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Who cares for the caregiver?

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Submitted by Diane Wild, Senior Consultant, Communications and Public Affairs

Originally published in Healthier You magazine (<http://thebeat.fraserhealth.ca/news/january-2016/healthier-you-magazine-now-online/>):

Brent Poley was a teenager when he began to go through manic periods followed by crashes into depression. At first, neither he nor his family knew what was wrong. Was it teen rebellion? Hormones kicking in? The behaviour seemed uncharacteristic for the caring boy with above-average intelligence, but then he was prescribed a number of medications that didn't relieve his symptoms either.

When he was finally diagnosed with bipolar disorder five years later, his mother Renee recalls being relieved. Though their journey wasn't over – he still had full-blown manic episodes every year, with 13 hospitalizations in 14 years – at least now they knew what path they were on.

Back then, there were fewer resources for people with mental illness, never mind their friends and families. Brent's family had to ask a lot of questions and dig for a lot of answers.

"I've had tremendous support from them," says Brent, who adds that support has grown to encompass others as well. "My mom has been an excellent advocate for people diagnosed with mood disorders."

More than 25 years after his diagnosis, and with a new medication that has been effective for him, Brent lives independently, works, has co-led support groups with Renee, and is an active participant in his community, including spending time at Langley's Stepping Stone's Clubhouse – a welcoming, supportive place for people with mental illness. Brent points out that it allows for a much-needed routine, and social connections.

Renee has continued to facilitate information and support groups, sometimes with her son. They, along with other families who struggled through the years of piecing together information and support the best they could, have helped spark an explosion of more awareness and practical support.

"I had the kind of career where I was a problem solver," Renee, a former union negotiator, says. "I was used to finding resources and pushing for more resources." She now counsels others to get educated on the major symptoms of their loved one's illness and on where to get the answers and the support they need.

Len Polak is the family support specialist with Fraser Health who works with family members like Renee to create additional supports for those with a loved one with a mental illness – and he points out that 'family' means the client's natural support system, related or not.

People in the Fraser Health region now have access to a Family Support Coordinator (<http://www.bcsc.org/branches/lower-mainland/fraser/abbotsford-branch/2010/04/fraser-region-individual-support-and-guidance/>) (1-877-717-5518) who can help them navigate the often-complex mental health care system, and learn how to take care of themselves so they can better support their loved ones.

"Often people need to sort out the difference between caregiving and supporting," says Len. "Someone who has just come out of the acute stage of an illness is vulnerable and may not be up to functioning to the point they might be in three months or six months into recovery," he says. "That's where family members tend to take on full responsibility without knowing a lot of times whether they are doing the right thing or not. Family support coordinators can help them sort out for themselves what they can take on and what they can't, and envision a time where they'll move away from a caregiving role to more of a support system."

The family support coordinators can help with guidance around the legal issues involved in trying to arrange treatment for someone who may not recognize they need it, how to convey any concerns to a case manager, where to find emotional support, and what options exist for self-care.

"When we meet with some families they may be feeling burnt out and need a break," Len adds. "For their own health and for the health of the relationship with their loved ones, they might need time away, or time at home alone, so the family support coordinators will work with them to come up with an individualized plan."

Fraser Health has a small amount of funds available that family support coordinators can use to facilitate time off for caregivers, though often a successful break doesn't require that funding.

A meet and greet service for families whose loved one is admitted to a Fraser Health hospital's inpatient psychiatric unit for the first time is provided by a family peer facilitator – someone who has been in their shoes and who can provide encouragement, emotional support, insights into the recovery journey, and talk about available resources.

Family and friends information groups as well as support groups are also available, offering emotional support and collective wisdom. Renee has helped facilitate some of these groups and has impressed Len with her dedication and compassion. With Len, Renee along with other family members also co-facilitate learning exchanges with staff on the impact of mental illness on the family, and the role family play in recovery.

“Great gratitude goes out to family members,” Len says. “Everyone writes their own story in their own particular way, and where we’re at right now, with more resources for families, has a lot to do with family members and people with lived experiences. Look at the clubhouses for example – they were created based on their voiced needs. We are able to ask what works, and from their perspective, what did you need when you were coming through the doors the very first time?”

Though she’s not done advocating for more mental health resources and information sharing, Renee sees a vast difference from the days when she was going to the library and bookstore developing the tools she needed herself.

“If the Early Psychosis Intervention (<http://www.earlypsychosis.ca/>) program had existed back then, we would have been so much better off,” she says as one example, referring to the provincial program to detect conditions that cause people to, at times, be unable to tell the difference between what is real and what is in their minds. The program also includes families as part of the treatment team right at the get-go.

Len credits Renee with helping build resources for those with mental illness and their loved ones, and Renee in turn credits her son with supporting her through the process of providing support to him and, as time went on, others facing similar circumstances.

“Brent has helped me help him. I think something that gets forgotten is that your own loved one helps you hang in there through the difficult times. You become a team,” Renee says.

Where to find help

Delivered in partnership with the BC Schizophrenia Society, Fraser Health offers a variety of education and support services to family members of people living with any mental illness diagnosis. Services include:

- Individual support:
 - Planning: includes discharge planning, treatment planning and advance planning
 - Recovery: includes education, self-care, skill development, problem solving, goal setting and general advice
 - Referrals: includes community resources, support groups and Fraser Health services
 - Advocacy: includes direct interventions, coaching and system navigation
- Individualized respite care
- Peer support groups
- Community workshops for families
- Community education on mental illness
- Online family support

For access to any of these services, anyone can call a family support coordinator in the Fraser Health region at 1-877-717-5518.

Comments

Mary Ann Sikora

I loudly applaud your efforts to provide support and community groups of those people that have a loved one with a mood disorder. I have walked this journey with my daughter from teenage hood to early 30's. I can only describe it as frustrating, heartbreaking, and very difficult. I am so happy that families can be supported as they negotiate this journey with their loved ones. It feels like the stigma of having a mood disorder/mental illness is finally starting to decrease. Congratulatinos on your amazing efforts to offer this service to families.

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