mental health in Vancouver.

Interviewer's remarks: This interview underscores the importance of voicing one's opinion. Some of the things Nicole talks about are in the process of being addressed, precisely because patients and families kept saying how important they are for them. We have a Family Policy and things like the communication protocol we mentioned last month because of this. Family and patients are involved in the Segal Building because people kept mentioning how important this would be. VGH is currently working on improving programming for acute patients, and has hired a psychologist to specifically deal with this issue. Family involvement works!

"I finally feel I have "The Library

Technician will

The Family Connections Support Group

The Family Support and Involvement Team has a new support group for family and friends of individuals with mental illness and/or substance use concerns.

The group is being held at the CIBC Centre for Patients and Families at the Jim Pattison Pavilion at VGH and is co-facilitated by a family member and supported by a Library Technician. We are very excited to pilot this approach of having an embedded Librarian Technician in the group and are grateful to the CIBC Centre for Patients and Families for partnering with us on this exciting endeavour. The Library Technician will provide research and up-to-date information based on the needs of the group, while showing participants how to access useful and reliable information by asking the "right" kinds of questions. In addition to all of this, we aim to create a welcoming and supportive space in which family members can share their experiences with each other and feel supported and strengthened in their efforts to help their loved ones.

The group runs twice a month and family members are free to attend on a regular basis or drop in as needed. We hope that having the group on the VGH campus will make it easier for families to attend who are supporting a loved one at the Psychiatric Assessment Unit (PAU), Inpatient Psychiatry or Willow Pavilion, though all family members and supporters are welcome.

DATE: Every first Thursday and third Monday of the month

TIME: 6:00 - 8:00 p.m.

PLACE: CIBC Center for Patients and Families at the Jim Pattison

Pavilion, Vancouver General Hospital, 899 W. 12th Ave

(behind the Information Center)

For questions or more information please contact:

isabella.mori@vch.ca, 604 290-3817 or becky.hynes@vch.ca, 604 313-1918





Family Connections



Education Series for Families

The Family Support and Involvement team at VCH is excited to offer an 8 week psychoeducation program for the family and friends of individuals who live with mental illness or concurrent disorders. This series offers information on mental illness and concurrent disorders, and will be co-facilitated by a VCH Family Support and Involvement staff and a family member. The series will also feature guest presenters on various topics.

Knowledge is power

Topics Include, but are not limited to:

- Understanding and accessing mental health services;
- Tools for effective communication among family, service users and service providers;
- Family involvement in the circle of care;
- Information on mental health and concurrent disorders;
- Understanding medication;
- Family support and self-care.

Date: Thursday evenings, March 3rd – May 12th, 2016

Time: 6:00 - 8:00 p.m.

Place: Raven Song Community Health Centre

This workshop is open to the family members and friends of individuals who live

with mental illness or concurrent disorders.

This is a closed group and registration is required.



Our next piece was submitted by T.F.T who describes her and her family's experiences and ways of coping as they supported her daughter who is battling an eating disorder. I was connected with T.F.T through the Provincial Eating Disorders Awareness Campaign (PEDAW). This piece is very timely because **February 1-7th 2016 is Eating Disorder Awareness Week**.



"When you're faced with any kind of illness, unfortunately, you aren't aware of the stress that you will endure until you're immersed in

it. "

When you're faced with any kind of illness, unfortunately, you aren't aware of the stress that you will endure until you're immersed in it. Some say that caring for someone who is ill, is more difficult on the caregiver than the person who is ill. I disagree when eating disorders are concerned. The voice and power an eating disorder has on one's mind is ruthless...in fact evil, resulting in countless health complications, many being life threatening. The loved one is incapable of seeing how dangerously ill they are, therefore, becoming very ambivalent to seeking and accepting help.

In the early stages of our daughter's illness, Donald and I didn't have any idea how seriously ill she would become or how quickly her health would diminish. We didn't give a lot of thought of how much it may exhaust us, or how her illness would affect those supporting her. We were asked numerous times throughout her illness how we coped. Our response was, we just do. When you're witnessing the vast destruction and torment of an eating disorder, you cope and get through it, especially when the one being inflicted upon is your daughter. Through my reflections, I realized we coped both consciously and sub consciously. Obviously, the answer to that frequently asked question was much more complex than those three words. There were numerous things and people that contributed in keeping us all in tact. The words that follow aren't my opinion or fact, they are, our lived experience. This is how we coped to keep our health and well being intact. We held it together and supported our daughter with everything we had, which gave her the strength and power to get well.

READING/RESEARCH. In the beginning we learned about anorexia. I did a lot of reading online, blogs and I read books about eating disorders. Reading other peoples stories helped to put ours into perspective. Doing so, helped me understand the complexity of eating disorders. This also made me feel like we weren't alone.

TAG TEAM!! Donald and I were very good at this. It is my hope that anyone supporting a loved one who is ill, is fortunate to have the kind of tag team support that I had/have in Donald. We both understood anorexia and were on the same page. We contributed different strengths, so putting those together only meant more love and support for her. Without fail, when I was having difficulty coping, Donald would be the strength and vice versa.

WRITING. I wrote my thoughts, my fears, my innermost feelings about watching our daughter slip away. I wrote down her words she spoke to me about this illness that was wreaking havoc on her mind, body and spirit. I wrote emails to family and friends updating them and explaining the vast complications of eating disorders. Putting fingers to the keyboard brought great relief!

FAMILY AND FRIENDS! Continuous prayers, love, positive words of encouragement from those close to us was helpful with keeping us in a positive mind set.

CANDLES. Lighting a single candle or an entire room of candles brings me peace and calmness. Most nights, until hospitalization, I would burn candles for all of us.

TEARS. I cried, a lot. Countless nights I cried alone. Times I cried with Donald, my mom and my sister, and with my dearest friend, Kathy. My tears were always accepted, understood and embraced.

JEFFREY & NELSON. Her older brothers remained strong and supportive throughout her illness. They managed to cope in their own ways. They didn't need to know about anorexia...they witnessed with their own eyes what it was capable of on a daily basis. They were afraid of losing her. There was an unspoken understanding that they knew she required a lot of care and attention. However, they knew Donald and I were there for them and they were there for us.

THE LITTLE THINGS...that had huge impact with maintaining our health and well being,

Endless care and compassion from the medical professionals at LifeLabs, our Eating Disorder Dr., counsellor, dietician, paramedics, our family Dr. & her staff.

We were given encouraging words and gifts from someone fighting this illness herself.

Kathy's words of encouragement on the phone during a frightening emergency room visit.

Kathy literally holding me up the day after admitting our daughter to St. Paul's Hospital.

Sleeping in her bedroom the first night of her being in hospital.

Drawing and writing to her while visiting her in hospital.

Spending moments with patients fighting ED's in St.Paul's.

Time with our cats.

Sleep.

My mom, Marie!

And now that she is recovered...spreading awareness about eating disorders.

DAY BY DAY. We took our daughter's illness day by day. Thinking ahead only overwhelmed us and made it difficult to cope with whatever was happening at that moment.

DETERMINATION, PATIENCE & HOPE! We were determined not to let anorexia win the war! Our patience never ran thin.

"Without hope, you're hooped." ~ N.H. McLachlan

"There is a sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than ten thousand tongues. They are messengers of overwhelming grief...and unspeakable love."

~ Washington Irving

^{**} Names and identifying characteristics have been changed in order to protect confidentiality.

"I knew I needed to understand the illness."



Our next piece was submitted by Sally Hull who is the Community Engagement Coordinator for the British Columbia Schizophrenia Society. Sally is a very active member of the community, and in addition to the meaningful roles that she describes below she is also an active member of the Family Advisory Committee.

I have been working for the BC Schizophrenia Society for the last five years. I first came to the Society when my oldest son was diagnosed with schizophrenia at the age of seventeen. He was already in the mental health system as he was born with a brain injury and has always presented a challenge. With this diagnosis, I knew I needed to understand the illness. It was my son's case manager who recommended I attend the education program, Strengthening Families Together. That made all the difference. I was with other people who were going through a similar journey. I learned about the brain, symptoms of mental illness, medication and how it worked, how to navigate the mental health system, and how to advocate for my son and look after myself through it all. I began to volunteer for BCSS and then was asked to join the provincial office staff.

We are a provincial organization. I receive calls from around the province and other places in the world because our website is prominent and has a lot of information. I learned how to provide support and coaching for families needing help for their loved ones. That has morphed to providing education and support for families in Vancouver and Richmond. The Vancouver Family Policy and the Family Coordinator team in VCH has made it easier to get information and help from the system. I believe we are going in the right direction.

The role I play at BCSS is to offer support when someone is not in the system or they have a relapse. I am there for families when the situation is challenging and they need support in getting the help their loved one needs, often in a crisis situation. I also work with families when their loved one is not in BC. I co-facilitate the Strengthening Families Together course and our support group and could not do it without the strong family facilitator volunteers.

Working as a team is what makes all the difference. We as family members cannot do it without the mental health system and the remarkable people who have dedicated their lives to look after a very challenging population.

From Grief to Action Support Group

Addiction is in my family; it took hold of my brother, my best friend. As one of his key support providers the consequences of addiction also took hold of me and it was devastating. As part of my recovery I decided to add my voice on behalf of families who struggle with inadequate treatment for their loved ones and the shame, blame and pain they feel. I became a volunteer to advocate on behalf of my brother so that his struggle would ultimately mean something. Volunteering was my way to begin to affect change in a system which is not meeting the needs of addicts and their families.

I am currently President of From Grief To Action, a volunteer-based not-for-profit association that provides a voice and support network for families and friends affected by drug use. It has been rewarding to see the recent inclusion of addiction in the health system and the movement to treat those who are suffering from addiction and concurrent disorders medically instead of criminally. While there continues to be marginalization and stigmatization of substance users, I remain hopeful that barriers are slowly being broken down and views are starting to change. While groups like the Family Advisory Committee, which I sit on, have made head way in including families as an integral part of the treatment continuum, families can continue to feel ostracized in their communities and by society when dealing with substance use issues. This has led me to volunteer at a bimonthly support group for families dealing with mental health and/or addiction and to share with others that they are not alone.

From Grief to Action is a volunteer-based not-for-profit association in British Columbia. They are a voice and a support network for families and friends affected by drug use. FGTA developed and published The Coping Kit for families. Available for free on their website, this toolkit offers practical advice and information for families who are supporting someone living with addiction. Topics addressed in the book include:

- Information about addiction
- Reliable information on drugs including risks, harm reduction, signs of overdose and withdrawal
- Communicating as a family
- Addiction treatment and support resource information
- How to find help
- Information about recovery

If you would like to receive a copy of this free resource, visit www.fgta.ca



PAGE 12 Parents Forever Support Group

Submitted by Isabella Mori . . .

The following is based on an interview with Frances Kenny, founder of Parents Forever.

What is Parents Forever?

Parents Forever is a professionally supported, mutual support group for parents and family members of adult addicted persons. It receives funding from Vancouver Coastal Health and the Boys and Girls Club.



When a person goes to your group for the first time, what can they expect?

I talk to every person before they come. On the web site they also learn what to expect at the meeting. When they come to their first meeting, they are often quite emotional. They are at the end of their ropes. Most have run dry in terms of helping their loved ones change, and start to realize they need help for themselves. In the meeting, they discover that they are not alone. They feel comforted by others in the group - that happens very organically. They aren't judged. They can see they are not the only ones suffering from often crippling guilt and get feedback from others on how they dealt with it. It's very empowering to hear from other people that they've found a way through it all, and to get back control over their lives.

What are some other components of Parents Forever?

PF is not a therapy group. We quickly move over to the practical side, e.g. tips on how to cope with demands for money. Mutual support can really help there: shared experience, shared resources. There is an education component – speakers come to the group, such as recovered addicts, lawyers, people who work at a treatment center. And the humour! The smiles and the laughing over something that we know wasn't the right thing to do – but, well, we're only human and infallible. Also, no-one is expected to change when they're not ready to change. We hope people want to move forward but there is no expectation around that. We never give advice, and we never try to "fix" a group member. Some of the crises that people experience are indescribable. But they come back and feel comforted, sometimes by just being there without saying anything, and getting hugs. Many parents see counsellors outside of the group to deal with the deeper emotions.

Can you give an example of a family member who has been helped through Parents Forever?

One grandfather ("Sam") is in his late seventies**. The granddaughter ("Ellie") has been struggling with addiction for years. An exceptionally intelligent person, Ellie can behave in an abusive and threatening way when she is in her addiction. Sam and his wife have struggled with this for 20 years, paid for treatment, what have you, the whole roller-coaster. Sam used to be quite afraid of Ellie but over the years he has learned to detach. He has learned to use an "inner editor" when communicating with Ellie, to have that "second sober thought," to say things like "call me back this evening" after a crisis phone call. Now he says, "I just surround her with a white light and hope that she is doing ok." Once in a while he still feels that he has no right to strive for his own goals, and that's one of the many reasons why he still comes to PF, "to get a refill". He can imagine all the group members of PF cheering him on to keep his boundaries and look after himself.

What are your hopes and dreams for Parents Forever?

There are so many people out there that are not benefiting from this yet. People come from as far as Bowen Island. The group is getting quite big. We desperately need more groups! It would also work really well if people came earlier in their loved one's crisis.

For more information, contact: Web: http://parentsforever.ca/; Ph: 604-860-4203; email: fkenny@uniserve.com

** Names and identifying characteristics have been changed in order to protect confidentiality.

Mood Disorders Association of BC (MDABC) – Mutual support groups for families of individuals living with a mood disorder. 2nd and 4th Tuesday each month, 7 - 9 p.m., Mount St. Joseph Hospital, 3080 Prince Edward St, Harvest Room A. 2nd Monday of each month, 6:30-8:30pm at Evergreen Community Health Centre (3425 Crowley) .Contact 604-873-0103

Raven Song Family Support Group— Support group for families who have a loved one living with mental illness. 2nd Wednesday of each month 6:30 – 8:30 p.m. at Raven Song Community Health Centre, 2450 Ontario Street, Vancouver. Contact Sally @ Tel: (604)270 7841 ext 2126

SPH Family Support Group- Support for families who have a loved one living with mental illness. Last Thursday of each month, 6-7:30pm. St Paul's Hospital, 1081 Burrard Street, Room 2B-169, 2nd floor, Burrard Building. To register, call Kaye 604-682-2344 local 68964

VCH Eating Disorder Program (VCHED)– **Family Support Group** – for friends and family members of individuals living with an eating disorder. 1st Wednesday of each month, 6 - 7:30 p.m., 3rd Floor, 2750 East Hastings, Vancouver. Contact Hella at 604-675-2531 ext 20689.

Parents Forever – Support group for families of adult children living with addiction. Group meets every 2nd Friday at St. Mary's Kerrisdale, 2490 W 37th Ave., Vancouver. Contact Frances Kenny, 604-524-4230 or fkenny@uniserve.com

Pathways Clubhouse Chinese Family Support Group – Education sessions for Chinese families who have a loved one living with mental illness. 2nd Saturday of each month., 1 – 4:00 p.m., Room 345/50, 7000 Minoru Blvd, Richmond. Contact Bessie.wang@pathwaysclubhouse.com or 604-276-8834, ext 12.

GRASP Support Group – GRASP offers peer-led mutual support groups for families or individuals who have had a loved one die as a result of substance abuse or addiction. 2nd Thursday of each month, 7-9 p.m. at Gilmore Community School 50 South Gilmore Ave, Rm 207. Please email graspvancouver@gmail.com to register.

SMART, Family and Friends - Support group for family and friends to learn and implement self care, boundary setting, and compassionate communication tools. Every Tuesday 6:30-7:30PM. Every other Friday 6:30-7:30 at Three Bridges Addictions 1290 Hornby Street, Rm 310. Call Oona @ 604-714-3480. Thursday 6:00-7:00PM at Raven Song 2450 Ontario Street, 1st floor. 604-872-8441.

Family Connections Support Group (FCSP)—Every first Thursday and third Monday of the month in the CIBC Center for Patients and Families at the Jim Pattison Pavilion, Vancouver General Hospital, 899 W. 12th Ave (behind the Information Center) For questions or more information please contact: isabella.mori@vch.ca, 604 290-3817 or becky.hynes@vch.ca, 604 313-1918

Family Support Groups



Sun	Mon	Tue	Wed	Thu	Fri	Sat
	1	2 SMART	3 VCHED	4 FCSP	5 Parents Forever	6
7	8	9 SMART MDABC	10 Raven Song	11 GRASP	12 SMART	13Pathways
14	15 FCSP	16 SMART	17	18	19 Parents Forever	20
21	22	23 SMART MDABC	24	25 SPH	26 SMART	27
28	29					

Notes

