

SHARE & CARE

THE RECOVERY OF HOPE ~ THE HOPE OF RECOVERY

BUILT ON PASSION

At The Caregiver Network, helping family caregivers to build a better life is their thing. You could even call it their obsession

If you've ever taken part in our teleworkshops, you're familiar with the routine. You register to participate and you're connected to expert information on any number of subjects that may interest you as someone caring for a relative with a mental illness.



For Stolow, a familial motivation

What you may not know is that the spark plug behind the idea is a non-profit company, The Caregiver Network (TCN). Headquartered in Montreal, it's a Canada-wide tele-learning operation working to support family caregivers coast to coast. Along with AMI, it has 200 other non-profit partners looking out for their own caregiver members. Locally the list includes such well-known names as the Alzheimer's Society of Montreal and the MS Society of Quebec.

The family connection

TCN was started as a pilot project in 2004 by Mark Stolow, now president, and Lucy Barylak, a long-time member of the healthcare community. Stolow's connection was personal. His mother had bipolar disorder.

"I began my caregiving life at 10 years old," he says. "I suspect my father found it difficult to cope. He didn't know what else to do, so he asked me and my brothers to stay home and make sure my mother was okay." When he was a psychology student at university, a social worker interviewed Stolow for a job. "She asked if I had any experience as a caregiver. I answered that I didn't think so. The truth was, I'd never heard that word before. To me I was simply being my mother's son. It took me months to finally grasp the difference between love and care."

You can love someone without reservation, Stolow explains, but caring for them is another story and requires its own store of knowledge. "Typically, caregivers trying to succeed on love alone will start looking for professional assistance when things

have reached the panic stage. Only then they may discover there are long waiting lists for the sort of help they need."

And that's what TCN wants to avoid. They don't provide direct service, no respite or home care, but something even more valuable

long-term: the resources to avoid the classic pitfalls. In the case of AMI members, that would include preparedness and planning. Do you fully understand your loved one's illness and what treatments are available? Do you know how to talk to the doctor? How to navigate the healthcare system? What will you need as a full-on caregiver? TCN makes it quick and easy to find out.

In addition to our teleworkshops, starting next fall we'll be collaborating with TCN to offer webinars. They're similar to the

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ST. MARY'S okays our peer support project

The good news came in April: thumbs up for our peer support initiative. The two-year pilot project will make our help available to care-

givers of elderly patients arriving at St. Mary's Hospital in a medical crisis.

Working with hospital ERs to support families dealing with the trauma of a relative's mental illness has long been a cherished goal of ours. Our partnership with St. Mary's is further proof that the aim is worth pursuing.

In this case, the project has a somewhat different slant. It's being funded by L'Appui Montréal, an organization that works with caregivers of seniors. To reflect their focus, guidance at St. Mary's will be offered to caregivers of elderly patients only, those being treated for a medical condition.

Many caregivers of seniors are elderly themselves and sorely need the extra support our project offers. It will make a difference in how they cope both short- and long-term, when their relative returns home. And it's a given that well-supported caregivers are less likely to find they need help of their own with problems such as depression and anxiety.

Our peer support program at the Douglas has been in operation since 2012. The project at St. Mary's will be evaluated throughout its two-year duration. □

Lawrence Feldman, a former Board member, offers his solution to the persistent challenge of how best to fight stigma. For over 30 years “Feldman’s Home” has welcomed the most marginalized of people living with mental illness

An insider’s take on combatting stigma

One of the toughest obstacles to bringing mental health awareness to the general population is stigma.

If a man reveals that he has a family history of a debilitating disease, then we have room for compassion and empathy to help and even suggest a solution to his dilemma. We will ensure that a diabetic does not eat too many harmful foods. We understand the relationship between the person and the disease.

But when a person discloses a mental health issue, we hesitate. The signs and symptoms of mental illness are unknown, confusing and scary to most of us. Without a complete picture, we cannot understand. Our response is protective: We start to fear and avoid getting too close. We need to admit the truth — that we don’t really know what to do to help.

Stigma often creates a faulty perception that people suffering from a mental illness are weak, unstable and non-productive. This unattractive image deprives them of the consistent support and empathy that are essential during a crisis.

For instance, many new mothers and their loved ones don’t understand the hormonal turmoil that occurs during and after birth and that postpartum depression is not a weakness or something to be ashamed of. The world of college students and the decisions they make because of psychological troubles is largely hidden and undocumented. First-time episodes among both adults and children promote fear and denial instead of a trip to a mental health professional.

We need to open our eyes as to how our behavior can fuel stigma. When we distance ourselves from the problems and lives of those who are suffering, or deny the signs and symptoms of men-

tal illness in our community, we are only feeding discrimination and biased judgments.

Over the years I personally have had multiple encounters with individuals who lack all understanding of mental health and mental illness. Their comments and reaction to people who are suffering are upsetting at best and a display of ignorance at its worst. In today’s information society, where knowledge is at our fingertips, it seems almost archaic that people come to conclusions about mental illness and those who are ill based only on their own fearful emotions and false understanding. It hurts when this happens. Anxiety, depression, mood swings, sleepless nights, anger, aggression, hopelessness, a lack of organization, will power and interest — these describe only the feelings, not the disease.

We unfortunately associate “crazy” with the mind, but our organs and hormones all share in the chain reaction that produces changes in our brain. How can my intestines or adrenal glands be crazy? How does my thyroid get to be called moody and wild? Why would the lack of a vitamin that is absorbed in my intestines make me nervous or feel sad?

Our bodies do not lie and with proper medical support there can be answers. The answer to bringing an awareness of mental health and its spectrum of issues to the general public is knowledge and understanding based on truth.

With an informed public, there will be no more distorted messages about mental health, no superstitious, unfounded dogma fueling stigma. We will be able to see mental illness as it really is.

From where I sit, educating ourselves is the very first step in that journey. □

This account has been condensed and edited.

IMPROVING LIFE FOR FAMILY CAREGIVERS

Recognizing the hardships and challenges family caregivers experience, the Mental Health Commission of Canada is making efforts to help ease their burden

In 2013 the Commission produced a document titled *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses*.

Written primarily for service providers, mental health managers and policy makers, it contains 41 recommendations for achieving more effective planning, implementing and evaluating of the mental health supports and services family caregivers need. The Commission hoped this would eventually result in an improvement in caregivers being able to provide their loved one with the best possible care; and, equally important, would also make it easier for them to attend to their own well-being.

This June the Commission launched a follow-up to the national guidelines document. *Taking the Caregiver Guidelines off the Shelf: Mobility Toolkit* is designed for anyone who wishes to promote the guidelines and put them into action. It aims to encourage broader understanding and adoption of the guidelines and offers suggestions on how to go about doing just that.

The practical tips include techniques for connecting through effective networking, selecting the right audiences, planning agendas and setting up meetings. There are case studies illustrating how the efforts of one person or a group to explain the guidelines to others have led to positive outcomes. The parties targeted ran the healthcare gamut from a hospital psychia-

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FUNNY HE SHOULD SAY THAT

Mike MacDonald, aka the King of Canadian Comedy, surprised our fundraiser crowd by putting the emphasis on serious

For anyone expecting a joke a minute from this celebrated comedian, last May's fundraising event proved quite the eye-opener.

But then again, Mike MacDonald has much to be serious about. Diagnosed with bipolar disorder over a decade ago, he also lives with what he describes as "other issues," including a one-time heroin addiction and a liver transplant that almost did him in.

He accepts the fact that he'll be taking a dozen or so pills daily for the rest of his life, but steadfastly rejects the

advice of those who warned him to avoid stigma by keeping quiet about his mental illness. "You play with the cards you're dealt," he says.

And if you play smart, MacDonald adds, you believe not that things *will* get better, but that they *can*. That realistic attitude helped see him through the bad times and "it's where you should put your hope," he counsels.

Our latest fundraiser was a beauty with good food to eat and bouquets of flowers everywhere. People flocked to view and bid on the artworks for sale, a Young Adults committee project. Every piece was sold that very same evening. Displayed alongside the canvases were the artists' upbeat answers to the ques-



tion *What does mental health mean to me?*

Serious yet entertaining, much like the evening itself. □



Bee by Hayes Nulman



Abstract by Ashley Tritt



Woman by Vanessa D'Aquila

25 STERLING YEARS — AND COUNTING

Ella Amir honored at our annual general meeting

First came the reports of last year's activities and it was good-news all around. Finances healthy? Check. Programs doing well? Check. And outgoing president Jean Claude Benitah had a surprise announcement: AMI has taken the plunge and become a property owner. We've purchased a small building at the corner of Decarie Blvd. and Bourret Ave. and will be moving into our new home early next year.

Hard to believe, but a quarter-century has whizzed by since Ella Amir took on the position of executive director as AMI's first paid employee. On her watch we've grown far beyond our families-helping-families roots and are today recognized by professionals for our programs and initiatives as a pertinent, effective presence in the mental healthcare community.

How to honor such a record? In addition to the awards we traditionally present at our AGM, we've established the AMI-Québec Ella Amir Award for Innovation in Mental Health. It will be given whenever the occasion is right to an individual or organization contributing in a significant and innovative way to promoting mental health in the community. Qualifying fields of activity will include research, service to family caregiving, advocacy and the fight against stigma. □



Martin Zidulka, Volunteer of the Year, "exemplifies everything important in supporting someone with a mental illness," said Evelyn Lusthaus, McGill University English professor



"What AMI did for me far exceeds what I did for them," said a visibly touched Amir (r), here with incoming president Anna Beth Doyle

Board of Directors 2015-2016



Executive Committee. Back l-r: Jean Claude Benitah, immediate past president; Norman Segalowitz, vice president; Joanne Smith, secretary. Front l-r: Donna Sharpe, treasurer; Anna Beth Doyle, president

Members: Michael Arruda, Elva Crawford, Guy Dumas, Moira Edwards, Danielle Gonzalez, Beverly Kravitz, Anne Newman, Lynn Nulman, Carol Plathan, Judy Ross, Lynn Ross, Mike Truesdell, Karen Waxman, Annie Young



In tribute to her many years of involvement with AMI, **Elva Crawford** receives the **Monty Berger Award for Exemplary Service**



Special Recognition went to **Moir Edwards**, a committed Board member for 20 years



Dr. Simon Amar of the MUHC presented his colleague **Dr. Tewfik Said** (above) with the **Exemplary Psychiatrist Award**, calling him "passionate, caring, open-minded, everything good in a psychiatrist"



"I've never met anyone so caring of patients and their families," said Susie Mintzberg (r) on turning over the **Award for Exemplary Service in the Field of Mental Illness** to psychiatric nurse **Jean Enright**

Go online for your annual report

AMI's 2014-15 annual report is available online at www.amiquebec.org/ar15. If you would like to receive a copy by mail, call us at 514-486-1448 (1-877-303-0264 outside Montreal).



A second **Award for Exemplary Service in the Field of Mental Illness** went to **Jim Carter** for his activities in protecting English language services. (Not shown: **Colin Coole**, a south shore community worker, received the **Extra Mile Award**)

SUMMER 2015

SUPPORT GROUPS

For family, friends and people with mental illness unless otherwise indicated

Mondays 7:00pm 4333 Côte Ste-Catherine Road unless otherwise indicated. No registration necessary For details visit amiquebec.org/programs-support

FAMILY for relatives and friends

July 6, 20; August 3, 17; September 21

SIBLINGS AND ADULT CHILDREN for relatives

July 20; August 17; September 28

BIPOLAR DISORDER

July 20; August 17; September 28

DEPRESSION

July 6; August 3; September 21

OBSESSIVE COMPULSIVE DISORDER

July 20; August 17; September 28

HOARDING GROUP (in collaboration with Quebec OCD Foundation)

July 6; August 3; September 21

KALEIDOSCOPE for people with mental illness

July 20; August 17; September 28

ANXIETY

July 6; August 3; September 21

SOUTH SHORE for relatives and friends

Wednesdays 6:30pm
Greenfield Park Baptist Church, 598 Bellevue North, Greenfield Park
July 8, 22; August 5, 19; September 9, 23

LIFELINE for people with mental illness

Alternative Centregens, 3820 Montée St-Hubert in St-Hubert
Call 450-651-0651 for dates and times

BOARD MEETINGS

Tuesdays 7:00pm at AMI
July 28, September 8

If you live with a hoarding problem, you hold the key to overcoming it. The thing is, you can't do it on your own. So says Gail Adams and she should know. Most of her life she, too, was a hoarder. She worked incessantly to conquer it with therapy and information gleaned from every source she could find, right down to research papers. (Professional help was and still is rare in

and afford it, can help you recognize that your thinking is distorted and how to go about viewing your possessions more rationally. But in the end, whether you prevail is up to you.

Hoarding is either learned behavior or it may be a reaction to childhood experiences. "I don't think people are born as hoarders," says Adams, "but I've never met anyone who had a happy childhood." Some studies show hoarding may run in families. At times a lack of familial love or social isolation turns possessions into a means of comfort. With some people it can start later in life, perhaps following a tragic event.

HOARDING CAN BE HELPED

Learn how. Register now for our new facilitated self-help group

Montreal and it's costly.) It was at Adams' instigation that our hoarder support group was set up seven years ago.

Now she's proposing a new type of help, a complement to the support group. Come September, Adams will be facilitating a self-help workshop for hoarders.

The program will be based on the second edition of the authoritative book *Buried in Treasures* (Oxford University Press, 2013). It will run for 15 weeks through to next January, including two follow-up sessions at the end.

This program is quite different from the support group in that it's structured. "We'll follow the same format as the book does and cover the different topics in the same order," Adams explains. The program is free but participants need to register. They also need to buy their own copy of *Buried in Treasures* and come prepared for the sessions by reading and doing the exercises indicated beforehand.

Buried in Treasures is considered by many to be the bible on the subject of hoarding. Apart from general information, the book has family sections explaining the right and wrong ways to help someone who's a hoarder and guidance for those wanting to improve their own situation. But trying to overcome hoarding all by yourself isn't the best approach. "It's not easy to do the reading and the exercises without extra help," says Adams. "In the workshop you'll get structure, motivation and support, all very important to succeed."

Complex and deep-rooted

There's no pill or other medication that works for hoarding. It's essentially a disorder of thinking and behavior, one that's deeply ingrained. Cognitive behavior therapy, if you can find it



Been there, done that

it was excruciating. Now it's not that bad at all. I may not want to discard something, but I know I can. That's the difference."

And that's where the self-help workshop comes in. It doesn't mean that at the end of 15 classes a hoarder's house will be beautifully clean. But the skills to reach that goal will be there, likely in less time than Adams experienced.

"I don't agree with those professionals who think there's no treatment for hoarding. That's very sad, because when a hoarder thinks it's hopeless they don't even try," she says. "I believe if you're ready to commit, there's no reason you can't succeed."

For more information or to register for the workshop, contact Adams at gfadams@sympatico.ca or call 438-886-2824. □

Whatever the root, working on a hoarding problem entails airing emotions that some would rather keep hidden. It's hard to change a life built around a hoarder way of thinking and there's no quick fix. At the heart of recovery is the ability to make decisions about which possessions to keep and which to let go. That requires motivation, time and learning how to prioritize. Adams sees herself as an ex-hoarder. "At first, getting rid of stuff was impossible," she says. "Then I could do it even though

Caregivers ... continued from page 2

try department to government officials and service providers. In one instance, the audience was workplace executives.

Prior to developing the national guidelines, the Commission held consultations with family caregivers to learn what they considered the essentials for effective caregiving. The groups cited four basic necessities:

- **Appropriate care for their relative, including access to services and supports that would maximize his or her potential for a fuller quality of life.**
- **Recognition of their relationships and caregiving roles along**

with meaningful inclusion in their relative's assessment and treatment planning.

- **Receiving information and timely support from knowledgeable service providers.**
- **Recognition and support of their personal needs in order to sustain their own physical and emotional well-being.**

The guidelines were based in large part on those essentials. The more quickly and widely they're implemented, the better the chances of developing an improved, family-friendly system of care with benefits for anyone affected in any way by mental illness. □

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workshops in that professionals of our choice will be speaking on topics in their area of expertise, but it's all done via computers.

Just a click away

"It may be online, but for any viewer it's like attending a conference in town," remarks Stollow. "You just go to our website and register, or you can phone us. Then you enter a web conference room and you're all set. Without stepping outside your door you'll receive information, education and support. The technology is interactive, so you can ask any questions you want or share your own knowledge with other participants. It's a good feeling of solidarity. We'll also be providing material that you can download. And if you choose, you can remain anonymous. For some people that's important."

Webinar technology has benefits for everyone. Presenters, whether they're one, three or a panel of five, can work from their offices and their message can be received anywhere. All they need is a computer with a webcam and access to the internet. It's all remote and it all works seamlessly.

As for us, our teleworkshops have economically expanded our reach into off-island communities and the upcoming webinars can only continue that trend. "AMI will be able to reach thousands of people at the drop of a website," is Stollow's optimistic prediction.

TCN thinks big. They spent six months upgrading their website and changed their name this past April (originally Care-ring Voice) to one that is more specific, more mature. As Stollow explains, "A network is a place for caregivers to connect. In a second sense,

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TRIBUTES & MEMORIALS

In honor of Kay Simpson
Joanne Smith

In honor of Rhonda and Sheldon Nutkevitch
Lynn and Andy Nulman

In honor of Faigie Stark and Seymour Coviensky
Lynn and Andy Nulman

In honor of Norma Nutkevitch
Lynn and Andy Nulman

In honor of Sylvia Itzhayek
Dawn and Bob Assaly

In memory of Joy Zeesman
Phyllis Schnarch

In memory of Marcello Quattrociochi
Sidney Copoloff

In memory of Sonia Weinzwieg
Sylvia Klein

In memory of Alan Kravitz
Pam Litman

In memory of Avram Kirstein
Lynn and Andy Nulman

In memory of Gerry Medicoff
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AMI-Québec extends sympathy to the bereaved and appreciation to all donors for their generosity.
If you wish to honor someone with a donation, please phone 514-486-1448 or visit amiquebec.org/donate/.

AMI-Québec Donation & Membership Form

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New Membership

Membership includes the quarterly *Share&Care*, other mailings and lecture announcements, access to the AMI library and all other activities. Complimentary membership is available for people with limited incomes.

Existing members receive their renewal notices in the mail

Membership (\$25 annual):	\$ _____
Donation:	\$ _____
Total amount enclosed:	\$ _____

Payment may be made by cheque, VISA, MASTERCARD or by phoning 514-486-1448

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Passion ... continued from page 7

our partners are part of our network. And a network is also a broadcaster of content, like CTV or NBC. We want to be that broadcaster and have some of the best minds in their field share information to make caregivers' lives better." TCN also likes the idea of peer-to-peer sharing and aims to develop more opportunities for caregivers to connect with each other on their website.

And Stolow has another, more personal plan for the future, something he calls caregiver self-assessment. "One of the biggest challenges for caregivers is that no one determines their needs. We want to create online tools to help them pinpoint where they are in the journey and what they need, then make resources available so they can meet those needs."

Stolow claims that TCN is now Canada's biggest tele-learning network to support caregivers. They got there with knowhow, enthusiasm and, yes, a boatload of passion. □

Our past teleworkshops are archived and can be found at our website, amiquebec.org/teleworkshops.

Reach TCN online at caregivernetwork.ca; in French, lereseauaidant.ca. Or phone 1-866-396-2433.



This issue of *Share&Care* has been made possible by an educational grant from Janssen Inc.

amiquebec

Agir contre la maladie mentale
Action on mental illness

AMI-Québec, a grassroots organization, is committed to helping family caregivers* manage the effects of mental illness through support, education, guidance and advocacy. By promoting understanding, we work to dispel the stigma still surrounding mental illness, thereby helping to create communities that offer new hope for meaningful lives.

* Family caregivers are those in the circle of care, including family members and other significant people, who provide unpaid support to a person living with mental illness.

Anna Beth Doyle, *President*
Norman Segalowitz, *Vice President*
Joanne Smith, *Secretary*
Donna Sharpe, *Treasurer*
Jean Claude Benitah, *Immediate Past President*
Ella Amir, *Executive Director*

SHARE&CARE

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Member of La Fédération des familles et amis de la personne atteinte de maladie mentale (Québec)