

The Family Voice

What your Family Advisory Committee is doing for you

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WHAT'S INSIDE

Vaccine fears and anxieties: How families can help	1
Message from the co-chairs	2
FAC member list	3
Meet the member: Pauline Lefebvre-Hinton	3
It worked for me!: Virtual Café Connection.....	4
Self-care corner: Nutrition.....	4
Where are your FAC members?.....	5
Reviews: My Lovely Wife in the Psych Ward: A Memoir; I'm Not Sick, I Don't Need Help!;	6
Resources	7
Family matters: Contact us!	8

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.



Vaccines now available! How families can help with fear and anxiety:

The COVID-19 pandemic has been challenging for many, but for those with an existing mental illness and/or addiction this time has been especially hard. With the roll out of the COVID-19 vaccines and the current prioritization (which includes people with a diagnosis of mental illness and/or a diagnosis of substance use disorder) many of us have the desire to have ourselves and our loved ones vaccinated. While the idea of this may be exciting to many, it can also provoke fear and anxiety. As a family member, we know you want to support your loved one as best you can. Here are a few ways to help your loved one feel more comfortable with the COVID-19 Vaccine.

Communicate effectively

Stay present and listen to your loved one's point of view. Remind them that you care for them and their health and maintain a space where they can talk openly about their fears and anxieties about the vaccine. If you are planning to get vaccinated share with your family member that you intend to get vaccinated as soon as it is available to you. Empathize and show understanding by

acknowledging their fears and anxieties. If you prefer to work on an activity, list the pros and cons to help support the decision making.

Share the facts

There is plenty of information online about the COVID-19 vaccine, and it's hard to know where to look. Remind your family member that there is scientific evidence to support the vaccines and offer to help with finding accurate information to support their decision. Here are some facts you may find helpful in your discussion with your family member (for more visit the CAMH website to read: [Covid-19 Vaccine resources for patients and families](#) available in eleven languages)

What is a vaccine? A vaccine tells your immune system to make antibodies that help your body fight against a germ that could hurt you. Scientists make vaccines to protect you and other people against germs, including bacteria and viruses such as the coronavirus. The COVID-19 vaccine works with your body's natural defences to fight off COVID-19, just like other vaccines do (such as vaccines for polio, the flu, and measles). Scientists and health care providers think fewer people will get sick with COVID-19 if more people have the vaccine.

How does the COVID-19 vaccine work? The COVID-19 vaccine is given through a needle. The COVID-19 vaccine trains your immune system to make antibodies against the coronavirus. If you are exposed to the COVID-19 virus after getting the vaccine, the antibodies are ready to help fight it off and stop you from getting sick. The vaccine does not contain the COVID-19 virus so it cannot give you COVID-19. Instead, the vaccine gives your body a recipe to make antibodies. Most of the vaccines require two shots to be fully protected from COVID-19.

Is the vaccine safe? How do we know? Yes, the vaccine is safe, and it is the main way we will beat COVID-19. The vaccine does not give you COVID-19, it only works with your immune system so that your body will be ready to fight the virus if you come in contact with it. Doctors and scientists have worked to make sure that the vaccine is safe to use. Scientists tested the vaccine with many, many people. They gave all the people in the tests a needle. Some people had the vaccine in their needle and some people got a needle that

didn't have a vaccine in it. Then the scientists looked at what happened to the people in both groups. Almost all the people who got the vaccine didn't get sick. A lot more people got sick who did not get the vaccine.

Move forward together

Encourage your loved one to talk to their doctor or care team who can provide them with professional support and answer any specific questions. Ask if they would like you to be present at their appointment for support. Be mindful of how often you are bringing up the topic of COVID-19 and give them some space to read information or think about what the doctor told them.

With active listening, patience and understanding, you may help your loved one feel more comfortable getting the COVID-19 vaccine. Moving with them from anxiety to action will give them protection and give you peace of mind.

Once you or your family member have decided to get vaccinated, visit the [Government of Ontario](#) website for more details on the rollout and the different "Phases". Depending on the Phase that you are included in there may be a wait before you can receive the vaccine. To find out if you or your loved one is eligible to receive the vaccine at CAMH visit the [Covid-19 Vaccine](#) booking page. If you do not qualify to receive the vaccine specifically at CAMH but have other risk factors according to the Government of Ontario website, visit the [Toronto Vaccination Clinic](#) website or your local public health unit website to see if you can get the vaccine at another clinic.

Message from the co-chairs

This spring and summer the Family Advisory Committee (FAC) will be recruiting new Family Advisors to join the Committee. The FAC includes up to 12 family members who support someone with a mental illness and /or addiction, and up to 3 CAMH staff from Patient and Family Experience. This partnership between families and CAMH staff creates an environment where we are able to create new initiatives and make improvements to quality, safety, and patient and family experience.

“The best part about being the Family Co-chair of the FAC has been witnessing the growth of patient and family engagement at CAMH and seeing the involvement of family advisors on committees, quality councils, and working groups throughout the organization.” Susan Conway.

“The best part about being the Staff Co-chair has been working with a committee of ambitious, creative, and passionate advisors who continue to bring fresh perspectives.” Ashley Bowe.

Together we have an objective to engage with families, patients, community members and health care providers in order to advocate for patient- and family-centred care and enhance the experience of both patients and their families at CAMH. As stated in our Vision Statement, our hope is that “Family will be integral members of the recovery process and will be embraced by and actively engaged at all levels of the organization”.

In order to fulfill our vision, mission, and objectives, we require family involvement on committees, quality councils, working groups, and projects at CAMH. We also have our own sub-committees for initiatives like the Family Voice Newsletter you’re reading!

We aim to have a FAC that reflects the diversity of patients and families at CAMH. As we enter into a new phase of recruitment we encourage applicants from diverse backgrounds and experiences within CAMH programs and services.



FAC member list, 2020–21

Top, from left: Susan Conway, John Im, Mara Jayenthiran, Pauline Lefebvre-Hinton, Miriam McCann, and Nicole Waldron.

Front, from left: Vivien Cappe, Gilda Martens, Thanisa Sundaralingam, Mary Beth Odell, Ashley Bowe.

If you have a few hours a month to offer and would like to be part of a dynamic team making a difference in quality, safety, and patient and family experience please email:

family.engagement@camh.ca or call the family resource centre at (416) 535-8501 to learn more.

We hope to hear from you!

—Susan Conway, mother, CAMH FAC co-chair and Ashley Bowe, sibling, CAMH FAC co-chair



Meet the member: Pauline Lefebvre-Hinton

What drew you to the FAC?

Twelve years ago, with the encouragement of a CAMH social worker I became involved with the Family Council, a group funded by CAMH to ensure families could advocate for their loved ones. The old Council functioned as an external body. From there, the Family Advisory Committee was created with a mandate to build a partnership between CAMH, clinical staff, and family members with lived experience. I was then asked to be part of the steering committee to develop the CAMH FAC’s Terms of Reference and later applied to become an advisor myself.

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

CAMH is committed to improving client care by positioning families as partners in care. This is reflected in the number of clinical committees that we have been invited to sit alongside CAMH staff on, with the result being, “the family voice is heard and trusted at all clinical levels of CAMH” and I have the privilege of being part of that team.

How long have you been supporting your family member?

20 years.

The best advice from another caregiver?

The most difficult thing for me was to ask for help. It was another family member seeing me struggle who told me that I needed to let go and accept support. She described it as a gift family and friends could give to me. Hearing it put that way, the walls came tumbling down.

Your favourite pearls of wisdom?

Make time for yourself. • Seek out other caregivers: it helps to know you're not alone. • Do not allow yourself to become isolated. • Trust your instincts, you know your family member best!

“It worked for me!”

Virtual Café Connection

In this new section of the *Family Voice* family members share what worked for them on their supporter journey.

“I was introduced to Café Connection on the CAMH Facebook page. When I joined I had no clue what it was all about. I decided to turn up, meet the team and join the featured activity. It turned out to be way beyond my expectations and offered me a chance to be myself and connect. They have so much to offer—support, information, education, knowledge—and answered many questions.

Café Connection is very well organized. We practise a self-care theme for the month and then share our experience and learnings. It feels very comfortable to participate and share. I learned to listen and understand other people's experiences and perspectives without being judged. It helps us understand the value of research to help the community grow together. Also a great space to voice your thoughts and concerns. I think that it is a great time to nurture and nourish our inner self and be connected.

It was thrilling to see the research team and understand the efforts and value of the projects at CAMH. Meeting people who work relentlessly behind the scenes is an honour.”

—Virtual Café Connection participant



Virtual Café Connection is a CAMH social and informational event that was created by the CAMH Family Resource Centre and the Family Advisory Committee. It is held monthly on the last Thursday of every month from 6:00-7:30pm. We use Webex as our platform to connect and if it's your first time we would be happy to support you with using the technology before you attend.

Please register by emailing family_engagement@camh.ca



Self-care corner: The Joy of Food

Food brings people together, it's the centre of many traditions, it's enjoyable, and is so much more than just nutrition. It may be the only occasion families have to gather together. Sharing the responsibilities of menu planning, grocery shopping and preparing a meal with others (even children) can have a lot of great health benefits. Being involved in meal preparation, even if it is as simple as choosing what to make or stirring a pot of soup, can increase interest and excitement around eating.

[Canada's Food Guide](#) emphasizes the importance of eating with others. Eating with

family and friends can contribute to a healthy lifestyle and improve mental health outcomes. Research shows that there is a link between good food and strong mental health.

Coming together with loved ones over a meal makes the experience of eating so much more enjoyable! Including: eating a home cooked meal, trying new foods, socializing, creating meaningful bonds, and sharing our food traditions and cultures. When we cook and eat with others it encourages us to focus on what we are eating. Some of the potential benefits of eating together are: increasing our intake of nutrient-rich foods, lowering the chance of skipping a meal, and giving you and your loved one(s) something to look forward to. By bringing our loved ones into the kitchen with us we can all learn healthy eating habits together and increase our sense of community. Cooking together makes time for laughter and conversation and makes you more mindful of the food you are eating.

If the idea of preparing an extravagant meal is not your thing or time is limited, that's okay because preparing food does not have to be a long and complicated process. There are many free recipes online that are simple and delicious! Check out the resources below, recommended by a Dietician Student at CAMH.

Resources:

- Foodland Ontario helps you choose fresh food from close to home, all while supporting local farmers and businesses. Check out Ontario.ca/Foodland/recipes to find health recipes that also give you the option to explore seasonal foods in Ontario.
- Cookspiration.com was developed by Dietitians of Canada, offering dietitian-approved recipes and a menu planning feature.
- For anyone looking to cut down on their food costs and maintain healthy eating try Budgetbytes.com.

—Christine Chappell, Dietitian Student at CAMH

—Vivien Cappe, mother, CAMH-FAC member

WHERE ARE YOUR FAC MEMBERS?

Highlight: BrainHealth Databank

The BrainHealth Databank is a project I've recently become involved with, along with patient and lived experience representatives and we are all very excited!

The BrainHealth Databank will become a repository of many sources of data that patients can choose to share — such as sleep and physical activity records from smartwatches, blood samples, brain images, and assessments from their health care visits with clinicians. The collection of this data will help scientists better understand and diagnose mental illness which will eventually lead to new treatments and prevention strategies.

This work is a commitment to patient privacy and ethical conduct at all levels. There are teams of experts involved to ensure this happens, including the vital input from patients and their families. Stay tuned for more information on the [BrainHealth Databank!](#)

—Susan Conway, CAMH FAC co-chair

FAC members are also representing family interests through:

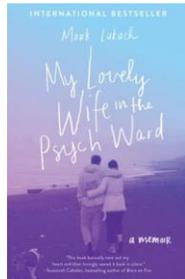
Internal committees and work groups

- Digital Health Steering Committee & Patient and Family Focus Groups
- Horizontal Violence, Anti-Racism, Anti-Oppression Working Group
- Virtual Café Connection Planning Committee FAC Subcommittee
- Communications FAC Subcommittee

External committees and projects

- OFCAN (Ontario Family and Caregiver Advisory Network)
- Royal Ottawa SPOR Grant Focus

Reviews: Books and more



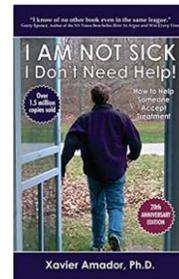
My Lovely Wife in the Psych Ward: A Memoir
Mark Lukach. Harper Wave, 2017. 320 pages,
\$19.99 paperback. International bestseller.

The Gist: A memoir of a young married couple whose relationship is redefined by mental illness. While living a dream life in California at the early stages of her marriage to Mark, Giulia suffers a sudden acute mental health crisis that lands her in the hospital for over a month. After recovering and subsequently having a son, Giulia goes on to experience mental health crises in the years that follow. Mark narrates the story of the painful initial years of his wife's mental illness, and how the couple learns to cope and move forward, both individually and together as a family.

The Good: As a married woman living with mental illness, this memoir helped me better understand many of the emotions, anxieties and challenges that my own husband has faced in our marriage. And as a caregiver of a sibling with mental illness, this memoir left me feeling less alone in my feelings of being terrified, exhausted and overwhelmed. This book was gripping and beautifully dealt with mental health and the battles it entails in a marriage.

The Bad: Some readers may find the author's privilege hard to relate to, as did I. This couple had an extreme amount of support and resources to deal with their very challenging situation. I often felt that this aspect of the memoir was not reflective of an "average" life.

— Mara Jayenthiran, sibling, CAMH-FAC member



I Am Not Sick, I Don't Need Help! Xavier Amador. Vida Pr; 4th ed., 2020. 254 pages,
\$27.79 paperback.

The Gist: "I'm not sick, I don't need help" is written for families seeking assistance in supporting their loved one navigate a mental health system holistically. It describes how to communicate effectively with your loved one, especially when they are not experiencing their condition as an illness and therefore choose not to seek treatment. Amador writes in a way that can be helpful to any family member on a recovery journey with their loved one. His personal experience with his brother and as a therapist brings an empathetic tone that validates the family experience while offering practical tools for compassionate communication.

The Good: What I found most interesting was his explanation of the four guiding principles of LEAP. Dr. Amador coined LEAP to help teach family members how to better communicate with their loved ones when they are uncertain about treatment options. LEAP is Listen, Empathize, Agree and Partner. He explains how this method helps readers improve their communication skills, develop trust, and turn combative situations into moments of partnership and understanding. He also reveals that not experiencing their condition as an illness is another symptom of a mental illness and cannot be reduced to stubbornness.

The Bad: It can be hard for families to accept that your loved one has the right to choose not to seek treatment. I believe this book will help family members to better understand what their loved one is going through and that to me, is well worth the read!

— Gilda Martens, mother, CAMH-FAC member

Resources

ACCESS CAMH provides 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, see: www.camh.ca/en/health-info/guides-and-publications/community-resource-sheets

CAMH 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 has materials on mental health and addiction, a lending library and information on community supports and family-focused events. It is now in the RBC Patient and Family Learning Space, McCain Complex Care and Recovery building. Until COVID-19 restrictions lift, the FRC is open virtually 9:00 a.m. to 4:45 p.m., Monday to Friday. **416 535-8501 ext. 33202**
Email: family.engagement@camh.ca

CAMH VIRTUAL CAFÉ CONNECTION is an informal gathering of CAMH friends and family members held the last Thursday of the month, 6:00–7:30 p.m.; call or e-mail for details to join virtually. **416 535-8501 ext. 33202**
Email: family.engagement@camh.ca
www.camh.ca/families

SUBSTANCE ABUSE PROGRAM FOR AFRICAN CANADIAN AND CARIBBEAN YOUTH (SAPACCY) provides support and counselling to Black youth (ages 13–24) and their families who are dealing with substance use and/or mental health problems. Family members can self-refer for an assessment. For more information, contact Access CAMH at **416 535-8501, press 2** or **1 800 463-6273**

ACROSS BOUNDARIES provides community mental health and addiction supports and services, and in-house programs that include individual and family supports, as well as a peer support group, men's group, women's group, community kitchen and more. Services are available in Caribbean dialects, Shona, Amharic, Harare, Xhosa, Afrikaans, Urdu, Tsonga, Swahili, Somali, Twi, Dari, Pashto, Farsi (Persian), Punjabi, Hindi, Bengali, Tamil and Mandarin. 51 Clarkson Ave., York **416 787-3007**
www.acrossboundaries.ca/

RECONNECT FAME FAMILY & CAREGIVER SUPPORT SERVICES offers families ongoing monthly support groups and one-on-one support across the GTA. The groups are drop-in format and are facilitated by family support worker. FAMEkids and FAMEyouth programming available. **416 248-2050**
www.reconnect.on.ca/

FAMILY OUTREACH AND RESPONSE PROGRAM, CMHA offers educational information, programs, support services and referrals for friends and family of people recovering from serious mental illness. toronto.cmha.ca/programsservices/family-support

MOOD DISORDERS ASSOCIATION OF ONTARIO (MDAO) provides information, resources and support groups for people with depression, anxiety and bipolar disorder, and for 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 14–35)
www.mooddisorders.ca or www.mdao.ca

NATIVE CHILD AND FAMILY SERVICES OF TORONTO offers children's mental health assessments and treatment (0–6 years and 6+ years), transitional support for women in domestic violence situations, women's and men's healing, family work, group programs (including Strengthening Families). 9:00 a.m.–5:00 p.m. Ninosche

program provides home support for ages 0–6.
30 College St., Toronto
416 969-8510

<http://www.nativechild.org/>

THE ONTARIO CAREGIVER ORGANIZATION is an independent nonprofit 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

THE SASHBEAR FOUNDATION offers Family Connections, an evidence-based 12-week group that meets weekly for education, skills training and support for people in a relationship with someone who has emotion dysregulation (e.g., borderline personality disorder). Groups are available across Canada.

info@sashbear.org
www.sashbear.org

TROPICANA provides culturally appropriate programs to youth, newcomers, people of Black and Caribbean heritage and others in need. Family supports include individual and group counselling and training for parents whose kids are in SNAP.

1385 Huntingwood Dr., Scarborough
416 439-9009
www.tropicanacommunity.org

New! Family Resource e-Bulletin

The Family Resource Centre and Family Advisory Committee have partnered in launching a monthly Family Resource e-Bulletin.

What to expect: Family-focused resources and events, new issues of the Family Voice newsletter, Café Connection reminders, and more!

Interested in subscribing? Click [here](#) to be added to the list of subscribers.

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, now in the RBC Patient and Family Learning Space, McCain Complex Care and Recovery building. Hours will be 9:00 a.m. to 4:45 p.m., Monday to Friday.

Would you like to receive new issues of the Family Voice Newsletter to your email inbox?

Scan the QR Code below using your smart phone camera and click the [link](#) to subscribe to our Family Resource e-Bulletin.



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