

SHARE & CARE

THE RECOVERY OF HOPE ~ THE HOPE OF RECOVERY

A BREATH OF FRESH AIR

YOU WISH THINGS WERE DIFFERENT IN
HOSPITAL FOR FAMILY CAREGIVERS?
AT ST. MARY'S THEY ARE

“Families are the ones holding the key. We can only accompany them.”

“We want to make sure that patients don't only count on us.”

Those are the principles that differentiate the Psychiatry department at St. Mary's Hospital. Small compared to other hospitals (only 11 psychiatrists on staff), community-minded and family-oriented, it's a place where preconceived ideas are set aside and everything is done to help patients and their

Politique de santé mentale [Quebec's action plan on mental health] to be promulgated for the first 19 of those years,” she says. “During that time I came to the conclusion that the main resource in psychiatry should be the patient and the family and the best approach we professionals can take is to give people the means of finding more effective ways to manage their problems and thus stop unnecessary suffering.”

The concept was a good fit at St.



Making St. Mary's special (l-r): Social worker Suzanne Pichette, Donald Desrosiers, Suzanne Lamarre. Absent: head nurse David Bérubé

families take the lead in resolving their problems.

Chief of the department is Suzanne Lamarre, who joined the hospital 10 years ago as an emergency psychiatrist with a big reputation in crisis intervention.

“I started my career as a psychiatrist in 1970 and waited for *la*

Mary's, where things have traditionally, though quite informally, been family-oriented. What Lamarre did was wholeheartedly sanction their approach so that it became the official department culture.

Donald Desrosiers, liaison nurse and coordinator of emergency and

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“Thanks for calling. I really need your help.”

People with questions reaching people with answers.

That's the Mental Health Family Link, coming to a telephone near you

Picture a time when caregivers coping with a loved one's mental illness will be able to dial a 1-800 number and receive the information, guidance and support they need from other, experienced caregivers. Sounds good?

It also sounded good to the Family Caregivers advisory committee of the Mental Health Commission of Canada. It was the largest and most ambitious of seven proposals the committee submitted to the Commission for approval in 2008; the one committee members favored because it had the potential to help the most people. The Mental Health Family Link program was given the go-ahead last January.

“It will start as a pilot project in Ontario,” explains AMI executive director Ella Amir, who heads the Family Caregivers advisory committee as well as the ad hoc Project committee charged with overseeing the program through to completion. “Eventually we expect to roll it out coast to coast, so no matter where a caregiver lives, help will be as near as their telephone.” Working with Amir on the Project committee are two Family Caregivers committee members and two from the Commission.

No one needs to be sold on the benefits of peer support. Telephone technology expands on that good idea by eliminating distance problems and making it easier to match compatible phone-mates. The Cancer Connection, an initiative of the Cancer Society of Canada, and a similar program running in B.C. are two successful examples of such an approach. Our own

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tele-conferences, though they operate somewhat differently, are basically the same concept.

Common ground

To access Mental Health Family Link, you will simply dial a 1-800 number. You'll reach a program coordinator who will enter all your pertinent information and the problem that's causing you grief. Shortly afterwards you'll be connected with a volunteer caregiver, someone who's been through what you're going through, who understands and can give you the answers you're looking for. "The peer matching will be done to suit the caller's wishes," says Amir. "What's important is that both individuals feel at ease during their conversations."

A project manager was hired last April. Robin Cross's qualifications include a background of working with crisis centres that offer telephone support. She's now developing a comprehensive work plan that covers

everything from setting up an office to hiring coordinators and recruiting and training the volunteers. These family caregivers will be working from their homes and it's vital that they're able to communicate effectively.



Amir (I) with her Project committee: Robin Cross, Sophie Sapergia, Ed Connors, Carol Adair, Norman Segalowitz

Also on the agenda will be some sort of outreach activities to familiarize the general public with the program and encourage

caregivers looking for help of any description to pick up their phones and call.

For the time being it's the Commission that's funding the Mental Health Family Link program. Down the road it will need to become self-sustaining with funding provided from outside sources. Also down the road, when the program is up and running well, is the dream of expanding it to include telephone peer support for consumers.

But first things first, and right now there's plenty to do in preparing for the pilot launch. The guesstimate is that will take place early in 2010. Hopefully, on the day that Mental Health Family Link opens for business, the phones will be ringing off the hook. □

A Breath of Fresh Air ... continued from page 1

crisis services, is a long-time colleague. "We can't work without families," he says flatly. "They're part of the treatment team right from the beginning and we make sure they understand that they're the ones who hold the key to their relative's recovery."

At St. Mary's, time spent involving families is not considered a chore but an investment in a patient's future. They're unhappy at the sight of patients being admitted with no family member on the scene and none available to contact. In Lamarre's opinion, there's nothing worse than having only a psychiatric team standing in for a family. In her experience that just makes a patient sicker.

Recognized, respected

Families with a relative in hospital for the first time are not left on their own for long. In a quickly-convened meeting that can go on for hours, not only is background information elicited, but the illness and hospital routines are discussed. Much time is spent drawing up a plan of action and a follow-up meeting is normally scheduled for several weeks later. Meanwhile, the family is free to call Desrosiers at any time. "I don't mean just a quick two minutes to learn if their relative has kept his appointment," he points out, "but all the time necessary to hear my advice on the best way to resolve an issue or handle a situation."

Much to families' relief, nobody plays the blame game. "Our approach in this department is collaboration, not control," Lamarre explains. "We don't want to change families. And it's useless for everyone to be accusing everyone else. What we do instead is help families and their ill relatives look for solutions together. That way they themselves can improve the way they deal with their problems."

In from Africa

Desrosiers' "all the time necessary" can stretch to days and beyond. A man from Africa, potentially of danger to himself, was recently admitted to Emergency. His sister and an aunt living here wanted him to be hospitalized, but he vehemently objected. The hospital placed two phone calls to the man's mother in Africa. Heeding her advice, they released the patient, who returned, as promised, with his mother when she arrived in Montreal. "If we had followed textbook practice, we would have kept the patient against his will in the hospital and there might well have been an escalation of violence and non-cooperation," says Desrosiers. "This way, he agreed to come back and now we'll work together instead of fighting each other."

"We'll now proceed at the patient's own pace," Lamarre adds. "It's not the way we expected things to happen, but we will be making progress, that's what's important. And it could never have happened without the family's participation."

Because of its small size, the St. Mary's Psychiatry department has traditionally outsourced services to a variety of community organizations — Forward House, Dollard-Cormier, Tracom and AMI, to name only a few — and considers them a vital part of its extended family. They are especially proud of winning our Exemplary Service Award because, in Lamarre's words, "it's an official recognition, an endorsement of the way we work and our faith in the power of family relationships." They would like to know more about our programs, perhaps forge even stronger ties. That would be good for both of us. We have a lot in common. □

MISUNDERSTOOD AND AFTER SO MANY YEARS

Many hospitals are still vague about how AMI helps families and how our help can help them, too. We're working on changing that

It's a complex relationship that exists between families, healthcare professionals and us as a family-support organization.

We receive a good number of referrals from hospitals, but we think there should be more, especially among families with a recently diagnosed relative who are facing the intimidating presence of mental illness for the first time. Why do hospitals not direct more families our way? We think we know.

For one thing, there's confusion about exactly how we operate. Yes, we help families through education, information, guidance and support. Does that mean we automatically buy into everything a family might say or do? "Certainly not," says executive director Ella Amir. "If all we offered was knee-jerk comfort, our job

would be a lot easier. Very often we're most helpful when we're shaking things up by pointing out a behavior pattern or outlook we see as counterproductive."

Not every family readily appreciates being told they need to make fundamental changes in their way of thinking. But given time, plus our education and support programs, change for the better happens. Hospital healthcare workers do meet with family members, of course, particularly when a relative is an inpatient, but despite their good intentions, they have too little time and far too much on their plate to be able to duplicate our level of long-term attention.

Sooner is better

Early help for families is as important as it is for their ill relatives. It's a given that

everyone's lot improves when parents and/or siblings understand how best to respond to their loved one's needs and keep themselves on an even keel, as well. In fact, says Amir, "There's research evidence to suggest that competent families have a positive impact on the clinical course of the illness." With roughly 50 percent of consumers living at home with their parents, it's ultimately in the best interest of psychiatry departments that families become as informed and knowledgeable as possible. And as early on as possible.

Missed opportunities abound. In the case of a first hospitalization, a family will often talk itself into believing that the illness is only temporary, that their relative will stabilize and the family will wake up one morning with things miraculously back to the way they used to be. These are the people who should quickly be made aware that they need help. It's simply not enough to hand out an AMI brochure and advise "call them when you're ready." It often takes a relapse and a readmission to hospital for families to face up to reality. By then maybe a year has gone by they've forgotten our name.

The bad old days

Once upon a time parents and bad parenting were routinely blamed for a relative's illness. While those days are gone, vestiges of the attitude still linger and can deter professionals from wholeheartedly encouraging families to seek out a family-support group for help with their emotional turmoil. Still, when parents worry that their relative's situation is their fault and ask what they've done wrong, most times the answer is likely to be: "You haven't done anything wrong. Nothing you could have done would have prevented it." That's good as far as it goes. A more complete and helpful response would be: "There are organizations where they'll work with you to diminish the impact of the illness on your family. You need to get in touch with them."

Plans afoot

On the recommendation of our Strategic Planning committee, the

continued on page 8

THE HIDDEN VICTIMS OF MENTAL ILLNESS

AMI members star in a poignant video about the experiences of family caregivers

Every year busy Montreal film producer Heidi Berger undertakes a project on a subject close to her heart, one for which she volunteers her time.

This year she chose mental illness and approached us with her irresistible proposition. The result is a skillful 12-minute video, *The Hidden Victims of Mental Illness*, focusing on five AMI members — Jean-Claude Benitah, Mike Santoro, Joanne Smith, Annie Young and Sharleen Young. They provide a rare and intimate look at what it means to a family when mental illness strikes and testimony as to how important help like ours has been.

The video was produced by a crew of three: Berger, cameraman Bill Stone and editor Les Bairstow. It's already been shown at several AMI events including our annual general meeting — and that's just the start. We plan on a busy future for the video as a means of enhancing our education, outreach and fundraising efforts. Make it a date to attend the Low-Beer lecture next fall — we're sure to be screening it there, as well. ■



Berger gives back — in spades

OUR 32ND ANNUAL MEETING: THE FINISHING TOUCH TO A FINE YEAR

It was one of those all-too-rare years when things went according to plan.

Our support, education, guidance and outreach programs made promises and delivered — as well over 2,500 people can testify.

We worked at confirming and expanding our presence in the mental healthcare community by strengthening our ties with hospitals and CLSCs.

Expenses were up, but revenues rose even more, thanks largely to our

third, highly successful fundraising event.

After the reports, the voting, the awards and the thank-yous were done, the meeting was treated to a screening of our new video, *The Hidden Victims of Mental Illness* (story on p. 3). The video speaks volumes about the needs of families who find themselves in the grip of a mental illness and the help they receive from AMI. It was a fitting cap to one of our most productive years yet. □



Two **Volunteer of the Year Awards** were handed out this year to **Sara Fleischman** (above) and to **Hugo Jimenez** (left). Francine Waters did the honors for both



Dr. Nadia Szkrumelak (l), associate psychiatrist-in-chief and External Services director, MUHC Mental Health Mission, receives the **Exemplary Psychiatrist Award** from Elva Crawford



Chief Psychiatrist **Suzanne Lamarre** (r) and **Angela Cusano**, ER nurse, accept the **AMI-Québec Award for Exemplary Service** on behalf of the Psychiatry department at St. Mary's Hospital

Board of Directors 2009-2010

EXECUTIVE COMMITTEE: Renée Griffiths, president; Annie Young, vice president; Danielle Gonzalez, vice president; Anna-Beth Doyle, treasurer; Joseph Lalla, secretary; Lorna Moscovitch, immediate past president

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*Mike Santoro presents the **Extra Mile Award** to **Elizabeth Gluch**, teacher, EMSB Special Needs Adult Education*



Heidi Berger** (r), producer of *The Hidden Victims of Mental Illness*, wins the **Certificate of Honor**, presented by **Ella Amir



***Joanne Smith**, board member, and her **Monty Berger Award for Exemplary Service**. **Ella Amir** shares the moment*

SUMMER 2009

SUPPORT GROUPS

Mondays 7:30pm 4333 Côte Ste-Catherine Road unless otherwise indicated

FAMILY for relatives

July 6, 20; August 3, 17; September 14, 21

SOUTH SHORE for relatives

10 Churchill Blvd., suite 205, Greenfield Park
Wednesdays 6:30pm
July 8, 22; August 5, 19; September 9, 23

PAC Parents of Adult Children

No meetings July or August
Resume at AMI September 8

SIBLINGS AND ADULT CHILDREN

July 20; August 17; September 21

DEPRESSION

for consumers and relatives

July 20; August 17; September 21

BIPOLAR DISORDER

for consumers and relatives

July 6; August 3; September 14

OBSESSIVE COMPULSIVE DISORDER

for consumers and relatives

July 20; August 17; September 14

KALEIDOSCOPE

for consumers

July 20; August 17; September 21

HOARDING GROUP (in collaboration with Quebec OC Foundation)

for consumers and relatives

July 6; August 3; September 14

LIFELINE for consumers

Alternative Centregens, 5770 Auteuil, Brossard
One Tuesday every month 1:00-3:00pm
For dates call 450-445-5427

BOARD MEETINGS

Tuesdays 7:00pm at AMI
No meeting in July; August 4; September 1

IN FROM THE COLD

Under-recognized, under-appreciated and under-funded, peer support is finally getting the attention it deserves

Anyone living with mental health problems who's been helped by peer support knows how important it is to their recovery process. So why then is the file on existing self-help resources and operations in Canada so thin?

Kudos to the Mental Health Commission of Canada (MHCC) for determining to set things right. They've allocated \$150,000 for a research study to get a fix on peer support initiatives and attitudes coast to coast.

Those responsible for writing the call for research proposals and guiding the document through to MHCC approval are two of the five-member Service Systems advisory committee: Loïse Forest, a consumer activist and long-time AMI member, and Laurie Hall, CEO of a consumer-owned and -operated courier service in Toronto. They formed the ad-hoc Peer Support Project advisory committee.

"There's anecdotal evidence that peer support is both beneficial and appreciated," says Forest. "but we're short on hard facts about what's going on and where it's happening. We know of peer support programs offered by organizations in the healthcare system, but we want to learn more. We're especially interested in consumer-run initiatives. We suspect there are many, but where are they, what are they offering, how successful are they and what are their problems? We're counting on the research to fill in the blanks."

From the nine submissions received from research resources, the contract was awarded to a team of four — a New Zealander, an Australian, a Quebecer and an Ontarian — all women, all consumers who have previously worked together. Their new assignment officially began in January and will ultimately take them right across Canada, the Northwest Territories and Yukon. Their final report is due March 31, 2010.

No substitute for being there

Peer support has a two-pronged base — recovery and helping. At its simplest it can

be having a companion for a trip to the doctor or one person discussing a problem with another. Some professionals hold that it's talking to anybody at all who understands recovery, but Forest disagrees. "To me that's not peer support," she says. "There needs to be a common history, consumers sharing real events in their lives with each other, exchanging experiences, disappointments and dreams. And discussing the best way to keep moving on the road to recovery. Lots of talking and lots of listening are fundamental."

Every week in her role as a peer support worker, Forest visits an apartment housing six people. "Some of them had been hospitalized for 20 years and now they're supposed to pick up the threads of their life and carry on like nothing happened. Well, that's impossible. They need help with the most basic things, like looking after themselves, house-cleaning and food shopping, not to mention learning how to integrate their illness into their new life. I'm a friend who understands. To me, that's when peer support is most worthwhile." So worthwhile and vital, in fact, that Forest believes for many people a solid recovery is impossible without it.

Four years ago Forest traveled throughout Quebec trying to locate self-help groups. "We came to the concept late here," she explains. "If there are 10 groups in all of Quebec, I'd be surprised. And yet in a tiny village in Abitibi I found one. It was such a small place, population 2,500, that the CLSC was in someone's house and a psychologist visited once a month. Yet

there were 10 people meeting every week in the basement. They were receiving \$500 a year from Centraide and that was it for funding. Nevertheless the group stays

together because the need to give and receive help is so powerful."

Peer support is an addition, not a replacement for biomedical treatment. It goes where medication can't. Historically, not all healthcare professionals have appreciated the distinction, although according to Forest that's slowly starting to change. One sign of the new attitude: there's formal peer-support

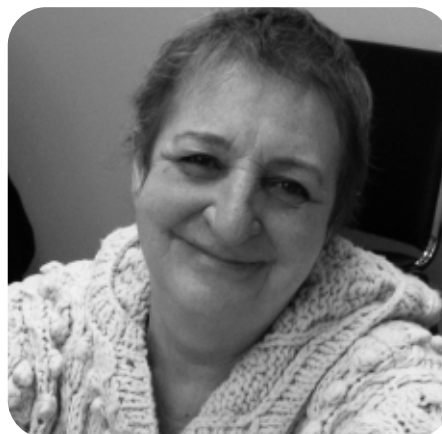
training now. A course with certification is being given in Quebec City and in the U.S. state of Georgia. Roy Muise, a Canadian based in Nova Scotia, has the distinction of being Georgia's first certified peer-support worker.

The ultimate goal

Once the research findings have been presented and absorbed, information on the status of peer support in Canada will be included in the MHCC's mental health strategy. Armed with the facts, the Commission will then be able to meet with the various governments to show them how important peer support is and to present its (hopefully iron-clad) case for funding.

The limited research done in the past indicates that consumers who benefit from peer support experience fewer psychiatric symptoms, have fewer hospitalizations and emergency room visits, maintain greater stability in the areas of housing and employment, and enjoy a better quality of life in general.

If it only served to help reduce the pressure on the mental healthcare system, government funding for peer support and self-help groups would be money well spent. It's not brain surgery. □



Forest: peer support does what nothing else can

Research will clarify the big picture

Partners for Mental Health: Canadians teaming up to make a difference

Since its inception, the Mental Health Commission of Canada has had the goal of developing a national mental health strategy. At the moment Canada has the dubious distinction of being the only G8 country without such a program on the books.

When the strategy is finally in place, Partners for Mental Health will be its very visible face across the country.

The idea behind Partners is to recruit a nationwide team of volunteers, people likely, but not necessarily, already involved in some way with mental illness. What they will all undoubtedly share as a team is a dedication to the goals of the strategy and a determination to permanently erase the negative image of mental illness that continues to exist in Canada.

This daunting task can be tackled from several angles.

Mental health literacy. Just as Canadians have now become increasingly conscious of, and work to improve, their physical health, they should be educated to have greater awareness and understanding of their mental health.

Improved services and support. Ongoing pressure needs to be applied so that provincial governments provide better mental health services and access to them. Ditto for community support services.

Stigma and discrimination. Attention must be paid to reducing the injurious effects of stigma and discrimination directed against those who are ill, the families who care for them and the professionals who treat them.

For those interested in making a difference by joining the Partners team: you can expect further news some time this fall. We'll keep you informed. Meanwhile, there's a website you can visit: www.mentalhealthcommission.ca. □

5-à-7 AMI-style. MORE THAN COCKTAILS ON OUR MIND

Some 50 guests gathered last April to sip a drink, nibble on snacks and absorb a valuable lesson about some of the difficulties faced by families caring for a relative with a mental illness.

Held at the home of AMI members Lynn and Andy Nulman, the event was themed "The Early Signs and Symptoms of Mental Illness." In a 45-minute address, Dr. Johanne Renaud, the Douglas Hospital's director of youth services, explained those signs and symptoms as they apply to teenagers and alerted her audience to the behavioral changes in children that could spell trouble.

The group was also treated to the first public showing ever of our new video, *The Hidden Victims of Mental Illness*. (Report on p. 3.)

The Organizing committee, sparkplug behind this event, has a second 5-à-7 planned for July. More than likely it won't be the last. □



Organizing committee members (l-r): Sherry Ellen, Karen Waxman, Randi Zemel, Pam Litman, Lynn Nulman

TRIBUTES & MEMORIALS

In honor of Anita Miller
Marylin Block

In honor of Joanne Smith
Marylin Block

In honor of Marion Verrall
Sally and David Verrall

In honor of Beppie and Pieter Boudens
Nina Mack

**In honor of Danny Berg's
special birthday**
Keila and Billy Finkelstein

In honor of Ronna Ellen
Sherry Ellen

In honor of Danielle Medina
Sherry Ellen

In honor of Lina Rappaport's birthday
Eva and Herbert Marx

**In honour of Phyllis Friedman's special
birthday**
Mona Golfman and Irwin Woods

In honor of Hayes Nulman
Jackie and Andy Kirstein

In memory of Lillian Dery
The No Name Book Club
Pierre and Peggy Belanger

In memory of Joan Shaw-Davies
Shirley and Bob Smith

In memory of May Gruman
Kay Simpson

In memory of Carole Wallace
Susanna Jack

In memory of Gino Motaferri
Berta Helferty
Diane Maheu

In memory of Ruth Goldsmith
Pat and Paul Rubin

In memory of Bernie Cohen
Pat and Paul Rubin

In memory of Gus Boudens
Kay Simpson

In memory of Al Evans
Kay Simpson

In memory of Debbie Richardson
Kay Simpson

In memory of John Simpson
Kay Simpson

AMI-Québec extends sympathy to the bereaved and appreciation to all donors for their generosity. For information, please phone 514-486-1448.

AMI-Québec Membership & Donation Form

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

- ☐ I wish to renew my membership
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- ☐ I have a family member with a mental illness
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Name on card _____ Exp. date _____

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5253 Décarie, Suite 200, Montréal, Québec H3W 3C3

Misunderstood ... continued from page 3

Advocacy committee along with education and outreach coordinator Sylvia Smith are working on a plan to reach out to hospitals in our area. "We're not thinking of cut-and-dried presentations," says Amir. "We see this more as informal dialogues instead, lots of talking and an exchange of opinions to explore ways we can work better together. Maybe we'll show our new video, but the rest of the agenda will likely be tailored to the hospital we're visiting." There's no fixed date yet for these meetings to begin, but it will certainly be some time this year.

Perhaps our message will go something like this: as mental health professionals, you deal with the illness of patients. Families, understandably, are not your primary business. But we specialize in families. For 32 years they've been our only business. Why not think of AMI as your outsource in the community, where families struggling to keep their balance and help an ill relative can get the information, guidance and ongoing attention they so desperately need.

As Amir says, "If talking with the hospitals has a positive effect on the referrals we receive from them, we'll be very pleased." ☐



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



AMI-Québec, a grassroots organization, is committed to helping families 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.

Mental illnesses, known to be biologically-based brain disorders, can profoundly disrupt a person's ability to think, feel and relate to others. Mental illness affects not only individuals, but also their families, friends and everyone around them.

Renée Griffiths, *President*
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Lorna Moscovitch, *Immediate Past President*
Ella Amir, *Executive Director*

SHARE&CARE

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Ella Amir, *Managing Editor*
Bryna Feingold, *Associate Editor*
Liane Keightley, *Designer*

Articles and comments are invited. Anonymity will be respected if requested. Guest articles reflect the opinions of the authors and do not necessarily reflect the views of AMI-Québec.
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Member of La Fédération des familles et amis de la personne atteinte de maladie mentale (Québec)

