

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 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.



Caregiver burnout: Why it happens, what to look for

It's a given that mental health and addiction problems have a tremendous impact on families. Many of us are the main (non-professional) care providers for our loved ones, as well as their tireless, vocal advocates in an often confusing and frustrating health care system. Indeed, as described in a report by the Family Mental Health Alliance, these caring family members:

- act as informal case managers, encouraging and supporting treatment, identifying and securing housing, and arranging for income assistance
- provide crisis intervention
- assist with system navigation
- advocate on behalf of their loved one
- monitor symptoms and try to lessen risk of relapse
- maintain records of treatments, medications and hospitalizations
- provide information on the context of a loved one's life, to assist professionals in understanding them as a whole person.

It's no wonder caregiver burnout is a reality.

What does burnout look like?

Those of us who care for a family member with a mental illness or addiction live, every day, with the impact and consequences of those issues. The impact is multi-faceted and often complex. It is emotional, physical, mental, financial, social and spiritual. In my own experience as a caregiver, the impact of my sibling's mental health and addiction issues has affected my life in many ways, including:

- emotional difficulties in coming to terms with my brother's diagnosis
- disagreements with other family members about the best way to address his problems, resulting in stress, anger, guilt and fear
- inadequate supports for both me and my brother led me to lose hope and become depressed at times
- financial difficulties associated with accessing timely supports for him (e.g., private drug rehabilitation program, housing, food, personal time off work)
- isolation from other family members and friends and feeling stigmatized and alone
- physical manifestations of stress and burnout including fatigue, loss of appetite and difficulty concentrating.

Who is helping caregivers?

We caregivers devote significant time, energy and resources to caring for our loved ones. But who is caring for us? Without adequate self-care and external support, caregiver burnout is almost inevitable. Therefore, it's important that caregivers take special steps to take care of themselves. After all, if we can't care for ourselves, how can we properly care for our loved one?

On a system level, we caregivers are in need of support and tools not only to better care for our family member but also to better care for ourselves. In the words of my FAC colleague, Nicole Waldron, "Many caregivers are suffering in silence taking care of their loved ones and it is inadvertently affecting their mental health. It is time to address the mental health of caregivers. If the needs of caregivers are not addressed, they will become the next patients."

Five ways to battle burnout

Some of these strategies were shared with me on my caregiver journey. Others I developed myself:

- If you are a sibling of someone with mental health or addiction problems, talk to your parents openly and honestly about your feelings. It's important that your parents pay attention to your life as well. Openness and honesty—although difficult at times—is what will help your family get through tough times.
- Talk with others who have been through similar experiences. You are not alone and you don't have to feel alone.
- Pace yourself. You can't do everything all the time. If you try to, you will inevitably burn out.
- If you don't look after yourself, how will you be able to care for your loved one?
- Find a way to laugh often!

Additional resources

Help for Caregivers and Family Members

<https://toronto.cmha.ca/help-caregivers-family-members/>

The Ontario Caregiver Organization, an independent non-profit funded by the Ministry of Health, is dedicated to caregivers. It offers:

- a 24-hour, seven-day-a-week helpline: 1 833 416-2273
- online chat 7:00 a.m. to 9:00 p.m., Monday to Friday: www.ontariocaregiver.ca
- a website with a huge range of resources: www.ontariocaregiver.ca

Being There: When Mental Illness Strikes Someone Near You. Katherine Farris and Larry MacDonald. www.beingthereguide.com

Caring Together: Families as Partners in the Mental Health and Addiction System

http://ontario.cmha.ca/wp-content/uploads/2006/11/caring_together_2006.pdf

Also see "Self-care corner: Self-compassion" on page 4 in this newsletter.

—Mara Haase, CAMH FAC member

Message from the Co-chair

The Family Advisory Committee (FAC), which resides within CAMH's Patient and Family Experience (PFE) team, supports family engagement in mental health and addictions at a provincial and sometimes national level. For these current and recent projects, we worked with:

- the **Change Foundation** to create a three-module e-learning for health care staff on family engagement and its important role in patient care
- the **Mental Health Commission of Canada** to create a guide for clinicians to increase their awareness of the necessity for family engagement and provide innovative ideas to support organizations
- **health care partners and other community leaders** (e.g., educators and police) in Prince Albert, Saskatchewan, to teach the importance of working with families to support patients with addictions. We also shared CAMH's journey creating the Office of Family Engagement.

We are always looking for new and exciting opportunities to partner, share our work, and learn from others!

—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



Meet the member: Mara Haase

What drew you to the FAC?

My experiences supporting a sibling with complex mental health and addiction challenges, and the frustrations I experienced at all levels (both at CAMH and elsewhere) in getting him the care he requires, motivated me to join the FAC. I also felt that us siblings in particular do not have a strong voice and that we are not always looked at as important partners in our loved one's care.

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

Currently I am the only FAC member who is supporting a sibling, so I am pleased to be bringing that unique perspective to the work of the committee. It's also been very rewarding to see how bringing the family perspective to CAMH has helped affect change in terms of improved supports for the families of those accessing services here.

How long have you been supporting your family member?

My brother has been struggling with mental health challenges and a substance use disorder for almost 15 years, and I have been supporting him all that time.

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. This is especially important given that family support is a very important factor in recovery. However, there is still much room for improvement, which is why the FAC's work is so important.

What would you say was the best piece of advice you received from another caregiver?

"You can't help your loved one if you aren't taking care of yourself first." Don't lose yourself in helping your loved one. Protect and nurture your own physical, mental and emotional well-being. Seek out support for yourself too! You don't have to feel alone.

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

If there is no struggle, there is no progress.

Self-care corner: Self-compassion

Supporting someone with a mental health and addiction diagnosis can be a long-term challenge filled with frustration, disappointment and doubt. Fear for the future, self-blame for the past, safety concerns, financial stress and more can lead to caregiver burnout.

No matter how stressful your responsibilities are, there are many things you can do to ease and even prevent caregiver burnout. Remember, you are not alone on this journey!

Learn self-compassion

It is normal to have negative feelings about your caregiving responsibilities and your loved ones' situation. Accepting your feelings does not make you a bad person. Give yourself credit for all of your hard work and well-meaning care. Acknowledging your caregiving efforts and forgiving the inevitable mistakes allow you to focus on the present so that you can move forward and accept the challenges of your caregiving role.

Ask for help

You are always a rock for your loved one, so let someone be your rock. Be realistic. There are limits to what you can do. Reach out and ask friends and family for help, join a support group, share your

story with others and don't be afraid to seek professional help for yourself.

Say no

Don't feel guilty turning down requests for extra volunteer positions or projects at work. Don't always be the first to offer help to others. Take stock of your personal limits. Knowing when to say no takes practice and courage.

Be flexible

Give yourself permission to allow your role to change as care needs change. Re-evaluate your schedule and roles as your needs and circumstances change.

Schedule time for yourself

Schedule "me" time doing something that you enjoy. Go to a movie with a friend, read a book, work on your hobbies, spend time in nature, hang out with a friend—whatever brings you joy.

Practise healthy habits

Make sure you eat regular meals and take time for a healthy snack. Keep well hydrated. Be aware of your consumption of tobacco, caffeine, alcohol and other drugs. Many of these can cause you to become more stressed instead of relaxing you. Sleep and exercise will help your mood and your energy level, too.

—Vivien Cappe, CAMH FAC member

—Mary Beth Odell, CAMH FAC member



Spotlight organization: The Gatehouse

Injury, whether physical, emotional or sexual, affects us all in different ways. Trauma is the

emotional response when an injury overwhelms us. The effects of trauma can show up in people in many ways including as depression, posttraumatic stress disorder (PTSD) and substance dependency. The inter-relationships of trauma, mental illness and addictions are well known. Indeed, for many people who receive mental health services, trauma remains unrecognized as an important factor in their mental illness.¹

Our experiences in childhood play a big part in shaping our health and well-being throughout our lives. As such, it is not surprising that people who have experienced childhood sexual abuse are at a higher risk of developing certain mental illnesses and problems with alcohol and other drugs. This is why it's important to find help as soon as possible. Connecting with others who care about and support people who've been abused can help protect them from the negative impact of childhood sexual abuse and help them heal.

The Gatehouse Child Abuse Investigation and Support Site ("The Gatehouse") is a community-based charitable organization that provides much-needed support, resources and community to survivors of childhood sexual abuse. Since its creation in 1998, the organization has provided thousands of children, youth and adults affected by childhood sexual abuse with a safe place to tell their stories, give them back their voices, heal their wounds and inspire them to see their own potential. The Gatehouse offers a variety of programs and services, including a 15-week peer-led support group program, police and child welfare worker investigation support, art therapy program, as well as training and suicide intervention.

The Gatehouse is located at 3101 Lake Shore Boulevard West in Toronto (at Kipling). People wishing to access services can self-refer over the phone or online:

416 255-5900

<http://thegatehouse.org/>

1 *Trauma: Common Questions*. CAMH.
www.camh.ca/en/health-info/guides-and-publications/trauma

—Mara Haase, CAMH FAC member

WHERE ARE YOUR FAC MEMBERS?

FAC members are representing family interests through:

External committees and projects:

- OFCAN (Ontario Family and Caregiver Advisory Network)
- Mount Sinai Health System: Informing the Strategic Plan
- Conflicts of Interest Advisory committee, Toronto Academic Health Sciences Network (TAHSN)

Internal committees and work groups:

- all three CAMH program Quality Councils
- Family Education Sessions, in partnership with the Family Resource Centre (FRC) and Access CAMH
- Constituency Council
- Clinical Quality Committee of the Board
- Schizophrenia Program Working Group (Complex Care and Recovery [CCR] sub-committee)
- Patient and Family Partners Project Steering Committee
- Recovery College Advisory Committee
- Phase 1C Kiosks Working Group
- Gifts of Light: Family and Friends Yoga Program
- Measuring Family Engagement: Slaight Family Centre research project
- Family Education Groups: re-design project with Slaight Family Centre
- Safe and Well Nominating Committee
- Family Social Evenings Planning Committee

bipolar disorder, and the fierce love and dedication of his mother (“Bird”). This is a journey that brings us through the despair, confusion and loss associated with mental illness, and shows us how the love of one person can inspire the strength required for the journey through recovery.

The Good: Zack details his story with riveting intensity, making the reader relate to just how real his delusions feel, giving us insight into the gut-wrenching experience of bipolar disorder. He describes this with hilarity one moment and heartache the next. His story is a reminder of our own vulnerability and the boundlessness of what it means to be human and to be loved.

The Bad: I would have liked to hear more about what the experience was like from Zack’s mom’s perspective. How did she stay so strong for her son and what was the experience like for her? It would have been interesting to devote a chapter to this.

—Katelyn Stewart, sibling



Genetic Me. Directed by Pernille Rose Grønkjær. Written by Lone Frank. 2014. 56 minutes running time.

The Gist: *Genetic Me* is a fascinating one-hour documentary exploring the origins of personality and brain function. Why do members of the same family, sharing many of the same genes and exposed to the same environment, interact and experience the world very differently? Danish science journalist Lone Frank goes on a hunt to discover the roots of her personality, and wants to find out whether she can change her unwanted traits. She asks: Do our genes determine our happiness and success in life, or are other factors at play that alter our life’s course?

The Good: Speaking with some of the world’s leading experts in the fields of neuroscience, psychiatry, genetics and human behaviour, Frank’s witty and intelligent interview style made the complex scientific subject of “nurture vs. nature” understandable. The film’s insights about personality and behaviour lifted the guilt and confusion I have felt about my loved one’s struggles. The genetic lottery is not always fair. *Genetic Me* gave me hope.

The Bad: This is a very balanced documentary that dives into the science of genetics, personality and destiny. That’s a good thing! However, some of the leading experts interviewed in *Genetic Me* point out some surprising research that may be troubling to some viewers.

For more about the film, see <https://geneticmefilm.com/> To watch for free, try https://youtu.be/At27wzKI_Gc

—Mary Beth Odell, CAMH FAC member

Resources

FAMILY RESOURCE CENTRE (FRC) at CAMH

The FRC offers a safe, welcoming space, with a child-friendly play area. It has a wide range of printed educational materials on mental health and addiction, a lending library, recommended resources and information on community supports, and a bulletin board where family-focused events are posted.

Drop in Monday to Friday, 9:00 a.m. to 4:45 p.m.

100 Stokes Street (Bell Gateway Building) ground floor, room 1314

Tel.: 416 535-8501 ext. 33202

Email: family.engagement@camh.ca

www.camh.ca/families

ACCESS CAMH

Providing centralized information, intake and scheduling for most CAMH services, Access CAMH makes it easy for patients, families and medical professionals to find the help and services they need with a single phone call.

Access CAMH Family Line at 416 535-8501, press 2, then listen to the choices, wait until 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

FAME (FAMILY ASSOCIATION FOR MENTAL HEALTH EVERYWHERE) RECONNECT

FAME offers families ongoing monthly support groups across the GTA. The groups are a 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)

This organization offers educational information, support services and referrals to friends and family of people recovering from serious mental illness from the perspectives of health care professionals and people with lived experience.

416 539-9449

toronto.cmha.ca/programsservices/family-support

THE ONTARIO CAREGIVER ORGANIZATION

This is an independent non-profit funded by the Ministry of Health, established in the spring of 2018, that's dedicated to caregivers.

1 833 416-2273 for 24-hour, seven-day-a-week helpline

Online chat 7:00 a.m. to 9:00 p.m., Monday to Friday and a website with a huge range of resources: www.ontariocaregiver.ca

MOOD DISORDERS ASSOCIATION OF ONTARIO (MDAO)

Information, resources and support groups for people across Ontario experiencing mood disorders (depression, anxiety and bipolar disorder), and for their families and friends. Services include the WRAP for Families program; drop-in groups assisting families, 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 aged 14–35)

www.mooddisorders.ca or www.mdao.ca

New family and friends programs!

Family and Friends Yoga welcomes all experience levels and provides the mats. Wednesdays from 5:30 to 6:45, Sacred Space, 2nd floor, 100 Stokes Street.

Café Connection is an informal gathering of CAMH friends and family members for conversation and a warm beverage. Third Tuesday of every month, 6:00–8:00 p.m., in the Family Resource Centre, ground floor, room 1314, 100 Stokes Street.

Call to register for yoga: 416 535-8501 ext. 33202; drop-ins welcome to Café Connection.

Family matters We want to hear from you!

Family members—including relatives, partners, friends, co-workers and others who come forward in times of need—play an essential role in supporting the care and recovery of people living with mental illness and/or substance use disorders.

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: CAMH's Family Resource Centre, room 1314, ground floor of the 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.

