

The Family Voice

What your Family Advisory Committee is doing for you

APRIL–AUGUST 2019

VOLUME 1, ISSUE 1

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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 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.



Back row (from left to right): Morgan Bush (staff), Nicole Waldron, Pauline Lefebvre-Hinton, Miriam McCann (Staff Co-Chair), Susan Conway (Co-Chair), Vivien Cappe, Rob Burns
Front row (left to right): Shahla Pezeshkzad, Gilda Martens, Leticia Urias
Absent: Mara Haase, Mary Beth Odell

Hello and welcome

We would like to welcome you to our first Family Advisory Committee (FAC) newsletter!

The aim of the newsletter is to provide information about the many family engagement initiatives happening at CAMH and the work of the FAC. The FAC is a committed and dynamic group of family members who partner with and are members of committees, councils and working groups at all levels of the hospital. The FAC works to ensure that the family perspective is always considered and incorporated in organizational activities, events and decision making. We are strong advocates for patient- and family-centred care!

We are encouraged and energized by the level of commitment from CAMH to engage families and ensure their voices are heard at all levels of the hospital.

It is with a sense of great satisfaction that we are able to share some of the successes of the past year along with information about family support and care. Support from families and friends are an essential part of a patient's recovery process. Your co-chairs, Susan and Miriam, would like to encourage you to drop by the Office of Family Engagement to find out more about our committee, ways you can contribute to the ongoing work we do, or simply to chat.

Your feedback is welcomed!

Thank you from the co-chairs:

Susan Conway, founding committee member

Miriam McCann, Manager, Patient and Family Experience

Introducing the FAC

"The creation of the Family Advisory Committee was part of CAMH's commitment to family engagement and a direct response to family feedback," says Miriam McCann, from the Office of Family Engagement.

"The committee was recruited through a broad call for interest within CAMH and in the community. Members were interviewed and there was a selection process. Particular care was taken to ensure diversity and a broad range of experience of family members," she says.

The FAC is a partnership between CAMH staff and people affected by a family member's mental health or addiction problems. It consists of 10 family member volunteers and two CAMH staff who advocate for patient- and family-centred care.

The committee was formed in July 2017, and began holding monthly meetings that August. Since then, it has become an integral part of the recovery process at CAMH. Committee members are now involved in all levels of the hospital, including the Patient Engagement Working Group, Program Quality councils and working groups, as well as special projects such as Patient Oriented Discharge Summary (PODS).

Externally, the FAC sits on the Ontario Family Caregiver Advisory Network (OFCAN), an advisory committee that connects groups in Ontario who support family caregivers of people with mental health and addiction issues.

"Families want to be part of the team. If we listen to the voices of families we will hear invaluable information. We will learn another side to the client's life," says Vivien Cappe, one of the founding members of the FAC. "Every piece that makes up a client's life is important and needs to be connected. Family is a huge piece of that puzzle and needs to be heard."

FAC member list, 2018–19

Robert Burns, Vivien Cappe, Co-Chair Susan Conway, Mara Haase, Pauline Lefebvre Hinton, Gilda Martens, Mary Beth Odell, Shala Pezeshkzad, Leticia Urias, Nicole Waldron. CAMH Co-Chair Miriam McCann; Carolynne Cooper, social worker liaison.

Meet Susan Conway



"I would never advise anyone to be a passive consumer of the health care system," says FAC founding member Susan Conway, whose son has been a client at the Slight Centre for the past three years. She has seen first hand the importance of family involvement and how paramount it can be for patients to have involved and supportive loved ones.

"I am made to feel a part of my son's team. This has helped him receive better care, and knowing we are contributing in a positive way has been empowering and helped our family cope better as well," she says. "Family engagement helps everyone involved."

As someone who has worked in health care for many years, Susan says it felt natural to advocate for her son and work with his care team, but she realizes this isn't so easy for other families. "I would like to find ways to ensure that families understand how to best advocate for their loved ones and collaborate with their care teams in constructive ways," she says.

"The family voice, at every level of CAMH, will help patients, families and care teams," says Susan. "We are all driven by the same goal, to improve the lives of those who courageously battle the challenges of mental illness. We need to not only educate and empower our families to be involved with their loved ones' care, but also move the agenda forward to prioritize patient- and family-centred care at the organizational level and beyond."

Self-care corner: Walk This Way

TIME: 10 minutes

At some point today, you will most likely walk. You may even go for a walk.

It's one of our greatest gifts, and when we manage early in life to use our legs to get around, it's cause for celebration. Parents call their parents just to report on the event. The very fact that walking—or whatever form of ambulation you use to get around—is so central to our lives makes it a ready focus for mindful, meditative attention.

WHERE ARE YOUR FAC MEMBERS?

Here's a look at where FAC members are representing family interests:

External committees

- OFCAN (Ontario Family and Caregiver Advisory Network): provincial
- Patient and Family Engagement Community of Practice: GTA hospitals
- Mental Health Commission of Canada – Engaging Families

Internal committees and work groups

- Program Quality Councils
- Family Outreach Tables, five to date
- Access CAMH Education Sessions: review and advise on updated programming
- ED Optimization Project and Focus Group
- Safe and Well Nominating Committee
- Clinical Quality Committee of the Board
- Constituency Council
- TAHSN (Toronto Academic Health Science Network)
- Recovery College Advisory Committee
- Patient and Family Engagement Strategy Working Group
- Upskilling Working Group – Nursing
- TAY (Transitional Aged Youth) Planning working group
- Academic Division Retreat
- Acute Care Program Family Engagement Quality Initiative
- ENCORE Therapeutic Neighbourhoods (for inpatients)

Here's a simple set of instructions for one form of walking meditation. There are many variations. This one relies on a pace that is close to how we might walk in everyday life, and in fact it can be adapted for walking in the street—just as long as you remember to pay attention to street-lights, other people, and not look like a zombie.

1. **Stand up STRAIGHT with your back upright but not stiff.** Feel your feet touching the ground and let your weight distribute evenly.
2. **Curl the THUMB of your left hand in and wrap your fingers around it.** Place it just above your belly button. Wrap your right hand around it, resting your right thumb in the crevice formed between your left thumb and index finger. (This creates some balance for you and keeps your swinging arms from being a distraction.)
3. **Drop your GAZE slightly.** This helps you maintain focus.
4. **Step out with your left FOOT.** Feel it swing, feel the heel hit the ground, now the ball, now the toes.
5. **FEEL the same as the right foot comes forward.**
6. **Walk at a STEADY pace, slightly slower than in daily life but not funereal.** When your attention wanders, bring it back to the sensations of your feet touching the ground.

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<https://www.mindful.org/walk-this-way/>



Spotlight program: Grief Recovery After a Substance Passing (GRASP)

Canada is in the midst of an opioid crisis. Since 2016, more than 8,000 Canadians have died from opioid-related overdoses,¹ resulting in a tremendous impact on families and loved ones left behind. Death by drug misuse, addiction or overdose is loaded with social and moral stigma, in addition to strong feelings of anger, helplessness, guilt and shame in the families. Unfortunately, society treats this loss differently than a death by any other cause. At a time when people who are grieving need compassion and support, they are instead judged, made to feel as though their loss isn't relevant because it was substance related, or that their loved one was a bad person because of their substance use or addiction.

Grief Recovery After Substance Passing (GRASP) was created to support people who have experienced the loss of a loved one due to drug misuse, addiction or overdose. GRASP offers a safe place of understanding and compassion. "An out-of-order death is so profoundly painful that it does not feel survivable," says GRASP Toronto Chapter founder and leader Andrea Rokis, who has lived through the loss of a family member in these circumstances. "GRASP groups provide solace and comfort where you know you are understood." Families who are shattered after the death of their loved one need a place where they can express their feelings and come to terms with their loss.

Groups provide bereaved families with a much-needed safe place for peer-to-peer sharing, caring, support and healing. A typical group is six to 12 people; if the group is 14 or larger, it is split into two smaller groups. Meetings are held every second Wednesday evening, from 7:30 to 9:30 p.m. and there is no donation required to attend. There is also no religious or spiritual

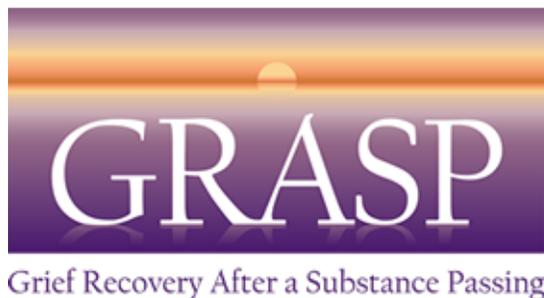
focus, and no standardized format. Unlike other bereavement groups, there is also no time limit on how long one can attend—about one-third of the group has been attending for more than a year and people are welcome to come back whenever they feel the need to connect.

Group details and schedule:

<http://grasphelp.org/toronto-chapter/>

—Mara Haase

¹ <https://www.canada.ca/en/health-canada/services/substance-use/problematic-prescription-drug-use/opioids/get-the-facts.html>

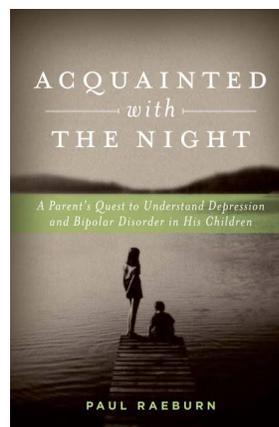


What's on the library shelf?

The Family Resource Centre (FRC) has a small curated collection of family-facing books that are available for family members to borrow. The publications range from how-to books on coping with mental health and addiction problems within the family to building resilience to first-person accounts of mental health crises people experience themselves or that their family members and friends experience.

Lending periods are flexible, as long as our books come back! Here are three "lightning" book reviews (read: short) written by past volunteers at the FRC.

If you'd like to write a review for *The Family Voice*, or learn about volunteering at the FRC, please call, drop in or send us a note at family.engagement@camh.ca.



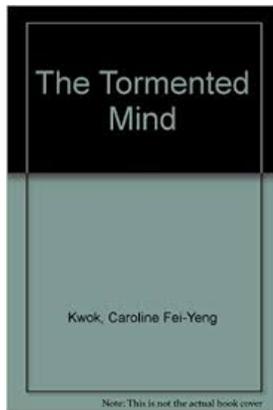
Acquainted With the Night: A parent's quest to understand depression and bipolar in his children. Paul Raeburn. Broadway Books, 2005, 320 pp. \$19.

The gist: Paul Raeburn, a reporter and a writer, outlines his journey and the struggle to deal with the depression and bipolar disorder of his son and daughter. The book follows Alex, the middle child, who has struggled with rage since the 5th grade, and the constant visits to psychiatrists and psychiatric hospitals. Raeburn also describe the struggles of his daughter Alicia with depression and self-harm since the age of 12. This book follows a family that has been pulled in multiple directions by mood disorders.

The good: This book was highly personal and made me feel like I was living the story with him. His accurate timelines and abundant in-depth detail allowed for full immersion in the story.

The bad: Originally the book seemed like a hard read because it takes a while to understand the seriousness of the disorders that the children are suffering from. It required patience to fully understand the depth of the family's struggles.

—Wafaa Khatau



The Tormented Mind. Caroline Fei-Yeng Kwok. C&R Publisher, 2000, 96 pp.

The gist: *The Tormented Mind* is by a Chinese-Canadian woman who addresses her own personal experience of having a mental illness. Her book is based on her experience of seeking medical help at various mental health institutions from the time of her initial diagnosis of bipolar affective disorder to complete recovery. It gives insight into the challenges of bipolar disorder, the stigma within her community, and how people's judgments can affect the recovery process for many patients.

The pros: This book is a great read for professionals working with clients who experience bipolar. It is also a wonderful resource for families to understand what their loved ones are experiencing and ways they can make their recovery a positive experience.

The cons: Because this is a personal memoir, it is important for readers to understand that not every individual will have the same experiences. They should instead use the information as a guide for helping others. It is about understanding each person in order to make his or her experience positive.

—Maham Khan

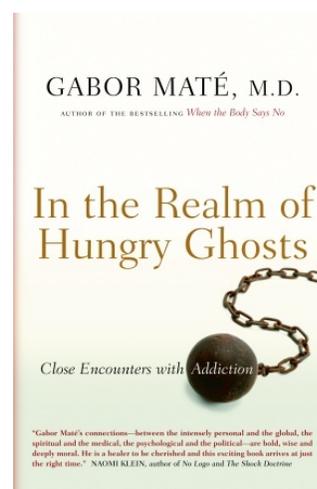
In the Realm of Hungry Ghosts: Close Encounters with Addiction. Gabor Maté. North Atlantic Books, 2010, 520 pp. \$27.56

The gist: In the book *In the Realm of Hungry Ghosts: Close Encounters with Addiction*, doctor and author Gabor Maté discusses stories of people whom he has worked with at the Portland Hotel Society in British Columbia. These clients live with concurrent disorders (mental illness and addiction), HIV/AIDS and mental health issues. The book is divided into seven parts, each dealing with different themes such as brain development, causes of addiction, and healing. Maté captures the stories through his lens with a complex simplicity and careful consideration.

The good: I enjoyed the raw and honest telling of these stories and appreciated Maté being able to address his own biases when working with his clients. The insightfulness that was evident in the storytelling was amazing.

The cons: It may not be everyone's cup of tea, in the sense that some readers may find it hard to get through if they don't enjoy a storytelling style of writing. If you're looking for a book with concrete facts about concurrent disorders, addiction, homelessness or mental health, this isn't it.

—Tineke Harrison



EVENTS AND RESOURCES

SUITS ME FINE

Thursday May 9, The Sandi and Jim Treliving Gymnasium is transformed for the annual Suits Me Fine client fashion show. It's the 15th year for the show, and Canadian fashion icon Jeanne Beker is hosting. It is a celebration of recovery, self-confidence, fashion and fun. Suits Me Fine is a clothing boutique that provides donated new and gently used clothing, essentials and accessories to CAMH clients.

camh.ca (and search Suits Me Fine 2019)

ONE BRAVE NIGHT CAMH

Friday, May 10, One Brave Night for Mental Health is a virtual campaign that challenges people to step into the spotlight and raise funds to support mental health. What's better than sharing a piece of yourself — your hidden talent — with the world? Sharing it for a great cause! Taking place on Register, and while you're fine-tuning your performance, rally your friends and start fundraising. Sing a song, read a poem, do a dance, host an art show.

camh.ca

Resources

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:

<https://www.camh.ca/en/health-info/guides-and-publications/community-resource-sheets>

CANADIAN MENTAL HEALTH ASSOCIATION- FAMILY OUTREACH AND RESPONSE PROGRAM

Offers educational information, support services and referral 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

<http://toronto.cmha.ca/programsservices/family-support>

MOOD DISORDERS ASSOCIATION OF ONTARIO

Runs Strengthening Families Together, a free nine-week program for families supporting a person aged 14–35 with a mood disorder or psychosis. Topics include causes, treatment and recovery, coping as a family, healthy communication, self-care and dealing with crisis.

416 486-8046

<http://www.mooddisorders.ca/program/programs-for-family-members>

KRASMAN CENTRE RICHMOND HILL

Provides a hub for psychiatric survivors and their families and friends, including Family Recovery Education Support Programs. They offer groups, one-on-one support and drop-in chat nights.

905 780-0491 ext.117

www.krasmancentre.com

SKYLARK CHILDREN, YOUTH & FAMILIES

Offers free individual and family counselling and support to children, youth and their families who live in Toronto. Counselling services are tailored to the individual strengths and needs of each young person and/or their family, using a range of evidenced-based treatments in a multi-disciplinary framework.

416 482-0081

Skylarkyouth.org

FAMILY CRISIS SUPPORT PROGRAM:
SCHIZOPHRENIA SOCIETY OF ONTARIO

PROVIDES Information referral services and supportive counselling to family members of people affected by serious mental illness in Ontario.

416 449-6830

www.schizophrenia.on.ca

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

<http://www.reconnect.on.ca/>

FAMILY SUPPORT PROGRAM
MICHAEL GARRON HOSPITAL

Offers an eight-week psycho-educational program for significant others or families of individuals with mental health difficulties. Program facilitated by mental health professionals.

416 461-2000 ext. 223

www.tegh.on.ca

NEW RESOURCE

MOOD DISORDERS ASSOCIATION
OF ONTARIO LIBRARY

The MDAO is introducing a new online database that will let you browse more than 700 books in their library. By clicking on the three circles below each book, you can access reviews of the book. Explore books on a wide range of topics including abuse, anxiety, assertiveness, grief, law, LGBTQ, medications, nutrition, pregnancy, self-esteem, stress, suicide, trauma, women's issues and youth.

1 866 363-6663

mdao.libib.com

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.

Sometimes the families who are supporting loved ones need support of their own. The **Family Resource Centre** (FRC) offers a safe, welcoming space, with a child-friendly play area.

Family members will also find a wide range of printed educational materials on mental health and addiction, a lending library of recommended resources and information on community supports, and a bulletin board where family-focused events are posted.

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

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