

Mission

The Schizophrenia Society of Ontario makes a positive difference in the lives of people, families and communities affected by schizophrenia and psychotic illnesses.

We envision a world without schizophrenia.

For this to happen:

Society must recognize schizophrenia as a serious brain disease

Excellence in service and treatment must become the norm

Stigma must be eliminated

A cure must be found

Mandate

Educate, Support, Advocate

Schizophrenia Society of Ontario Background

The Schizophrenia Society of Ontario (SSO) provides support, education, and advocacy on behalf of individuals, families and communities affected by schizophrenia and psychosis. We are a province-wide organization offering our services through local chapters and volunteers in cities and towns throughout Ontario. Some of the programs and services provided by the SSO include:

Ask the Expert

The Schizophrenia Society of Ontario's Ask the Expert program provide free confidential telephone/email information and support to individuals and families living with schizophrenia and psychosis as well as professionals in the healthcare, social work and justice fields. Ask the Expert addresses practical questions about living with schizophrenia and psychotic illnesses, as well as provides guidance on how to navigate the mental health system and shares information on local resources. It also facilitates local support groups that enable people to come together and share vital information. All questions and responses are kept private and confidential. Services include:

- Helpline and online support
- One on One Counselling
- Support Groups

Early Intervention

Early Intervention programs are designed to provide assistance to individuals experiencing their first episode of psychosis. With Early Intervention there is less disruption to the individual's relationships, and less strain on both the individuals and families in question. Individuals experiencing a first episode of psychosis are more likely to make a full recovery, find the appropriate treatment more quickly, and go on to lead fulfilling lives. Services are provided close to home, in communities across Ontario, at flexible times and locations to facilitate access.

With the help of this vital program, individuals experiencing their first psychotic episode can receive assistance and support quickly. Families who may feel overwhelmed by the circumstances can also rely on help, support and guidance from the program.

Strengthening Families Together

Strengthening Families Together is a ten-week long, psycho-educational program for families and friends of individuals with schizophrenia and other related disorders. It provides Canadian-based information on the topics associated with living daily with a mental illness, such as understanding the signs and symptoms of the major mental illnesses, learning about the causes and treatment options, developing coping skills, navigating the mental health care system and learning effective advocacy strategies. The program allows for flexibility, and can be adapted to meet the needs of the local community.

Be The One/youth engagement

The Be The One Program is a province-wide mental health awareness and social-action initiative which recognizes young people as powerful agents of change and leaders of tomorrow. The program will provide young Ontarians with the tools required to recognize the signs and symptoms of mental illness and to seek help for themselves or for others if required. Be The One encourages and supports youth to be community leaders in breaking down the stigma associated with mental illness. Be The One is an active project for youth across the province that will encourage them to become policy writers, decision makers and change activists within the field of mental health. Leading the initiative is a Youth Advisory Council composed of young people with diverse backgrounds from across the province.

Investing in the Future Scholarship Program

The Schizophrenia Society of Ontario offers Canada's only scholarship program dedicated to helping people impacted by schizophrenia and psychotic illnesses attend post-secondary education. Whether these young people are living with the illnesses, have a parent affected by them, or have made a difference in positively addressing stigma in their communities, the Investing in the Future Scholarship Program opens the door to education opportunities and enables recipients to realize their dreams.

This access to education will not only provide a reason to hope, it will transform lives. Scholarship recipients have greater job opportunities, increased self-esteem, a better sense of personal fulfillment

and bright futures. To date the SSO has handed out over \$100,000 to courageous young people across Ontario; enabling youth to access post-secondary education is an investment in the future for Ontario and a powerful expression of hope for these courageous and remarkable young people.

Justice and Mental Health Program & ANCRSS

The Schizophrenia Society of Ontario's Justice and Mental Health (JAMH) program is the only one of its kind in Canada. The JAMH program supports families of people with serious mental illnesses who come in contact with the law. When an individual with a mental illness is charged with an offence, families and caregivers are often left in the dark. Knowledge gaps regarding how the justice system works and what options are available to their loved one make them ill-prepared to take on a support or advocacy role.

The JAMH program welcomes these families and offers the support and direction required to navigate these difficult times. As a province-wide program, JAMH has ensured accessibility of its services through telephone, e-mail, and online support and provides its assistance on either a short term or on-going basis, depending on the need. Whether families require emotional and navigational support throughout their experience or just an answer to one question, the JAMH program is here to help and offer hope.

The JAMH program also works to promote change in the justice system through public education and capacity training of professionals who serve this population.

ANCRSS

ANCRSS (pronounced anchors) is a program under the Schizophrenia Society of Ontario which operates as a Canadian based e-mail support group. Our members have a family member or loved one who suffers from schizophrenia, bipolar or clinical depression. They have come into conflict with the law as a result of their illness and have become involved in the forensic/criminal justice system.

Family Support Groups/sibling support groups

The Schizophrenia Society of Ontario has a long history of providing support to families impacted by mental illness. Through SSO's Ask the Expert line, families receive the best combination of information, supportive counseling and system navigation.

Family Support Programs available through the Schizophrenia Society of Ontario:

- Individual counseling
- Family counseling
- Family support groups
- Peer-support

Policy & Advocacy

For over 30 years, the Schizophrenia Society of Ontario has been advocating for policy and system changes that will improve the lives of people living with mental illnesses and their families, providing them a reason to hope. The grassroots focus of the SSO ensures that the needs and concerns of program participants – individuals and families living with schizophrenia and psychosis, as well as professionals we work with – inform both our programs and services and our advocacy efforts.

Access to Treatment is the cornerstone program guiding all of SSO's public policy and advocacy work. Our commitment to community engagement, empowerment and system change has led us to draw upon the strengths of those directly affected by schizophrenia and psychotic illnesses, as well as mobilize individual sectors and organizations to advocate for change. The SSO will continue to strive to improve access to treatment for the thousands of Ontarians dealing with schizophrenia and psychotic illnesses, providing a reason to hope.

Research & Knowledge Exchange

Research is critical to improving the lives of those living with serious mental illnesses in Ontario. Research has always been a high priority for the Schizophrenia Society of Ontario and we are proud of our past commitments, funding over 20 research projects with close to \$2 million. Between the years 2012 and 2015, SSO's research department will focus on building internal research capacity, expanding the number of research projects funded, introducing program evaluation measures to assess effectiveness and increasing knowledge exchange efforts.

Knowledge Exchange

Knowledge Exchange is a central aspect of the research program at Schizophrenia Society of Ontario. Knowledge Exchange is the process by which researchers, policy developers and healthcare decision makers engage with each other in the development and application of research knowledge to make the best decisions. The process makes it a perfect opportunity for dynamic information sharing, and illustrates why it is much more involved than simple data swapping. At the SSO research results are shared widely with families, individuals living with serious mental illnesses, service providers and other researchers. Research findings will be utilized to improve supports and services, as well as to identify needs and develop programs to meet them.

The Story of the Iris

The Schizophrenia Society of Ontario adopted the Iris as an emblem for its crusade against mental illness in 1994. *Les Irises* was painted by Vincent van Gogh in 1889, in the garden of the asylum at St. Remy, in the south of France. Throughout his life van Gogh struggled with mental illness, now believed to have been schizophrenia. The period he spent at St. Remy was his most desperate battle with the disease.

While in the asylum, van Gogh wrote numerous letters to his brother Theo. In one of these letters, Vincent wrote a haunting account of his illness: “As for me, you must know I shouldn’t precisely have chosen madness if there had been any choice? What consoles me is that I am beginning to consider madness as an illness like any other, and that I accept as such.”

During this period of his life, van Gogh reportedly painted at a frantic pace. He was discharged from the asylum, but the illness recurred and the following year he committed suicide. His paintings from this period are regarded by experts as his greatest works.

Throughout folklore, the iris has been regarded as the symbol of faith, hope and courage, one for each of its three sets of petals, and was given as encouragement to anyone who was suffering. At its core, the SSO logo is an evolution of the iris, our iris unfolds as the positive, life affirming, and graceful “hands of hope”.

The Schizophrenia Society of Ontario – A History

The Schizophrenia Society of Ontario (SSO) was founded in 1979 as a non-profit organization by Bill and Dorothy Jefferies. Bill had two brothers and a son who developed schizophrenia. After a 30-year teaching career, he set out to change the world's awareness of the illness, beginning by placing a small ad in an Oakville newspaper asking families of people with schizophrenia to attend a meeting to "share and educate".

About 80 people attended that first meeting in a local church basement. At that point in history, families were not treated very well by mental health professionals and were often blamed for the illness of their family member. Oakville became the first Chapter of the Friends of Schizophrenics. That same year Bill travelled the Province and founded the Ontario Friends of Schizophrenics, and later the Canadian Friends of Schizophrenics. In 1983 he founded the World Schizophrenia Fellowship. In 1995, in response to increased awareness and sensitivity to the harm done in labelling a person "schizophrenic", the names of the organizations were changed to the Schizophrenia Society of Ontario, Schizophrenia Society of Canada, etc.

When Bill Jefferies died in 2002 at age 86, he left an invaluable legacy of organised committed support for the families of people with schizophrenia through the work of the Schizophrenia Society of Ontario and its sister Societies.

Today the Schizophrenia Society of Ontario is a dynamic organization with active members all across the province, working together to bring a reason for hope to individuals, families and communities living with schizophrenia and psychosis.

Schizophrenia Society of Ontario Signature Events

Peace of Minds Yogathon

SSO's annual Yogathon event brings together yoga enthusiasts from all across Ontario to raise money and awareness for schizophrenia. Over the years, SSO's Yogathon has grown into a must-attend event. The Yogathon is ideal for participants who want to breathe, stretch, and relax -- while raising funds and awareness for SSO's youth engagement programs.

Since its establishment the Yogathon has increased its reach, with events happening in communities across Ontario, alongside the flagship event in Toronto. Yoga studios from across the province host mini yogathons of their own, and for 2013 live streaming of the flagship event will be available. Visit the SSO's website at www.schizophrenia.on.ca for details about the 2013 event, which is happening on February 23.

Peace of Minds Walk

Each May families, friends and supporters of the Schizophrenia Society of Ontario take a walk with us throughout the province and give "Peace of Mind" to over 130,000 individuals who are living with schizophrenia.

You can get involved by joining one of the walks taking place across the province, or organizing your own! The 2013 Peace of Minds Walk will mark the 20th anniversary of the event. Visit the SSO's website at www.schizophrenia.on.ca for details on this special milestone fundraiser happening in May, 2013.

Drive to Survive Golf Tournament

In 1998 Harry and Shirley Young had the inspirational idea of creating a golf tournament to raise funds for schizophrenia. Annually since then the Drive to Survive Golf Classic has been a rousing success for the SSO. Happening annually, the event brings together SSO supporters, friends and volunteers for a day of golfing, dining and fun. Visit the SSO's website at www.schizophrenia.on.ca for information on the 2013 event, happening in June, 2013.

Annual Investing in the Future Scholarship Gala Dinner

This event, held yearly in the fall, celebrates young people directly impacted by schizophrenia and psychosis who are the recipients of the scholarships – Canada's only scholarship program specifically for young people affected by schizophrenia and psychotic illnesses. This supports their dream for pursuing educational endeavors that will lead to a future filled with hope and success. Scholarships are available for individuals living with schizophrenia or psychosis, as well as for individuals whose parents or siblings are living with schizophrenia or psychosis and also for those who are the champions of mental health within their communities.

Schizophrenia Society of Ontario Profiles:

Mary Alberti, Chief Executive Officer

Mary Alberti is a dynamic and creative leader with over twenty years experience in the non-profit sector. Since 2001 she has held the position of Executive Director/CEO of the Schizophrenia Society of Ontario, where she has developed and orchestrated an organizational review that resulted in a new organizational vision, mission and brand as well as the redevelopment of all organizational systems and structures congruent with the new mission and mandate.

Prior to joining SSO, Mary was the Director of Community Services at the Family Service Association of Toronto, a \$12 million community service organization serving 13,000 diverse clients per year. She also worked as a Policy Analyst for the Municipality of Metro Toronto and has had experience as a consultant working in the corporate sector as well as partner in her own consulting group. Key focus areas have included organizational development and diversity. She has served on the Board of several community agencies over the years and continues to be interested in organizational effectiveness in the provision of services.

Mary's commitment to working in the area of schizophrenia comes from her passion to ensure everyone has the right to a good quality of life, no matter their life circumstance. She has worked with many different communities and sectors including organizations working within the fields of developmental disabilities, mental health, female abuse, immigrants and refugees and seniors.

Norm Tasevski, Board Chair

Norm Tasevski is the co-founder and Partner with Venture Deli – a company that accelerates the growth of, and facilitates investment in, ventures that matter to the world. Before launching his own company, Norm worked as a Social Entrepreneur-in-Residence with the Social Innovation Generation (SiG) program at MaRS, and prior to that was a Consultant with a boutique management consulting firm called Aperio. He teaches social entrepreneurship at the University of Toronto, the Schulich School of Business, and the University of Waterloo.

Before entering the field of social innovation, Norm was Managing Director of the York Consulting Group, and prior to that was a Senior Policy Advisor with the provincial Ministry of Community and Social Services. A recipient of the Marshall Cohen and the Ian MacDonald awards for academic excellence and community involvement, Norm has an MBA from the Schulich School of Business, and a BAH in Political Studies from Queen's University.

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About Mental Illness

In 2012 the Mental Health Commission of Canada, along with the provincial government of Ontario, released their new mental health plans. Both promote mental health and well-being for all, but a term like mental health can be difficult to comprehend – what exactly do we mean when we talk about mental health? The Canadian Mental Health Association tells us that mental health is the balance of all aspects of life – social, physical, economic and mental. Mental illness is a general term that refers to a broad group of illnesses of the brain that affect thinking, feeling, sensation and perception. Mental illness has many forms and each individual's case is different. Signs and symptoms of a mental illness include but are not limited to, social withdrawal, decline in academic or work performance, unusual excessive energy, high anxiety, intrusive thoughts. Treating a mental illness is possible with the right combination of support and services, but there is no cure for serious mental illnesses.

With mental illness so prevalent in society, why isn't it more discussed? The answer is stigma, the biggest barrier in accessing treatment and maintaining a good quality of life for individuals living with mental illnesses. In the workforce in Canada, 1 out of every 4 -5 employees is impacted by a mental health issue, and many choose to go untreated for fear of labelling. (Mental Health Commission of Canada, *Opening Minds* Brochure, 2009)

About Schizophrenia

Schizophrenia is a treatable brain disease characterized by profound disruptions in thinking, language, perception and the sense of self. It often includes psychotic experiences, such as hearing voices or seeing hallucinations. Schizophrenia affects 1 in 100 people and occurs in every race, culture, and socio-economic group. It occurs equally in males and females. In Canada, approximately 300,000 people live with the disease, of whom 130,000 live in Ontario. The disease usually begins when people are in their teens or early twenties, although it can occur later in life. Because it strikes young people in their formative years, it is often referred to as "youth's greatest disabler". Males usually develop schizophrenia at an earlier age than females. In most cases, schizophrenia begins gradually - so much so that it is often months or years before the individual or their family recognizes that something is wrong. With some people, however, the onset is very rapid.

Schizophrenia is a treatable disease. With the proper combination of treatment and supports, individuals living with schizophrenia and psychosis can go on to lead meaningful and productive lives.

How is schizophrenia treated?

Schizophrenia is treatable; however, because the disease varies in severity from one person to another, the intensity of treatment will vary accordingly. Some people will require hospitalization during the course of their illness while others can be treated effectively in the community.

The foundation of all treatment is anti-psychotic medications, also called neuroleptics, which help to manage the symptoms. Once these are controlled, then different forms of therapy, such as psychotherapy or cognitive behavioural therapy, are important to help the individual understand the illness and learn to cope with its impact. For many people, treatment also involves the services of a case manager or social worker who will help them comply with their treatment, and direct them to rehabilitative programs that will make it easier to restore their ability to function in the world.

Stigma

Stigma is defined a mark of shame or discredit. Stigma is hurtful and can be dangerous. It can make it difficult for someone with schizophrenia to be accepted by others and lead to discrimination. Because of stigma and its associated discrimination, people with schizophrenia can find themselves being denied housing, education, employment, income, criminal justice, parenting, and other basic rights that most of us take for granted. Individuals living with schizophrenia and psychosis can find themselves feeling like they must hide their illness in order to be treated fairly. The limited access to resources like housing and employment opportunities also perpetuates the stereotypes of people living with the illnesses.

The first and most important step towards ending stigma is educating the general public to increase awareness about mental health and mental illnesses. The Schizophrenia Society of Ontario offers specialty training on stigma reduction and mental illness acceptance to various groups including businesses, teachers and healthcare professionals who work directly with individuals living with serious mental illnesses. In-service training programs share best practice approaches with individuals who are in positions to make a positive difference in the lives of people living with a mental illness. A variety of print and online resources are also available.

Myths About Schizophrenia

- Schizophrenia is a split personality or multiple personality disorder

This is not the case. Confusion can stem from the very word itself, 'schizophrenia' comes from the Greek meaning "split mind." This splitting refers to the fragmentation of the individual's thinking and feeling process, NOT the splitting of the person into two personalities. Multiple Personality Disorder is a serious mental illness, but is very different from schizophrenia. For more info on Multiple Personality Disorder please visit: <http://www.ontario.cmha.ca/>

- Men and women with schizophrenia are mentally "retarded"

Schizophrenia and developmental disability are different conditions. Schizophrenia occurs in people of all levels of intelligence, often in talented and creative men and women. Schizophrenia can cause some cognitive problems such as poor concentration and difficulty with abstract thinking, however it does not affect overall intelligence.

- People with schizophrenia cannot work

British and American studies have both shown that people with schizophrenia are more likely to stay out of the hospital if they are employed at meaningful work. While many people are able to work successfully in full-time employment, for others, part-time, casual or volunteer work are best. Work is a vital part of rehabilitation. It increases self-esteem, reconnects with the community, gives a sense of belonging and provides a meaningful use of time.

- People with schizophrenia are not able to make decisions about their own treatment

Most people with schizophrenia are both able and eager to participate in decision making about their treatment. They know how they feel when on a certain medication better than anyone else does. However, during the onset of the illness or during a relapse that may occur, the person may experience a degree of lack of insight and require more help and support. Research shows that patient and family involvement improves outcomes and increases the likelihood of adherence to a treatment plan.

- Men and women with schizophrenia have to be institutionalized

Many people with the illness can be treated in the community with no admission to hospital. Innovative alternatives such as supported living in the community can be highly effective. Even those who are acutely psychotic may be treated in carefully supervised and professionally staffed community settings.

- Men and women with schizophrenia are likely to be violent

Unfortunately, mental illness and violence are closely linked in the public mind. However, those with schizophrenia who are receiving proper medical treatment are no more dangerous than healthy individuals from the same population.

People with schizophrenia are much more likely to be violent toward themselves or a family member than the general public. When people with schizophrenia do commit violent acts, it is usually because they are not getting proper treatment.

People with severe mental illness who are not receiving treatment are six to seven times more likely to be physically violent than the general population. The vast majority of people with serious mental illness are not violent. For the small subset of the population who is at increased risk to commit acts of violence, three circumstances are usually involved:

They do not adhere to taking prescribed medications to control symptoms;

They have a history of violence or volatile behaviour;

They use/abuse alcohol and drugs.

- Poor parenting causes schizophrenia

No good evidence supports the theory that family environments cause schizophrenia. And very strong evidence supports biological factors as the primary cause. Coping with a family member who has schizophrenia is extremely demanding. Families need empathy and support just as those with schizophrenia do.

Facts About Schizophrenia

- Schizophrenia is a common illness.
- Schizophrenia is ranked the third most disabling condition in the world. (The Lancet, 1999)
- It is found all over the world in all races, cultures and social classes.
- People with schizophrenia are men and women, family and friends, neighbours and students.
- Worldwide and in Canada, it affects 1% of the population (1 in a 100).
- Over 130,000 people in Ontario are affected or will be affected in their lifetime.
- Schizophrenia is a neurological brain illness.
- Schizophrenia is a serious but treatable brain disease.
- Schizophrenia is a mental illness with symptoms of “psychosis.”
- Schizophrenia is an illness that affects a person’s perceptions, thinking, feelings and behaviour.
- Schizophrenia is not a “split personality.”
- Schizophrenia is one of youth’s greatest disablers.
- Most frequently the illness occurs in the 16 to 30 year old age group.
- Very often the individual has a perfectly normal childhood until the onset of the illness. It can also appear later in adulthood. However, onset after the age of 35 is less common, and after the age of 40 is rare.
- Men and Women are affected. Generally men between the ages of 16 to 20 will experience schizophrenia for the first time. Generally women between the ages of 25 to 30 will experience schizophrenia for the first time. Each person’s experience with the illness is very individual and symptoms may occur in children as young as 12 years of age.
- People with schizophrenia can become discouraged, feel hopeless and sometimes become suicidal.
- Depression is the most prevalent cause of suicide for people who have schizophrenia. (National Institute of Mental Health – USA)
- Suicide is the leading cause of premature death among people with schizophrenia; 10% will die from suicide. (Harkavy-Friedman, J.M., & Nelson, E. (1997). Management of suicidal patients with schizophrenia. Psychiatr Clin North Am 20(3).)
- Schizophrenia is socially isolating.
- Many people with schizophrenia live with their families and most have difficulties socializing.
- 60% to 70% percent of people with schizophrenia do not marry or partner. (Public Health Agency of Canada)
- As many as 30% of Toronto’s homeless people suffer from severe mental illness (City of Toronto (1999, January). Taking responsibility for homelessness: An action plan for Toronto. Report of the Mayor’s Homelessness Action Task Force.)
- The total cost of schizophrenia to Canadians, including health care (more hospital beds are used by patients with schizophrenia than any other disease), is estimated to be \$6.85 billion per year. (Current Medical Research and Opinion, Volume 21, Number 12, December 2005, pp. 2017-2028(12))
- 1 in 5 people in Canada experience a mental health problem or illness with a cost to the economy of well in excess of \$50 billion (CMHA Fact Sheet)