

The Family Voice

What your Family Advisory Committee is doing for you

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VISION

Family will be integral members of the recovery process and will be embraced by and actively engaged at all levels of the organization.

MISSION

The Family Advisory Committee (FAC) is a partnership between CAMH staff and family members affected by a family member's mental illness and/or addiction. The CAMH FAC will engage with families, patients, community members and care providers to improve client care and enhance the experience of both patients and their families at CAMH.

DEFINITION OF FAMILY

Any person or group of people someone identifies as belonging to their family or significant circle of support.



Meet the treatment team

Patients at CAMH, whether they're inpatient or outpatient, meet many people during their care. Depending on treatment needs, your family member's interprofessional care team may include some or all of these health care providers:

Psychiatrist: A psychiatrist is a medical doctor who has special training in treating mental illness. They can assess people who may have a mental illness, prescribe medications to treat their symptoms, and provide therapy or counselling.

Nurse: A mental health nurse gives emergency and crisis care, dispenses medication, does assessments, monitoring, counselling and helps with activities of daily living so patients can manage their mental illness and live fulfilling lives.

Psychologist: A psychologist has specialized knowledge of mental health problems. They often give tests to find out how people are functioning in areas such as intelligence and personality. They can test to assess brain function. Psychologists can also see people for therapy and counselling.

Social worker: A social worker bridges the gap between treatment and the community. They do assessments, provide therapy, and can organize

and, if necessary, supervise visits with your family member. Social workers can help find housing, get financial support and contact other community supports on behalf of your family member.

Recreation therapist: A recreation therapist helps people spend their free time in healthy ways, assisting them to exercise their bodies by playing sports, walking and keeping fit, and exercise their minds by playing games and taking part in a wide range of social activities.

Occupational therapist: An occupational therapist can help with everything from daily tasks to gaining employment skills. They help your family member to see their strengths, and they support opportunities for learning and developing daily living skills.

Spiritual and religious caregiver: They visit patients and families, and provide support and worship services in different faith traditions. The team helps people find meaning, purpose, hope, connection, values, identity, and deal with loss.

Peer support workers: These trained workers use their lived experience with mental illness and/or addiction to help clients set and reach their recovery goals. They work collaboratively with them as coach and liaison, and help clients to advocate for themselves.

Pharmacists: These invaluable members of the team respectfully dispense medication, and are available to discuss effects, side-effects, interactions and safe administration with your relative and, if invited, with you as well.

Dieticians: These regulated health professionals deal in nutrition, food and healthy eating, helping clients improve their physical health, and with it, their mental health. Their work can include the management of diabetes, weight, Celiac disease, poor intake, and eating disorders.

—Mara Haase, CAMH FAC member

Message from the Co-chair

Every year in November patients and families get to tell CAMH about their care at CAMH by filling in an Ontario Perception of Care (OPOC) survey.

Those surveys are analyzed by the Patient and Family Experience Team at CAMH, and the

feedback we receive helps us understand what we are doing well, and where we need to make improvements. The team then takes these results back to patients and families to hear their quality improvement ideas.

One project that came from these ideas—the co-developed Café Connection—is an opportunity for families to connect, learn and share their experiences with other families.

We start connecting with family members and patients in the summer to hear your ideas for change. If you would like to share your thoughts please email family.engagement@camh.ca, fill out our survey [https://is.gd/survey_OPOC2019], or drop in to the Family Resource Centre!

—Miriam McCann, Manager,
Patient and Family Experience



FAC member list, 2019–20

Back row, from left: Susan Conway, John Im, Mara Haase, Pauline Lefebvre-Hinton, Miriam McCann, Nicole Waldron. *Front row, from left:* Vivien Cappe, Gilda Martens, Thanisa Sundaralingam, Mary Beth Odell and Ashley Bowe. *Absent from photo:* Shahla Pezeshkzad and Robert Burns.

Internal working groups and committees the FAC is on: all three CAMH program Quality Councils, Schizophrenia Program Working group (CCR Subcommittee), Gifts of Light: Family and Friends Yoga Program, Café Connection Planning Committee, the Patient and Family Partners Project: Steering Committee and many others.



Meet the member: Robert Burns

What drew you to the FAC?

I believe if we can make the family experience a better experience, then the patient experience will be a better one as well, and more people will be helped. So when the opportunity came up at CAMH, I wanted to give back and get involved with an organization like FAC that was committed to helping families and was striving to make sure the family experience is a better one.

What's been the most rewarding thing you've done on the FAC?

The most rewarding thing for me personally was spending a day with physicians and CTO [community treatment order] co-ordinators from across Ontario at a knowledge exchange. It was a great way to learn—not just by listening, but I made a presentation on the CTO journey as a caregiver and substitute decision maker—and it was on my birthday! A great gift to me and I hope it was meaningful to others as well.

How long have you been supporting your family member?

Our youngest has been struggling with a mental illness for about the last six years. His first hospitalization was at CAMH five years ago in February 2015.

Have you felt a shift in how family members are regarded by mental health professionals?

There has been some improvement in terms of care providers seeing family members as partners

in care, in some settings more than others. However, there is still much room for improvement, which is why the FAC's work is so important.

What is the best piece of advice you received from another caregiver?

I have received timely advice and input from many people all along the way through the various twists and turns as a caregiver. What I've learned is there is no "blueprint," but by continually tapping into those around me I have received extremely valuable advice that has helped me to be a better caregiver and father.

Do you have a favourite saying or pearl of wisdom to pass on?

Sherly Sandberg wrote a book called *Lean In* about two years before my son was first hospitalized. The book was not on mental illness, but I think the saying is very appropriate for caregivers. Some days are very difficult as a caregiver, and often more difficult for the one with the illness. However, by "leaning in" I have found silver linings, learnings, and rays of sunshine at times that have been difficult and dark. So for me this means a lot—keep leaning in and do not give up, hope that over time things will get better for your loved one and, maybe, things will be made better for others along the way.

Self-care corner: Yoga

Everyone knows that self-care is important when you take care of someone with any illness, mental or physical. I have tried many different self-care strategies, and I think I have finally found one that works for me.

I have been taking Evonne Sullivan's Family & Friends Yoga class every Wednesday at CAMH. I am finding it very beneficial for my physical and mental health. It's an hour and fifteen minutes of "me" time and an important part of my self-care and wellness. It is very grounding and helps to relieve the day-to-day stress in my life. It helps me to feel strong physically and emotionally.

At the start of each class Evonne says:

"We take a few moments to come into the present moment. Starting to bring your awareness to this room, the present moment...knowing that this is where we are now. It is your practice, your mat, your day.

Begin to notice your breath, following your inhale and exhale."



And so begins my "me" time.

Why is yoga good for self-care? Practising yoga is the act of taking time for one's own self-care. It offers mental, physical and emotional benefits, as well as being a resource for healing.

How does it help immediately? Yoga (breathing, mindfulness, movement and postures) in the present moment can assist with anxiety or stress through calming and grounding techniques. Vice versa it can assist with depression or fatigue through energizing and uplifting practices. Yoga also provides relaxation, a sense of ease and a temporary break from life's stressors.

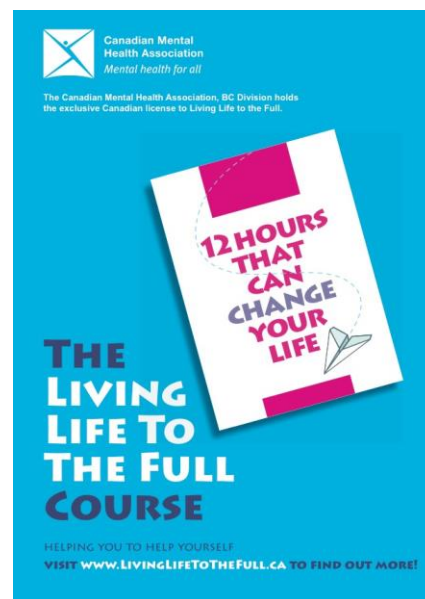
How does it help mid-term or long-term? The long-term practising of yoga brings about changes in brain and nervous system functioning, which has the potential to aid with mental health challenges such as stress, anxiety, fatigue, depression, trauma and addictive behaviours.

How do I start? You can attend Family & Friends Yoga, or check out studios that offer gentle yoga or beginner classes. Tell the instructor it's your first class when you arrive. You can also check YouTube for beginner classes. During class you can come into resting postures or take breaks. Check in with yourself regularly to discover what is right for you. If you have health concerns, make sure to consult with a physician before starting.

Friends & Family Yoga is typically held Wednesdays from 5:30 to 6:45 p.m., at 100 Stokes Street in the Sacred Space on the second floor. Yoga mats are provided. COVID-19 guidance has put in-person classes on hold for now, but you can connect directly with Evonne for virtual classes at info@evonnesullivan.com

Evonne Sullivan is a featured guest on You've Changed: A CAMH Wellness Podcast, episode 02: <https://soundcloud.com/camhnews/youve-changed-episode-02>

—Gilda Martens, CAMH FAC member



Family learning: Living Life to the Full

Living Life to the Full is a fun and engaging eight-week course that provides people with effective tools to maximize their ability to manage life's challenges. It's a 12-hour investment that can change your life.

The course is based on the principles of cognitive-behavioral therapy (CBT), which focuses on understanding how your thoughts, feelings and behaviours work together to affect your well-being. CBT is a psychological treatment developed through scientific research that has been proven to work well for many kinds of problems. These sessions are based on CBT work by Dr. Chris Williams, an expert and trainer in CBT and Professor of Psychological Psychiatry at the University of Glasgow.

This approach teaches that all the things we experience, think, feel and do are interconnected. Just as an event, thought, feeling, behaviour or physical symptom can start the chain reaction that gets us down, so too can we reverse the process and use this interconnection to rebuild happiness.

Participants are taught how to deal with their feelings when fed up, worried or hopeless, and learn skills to help them tackle life's problems. Each 90-minute session focuses on a different topic, such as: Why do I feel so bad?, Why does everything always go wrong?, The things you do that mess you up, and 10 things you can do to feel happier straight away.

Most Canadian Mental Health Association Ontario branches deliver the program for [adult caregivers 55+; for caregivers of any age who support people living with autism](#); and, likely in the near future, for youth ages 13 to 18.

Contact H  l  ne Roussel at 416 977-5580 ext. 4135 or hroussel@ontario.cmha.ca

—Gilda Martens, CAMH FAC member

Spotlight organization: The Ontario Caregiver Organization

When you support someone with a mental or physical health problem, you earn the title of caregiver. Caregiver distress and burnout are on the rise, particularly among those caring for someone with a mental health challenge. In Ontario, caregivers now have a new voice: The Ontario Caregiver Organization (OCO), which was created in spring 2018 to support Ontario's 3.3 million caregivers.

A 2019 opinion poll conducted by the OCO indicates that 46 per cent of caregivers who support someone with a mental health challenge are not handling the situation well. They are not coping well emotionally (57%), nor coping well physically (47%), often feel anxious or worried (87%), and frustrated, helpless and trapped (82%), and have disturbed sleep (80%).

In response, OCO worked with caregivers to identify what they need to support their own mental health, and created [The Caregiver Wishlist: Caring for the Mental Health of Caregivers](#). Wishes of caregivers include greater empathy and respect, help navigating the health care system, timely access to services, and caregiver mental health support. This wish list is the foundation for OCO's future work.

The Ontario Caregiver Helpline was created to address the most pressing need: a single point of access for information and support. Calls are taken in English or French, 24/7, by community resource specialists who understand the unique needs of mental health caregivers, and are supported by the [Ontario 211 Community and Social Services Help Line](#)'s database. Resources include health care, housing, income support, mental health and addiction services. Where available, eligibility criteria and other pertinent information is shared with callers.

If you need support or have care questions, call the 24/7 Ontario Caregiver Helpline: 1 833 416-2273 or use the live chat Monday to Friday, from 7:00 a.m. to 9:00 p.m. at ontariocaregiver.ca.

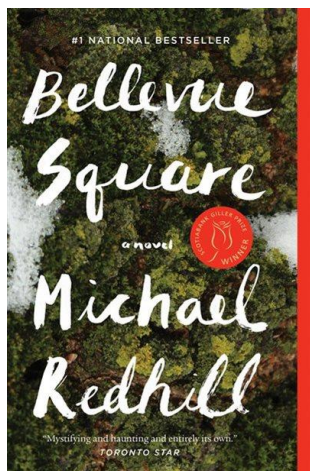
—Vivien Cappe, CAMH FAC member

—Mary Beth Odell, CAMH FAC member



Reviews: Books and more

The FRC has a small curated collection of family-facing books available for borrowing. If you'd like to write a review for *The Family Voice*, please call, drop in or send us a note at family.engagement@camh.ca.



Bellevue Square. Michael Redhill. Doubleday Canada, 2017. 288 pages, \$21 hardcover. Winner of the 2017 Scotiabank Giller Prize.

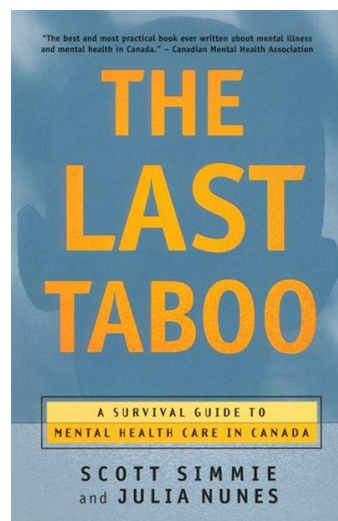
The Gist: A novel about a Toronto woman who fears for her sanity—and then her life—when she learns that her doppelganger has appeared in a local park. A story about mental illness, identity, perceptions and how we see ourselves through the eyes of others, set in Kensington Market's Bellevue Square.

The Good: Aside from enjoying the many references to familiar downtown Toronto institutions and landmarks including Kensington Market and CAMH, the author explores mental illness in a way that held my interest throughout the book. I found the nuanced depictions of the eccentric characters in *Bellevue Square* to be human, honest and empathetic. *Bellevue Square* is a very well-written, captivating story.

The Bad: The plot may be a bit too bizarre for some readers, and the ending left a lot of abandoned plot lines. Not the best read if you like a linear story with a crisp beginning, middle and end. I also had a difficult time determining what

was real and what was in the protagonist's head, but maybe that's the point?

—Mara Haase, CAMH FAC member



The Last Taboo: A Survival Guide to Mental Health Care in Canada. Scott Simmie and Julia Nunes. McClelland & Stewart, 2002. 352 pages, \$22.99 paperback.

The Gist: A one-stop shop for those new to the world of mental illness who seek a better understanding of mental disorders, and who are looking for practical information on how to navigate the Canadian mental health care system.

The Good: Peppered with first-person accounts of the complexity of mental illness from the perspective of the patient and their family and friends, *The Last Taboo* brings to life the bewildering onset of mental illness and the many challenges that follow.

The authors—Canadian journalists—use plain language to cover what mental disorders are, the roles played by families, friends and co-workers in recovery; the complexities of finding effective care; the challenges of the Mental Health Act; the pros and cons of medications; alternative treatments; suicide and its effect on families; and finally, the lasting damage of societal stigma.

The first-person accounts in *The Last Taboo* movingly describe how the signs of mental illness creep into our lives, both subtly and dramatically, which may help dispel the self-blame many family

members feel at the beginning of a mental health crisis. For certain, readers of this book will find well-balanced, practical information about mental illness management and recovery.

The Bad: This was written in 2002, so information could use updating. It is remarkable, however, how relevant the book remains after 18 years.

—Mary Beth Odell, CAMH FAC member

15 Canadian books to read about mental health

Thank you to [CBC Books](#) for this amazing list of works to read at a time when mental health is being stretched like never before. Please see the original article for writeups on all the books mentioned at www.cbc.ca/books/15-canadian-books-to-read-about-mental-health-1.5444278.

A Mind Spread Out on the Ground, by Alicia Elliott (Doubleday Canada, 2019)

Angry Queer Somali Boy: A Complicated Memoir, by Mohamed Abdulkarim Ali (University of Regina Press, 2019)

From the Ashes: My Story of Being Métis, Homeless, and Finding My Way, by Jesse Thistle (Simon & Schuster, 2019)

Hello I Want to Die Please Fix Me: Depression in the First Person, by Anna Mehler Paperny (Random House Canada, 2019)

Be With: Letters to a Caregiver, by Mike Barnes (Biblioasis, 2018)

To the River: Losing My Brother, by Don Gillmor (Random House Canada, 2018)

Waiting for First Light: My Ongoing Battle with PTSD, by Roméo Dallaire (Random House Canada, 2019)

Fire Song, by Adam Garnet Jones (Annick Press, 2018)

That Time I Loved You, by Carrienne Leung (HarperCollins Publishers, 2018)

Heart Berries, by Terese Marie Mailhot (Doubleday Canada, 2018)

The Woo-Woo: How I Survived Ice Hockey, Drug Raids, Demons, and My Crazy Chinese

Family, by Lindsay Wong (Arsenal Pulp Press, 2018)

Dear Scarlet: The Story of My Postpartum Depression, by Teresa Wong (Arsenal Pulp Press, 2019)

Brother: A Novel, by David Chariandy (McClelland & Stewart, 2018)

Break in Case of Emergency: A Novel, by Brian Francis (HarperCollins Canada, 2019)

The Ghost Garden: Inside the Lives of Schizophrenia's Feared and Forgotten, by Susan Doherty (Random House Canada, 2019)

Podcasts for caregivers

The Change Foundation got a major opportunity to showcase the work it does with caregivers in Ontario on the [Parents Are Hard to Raise](#) podcast, an American radio talk show. There are seven episodes, all of them excellent, and we suggest you start with [Embrace—Caring for those with mental illness and addiction \(episode 121\)](#). The other episodes are 111, 117, 119, 124, 125 and 127; read the descriptions here: <https://changefoundation.ca/parents-are-hard-to-raise/>

Resources

ACCESS CAMH

Providing centralized information, intake and scheduling for most CAMH services, Access CAMH makes it easy to find the help and services you need with a single call. Access CAMH Family Line is 416 535-8501, press 2, listen to the choices to the end, and you'll be connected.

For community resources on a wide range of topics, check out: www.camh.ca/en/health-info/guides-and-publications/community-resource-sheets

FAMILY INFORMATION AND SUPPORT

CENTRE phone line is an information and support resource for CAMH families during COVID-19. It includes a recorded message on current CAMH policies and where to find more information on a variety of topics. Callers can also leave a message with questions about services and supports: 416-535-8501 ext. 33472.

FAMILY RESOURCE CENTRE (FRC) at CAMH

A safe space, with materials on mental health and addiction, a lending library, and information on community supports and family-focused events. Usually open Mon. to Fri., 9:00 a.m. to 4:45 p.m.; closed until COVID-19 restrictions are lifted.

Café Connection is an informal gathering of CAMH friends and family members. Typically the third Tuesday of the month, 6:00–8:00 p.m.; call for hours when COVID-19 restrictions are lifted.

100 Stokes Street, ground floor, room 1314

Tel.: 416 535-8501 ext. 33202

Email: family.engagement@camh.ca

www.camh.ca/families

FAME (FAMILY ASSOCIATION FOR MENTAL HEALTH EVERYWHERE) RECONNECT

FAME offers families ongoing monthly support groups across the GTA. The groups are drop-in format and are facilitated by FAME staff. One-on-one support is also offered.

416 248-2050

www.reconnect.on.ca/

FAMILY OUTREACH AND RESPONSE PROGRAM, CANADIAN MENTAL HEALTH ASSOCIATION (CMHA)

Educational information, support services and referrals for friends and family of people recovering from serious mental illness, from health care professionals and people with lived experience.

416 539-9449

toronto.cmha.ca/programsservices/family-support

THE ONTARIO CAREGIVER ORGANIZATION

Independent non-profit dedicated to caregivers.

1 833 416-2273 for 24/7 helpline

Online chat 7:00 a.m. to 9:00 p.m., Mon. to Fri.

www.ontariocaregiver.ca

MOOD DISORDERS ASSOCIATION OF ONTARIO (MDAO)

Information, resources and support groups for people with depression, anxiety and bipolar disorder, and their families and friends. Services include WRAP for Families; drop-in groups and short-term professional counselling for families.

1 888 486-8236 or 416 486-8046

416 486-8046 ext. 300 (line for family members of youth ages 14 to 35)

www.mooddisorders.ca or www.mdao.ca

Online learning for families

[Empowering Families](#) is a series of online courses created by CAMH to support you, as a caregiver, through a time that is stressful and overwhelming. Topics include understanding your relative's problem, the impact that can have on you and your family, ways to support them and how to practise self-care. You can access the material anytime, choose which sections you want to do, and work at your own pace. You can find [Empowering Families Affected by Substance Use Problems](#) and [Empowering Families Affected by Psychosis](#) at <https://moodle8.camhx.ca/moodle/> along with tutorials on mental health and youth, depression, addiction and more.

Family matters

We want to hear from you!

Family members—including relatives, partners, friends and co-workers—play an essential role in supporting the care and recovery of people living with mental illness and/or addiction.

Do you have an experience or story to share?

Do you have feedback about your experience at CAMH?

Your voice matters and we want to hear from you!

How to share feedback with CAMH's Family Advisory Committee (FAC):

- Phone: 416 535-8501 ext. 33202
- Email: family.engagement@camh.ca
- In person when COVID-19 restrictions lift: Family Resource Centre, room 1314, Bell Gateway Building at 100 Stokes Street on Queen Street site. Hours are 9:00 a.m. to 4:45 p.m., Monday to Friday.

The logo for CAMH (Canadian Mental Health Association) is displayed in a large, bold, purple font.