FIRST SYMPOSIUM ON YOUNG CARERS
A call for funding awareness and support for young carers

A first Quebec-based symposium titled Putting Young Carers on the Map helped galvanize a call for action to better recognize and support young caregivers. Close to 100 people attended, representing the government, education, health, and community sectors. Organized by AMI-Quebec in collaboration with the Regroupement des Aidants Naturels du Quebec (RANQ), the symposium was funded by Health Canada through the Community Health and Social Services Network (CHSSN).

Held on March 22 in Montreal, the symposium provided an opportunity for reflection on the special circumstances of young carers in Quebec and their need for support. To mobilize such support, the engagement of the education, health, and social services sectors is critical, as well as the increased awareness of the public at large, of the issues faced by young caregivers and their major contribution in restoring or maintaining the quality of life of individuals who are sick, aging, or living with a disability. Being a young caregiver can be a positive experience, as long as they are well supported. There is a substantial body of research on the state of mental and physical health of young people, the causes of dropping out of school or suicide. We must expand our knowledge to better understand the association between being a young carer and these different potential outcomes.

The symposium program included an overview of the issue, the evolution of a young carers project in Ontario, research projects in Quebec, a cultural perspective, testimonials of young carers, and a panel discussion. Marguerite Blais, Minister Responsible for Seniors and Informal Caregivers, addressed the participants.

A growing number of young people provide an increasing level of unpaid care to family member(s) with chronic illness, disability, mental health or substance use issue and/or problems related to old age. According to Stats Canada, in 2012 there were over 1.2 million caregivers aged 15 to 29 in Canada. However, it is possible for young carers, and a panel discussion. Marguerite Blais, Minister Responsible for Seniors and Informal Caregivers, addressed the participants.

I n 1969, Elizabeth Kübler-Ross identified the five stages of grief, namely “denial, anger, bargaining, depression, and acceptance.” These five stages – initially intended to name the stages of a person’s coming to term with death – evolved to include all forms of grief for families as well. As a Western culture, we have accepted Kübler-Ross’ vocabulary because it follows linear thinking and implies finitude. We are a “culture of mastery” and have a hard time accepting that some problems do not have solutions.

“Grief is in two parts. The first is loss. The second is the remaking of life,” suggests American writer and journalist Anne Roiphe. In a lifetime, grief is inescapable. Apart from the ‘typical’ grief resulting from natural loss of a loved one due to old age, we often experience complex grief. In some instances, certain people have the misfortune to lose a loved one swiftly and traumatically, like in a car accident, a terror attack, or by overdose. Other times, the loss happens incrementally, where a loved one experiences degenerative health, including various forms of mental illness or dementia.

Dr. Pauline Boss is an emeritus professor at the University of Minnesota who spent more than four decades working with individuals and families suffering with “ambiguous loss,” a term she coined in the 1970s to identify this complex grief of “loss without closure.” Two types of ambiguous continued on page 2
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someone as young as 8 (or even younger) to be a carer. Almost half of young caregivers care for more than one person with various health conditions, and more than a third take care of grandparents. It is intriguing that young carers devote a similar amount of time to their caregiving activities as their 45 to 54 year old counterparts, the most common caregiver age group. It is also important to note that one out of every thousand young caregivers receive support in Canada, compared with 1/14 in England and Wales. Very little attention has been paid so far to these youth in Quebec, with no dedicated support services or policies acknowledging their care-work.

The ultimate goal of the symposium was to encourage the development of a legal framework that could promote both awareness and support for young carers. In the wake of the provincial budget, the RANQ and AMI-Québec hope that some of the $21 million allocated for caregivers would help increase awareness and develop support programs specifically addressing young caregivers.

Ambiguous Loss ... continued from page 1

loss are recognized as, perhaps, the most painful type of grief – no logical reason can be found and the loss cannot be rationalized: (i) “physical absence and psychological presence” (like the traumatic loss of a missing child), and (ii) “physical presence and psychological absence” (like the loss felt with Alzheimer’s patients).

In an interview with Krista Tippett for On Being, Dr. Boss underscores the importance of reducing stress levels of individuals and families experiencing ambiguous loss and encourages coming to terms with not finding closure. She exhorts that, as a culture, we modify our “getting over it” mode of thinking to help decrease the anxiety levels of individuals and families experiencing grief. She offers suggestions to lessen the anxiety and stress associated with ambiguous loss.

We want grief to have a finite timestamp, so we can “move on with things.” Dr. Boss recognizes this pattern of mythic thinking as outdated. She suggests loss is so complicated and illogical that we need to accept there is no possible end date with grief. On a societal level, she urges us to move away from linear thinking, from simply expecting people to “move on.” Loss is messy and non-linear. There are “ups and downs” of living with grief, but the intensity and frequency of the experiences of grief move “farther apart,” over time. According to Dr. Boss, we need to understand that life is possible with loss, “clear or ambiguous”.

Having meaningful human connections helps with the process of learning to live with grief and the stress that comes with it. Individuals and families experiencing ambiguous loss go through incredible pain. According to Dr. Boss, it is typical to experience “symptoms of grief that carry on, let’s say, even for five or ten years, if it’s a caregiver of an Alzheimer’s patient.” In this case, the caregiver experiences long-term chronic grief.

The sadness of a caregiver, however, is not to be confused with depression. According to Dr. Boss, caregivers of individuals suffering from mental health issues or dementia are often said to be depressed, which adds an enormous amount of anxiety and can intensify the anguish. Dr. Boss has found that having a name for the experiences has helped stress reduction. “What you’re experiencing is ambiguous loss because your loved one is ... [here, but not here]. It is the most difficult, most stressful loss there is. But it is not your fault.”

There are other ways to reduce stress levels and come to terms with living with grief. To help ease the enormous pain, Dr. Boss encourages implementing the Eastern idea of “paradoxical thinking.” To live with ambiguous loss is to “hold two opposing ideas in your mind at the same time.” Children can more easily adopt this idea than adults, but the latter can assimilate as well. Caregivers of dementia patients, for example, should accept the idea that their loved one is “there, but...not always there.” Having the ability to hold “two opposite ideas in your mind” simultaneously is instrumental in reducing stress and decreasing the intensity and frequency through the grief experience.

The “remaking of life” after loss is ongoing and difficult, and culturally needs to be “normalized.” Understanding that you are suffering from complicated loss and that it is not your fault is an essential approach to help ease the pain. In turn, you can then implement “paradoxical thinking” and learn to live with ambiguous loss.

A 5 minute recap of the Young Carers Symposium can be viewed on our YouTube channel: http://bit.ly/YTYoungCarers0319.

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COULD THE OPPOSITE OF ADDICTION BE CONNECTION, NOT SOBRIETY?

A fresh outlook on addiction in Johann Hari’s book

Viewing drug addicts as law-breakers that need to be punished has been common for many years. It has been more than one hundred years since drugs were first banned in the US, however instead of registering meaningful successes on the war against drugs, addiction has become an even bigger concern. Troubled by this unsettling reality, British journalist Johann Hari embarked on a fact-finding mission. He wanted to understand why did the drug war start, why does it continue; why can some people use drugs with no problem while others can’t? What really causes addiction? What happens if radically different policies were tried?

"It is not the drug that causes the harmful behaviour, it’s the environment."

Chasing the Scream: the First and Last Days of the War on Drugs (2015) is Hari’s excellent manifesto on drug addiction. He describes in detail how the war on drugs started in the US, what fuelled it and what were its consequences. Beyond the facts, Hari is a captivating storyteller, which makes his book a fascinating read. He travelled the world and met dozens of people who are, or have been, involved in attempts to address addiction from different perspectives.

Bruce Alexander, a professor at Simon Fraser University in British Columbia, told Hari that in an attempt to understand addiction he created an experiment where rats were divided into two cages: in one cage the rats lived in solitary confinement where they only had their fix (morphine). The other cage, a ‘paradise for rats’, contained everything a rat could want – wheels and coloured balls, the best food, and other rats to play with. He called it Rat Park. In both cages the rats had access to two drinking bottles; one contained only water and the other contained morphine (an opiate rats process in a similar way to humans and that behaves like heroin when it enters their brain). Alexander and his team discovered that the rats in the isolated cages used up to 25 milligrams of morphine a day, but the rats in the happy cages used hardly any morphine at all – less than 5 milligrams. Alexander’s conclusion was that it is not the drug that causes the harmful behaviour, it’s the environment. An isolated rat will almost always become a junkie. A rat with good life almost never will, no matter how many drugs are available to him. As Alexander put it, “addiction is not a disease, it is an adaptation. It’s not you, it’s the cage you live in.” In other words, if you change the social circumstances for most drug users you could change their behaviour!

Alexander believes that being cut off from meaning in “our hyper-individualistic, frantic, crisis-ridden society makes most people feel socially or culturally isolated,” and this goes against an innate, evolutionary need to bond. Peter Cohen, Alexander’s friend, argues that instead of using the word “addiction” we should shift to “bonding”.

One recovering heroin addict said that addiction is a disease of loneliness, and it appears that heroin subculture gives addicts bonds with other human beings. “It’s a lot better to be a junkie than to be nothing at all... This is life. It’s better than no life”, says Alexander. Human beings become addicted only when they cannot find anything better to live for and when they desperately need to fill the emptiness that threatens to destroy them, he says.

"Addiction is a disease of loneliness."

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Hold the Date

AMI Rocks October 16, 2019 at the Corona Theatre

Get ready to party on October 16, 2019 at the “AMI Rocks” fundraising event. Musical entertainment by the MTL band, performance by hip hop dancer and mental health advocate Michael Prosserman, and event emcee Andy Nulman.

"Could the opposite of addiction be connection, not sobriety?"
Once a year we come together and take a look at the past year, present awards, and socialize while looking forward to the future. Fifty people joined us for our Annual General Meeting this year. At this AGM, we celebrated three years in our new, permanent home. Norman Segalowitz, President, described our situation this way: “AMI-Quebec remains one of the largest, if not the largest, organizations of its kind in Quebec. The overall picture for AMI is strong. Programs are flourishing—they have expanded to the point that we may soon be pushing the limits of our new building. Our infrastructure is in good shape, and we are doing relatively well financially—although I always like to remind people never to become complacent about our finances! We have an absolutely incredible group here at AMI—our staff, our volunteers, our Board members, and our Executive Director. Our accomplishments are due to them. And because of them, next year is going to be just as successful as ever.”

Suzanne Herscovitch was presented with the Extra Mile Award for her tireless work with Montreal Walks for Mental Health. “What she has accomplished in the latter part of her community career for mental health will surely leave a legacy for many years to come.”—Pam Litman

Added Diana Verrall, Walk Committee Member, “Thank you, Suzanne, for making a difference in our world, for making people living with mental illness, and their families and friends, feel like they are not alone. For helping our city understand that there is no shame in dealing with mental health issues, and for putting on one heck of a party year after year!”

Norman Segalowitz has been President of our board for the past two years, and was awarded the Monty Berger Award for Exemplary Service. Anna Beth Doyle, our immediate past president, said that Norm is “amazingly dedicated to AMI, always ready to spend extra hours of work to improve its directions. We have been particularly fortunate to have you be our President over these past two years of consolidation and expansion of AMI’s position as an important community organization. Your perceptive insights, clear thinking, and leadership are unsurpassed in helping all of us work to achieve AMI’s objectives.”

Mary Anne Levasseur (right) presented the Exemplary Psychiatrist award to Dr. Amal Abdel-Baki, saying, “Dr. Abdel-Baki is a dedicated, open-minded and compassionate person who works tirelessly with young people and their family caregivers, ensuring their voices are heard and that they are partners in their own health-care experience.”

Meet our board at amiquebec.org/board

The AMI-Québec Award for Exemplary Service in the Field of Mental Illness was created in recognition of individuals who provide extraordinary care to persons with mental illnesses and to their families. Mary Anne Levasseur has been the Coordonnateur and peer facilitator of Family Peer Support in the Prevention and Early Intervention Program for Psychosis (PEPP-Montréal) at the Douglas Mental Health University Institute, the National Lead and Coordinator of ACCESS Open Minds Family and Carers Council, a Founding Member of the Patient Advisors Network, and more.

“We owe a tremendous debt of gratitude to dedicated and talented people such as Mary Anne who help make our communities more caring and responsive to the needs of people with mental illness and their carers,” said Norman Segalowitz.
SUMMER 2019

SUPPORT GROUPS
For family, friends and people with mental illness unless otherwise indicated.
For details visit amiquebec.org/support
Mondays 6:30pm 4333 Côte Ste-Catherine Road (near Côte-Sainte-Catherine metro) unless otherwise indicated. No registration necessary.

FAMILY for relatives and friends
July 8, 22; August 12, 26

BPD for relatives and friends
July 8; August 12

ANXIETY
July 8; August 12

BIPOLAR DISORDER
July 22; August 26

DEPRESSION
July 22; August 26

HOARDING
July 22; August 26

OBSESSIVE COMPULSIVE DISORDER
July 8; August 12

KALEIDOSCOPE for people living with mental illness
July 8; August 12

SOUTH SHORE for relatives
Wednesdays 6:30pm
Greenfield Park Baptist Church, 598 Bellevue North, Greenfield Park
June 26; July 24 (Cancelled on July 10)
New location starting in August: ARC, 106 Churchill Blvd.
Greenfield Park
August 21 (Cancelled August 7)
For people living with mental illness on the South Shore
Alternative Centregens, 462 Sainte Foy Blvd, Longueuil, QC J4J 1Y2
Call 450-651-0651 for dates and times.

BOARD MEETINGS
Tuesdays 7:00pm at AMI
July 23, September 3

Go online for our Annual Report
Visit www.amiquebec.org/annualreport19

Carl-Olivier Riambon is our Volunteer of the Year. He has worked closely with Sylvie Bouchard in our Borderline Personality Disorder programs. In presenting the award, she said, “It can be a long and difficult road for both the person with BPD and for those who love them. For this reason, individuals like Carl, who have the courage to come forward and share their story, are essential. Not only has Carl helped break the stigma around the illness, he has also been very instrumental in normalizing it, making it more approachable. By shedding light on the inner experience of a person with BPD, Carl is making it easier for family members, partners and friends to support, guide, and create a climate of trust and connection. Carl’s courage and his devotion to the cause has been a tremendous source of hope and inspiration to me and to a large number of families.”

The Ella Amir Award for Innovations in Mental Health was presented to Josée Parent (centre). Judy Ross has known her for years, and explained that “Josée is more than a visionary. Her determination to help those between the ages of 18 and 35 with special needs in mental health has resulted in a brand new residence providing 18 single bedroom apartments in a wonderful family-like living space. ‘My Shack...My Choices...My Future’ is the first in Estrie region of the Eastern Townships to offer bilingual services in the supervised housing sector along with a mental health-focused living environment. Josée has been ‘hands-on’ in every aspect from the beginning. And now that her plan has come to fruition? She is spending almost 24/7 volunteering at Mon Shack.”
Injectable Mental Health Drugs

For people who forget to take medication, may think they are well enough that they don't need them anymore, or hear voices telling them to stop taking their medication, having a monthly injection can help manage symptoms in a more effective way than taking pills every day.

It is easy to forget or be irritated by taking pills every day. Injectables do the same thing, but slowly release antipsychotic medication into the body over days, weeks, or even months. Some injectables need to be administered every two weeks, but some only need to be given every three months.

The most common Long Acting Injectable (LOI) medication is for psychosis. Several studies have shown that only 40-60% of people living with schizophrenia take their oral medications consistently. Being inconsistent with medication can cause a recurrence of symptoms. Starting medication again takes time to take effect and going on and off meds is tough on the body.

Before going on an injectable medication, a doctor will prescribe the oral version of the medication to make sure that it has the desired effect and that side effects are minimal.

What are the negatives? Like all medications, there can be side effects. This is true for both oral and injected medications. Adjusting the dosage can often mitigate these negative effects. LOIs mean seeing your doctor on a regular basis; you need to make time for these appointments.

These kinds of injections are not the same as forced injections that can happen in an emergency situation in hospital. Someone who has experienced this kind of injection may be reluctant or afraid to take a LOI. Talk to your doctor about your concerns and don't be afraid to ask questions. LOIs act very differently than injections that are given in an emergency setting, and can improve your quality of life.

Sam McAdam: A Decade of Giving Back

Samantha McAdam has been a Support Group Facilitator at AMI-Quebec for over a decade and will be moving away to the United States this summer.

Program Coordinator Marc Griffin reflects on what it’s been like working with Sam:

I had just been hired by AMI and shyly arrived at a holiday party in our office; I was surrounded by strangers and Sam introduced herself and made me feel welcome. From the start, her bubbly yet modest demeanour shined through. At the end of that party, while everyone was leaving, I heard water running in the kitchen. Samantha was alone washing all the dishes. That was the type of volunteer she was. Sam was so warm and compassionate towards everyone in her Support Groups. I’ll miss our conversations and all the heart she put into AMI.

Samantha in her own words:

Throughout my time volunteering with AMI-Quebec, I have met so many wonderful people, and have learned so much, whether from staff members, other volunteers, or participants themselves. It is such a great feeling to see people from all walks of life connecting and finding solace in each other, especially when they are facing such hardships; to see the look of relief when people realize they are not alone. It is both an incredible and humbling experience to be part of someone else’s journey and to know that I have helped in some small way.

I am so grateful for my time spent at AMI and will miss this community greatly. My experiences have equipped me to be a better helper and friend to those around me. Some things that I have learned: mental illness does not discriminate, hardships are sometimes what connects us to our humanity, and you might be in what seems like an impossible situation, but in the end you will be ok.

If you would like to volunteer at AMI-Quebec you can apply here: https://amiquebec.org/volunteer

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Hari quotes scientists who explain the difference between physical dependence and addiction. “Physical dependence occurs when one’s body has become hooked on a chemical, and you will experience some withdrawal symptoms if you stop; addiction is the psychological state of feeling you need the drug to give you the sensation of feeling calmer.” With this understanding, Hari describes a number of programs across the world that have confronted addiction in newer, more humane ways.

In European countries that provide addicts with safe rooms where they are watched over by nurses as they use their drugs, deaths from overdose have ended.

In Vancouver’s Portland Hotel Society, where a safe ground was established for people to go to inject their drugs, the addicts were starting to look at themselves differently. They found the will to live. Bud, an addict, felt for the first time in his life as if he had a home, a community, and people to fight for. His life was becoming like Rat Park; he wanted to be fully alive as a person making a difference in the world. It was an attempt to reverse the common approach where “the war on drugs is a war against hope and compassion and care.”

An alternative view emerged, suggesting that many of the harms of drugs are associated with the laws around them rather than with the drugs themselves. And if the minority of addicts are determined to continue their drug use it’s better to use drugs from the clinic than drugs from the Mafia.

“The opposite of addiction is not sobriety, it’s connection.”

Viewing drug addicts as sick persons rather than criminals, in Portugal the persecution of drug users and addicts officially ended in 2001. Treatment is based on respect rather than on punishment; it was felt that when you give hard-core addicts the option of a safe legal prescription and allow them to control the dose, the vast majority would stabilize and then slowly reduce their drug consumption over time. Prescription, they argued, is not an alternative to stopping drug use, it is – for many people – a path to it. “The goal is to gradually build a life for addicts so they can put something else into that empty glass: a social network, a job, some daily pleasures, a chance to recover the control they have lost. You need to change the culture so people find life less unbearable... we have to build a society that looks like Rat Park and less like rat race”, says Hari.

In the USA, 90 percent of the money spent on drug policy goes to policing and punishment, with 10 percent going to treatment and prevention. In Portugal the ratio is the exact opposite. In Portugal, those running the program believe that if you removed the stigma and shame caused by making addiction a crime, it would be possible to invite addicts into a welcoming web of care and treatment and support because, they argue, using drugs is only a symptom of some suffering. Once you address the suffering, symptoms can start to dissolve. Since drugs aren’t going away, you need instead to give people the internal tools – the confidence, the knowledge, the support – to make right decisions for themselves.

The result is that in Portugal more people use drugs, yet addic-
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tion fell substantially. Punishment – shaming the person, incarcerating them, making them unemployable – traps them in addiction. Taking that money and spending it instead on helping them to get jobs and homes and decent lives makes it possible for many of them to stop.

In Washington, a campaign to legalize drugs was driven not by the view they are safe, but because they are dangerous. It’s precisely because they are dangerous that it’s critical to take them back from the gangsters and cartels and hand them to regulated stores; the tax money gained would pay for prevention and treatment.

The understanding that binds these newer programs and others is that the opposite of addiction is not sobriety, it’s connection. “If you are alone, you cannot escape addiction. If you are loved, you have a chance.” What has the potential more than anything else to kill this attempt at healing is the war on drugs.

— Ella Amir

Chasing the Scream is available in the AMI library.