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SCHIZOPHRENIA  
SOCIETY OF CANADA

SCS<sup>MC</sup>

SOCIÉTÉ CANADIENNE  
DE LA SCHIZOPHÉNIE

Learning About  
Schizophrenia

# Rays of Hope

A REFERENCE MANUAL FOR  
FAMILIES & CAREGIVERS

Fifth Revised Edition

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Fifth Edition



## Dedication

“To the thousands of families and their loved ones who deal with schizophrenia every day of their lives: Your courage, endurance, and hope for recovery are a source of inspiration for all.”

## Prologue

It is with pride and pleasure that the Schizophrenia Society of Canada (SSC) releases the fifth edition of our Reference Manual for Families and Caregivers.

This publication has provided valuable information and guidance for families and other people who care for someone living with schizophrenia or psychosis for over twenty years. Over three hundred and fifty thousand Canadians have schizophrenia, a disorder that, if left untreated, has the potential to disrupt young people's lives just when they are in the critical stages of education and/or career planning.



The lifetime emotional, social, and financial consequences experienced by individuals with schizophrenia and psychosis can have significant effects on their families. Family responses to having a family member with schizophrenia may include caregiver stress and burnout, fear and embarrassment about illness signs and symptoms, uncertainty about course of the illness, lack of social support, and stigma.

Many family members may be frightened and confused by their family members' strange new beliefs or behaviors, decreased energy levels, loss of motivation, or cessation of usual activities. Marital and sibling relationships can be severely tested in response to the symptoms of schizophrenia and psychosis. Most often families do not know how best to respond to these changes in their family member with schizophrenia or psychosis and need guidance, support, and direction.

But the outlook for people with schizophrenia and psychosis continues to improve as the discovery of new antipsychotic medications and our understanding of recovery increases. It is now well established that people can learn how to live with and recover from enduring mental illness. This has led to a growing awareness of the potential for people with schizophrenia to recover a sense of mastery over their life and illness, and of the various elements that can promote recovery (See Chapter 14, Recovery and Rehabilitation). Major advances in drug therapy and psychosocial interventions work together to enhance the potential for people with schizophrenia and psychosis to live meaningful lives and contribute to community. Although there is not yet a cure, over the years, research has revealed the biological and genetic links, as well as the environmental impact on gene expression, to the origins of schizophrenia and has contributed to the better quality of treatment options we now have.

Unfortunately, however, funding for schizophrenia research in Canada continues to be lower than for any other major illnesses. Since a cure depends upon research, SSC is committed to raising money for research and does so through the Schizophrenia Society of Canada Foundation.

This guide will provide insights into the challenges that a person recovering from schizophrenia or psychosis must face, understanding of the disorder itself, and its symptoms, treatments, services and supports. It will explore the impact of the illness on families and offer suggestions on how to cope with schizophrenia, make sense of the mental health service system and foster recovery. It is through understanding that people with schizophrenia and their families will find their path to coping and recovery.

Besides updating the previous edition of Rays of Hope with more current information, this fifth edition boasts two newly added chapters, both which are relevant to the current circumstances of our world. One of the new chapters considers self-care for you, as family members and caregivers, and the importance of taking care of your physical health, mental health and spiritual health, as you support and care for your family members. The second new chapter offers information relevant to COVID-19 within the context of people living with schizophrenia or psychosis during this unique and challenging time. It is hoped that you will find these additions helpful.

Our roles with SSC bring us into contact with numerous families of individuals with schizophrenia who devote many volunteer hours of their lives to improve the quality of life for other people. We urge you to come and meet them, in this book and through the provincial schizophrenia societies across Canada. Then you too may help brighten the lives of those who have been touched by schizophrenia and psychosis.



## Acknowledgements

Over the years, many experts including people with lived experience of schizophrenia and psychosis, family members, physicians, and mental health service providers have contributed to the wealth of knowledge, understandings, and updates contained in the various editions of Rays of Hope. As well, many credible websites and research papers have been used to inform the various edits along the way. Rays of Hope is based upon an understanding and application of the recovery philosophy which communicates a positive and hopeful message: "Schizophrenia is treatable and recovery of a quality of life is possible with the support of a caring community."

The Schizophrenia Society of Canada would like to acknowledge Fran Schellenberg for leading the updates and edits contained in this fifth edition, and for creating the chapters on self-care and on COVID-19. Our acknowledgement and appreciation are also expressed to Marg Synyshyn (Winnipeg), Wilma Schroeder (Winnipeg) and Dr. Nina Kuzenko (Winnipeg) for their consultations and contributions on specific sections in this fifth edition. We would also like to thank the individuals with lived experience, Cam Webster (Victoria) and Tracy Kosowan (Winnipeg), who contributed their personal stories to this edition, and the mother of a son with schizophrenia who shared her story of challenge and hope, all in Chapter 10.

We believe the results of all the efforts contributed over the years to this guide have benefited and will continue to benefit families and their loved ones who live with schizophrenia or psychosis, as well as professional caregivers, and the community at large. We can all benefit from a clearer understanding of schizophrenia, psychosis and the recovery process.

As always, while the information contained herein has been gathered from many credible sources and reviewed by experts, it is not intended to replace consultation with professionals.

Production of the fifth edition of Rays of Hope, including the COVID-19 chapter, was made possible through funding from the COVID-19 Employment & Social Development Canada Emergency Community Support Fund, which is administered by the United Way Centraide Network.



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United Way  
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Recovery from mental illness is possible but it takes the support of a caring community!

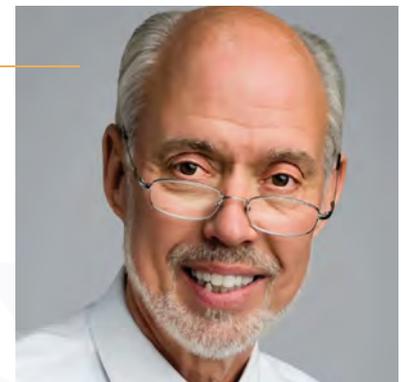


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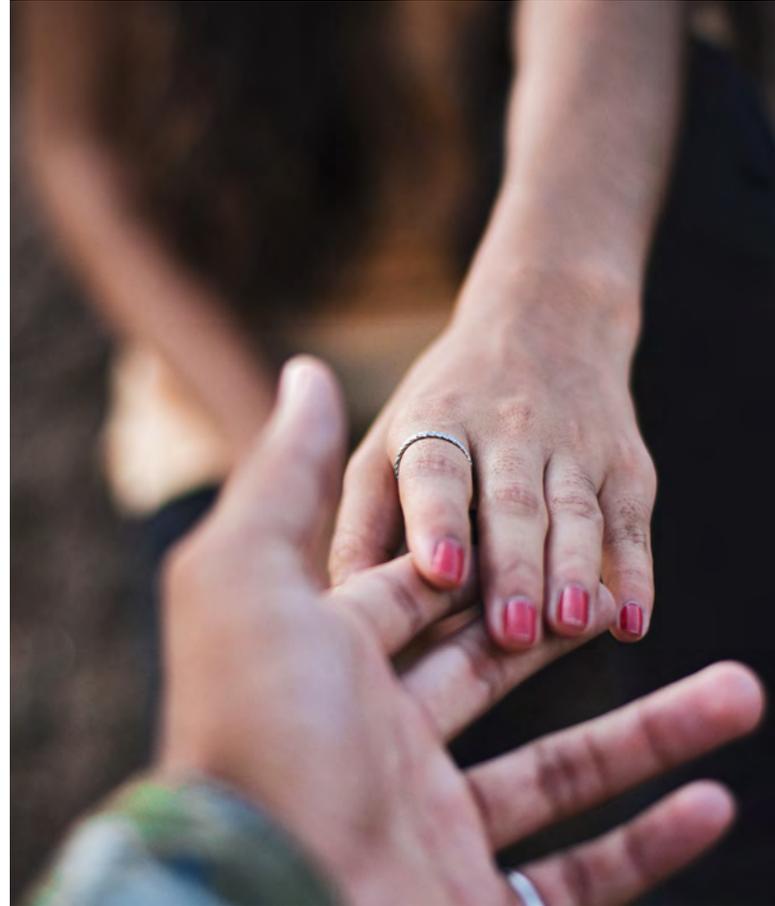
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# Chapter 1

## Introduction

Through the ages the Iris flower has been regarded as a symbol for faith, hope, and courage. The Schizophrenia Society of Canada (SSC) chose the Iris as its national emblem, hoping that it would offer encouragement to the persons and families experiencing schizophrenia.

Like the Iris, this book is also meant to impart support and strength by offering the reader information that will help to deal with some of the fundamental issues related to schizophrenia. It is designed as an educational tool for families, friends, and caregivers of persons who exhibit signs of the disorder, and/or are diagnosed with it.

Since the first edition of this book, significant progress has been made, both in the treatment of schizophrenia and in the establishment of the recovery philosophy in mental health. New drug therapies have emerged, and pharmaceutical companies continue to research and develop medications to treat schizophrenia. Recovery refers to “living a satisfying, hopeful and contributing life, even when a person may be experiencing ongoing symptoms of a mental illness” (Mental Health Commission of Canada). And while drug therapy remains a key cornerstone of recovery, we know that there are many other factors that contribute to recovery and a positive quality of life. Because being connected to community is a major key to recovery, psychosocial services, peer supports and other supports can make a big difference in the quality of life of persons with schizophrenia. Various programs are available to help people develop their social skills, learn job skills and get jobs, deal with stress and distress in their lives, understand their illness and its impact on their lives, and achieve the best recovery possible.

While it is possible that an individual may need to spend time in a hospital or a mental health centre during the course of their illness, most treatment and recovery of people living with schizophrenia typically occurs in the community. There are many community-based services in areas across Canada such as early psychosis programs, crisis response systems, Programs for Assertive Community Treatment (PACT or ACT) teams among other emergency, treatment, rehabilitation and housing services. Self-help/peer support, which can take the form of individual and group supports or more active peer-operated initiatives, provide social connections, practical help, links to community, and ways to make a contribution. Other informal community resources outside the professional mental health system, such as community recreation facilities, faith-based communities and interest groups, play a key role in recovery as bridges to the natural community, beyond the label of mental illness.

Of course, family members know well that families are often the ones who help their loved ones find social or recreational outlets, or pathways to employment or education. Organizations such as the Schizophrenia Society represent another critical piece of the picture in connecting families and supporting them to play their vital role, as well as supporting people with schizophrenia themselves on their recovery journey.

Much has been learned about schizophrenia, thanks to ongoing research. Evidence supporting biological cause is abundant, and now points at genetic origin. It is exciting to know that awareness about schizophrenia has improved, and continues to grow, hopefully at an increasing pace. This is important not only for support of research, but also for those who experience the disorder. A better understanding in society helps all those affected – bringing them empathy, compassion, friendship, and maybe even saving some lives!

Parts of this reference manual extends practical advice based on experience; experience that families have willingly shared for the benefit of readers. They have learned the importance of being armed with knowledge to deal with schizophrenia. It is upon their advice that various ideas and topics have been chosen. It is hoped that it will provide a good start to learning about schizophrenia.

The scope of this publication is broad and is not meant to replace medical advice. It provides credible information, along with at least two important messages: one is that, despite the real challenges of schizophrenia, there is reason for hope! We know that people with schizophrenia, with the right supports, can live fulfilling, meaningful lives, and that families can make a difference when they believe in the possibilities for their family member. Many people say that a key element for their recovery was having someone who believed in them and shared their faith that things would get better. In fact, science has started to demonstrate the importance of families' faith in their family member; one such study showed that adults with schizophrenia reflected their mothers' attitudes and beliefs about them<sup>1</sup>.

Remember – it is only through understanding that you will find true compassion, the strength to cope, and the hope that is in the promise of recovery.

The second message, from the families who have shared their experience for this manual, is that you need the support of others in order to find your own “rays of hope”. Family members know how complex and devastating schizophrenia can be and that it is difficult to manage on your own. By joining a support group with other families, you can learn useful tips and strategies for dealing with the health care system, establishing your rights, and getting appropriate help for someone who is ill. You can also provide one another with practical and emotional support, and lessons learned about the possibilities of recovery. Coping with schizophrenia can be easier when you are not facing it alone.

It is hoped this book will help you with some of the issues and challenges that schizophrenia presents and offers you many rays of hope. To understand more about the importance of hope and recovery in the lives of individuals with schizophrenia and other significant mental illness, you are encouraged to follow this link to an important video entitled “Recovery: Hope Changes Everything” <https://www.mentalhealthcommission.ca/English/media/3675>

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1 Markowitz, F., Angell, B and Greenberg, JS. (2011) Stigma, Reflected Appraisals, and Recovery Outcomes in Mental Illness. *Social Psychology Quarterly*, June 2011 74: 144-165.

## Chapter 2

# What is Schizophrenia?

### Defining Schizophrenia

Schizophrenia is an extremely complex mental disorder: in fact, it is probably many illnesses masquerading as one. It is generally believed that “a combination of genetics, brain chemistry and environmental factors contribute to the development of schizophrenia<sup>2</sup>. The disorder is characterized by delusions, hallucinations, disturbances in thinking and communication, and withdrawal from social activity. Schizophrenia is a severe but treatable brain disorder which affects a person’s ability to know what is reality and what is not. A simple explanation of how the brain works helps us to define schizophrenia.

There are billions of nerve cells in the brain. Each nerve cell has branches that transmit and receive messages from other nerve cells. The nerve endings release chemicals, called neurotransmitters, which carry the messages from the end of one nerve branch to the cell body of another. In the brain of a person with schizophrenia, something goes wrong in this communication system.

In *Schizophrenia: Straight Talk for Family and Friends* (p. 41), Maryellen Walsh uses the analogy of a telephone switchboard to explain schizophrenia. “In most people the brain’s switching system works well. Incoming perceptions are sent along appropriate signal paths, the switching process goes off without a hitch, and appropriate feelings, thoughts, and actions go back out again to the world... in the brain with schizophrenia... perceptions come in but get routed along the wrong path, or get jammed, or end up at the wrong destination.”

The disorder may develop so gradually that it is undetectable in the person for a long time, or it may have a very sudden onset with rapid development. It most commonly strikes between the ages of fifteen and twenty-five years and has therefore been referred to as “youth’s greatest disabler”. Schizophrenia is found worldwide, affecting people of all races, cultures, and social classes. It affects people in all walks of life. In Canada one in every one

Schizophrenia is undoubtedly an intimidating illness; perhaps difficult to grasp at first. Learning as much as you can about the disorder will help you assert as much control as possible over its impact on you, and your family.

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2 Mayo Clinic website. Schizophrenia; <https://www.mayoclinic.org/diseases-conditions/schizophrenia/symptoms-causes/syc-2035444315Dec2020>

hundred persons is diagnosed with this disorder in their lifetime; over three hundred and fifty thousand people in all. Schizophrenia does not discriminate, but occurs in men and women, affecting one percent of the global populace.

## Causes of Schizophrenia

The precise causes of schizophrenia remain unknown and as mentioned previously, are likely to be diverse, involving genetic factors interacting with environmental risk factors at crucial phases of development. Changes in key brain functions, such as perception, emotions, and behavior, indicate that the brain is the biological site of schizophrenia.

## Biological/Genetic Theories

Some researchers suspect neurotransmitters (the substances through which cells communicate) or nerve cells within the brain may be involved for certain subtypes of schizophrenia<sup>3</sup>. Other research suggests that specific protein levels in the brain may increase the risk of certain subtypes of schizophrenia<sup>4</sup>.

To a large extent, the activity of neurotransmitters is controlled by genes, and there is very strong evidence indicating that genes are involved in causing schizophrenia. This evidence derives from family, twin and other studies. Schizophrenia occurs in 1% of the general population, but the risk is increased if a relative is affected. There is about a 10% chance of developing the illness when a sibling or one parent has schizophrenia; when both parents have schizophrenia, the risk rises to approximately 40%-50%<sup>5</sup>. Nieces, nephews, or grandchildren of someone with schizophrenia have about a 3% chance of developing the disorder. Recently, a study found that the chance that an identical twin will be affected with schizophrenia if his/her co-twin has this illness was 79%<sup>6</sup>. Genetic counselors can be helpful in providing risks tailored to the individual's family illness pattern. On the other hand, most people living with schizophrenia do not have another family member with this illness.

Researchers have been able to identify a gene called C4 that increases the risk of schizophrenia<sup>7</sup>. Further research is needed to validate these findings, however this and other findings could help in diagnosing and eventually in developing more specific treatments for the underlying causes of schizophrenia instead of just its symptoms.

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3 Khan, Revah, Pasca. Neuronal defects in a human cellular model of 22q11.2 deletion syndrome. September 2020

4 Nicifor, et al. Increased Protein Insolubility in Brains From a Subset of Patients with Schizophrenia. The American Journal of Psychiatry. May 2019

5 Healthline website. Is Schizophrenia Inherited? <https://www.healthline.com/health/is-schizophrenia-hereditary> 15Dec2020.

6 Hiller R, et al. (2017). Heritability of schizophrenia and schizophrenia spectrum based on the Nationwide Danish Twin Register. Biological Psychiatry 2017.08.017

7 Sekar A, et al. Schizophrenia risk for complex variation of complement component 4. Nature. DOI: 10.1038/nature.16549

## Environmental Theories

Genetic factors clearly play a major role in the development of schizophrenia, but there is evidence that environmental risk factors interact with genetics in the development of this disorder. Research has demonstrated to varying degrees risk factors that occur before birth and after birth, during childhood and later in life. Some of these risk factors have been well documented while some are less certain.

### Early Life Risk Factors

Some obstetric complications, such as hypoxia, have been cited as contributing to “the causation of schizophrenia”, but “only in combination with other risk factors, most specifically susceptibility genes.”<sup>8</sup> As well, children of mothers exposed to influenza during the first trimester of pregnancy was found to increase the risk of schizophrenia sevenfold<sup>9</sup>.

Adverse experiences in childhood/childhood trauma have been identified as a risk factor. Several studies have demonstrated a strong association between childhood stress and trauma, particularly in the form of abuse and neglect, and an increased risk of developing schizophrenia.<sup>10</sup>

### Later in life <sup>11,12</sup>

#### Drug abuse

Cannabis use is considered a risk factor for the development of schizophrenia in young people and also poses a risk of triggering an earlier onset of schizophrenia in people who are predisposed to develop the disorder. It is not clear whether cannabis misuse can trigger schizophrenia onset in those not previously vulnerable.

#### Migration and risk associated with ethnicity

There is some evidence that the risk of schizophrenia is higher among immigrant groups, depending on certain characteristics and their current socioeconomic status.

#### Urbanicity

Urban settings have been shown to have an increased prevalence of psychosis compared to rural settings. It has been suggested that this could be related to variables such as toxic exposure, social class, social isolation, and overcrowding.

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8 Dean K et al. Environmental risk factors for psychosis. *Dialogues Clin Neurosci*. 2005 Mar; 7(1): 69-80

9 Dean K et al. Environmental risk factors for psychosis. *Dialogues Clin Neurosci*. 2005 Mar; 7(1): 69-80

10 Popovic, David et al. Childhood Trauma in Schizophrenia: Current Findings and Research Perspectives. *Frontiers in Neuroscience*. 2019; 13:274.

11 Dean K et al. Environmental risk factors for psychosis. *Dialogues Clin Neurosci*. 2005 Mar; 7(1): 69-80

12 Centre for Addictions and Mental Health. Website: Schizophrenia

### Social adversity and life events

The lower class of society is typified by poverty, homelessness, and unemployment. People of this class, few of whom have finished high school, suffer from lack of medical care, adequate housing and food, decent clothing, safety, and vocational training. Low social class has been consistently found to be associated with schizophrenia, but it is complex and not consistent in findings. Personal socioeconomic disadvantage (not parental) had the greatest impact on onset of schizophrenia.

Initial and early psychotic episodes are more likely than later episodes to be preceded by life events.

### Nutrition

While scientists recognize that proper nutrition is essential for the well-being of a person with the illness, they do not agree that a lack of certain vitamins causes schizophrenia. Cures with megavitamin therapy are not proven and are often very expensive. Some people do improve while taking vitamins; however, this may be due to the antipsychotic medication they are taking at the same time, the therapeutic effect of a structured diet, vitamin and medication regime.

### The Future of Research

The more research reveals about the causes of schizophrenia, the better we understand this disorder, and the better treatment options that are able to help us. In research lies hope for a future cure of this illness.

Yet, although medicine and research represent a critical piece of the picture, they are not the only piece. There are many different strategies for helping people with schizophrenia to lead the most fulfilling lives possible, and to move forward on their journey to recovery. While continuing to encourage the role of research in addressing schizophrenia, and the hope for a cure one day, there is much we can be doing in the meantime. Understanding, practical and emotional support, and belief in people's potential for a reaching their potential can optimize the quality of life for people with schizophrenia.

There is hope. And hope begins with you!

## Putting the Puzzle Together What it is... What it is Not!

### Schizophrenia is:

- A complex mental illness that affects a person's thoughts, feelings, and perceptions.

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- Develops from a combination of biological and environmental risk factors.

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- Identified by internationally agreed upon and fairly specific symptoms

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- A disorder with initial onset typically in people in their prime (age 15-25 years)

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- Recovery is possible and depends on treatment options, community supports, and hope!

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### Schizophrenia is Not:

- A split personality or a multiple personality.

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- The result of any action or personal failure by the individual.

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## Chapter 3

# Recognizing Schizophrenia

### Symptoms

Just as other illnesses have signs or symptoms, so does schizophrenia. The symptoms may vary, however, between individuals. Symptoms may develop slowly over months or years or may appear very suddenly. While not always symptomatic, persons with schizophrenia will display symptoms as they struggle to discern reality from their own perceptions. Their level of functioning will deteriorate in areas such as:

- Work or academic achievements
- Personal care and hygiene
- Interaction with others

Personality changes are a key to recognizing schizophrenia. At first, the changes may be subtle, minor, and go unnoticed. As they worsen, they become obvious to family members, friends, teachers, and/or coworkers. There is a loss of feelings or emotions, and a lack of interest and motivation. A normally outgoing person may become withdrawn, quiet, moody, suspicious, and/or paranoid. The person may laugh when told a sad story, may cry over a joke, or may be unable to show any emotion at all.



One of the most profound changes is in the person's ability to think clearly and logically. Thoughts may be slow in forming, or come extra fast, or not at all. The person may jump from topic to topic, seem confused, or have difficulty reaching easy conclusions. Thinking may be colored by delusions and false beliefs that resist logical explanations. One person may express strong ideas of persecution, convinced that he/she is being spied on or plotted against. Others may experience grandiose delusions and feel like Superman – capable of anything and invulnerable to danger. Others still may feel an unusual strong religious drive or bizarre mission to right the wrongs of the world.

As the symptoms of schizophrenia become noticeable, the person will likely experience a sense of alarm and fear. Obviously, the sooner the symptoms are recognized and diagnosed, the sooner the person will benefit from medical and other kinds of help. Once you've confronted the disorder and the fear that goes along with it, you're on your way to recovery.

When people have schizophrenia, perceptual changes turn their world topsy-turvy. The nerves carrying sensory messages to the brain from the eyes, ears, nose, skin, and taste buds become confused, and the person sees, hears, smells, and feels sensations which are not real. These are called hallucinations. It is not difficult to understand why individuals who experience these profound and frightening changes will often try to keep them secret, deny that anything is happening, or avoid people and situations where they may be discovered. The feedback they receive when they express hallucinations or delusions is disbelief. People with schizophrenia, therefore, feel misunderstood and rejected, and cease to share their thoughts as a result.

These intense internal experiences trigger other feelings of panic, fear, and anxiety – natural reactions under the circumstances. These feelings can further amplify their extreme emotional state. The psychological burden may be intense: most of it kept inside, its existence denied. The pain of schizophrenia is further accentuated by the persons' awareness of the anguish they are causing their family and friends. People with schizophrenia require a lot of understanding, patience, and reassurance that they will not be abandoned. Unfortunately, social prejudice and discrimination can inhibit someone from reaching out for help and ultimately, it can affect the recovery process.

## Defining Positive and Negative Symptoms

Understanding the terminology used by medical professionals can help you in your efforts to deal with this illness. The symptoms of schizophrenia are classified into two categories: positive symptoms and negative symptoms.

### Positive Symptoms

#### Hallucinations

Hallucinations are thought to be a result of over-sharpening of the senses and of the brain's inability to interpret and respond appropriately to incoming messages. Persons with schizophrenia may hear voices or see visions that are not there or experience unusual sensations on or in their bodies. Auditory hallucinations, the most common form, involve hearing voices that are perceived to be inside or outside of the person's body. Sometimes the voices are complimentary or reassuring. Sometimes they are threatening, punitive, frightening, and may command the individual to do things that may be harmful.

## Delusions

Delusions are strange and steadfast beliefs that are held only by the person living with the disorder. They are maintained despite obvious evidence to the contrary. For example, someone with schizophrenia may interpret red and green traffic signals as instructions from space aliens. Many people with schizophrenia who suffer from persecutory delusions are termed paranoid. They believe that they are being watched, spied upon, or plotted against. A common delusion is that one's thoughts are being broadcast over the radio or television, or that other people are controlling the person's thoughts. Delusions are resistant to reason. It is of no use to argue that the delusion is not real.

## Disorganized Thought and Speech

Disorganized thought and speech refers to problems in the way that a person with schizophrenia processes and organizes thoughts. For example, the person may be unable to connect thoughts into logical sequences. Racing thoughts come and go so rapidly that it is not possible to catch them. Because thinking is disorganized and fragmented, the person's speech is often incoherent and illogical. Thought disorder is frequently accompanied by inappropriate emotional responses: words and mood do not appear connected to each other. The result may be something like laughing when speaking of somber or frightening events. Altered sense of self is a term describing a blurring of the person's feeling of whom he/she is. It may be a sensation of being bodiless, or nonexistent as a person. The individual may not be able to tell where his/her body stops and the rest of the world begins. Or he/she may feel as if the body is separated from the person. Disorganized behavior may also be apparent as the ability to complete daily activities may be affected.

## Negative Symptoms

### Reduced Motivation or Apathy

Reduced motivation or apathy is a lack of energy or interest in life that is often confused with laziness. Because persons have very little energy, they may not be able to do much more than sleep and pick at meals. Persons with schizophrenia can be experiencing life without any real interest in it.

### Blunted Feelings or Reduced Emotional Expression

Blunted feelings or reduced emotional expression refers to a flattening of the emotions. Because facial expressions and hand gestures may be limited or nonexistent, individuals with schizophrenia seem unable to feel or show any emotion at all. This does not mean that the individuals do not feel emotions and are not receptive to kindness and consideration. They may be feeling very emotional but cannot express it outwardly. Blunted affect may become a stronger symptom as the illness progresses.

### Loss of Interest

Loss of interest in things that previously brought them pleasure and joy may occur. However, as people start to recover, interest in these things may return.

### Reduced Verbal Communication

Reduced verbal communication also referred to as poverty of speech, means that people with schizophrenia may not speak much and when they do, they may be vague and less spontaneous. Replies to questions also may be brief.

### Social Withdrawal

Social withdrawal may occur as a result of depression; a feeling of relative safety in being alone; being caught up in one's own feelings, and/or fearing that one cannot manage the company of others. People with schizophrenia frequently lack an interest in socializing, or at least the ability to demonstrate or express this interest.

### Cognitive Function

Cognitive function may also change and can affect a person's ability to concentrate and pay attention. It may also affect abilities such as processing information, planning and organizing, and reasoning and judgement.

People with schizophrenia may also exhibit signs of **depression**, which involves feelings of helplessness and hopelessness that may stem in part from realizing that schizophrenia has changed one's life; that the feeling experienced in the psychotic state is an illusion, and that the future looks bleak. Often persons believe that they have behaved badly, destroyed relationships, and are unlovable. Depressed feelings are very painful and may lead to talk of, or attempts at, suicide.

### Anxiety symptoms

Anxiety symptoms can occur in up to 65 % of person living with schizophrenia and may reach the threshold for diagnosis of various comorbid anxiety disorders, including obsessive-compulsive disorder (OCD) and post-traumatic stress disorder (PTSD). Generalized anxiety is understandable as the person attempts to manage their illness while navigating life<sup>13</sup>.

## Early Warning Signs of Onset

The following is a list of early warning signals before psychosis, identified by the National Alliance on Mental Illness (NAMI):

- A worrisome drop in grades or job performance
- Trouble thinking clearly or concentrating
- Suspiciousness or uneasiness with others
- A decline in self-care or personal hygiene
- Spending a lot more time alone than usual
- Strong, inappropriate emotions or having no feelings at all

One of the difficulties in reading the early warning signs of schizophrenia is the easy confusion with some typical adolescent behaviors. Schizophrenia can begin to affect an individual during the teen years, a time when many rapid physical, social, emotional, and behavioral changes normally occur. There is no easy method to tell the difference. It's a matter of degree. Family members that were consulted in the development of this book tell of varying experiences. Some sensed early on that their child, spouse, or sibling was not merely going through a phase, a moody period, or reaction to the abuse of drugs or alcohol. Others did not feel their relative's behavior

13 <https://pubmed.ncbi.nlm.nih.gov/26482261/>

had been extraordinary. If concerned, the best course of action is to seek the advice of a trained mental health specialist.

The signs of **early onset or first episode** psychosis noted by the NAMI include:

- Hearing, seeing, tasting or believing things that others don't
- Persistent, unusual thoughts or beliefs that can't be set aside regardless of what others believe
- Strong and inappropriate emotions or no emotions at all
- Withdrawing from family or friends
- A sudden decline in self-care
- Trouble thinking clearly or concentrating

Many families that informed this book noticed that there was no logical flow of ideas during conversation. Others noticed that their relative began speaking out loud to no one and did not seem to hear other people speaking to him/her. One young man began researching all religions and cults. Another young man began turning off all radios because he believed that he was receiving messages through this medium. In some families, their relative destroyed his/her bank book, birth certificate, and photographs. Signs of paranoia became apparent in many cases. A relative would begin talking about plots against him/her and had evidence that he/she was being poisoned. One man said that whenever his wife saw people talking, she assumed they were talking about her.

Families recalled reaching a point where they could not accept the differences in behavior any longer. Many commented that there was much confusion in the home, with some resentment and anger toward the person behaving strangely. Siblings often felt that their brother or sister was merely lazy and shirking responsibilities; children were embarrassed and confused by their parent acting so differently; parents disagreed on how to handle their child's problems; or the stability of the family frequently suffered. All contributors stressed that you should not wait for tensions to reach such extreme levels. You should seek outside help from your family physician or some other appropriate source.

It is important to remember that early diagnosis leads to early treatment, taking you to the path of recovery.

## Schizophrenia in Children & Adolescents

### Childhood Onset

Childhood-onset schizophrenia (onset by age 12) is a rare, clinically severe form of schizophrenia that is associated with disrupted linguistic and social development long before the appearance of definitive psychotic symptoms. In its early phases, the disorder is difficult to recognize. Child psychiatrists look for several of the following early warning signs:

- Difficulty discerning dreams from reality
- Seeing things which aren't really there

- Hearing voices which are not real
- Confused thinking
- Vivid and bizarre thoughts and ideas
- Extreme moodiness
- Odd behavior
- Paranoia (thinking people are deliberately trying to harm them)
- Behaving younger than their years
- Severe anxiety and fearfulness
- Not being able to discern television from reality, and/or
- Severe problems with making and keeping friends

Rather than an acute onset, schizophrenia in a child may occur slowly, over a long period of time. The child may become shy or withdrawn when he/she used to enjoy interacting with others. He/she may start talking about strange fears and ideas or say things that don't make sense. You may notice your child suddenly clinging to you a lot. It may be that the child's teachers notice some of these early signs being exhibited at school. Two of the most commonly reported psychotic features in children are auditory hallucinations and delusions.

### Diagnosis

Assessing possible psychosis in a child requires multiple sessions to establish the mental status of the child; details of the child's history including school reports, any neuropsychological test data, speech and language evaluations, and neurological and genetic consultations. If your child is experiencing hallucinations and/or delusions, this evidence alone is insufficient to diagnose schizophrenia.

The Mayo Clinic notes that some of the earliest signs of childhood schizophrenia may include developmental problems, such as language delays, late or unusual crawling, late walking, or other abnormal motor behaviors, such as rocking or arm flapping: Some of these signs and symptoms may also be common in children with an autism spectrum disorder. Ruling out these developmental disorders is a first step in diagnosis.

Children who have been diagnosed with schizophrenia should be monitored very closely for several years. As new information becomes available from observing the child, the diagnosis may need to be re-evaluated.

### Treatment and Services

Children who have been diagnosed with schizophrenia will usually benefit from medication (to diminish their symptoms) and psychosocial supports. Many issues should be considered in developing a treatment and

Facing the possibility that your child might be experiencing schizophrenia is undoubtedly heartbreaking. The best way to help your child and cope with this disorder is to make knowledge your suit of armor and hope your ally!

recovery plan including the child's current clinical status, cognitive level, developmental stage, and the severity of the illness. To support the therapeutic relationship with the child, it is important that he/she has a consistent group of caregivers to enable him/her to form a trust in his/her care. At this age, persons with schizophrenia will have difficulty understanding the nature of their illness. It is, therefore, important for parents or guardians and caregivers to know how to recognize changes in mood, behavior, or thought processes that may indicate relapse in order that treatment can be obtained quickly.

Researchers feel that early detection of clinical deterioration is important because psychotic relapses may have a cumulative effect and impede a good recovery level of functioning. Parents should seek counseling on how to recognize the symptoms and behaviors associated with their child's disorder; how to provide the least stressful environment for the child, and problem-solving strategies to deal with disturbing behaviors. Both first generation and second generation neuroleptic drugs are acceptable first-line treatments for children with schizophrenia. Choosing a type of antipsychotic is based on past response, family history of response, cost, and the person's tolerance of side effects.

In order to sustain a good recovery, it is best to minimize stress for your child. As children recover, they can be integrated back into their environments of home, community, and school. Children with schizophrenia may need individualized school programs and special activities. Strong levels of support from parents and caregivers will be important, especially because of the child's vulnerability to relapse. Psychosocial interventions applicable to your child include occupational therapy that focuses on activities of daily living, social skills training, speech and language therapy, and recreational and art therapy. During the stable phase it is important to monitor the child's cognitive impairments as well as assets. This information can be helpful in planning the child's treatment and can better prepare him/her for adjustment into adulthood. If you are concerned, have the child completely evaluated by a psychiatrist. Families that were consulted for this book recommend that you ask your physician or pediatrician to refer your child to a psychiatrist who is specifically trained to work with children who have schizophrenia.

There is strong evidence to suggest that early treatment with antipsychotic medications can prevent detrimental changes that may result from prolonged untreated psychosis.

#### Adolescents With Schizophrenia

Schizophrenia has its peak onset from approximately age 15-25. Therefore, the first signs of the disorder frequently appear during adolescence. Adolescence is a challenging stage for any family, but when an adolescent is diagnosed with schizophrenia, the challenges can feel daunting.

Sometimes a person does not recognize their illness and refuses treatment. Your province has mental health legislation that will enable you to get help for your relative. Consult your provincial Schizophrenia Society or similar local mental health organization that can provide further guidance regarding this, and a mental health or legal professional with expertise in these matters.

## Recognizing the Symptoms

Early onset might signal a more severe form of illness, possibly associated with stronger genetic predisposition (family history of schizophrenia), or more premorbid abnormalities (long-standing abnormalities that existed prior to the first onset of symptoms), e.g., learning disorder, autism spectrum disorder (disorders with autistic-like characteristics), impaired social skills, etc.

While the major symptoms of schizophrenia in adolescents are essentially the same as in adults, it is often difficult in young people to discriminate schizophrenia from affective psychoses (e.g., depression or bipolar disorder with psychotic features, or schizoaffective disorder). This is because symptoms may appear mixed and undifferentiated in first psychotic episodes in young people. There is, unfortunately, no definitive test for any of these disorders, and the diagnosis relies heavily on observed and reported symptoms. It is therefore difficult to be one hundred percent certain about the diagnosis in the early stages of illness, especially in children and adolescents, and the diagnosis may be revised in the first few years.

Early onset cases often tend to have a gradual, insidious onset of illness, rather than an abrupt onset. There is often a long period of gradual deterioration in functioning over months or years, referred to as the prodromal period, which precedes the onset of overt psychotic symptoms (e.g., delusions, hallucinations, grossly disorganized thinking, and generally being out of touch with reality). The prodromal period may be characterized by apathy, withdrawal, speaking less, declining interests and school performance, loss of contact with friends, loss of initiative, bizarre or occult interests and preoccupations, odd behaviors or rituals, neglect of hygiene and grooming, and disorganized thinking manifested as difficulty concentrating or engaging in coherent conversation.

The use of drugs or alcohol may act as a trigger (for an illness that was inevitably going to develop at some point in time) or can signify the adolescent's way of dealing with his/her symptoms (to relieve or mask them). Psychosis that is purely drug or alcohol induced should resolve within days or weeks of not using these substances. Other possible signs include unruly, antisocial, delinquent-like behavior, or aggression.

The prodromal period may resemble depression, and it may be difficult to distinguish schizophrenia at this early stage, especially since an adolescent becoming ill with schizophrenia may feel depressed. It is more likely, however, that the individual's mood can be described as blunted or flat rather than sad, and there may seem to be an inability to experience or express appropriate emotion at all.

## Treatment and Services

Early psychosis prevention and intervention services are for adolescents and young adults experiencing a first episode of psychosis. Typically, these services do not require a referral from a physician so that easy and rapid access to assessment and intervention can occur. Early psychosis services offer a comprehensive range of intensive interventions such as individual engagement, pharmacotherapy, psychosocial and educational supports, psychoeducation, and cognitive behavioral therapy. There are many early psychosis services across Canada, and you can find out about those in your area by contacting your local Schizophrenia Society or similar organization. Further information on early intervention is found in Chapter 5.

Acute psychotic episodes (including some first episodes), may require hospitalization for assessment and stabilization. Further treatment can be provided on an outpatient basis in a hospital clinic staffed by a psychiatrist and a nurse. Individuals whose course of illness has stabilized, and for whom a medication regime

has been established, may be able to receive their treatment from a non-hospital-based psychiatrist, a family doctor or a pediatrician. Many people do require re-admissions to hospital for acute psychotic episodes, especially in the first few years.

The issues regarding medication treatment for adolescents are much the same as for adults. Certain factors are of added importance in adolescents, such as the need to optimize cognitive (intellectual) functioning (alertness, concentration, memory etc.) as much as possible to facilitate the continuance of academic studies. Certain side effects of medication, such as weight gain and acne, are particularly problematic for adolescents and may lead to non-adherence with treatment. Adherence is generally a major problem for adolescents, and often requires extra effort on the part of parents to help ensure that their child takes the medication.

A supportive, empathic and stable relationship with the attending doctor is naturally important in ensuring adherence with medication, as adolescents with schizophrenia are frequently mistrustful and guarded, if not overtly paranoid, and lack insight about the need for treatment.

It is important to note that, while medical treatment is a critical tool in addressing schizophrenia, there are many other important tools available. For example, once the symptoms are stabilized, the doctor, nurse or other community-based therapist can engage the individual in ongoing supportive counseling, talking about day-to-day events and stresses, encouraging the adolescent to verbalize thoughts and feelings and develop better reality-testing and problem-solving abilities. Numerous studies have shown immediate and long-term results of Cognitive Behavioral Therapy in reducing positive and negative symptoms in people with schizophrenia.<sup>14</sup> Access to a peer support and other psychosocial supports to help your family member maintain ties to friends, school or work are also important in promoting recovery. These are addressed further on in this document in the sections on daily living, educational/vocational needs and social needs.

Community based mental health services typically include a wide range of programs designed to help people experiencing a range of mental health problems and illnesses. A community mental health worker or team may be assigned to help an adolescent with mental illness and his/her family with a full range of needs in a flexible, community-based manner. The mental health worker develops a relationship with the individual and his/her family, and may assist in liaising with mental health services, linking the individual to appropriate services or supports for his/her various needs (e.g., residential, financial, educational, vocational, social), supporting the individual's recovery goals, and providing crisis support when necessary. For more information on this subject, please refer to Chapter 8.



14 Candida, M et al. Cognitive-behavioral therapy for schizophrenia: an overview on efficacy, recent trends and neurobiological findings. MedicalExpress, (Sao Paulo, online) vol3 no.5 Sept/Oct 2016

## Coping With Your Teenager's Illness

Families usually need a lot of emotional and practical support while coming to terms with their loved one's illness and steering their way through the turbulent first few years. In many cases the first few years are the worst, and the illness may begin to stabilize thereafter. The diagnosis represents for many parents a devastating loss of ideals and expectations. Understandably, you may go through a grieving process as you struggle to accept the new reality.

It is important to note that stressful family interactions (e.g., high levels of hostility and criticism) just like other stresses can contribute to relapse of symptoms in individuals who are already living with schizophrenia. Families can benefit by receiving as much education as possible about the illness and its management, including information about how to minimize communication and interaction patterns that might cause added stress for all involved. Parent support is available in the form of family meetings with a social worker or a peer support specialist, to address the impact of the illness on the family, and to obtain help in working out the best way to manage the individual's behavior and communicate effectively with them. Parent and sibling support groups can also be very helpful. Remember that as family and caregivers, you are part of the solution, not part of the problem. Family education can lead to fewer relapses.

Families have become increasingly empowered in recent years, becoming a most important lobby group, and influencing policy and funding for schizophrenia. To the greatest degree possible, parents should participate in their child's treatment and recovery, regularly attending appointments with their child's doctor or nurse, and providing useful information regarding their child's symptoms and functioning (while respecting the adolescent's increasing need for a degree of privacy and autonomy and avoiding infantilizing the adolescent). Relationships with adolescents can be stormy sometimes, as they may vent frustration and anger on the people with whom they feel the most secure. But sharing your child's hope for recovery can be an important bond.

The needs of siblings should also not be forgotten during the illness. Siblings need love and attention, reassurance and explanations for their mentally ill sibling's behavior. They may be grieving as well.

Your adolescent, like anyone else, will need a secure place to live, meaningful activities, and social relationships, elements of daily life that are addressed in the sections that follow. Many people with serious mental illness say that what they need most in life is "a home, a job, and a friend" or, as one person has put it, "somewhere to live, something to do, someone to love". When you read the following sections that talk about meeting these basic needs, it helps to remember that all interventions should support a person's self-sufficiency, self-determination, inclusion in community, and ability to make a contribution as much as possible. That is the clearest route to recovery.

## Daily Living

There are many things that you can do to care for your adolescent at home. You can support your adolescent to stay in treatment and take his or her medications; you can support their recovery; and you can help them deal with symptoms and learn skills to help them in their daily living in the community. Showing your love and understanding and working together as a family can all be helpful. Educating yourself about schizophrenia and recognizing your own and others' stigma toward the illness will be helpful to both you and your teen. It is important to contact the health care provider if your adolescent is having difficulties.<sup>15</sup>

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15 MyHealth.Alberta.ca Schizophrenia in Your Teen: Care Instructions. <https://myhealth.alberta.ca/Health/aftercareinformation/pages/conditions.aspx?hwid=ug6024> 18Dec2020

There may be a time when a person with schizophrenia needs to leave the family home and live in a structured, supervised residential setting. This may be necessary due to behavior that is too difficult to manage at home, or too disruptive to siblings, or it may be a developmentally appropriate stage in separation from parents and preparation for semi-independent or independent living. Strained family relationships can sometimes improve when adolescents with mental illness and their family have more space and time to themselves, and there is less day-to-day stress in their relationships.

### **Educational/Vocational Needs**

Once young people are in the recovery stage, they should be encouraged to continue with academic studies or job training, or work which, in turn, will support the recovery process. Adolescents with schizophrenia may have special educational needs. Fortunately, schools, colleges and universities are increasingly attuned to the needs of students with mental illness. Supports of accommodation such as additional time to complete course work, an adjusted schedule, or a reduced academic load can help these students succeed.

Older adolescents may benefit from post-secondary education at a college or university, most of which have student services that provide accommodations to students with disabilities. In fact, some higher education institutions even have support programs specifically for students with psychiatric disabilities.

For those who are interested in entering the workforce, there are programs that provide assistance with vocational training and job placement. For some young people, part-time or volunteer work may be the best starting point. Financial support in the form of a government disability pension may be available if needed.

It is important for parents to have hope that their son or daughter will recover and return to school or work to the greatest degree possible. This may mean taking a lighter course load or taking longer to graduate, but usually as long as their symptoms are under control, they can achieve their goals!<sup>16</sup>

### **Social Needs**

Schizophrenia can lead to impairment of maturational development, social skills, loss of initiative, and frequently, paranoia. The result is often active social avoidance. Peer relations are critical to normal adolescent development. Adolescents with schizophrenia may need help in improving their social skills and reconnecting with peer groups. Some adolescents recovering from an acute psychotic episode and hospitalization may be successful at reconnecting with old friends. Others find it easier to relate to peers who have also experienced mental illness. Social reintegration may occur naturally through participation in mainstream social activities in the community such as clubs, interest groups, faith groups, as well as in self-help or peer support initiatives and activities. It can also be assisted by participation in social skills training groups, psychiatric day programs, or structured social activities.

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16 National Alliance on Mental Illness. A Diagnosis of Mental Illness Need Not End a College Career. <https://www.nami.org/Blogs/NAMI-Blog/March-2018/A-Diagnosis-of-Mental-Illness-Need-Not-End-a-Cole>



## Outlook

Realistic expectations may need to be set in terms of an individual's functioning, but these can be balanced with hope that recovery is possible. There is much more room for optimism now than in the past. The goal of recovery is not only to help adolescents and young adults regain as much as possible of their previous level of functioning, but also to help them to progress with the developmental tasks appropriate to their age and to continue on the life trajectory they had started. A recovery plan needs to take into account the individual needs of adolescents and young adults, with their uniquely evolving personalities, and particular home and social circumstances. Recovery is about helping the person to reach their potential.

With early and continuing treatment (medication and psychosocial services and supports) and ongoing research to improve treatments, there is now more hope than ever for adolescents with schizophrenia. In addition, the more we understand the potential for recovery, the better we are able to enhance the recovery process by helping young people with schizophrenia stay connected to school, friends, work, and community, to their goals and sense of purpose, and to their own positive sense of self.



## Chapter 4

# Diagnosing Schizophrenia

### Other Similar Illnesses

There is as yet, no lab test to diagnose schizophrenia. Therefore, the diagnosis is based on information gathered through a thorough assessment — what the person says, what the family reports, and what the doctor observes. To reach a diagnosis of schizophrenia, other possible explanations and other physical illnesses that have symptoms like psychosis, must be ruled out.

If your physician does diagnose schizophrenia, do not assume that he/she has ruled out the possibility of another illness. Do not hesitate to ask about other illnesses and ask on what grounds the doctor has determined that schizophrenia is the diagnosis. Where an illness as confusing and variable as schizophrenia is concerned, requesting a referral to a psychiatric is advised, whether or not you are satisfied with your doctor's response. A request of this nature is perfectly acceptable. Do not feel that the doctor will take it as a personal criticism.

Caution is in order because seemingly telltale symptoms, even in combination, may not be evidence of schizophrenia. They might be evidence only of an overworked imagination or extreme stress due, for example, to a death in the family, or break-up of a marriage. Today, increasingly precise diagnosis helps to ensure that warning signs are not misinterpreted.

Sometimes schizophrenia-like symptoms may occur with other illnesses such as Huntington's disease, phenylketonuria, Wilson's disease, epilepsy, tumour, encephalitis, meningitis, multiple sclerosis, Alzheimer's disease, Parkinson's, Bipolar Disorder, and numerous other diseases. Typically, schizophrenia is diagnosed when these other conditions are excluded as the source of psychotic symptoms.

A diagnosis that confirms schizophrenia may feel heartbreaking for you and your family. Remember there are many others, like you, who have experienced the same kinds of feelings. They can offer you empathy, support, ideas for helping your family member, and the hope that recovery is possible.

## Seeking Medical Attention

Family members will likely be the first to recognize the need to get medical attention for a loved one. Take the initiative. Ask your family doctor for an assessment if mental illness is suspected. Any physician can make a diagnosis however it is best made or confirmed by a doctor that specializes in mental health such as a psychiatrist. This may occur via a physician referral to a psychiatrist, or within the context of an early psychosis intervention service (in the case of a first episode psychosis), or through an intake process via your local health authority. You can also approach your local Schizophrenia Society or other similar organization for support in navigating the mental health system to get a diagnosis.

It is important to realize that your relative may be genuinely unaware of the abnormality of his/her symptoms — remember that the person believes that the hallucinations, delusions, or other symptoms are real. They may, therefore, resist any suggestion to see a physician. Even if people living with schizophrenia are aware that something is wrong with them, their confusion and fear about the problem may convince them to deny its existence or abnormality. As well, society's social prejudice or stigma towards people with mental illness is a major reason why people do not seek help.

Efforts to have your relative agree to visit a doctor will likely be more successful when made without reference to strange behavior (e.g., “You’ve been acting really weird lately”, or any reference to the feelings of others; “Your behavior has been upsetting this family”). Encouraging the person to seek medical attention based on symptoms such as insomnia, lack of energy, or sadness will more likely be perceived as helpful and non-threatening. If your relative agrees to see a doctor, ask the receptionist for a double booking (most appointments are only 10 or 15 minutes long) so that you will not feel rushed. After you have arranged the appointment, you may want to send the doctor an email/letter outlining your concerns as clearly as possible. In addition to assisting the doctor, this will help you be clear about what has been happening. The following is a sample letter:

Dear Dr. Smith,

I have made an appointment for my daughter, Jane, to see you on Monday, May 8, at 10:00 a.m.

Three months ago, Jane began acting in an unusual manner. The following are some of the behaviors that our family has noticed: she cannot sleep at night; has dropped out of her favorite activities; refuses to see any friends; cries two to three hours a day, and will not allow anyone to touch her.

I have enclosed copies of her last two school reports, and a list of comments made by her friends. I believe that a medical assessment is necessary, and I am anxious to hear your opinion.

Sincerely,

Jane's Mother and/or Father

If your relative refuses to see a physician, however, you should still make an appointment and go on your own. Again, request a double booking, and send a variation of the above letter. After you have visited with the doctor, you may find it easier to get your relative to agree to an appointment.

If you have succeeded in convincing your family member to go to the doctor, you need to be aware that this first visit may not resolve anything or answer any questions. Families who have been through this admitted that they had hoped this doctor's visit would be the cure-all, and were frustrated when nothing seemed to happen. During a doctor's appointment, your relative may not exhibit the behavior that you have seen. Some people find talking to a doctor very stressful, and many people with schizophrenia have said that they found themselves going blank during the visit.

However, many people with schizophrenia also said that their fear of going to the doctor was somewhat alleviated when the doctor was able to ask the right questions. Because of the letter received in advance, the doctor was able to focus on the symptoms that were bothering the ill person, and the individual found that he or she was more willing to open up to the doctor. For example, people found it comforting if the doctor said something like: "I understand you've been crying a lot lately. You must feel very confused about this." It is important that you are prepared to supply information to the physician and/or psychiatrist to help them make an assessment.

For further information on recognizing and managing psychosis and schizophrenia in adults, as stated previously, the National Institute for Health and Care Excellence has developed helpful, evidence-based guidelines that aim to improve care and recovery. Please check out their website.

## If the Person Who is Ill Refuses to See a Physician

If your relative refuses to go to a doctor's office, you could try to arrange for a house visit by the doctor if this is something that your doctor does. If a physician does agree to visit the person at home, try to prepare your relative ahead of time. Encourage him/her to cooperate as best you can, but understand that the person may still refuse to talk to the doctor. If you cannot arrange for a home visit by a physician, or are having trouble getting the person to talk to a doctor, seek assistance from your local mental health clinic. They may be able to direct you to alternative options (e.g., a mobile crisis response team, an assertive community treatment team, etc.).

After you have unsuccessfully exhausted all available avenues for a voluntary physical/mental examination by a psychiatrist or physician, you may consider having a compulsory examination ordered by a judge. All provinces in Canada have mental health legislation provisions that allow any person to apply to a judge for the compulsory psychiatric examination of another person. Mental health laws require that if you request such an order, evidence must be provided to the court that shows the person is suffering from a mental disorder, is refusing to see a physician, and meets criteria for harm or deterioration concerns as specified by the provincial legislation. If you have kept records it is a good idea to offer them to the judge, as they may be helpful to the decision process. Since the procedures and criteria for these court orders differ between provinces, it is advisable to seek assistance from a mental health professional or lawyer who has expertise in these matters. Your local Schizophrenia Society or similar mental health organization may also be able to help you. If a court order for examination is granted, it is usually the police who take the person to a physician. A medical examination is performed to determine if involuntary admission to hospital is warranted under provisions of the provincial mental health legislation.

If the person refuses to see a doctor during a crisis that involves violence or endangerment, and the police get involved, the police are authorized by provincial Mental Health Acts to take the individual to a hospital or physician for examination. The physician then decides whether or not the person will be admitted to a clinic or hospital on an involuntary basis.

## Tips on Obtaining Medical Help: What You Can Do

The assessment and treatment of schizophrenia should involve experts in schizophrenia. Consult with your family physician or psychiatrist before accepting any unusual treatment or changing your current treatment program. If you have questions or lack confidence in the advice you receive, remember that you have the right to seek another opinion from another psychiatrist, locally or elsewhere.

When seeking a specialist, you will want someone who is medically competent, who has an interest in the disorder, and who has empathy with people who experience it. More specifically, you will want assistance from a psychiatrist who:

- Believes that schizophrenia is a biological disorder that interacts with environmental risk factors
- Takes the time to do a detailed history
- Screens for symptoms and problems that could be related to another illness
- Prescribes antipsychotic drugs with due caution and care
- Reviews medications and the status of your family member regularly
- Is interested in the individual's entire welfare, and makes appropriate referrals for aftercare, meaningful daily activity, housing, social support and community connections and financial aid
- Is interested in the individual's own perspectives and goals, and takes these into account in the treatment process
- Respects the individual's need for a positive sense of self, a sense of belonging, and sense of purpose and meaning, and supports these steps toward recovery
- Involves the family in the treatment process
- Explains the person's status fully and clearly
- Believes recovery is possible!

Anyone who tells you that schizophrenia does not exist, or that you should avoid medical treatment if you have it, is not acting in your best interests. Also, individuals who offer guaranteed treatments and cures must be regarded with extreme caution.

The world of medicine is important to the recovery of people with schizophrenia. Explore it diligently, and get the best it has to offer. The person needs and deserves the best, and so do you!

## Keeping Records

When you start seeking medical attention for the person, it is important to begin, and maintain, a diary or record of your relative's illness, noting his/her behavior patterns, any treatment he/she undergoes, and all the steps you have taken to help your relative. Although this may require considerable effort, experienced family members strongly emphasize the value of record keeping. It will greatly assist you in relaying history to the attending physician(s) and other caregivers, in keeping symptoms and issues organized in your thoughts; as well as being a useful reference should relapse occur. Records also provide useful information to help a physician or a judge make decisions regarding involuntary hospital admission.

The record should be clear, precise, and in point form. Avoid vague words and rambling descriptions. Medical practitioners stress the importance of listing behaviors that can be observed and measured. For example, you are noting a particular behavior if you say that Joe refuses to wash and wears the same clothes every day. This is more useful than saying that Joe looks scruffy. It is also more useful to tell the doctor that Susan cries every night for at least one hour, than to tell the doctor that Susan seems so sad lately. Write down the details of the noted behavior, and include the day, time and duration, if applicable. Keep a record of your appointments with your doctor and keep copies of all correspondence.

It is essential that you treat your record as a confidential document, one that should be used with discretion. If your relative has paranoid tendencies, knowledge of your record may only convince him/her that you are spying. On the other hand, some families have found that it is helpful to have their relative's involvement in the record keeping. If you feel it is appropriate, encourage your relative to jot down his/her thoughts and feelings.

You may think that record keeping is just another thorn in your side. The benefit, however, is not only practical but somewhat therapeutic. By documenting important information, you are relieving yourself of the burden to remember.

## Initial Assessment

Families are encouraged to read "Hope and Recovery: Your Guide to Living with and Beyond Schizophrenia (<https://schizophrenia.ca/wp-content/uploads/2020/05/Hope-and-Recovery-Guide.pdf>) that was produced through a partnership between the SSC and the Canadian Psychiatric Association (CPA). The project adapted the CPA's Clinical Guidelines for the Treatment of Schizophrenia into a user-friendly format to assist individuals and families as they navigate their way through assessment and treatment of the illness.<sup>17</sup>

The initial assessment of the individual should include both a physical examination, and a clinical investigation preferably by a psychiatrist. Generally speaking, a person with a normal health history will undergo tests such as a drug screen, general chemistry screen, complete blood count, and urinalysis. Brain imaging scans may be ordered if neurological signs or symptoms of other brain diseases are present. Neurocognitive testing should be performed. Measurements of intelligence, memory, attention, command functions, language, and visual and motor skills can reveal both preserved and impaired mental abilities — indicating functionality at the community level (and perhaps guiding rehabilitation plans).

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17 Schizophrenia Society of Canada. <http://publications.cpa-apc.org/browse/documents/676January2021>

The psychiatrist should make specific inquiries relating to the following:

- Positive, negative, and disorganized symptoms, and changes in functioning
- When the psychotic symptoms began and possible precipitating factors (e.g., substance use/abuse)
- Substance use/problematic substance use
- Any history of suicidal thinking and behavior
- Any history of violence, verbal or physical
- The person's general medical history
- Any family history of schizophrenia (including treatment received), other psychiatric disorders (including addictions and suicidal behavior), and inherited medical illnesses
- The current lifestyle of the individual, including housing environment, finances, social network and activities, school environment, work environment, and general functionality in the community
- A developmental history, including social and academic functioning, both in childhood and adolescence

These questions will give the psychiatrist clues to, for example, the potential outcome of treatment (the longer the duration of untreated psychosis, the greater the likelihood of poorer results); whether and where the person should be hospitalized; and whether other biological investigations should be performed.

Arming yourself with knowledge is the best way to help you and your relative, as well as the medical experts with whom you will be working. Asking your psychiatrist questions is not only a reasonable approach to participating in the individual's assessment, it is necessary to satisfy yourself with information. A good health professional will expect this.

Do not be afraid to exhibit your concerns and demonstrate your commitment – the role you play entitles you to the knowledge that will help you deal with this disorder. Here are some potential questions to which you are entitled to have answered by the psychiatrist if you so wish:

- What is the diagnosis? If your current evaluation is a preliminary one, how long will it take to ascertain a definite evaluation?
- Do you feel confident that the possibility of other illnesses has been ruled out (e.g. thyroid problems, diabetes, etc.)? Have tests been done to rule out other medical problems?
- Has a neurological examination been conducted? What tests were performed, and what were the results? Are there any additional tests that you would recommend at this point in time?
- Would you recommend an independent psychiatric or other specialist's opinion at this point in time?
- What kind of treatment and recovery plan do you suggest? How will it work, and what results should we expect? What will your role or contribution to the treatment and recovery process be?
- Will other health professionals be involved in the treatment and recovery plan? If so, how can we ensure their services will be coordinated?

- When are the best times to contact you? Where can we best reach you? To whom can we refer our questions or problems when you are not available?

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- How often will the person be seen by the various health care providers involved?

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- How soon before we can expect signs of progress to be evident? What will be the best evidence that the individual is responding to the treatment program?

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- How much access will the family have to the health caregivers involved? What do you see as the family's role in the treatment and recovery program?

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- What medication(s) are you proposing (ask for name and dosage level)? What is the biological effect of this medication? What are the risks and side effects associated with it? How soon will we know its effectiveness? How will we know it is working? What will it ultimately accomplish?

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- Are there other medications that might be appropriate? Why do you prefer this one?

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- Are you currently treating other people with schizophrenia?

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- How familiar are you with support groups and agencies that can help us? What about peer support groups for the person with schizophrenia?

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- How do you monitor medications (e.g., regular blood tests)? What symptoms indicate that a change in dose may be required? Will you be monitoring for depression? How do we ensure medication is taken on a daily basis? How often will you reassess the person? How do you reassess the individual?

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- What can we do to help you during the treatment process? If hospitalization is required at some point, which hospital do you suggest? What is the best way to ensure the family will be included in plans to discharge the person from the hospital? What are the laws about committal and compulsory treatment? What is your philosophy on them?

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- Do you have any suggestions about dealing with psychotic episodes? Who do I turn to in the event of an emergency or crisis?

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- How are your services recovery-oriented? What do you believe enhances the recovery process?

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Once again, be sure to keep a record of all your questions and the responses. You'll be happy to have it as a reference source.

## Chapter 5

# Early Intervention

While Canada does not have a national early psychosis strategy, there is much evidence-based information that is available to service providers and family members. For example, the National Institute for Health and Care Excellence has developed the NICE guidelines which covers recognizing and managing psychosis and schizophrenia in adults.<sup>18</sup>

Psychosis responds well to treatment, especially when it is identified early. Early psychosis intervention involves early identification followed by comprehensive, individualized strategies that incorporate the use of low-dose anti-psychotic medications with education and psychosocial interventions. Research indicates that this approach can promote full recovery from early psychosis and that the sooner the psychosis is appropriately treated, the better the outcomes.

### Definition and Barriers

Early intervention refers to the recognition of the onset of psychosis (either prodromal stage or first episode of psychosis), and the immediate response to it. We already know from Chapter 3 some of the early warning signs before schizophrenia/psychosis (as per the National Alliance on Mental Illness). Once again, they include, but are not limited to, the following:

- A worrisome drop in grades or job performance
- Trouble thinking clearly or concentrating
- Suspiciousness or uneasiness with others
- A decline in self-care or personal hygiene
- Spending a lot more time alone than usual
- Strong, inappropriate emotions or having no feelings at all

These symptoms tend to precede the onset of schizophrenia and are known as the early course of schizophrenia. Hallucinations, delusions, and/or thought disorder are examples of psychosis, or the acute stage of schizophrenia. (It is important to note that psychosis is not limited to schizophrenia but appears in other mental disorders as well.)

18 <https://www.nice.org.uk/guidance/cg178>

Early psychosis intervention holds much promise. But its success depends on how “early” the intervention begins. Ideally, it should be as soon as possible following the start of psychotic symptoms. Unfortunately, however, psychosis often remains untreated for many months. In fact, some people live with untreated psychosis for years.

There are three major hurdles to early intervention. The first is recognition that there is a problem. Studies of people experiencing their first episode of psychosis have demonstrated that they typically remain undiagnosed and untreated for several years.<sup>19</sup> Stigma, fear and a sense of helplessness may trigger an avoidance type of reaction by the person and the family. For example, parents may dismiss the person's behavior as being that of a normal teenager. Another reaction might be to blame the behavior on a perceived problem with alcohol or other substance abuse. It may be that the person senses that he/she is experiencing something out of the ordinary but does not want others to know about it. It may also be that the person does not realize that he/she is experiencing anything unusual. For example, if the person is having delusions, he/she likely believes the delusion is reality.

Unfortunately, failure to recognize the problem means that the person will likely not seek help until the illness reaches an acute stage. While this lack of acceptance and commitment to do something about the problem is understandable, it becomes the second major hurdle to early intervention. Without treatment, the illness cannot be addressed. Without acceptance, treatment is unlikely to occur. In many cases the person can continue to function (e.g., in academic, athletic, or career roles) for years while experiencing symptoms of psychosis, and therefore may choose not to seek treatment until such time as he/she can no longer function.

Once help is sought out, getting access to care and treatment is the third hurdle to early intervention. This third hurdle is attributable to a lack of education, awareness, and expertise within the health care system. Understanding of mental illness and its symptomatology is key to proper assessments, diagnoses, and effective treatment of schizophrenia. Research indicates that most people with schizophrenia consult a health care practitioner several times before an accurate diagnosis is made and treatment initiated. This policy of waiting for a complete and accurate diagnosis before commencing treatment is problematic since the process can take up to a year, during which time the person continues to suffer.

Poor communication is a component of the access to treatment barrier. The person may not be able to adequately express his/her feelings and experiences, leaving a physician with the wrong impression, or at least impeding the diagnostic process. Also, families and individuals complain that when they learned of the illness, little or no information about the diagnosis, treatment, and available support was communicated to them by health care professionals. This could be due to the person's inability to process the information while unstable, meaning that the timing of communication was inappropriate. It could also be that the manner in which the communication

Not all people with schizophrenia have classic textbook symptoms. Every person's experience is unique. If you notice strange and unusual behavior in your loved one, he/she may need help. It is advisable to consult a health practitioner with mental health expertise immediately.

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19 Ho, Beng-Choon et al. Untreated Initial Psychosis: Relation to Cognitive Deficits and Brain Morphology in First-Episode Schizophrenia; American Journal of Psychiatry 2003 Jan; 160(1):142-8.

was made did not suit the recipient, so delivery of information was not successful. Another factor could be insufficient family involvement, caused by the confidentiality requirement and failure to get the person's permission for release of confidential information. The danger of insufficient information is twofold.

The first problem is it prevents people and their families from getting the help and information they need to deal with the diagnosis. The second danger is it may lead to the development of unrealistically high, or overly pessimistic, expectations for the person's recovery.

The good news is that over the past two decades, early psychosis intervention for young people has become increasingly understood and accepted and has had rapid growth during that time with many excellent programs to be found in Canada as well as other countries throughout the world. Young people who experience a first episode of psychosis and are referred quickly for medical help have a good chance of receiving early intervention services that are geared to their age and developmental needs and have excellent potential for recovery.

## Rationale and Benefits

Research tells us that one of the biggest obstacles to a good recovery from schizophrenia is the length of time the illness has existed before treatment commences. The problem is that before the person is treated for the illness, he/she is at risk of losing important skill sets such as social and occupational skills. This is particularly true for adolescent individuals who are in the crucial period of maturation, when much psychological and social development occurs. It is also likely that the person's relationship with family will be strained, and his/her pursuit of education or employment interrupted. While medication addresses psychotic symptoms, once these skill sets are lost the person risks continuing to experience a decrease in functioning, resulting in a poorer quality of life, and possibly making the person more prone to suicide, depression, aggression, problematic substance use, anxiety disorders, and cognitive impairment.

It may be more likely that a person will be open to treatment and insight into the illness while still in the early stages of it. Once the positive symptoms (e.g., delusions) have progressed, it may be more difficult to engage the person in treatment. The earlier in the illness that people get interventions, the easier it is to minimize the resulting disability they experience. Some research has noted that long durations of untreated psychosis have been associated with:

- More severe symptoms, including depression and anxiety
- Poor social and overall functioning and quality of life
- Low response to treatment<sup>20</sup>

On the other hand, the message of early psychosis intervention is one of hope. When a young person receives treatment and supports early in the process, he or she is more likely to retain ties to school, friends, or work - to stay on his or her life trajectory. As one early psychosis intervention website states: "Psychosis is treatable; recovery is expected."

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20 Neura.SchizophreniaLibrary. Schizophrenia Fact Sheet; August 2020.

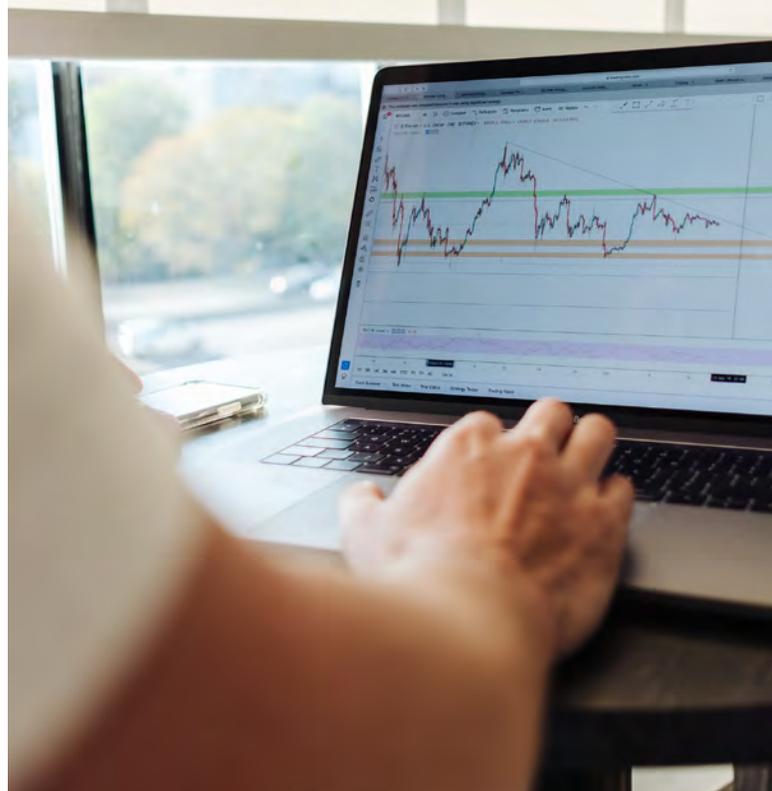
## Scientific Data

In November 2002, the National Library of Medicine reported incidental radiological findings on brain magnetic resonance imaging (MRI) in first-episode psychosis and chronic schizophrenia. The findings show that individuals with chronic schizophrenia were more likely to have clinically significant abnormal scans than individuals with first episode psychosis.<sup>21</sup>

Some research suggest that immediate treatment of the emerging positive symptoms of schizophrenia can greatly reduce the duration of illness, the severity of symptoms, and the impact on the family and community.<sup>22</sup> Early intervention (treatment received immediately after the first episode of psychosis, or during the prodromal phase) contributes to better recoveries. Both the Prevention and Early Intervention Program for Psychosis (London, Ontario) and Early Psychosis Prevention and Intervention Centre (Australia) programs report that individuals who receive appropriate treatment within six months of the onset of psychosis, experience better recoveries than those whose treatment was delayed for more than six months.<sup>23</sup>

Several research studies in the UK and some countries in Europe have demonstrated various positive results of early intervention services, including, for example, improved clinical, social and vocational outcomes and reduced hospitalizations (Singh 2010). These services have also been found to significantly reduce the risk of a second episode (Alvarez-Jiménez 2011).

As well, a 2018 research study that looked at the effectiveness of early psychosis prevention found that people with first-episode psychosis who used early intervention services “had mortality rates that were four times lower than those with first-episode psychosis who did not use these services, as well as better outcomes across several health care system indicators.”<sup>24</sup>



21 Lubman, D I. Incidental radiological findings on brain magnetic resonance imaging on first-episode psychosis and chronic schizophrenia; *Acta Psychiatrica Scand.* 2002 Nov; 106(5): 331-6.

22 Early Psychosis Program (EPP) Web site: [www.eppic.org.au](http://www.eppic.org.au)

23 PEPP Web site, Putting the Pieces Together, Early Recognition of Psychosis, p. 1

24 Anderson Kelly et al. Effectiveness of Early Psychosis Intervention: Comparison of Service Users and Nonusers in Population-Based Health Administrative Data *The American Journal of Psychiatry*, March 2018.

The motivation for early intervention is to reduce the burden of illness for those with psychosis and their families. The benefits of immediate treatment are very encouraging:

- Less interruption in the life of the person

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- Less strain on the person's family

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- Greater chance of reintegration into social activities, academic and/or career pursuits

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- Reduced chance of suicide

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- Less chance of chronic illness (frequent relapses) and disabling disorders (depression, alcohol or substance abuse, anxiety), and

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- Overall better functioning and quality of life leading to recovery

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Having said the above, a very recent research study suggests that “if a potential long-term benefit of early intervention is to be realized, attention must be focused on preserving the initial benefits of treatment over the lifespan”.<sup>25</sup>

## The Need for Public Education

Recognizing and accepting that a problem exists, and seeking help are the first steps to receiving treatment for schizophrenia. But how is a person to know that what he/she is experiencing is not something to run and hide from – but rather something that should be treated, sooner rather than later? If and when they do seek medical assistance, how can people dealing with symptoms of schizophrenia be sure they will get an appropriate response? The best answer is decreased stigma and social prejudice, and increased public education, and better training of health professionals.

Everyone should be educated about schizophrenia and other severe mental illness. Most specifically students, teachers, guidance counselors, youth leaders and other people who interact with children and youth should be prioritized for education and awareness. As well, persons who work in the medical/health care system; families with a history of schizophrenia (whose children are at greater risk of developing the disorder); young people who exhibit symptoms of alcohol or problematic substance use should all be educated. Family physicians should have specific training to help them detect mental illness in its early stages. Emergency care units and mental health units of hospitals should have specific training in not only recognizing the early symptoms of schizophrenia, but also minimizing the trauma of a first episode of psychosis for the person, and minimizing the trauma associated with subsequent hospitalizations for individuals as well.

As we know, the onset of schizophrenia occurs at a young age (between ages fifteen and twenty-five). Young people are typically still dependent on parents, teachers, athletic coaches, guidance counselors, clergy, youth agencies and others for direction in their lives. These people can be influential in a young person's life, and it is very important that they receive education and training on mental illness, and the early signs of its onset. Awareness will improve the chance of recognition, and once suspected, a teacher or other figure of authority and influence may help the person to accept the problem and seek treatment. If the person has a

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25 Goff, Donald C. Does Early Intervention Improve the Long-term Course of Schizophrenia? *American Journal of Psychiatry*; published online on 4 March 2020.

good relationship with a teacher or family doctor, wherein he/she trusts the professional, and feels treated with respect and concern, then there is a good chance that this individual will be one of the first points of contact for the youth. It is essential that such individuals be educated about the warning signs of mental illness, and about taking a distressed young person's complaints seriously. The person with schizophrenia is more likely to seek help voluntarily with the help of someone knowledgeable about mental illness with whom he/she enjoys a healthy interpersonal relationship.

Such a relationship can also contribute to an ongoing treatment plan, if the professional is diligent in maintaining contact with the person, offering encouragement and support where appropriate.

Once people with schizophrenia embark on the pathway to treatment, the experiences they have will impact their recovery. Thus, it is equally important that doctors and other gatekeepers (nurses, social workers, therapists, and other service providers) of the health care system respond adequately and appropriately to a person's request for help. Lack of information leads to delays in treatment. And these delays not only prolong the person's symptoms and their social consequences (such as shame from internalized stigma and isolation from peers, work and education), but also interfere with the start of the recovery process, when time is of the essence.

The trauma of a first episode of psychosis can be exacerbated by: being treated in an unsuitable environment; not getting meaningful human attention; not having one's own perspectives and hopes heard and validated; not getting sufficient follow-up and support from community services; and the stigma attached to mental illness.

While hospitalization is necessary in some cases, much treatment can begin in outpatient or community-based clinics and programs. Gatekeepers need to be aware of available sources of treatment and supports in their community, as well as have up-to date knowledge and training specific to the needs of both individuals and their families dealing with schizophrenia (e.g., young people usually require lower doses of medication than older people for effective treatment of psychosis).

The emergency room or a crisis response centre is often where a person experiencing an episode of psychosis will go. Unfortunately, emergency rooms can be very stigmatizing places to go. Some emergency rooms have mental health specialists/teams with expertise in assessing early psychosis. Gatekeepers should also have referral networks so that individuals do not get lost in the medical system but are closely followed by the appropriate practitioners. If a person's first contact with treatment is severely negative, he/she is not likely to want to remain in the care of the medical system. Social prejudice or stigma is a major reason why people with mental illness do not seek help! Healthcare providers are not immune to their own negative views towards those living with mental illness.

Many people and their families report being shocked and angry by the traumatic and stigmatizing experience of hospitalization. Their message is that forcible confinement, isolation, discouraging psychiatric ward environments, and insensitive treatment are far too overwhelming for a young person, and sometimes have more long-term ill effects than the actual experience with psychosis. Young people with schizophrenia need lots of human contact, reassurance, encouragement, counseling, and support to accept their illness and to maintain their faith that recovery is possible.

One of the advantages of having an educated public is that it is easier for the person and his/her family to engage the support of their community. If schools and teachers understand the illness and what the

student needs to succeed, then they can help the young person as he/she tries to continue studies. If work environments have a good awareness of mental illness and appropriate workplace accommodations, they are more likely to support a person with a mental illness who tries to continue his/her career pursuits. Community support is key to an individual's recovery and should be engaged as soon as the person's symptoms are stabilized. It is counter-productive to prevent the person from doing activities he/she is capable of until a firm diagnosis is first made since that can take one or more years. Families will also need hands-on support from their community. They may require respite services and are likely to need the help and understanding of other relatives and friends. People generally want to be helpful to those in need, and public education fosters the ability of the general public to respond appropriately to schizophrenia, while removing the stigma attached to it.

## The Importance of Individual and Family Psychoeducation

There have been several reviews and research projects that have highlighted how important psychoeducation is to individuals with first episode psychosis and their families. For example, it has been demonstrated that psychoeducation, along with identification of warning signs and stress management has resulted in positive outcomes, including reduced readmission to hospital.<sup>26</sup> Another analysis concluded that psychoeducation that included family members were "more effective in reducing symptoms and preventing relapse".<sup>27</sup>

The Cochrane analyses on psychoeducation for schizophrenia found that "psychoeducational interventions significantly reduced relapse and readmission rates, enabled fewer hospital days, increased medication adherence, increased satisfaction with mental health services, and improved quality of life."<sup>28</sup> Psychoeducation for individuals has also been shown to "strengthen the individual's self-efficacy and empower them to improve their wellbeing".<sup>29</sup>

The SSC offers several psychoeducation opportunities including the Family Recovery Journey, a five week education course for family members; Strengthening Families Together, a multi-week education and support group; and other peer support resources. Contact your local schizophrenia society or other similar mental health organization to learn more.

Psychoeducation for people with schizophrenia and their families directly impacts the treatment and recovery process. Without an understanding of the illness, people are less likely to fully participate in a proper treatment and recovery plan, and families are less likely to know how to help and support the person.

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26 Penn LD, Waldheter JE, Perkins OD, Mueser TK, Lieberman AJ. Psychosocial treatment for first-episode psychosis: a research update. *Am J Psychiatry* 2005; 162 12:2220-2232.

27 Lincoln ML, Wilhelm K, Nestoriuc Y. Effectiveness of psychoeducation for relapse, symptoms, knowledge, adherence and functioning in psychotic disorders. *Schizophr Res* 2007; 96 (1-3):232-245.

28 Xia J, Merinder LB, Belgamwar MR. Psychoeducation for schizophrenia. *Cochrane Database Syst Rev*. 2011;(6):CD002831.

29 Bauml J, Frobose T, Kraemer S, Rentrop M, Pitschel-Walz G. Psychoeducation: a basic psychotherapeutic intervention for patients with schizophrenia and their families. *Schizophr Bull* 2006; 32 (S1):S1-S9.

## Early Intervention Strategies

### What To Look For in Assessments

An individual exhibiting signs of onset of illness or full-blown psychosis should be immediately and rapidly assessed by a physician. Ideally, the person should be assessed in a setting that is non-threatening, and that minimizes stigmatization. Examples of such environments include the young person's own home, the office of his/her family physician, or a community clinic or crisis response centre with mental health experts specifically trained to handle these situations.

There are two components to a full and proper assessment for mental illness: the psychosocial component and the physical component. The health practitioner should be asking questions about the person's social relationships, school or work performance, recreational pursuits, ability to manage finances, attention to hygiene and clothing, religious/spiritual activities, interaction with family members and/or others in the home environment, and attention to housework. Your relative should also be assessed on his/her current strengths and functionality (e.g., academic standing, athletic abilities, job abilities, social abilities) in order that clinicians can target treatment and services to support the person's existing capabilities. Cognitive and intellectual functioning is assessed by gathering information about academic and home functioning with input from family members. Functions should be closely monitored for any changes and the rate at which change takes place. Medical information that is relevant from birth and through the developing years is gathered from the parents. The individual should also be given a complete psychiatric assessment, including details on academic, occupational, recreational, and social history.

The person should also undergo basic neurological and general physical examinations prior to engaging in drug therapy. Any movement abnormalities the person may have should be determined. Testing for glucose, electrolytes, complete blood count, cholesterol profile, and liver, heart, kidney and thyroid function may be done as a baseline prior to starting certain medications. Height, weight and abdominal circumference should be measured. If relevant, testing for HIV and sexually transmitted diseases could be done. A urine toxicology screen (checking for street drug or marijuana use) could be done if substance use is a concern.

It is essential that any existing medical problems be fully investigated, as they could contribute to more severe psychoses, or other concerns such as depression. It is recommended that your relative undergo diagnostic reassessments several times each year. This will help prevent the possibilities of misunderstandings surrounding the diagnosis, and the chance of having unrealistic expectations. Re-examinations will also help to ensure the person is given the appropriate treatment, services and supports to help him/her recover. Thorough psychosocial and physical assessments should provide information that will give the individual and his/her family as clear a picture as possible on the status of the illness and its impact to date. This will help the person and family members to develop realistic expectations for the person's recovery. Also, the more complete the assessments, the better able the physician is to prescribe treatment that suits the particular circumstances of the individual.

## Eight Principles of Treatment

The purpose of drug therapy and psychosocial interventions for schizophrenia is to help the person recover hope, satisfaction and meaning in life to the greatest extent possible. Treatment is a major key to recovery. It is important for family members to be aware of ways to help ensure the person gets the full benefit of a treatment

plan and adheres to it as prescribed. The following principles of treatment will help to promote a successful recovery:

1. The development of a strong, empowering and enduring relationship with the treatment team
2. Attention to the comfort and wishes of the person
3. Attention to the personal goals or recovery goals of the person (hopes and dreams)
4. Comprehensive and individual centered treatment
5. Ongoing intensive treatment for several years following the first episode of psychosis
6. Age – and stage – appropriate treatment
7. Attention to the pace and timing of community reintegration
8. Early family involvement<sup>30</sup>

### **Development of a strong, empowering and enduring relationship with the treatment team.**

Surveys of individuals and families tell us that a good relationship with one or more members of the treatment team promotes long-term adherence to the treatment and recovery plan. If a person trusts someone involved in his/her therapy, and feels comfortable approaching and confiding in the practitioner, he/she is more likely to follow the prescribed treatment. In addition, people's meaningful input into their own treatment plan and its goals can be a significant contributing factor to recovery.

### **Attention to the comfort of the person.**

When someone experiences psychosis, it is very distressing. The response he/she receives while undergoing the acute episode of schizophrenia could make the situation worse. If the individual is traumatized when hospitalized; experiences poor and confusing assessments; feels he/she is not being heard, or if he/she suffers strong side effects from drug therapy, then it is less likely the person will want to participate in treatment.

### **Attention to the personal goals or recovery goals of the person.**

The focus of intervention should be comprehensive and not only on the symptoms of the illness, but on the personal goals and aspirations of the person. The individual should be encouraged that he or she can still have a future with hope by attending school, getting a job and engaging in social relationships. Certain supports and accommodations may be necessary to empower the person to reach their goals.

### **Comprehensive and individual-centred treatment.**

Antipsychotic medication, psychosocial therapy, and talk therapy (e.g Cognitive Behavioral Therapy or Cognitive Remediation or Acceptance Commitment Therapy) coupled together are essential elements of a recovery plan. Every individual is unique, and people with schizophrenia should have individualized treatment

30 Ehmann, Tom & Hanson, Laura, Early Psychosis A Care Guide, 2002, University of British Columbia.

plans designed to meet their particular needs and recovery goals, support their strengths, address their weaknesses, and help them maintain a good level of self-esteem and functionality. The goals of treatment should include:

- The improvement of psychotic symptoms

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- The reintegration of the person to his/her normal roles and environments as quickly and effectively as possible

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- The prevention of depression, anxiety and other secondary symptoms

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- The support and improvement of the person's self-esteem and capabilities, and

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- The maximization of the person's quality of life

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### **Ongoing intensive professional involvement for at least several years following the first episode of psychosis.**

Many people who experience an acute episode of psychosis may have to take antipsychotic medication for the rest of their lives. It is important that antipsychotic treatment be continuous, as interruptions may lead to a relapse. If the person frequently stops treatment, he/she is less likely to make a complete recovery. Psychosocial therapy should also be ongoing and intensive, for at least several years after the first episode of psychosis, in order to support adherence to drug therapy, and promote a complete recovery.

Should a person decide he/she wishes to see if they can “do without medication”, a harm reduction approach should be taken with the doctor working with the person rather than abandoning them or threatening not to continue as their doctor.<sup>31</sup>

Adolescent individuals need help if a transfer of health care services is required when they reach adulthood. The family should be advised well in advance if services will cease at a certain age, in order to arrange for continuing alternative care.

### **Age – and stage – appropriate treatment.**

It is important that both medication and psychosocial interventions be tailored to the age of the individual, as well as to his/her stage in life. For example, young people require lower doses of antipsychotic medicine to maintain stability. Students may need different services than people who are pursuing careers. A female's medication may need to be changed if she decides to bear children. Treatment needs to fit the person's needs and goals as he/she progresses through life.

### **Attention to the pace and timing of community reintegration.**

A primary goal of early intervention is getting the person reintegrated into his/her social, occupational, scholastic, athletic, domestic, and other roles as soon as possible. It is important that the plan for reintegration be sensitive to the person's ability to cope. If done too quickly, reintegration may cause the individual to be overwhelmed and possibly suffer a relapse. Failure to reintegrate successfully will also likely have a negative impact on the person's confidence and self-esteem. The timing and pace of reintegration to each former or new activity must be carefully handled.

31 The Icarus Project and Freedom Centre. Harm Reduction Guide to Coming off Psychiatric Drugs; June 2012.

**Early family involvement.**

The concept of early intervention suggests that family members also should be involved as early and as fully as possible. They should be educated about the illness, recovery and the importance of their participation in the treatment/recovery plan should be emphasized. It is also important that disruption to the family unit be minimized. Chapter 9 deals with the role of the family as well as helping family members cope with schizophrenia.

Individuals who are considered at risk of schizophrenia (e.g. a child of someone with the disorder) and are complaining of anxiety, depression, and/or insomnia should be treated for these complaints, be educated on addressing stress factors in their lives, and be closely monitored for development of psychosis.

## Medication and Side Effects

This subject is dealt with in detail in Chapter 8. It is worth mentioning, however, that young people who experience a first episode of psychosis tend to be more sensitive to the effects of antipsychotic medication. An adolescent with schizophrenia should, therefore, be given a low dosage of medication to start. If it is evident that the dosage is insufficient, it should be increased very slowly. In general, young people require much lower doses than adults do in order to have their positive symptoms effectively treated.

The advantage of lower dose medication is the minimization of side effects. An initial period of approximately one week should determine if the person is tolerating the medication (e.g., symptoms are decreasing with minimal or no side effects). If there is no significant change in symptoms after four to six weeks, then another type of antipsychotic medication should be considered. Much of the improvement the person will experience will occur in the first six months of treatment.

**Alcohol/Problematic Substance Use**

For people with schizophrenia, alcoholism and other substance use disorders occurs up to fifty percent more often than in the general population. It is important for family members to be aware of the signs of alcohol and/or problematic substance use, and to understand that the problem may be an indication of the presence of psychosis or the early stages of schizophrenia, particularly if there is a risk factor present. They also need to understand how alcohol and street drugs can cause extra complexity and challenge for people with schizophrenia. Learning to say “no” or reducing potential harms in their decision to use a substance or not use a substance is also important. Chapter 8 provides more detailed information on this subject.

**Both mental illness and problematic substance use should be seen as primary disorders and treated simultaneously!** Family members are advised to pursue integrated mental health and problematic substance use services for their family member. Treatment should emphasize strategies to solve existing alcohol or drug use (e.g., professional help; self-help groups; avoiding problem environments; learning to say “no”). It should also help individuals to understand the advantages of abstaining from alcohol and street drugs and use motivational techniques to promote a healthy lifestyle.

## Chapter 6

# Dealing With Crisis Situations

**It is always important to take appropriate action and call for help from a qualified individual, such as a crisis mental health professional, the police, emergency medical service if someone is at risk of harming themselves or someone else. This is so even if the person does not want help at that time.**

### Do's & Don'ts

During a crisis episode related to schizophrenia or psychosis, a person will exhibit some or all of the following symptoms: hallucinations, delusions, thought disorder, and disturbances in behavior and emotions. Families who have been through these psychotic episodes warn that no amount of preparation can fully protect you from the shock, panic, and sickening dread you will feel when someone experiences psychosis. It is important to understand that the person may be as terrified as you are by what is happening: voices may be giving life-threatening commands; snakes may be crawling on the window; poisonous fumes may be filling the room. You must get medical help for the individual as quickly as possible, and this could mean hospitalization. If he/she has been receiving medical help, phone the doctor or psychiatrist for advice. Otherwise, try to get him/her to a mental health crisis clinic or an emergency department of a hospital. If there is a Mobile Crisis Team or a Crisis Hotline available in your community, you may also call them for help.

#### Do's

Your main task is to de-escalate the situation. Here are some things that can help with that task:<sup>32</sup>

- Try to remain as calm as possible.
- Evaluate the risks, for example whether the person is at risk of harming themselves or others.
- Speak in a clear and concise manner. Use short and simple sentences.
- Speak quietly and use a comforting and non-threatening tone. Repeat things if necessary.
- Be patient. Let the person have time to process information and respond.
- Try to comply with any requests they have unless they are unsafe or unreasonable.
- Try to keep the person, yourself and others who may be around, safe. Make sure you have an exit accessible if the person seems agitated.

32 Workplace Strategies for Mental Health, Canada Life.  
<https://www.workplacestrategiesformentalhealth.com> 28 Jan 2021.

**It may also be helpful to:**

- Decrease other distractions; turn off the television, radio, etc.
- If other people are present, ask them to leave the room.
- Allow the person to have emotional and physical space. Don't stand over him/her or get too close or stare at them.

**Don't's**

- Do not dismiss, minimize or argue with the person about the content of the hallucinations or delusions and don't act alarmed or horrified by them. Listen in a non-judgemental manner.
- Do not laugh at the person's hallucinations or delusions.
- Don't shout. If the individual appears not to be listening to you, it may be because other voices are louder.
- Avoid patronizing, authoritative statements such as, "You are acting like a child," or "You'll do as I say, young lady." Don't threaten or challenge the person into acting out.
- Avoid continuous eye contact.
- Don't block the doorway.

It is far better, if possible, to have the person go to the crisis clinic or hospital voluntarily. You can start by asking the person how he or she would like to be helped. You can also suggest that you take the person to see a doctor or mental health professional. If you do not think he/she will listen to you, see if a friend that the individual trusts can talk the person into going. Some have found that presenting the person with a choice is more effective. "Will you go to the hospital with me, or would you prefer that John take you?" Such an approach may reduce the person's feeling of helplessness. Offering choice, no matter how small, provides some sense of being somewhat in control of the horrible situation in which persons find themselves.

However rare, be aware that a psychotic episode may involve violence. In such situations, there is no time to talk calmly to the person, or to phone the doctor or psychiatrist to ask for advice. Because the individual is in an altered state of reality, he/she may try to act out the hallucination – for example, shatter a window. Individuals may threaten to harm themselves, to hurt you or someone else, or to damage property. In such situations, you must do whatever is necessary to protect yourself and others (including the person) from physical harm. It may be that the wisest course is to leave the premises and immediately call for help. The alternative might be to secure him/her in a room while you phone or go for help. Such an action, however, is advisable only under extreme circumstances. Depending on the situation, it



may be unwise to drive the person to the hospital by yourself. In such charged situations, your only choices may be to phone a mental health crisis line/crisis response team, or the police. Keep in mind that the police (and a crisis response team) have authority under your provincial mental health laws to take the person to the hospital if he/she meets the criterion of the legislation.

Crisis situations are indeed taxing on your physical and emotional strength. The more you stay in control of your reactions, the better you will be able to cope, and to help the person at this crucial time. Remember, this period will pass!

## Calling 911

If your family member is unwilling to go to a mental health crisis clinic or hospital with you, you will need to call 911. When you call 911, explain to them that it is a mental health emergency, in case there is a mental health crisis team that may be able to respond. Briefly describe what your family member is doing – for example, if they are making threats, damaging property – and state that you need assistance to get him/her to a mental health crisis centre or a hospital. Make sure that the police know whether the person is armed, and whether or not there are accessible weapons in the home.

Families who have been through a crisis often found themselves hesitant to involve the police. They felt that they would be treating their relative as a criminal, and that they would be giving up and abandoning the person. However, in some situations there is no other choice. Some families discover that the statement, “I am calling the police,” calms their relative. One father said that the sight of the police uniform helped to diffuse the situation. But another father, disagreeing with this tactic, warned that because his daughter was paranoid, seeing a police officer in her home was like waving a red flag, and infuriated her further. Try to trust your instincts: you know the person best and have a better chance of judging how he/she may respond to different helpers. The traumatic effect for some of being “picked up by the police” should not be underestimated, however there are circumstances where it may be the only option.

It is possible that police may be teamed up with a mental health professional to respond to a crisis call, but this is not always the case. When the police arrive, be prepared for a variety of responses.

It is important to note that some police officers are specially trained to know how to handle psychiatric emergencies. Some police officers have little knowledge of, or experience in, dealing with this sort of crisis. Some officers may be extremely sympathetic, while others may be quite apathetic. You might be asked by the police to lay a charge. Be sure you understand the implications of this action: ask the police what the charges are. Know too that your own attitude or emotional state may be a factor in conditioning police reaction. In your record, document everything that happens when you phone 911: note how long it took for someone to respond to your call; note the officers’ names and badge numbers; note briefly how they treated you, and how they handled the situation. Once in your home, the police will try to assess the situation and decide what should be done. While the police are present, you may have a chance to phone the person’s doctor or psychiatrist to ask for advice. Inform the police if you have been advised by the doctor to take the person to a particular hospital.

After the crisis team and/or police have the information they need, they may take the person to a hospital emergency department. If the person refuses to go the hospital, the police have the authority under provincial mental health legislation to force him/her to go. The specific criteria the police officer uses to determine if a compulsory examination is warranted may differ from province to province. Essentially all legislation provides

that if the person appears to have a mental disorder and appears to present an actual or potential danger, either to him/herself or others, then the police may enforce a visit to the hospital. It is the responsibility of the police to report all relevant information to the attending physician. They are usually required by law to stay with the individual until an assessment is carried out. If you have not been able to go with the police to the hospital – although you should go if at all possible — be sure to follow up with the attending police officers. We also recommend that you speak directly to the attending physician. You may need to ask the emergency head nurse for help to reach the doctor. You also need to find out if the person has been admitted to the hospital, and whether or not treatment is being given. Find out the name of the admitting physician. Be sure to keep a record of all this information.

## Emergency Planning

Contributing families recommend strongly that you have an emergency plan in place for crisis episodes. For example:

- Keep a list of phone numbers handy for: the police, the doctor, the psychiatrist, and an emergency centre for psychiatric admissions. Find out if there is a crisis hotline in your region or a mobile crisis team.
- Ask the person's doctor or psychiatrist (ahead of time) which hospital (if necessary) to go to in case of an emergency.
- Know which family members, friends, and caregivers the individual might trust most in an emergency.
- Find out whom you can phone for support at any time of the day or night.
- If applicable, decide who will take care of other children.
- Consider explaining the situation ahead of time to your local mental health crisis team and your local police department to make them aware of your circumstances and get their advice on emergency responses.
- Know that the crisis situation may be less frightening to the person if the emergency procedure has been explained and is anticipated.

In crisis situations, you expect the individual to be admitted, if not voluntarily, then involuntarily. However, this may not be the case. He/she may refuse to be admitted, and the medical examination may not result in an

assessment that would support involuntary admission. If you are not able to be at the hospital, it is possible that the person may be allowed to leave before you are notified. If he/she is not admitted involuntarily, yet admission is recommended, families who have been through the experience strongly suggest that you consider telling your family member that returning home is not an option. Without the alternative of returning home, the hospital may appear to be a safe haven to the person. It isn't always easy to make decisions during a crisis. If you've already experienced a crisis, make plans so you will be prepared in case it happens again.



## Chapter 7

# Acute Episodes and Hospitalization

If persons have an acute flare-up of symptoms, short-term treatment strategies are needed. Whether or not they need admission to hospital, you and the treatment team will need to consider immediate safety, a full assessment, and short-term treatment measures. Once the acute phase has passed, individuals, family and treatment staff can consider medium and long-term treatments, services and supports.

### Hospitalization

When the person has an acute psychotic episode, hospitalization may be necessary — depending on the nature of the episode. Sometimes, an episode is mild or moderate in severity, and does not require the security or level of observation, and intensity of treatment, provided by a hospital. In these cases, a Crisis Stabilization Unit or intensive outpatient treatment can achieve all that would be accomplished by admission to hospital. When a psychotic episode is more severe, admission may be necessary. Admission depends on various factors, including the range of alternative community based and outpatient services, the ability of the person to function at home, and the availability of support from community services, friends, family, and caregivers.

It is always preferable for a person to voluntarily consent to being admitted to hospital rather than being admitted involuntarily. Voluntary admission is not possible, however, if the person is not mentally capable of consenting to the admission. Sometimes there are potential problems involving safety that preclude voluntary admission. In these cases, involuntary admission to hospital is then usually the only option. Involuntary admission criteria are set out in your provincial mental health legislation. The specifics may differ between provinces, but all mental health laws require that the person have a mental disorder, and likely to harm him/herself or someone else or likely to suffer significant mental or physical deterioration.

In most jurisdictions an involuntary admission to hospital can be made when one physician, after examining the person, issues a certificate under the Mental Health Act. This authorizes the person's admission to hospital for a short time (e.g., one to three days) for examination and emergency treatment. A second medical certificate must be issued in hospital in order for the person to remain in hospital for longer periods. If the person refuses to see a physician, it may be possible for a judge to order the person to have a compulsory examination, which can lead to involuntary admission. The police may also be able to take the person to a physician for an examination. The physician may then issue a certificate for the person to be admitted for an inpatient examination period at the hospital.

If the person is admitted to hospital, the first priority is to ensure his/her safety. To do so, hospital staff will need to know his/her medical and psychiatric history including a complete history of medication, allergic reactions and if any substance use. If the immediate safety of the person is at risk, he/she will likely be medicated promptly. For agitated or aggressive patients, short-acting medicines are sometimes needed. These can be either antipsychotics, or benzodiazepines (e.g. Valium or Ativan). It is best if the individual agrees to take oral medication, giving him/her a sense of participation in resolving the crisis. However, the physician can also suggest injectable medicine.

Once safety is established, a full assessment can begin. The first step is often a thorough psychiatric examination, and a psychosocial assessment regarding the person's entire life circumstances. Family members or close friends can provide crucial information, both about the circumstances leading up to the current episode, and about relevant personal history. A complete physical check-up, which can include blood and urine samples, is usually arranged at this stage. When admitted to a hospital, the staff may suggest that the family take the individual's valuables and money home, or they may be kept for safekeeping until discharge. Some families suggest that it is worth making a list of these and any items of clothing and other personal effects that the person takes to the hospital. This can be helpful to hospital staff and is a safeguard against subsequent misunderstandings.

The results of a full assessment should provide or confirm a diagnosis, and a preliminary treatment plan. For individuals remaining in hospital, that plan almost always includes daily medication. It should also include good nursing care, and emotional support provided by hospital staff. Regardless of the severity of the acute episode, hospital staff are expected to treat the person with respect and sensitivity. In the first few days of the acute phase of illness, it is the medication together with a therapeutic environment that makes up the bulk of treatment efforts.

Once medication and support are successful in reducing symptom severity, more insight-oriented activities can be added to the treatment plan. A number of activities can be added in the later stages of hospitalization (or at home if not hospitalized) once the most severe part of the episode is over.

The person can:

- Learn more about the illness
- If it was a relapse, try to figure out what may have triggered it and create a relapse prevention plan
- Negotiate a more long-term treatment plan with local mental health services
- Plan for a gradual return to work or school, after the leave of absence
- Begin to resume recreational activities
- Create an Advanced Psychiatric Directive for use when in crisis again.

Not every individual will be able to begin rehabilitation activities after a few weeks in hospital; many will need a longer stabilization phase. In the short-term, however, it is crucial that family members and caregivers build a constructive relationship with the treatment team.

## Building Relations with Health Professionals

One of the strongest findings in the research literature is that the regular involvement of family members and caregivers has an important positive effect on the life of persons living with schizophrenia. Regular involvement can begin at the assessment stage and continue throughout the acute and long-term stages of treatment, rehabilitation, and recovery. Your family member will, of course, have the say as to the degree of involvement you, as caregivers, will have in his or her recovery plan.

Below are some suggestions that can help you build a constructive relationship with hospital staff. The nature of your involvement during outpatient care will be discussed in a later section.

Your main goal during the treatment of a person's acute episode, whether in or out of hospital, is to establish effective communications with mental health professionals. When a person's family arrives at the hospital, especially when it is a first hospitalization, they are typically in a state of panic and shock. They want to know what is going on and what will happen next. They may not fully understand hospital procedures. Experienced families advise that it is important to remember your objective – to get appropriate help for your family member. They suggest a number of things you can do that will assist you in your efforts.

- Keep a record of everything while you still remember. List the questions you ask, the responses you're given and the names and phone numbers of the staff attending the person. Keep a record of the treatment given, including dates and times. Keep copies of anything you mail, and all notices and letters you receive from the hospital.
- Recognize that hospital staff and other health care professionals are there to help your family member. Make it clear that you understand that this is their prime responsibility, and that you are ready to do all you can to help them. Try to establish a partnership type of relationship between the psychiatrist, your family member, and yourself.
- Find out the names of the assigned psychiatrist, psychiatric nurse, and social worker. These are the people responsible for the treatment of your family member. You should be able to communicate with them if you have any questions or concerns.
- Learn about "release of information" forms or "disclosing personal health information" forms and what you are able to negotiate in terms of release of information.
- Be polite and assertive when talking to hospital staff. Use sentences such as, "Please help me," and "Please tell me where I can get information about..."
- Ask for a meeting with the assigned psychiatrist and social worker. Try to get to know them at the first meeting. Come prepared with a written list of questions. Let them know of your willingness to provide them with information about the person.



- Keep all conversations to the point. Ask for specific information. Some sample questions to ask the health care professionals are: What specific symptoms are you most concerned about? What do these indicate? How do you monitor them? What is the medication being given? How often? How much? Are there any side effects? What can be done about them?

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- Ask for clarification if you don't understand. Do not settle for jargon and vague information.

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- If the psychiatrist is too busy to talk to you, write out what you want to ask or say (in point form), and deliver (or email) the letter to his/her office.

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- If you phone to speak to someone who is not available, leave your name, your family member's name, and your number. Let them know the best times to call and ask them to leave information on your voice mail/answering machine if you aren't available.

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- Understand that health care staff are bound by confidentiality legislation. Unless your family member agrees to the sharing of his or her personal health information, it may be difficult for hospital staff to share information with you.

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- Consider having a friend or relative who is less directly involved come with you to meetings at the hospital. This person's role is to remain calm and reasonable should you become overwhelmed by emotion and frustration.

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- If you feel that your family member is being badly treated or is not receiving adequate care, and if polite approaches to the treatment team fail to resolve your concerns, you may wish to raise the matter with the social worker assigned to your family member or another person in charge. If this does not resolve the problem, you should write a letter and send it to the head of the hospital, or clinic. Be specific and brief in your letters.

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- Consider sending copies to the College of Physicians, Nursing, etc., if a situation arises in which you think it is an appropriate action.

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- Become a member of a local mental health or self-help organization. When all else fails, help from your provincial Schizophrenia Society or similar organization may possibly allow you to cut through hospital red tape and get answers.

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- Families who have had loved ones hospitalized warn that you should avoid actions that are not helpful.

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- Do not be rude. Do not let your fears and anxieties turn into anger. Do not approach the situation with a chip on your shoulder. The illness is the enemy, not the hospital staff.

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- Do not bother the staff with unnecessary special requests and excessive demands.

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- Do not make long, detail-filled telephone calls to the staff.

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- Do not allow yourself to be intimidated. Do not try to intimidate the staff.

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- Do not come late to appointments. If your appointments are cancelled repeatedly, put your concerns in writing.

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**Some tips on relating to the hospitalized person include:**

- Familiarize yourself with the routines of the ward.

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- Discuss what is happening with the person. Tell him/her about your efforts to help the situation.

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- Don't spend every day/all day, with the individual while he/she is in the hospital as your continual presence may interfere with the treatment process.

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- Respect the individual's wishes. If, for example, he/she seems upset by long family visits, make your visits brief and share them with other loved ones and friends.

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- Do not undercut staff or criticize specific staff members in front of the person.

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- Do not criticize training or activity programs in front of the individual.

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- Consider the person's complaints realistically. Act on those complaints that appear to be real rather than imagined.

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- Do all you can to make it clear to the person that this period of hospitalization is important for his/her health.

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- Try to convey an optimistic attitude, that things will get better and that the person will eventually leave the hospital and get on with his/her life.

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- Do not interpret everything about the person as being "the illness." Listen to how they understand what is going on with them without arguing.

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## Planning For Discharge

When the person is in the hospital, make sure the staff is aware of your desire to be involved in discharge planning. The discharge plan (sometimes called a recovery plan or a treatment plan) should begin as soon as possible following admittance. An individual's discharge plan may involve a number of people. Overall coordination of the plan, however, should be the responsibility of one person: a designated nurse, case manager, team leader, social worker, or other caregiver (depending on the hospital's processes and systems). It is important to find out who the person in charge is and direct your communications to him/her. Families suggest that a letter or email to this person is often more effective than a telephone call. An example of such a letter/email would be:

Thank you for the care you are giving my son/daughter, \_\_\_\_\_.  
 (If you can, give a specific example of help that has been particularly important to him/her.) I would like to meet with you to learn about and discuss options for discharge and continuing care and recovery.

Families also suggest that you have a note put on the individual's file to remind staff to alert you about approaching discharge. Hospitals are busy places, and the staff may forget to keep you informed. In most

provinces and territories, a social worker will be assigned to the person during the hospital stay. This person can advise you and the individual about the social services and community programs available upon discharge. He/she can also help advise whether it is best for the person to return home, or if alternative housing should be considered. It is important to involve family members, including brothers or sisters, in meetings with the social worker and the individual when this is possible and appropriate. Be sure to

Keep in mind that you have your limitations: you may not be able to be all things to the person.

consult with the psychiatrist on all plans for the person. If the individual has had multiple hospital admissions because he/she does not take treatment in the community, assisted treatment mechanisms are provided by provincial mental health legislation and should be discussed with the psychiatrist. Examples of assisted treatment mechanisms include conditional leave from hospital and community treatment orders (again, these may differ from province to province). It is important that the advice of both the social worker and the psychiatrist are in sync.

You will likely have a number of concerns about what will happen when a person with schizophrenia returns home after discharge from the hospital. You need to know how to best support him/her, what to say, what expectations are realistic, and how to support the person's sense of purpose and hope for recovery. Families who contributed to this book recommend that you should strive to help the person to become as independent as possible and to achieve their greatest potential. The person's ability to do so will depend a great deal upon what he/she was like before becoming ill. The age of onset of the illness may also be a factor in how the person can cope. Normally, the more skills and social development acquired before the illness, the greater the person's ability to function. But it is important to remember that recovery is possible!

The process of helping the person achieve greater independence, connection to community, and recovery really starts upon discharge from the hospital. Recognize that it will involve much trial and error. Families who have been through this experience urge you to keep the process in perspective with schizophrenia as with any other major illness – heart disease, cancer, diabetes – where the person and the family must learn to cope with new and more demanding circumstances. For the individual, diet, exercise, work and social obligations will represent a considerable challenge. Taking medication regularly and attending therapy sessions or a self-help group may need to become part of the person's lifestyle for the first time. Family members and friends need to learn the most effective ways of speaking to, and behaving toward, the person who is ill.

One of the first things you should do before the person returns home is to think about basic safety precautions. Although you may be hopeful of a permanent or long-term remission in the future, the course to recovery from schizophrenia is often accompanied by symptoms and not without setbacks; at some periods, safety may be the priority concern. If the person is disoriented, depressed, or begins to talk of suicide, you need to be aware of the potential dangers of matches, drugs, poisons, sharp objects and so on. Many people with mental illness are heavy smokers. You should decide ahead of time what sort of house rules you want with regard to smoking. Be sure the person understands the risks involved of driving when tired or sleepy from medication.



A Discharge Checklist can be a useful guide to ensure that the seven main areas essential to a good discharge plan (sometimes called a recovery plan or a treatment plan) are covered:

- 1.** Medication information should be listed on the discharge form as soon as it is known. Instructions regarding dosage, times, and any special requirements such as the need to take the drugs with food or milk, should be noted. This information usually comes from the attending doctor(s), nurse(s), or hospital pharmacist.

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- 2.** Living arrangements must be determined ahead of time. If the person is not going to live with his/her family, the type of residence suitable to his/her capabilities needs to be decided. Some boarding homes provide medication supervision, while others expect clients to be responsible for their own medication. Ensure that the person resides in an environment where he/she will obtain the support needed to remain in the community, thus avoiding recurrent hospitalization.

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- 3.** Follow-up community support is necessary for all people with schizophrenia. In addition to continuity of medical care, some people may require referrals to day programs, support groups, or alcohol and other problematic substance use programs, along with health professionals such as dentists, eye doctors, gynecologists, etc.

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- 4.** Most people with schizophrenia must relearn social skills and other basic life skills to realize a good recovery. All psychosocial rehabilitation options should be included on the discharge planning form.

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- 5.** Before the person is discharged, it is important that he/she understands how to recognize the symptoms of schizophrenia and develop recovery goals. It may also be appropriate to educate the person on birth control and sexually transmitted diseases.

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- 6.** Arrangements for transportation to therapy appointments and activity programs should be part of the discharge plan.

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- 7.** If the person requires financial assistance, the treatment team should be notified in order to ensure the appropriate applications are filed before discharge.

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## Chapter 8 Treatment

### Treatment During the Stabilization Phase

Individuals should leave the hospital with a treatment/recovery plan that will both minimize symptoms and maximize their quality of life. Such a plan will almost always include taking antipsychotic medication for an extended period of time. Beyond that key element, the treatment and recovery plan for the stabilization phase

Discharge from hospital means only that the person's treatment has been properly started, and that he/she can safely continue treatment as an outpatient. It does not mean that treatment is complete.

should reflect persons' needs, as well as their wishes or preferences as they begin their recovery journey. Your outpatient or mental health service may offer individual or group psychotherapy, life skills training, physical activities, and occupational therapy. Outpatient staff can also provide help with respect to government social services or disability pensions, and housing support programs. Family education programs are often separate from activities that involve the person recovering from illness and provide help on how to understand and support the person.

During the stabilization phase, individuals may still be fragile, both neurochemically and psychologically. Symptoms of moderate severity may still be present, as medications can take many weeks or even

months to reduce symptoms. As such, the best treatment activities may be more basic and gentle than they need to be in the later, stable phase. It may be better to have more structured and less complex treatment activities. Complicated psychosocial treatments, such as those described in the Stable Phase section below, can begin when symptoms have lessened, and more complex cognitive functions have had time to recover.

Sometimes programs offer outpatient treatment services which are grouped together into a Day Program, where individuals make a commitment to a block of group activities for several days per week. Other services allow individuals to pick and choose from groups, so that their activities more closely reflect their needs. Individual counseling may or may not be part of these Day Programs. Outpatient treatment services are not standardized across the country, due to variances in resources of health regions (even non-existent in some regions). You should however be able to obtain a list of outpatient services from your local hospital, your provincial Schizophrenia Society or similar organization, or the Canadian Mental Health Association in your area.

## You are Important to the Person's Well Being

The following suggestions may help you understand how to behave around the individual during the early stages of treatment. Note that what works for one individual may not work for another. Ask the attending doctor(s), social worker(s), and other health professionals which strategies are best suited following discharge from the hospital, or after an acute episode. They can guide you on the matter of interacting with your family member and whether or how hard you should push him/her to do chores, get a job, attend school, or participate in other therapeutic programs.

- Speak with a slow-paced and low-toned voice. Use short, simple sentences to avoid confusion. If necessary, repeat statements and questions using the same words.

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- Explain clearly what you are doing, and why you are doing it. For example, "I am putting your clean clothes in your closet. You can choose which clothes you want to wear today".

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- Establish a structured and regular daily routine. Be predictable. Be consistent. Do not say you will do something and then change your mind.

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- Offer praise continually. If the individual combs his/her hair or shaves after three days of not doing so, comment on how attractive he/she looks.

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- Avoid over-stimulation. Reduce stress and tension. For example, eating meals with the family may be too overwhelming at first.

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- Encourage, but never force, the person to take his/her medication and to keep all medical appointments.

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- Keep an optimistic attitude as much as possible; research suggests this can influence the attitude of the person with the illness<sup>33</sup>

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- Share the person's hope that things will get better.

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With time, the person may show signs of being able to handle more responsibility. Keeping in mind the above guidelines for behaviour, here are some strategies for the next steps (once the initial adjustment period is over).

- Discuss with the person how he/she feels about doing more things.

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- Begin with mastery of self-care tasks: personal hygiene, getting dressed, and eating scheduled meals.

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- Assign household responsibilities that are within the person's abilities. Watch to see if the person prefers to work alone or with others. For example, he/she may like to wash dishes, but prefer not to have someone beside him/her drying the dishes.

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- Encourage, but never push, the individual to be part of social gatherings if appropriate. One or two friends over for dinner may be manageable, whereas an all-day gathering of the clan – for example, a wedding – may cause undue stress and frustration.

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- Discuss plans with the person for an outing once a week. A drive and a walk in the country may be fun, whereas a trip to the city may be too noisy and tension filled. If the individual enjoys coffee and doughnuts, plan a break around going to the donut shop, rather than a restaurant where menu choices may be confusing.

33 Markowitz, F., Angell, B and Greenberg, JS. (2011) Stigma, Reflected Appraisals, and Recovery Outcomes in Mental Illness. *Social Psychology Quarterly*, June 2011 74: 144-165

- Do not be too inquisitive. Do not always ask questions such as, “What are you thinking about? Why are you doing that?” Talk simply about local or world events: “Did you hear about the new movie starring...”
- Understand that although it may be very difficult for the individual to have a conversation with you, he/she may enjoy your company in other ways. Consider watching television, listening to music, or playing cards. Talk about childhood events. Some people also appreciate being read to.
- Avoid constant, petty criticism. Identify the major behaviours and learn to deal with them in an honest, direct manner. For example, in many families, lack of personal hygiene is a source of frustration. But saying things like, “Why can’t you wash?” or “You smell awful,” does not have a positive effect in solving the problem. It is better to present the problem as your own. “I do not like the way you smell. I have a problem with the fact that you do not shower regularly. How can we work out an agreement that you will shower daily?”
- Be forgetful. Say something like, “I forgot the milk. Can you get it please?”
- Encourage the person to take responsibility. For example, leave instructions about starting dinner in case you are late getting home that night.
- Try to teach the person how to deal with stress in a socially acceptable manner. For example, if he/she is in a public place and begin to feel panicky, they can go to a washroom or another quiet place if there is one, until the feeling has passed.
- Remember that sometimes, family members are often the only friends the person has. So, try to be a friend; talk as a friend would. “I’d really like to see this movie. Would you come with me tonight?”
- If you are part of a faith community, encourage someone from that community to befriend the person. (Look for someone from his/her age group.)
- Always try to put yourself in the person’s shoes. Respect his/her feelings. Saying, “Don’t be silly. There’s nothing to be afraid of,” is not helpful. Allow the person to feel frightened by saying something like, “It’s all right if you feel afraid. Just sit here by me for a while.”
- Respect the person’s concerns about his/her illness. Often, individuals with schizophrenia ask their families not to go public – that is, not to become a public speaker or to give interviews on behalf of their support group. Although some families may feel they have a lot to offer in terms of helping others, most will decide to abide by the individual’s wishes.

## Treatment and Supports in the Stable Phase

In planning ongoing treatment and support for someone with schizophrenia, it is essential to have a strategy that integrates both pharmacological and psychosocial interventions. In this sense, treatment mirrors the causes of the illness itself: it is best to think of schizophrenia as a condition where excess levels of stress trigger a pre-existing vulnerability. That being the case, the individual will do best when treatments target both vulnerability and stress. To do that, a combination of medicine and psychosocial interventions is used. Medicine raises the

“...A good family environment can be a major factor in improving the chance of stabilizing the illness and preventing serious relapses.”

– Dr. Ian Falloon, et al.

vulnerability threshold, e.g., the amount of stress a person can manage before feeling distressed. Psychosocial approaches, on the other hand, allow people to manage the kind and amount of stressors, so they don't become excessive. The psychosocial approaches outlined below include education, family intervention, stress management, life-skills training, and case management. First, though, let's become familiar with medication issues.

## Medication

Medication is a key cornerstone of treatment for schizophrenia. Once the acute stage of a psychotic episode has passed, most people with schizophrenia will take medicine for a long time. This is because vulnerability to psychosis doesn't go away, even though some or all of the symptoms do. Many studies have noted an association between "poor or inconsistent adherence to antipsychotic medications and relapse in individuals with schizophrenia".<sup>34</sup>

Relapse rates are further reduced by adding other treatment measures (as described in the Psychosocial Treatment section). Medication use, for how long and which ones, should always be a point of discussion with the treatment team. Medication has a significant preventive role in the long run, as well as a symptom-relief role in the short run.

Specialists in schizophrenia describe antipsychotic medications as being either first-generation or second-generation. Second-generation medications provide effective symptom relief and have fewer side effects than first-generation medications. The medication treatment for people with schizophrenia is unique to each person. It will depend on a number of factors including severity of symptoms, overall health, presence of other conditions, etc. Finding the right balance of medications – whether they are first- or second-generation – that provides ongoing symptom relief will take some time.

Second-generation antipsychotics are recommended as first-line treatment because they are more effective than first-generation antipsychotics for treating negative, cognitive and depressive symptoms.

Each drug has two names: the generic or chemical name (first column below), and the brand name used by the pharmaceutical company that manufactures it (second column below). The table below lists some of the more common antipsychotic medicines available in Canada, however financial coverage of medication may vary between provinces.



34 Alphs, Larry. Factors associated with relapse in schizophrenia despite adherence to long-acting injectable antipsychotic therapy. *International Clinical Psychopharmacology*, July 2016, Volume 31, Issue 4, 204-209.

## Older or First Generation Antipsychotics

Chemical Name	Generic Name
CHLORPROMAZINE	(once marketed as Largactil)
FLUPENTHIXOL	Fluanxol
AFLUPHENAZINE	Modecate
ZUCLOPENTHIXOL	Clopixol
LOXAPINE	Loxapac
HALOPERIDOL	Haldol
PIMOZIDE	Orap
TRIFLUOPERAZINE	Stelazine

## Newer or Second Generation Antipsychotics

Chemical Name	Generic Name
CLOZAPINE	Clozaril
OLANZAPINE	Zyprexa
RISPERIDONE	Risperdal
RISPERIDONE	Risperdal Consta (IM)
PALIPERIDONE	Invega
PALIPERIDONE (PALMITATE)	Sustenna (IM)
QUETIAPINE	Seroquel
ARIPIPRAZOLE	Abilify
ZIPRASIDONE	Zeldox

IM = Intramuscular Injection.

While there are more common side effects for any medication, some of the antipsychotics may have more particular ones. Most people do not experience major side effects – though the treatment team will be asking and watching for any. Each medication has about 15-20 years of development and clinical trials before it gets approved to market and would not come to market unless the regulating bodies feel it is safe. Never hesitate in asking the treatment team about side effects of medications.

There are some excellent public websites that explain in more detail antipsychotic medication, their use, and potential side effects. Please ensure that information obtained over the internet comes from a reputable source.

The dosage for each individual depends on a wide range of factors, including physical differences (such as sex, weight, metabolic rate), physical health, and the severity of the symptoms. There are two basic forms of administration. The most common is pills, taken by mouth. Some medicines are also available in liquid form. Oral medication requires consistent use to ensure a steady supply of medicine, every day, to the body. Some antipsychotics are available in an injectable form. A short-acting injectable drug can be used for rapid treatment, for example, when someone is extremely frightened or agitated. A longer-acting injectable form is used when a person can't or won't take oral medicine every day. This increases the options for people with schizophrenia that have difficulty taking medicine on a daily basis. A June 2003 issue of the American Journal of Psychiatry reported that Risperidone, the first atypical antipsychotic available in long-acting injectable form, is well tolerated and effective in schizophrenia. Since then, three new risperidone formulations have been developed that offer advantages over previously available risperidone-based long-acting injections.<sup>35</sup>

Most antipsychotic medications work equally well overall, although how a drug will work is highly individualized. No drug or type of drug works equally well for everyone who takes it. When the same drug is given to several individuals, "one-third will find that it works well; another third will find that the drug helps only with some

35 Clark, Ivan & Taylor, David. New Formulations of Risperidone: Role in the Management of Psychotic Disorders. CNS Drugs, May 2020, (34) 841-852.

symptoms; and the final third will find that it does not help at all".<sup>36</sup> For this reason, people may need to try different antipsychotics before finding the one that works best for them.

Clozapine is currently the best choice for people with schizophrenia who have had a poor response to other medications. However, it requires monitoring of white blood cell counts, so it is not typically the first choice for treatment.

Sometimes a physician may prescribe medicine for other symptoms, such as depression or anxiety. The individual might also need to take other medicines for general health problems. There are always implications for combining drugs and the psychiatry team should always be made aware if a family doctor is starting a new medication for a physical health problem. The prescribing doctor must be made aware of all medications, herbs, cold remedies, coffee, cigarettes, and street drugs the person is using.

New antipsychotic medicines continue to be developed, guided by research strategies that are increasingly complex. Unlike with older medicines, it is no longer sufficient to show simply that a new medicine is effective for the positive symptoms such as hallucinations and delusions. Pharmaceutical companies must also evaluate improvement in negative symptoms, as well as assess the cognitive effects. The safety and tolerability (e.g., side effects) of drugs is more carefully assessed than ever before. Individuals and their families are also interested in the degree to which quality of life is improved. Governments want to be assured that new medicines are cost-effective. Scientists want to know the mechanism and site of action of new medicines, in the hope that new understandings of the cause of schizophrenia will follow. Most of these issues are assessed over many years, and clinical trials now assess particular subgroups of people with schizophrenia. For example: people with severe, acute episodes; outpatients whose condition is stable but who only partially respond to their current medicine; those with and without accompanying depression; and those with little or no response to several medications. The research that guides the development of new medication is complex because our understanding of the illness is more complex.

## Side Effects of Antipsychotic Medicine

The most common reason people stop taking medication is that they don't understand its importance. The next most significant reason is the side effects of the medicines themselves which can interfere with one's personal goals. Side effects cause different levels of discomfort and vary from person to person. Side effects can be classified into short-term and persistent effects.

Short-term side effects appear relatively soon after starting a medication. They are highly dependent on the particular medicine and its dosage. Short-term side effects often go away by themselves after a few days of therapy. If they do not, an alternate medication may be prescribed by the attending physician. Side effects to watch for include:

- Muscle problems: stiffness, prolonged tension, or even muscle spasms
- Movement problems: shakiness or jerkiness
- Dry mouth, blurred vision, constipation, and difficulty urinating

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36 Centre for Addiction and Mental Health website, "Antipsychotic Medications". <https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/antipsychotic-medication>

- Drowsiness
- Lack of energy, sometimes called lethargy
- Restless legs (akathisia)
- Dizziness when sitting up or standing up quickly
- Increased appetite and weight gain leading potentially to diabetes
- Change in hormones, particularly those relating to sexuality and reproduction
- Decrease in libido
- Difficulty with erections, ejaculation, and reaching orgasm (if this problem persists, your physician may consider using another drug to solve it), and/or
- Loss of menstrual periods

Persistent side effects, on the other hand, are those that don't go away when the medicine is stopped. The most common of these is tardive dyskinesia (TD), the symptoms of which are involuntary muscle movements. TD most often appears in facial movements, e.g., of the mouth, tongue, and lips. Sometimes it appears as jerky movements of the limbs, or other muscles. The risk of TD increases with age, and with the length of time a person has taken the TD-triggering medicine. Sometimes, persons with schizophrenia are not so much bothered by the side effects themselves but are embarrassed by them when they are around other people. For example, they are embarrassed by involuntary movements, or don't wish to explain to others why they have less interest or energy than they used to have. In this case, support from family and friends can be invaluable.

An acute, life-threatening side effect known as neuroleptic malignant syndrome (NMS) can occur when using an antipsychotic, especially early in the treatment process, or if dosage levels are rapidly increased. It may appear when an antipsychotic medication is used in combination with other drugs. Rigidity, hyperthermia, delirium, and autonomic instability are indicators of NMS. If these symptoms appear, a physician will order all medication stopped, and will likely hospitalize the person in order to establish supportive treatment and a future course of therapy.

Hyperprolactinemia is a condition wherein the levels of serum prolactin in the body are elevated. The most significant result of this condition is a deficiency in estrogen or testosterone (hypogonadism). Disturbances of the menstrual cycle and an ovulatory cycle may result; fertility may be impaired; and sexual dysfunction may be caused or exacerbated. As well, loss of estrogen makes women vulnerable to osteoporosis, cardiovascular problems, and dementia. If this side effect occurs, prolactin levels should be monitored by the doctor, but treatment of schizophrenia should remain the priority. The physician may combat the problem by reducing the medication dosage, by changing to a different type of antipsychotic, or by prescribing additional drug treatments. Females should be aware that decreasing serum prolactin levels in the body (to counter hyperprolactinemia) could increase chances of conception.

A common complaint about antipsychotic medication is sudden weight gain. Some antipsychotics cause more gain weight than others. Adding another medication to combat this problem may help, but this strategy is still in experimental stage. The key to managing weight gain is having a healthy lifestyle that includes good dietary habits. For more information on this subject, please refer to Chapter 9, Medical Comorbidity of Schizophrenia.

It is important that individuals and their family members understand as much as possible about side effects. This knowledge can prevent many misunderstandings – for example, you will not mistake lethargy for laziness, or become frightened by tremors, and you will be able to provide valuable information to the attending physician. As a caregiver, your observations provide the treatment team with critical information, and it is important to document all you can about how the person is responding to the prescribed medication. For more information about side effects, you can consult your pharmacist.

The Centre for Addiction and Mental Health suggests the following to help control possible side-effects, which you can encourage your family member to do:

- Regularly exercise and eat a low-fat, low-sugar, high-fibre diet to help prevent weight gain and constipation
- Use sugarless candy or gum, drinking water, and brush teeth regularly to increase salivation and ease dry mouth
- Get up slowly from a sitting or lying position to help prevent dizziness.

Remember these general principles of drug therapy:

- Antipsychotic drugs are, for the most part, safe drugs; however, they may cause multiple side effects that can have an adverse impact on the person's ability and willingness to adhere to treatment.
- Side effects are a cost of antipsychotic treatment that must be monitored throughout treatment.
- Side effects are not constant over the course of treatment; some (for example, acute stiffness) are more likely to be short term, and others (for example, tardive dyskinesia) to be longer term.
- The person's own perception of the severity and importance of a side effect is a crucial component of side effect evaluation. Do not downplay the person's experience with side effects.
- Discuss the issue of side effects with the prescribing doctor.

## Psychosocial Interventions

Following an acute episode of psychosis and diagnosis of schizophrenia, your family member will likely need help adjusting to life with this disorder, much like someone who was just diagnosed with diabetes has to adjust and become knowledgeable in how to stay healthy. For individuals with schizophrenia, coping with school, a job, living independently, and even caring for themselves can generally be achieved with medication, and psychosocial treatment (may also be referred to as psychosocial intervention or rehabilitation). Psychosocial intervention can consist of one-on-one counseling or training, group support, activity programs, and/or daily monitoring and communication with caregivers.

The best strategies are those that integrate medicine with psychosocial interventions. There is strong evidence that psychosocial interventions improve outcomes for adults with schizophrenia.<sup>37</sup> By combining psychosocial

37 Norman, Ross et al. Canadian Treatment Guidelines on Psychosocial Treatment of Schizophrenia in Adults, *The Canadian Journal of Psychiatry*, 2017 Sep; 62 (9):617-623.

approaches with good medication practices, the person will reduce the need for readmission to hospital, reduce the severity of his/her symptoms, and be less distressed by remaining symptoms. Adding psychosocial interventions increases work and school functioning, improves quality of life, and provides needed support to people and their families. The effect of adding a psychosocial component to a recovery plan is not trivial. There is further evidence to show that combining medicine, family-based treatments, and social skills training can reduce the relapse rates even more.

In an illness with lifelong vulnerability, the most important treatment component is a therapeutic alliance between the person, the treatment team, and family members. Listening to the person's concerns and life goals will help family members develop empathy as well as a special rapport with the person – two critical components of a successful recovery plan.

Persons with schizophrenia should persistently try to set recovery goals, and realistically assess progress on a regular basis. The intensity of psychosocial interventions should reflect the amount of help needed to make progress towards their goals.

The most intensive interventions are those in the first year after an acute episode of psychosis. For many individuals, the intensity can be reduced over time. Others, however, will continue to need frequent monitoring, crisis intervention (including after-hours services), and an intense level of service on an ongoing basis.

All recovery plans should include a relapse prevention/crisis response plan. The person, like most people, will get distressed from time to time. However, if that normal distress goes on too long, or becomes too severe, it may develop into an episode of psychosis. It is therefore important to learn to recognize the early warning signs of psychosis/relapse, and to respond without delay to reduce the distress. This is best accomplished if the early signs from previous episodes, and a crisis response plan, have been identified in advance.

The psychosocial treatment team can provide services that are not strictly related to treatment. For example, they can tell you how to obtain disability benefits. They can also help to arrange alternate housing if that is needed. They can support the individual in working toward goals related to recreation, school, volunteering, or work.

A minimum level of mental health services for a person with schizophrenia should include prompt access to a physician, early involvement of family members, provision of information about the illness to the person and his/her family, and provision of adequate housing and financial assistance. For the minority of individuals who relapse frequently, and whose needs strain the ability of family members and caregivers to provide support, intensive case management is often necessary.

Family interventions, supported employment programs, and cognitive-behavioural therapy are some of the most recommended psychosocial interventions for people with schizophrenia. Other types of interventions such as social skills training, and life skills training are also recommended under certain circumstances. As well, it is broadly agreed upon that all individuals and families should be provided with psychoeducation about schizophrenia and its treatment.<sup>38</sup>

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38 Norman, Ross et al. Canadian Treatment Guidelines on Psychosocial Treatment of Schizophrenia in Adults. The Canadian Journal of Psychiatry, July 13, 2017.

## Psychoeducation

As we learned in Chapter 5, people with schizophrenia (and their families) need to understand the basic issues about the causes of the illness, as well as the various treatment strategies for it. Individuals do much better when they understand their own experiences in terms of the various features of the illness, and how their specific treatment and recovery plan will reduce their symptoms and help them achieve their goals. They need to know how the illness may complicate their problem-solving abilities, how to cope with stressors, and how schizophrenia may affect their plans for the future. They also need to know that their own perspective will be heard and respected, and that the treatments, services and supports available to them will help them along the path to attaining their personal goals and finding their own meaning in life outside of the illness.

Education can be provided on a group or individual basis; teaching packages with designed curriculum modules are available for use with groups. As with any education program, regular information sessions with interactive discussions are much more powerful than simply reading a book or attending a single lecture.

## Family Involvement

A review of 25 studies examining family interventions found a 20% reduction of relapse when involving the relatives in the treatment during maintenance phase.<sup>39</sup>

Psychosocial treatment guidelines now advise the inclusion of family members right from the beginning, since they are usually the primary source of support for people with schizophrenia. At the very least, this means consulting the family in the assessment process, and considering the family perspective in preparing the recovery and treatment plan. For the sake of the person, as well as family members themselves, it is crucial that a working alliance develop between the treatment team and the family. Involving the family also means providing psychosocial education about the illness. This basic information is usually presented in several sessions and can be provided either to individual families or in a group format. Group sessions are offered by hospitals (or clinic staff), local schizophrenia society groups, the Canadian Mental Health Association, or other family associations.

Where family members are able, and when their family member gives consent, they can also become directly involved in the treatment of the affected individual. In so doing, course and outcome are dramatically improved: relapse rates, which are cut in half by good medication practices, can be further cut in half if the family acquires appropriate information and skills related to the pursuit of good health. Family-based treatment usually includes:

- Helping family members develop effective ways of coping with this difficult illness
- Understanding the recovery and its process
- Improvement of communication skills
- Relapse prevention strategies, including the identification of early warning signs
- Stress management training, and
- Ways to provide support to each other during times of crisis

Many controlled research studies have shown that these treatments help all kinds of families and people, not

39 Bighelli, Irene et al. Psychosocial treatments for relapse prevention in schizophrenia: study protocol for a systematic review and network meta-analysis of randomised evidence. *BMJ Journals*, Volume 10, Issue 3

Other components can be added, depending on the needs of the person and family. A home visit often helps to build trust and helps the clinical staff to become familiar with the person's circumstances. Similarly, the needs of siblings are sometimes considered as part of the treatment plan. In light of the diverse needs of families, these issues must be addressed specifically and individually.

just those experiencing friction or frustration. As one of the best practices in schizophrenia, family involvement in treatment and recovery can now be considered the default option. That is, it should be part of the normal course of psychosocial intervention, unless there is a compelling reason not to do so.

### **Supported Employment Programs**

Employment is seen as a realistic goal for the majority of people with schizophrenia. For many people with schizophrenia, being employed signifies a return to a "normal" life and a part of their recovery. It helps to boost their self-esteem, helps them to gain meaningful involvement in society, and reduces to some degree the self-stigma of being a "mental patient".<sup>40</sup>

Supported employment, and in particular the Individual Placement and Support (IPS) model, most successfully uses an approach that includes a rapid job search based on the individual's choices of jobs that match their interest and skills and couples that with individualized job development. A mental health and employment team would facilitate the job finding and would provide ongoing supports as they are needed.<sup>41</sup>

For over 20 years, IPS supported employment has gained much support in the research which shows that most people with schizophrenia who want to work can in fact succeed in competitive employment.<sup>42</sup> Availability of supported employment options will vary across jurisdictions. It is important to check into what is offered by your local mental health and vocational services system.

### **Cognitive Behavioral Therapy**

Much evidence supports the immediate and long-term effectiveness of cognitive behavioral therapy in reducing both positive and negative symptoms of schizophrenia<sup>43</sup> when it is used adjunct to medication management.

40 Drake, Robert E. Employment and Schizophrenia: Three Innovative Approaches. *Schizophrenia Bulletin, The Journal of Psychoses and Related Disorders*, Oxford Academic, December 2017.

41 Drake, Robert E. Employment and Schizophrenia: Three Innovative Approaches. *Schizophrenia Bulletin, The Journal of Psychoses and Related Disorders*, Oxford Academic, December 2017.

42 Drake, Robert E. Individual placement and support services boost employment for people with serious mental illness, but funding is lacking. *Health Aff (Millwood)*. 2016; 35: 1098-1105.

43 Candida, Maristela, et al. Cognitive-behavioral therapy for schizophrenia: an overview on efficacy, recent trends and neurobiological findings. *Medical Express*, vol. 3 no. 5 Sept/Oct 2016.

Cognitive behavioral therapy is an evidence-based talk therapy that was first developed for anxiety and depression. It raises an individual's awareness of their own thoughts and behaviors and how those affect their emotions. Some research suggests that cognitive behavioral therapy is especially recommended for individuals "experiencing a recent onset of psychosis and those at risk of developing psychosis".<sup>44</sup>

### **Social Skills Training**

Social skills can range from basic skills such as making eye contact and giving compliments, to more complex issues such as making requests, giving feedback, and generally being more assertive. Social skills training is offered for several reasons. Firstly, the source of much stress in anyone's life is interpersonal. Learning communication skills will help most people reduce stress, and in the case of people with schizophrenia will also reduce the risk of relapse. Secondly, many people with schizophrenia are still in the process of maturing when they develop the illness. They may, therefore, be awkward or quite shy, since they haven't had the opportunity to acquire the social skills that are part of normal adolescent development. Alternatively, social skills that had been acquired may have been lost due to a lengthy illness. Finally, some people with schizophrenia find complex social situations to be overwhelming. This can be a feature of the illness itself, either in the acute or the stable phase.

By learning social skills, individuals can engage in as little or as much social activity as is good for them at any point in time. Not only do people feel better about, and do better in, social relationships, having good social skills lowers their stress levels and helps them to enjoy a better quality of life. Social skills training is now one of the best practices in psychosocial treatments for people with schizophrenia.

### **Life Skills Training**

Life skills training focuses on helping individuals learn to do things like manage money safely, manage household tasks, and self-care activities. There is no definitive determination as to whether life skills training is successful in the long term, but some independent studies have demonstrated that when life skills training occurs in an individual's natural setting, it does improve symptoms and quality of life.<sup>45</sup>

## **A Word on Case Management**

Case management is a general term used to describe the assessment, coordination and provision of various components of a treatment/recovery plan for people with serious mental illness. Over the years, there have been many different models of case management. Case managers are typically a social worker, a nurse, or another professional. Intensive case managers often have smaller caseloads and are typically involved with individuals who are at high risk of hospital readmission.

Most provinces and territories now provide intensive case management, often called Assertive Community Treatment (ACT), named after the first and best-known program). Here, a case manager will make weekly or even daily contact, to help plan meals, organize personal hygiene, supervise medication, and arrange visits to the dentist or family doctor. The case manager can also help the client attend a Club House program, or other

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44 Hardy, Kate. Cognitive Behavioral Therapy for Psychosis (Fact Sheet), Stratford University Department of Psychiatry and Behavioral Health.

45 Mair, H., & Bradshaw, T. (2004). Life Skills Training in Schizophrenia. *The British Journal of Occupational Therapy*, 67 (5), 217-224.

structured recreational activities. Case management is offered on an unlimited basis, with a 24-hour on-call capacity, and often is in place for many years. For more details on rehabilitation programs, refer to Chapter 12, Best Practices in Rehabilitation.

There is good evidence that “intensive case management is associated with increased contact with psychiatric care, increased independent living, and a lower likelihood of being admitted to hospital or dropping out of treatment for up to 12 months”.<sup>46</sup>

## Physical Illnesses

People with schizophrenia are less likely to recognize, or have recognized by others, a physical illness. It is, therefore, important that the attending physician ask specific questions to uncover any ailments. People with schizophrenia are subject to higher incidence of smoking, caffeine ingestion, alcohol or problematic substance use, self-neglect, obesity, heart disease, and diabetes – as a result they have a higher than normal mortality rate. They should be monitored on a regular basis for cardiovascular disease, diabetes, respiratory and genitourinary problems, and conditions involving the endocrine and neurological systems. The physician or psychiatrist with primary clinical responsibility for the person should monitor for these and other physical illnesses, along with psychiatric symptoms. They should also perform reassessments along with physical examinations every year.



46 NeuRA website, Australia. September 2020.

<https://library.neura.edu.au/schizophrenia/treatments/psychosocial/therapies-psychosocial/case-management/>

## Chapter 9

# Medical Comorbidity of Schizophrenia

### Definition and Facts About Comorbidity

Like all people, those who have schizophrenia can experience other illnesses. The term comorbidity refers to disorders, whether medical or psychiatric, that coexists with schizophrenia. Medical comorbidity can be associated with poorer physical health as a result of mental health problems. For example, some people with schizophrenia have an inactive lifestyle as a result of their disorder. This in turn can lead to obesity, and obesity leads to various health problems. So, the psychiatric disorder and medical problems can be interrelated.

As with the general population, susceptibility to physical health issues increases with age. However, people with schizophrenia have a reduced life expectancy than the general population, with one Canadian study reporting that people with schizophrenia die on average eight years younger than people without schizophrenia.<sup>47</sup> Some literature suggests that life expectancy is reduced by up to 10 to 20 years. A recent review of studies addressing mortality in schizophrenia in Europe suggests that the higher mortality rate is predominately due to “natural” causes (cardiovascular diseases and cancers) and suicides.<sup>48</sup>

This differential may be due to a number of reasons:<sup>49</sup>

- Late diagnosis and poor treatment or physical illness: A recent study suggests that people with schizophrenia “are not benefiting from public health and health care interventions to the same degree as individuals without schizophrenia”.<sup>50</sup>
- Metabolic side effects of antipsychotic medications
- Unhealthy lifestyle
- High risk of suicide

47 Gatov, Evgenia et al. Trends in standardized mortality among individuals with schizophrenia, 1993-2012: a population-based, repeated cross-sectional study CMAJ September 18, 2017.

48 Piotrowski, Patryk et al. Cause of mortality in schizophrenia: An updated review of European studies.

49 Laursen TM, Nordentoft M, Mortensen PB (2014). Excess early mortality in schizophrenia (PDF) . Annu Rev Clin Psychol. 2014;10:425-4

50 Kurdyak, Paul (CAMH). People with Schizophrenia are Dying Younger. Science News. September 18, 2017.

It is important that people with schizophrenia and their families learn about comorbid conditions and how to recognize their symptoms. While medical intervention cannot always reduce some of the factors that contribute to comorbidity, awareness by people with mental illness and their family members can help to support lifestyle adjustments, and to get treatment that can keep related illnesses under better control.

Psychiatrists specialize in mental health. Since schizophrenia is a serious and complicated disorder, psychiatrists tend to put their treatment focus on helping the person to recover from the mental disability it causes. While psychiatrists are medical doctors, their expertise in diagnosing and treating physical health issues is not the same as a family doctor or internal medicine specialist (the opposite being true as well, i.e. family doctors and internal medicine specialists do not have the expertise in diagnosing and treating mental health issues). Psychiatrists often refer to the family doctors if they suspect physical health issues, but it is important for individuals to see a family doctor on a regular basis for routine 'check ups', as with everyone. A treating psychiatrist may assume that the individual with schizophrenia is healthy unless otherwise informed, or that the person is being monitored for medical fitness by a physician. Many people, however, do not have a family doctor, and may have difficulty getting access to one. There are shortages of physicians in various communities across Canada, and many family physicians will not take new patients. Individuals may, therefore, be relying upon the treating psychiatrist for overall health care. If this is the case, it is important that the psychiatrist be aware of this situation and understands that the individual depends on him/her to monitor for illnesses associated with schizophrenia.

It is a good idea for family members of people with schizophrenia to consult with the person's psychiatrist on a regular basis (e.g., annually, semi-annually, or as required), especially if there are no other physicians involved in their loved one's care. (Please note that if the person is over the age of eighteen years, the family will require a written consent of the individual before the psychiatrist will discuss the case. For more information, please refer to Chapter 11: Coping with Schizophrenia, section on Confidentiality.) The family and person should discuss overall physical and mental health with the psychiatrist and/or the family doctor, and appropriate testing for physical and mental condition should be performed. Complete psychological and physical assessments should provide information that will give the individual and his/her family as clear a picture as possible on the health and medical status of the individual. It is essential that any existing medical problems be fully investigated. Many health problems can be treated (e.g., diabetes, obesity) either with adjustments in diet or lifestyle or medications. The sooner a problem is detected the more likely it can be controlled, and then the risk the concern poses to the health of the person is decreased.

In this book, the importance of family involvement with the treatment team is emphasized. Families and caregivers help the person with schizophrenia in the management of, and recovery from, schizophrenia. Family involvement is also important to the medical health of the individual. For example, the person may not report symptoms of conditions such as diabetes to the treating psychiatrist or physician.

Family members should educate themselves about the comorbid illnesses related to schizophrenia, so they can recognize their presence in the person, and help the person get treatment if and when necessary.

People with schizophrenia often lack the insight or awareness of their medical condition. They may also have trouble communicating their symptoms or may provide incorrect medical history to the treatment team. Individuals with schizophrenia may also be victims of a fragmented health care system. They may discuss their physical complaints with a nurse or case manager, but the message may not get the attention of the treating psychiatrist. It is important that families of people with schizophrenia become aware of the important medical comorbidities in schizophrenia, and families themselves with typical symptoms of these conditions. Families must also ensure that either the person or a family member communicates accurate medical history to the treating psychiatrist, as well as any concerns or symptoms that develop.

## Common Comorbid Conditions

The most common threats to the health of a person with schizophrenia are:

- Obesity
- Cardiovascular Disease
- Diabetes

## Obesity

Obesity is both a medical comorbidity and a risk factor for other disorders. It is generally defined by a body mass index (BMI) calculation. This is a standard measurement that compares body weight to body height to determine a body mass. The Canadian Standard BMI says that a calculation of greater than twenty-five indicates overweight, and thirty and over indicates obesity. When physicians want to get an indication of the risk of disease from obesity, they will often use the BMI as a starting point along with the individual's waist measurement. As well, they will consider other functional and medical factors in their assessment.

There is evidence that individuals with schizophrenia have a “2.8 to 3.5 increased likelihood over that of the general population of being obese”.<sup>51</sup> This is significant as according to the Public Health Agency of Canada's website, obesity significantly increases the risk for several chronic diseases, most specifically type 2 diabetes, some cardiovascular diseases, certain types of cancer, and osteoarthritis.

Some other non-medical risks for obese people with schizophrenia may include:

- Not adhering to the treatment plan (including antipsychotic medication)
- Having a diminished quality of life
- Social withdrawal, and
- Stigmatization

51 S Coodin. Body Mass Index in persons with schizophrenia. Can J Psychiatry. 2001 August;46(6):549-55.

People with schizophrenia who are also obese are three times more likely not to adhere to treatment than people of normal weight. It is, therefore, essential that the antipsychotic medication used by individuals maximize their overall quality of life, otherwise they are less likely to take the medication as prescribed, and therefore more likely to suffer from relapse.

There is a stigma that goes along with obesity. People with excessive weight tend not to be well embraced by society and may be very self-conscious as a result. This leads to social withdrawal and a diminished quality of life for many people who experience obesity. For people with schizophrenia, the stigma already attached to the illness, coupled with the lack of self-confidence that comes from being overweight, can seriously impact their quality of life.

Social isolation in turn can lead to increased inactivity, especially when coupled with low socio-economic status. The less active a person is, the more prone he/she is to gaining weight.

## Typical Causes of Weight gain Include:

### 1. Poor Dietary Habits

- People with schizophrenia are more likely to eat a diet that is high in fat and refined carbohydrates and eat less fiber, fruit and vegetables than the general population.<sup>52</sup>
- Eating on the run and snacking (especially in the evening) are big contributors to an unbalanced and unhealthy diet.
- Eating lots of fatty and sugary foods like biscuits, sweets, cakes, muffins, and chips can lead to fluctuations in blood sugar or regularly skipping meals.
- Eating too many simple carbohydrates produces a high sugar level in the body, which turns into fat.
- Not eating three healthy meals a day, with a proper daily balance of protein, grains, vegetables, and fruit will likely lead to snacking, and eating inappropriate foods.

### 2. Lack of Exercise

- People with schizophrenia are particularly prone to physical inactivity.
- Feelings of fatigue, depression, or anxiety can drain one's energy, making it difficult to be motivated to exercise. However, the more inactive one is, the more tired and less vibrant a person tends to feel.

### 3. Age

As people get older, there is a tendency to want to slow down, or not feel as strong or able to be physically active. Again, the problem is that the more inactive the body is, the more likely it is to feel stiff, sore, or tired. Physical movement is necessary to maintain good blood circulation to all the body's hundreds of parts. Poor circulation, and lack of use of muscles, can lead to stiff-ness and soreness. While activities may have to be modified as one ages (e.g., a fast-paced walk as opposed to running), it is just as important to exercise when you are older. It is interesting to note that drug-induced weight gain (see section on medications below) is lower for people over sixty years of age than for younger adults.

52 McCreadie R, Macdonald E, Blacklock C, Tilak-Singh D, Wiles D, Halliday J. Dietary intake of schizophrenic patients in Nithsdale, Scotland: case-control study. *BMJ*. 1998;317(7161):784–5.

#### 4. Gender

There is some scientific evidence that suggests females who experience schizophrenia may have a higher risk of weight gain than males. For example, research led by Dr. Tony Cohn of the Centre for Addiction and Mental Health in Toronto shows that the prevalence of obesity for women with schizophrenia is three times that of the general population. Males with schizophrenia tend to be two times more obese than men without the disorder.

#### 5. Problematic substance use

For people with schizophrenia, alcohol use disorder and other problematic substance use occurs up to fifty percent more often than in the general population. Long-term alcohol abuse can lead to poor dietary habits, lack of physical activity, depression, and overall poor physical and mental condition. Alcohol is high in calories, and excessive intake means that the person is adding many empty calories (likely on a daily basis) to his/her diet. Since they are not likely to burn these extra calories off with vigorous exercise, people with schizophrenia that regularly have a high intake of alcohol are prone to weight gain.

#### 6. Antipsychotics And Other Psychotropic Medications

Gaining weight is a very common side effect of some antipsychotic medications and affects between 15 and 72% of individuals using them.<sup>53</sup> Some drugs, such as second generation anti-psychotics, are more likely to cause weight gain than others. If your family member is bothered by excess weight, it is important to have a discussion about this with the physician/psychiatrist.

Weight gain can plateau after a certain period of treatment (e.g., in the first few months, or not for a year). Most weight gains are in the first year of treatment but may continue at a slower rate for several years. Of all the second generation antipsychotic drugs, Ziprasidone (Abilify) and aripiprazole appear to be least likely to lead to significant weight gain.<sup>54</sup>

Weight gain caused by antipsychotic treatment is a concern because of the significant morbidity and mortality associated with it. It also creates concern because obese individuals with schizophrenia are thirteen times more likely to request discontinuation of their medication because of weight gain. While the exact cause of drug-induced weight gain is not clear, it appears the physiological impact of the second generation antipsychotics leads to appetite stimulation.

In addition, one of the side effects of some antipsychotics can be sedation, increasing the likelihood that individuals will be less active, and therefore gain weight more easily. Some people with schizophrenia are treated with other psychotropic medications, or medications used to assist the effectiveness of antipsychotics. Some of these medications are known to promote weight gain as well (e.g., lithium, mood stabilizers including valproate, tricyclic antidepressants and SSRI's, and mirtazapine).

53 Citrome L, et al. Incidence of cardiovascular outcomes and diabetes mellitus among users of second-generation antipsychotics. *J Clin Psychiatry*. 2013;74(12):1199–206.

54 Maayan, Lawrence, and Correll, Christoph U. Management of Antipsychotic-Related Weight Gain. *Expert Rev Neurother*. 2010 Jul; 10(7): 1175-1200.

When a psychiatrist or physician prescribes a second generation antipsychotic medication to alleviate the symptoms of schizophrenia, he/she should take the following factors into consideration:

- The person's overall health and condition

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- The severity of the symptoms

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- The person's age

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- The individual's family history of obesity-related risk factors

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- The history of adherence to the treatment plan

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- The person's weight; BMI, and his/her glucose and lipid levels before medication

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- Any prior sensitivity to drug-induced weight gain

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- The person's tolerance level for weight gain – both from a psychological, and an overall physical health standpoint, and

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- The person's ability and willingness to manage an increase in his/her weight

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It is a good idea for family members to meet with the prescribing physician to discuss the choice of antipsychotic treatment. You may be able to give the doctor very useful information on your family member's background, lifestyle, condition (since the onset of illness), and family history. You can also help evaluate whether or not your family member will likely be able to deal with the psychological aspects of a weight gain. You may also discuss ideas on how to support your family member to have a good diet and exercise routine.

### **Strategies to Support Your Family Member to Monitor, Prevent, and Manage Obesity**

- Monitor weight

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- Encourage a healthy balanced diet

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- Encourage exercise regularly (at least three times per week)

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- If necessary, support them in seeking help from a support group and/or health professional

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- Encourage them to keep alcohol intake to a minimum, and to avoid the use of street drugs; and

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- Support them in consulting with the prescribing physician at least every six to twelve months to ensure the antipsychotic treatment is maximizing quality of life

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The best way to start monitoring your family member's weight is firstly, to have them get weighed. The next step is to find out whether his/her weight is within the healthy range for his/her height (ask your general practitioner, or a member of your treatment team for guidance about what a healthy weight would be for you). It is a good idea to check weight once a week if possible. Encourage them to weigh themselves at the same time of the day (e.g., when they first rise for the day, before lunch, before bed, etc.). This is important because their weight will fluctuate during the day. Another good way to monitor their weight is to keep a check on whether their clothes fit you – if they start to become tight, it is a sign that they are gaining weight.

Of course, the key component to maintaining a healthy weight is to eat a healthy balanced diet. To find out whether their diet is appropriate, encourage them to start by keeping a food diary: make a note of their typical day's diet. For the first few days, they can observe what it is they eat during the day. This exercise will help them identify potential pitfalls and problem foods, or particularly difficult times of the day. At the end of the week, with your support if necessary, they can analyze their overall diet and try to identify problem areas. Then they can be encouraged to try to follow a healthy balanced diet, one that includes protein, vegetables, fruit, and whole grains. If your family member is agreeable ask a member of their treatment team or other health professional for nutrition counseling. A nutritionist should be able to suggest the types and portions of food they should be eating on a daily basis. A sensible eating plan is one that will fit in with their lifestyle so that they follow it. Try to support your family member to strive to eat three regular meals a day (not to skip meals), and to avoid eating on the run and snacking. Planning their day's diet when they get up in the morning will help to ensure they eat well throughout the day. It is also important for them to avoid eating fatty and sugary foods (e.g., biscuits, sweets, cakes, muffins, and chips), and excessive amounts of simple carbohydrates (e.g., breads, starches {potatoes, rice, etc.}, fruit juices, and cereals).

If they find they need to lose weight, and find it difficult to do it alone, you can suggest, support them in thinking about joining Weight Watchers or a similar support type group that is designed to give regular encouragement and help with diet. Their physician should always be consulted before joining such an organization.

One way to improve health and maintain a healthy weight is to exercise regularly (at least three times per week). This may be one of the last things the person feels like doing, especially if he/she is experiencing fatigue, depression, or anxiety. Family members are advised to encourage the person to exercise, perhaps by incorporating it into the family's routine. It may be helpful to note that exercise can actually make one feel more energetic, more relaxed, and improve the spirits. It is good for the mind as well as the body. It can also be a natural way to meet people. Of course, it is always wise to speak to the individual's physician before embarking on a new exercise program, especially if the person is not used to exercising. The person may wish to consult the treatment team on the subject and get their feedback. They may have helpful tips on how to approach exercise and get fit safely.

It is quite easy to introduce physical activity into one's lifestyle. It is not necessary to join an expensive club or gym. Simply find something the person (or entire family) enjoys doing and set some time aside for it every week. A person is more likely to stick to an exercise routine if it is an activity he/she likes. Here are some suggestions for the person (or the whole family):

- If you like walking, this is an excellent form of exercise and can be done in the town or country. Set aside at least 20 to 30 minutes of the day for a walk. You could combine it with a visit to the store, or to your local day centre or community centre. Perhaps there is someone in your family or at your support group who could accompany you?
- Running groups and clubs are quite popular in urban centres. They teach you how to run, helping you to slowly build up your stamina through a pre-designed program. They meet on a regular basis (e.g., weekly) to do group training.
- If there is a municipal swimming pool nearby, try swimming two or three times per week. In the winter, arenas usually offer public skating at very reasonable prices.
- If you like cycling and have (or can borrow) a bicycle, find a safe route to go cycling.
- Do a few more things around the home or garden. For example, household activities such as cleaning or gardening can be good exercise and may also help you get into a good daily routine.

The primary reason for avoiding the use of alcohol and/or street drugs is the serious health risk they pose to the person with schizophrenia. In addition, alcohol adds lots of calories to a daily diet, but not lots of nutrients. If you have a regular habit of drinking alcohol, beware of the calories you are taking in. Reducing alcohol intake, or avoiding it altogether, is a positive step toward maintaining a healthy weight. It is not wise to use street drugs for health reasons, but also because they may stimulate appetite, and impair your judgment.

If the individual feels that the medication is the reason for his/her weight gain, and the weight gain is not manageable and is adversely affecting his/her quality of life, then a discussion with the prescribing physician about the antipsychotic treatment is warranted. The physician may change the dosage of the medication, or suggest another choice of drug treatment, or consider additional medication to help with weight management. However, the physician may first wish to do a risk-benefit analysis of the current medication. In other words, the doctor will weigh the risks and benefits of continuing the current treatment by comparing the side effects of the medication (e.g., weight gain) with the effects of psychotic episodes. One of the physician's key concerns is preventing the person from relapsing, but he/she will also be keeping in mind the ultimate goal of improving the quality of life of the individual. The physician will also be aware that individuals are more likely to be motivated to continue taking antipsychotic medication if they experience more positive effects (than negative side effects) of the treatment.

## Cardiovascular Disease (CVD)

The term cardiovascular disease refers to strokes, and diseases and injuries of the cardiovascular system which is made up of the heart, the blood vessels of the heart, and the veins and arteries throughout the body and brain. Over the past two decades, cancer and heart disease have been the two leading causes of death in males and females in Canada.<sup>55</sup> Statistics Canada reported that in 2019, diseases of the heart combined with cerebrovascular diseases accounted for 23.3% of deaths in Canada. Heart and Stroke (Canada) indicates that nine in ten Canadians have at least one risk factor associated with heart disease and stroke. The good news Heart and Stroke notes is that almost 80% of premature heart disease and stroke can be prevented by healthy lifestyle behaviors. The other good news is that heart disease outcomes are improving over time.

### Risk Factors for CVD

The risk of heart disease or stroke is even greater for people with schizophrenia than for people in the general population. They also have a more than doubled risk of dying from cardiovascular disease than the general population.<sup>56</sup>

There are two categories of risk factors for heart disease – one category is factors that can be modified, and the second category consists of risk factors that are not changeable.

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55 Statistics Canada website. Deaths 2019. <https://www150.statcan.gc.ca/n1/daily-quotidien/201126/dq201126b-eng.htm>

56 Berry, Alexandra, et al. Investigating the Agreement Between Cardiovascular Disease Risk Calculators Among People Diagnosed with Schizophrenia. *Frontiers in Psychiatry*, December 2018.

## Risk Factors for Heart Disease<sup>57</sup>

### Modifiable

- Physical inactivity
- Diet
- Obesity
- Smoking
- Abnormal levels of lipids (fats)
- Hypertension

### Non-modifiable

- Advancing age
- Gender
- Family history
- Diabetes
- Ethnicity
- Socioeconomic status

Obesity and diabetes are not only comorbid conditions of schizophrenia, but they are also important contributing risk factors to heart disease. Smoking is probably the most common risk factor for heart disease.

Hypertension produces structural changes within arteries that narrow the arterial openings, which may lead to aneurysms (an excessive localized enlargement of an artery) and necrosis (the death of tissue caused by disease or injury). The effects of hypertension manifest themselves after several years, and are made worse by other risk factors such as smoking, diabetes, obesity, an inactive lifestyle, high amounts of salt in the diet, and stress. Hypertension tends to increase with age.

Psychological factors, such as stress, anxiety, depression and hostility, have also been demonstrated to contribute to cardiovascular disease.

Physicians sometimes use a chart known as the Framingham chart to calculate a person's ten-year risk for heart disease. The chart assesses risk based on the following risk factors: age, gender, systolic blood pressure, HDL cholesterol, smoking, and total cholesterol. A point system is used to evaluate each risk factor, and the total number of points then corresponds to a person's percentage chance of having a heart disease within the next ten years.

57 World Heart Federation website. <https://www.world-heart-federation.org>

## CVD and Antipsychotics

There is evidence that first-generation as well as second-generation antipsychotics contribute to an increased risk of cardiovascular diseases.<sup>58</sup> It has been proposed that second-generation anti-psychotics cause more weight gain and cause more metabolic problems than the first-generation anti-psychotics.<sup>59</sup> The choice of antipsychotic medication must be carefully weighed against the risk of CVD.

### Strategies to Support Your Family Member to Detect CVD Risk Factors:

- Encourage them to get their blood pressure measured at every medical check-up
- Support them in monitoring their weight
- Support them in getting checked for metabolic syndrome
- Support them in having their lipid levels measured, and
- Encourage them to ask their doctor to test their blood sugar for hyperglycemia and diabetes

It is important to have a complete check up with all of the above measurements before you begin antipsychotic treatment, and on a regular basis once you are undergoing drug therapy. (See Chapter 4, section on Initial Assessment, and Chapter 5, section on Early Intervention Strategies – What to Look for in Assessment for more information.) If your family member is diagnosed with dyslipidemia (abnormal lipids), hypertension, or diabetes the physician will likely recommend medication to control these conditions.

### The bBest Way to Minimize the Risk for Cardiovascular Disease is To:

- Eat a healthy diet
- Keep active and exercise regularly
- Don't smoke, and
- Have antipsychotic medications assessed on a regular basis (e.g., every six months to one year)

## Warning Signs of Heart Problems

People with schizophrenia and their family members should be aware of the warning signs of a heart attack. The most common symptom is of course chest pain and discomfort. The Public Health Agency of Canada identifies these other symptoms of heart attack:

- Shortness of breath
- Paleness, sweating or weakness

58 Pereira L, Budovich A, Claudio-Saez M (2018) Monitoring of Meta-bolic Adverse Effects associated with atypical antipsychotic use in an outpatient psychiatric clinic. *J Pharm Pract* 32:1–6. doi: 10.1177/0897190017752712.

59 Szmulewicz AG, Angriman F, Pedroso FE, Vazquez C, Martino DJ (2017) Long-term antipsychotic use and major cardiovascular events: a retrospective cohort study. *J Clin Psychiatry* 78:e905–e912.

- Chest pain with possible feelings of fullness, burning, pressure, tightness, squeezing, heaviness, discomfort, crushing pain.

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- Pain in the chest, neck, jaw, shoulder, arms, or back

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- Nausea, vomiting and possible indigestion

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- Cool, clammy skin, and/or

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- Anxiety or fear

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If your family member is experiencing any of the above symptoms that may indicate a cardiac event, call 911 or your local emergency number. The person may need to be taken immediately to the emergency ward of a hospital or be attended by a medical emergency service unit. The faster the person gets help, the better the chances of surviving a heart attack.

The person should stop all activity and sit in a comfortable position. If he/she is experiencing chest pain, they may chew and swallow one adult 325mg tablet of aspirin (or two 80mg tablets), unless they are allergic to aspirin or have been told by the doctor never to take aspirin. No other pain medication (e.g., acetaminophen or ibuprofen) should be taken.

If the person is not breathing normally, or coughing, or not moving then he/she requires help from the nearest people around them. CPR (cardiopulmonary resuscitation) should be started right away, and continued until emergency help can take over.

### Rare Side Effects

People with schizophrenia and their families may come across information on antipsychotic drugs that at first glance could be alarming. The Canadian Government (Health Canada) has made ruling that require some pharmaceutical companies to post warnings on their products to alert users to specific conditions or side effects that may occur during treatment. These rulings resulted from concerns relating to history of cardiac problems with older antipsychotics, antihistamines and sertindole. The labels do not mean that the patient will experience the condition, but rather that users should be educated about the potential side effects so as to recognize signs of onset, and/or to ensure they are regularly monitored by a physician. It is also possible to have a warning that pertains to particular patient populations (e.g., those of various ethnic origins) for which there may be potential side effects. One of these effects is QTc prolongation.

Prolongation of the QTc interval is a condition that may be induced by drugs such as diuretics, quinolone antibiotics, and some antipsychotics. The QTc interval is the length of time that it takes for the heart ventricles to electrically discharge and recharge. An electrocardiogram (ECG) can be performed on a person to measure QTc interval, and test for prolongation. A clinically significant prolongation of the QTc interval would be an

It is particularly important that people with schizophrenia pay attention to the risk factors of cardiovascular disease. Maintaining a healthy lifestyle is the best prevention against heart problems. People with schizophrenia should have regular medical check-ups to monitor for CVD risk factors.

increase greater than a count of thirty. If the QTc interval is increased to greater than a count of five hundred, the person may be at risk of sudden death from arrhythmia (an irregular heart rhythm or ventricular fibrillation), or a condition known as torsade de pointes. Torsade de pointes is extremely rare but can lead to sudden cardiac death. Most cases of torsade de pointes have occurred in patients with a QTc interval greater than a count of five hundred on an ECG. The greater the QTc prolongation, the greater is the risk of torsade de pointes. It has been widely proposed that second generation antipsychotics have a lower tendency to prolong the QT interval when compared to first generation antipsychotics.<sup>60</sup>

People with schizophrenia who have been diagnosed with a QTc interval prolongation should immediately contact a physician, and be referred to a cardiologist on an urgent basis, if the following symptoms occur:

- Light-headedness
- Dizziness
- Palpitations
- Fall in blood pressure
- Temporary loss of consciousness due to a fall in blood pressure

The physician will likely obtain an ECG, check the person for levels of serum potassium, magnesium, and calcium, and check thyroid hormones. He/she will also inquire about family history of loss of consciousness due to fall in blood pressure, and any sudden deaths in the family. It may, therefore, be useful to have a family member attend the medical visit with the person. If the QTc interval is greater than a count of five hundred, it is a signal to the physician to change the antipsychotic treatment.

It should be noted that some people naturally have longer QTc interval than others.

It should also be noted that QTc interval prolongation can be reversed if drug therapy is discontinued.

Individuals taking medication should understand their family history, their own medical history, and the potential side effects of the treatment they are undergoing. People with schizophrenia and their family members can ask questions of the prescribing physician, pharmacist, and other members of the treatment team to educate themselves about the antipsychotic therapy they are receiving. It is important to remember that antipsychotic treatment is a key to recovery.

For more information on  
CVD, call the Heart and  
Stroke Foundation of Canada:  
[www.heartandstroke.ca](http://www.heartandstroke.ca)

60 Ozeki Y, Fujii K, Kurimoto N, Yamada N, Okawa M, Aoki T, et al. QT Prolongation and antipsychotic medication in a sample of 1017 Patients with Schizophrenia. *Progress in Neuro-Psychopharmacology & Biological Psychiatry*. 2010;34:401-105. doi: 10.1016/j.pnpbp.2010.01.008. [PubMed] [Google Scholar]

## Diabetes

Diabetes is a chronic disease wherein the body either can't produce insulin or can't properly use the insulin it produces. It is a leading cause of death by disease. If left untreated or unmanaged, the high levels of blood sugar associated with diabetes can result in complications including: heart attack, stroke, blindness, kidney failure, limb amputations, and sexual dysfunction (i.e. impotence).

People with schizophrenia have a two to four times higher risk of developing Type 2 diabetes than people in the general population. Ninety percent of people with diabetes have this type of diabetes. The risk factors associated with Type 2 diabetes include: weight, inactivity, age; a family history of diabetes; an experience with diabetes during a pregnancy; race or ethnicity – certain people including Black, Hispanic, Indigenous, and Asian are at higher risk; abnormal level of cholesterol or other fats in the blood; and high blood pressure. Obesity is strongly correlated with a higher risk of diabetes. There is also some evidence that both conventional and second generation antipsychotics may cause glucose intolerance (hyperglycemia) leading to diabetes.

It is not presently clear which specific drugs have a higher or lower potential to induce diabetes. However, a previous study in the United States in 1999, which analyzed almost thirty-nine thousand outpatients with schizophrenia over a four-month period, found that all patients on antipsychotics had a higher prevalence of diabetes, and people on second generation antipsychotics were nine percent more likely to have diabetes than those undergoing first generation antipsychotic treatment. The findings indicated that the patients completely recovered from diabetes when the antipsychotic treatment was discontinued, and that hyperglycemia promptly recurred when the antipsychotic treatment was reinstated. This finding indicates that this side effect is reversible and drug-related. It is not yet known whether the drugs cause the diabetes or simply hasten its onset.

In a separate U.S. trial, forty-eight patients tested showed significant hyperglycemia and diabetic complications can occur during treatment with atypical antipsychotics with or without a change in weight. Studies in the United Kingdom indicate individuals taking olanzapine had the greatest risk of diabetes, and individuals on risperidone or typical neuroleptics had a slightly increased risk of diabetes. In a fifty-two week controlled trial that compared risperidone with ziprasidone, two cases of diabetes were found in people on risperidone, while none were found in people taking ziprasidone. It is important to note that studies are ongoing, and conclusive evidence has not yet been established. It is also important to remember that when other risk factors of comorbid conditions of schizophrenia are considered (e.g., obesity, inactive lifestyle, etc.), the risk of diabetes is already considerably high.

### Symptoms of Diabetes

People with schizophrenia and their family members should be aware of the physical symptoms of diabetes. All observations should be reported immediately to the individual's physician or psychiatrist. Metabolism should be intensively monitored to reduce the risk of developing diabetes and hyperglycemia. It is important to remember that people often lack the insight to recognize or complain of the physical symptoms of diabetes. Also, people with Type 2 diabetes may not display any symptoms.

Typical signs and symptoms of diabetes include the following:

- Unusual thirst

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- Frequent urination

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- Unusual weight loss

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- Extreme fatigue or lack of energy

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- Blurred vision

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- Frequent or recurring infections

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- Cuts and bruises that are slow to heal, and

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- Tingling or numbness in hands or feet

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### **Treatment of Diabetes**

Scientists believe that lifestyle is closely linked to diabetes, and that people can prevent or delay the disease through healthy eating, weight control, exercise, and good stress management. The earlier diabetes is diagnosed, the better. Type 2 diabetes is controlled through exercise and meal planning and may require medication and/or insulin to assist the body in making or using insulin more effectively.

The first step in treating this disease is to become educated about the condition. Knowledge is key to making healthy lifestyle choices that will keep diabetes under control. The second step is self-discipline which is essential to regulate eating habits and plan meals on a daily basis. What a person eats, when they eat, and how much they eat plays an important role in regulating how well the body manages blood sugar levels. It is particularly important that the person with diabetes maintain a healthy weight in order to control type 2 diabetes. As well, regular exercise helps to lower blood sugars in the body. Stress reduction is also important in the day-to-day management of diabetes.

People with schizophrenia who are diagnosed with diabetes may need extra help and support to adjust to the disease, and to adopt a lifestyle that helps keep diabetes under control. The treatment team may be able to help the individual with a diet plan or recommend a dietician who can help. It is a good idea for the individual and family members to sit down with the dietician and discuss the lifestyle, favourite foods, and culture of the person with schizophrenia. This will help the dietician to fit meal planning as close to lifestyle as possible and include the foods the person enjoys eating.

### **Diet Tips**

Encourage/support your family member to:

- Eat three regular meals a day (no more than six hours apart) to help his/her body control blood glucose levels

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- Limit foods that are high in sugar (sweets, soft-drinks, desserts, candy, jam, and honey)

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- Limit high fat foods (chips, fried foods, pastries) in order to help maintain a healthy weight

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- Eat more high fiber foods to help keep blood glucose and cholesterol levels down
- Drink at least 6-8 glasses of water every day
- Monitor your salt intake as high blood pressure is a potential complication of diabetes, and
- Avoid alcohol

A person with diabetes will need to take good care of his/her feet. High glucose levels may eventually lead to poor blood flow and loss of feeling which can lead to foot problems. In order to prevent problems with the feet, encourage/support your family member to:

- Keep his/her blood glucose levels in his/her target range
- Wash feet daily with warm (not hot) water and pat dry
- Check feet daily for sores, blisters, injuries, red and warm areas that change in color, as well as any strange odour
- Make sure to wear shoes with good support, and socks that fit well so as not to hurt their feet
- Don't walk barefoot
- Keep toenails properly trimmed; and
- Use lotion on the soles of the feet to prevent dryness and cracking

### **Blood Glucose Levels**

As with schizophrenia, it is important for people with diabetes to take any medication that is prescribed. People with diabetes should make regular visits to their physician to monitor their condition. The physician will then tell them about their appropriate target range for their blood glucose level. Everyone's target range is different. The physician will also tell the person how often to check blood glucose levels. The person and family members must be fully trained in how to test blood glucose levels. A pharmacist or a trained health professional can tell you which blood glucose meter to purchase.

#### **Your family member should also know:**

- The size of the drop of blood needed
- The type of blood glucose strips to use
- How to clean the meter
- How to check the meter is accurate, and
- How to code your meter

It is very important for the person to keep his/her blood glucose level as close to his/her personal target range as possible. The way to do this is by having good regular eating habits, an active lifestyle, and possibly taking medication. If the blood glucose level is low, it may mean that they have had more activity than usual; haven't

eaten on time; eaten less than they should have; taken too much medication, or are experiencing effects of drinking alcohol.

**Symptoms of a low blood glucose level include:**

- Shaking or light-headedness
- Nervousness or irritability
- Confusion
- Frequent hunger, even after eating regular meals
- An increase in heart rate
- Sweating or headache onset
- Feeling weak, and/or
- Numbness or tingling on the lips or tongue

**If blood glucose level is very low, the person will:**

- Become confused and disoriented
- Lose consciousness, and/or
- Have a seizure

It is important to respond quickly to a low level of blood glucose. The person will likely need assistance in the above situations. It is very important that he/she always wear a MedicAlert identification so that emergency personnel and other people will understand his/her symptoms, and be able to help. People with diabetes (possibly with help from family members) should immediately test their blood glucose level if a low level is suspected. If that isn't possible, it is still better to react immediately to treat the problem. The person should do one of the following:

- Eat five glucose tablets
- Drink  $\frac{3}{4}$  cup of juice OR regular soft-drink
- Eat eight lifesavers or five hard candies, or
- Eat three teaspoons of honey

If after ten to fifteen minutes, there is no improvement:

- Check the blood glucose level again with the meter
- Treat again by eating or drinking something from the list above
- Have a snack that combines carbohydrate and protein (e.g., cheese and crackers, or half of a sandwich)

**BE PREPARED!** It is important to discuss prevention and emergency treatment with a trained health professional. Both the person and family members should know how to respond to a situation involving low blood glucose levels. It is a good idea for the person to carry glucose tablets or hard candies on him/her at all times.

If the person experiences high blood glucose levels, it is important to call or visit his/her physician. High blood glucose levels can occur when food intake, activity, and medications are not in balance. They may also occur when the person is sick or experiencing more stress than normal. Signs that blood glucose levels are high include an increase in thirst; more frequent urination, and/or an increase in fatigue. The physician may have to adjust the medication and/or insulin, recommend a change in diet; or suggest that physical activity be increased.

When the person with diabetes gets sick (e.g., with flu, colds, or any other illness), it is very important that he/she continues to take his/her diabetes medication. Also, he/she should talk to a pharmacist before taking any medication to treat the illness.

When your family member is sick, it is very important that they:

- Drink plenty of sugar-free fluids or water

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- Replace solid food with fluids that have glucose if they can't eat as much as normal – they should try to drink or eat ten grams of carbohydrates every hour.

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- Call the family physician, or go to a hospital if they vomit more than twice in a twelve hour period

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- Continue to take prescribed insulin – they may need to take more than usual depending on blood glucose levels

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**Other tips for people with diabetes:**

- Don't smoke

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- Visit the dentist regularly, and

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- Visit the eye specialist at least once every two years.

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**Diabetic Ketoacidosis**

A condition known as diabetic ketoacidosis is a potential side effect of second generation antipsychotic medications. Studies have shown that individuals who are male, around the age of forty, non-Caucasian and who take second generation antipsychotics (particularly clozapine and olanzapine) may be at risk. It is essential, therefore, that people with schizophrenia who are treated with clozapine or olanzapine have their blood glucose levels monitored regularly.

Ketoacidosis is a severe and life-threatening complication of diabetes that is the result of high blood sugar levels and ketones. It often arises when diabetes is not properly controlled, or when other illnesses occur. Ketoacidosis usually develops slowly, but if vomiting occurs it can develop in a few hours, possibly causing coma or even death. People with diabetes and their family members should watch for these symptoms:

## Symptoms of Diabetic Ketoacidosis

### Early Signs:

- Thirst or a very dry mouth
- Frequent urination
- High blood sugar levels, and/or
- High levels of ketones in the urine

### Later Signs:

- Constant fatigue
- Dry or flushed skin
- Nausea, vomiting, abdominal pain, or general muscle pains
- Difficulty breathing (short, deep breaths)
- Fruity odour on the breath, and/or
- Confusion or difficulty focusing

For more information on diabetes, call the Canadian Diabetes Association. Some of the above information was taken from their Web site: [www.diabetes.ca](http://www.diabetes.ca)

If these symptoms appear, the person should be seen immediately by a physician for treatment.

It is important to remember that diabetes is a serious illness. It can, however, be controlled through proper management and treatment. Family members may need to pay extra attention to the physical well-being of a person with schizophrenia who has diabetes. Diligence is required to ensure the person eats regularly and properly and maintains a healthy lifestyle.

## Smoking and Schizophrenia

Tobacco smoking is a common habit for people with schizophrenia. Up to 90% of people with schizophrenia have an addiction to nicotine which is three times that of the general population.

One of the reasons smoking may be so popular with people who have schizophrenia is that smoking may lessen the negative symptoms of the illness and improve the processing of auditory stimuli. This is due to the effect nicotine has on dopamine activity in the brain. Another reason that smoking may be so popular among people with schizophrenia is that it makes them feel more comfortable in social settings.

Smoking increases the metabolism of antipsychotic drugs, and individuals who smoke may need higher doses of medicine to control their illness. Higher doses of antipsychotics, however, lead to an increased susceptibility of weight gain, dyslipidemia, hypertension, and diabetes.

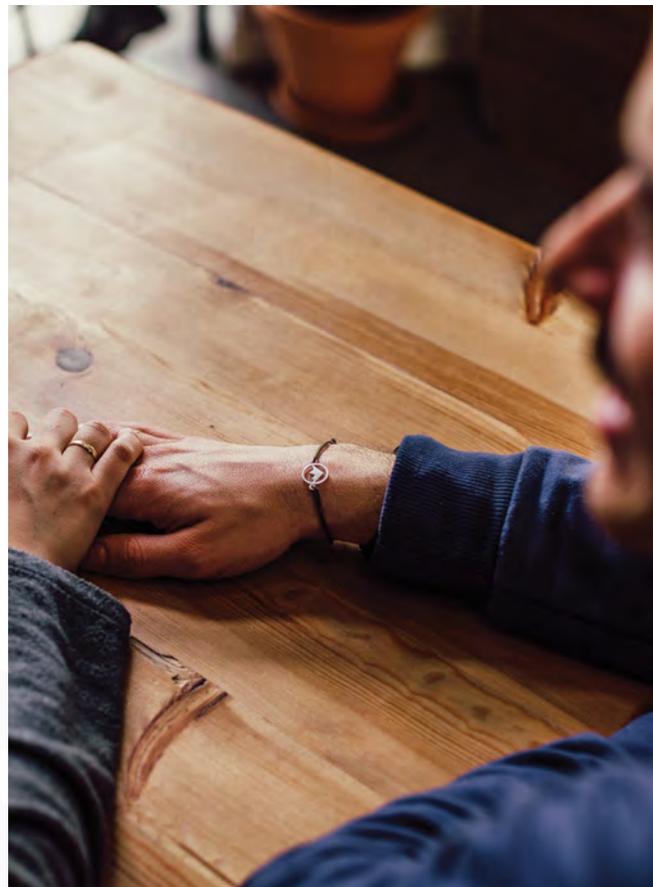
Studies show that people who are treated with old or first generation antipsychotic drugs tend to smoke more than those who undergo newer or atypical antipsychotic therapy.

Smoking is strongly linked to cardiovascular disease, lung diseases, cancers, and many other serious ailments. People with schizophrenia who smoke are advised to quit this deadly habit. Any gratification that the smoker enjoys is highly outweighed by the negative risks involved. Members of the treatment team may be able to offer suggestions on methods for quitting smoking. Also, smoking cessation programs for hospital outpatients of schizophrenia may be available in your community.

Smoking has very serious, and even deadly, consequences.

## Key Messages on Co-Morbidity

- Medical comorbidity of schizophrenia is a serious matter due to its prevalence and its nature.
- It is important that individuals and their family members be educated about related illnesses. Be aware of the signs and symptoms that indicate problems such as obesity, heart disease, and diabetes.
- Ensure that either the psychiatrist or a family physician is looking out for medical comorbidity in the person with schizophrenia.
- It is important that people with schizophrenia live a healthy lifestyle to prevent comorbid disease.
- It is necessary that people have regular medical check-ups and be tested for risk factors of comorbid conditions.
- People who do have a comorbid condition (e.g., obesity, cardiovascular disease, diabetes) need to be diligent about their health and lifestyle, and need to be monitored by a physician



## Chapter 10

# Living With Schizophrenia

### What it is Like to Have Schizophrenia – Personal Stories

There is nothing that is as inspiring and moving as hearing people's personal experiences and journeys with schizophrenia and other mental illness. In this chapter you will hear the personal stories of two individuals with lived experience and one family member of an individual with schizophrenia.

#### **A Personal Story by Cam Webster**

"Hello, I am Cam Webster, I'm 25 and I am in the category of the 1 in 5 people who will experience mental illness in their lifetime. Growing up I had a normal childhood, I did numerous sports such as soccer, hockey, baseball, judo, boxing, swimming, skiing and cross country running. I played a few different musical instruments and also did lots of wilderness activities. I had lots of friends and was excited for the future. I had no history of mental illness in my family and I did not show any signs of mental illness growing up. So when I became sick it was an unexpected shock to everyone.

I was first hospitalized in the psych ward less than one month after my 19th birthday. I was diagnosed with "Psychosis N.O.S. (Not Otherwise Specified)" and spent 11 days in the hospital. It is a brain illness that is caused by having a surplus of one of the neurotransmitters, dopamine in the brain. It causes hallucinations which are false sensory experiences that can affect any of the 5 senses, the most common of them being auditory. I remember hearing people talking about me in what sounded like their voice when I was around them or even by myself, almost always saying negative things about me. But looking back I realise it was just hallucinations. I knew people who would hallucinate the sense of smell too, they would smell something burning wherever they would go. Or there were others who visualized someone holding a knife near them. I had Delusions as well; it is false fixed beliefs that are not based in reality. For me some of the delusions were things such as, thinking people were beating me up when I went to sleep. Or that there were hidden cameras and microphones hidden all throughout the house.

I was also convinced that the nurses in the psychiatric ward were injecting me with diseases and that was why they were doing all the blood tests on me. I was even afraid of going outside because I thought there were people on the roof of my house who would attack me. It didn't

make any sense, but that's what you believe when you're in psychosis. You truly believe that these things will happen. The last symptom is disorganized thinking, it causes impairments in attention, memory and executive functioning. My thinking was so disorganized that I could barely hold a conversation with anyone. I couldn't focus enough to even be able to read for more than a minute. I would also watch a movie and then rewatch it a week later because I couldn't remember anything that happened in the plot, it felt like I was watching it for the first time.

The psychiatrist gave me a prescription for antipsychotic medication and I was instructed to take them every evening. They also recommended that I go to the rehabilitation programs, where I learned valuable methods of therapy as well as coping mechanisms that are still useful to me to this day. Since stress can cause a relapse I was recommended by my psychiatrist to not go back to work 5 months, so I could focus on my recovery. I kept my illness a secret from most due to fear of stigma, only telling close friends and family. Stigma is the disapproval of, or discrimination against, a person based on perceivable social characteristics that serve to distinguish them from other members of a society. I was so afraid of the stigma related to mental health. I was terrified that they would judge me or think that I was dangerous and not want to be associated with me. But if you look at the statistics you realize that mentally ill people are more likely to be the victim of a crime than to commit one.

Once I went back to work people were asking me why I left for so long without saying anything. I was afraid of the stigma related to mental health, so I made up a story that I went on a vacation with my family and then started taking courses at school and that was what I had been up to for the last five months. That all changed when I saw all the interest mental health was getting during the Bell Lets Talk campaign. Bell did great work raising awareness and breaking down stigma by bringing attention to difficult issues. After hearing candid optimistic stories from successful celebrities such as Demi Lovato, Clara Hughes and Dwayne The Rock Johnson to name a few. Realising that they too had demons and hardships to deal with it. As well as other ordinary humans sharing their story and getting the ball moving to start having conversations and realising that you don't have to be ashamed of telling anyone you have a mental illness. This campaign changed my view and gave me the confidence to share what had happened to me and not be afraid of people finding out. So I decided to be open about my diagnosis and the experience I was left with. I made a Facebook status explaining what had happened to me as well as bringing it up with my co-workers and friends who were unaware of it. I was met with great support from everyone who I conversed with on the subject. Even though no one who found out about my illness judged me, it made me realise that a big part of the stigma I was dealing with was the fear of stigma itself.

Although everything was getting better, I went back into everything too fast. Instead of taking things slow, I jumped right in. I went from working 0 hours a week to working 20+ hours with not a lot of sleep, so I wasn't coping well. I had a relapse and ended with a suicide attempt. This landed me, again, in the psych ward. This time I was there for 37 days. After I was released from the hospital I went back to various different mental health groups around the city. It was very comforting to converse with people of all different age groups about mental health and how they were recovering from their own battles with it. After I had my symptoms under control I went back to work part time, I tried a course at college but my cognition wasn't where it needed to be to get a good mark so I dropped out. Then my psychiatrist changed my diagnosis from Psychosis

N.O.S. to Schizoaffective disorder. Schizoaffective disorder means I have schizophrenia, as well as symptoms of a mood disorder, for me that is depression. Roughly 1% of the population suffers from schizophrenia. The defining feature of Schizophrenia is Psychosis, which means loss of contact from reality; delusions and hallucinations are hallmarks of the illness. Schizophrenia is typically a lifelong illness with no cure; some of the symptoms such as delusions and hallucinations can be treated with antipsychotic medications and C.B.T. (Cognitive Behavioural Therapy). But other symptoms such as apathy (lack of interest, enthusiasm, concern), anhedonia (lack of pleasure in normally pleasurable things), avolition (lack of initiation and motivation), flattening of affect (facial expression) as well as impairments in cognition have no medication to effectively treat them.

More hospital beds in Canada (8%) are occupied by people with schizophrenia than by sufferers of any other medical condition. Despite the limitations this illness puts on me, I'm still able to live my life in a way that I enjoy. I am back doing school and work part time, as well as attending mental health programs in Victoria that teach me how to properly manage my symptoms. I have facilitated support groups and workshops related to mental health in Victoria. I'm currently a Mental Health and Addictions student at Camosun. Telus also did a documentary about me and my recovery as well as my love for boxing. I find a lot of times people think Schizoaffective Disorder looks like the person muttering to themselves on the bus or stuff like that, but in reality it looks like your neighbor or the person you work with. John Nash, a famous Nobel Prize winning mathematician, has Schizophrenia. With that being said, no one really wants to have Schizoaffective Disorder, but you can still do 'normal' things with it. I can still do everyday things with the disorder. I have worked various different jobs in different fields. I do kickboxing and I run every day, as well as doing weightlifting workouts. I'm in a basketball league. I have the disorder, but it doesn't define or change my interests or what I do. I'm back doing all the things I love, and I feel very confident and excited about my future.

I still have some minor symptoms, but it's something that you learn to cope with and eventually it gets easier. I feel like it's also made me a better person; stronger and more compassionate. I wouldn't be who I am today without it. It showed me how strong I am, and it motivates me every day to help people who may be going through a similar situation. I'm sharing my diagnosis because I believe that awareness of mental illnesses is paramount, it is better to know that it affects someone you have met, rather than it just being a statistic."

### **A Personal Story by Tracy Kosowan**

"Growing up, I was always an exceptional student with a tendency for perfectionism. I graduated at the top of my high school class. At one point in my adult life, I was working two jobs and one of my jobs became very stressful because of being understaffed. By the summer of that year I had my first psychotic episode. I had not used drugs, but I did have an aunty who had schizophrenia. To date I have had four psychotic episodes, and I also have a diagnosis of schizophrenia.

I have experienced many different symptoms including a variety of delusional beliefs. One was that I felt something really bad was going to happen if I did the wrong thing; that I was at the center of a big experimental conspiracy and I absolutely had to do everything right. I would

sometimes become almost nonverbal and frozen as I tried to process reality.

By my third episode, I started to have hallucinations. I would hear things inside my head – sometimes sounds and sometimes voices. I thought that I was getting them “beamed” to me by satellite. I was also getting visual hallucinations that looked like transparent, ghostlike figures. I would fight the transparent figures, alone in my room at night. I wanted them to leave me alone, so I would punch and kick at the air. (I never saw ghosts in public, so I never acted this way in public – keeping up the façade that I was ok.) I experienced tactile hallucinations – feeling things on the skin or around you that aren’t really there.

When I would be in public around children, I was really worried that they were in danger. Specifically, I thought that someone wanted to dig their eyes out. So whenever I walked by a child, I would say in my head “No one digs their eyes out,” as if my words could protect them.

At my worst point I was living in a state of constant fear and paranoia, absolutely unable to trust other people or reality as a whole. While my symptoms were getting worse, my life was falling apart. I lost 5 jobs due to mental illness. I also moved 4 times because of it; mostly because I couldn’t trust my roommates. I had problems in almost all of my close relationships – with family, with friends, and with partners. It took me 4 years to get diagnosed, but eventually I did end up in the hospital. I stayed there for a month and started on medication. But the journey did not stop there.

One of the struggles that I experienced in my recovery was adjusting to life on antipsychotic medication. I feel like we are all made up of many things – thoughts, feelings, beliefs, values, opinions, and interests. Imagine a white board with all the important things about you written up on it. At my most acutely ill, everything about me was influenced by the illness. But my medication took it all away. It was like my personal “white board” had just been erased, and I was left an empty shell of a person.

Instead of positive symptoms, I now had negative symptoms or side effects. I was slowed down in movement and speech because of the sedation. Poverty of thought, poverty of speech, no motivation, no energy, depressed mood, loss of interest in life, flat affect, the need for way more sleep. Some of these symptoms have gotten better over time and as my medication was adjusted.

In the early stages of my recovery, I would stay in bed all day with the shades drawn and try to sleep the illness away. I would wake in disappointment, my life still in shambles. I had suicidal thoughts for the first year of my recovery, but I never made a serious plan to act on them.

I began to educate myself about my illness. I would do research at home and attended the early psychosis program here in Winnipeg called EPPIS. This was important as it has helped me have insight as to when my symptoms are coming back.

I feel fortunate that all of the relationships that were tumultuous at the time of my psychosis have been repaired. I can see how a person with psychosis/schizophrenia can easily lose their support system. When I go out with my friends, I have a better time than I did in the early days when it was difficult for me to have a conversation.

Peer Connections Manitoba (previously the Manitoba Schizophrenia Society) has helped me in

my recovery to rebuild my life. I think part of having this illness is that it can feel like your life gets ripped away from you, and it is up to you to get it back. I eventually started volunteering with the organization. I helped to facilitate the “Hearing Voices that are Distressing” workshop – a simulated experience of the audio hallucinations of schizophrenia. I also began sharing pieces of my story and speaking to high school psychology classes. Volunteering was a good first step that has led to me working for Peer Connections, in the role of a Peer Support Worker. As a peer support worker, I’m not a counselor or a therapist, but I can offer the perspective of someone who has lived experience with the illness and with the process of recovery. As I continue to help others, I feel that the years that I spent dealing with illness were not wasted – indeed they were a valuable learning experience. I am proud to have a supportive workplace that hired me, not in spite of, but because of, my lived experience with this mental illness.

I really struggled with writing this because I don’t necessarily see myself as doing “well”. I feel like I exist now but I’m not alive in the way I was before. I feel like the part of me that creates meaning out of my experiences has been altered, and every day feels the same. I have to tell you, that recovering from schizophrenia is hands down the hardest thing I have ever done in my entire life. I have been recovering for about nine years, and I have struggled, every day, for the past nine years. BUT I can tell you that I struggle less today than I did when I was first diagnosed. I struggle less now than I did when I was acutely psychotic. And my hope is that as time goes on, I will struggle less and less. I am by no means complete; my recovery is a work in progress.

I would like to end with a quote that I wrote shortly after my most recent hospitalization as it sums up the process of recovery for me: “Sometimes life gives you lemons. And sometimes life gives you a handful of gravel, or grass clippings, or heavier things, and says, ‘Here. Make something of this too.’”

### **A Personal Story by a Mother of a Son with Schizophrenia**

“Hope is practiced here...

As I sit here to write our family’s experience with schizophrenia, my intent is to share with you the hope we have for our son’s recovery. Before I do, it is important to let you know where we as a family are at. Currently, after two years of recovery, we are experiencing a second relapse in six months. This is important for you to know, because when I talk about hope it is not because we have some light version of psychosis or are extraordinary in any way. When we first started to realize our son was going through more than teenage angst, we started to share our challenges with family, friends, and colleagues. We were heartbroken and needed the support of all our community. The illness (which we were baffled by at the time) was taking away our son. Our boy was a straight “A” student, with tonnes of friends, who played sports, and was always laughing. We did not know how to help or where to turn.

I have tried so many times to write all the details of our family’s experience with psychosis. Yet, each time I write it I know that I cannot tell the full story without our son being ready for the story to be told. I had a friend once share with me that the one who is ill needs to be in the centre of a ring of support and all those that could would be the rings of protection around them. This is who we are as a family. So, while I wish I could share each detail, now I understand why so many

stories do not. They are not our details to share.

If you are reading this, you might be like me, searching for stories that have glimpses of others' lives so you can find ways to navigate yours. What I would like to share is that there are many things that give us hope. When we hear our mental health practitioners say that recovery is not only possible, it is expected, we feel hope wholeheartedly. We have had many interventions with police officers who have come across our son and treated him with respect and dignity. I know there have been many stories today of police not responding with compassion. And, we have feared this too. But, our experience has been one of absolute respect. This was especially true of a very young officer who stood in emergency with our son because instead of treating him as erratic and inappropriate, he trusted his instinct and sought help for him. Then the Integrated Mobile Crisis Response Team's (IMCRT) police liaison guided a group of other officers to bring our son to the hospital when he did not want to go. The officer was firm but he was 100% respectful and expected that of the team he led.

I know for many they fear stigma or judgment, but we have hope for change. Our friends have listened with only empathy when we talk about schizophrenia. In our circles, this part of our life is not taboo. Our other sons have shared our ups and downs with their friends. We have always told them to trust their friends to learn with us. Once after a relapse, our son asked what he could say to his close friends. We said to share exactly what was happening and how he was feeling. He did and they responded with curiosity and kindness. Our parents and extended family, also learn with us, speak openly to their friends, and learn about psychosis alongside us.

And, we see hope in the future of our health care system and the path towards patient-oriented care. Just the other day, I met with a group of professionals who invited a few of us with lived experiences to help bridge the knowledge gap between patients and their circle of support, once their loved ones are discharged from the hospital. This kind of thoughtful approach to recovery gives us tremendous hope.

When someone says recovery, our eyes light and our hearts fill up. As a family, we often live day to day, going through the ups and downs of grieving and recovery. We have had many low points where we felt heartbroken, scared, alone, blindsided, sad, angry, and confused. We have cried and hugged and cried and hugged again. We draw from what we have learned over the years. The wisdom that keeps us going is to trust your community of support, believe in your instincts, ask questions, lead with love, keep reaching for help, and let hope keep you strong. There are people that want to help. Be picky, but when you find people that work for your family, bring them into your circle of support. None of this is easy. However, you and all those around you are so much more capable than you think. Our family works on the mantra that there is hope; and with hope there is recovery; and with recovery, there is fulfillment.

Hope is practiced here. It is what gives us the strength to keep moving forward. One day, it is my hope that together with our son, we can share our entire recovery story. For now, I can only give my perspective that I believe there is hope in recovery all around us and because of all of us."

## Effect on Family Members

When a family learns that their child has schizophrenia, their emotions are similar to those experienced when a major illness, catastrophe, or accident occurs. They feel shocked, sad, angry, and dismayed. Some affected families have described their feelings as follows:

Feeling	
<b>Sorrow</b>	"We feel like we lost a child."
<b>Anxiety</b>	"We're afraid to leave him alone or hurt his feelings."
<b>Fear</b>	"Will we be safe from physical harm? Will the person harm himself or herself?"
<b>Shame &amp; Guilt</b>	"Are we to blame? What will people think?"
<b>Feelings of Isolation</b>	"No one can understand."
<b>Bitterness</b>	"Why did this happen to us?"
<b>Ambivalence Toward the Person</b>	"We love him a great deal but when his disability causes him to be cruel, we also wish he'd go away."
<b>Anger and Jealousy</b>	"Siblings resent the attention given to the family member."
<b>Depression</b>	"We can't talk without crying."
<b>Complete Denial of the Illness</b>	"This can't happen in our family."
<b>Denial of the Severity of the Illness</b>	"This is only a phase that will pass."
<b>Blaming Each Other</b>	"If you had been a better parent..."
<b>Inability to Think or Talk About Anything But the Illness</b>	"All our lives were bent around the problem."
<b>Marital Discord</b>	"My relationship with my husband became cold. I seemed dead inside."
<b>Divorce</b>	"It tears a family apart."
<b>Preoccupation with Moving Away</b>	"Maybe if we lived somewhere else, things would be better."
<b>Sleeplessness</b>	"I aged double time in the last seven years."
<b>Weight Loss</b>	"We have been through the mill, and it shows in our health."
<b>Withdrawal from Social Activities</b>	"We don't attend family get-togethers."
<b>Excessive Searching of the Past for Possible Explanations</b>	"Was it something we did?"
<b>Increased Drinking or Use of Tranquilizers</b>	"Our evening drink turned into three or four."
<b>Concern for the Future</b>	"What's going to happen after we're gone? Who will take care of the person?"

## The Blame and Shame Syndrome

Unfortunately, a common tendency is for family members and the person to blame one another. Research shows that parents can feel a “profound guilt over having contributed or not prevented the disorder, over not being ‘good’ parents and feeling ambivalent towards an ‘intimate stranger.’”<sup>61</sup> The research further suggests that “guilt is compensated by absolute dedication to the son or daughter’s care, at the expense of their own well-being”.<sup>62</sup>

Moreover, sisters and brothers often share the same shame and fears that their parents do.

In the following story, a parent describes blame and shame from personal experience:

“I have two sons. My older son is 22 and is in an advanced stage of muscular dystrophy. My younger son is 21 and has been diagnosed as chronically mentally ill. The son that is disabled physically has many special needs. He gets emotional support everywhere he turns. His disability is visible and obvious and the community, family and friends open their hearts to him, and go out of their way to make his life better.

My other son, on the other hand, is misunderstood and shunned by all. He is also terribly disabled but his disability is not visible. His grandparents, aunts, uncles and cousins all think that he’s lazy, stupid, weird, and naughty. They suggest that somehow, we have made some terrible mistake in his upbringing. When they call on the phone, they ask how his brother is and talk to his brother, but they never inquire as to him. He upsets them. They also wish that he’d go away.”

With time, a good understanding of the illness, and support from others who are experiencing the same challenges, family members can learn to share their feelings and stop destructive blame and shame. In the process, many families discover great strength and deep reserves of love for one another.

## Impact on Siblings

All family members are affected when a loved one develops schizophrenia. Once a diagnosis has been made, it is best that parents explain the disorder and its implications on the family’s lifestyle. Siblings will need the direction from their parents to help them understand the strange behaviour of their brother or sister. They have likely suspected that something out of the ordinary is happening, and are probably very confused, frustrated, or even frightened. Like the parents, they too are experiencing a sense of loss of someone they love.

61 Darmi, E. et al. Caring for an intimate stranger: parenting a child with psychosis. *Journal of Psychiatric and Mental Health Nursing*, 2017 May 24(4): 194-202.

62 Ibid.

NEVER BECOME a moth around the flame of self-blame... It can destroy your chance of coping, FOREVER. It can destroy YOU...”

– Dr. Ken Alexander,  
14 Principles for the Relatives

## Feelings

Parents can expect that their well children may experience the following feelings:

### Guilt

knowing their own lives are better than their ill siblings.

### Fear and anxiety

that they themselves will develop the illness (or that perhaps their offspring will have schizophrenia).

### Sadness and grief

for the loss of the person their brother/sister used to be.

### Embarrassment

in front of their friends or in public, as a result of their sibling's strange behaviour.

### Anger and resentment

at the disruption of family life, and the resulting decrease in attention they get from their parents.

### Empathy and love

for their brother or sister.

Everyone feels more in control of a situation when they understand it. Ensure that siblings are well informed about their brother or sister's illness, its symptoms, treatment, and recovery plan on an ongoing basis. This will help them to know what to expect from the person, and to understand the person's limitations, capabilities as well as their aspirations and goals.

## Relationships within the Family

The dynamics of the family relationship will undergo some change – it can't be avoided. The best way to deal with this change is to keep the channels of communication open for the benefit of everyone concerned. For example, your well children are likely to notice the anxiety you are feeling as you struggle with your child. This may in turn impact their sense of security. They know their sibling needs more attention than they do, but emotionally accepting this fact is difficult. They need reassurance that you are okay and are there for them. The relationship between siblings who are well may change for the worse or the better following a diagnosis of schizophrenia. The illness may hurt a previously close relationship, particularly where paranoia is present. Conversely, it may bring two siblings who had little interest in one another closer together because the well sibling feels a sense of compassion and commitment toward his/her brother or sister.

When a family member develops mental illness, a sibling may react by withdrawing from family interaction. He/she may want to spend more time with friends or doing extra-curricular activities. It is equally possible that the sibling may become more parent-like, deeply involving him/herself with the person and his/her illness and

taking on a protective role. It is important that well siblings be encouraged to find a healthy balance between their own lives and their family life.

### **Coping Strategies for Siblings**

The better educated siblings are about their brother or sister's illness, the better able they are to cope with schizophrenia. If siblings understand the loved one's behaviour as a symptom of a brain disorder rather than as intentionally destructive or disruptive, their negative reactions will be tempered.

Parents are encouraged to be forthright and open about schizophrenia. As well, if the person is comfortable talking about his/her illness, well siblings should discuss it with him/her. Openness is more apt to foster a caring environment. Parents are encouraged to listen to their children's concerns about the sibling. If they feel understood by you, they can better cope with the situation. Well siblings should also be able to confide in their friends. This will reduce the likelihood of feeling isolated, and thus "burdened" by the disorder. They may also benefit from seeing a counselor or visiting a support group so they can share their experiences, and know they are not alone. It is important that they feel others care about what they, too, are going through.

Well siblings should be encouraged to maintain a relationship with their brother or sister. Common interests may still exist, or a sibling can at least be a compassionate ear for their sister or brother. It is important that well siblings understand that their brother or sister is still capable of getting enjoyment from life and people, even if they can't express it. It is also important that they understand that recovery is possible for their sibling, and what recovery means for their sibling – what it might look like.

### **Coping Strategies for Parents**

Well children need the attention and support of their parents on a regular basis. Parents need to recognize that balancing the needs of all their children is extremely challenging. It may help if each spouse takes turns spending time with the well children for a period, and the child with mental illness other times. If at all possible, solicit the help of other relatives or friends. Allow your well children to decide how involved they want to be with their sibling. Forcing the matter will only create a friction that may negatively affect your child. It is also a good idea to consider the future care of your child. When you are no longer able to take all the responsibility, who will look after his/her interests? Discuss this situation openly with your family. Well siblings should have the opportunity to consider and make informed decisions about how much or little responsibility they are willing to take on, without having to feel guilty about their choices. Family education and peer support opportunities can be helpful with these types of issues. Contact your local schizophrenia society or similar organization to find local available groups.

## **Living Arrangements**

There are a number of options for your family member's living arrangements. Some of these include living: at home with parents or family; in an apartment, in a room, or in shared accommodations with supports; in a small group home; in a boarding house. The level of functionality of the person as well as their age will be key determinant when examining housing options. It is, therefore, important to understand the level of support or supervision that each option offers. For example, group homes or supportive housing settings may vary considerably in the degree of support they offer. Supervision may range from 24 hours a day onsite, to one

person dropping in a few times a day to periodically. There may or may not be in-house counseling or life skills training. Rules and policy may vary considerably. It is obviously necessary to know precisely what is offered before you and your relative can make a decision whether a particular living accommodation is appropriate. Mainstream boarding houses and shared accommodation may offer little supervision, and housing in the form of an apartment requires an ability to function well in an independent situation, although depending on your location, there are some programs wherein people living independently can still get considerable individualized support. Initially no matter what the accommodation, a considerable degree of family support is advisable.

Because there may be waiting lists for many residential settings and programs, it is advisable that your family member (with your support) get his/her name on a list as soon as possible, once a mutually satisfactory decision has been reached. A decision about housing can often be emotional.

Families that were consulted for this book suggest the following guidelines to help you with your decision. It is important to note that these are very general statements and that each family needs to decide what is in the best interest of all.

In general, at-home arrangements may work best under the following circumstances:

- The person has insight and functions at a fairly high level, has friendships, and is involved in activities outside the house
- If there are young children, their lives are not negatively affected
- Interaction among family members is relaxed, and
- The person intends to take advantage of available support services

In general, at-home arrangements may not be appropriate in the following circumstances:

- The main support person is single, ill, or elderly
- Children become frightened and resentful
- Marital relationships deteriorate
- Most family concerns revolve around the person with schizophrenia
- No support services are used, or services are not available, and
- The individual is habitually aggressive, and the threat of violence disturbs the household.<sup>18</sup>

If the individual prefers to live at home, the family as a group should have interviews with the primary mental health worker or an involved therapist to clarify treatment issues. You should keep a record of how the situation works and how all family members are affected. This will help you to evaluate how well things are, or are not, working. The record may also be useful, if needed, to demonstrate to the person that a different housing environment is required.

Families often feel very guilty if they must make the decision not to have the person live at home; this appears to be especially true for women. If your experience is similar, consider the following comments of a mother who

had to make this decision: "A break should be made at some point, and often it is easier for the person to adjust to the transition to a group home, boarding home, or whatever, while you are still available to give support and encouragement, as well as your assistance to participate in activities offered in the community. Otherwise, they will eventually have to make this adjustment without your help."

## Independent Living

If individuals achieve a good level of functional recovery, one of their goals might be to eventually have an independent living arrangement (once they have attained an appropriate age). You may want to gradually begin to plant this concept in the person's mind. Subtle hints can be dropped such as: "If you decide to live on your own..."; "When you decide to live on your own..."; "When you start to live on your own, you'll need to know how to do your own laundry."; "When you live on your own, you'll be glad you learned how to use the laundromat." Time should be allotted between progressive statements to allow for digestion and acceptance of the idea. Leaving the family home is difficult, but a necessary part of life for all of us.

Consult with a social worker, community resource person, or other appropriate experts regarding the move toward independent living.

Families suggest that at some point you and the individual make a commitment about when the move will occur. Work together (with the mental health worker or social worker, if there is one) to set a date that allows plenty of time to seek and approve accommodation, and to determine what extra supports may be needed. For example, you may come to an agreement that in six months, on May 1, John will be ready to live on his own, in whatever form of housing he and you have decided will be best.

Once the move has been completed, persons may feel some resentment about it. It is very important to help them so that they do not feel abandoned by you. You may have to make an extra effort during the first few weeks to reinforce the idea of the move as a positive step.

- Be a friend. Call and visit the person often and make dates to go places and do things.
- Offer praise and support to increase self-esteem.
- Respect the person's wishes and concerns as much as possible.

As well as emotional support, you may have to get involved in such tasks as housework, shopping, cooking, and management of finances. The amount of daily assistance the person needs will, of course, depend on the condition of his/her illness, what he/she is willing to accept from you, what community-based supports are available, etc. Families stress the importance of working with the individual as you do these tasks.

Allowing for your family's background and traditions, the relationship should become less intense over time. This will be an individual decision that occurs over time. At first the person may wish to come home every

weekend. This may feel fine for the first few weeks or months. Then, however, you may want to begin to pick the occasional weekend when he/she will not return home. You should have a valid reason, such as “We’ll be away that weekend.” Gradually decrease visits to one or two weekends a month. You may also find that at first, the person will phone home constantly, often three or four times a day. If this persists, the use of an answering machine may be advisable. You can then return phone calls as you deem appropriate. As time passes, the person should become more confident and comfortable with his/her living arrangement, and the number of phone calls and visits should settle into a reasonable pattern.

## Drugs & Alcohol

According to the Schizophrenia Society of Canada, studies have shown that approximately 50% of people with schizophrenia also have problems with drugs and alcohol. This combination of mental illness and substance use disorder is often called “concurrent disorders” or “co-occurring disorders”.<sup>63</sup>

Individuals with schizophrenia and other psychotic disorders most commonly use substances that are affordable, easily accessible and readily available, such as alcohol, cannabis and nicotine. However, tranquilizers and sleep medications may also be misused.

It is advisable to have a frank discussion with your family member about the risks associated with drugs and alcohol. The approach you take should be consistent with the degree of the person’s level of maturity. You may wish to consult his/her therapist about the best way to do this.

Depending on their circumstances, some people with schizophrenia can be highly vulnerable to the temptations of drugs and alcohol. They need to be fully aware that the use of drugs or alcohol can impair the effectiveness of their antipsychotic medication. Consumption of street drugs or alcohol can create symptoms of psychosis that are difficult to distinguish from those of a psychotic episode caused by schizophrenia. Street drugs taken by injection add the extra danger of possible infection by the virus that causes AIDS (Acquired Immunodeficiency Syndrome) and/or Hepatitis C. Overdose is also an unfortunate reality for some people who use street drugs.

Treatment for co-occurring schizophrenia and problematic substance use needs to be viewed in an integrated, holistic way to help those affected. Most provinces adopt a treatment approach that considers co-occurring disorders. Continued collaboration (or even integration) between mental health and problematic substance use systems need to ensure that the necessary resources and expertise are available for effective treatment.

For more information on the effects of alcohol and street drugs on the recovery process, please see:

<http://www.schizophreniaandsubstanceuse.ca>

<http://www.cannabisandpsychosis.ca>

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63 Schizophrenia Society of Canada. Schizophrenia and Substance Use; Information for Consumers.

## Sexuality, Family Planning, Pregnancy & Parenting

Historically, the sexual health of individuals with schizophrenia has received little attention from clinicians and researchers. Still, it is well accepted that the illness and the antipsychotics used to treat it can cause sexual problems in both sexes. These include diminished desire, problems with obtaining and/or maintaining an erection, abnormal ejaculation, and orgasmic dysfunction.<sup>64,65</sup>

“No one ever asks us about this (sex). There is the assumption that because I have schizophrenia, I shouldn’t have a sex life”.

– Anonymous woman with schizophrenia

Having schizophrenia does not eliminate sexual feelings (although they may be altered during the illness). Sexual side effects can be of great concern to the person experiencing them and can also be a key reason for not complying with drug therapy. It is usually during the recovery phase that sex becomes an issue. As an example, a sexual relationship that existed prior to the illness will often be put on hold during the acute phase. As symptoms of the illness abate, and the person begins to recover, interest in a romantic relationship may be revived. Interest in sexual activity may signal resumption of normal development, as the person regains his/her identity and is prepared to seek close relationships again. Successful resumption of sexual activity can help to facilitate the establishment of intimate adult relationships.

It is important to developmental recovery that people with schizophrenia be educated about sexual side effects that can occur, and that if they do experience them, that they report them to their physician(s). Ideally, doctors should actively question the people that they provide care to about sexual side effects of medication. The impact of the side effect on persons should be explored. Treatment options should be openly discussed with individuals, so that they understand the costs and benefits of potential solutions to the problem. It is possible, for example, that by reducing the dose of antipsychotic medication, the side effect may decrease. It may also be feasible to try different medications. This may be helpful since not all medications cause the same severity of sexual side effects, and individuals may be sensitive to side effects from some drugs more than others. It is most important that people with schizophrenia realize that there are ways of treating sexual side effects without ceasing drug treatment for their disorder.

### Women & Sexuality

Gender differences affect the impact schizophrenia has on women and men. Women with schizophrenia often have the greater social functioning recovery. They date, they have active sex lives, get married, and raise children at greater numbers than their male counterparts. It is, therefore, important to ensure individuals are educated on family planning matters.

64 Knegtering H, van den Bosch R, Castelein S, Bruggeman R, Sytema S, van Os J. Are sexual side effects of prolactin-raising antipsychotics reducible to serum prolactin? *Psychoneuroendocrinology*. 2008;33:711–717.

65 Baggaley M. Sexual dysfunction in schizophrenia: focus on recent evidence. *Hum Psychopharmacol*. 2008;23:201–209.

A review of literature undertaken in 2018 showed that women with schizophrenia are targets for sexual harassment and violence, in their own homes, on the streets, and in institutions.<sup>66</sup> This review also suggests that women with schizophrenia “are vulnerable because of isolation, passivity, cognitive defects, psychotic symptoms, substance abuse, homelessness, and poverty, and, as a consequence of exploitation, they suffer shame and guilt, increased severity of psychotic symptoms, and increased risk of sexually transmitted disease, unwanted pregnancy, and abortion.” Psychiatric assessments rarely consider sexual exploitation and women typically will not disclose these aspects of their life. Recognizing this, family members can support the sexual safety of their loved ones by, for example, asking about institutional policy in this regard and about how staff keep individuals safe in hospital settings, and by educating their family member on how to keep safe in the community.

## Family Planning

Women with serious mental illness infrequently use contraception even though they may have high rates of sexual partners over their lives.<sup>67</sup>

This results in a high prevalence of sexually transmitted infections. As well, it has been noted that “while the overall rate of pregnancy in women with schizophrenia of child-bearing age is lower than in the general population, the percentage of pregnancies that are unwanted is higher than that in the general population.”<sup>68</sup>

Given the above, mental health professionals should provide family planning counseling, but it is not always common practice. It is a good idea to seek out this service, where available, in order that the person receives psychosocial skills training to reduce the possibility of pressured sex, and to understand the various methods of contraception.

Oral contraceptives are difficult for many women to remember. They also affect mood in some people with schizophrenia. Condoms are only effective if the person understands proper usage but will not provide protection in the many instances of unplanned or pressured sex.

Intra Uterine Devices (IUDs) may be a reasonable alternative for women with schizophrenia. Often the optimal choice of contraceptive is long-acting hormone injections. They usually last three months and do not have any clinically significant interactions with anti-psychotic medication. Generally, however, women with schizophrenia should be educated on all forms of contraceptives that are available in order to make informed choices.

Antipsychotic medication can affect both sexual libido and activity. This intimate area of human functioning may be difficult for individuals to discuss but being open about such concerns can not only greatly reduce them, but lead to solutions that improve quality of life.

66 Seeman, Mary V. Sexual exploitation in women with schizophrenia. Research Gate, April 2018

67 Seeman, Mary V. Prescribing Contraceptives for Women with Schizophrenia; July 2011: Journal of Psychiatric Practice: 17(4): 258-269.

68 Ibid.

## Pregnancy

For women with schizophrenia, pregnancy is a complicated situation. Pregnancy appears to worsen mental health for some women with schizophrenia. Psychotic denial of the pregnancy poses high risks for poor outcomes in women with schizophrenia if this is not addressed.<sup>69</sup> They may refuse prenatal care, may fail to recognize labour, etc.

This section identifies some of the special considerations for women with schizophrenia. While there is a lot to consider, it is important to note that with sufficient prenatal and post-natal care and attention, the experience of motherhood for a women with schizophrenia can be a positive one.



In terms of medications, currently available information is not enough to conclude that any antipsychotic drug is safe for use during pregnancy and lactation.<sup>70</sup> Having said that, the risks of discontinuing antipsychotic medication must be weighed against its effects on the fetus. A state of psychosis will impair the woman's ability to properly care for herself and her unborn baby. Her stress levels are likely to be high and she may not eat well. As well, the risks of violence, suicide, premature self-delivery attempts, or precipitous delivery are very significant during acute psychotic episodes. There are potential lasting effects on a woman who stops treatment for schizophrenia, since it is consistency of drug therapy that results in significantly better recovery over the person's lifetime.

Due to the risks of discontinuing antipsychotic treatment, it is important that the person and his/her family be well informed about the various psychotropics and their known effects on the fetus. Several studies on the risks to offspring have been undertaken, and your physicians should have knowledge of available data. In order to make a reasonable risk-benefit that will aid the decision process, ask the doctor(s) about antipsychotic agents and congenital anomalies, fetal development, malformed babies, enduring behavioural changes in offspring, and any other neonatal side effects of antipsychotics, and any other drugs for side effects.

Physicians will evaluate the risks of discontinuing and continuing psychotropic treatment during pregnancy. An individual's capacity to understand and participate meaningfully in a decision about drug therapy should of course be considered. Physicians will pay careful attention to nutrition and prenatal vitamin supplements and should make known the additional risks of cigarette smoking during pregnancy.

It is important to realize that challenges of pregnancy to women with schizophrenia do not end with childbirth. The postpartum period presents a high risk for psychosis. In one study, "fifty-five percent of mothers with schizophrenia experienced a psychiatric episode during the first year postpartum, most often in the first three

69 Solari, Hugo et al. Understanding and Treating Women with Schizophrenia during Pregnancy and Postpartum. *Journal of Population Therapeutics and Clinical Pharmacology*. Volume 16 No.1 2009

70 Yassar I Odhedjo et al. Safety and Efficacy of Antipsychotics in Pregnancy and Lactation. *Journal of Alcoholism and Drug Dependence*. May 20, 2017.

months, and were also more likely to be depressed than controls".<sup>71</sup>

The implications of postpartum problems extend to the mother and child relationship. Where hospitalization is necessary, new mothers tend to avoid inpatient care because they don't want to be separated from the baby. Literature suggests that approximately 50% of mothers with schizophrenia lose custody of their child; the other 50% of course maintain custody. The former can be devastating to a woman who values being a mother.<sup>72</sup> Symptoms may be sufficiently severe to cause the mother to neglect caring for herself and her baby, or worse, positive symptoms may result in physical risk to the child. She may also forget to attend pediatric, obstetric, and other medical appointments.

While the new mother with schizophrenia should resume her drug therapy following delivery, she will want to avoid sedating medications, particularly if the baby is breast fed, as they may sedate the baby, or render the mother unable to hear the child crying during the night.

The stress involved in being a new mother, combined with sleep deprivation may be overwhelming for a person with schizophrenia. The addition of psychotic symptoms exacerbates an already difficult situation. Special care must be taken during the postpartum period to ensure the mother is coping with her baby's care, along with her own. Ongoing medical care can help to address problems as they arise, especially if it provides the mother with continued custody or access to her child.

## Parenting

The prospect of parenting poses complex challenges to a person with schizophrenia. Besides the financial burden involved in raising a child, the parent with schizophrenia may be disadvantaged by the disorder in some of the following ways:

- Reduced ability to understand facial expressions and nonverbal cues from children.
- Reduced ability to provide stability, nurturing, and stimulation of the child.
- Impaired behavioural responses that may cause excessive distancing from the baby or excessive involvement with the child.
- Decreased ability to distinguish their own needs from those of their children.
- Compared to the general population, mothers with schizophrenia are less likely to be married or cohabiting at the time of childbirth, or to have someone to help them raise the child.<sup>73</sup> If married, there is a higher chance that the spouse also has a psychiatric disorder. In either case, the result is a lack of needed parental support for the child.
- As previously mentioned, many mothers with schizophrenia will experience loss of child custody. Often

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71 Howard LM, et al. The psychosocial outcome of pregnancy in women with psychotic disorders. *Schizophrenia Research* 2004; 71:49-60.

72 Seeman, Mary V. Intervention to Prevent Child Custody Loss in Mothers with Schizophrenia; *Hindawi Schizophrenia Research and Treatment*: Volume 2012 Article ID 796763.

73 Miller and Finnerty. Sexuality, pregnancy, and childrearing among women with schizophrenia-spectrum disorders. *Psychiatr Serv.* 1996 May; 47(5): 502-6.

this will occur intermittently with periods of visits and regaining custody.

For the child, there are risks both in remaining with a parent who is acutely psychotic, and in being separated from the parent. It is believed that children are generally better off remaining with the ill parent except in instances of child abuse or gross neglect. If a mother with schizophrenia has the support of her family, spouse, and/or extended family connections along with a good comprehensive treatment and recovery plan, the prospects of good parenting are much improved.

## Intimate Relationships

People with schizophrenia may have difficulty maintaining intimate relationships. Marital relationships that involve a spouse with schizophrenia may be susceptible to breakdown because couples lack the specialized coping skills required to deal with the disorder. People with schizophrenia also find it difficult to start intimate relationships because they are isolated from the social streams that young people use to meet potential mates. In particular, men who experience schizophrenia often feel they have a disadvantage when it comes to attracting female partners.

Family members can help the person by encouraging him/her to get involved in peer support groups, church social groups, or other community groups where he/she can interact with others. The treatment team can also help the person to develop the social skills he/she requires to socialize with others (see Chapter 8, Treatment, section on Social Skills Training for more information). With support from family and friends, the person can pursue intimate relationships.

## Elderly People With Schizophrenia

The prevalence of schizophrenia in older adults “is set to double and reach 1.1 million people in the US by 2025 and 10 million worldwide by 2050”.<sup>74</sup> Older adults with schizophrenia includes those that had an early onset and those with a later onset. Unfortunately, however, there is very little research and policy attention given to this issue. It is important that new age-appropriate services and treatments to improve the course of treatment for older adults with schizophrenia be considered a priority given the above prevalence trajectory.

Elderly people with schizophrenia often take several medications for various physical conditions, along with anti-psychotic drugs. Extra attention to medication is therefore required, to ensure that there will be no complications with drug interactions. As well, the type of medication being used should be reviewed for its side effects on elderly persons. It is possible that dosage levels may be reduced as the person gets older and exhibits continued stabilization.

Ensure the elderly person in your life receives proper medical reassessments for schizophrenia, concurrent physical illnesses, sensory deficits, and medication side effects.

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74 Waqas, Ullah Khan and Rajji, Tarek K. Schizophrenia in Later Life: Patient Characteristics and Treatment Strategies; Psychiatric Times: 28 March 2019; Volume 36, Issue 3.

# Chapter 11

## Coping With Schizophrenia

### Role of the Family

- Provide plenty of support and loving care for their family member with schizophrenia. Help them to accept the diagnosis. Show by your attitudes and behaviour that there is hope, that symptoms of the disorder can be managed, and life can be satisfying and productive. Recovery is possible!
- Help the person with the illness to maintain a record of information on what symptoms have appeared, what medications were taken and in what dosages, and the effects of various types of treatment.
- Ensure that the person continues to receive treatment after hospitalizations. This includes taking medication, keeping doctors' appointments, going for follow-up treatment, and participating in social, recreational and vocational programs.
- Provide or support a structured and predictable environment. The recovering individual will have problems with sensory overload. In order to reduce stress, where possible plan activities for each day and keep big events to a minimum. Support keeping routines simple and allow the person time alone each day.
- Be consistent. Caregivers should agree on a plan of action and follow it. If you are predictable in the way you handle recurring concerns, you will help to reduce confusion and stress for the person.
- Maintain peace and calm at home and/or in the individual's home environment. You will want to keep voices down and speak at a slower pace. Shorter sentences will also help to reduce stress. Avoid arguing about delusions (false beliefs).
- Be positive and supportive. Being positive will probably be more helpful and effective in the long run than criticism. Like anyone else, people with schizophrenia need to know when they are doing well. Their self-esteem is fragile and needs to be boosted regularly. Encourage all positive efforts. Express appreciation for a job even half-done because schizophrenia creates a lack of confidence, initiative, patience, and memory.
- Listen to and acknowledge the person's hopes and dreams, and work with him/her to set realistic recovery goals. Encourage the person to identify and gradually regain former strengths, skills and interests, and to try new things as well, by taking small steps. If goals are unattainable or if you nag, stress can worsen the symptoms.
- Gradually support increased independence when the person shows the ability to handle greater responsibility and is able to complete various types of chores. Some re-learning may have to occur about the handling of money, cooking and housecleaning. If outside employment is too difficult, support the person in learning how to use time constructively.

- Together learn how to cope with stress. Anticipate ups and downs and prepare accordingly. A person with schizophrenia needs to learn to deal with stress in an effective manner. Your positive role modeling will be most helpful.

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- Encourage the individual to get out into the community. Led by his/her interests and suggestions, support him or her to select an appropriate activity when trying something new. If requested, go along the first time for moral support.

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- Be good to yourself. Your good health is very important, even crucial, to the best functioning of your entire family. Let go of guilt and shame. Take comfort and gain strength from the positive things your family has experienced together.

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- Establish realistic expectations and goals for yourself within your own life. Make sure you are allotting yourself time for extracurricular activities, hobbies, physical exercise and sports, etc. You need time for yourself in order to rejuvenate and maintain the stamina necessary to help others.

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- Value your own privacy. Keep up friendships and outside interests and lead as orderly a life as possible.

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- Do not neglect other children. Brothers and sisters often secretly share the guilt and fear of their parents. They may worry that they too may become ill. When their concerns are neglected because of the child, they can become jealous or resentful. These children need your love and attention, too.

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- Learn from and enjoy the support of others who are dealing with similar issues. Check to see what resources are available in your community. You can share and learn from the experiences of others, you can benefit from educational programs and discussions, and you can work cooperatively with others to improve and increase services.

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- Call a mental health organization in your region and ask if there is a family or parent education program that you can join.

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- Join your provincial Schizophrenia Society or similar family support organization in your area. These community resources offer support, education, help and hope to families who may be experiencing a crisis.

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## Encouraging Medication

This is one of the most frustrating problems. It may be hard to understand why someone with schizophrenia would refuse to take medication when its necessity is so obvious to everyone else. Families have found that there are five main reasons why someone might refuse medication:

1. The person may lack insight about the illness. Not believing that he/she is ill, he/she sees no reason to take medication. Or some individuals think that it is the medication that causes the illness. If the illness involves paranoia, the ill individual may view the medication as part of a plot to prevent him/her from functioning.

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2. The person may be suffering from unpleasant side effects as a result of the medication and believe that it causes more problems than it solves by interfering with his/her personal goals, like going back to school, etc.

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3. The person may be on a complicated medication scheme that involves taking several pills a day. He/she may find the regimen too confusing and may resent the constant reminders of illness.

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4. The person may feel so well that he/she either forgets to take the medication or thinks that it is not necessary anymore.
5. The individual may welcome the return of particular symptoms such as voices that say nice things and make him/her feel special.

People with schizophrenia need to take prescribed medication, and the following is a list of ideas and guidelines to help you encourage drug therapy:

- The initial medication dose must be continuously monitored. Therefore, you should always listen to the person's complaints about side effects. Do your best to empathize with any distress about medications.
- Positive symptoms will not reappear immediately upon discontinuation of medication. Antipsychotic drugs stay in the system for six weeks to three months. This grace period gives you some time to deal with the problem. After three months, however, getting back to a maintenance level may mean starting over at a higher than maintenance dosage.
- Explain to the person that he/she may end up back in the hospital if medication is not taken. (This should not be a threat). Some people will not accept warnings, and still others may not mind returning to the hospital.
- If other people in your family are on medication, turn pill taking into a ritual. Everyone could take their medication at the same time (even if it is a vitamin pill). It is easier to take one pill a day than six. Talk to the doctor about the form in which the person is receiving medication.
- For people who keep forgetting to take oral medication, the use of a weekly pill box can be an effective tool.
- Never sneak pills into food. If paranoia exists, this will increase it. Trust will never be established.
- More people go off oral medication than injectable medication. With injections, you are sure the person is getting his/her medicine. He/she can't spit it out, hide it under the tongue, etc. Discuss the pros and cons of switching medications with the doctor. (Health care professionals note that there is a downside to injections: possible feelings of humiliation, loss of control, and the potential for build-up of medication over time.).
- Injectable medication is given once a week or once every few weeks, depending on the type of antipsychotic. If your family member is on injectable medications, consider arranging some time together built around going for the medication – seeing a movie, going for lunch, etc. Let the person know that you are proud of the way in which he/she is handling the need for medication.

### Using the LEAP Method of Communication

Often, trying to convince our family member with schizophrenia to take medications using logic is unsuccessful and frustrating. An evidence-based approach to communicating in these situations called LEAP – listening, empathizing, agreeing, and partnering

Do your best to be calm and reasonable about getting the person to take medication. If you push too hard, you may make it more difficult for him/her to move to greater independence. A period of learning through experience may be necessary.

– was developed by Dr. Xavier Amador, a psychologist and respected mental health champion. This approach works by developing a partnership and trust with a family member who lacks insight into their illness and the need for treatment.

**The four steps to this approach involve<sup>75</sup>:**

- **Listening** reflectively and without judgement. Let your family member know that you hear what they are saying, (without agreeing or disagreeing), and reflecting what they said back to them without changing the content or meaning.
- **Empathizing** with their experience. Express an understanding of what they are going through and that you are listening, so they feel understood and respected. This can result in them being less defensive and more open to them listening to your ideas.
- **Agreeing** on what you can agree on. Find things that you can agree on. Try to focus on your family member's perception of the problem. Try not to give your opinion unless they ask for it.
- **Partner** with your family member. Being a partner is all about developing trust. This step is about working together to accomplish the goals you and your family member have agreed on.

Dr. Amador explains, "LEAP focuses on transforming the relationship first. You do not win on the strength of your argument; you win on the strength of your relationship. With LEAP, your opinions are no longer like a lot of hot air and are more like the wind in a sailboat's sails that moves the person where you want him—to safe harbors."<sup>76</sup>

## Legal Issues

### Mental Health Legislation

All provinces and territories in Canada have mental health legislation, usually referred to as Mental Health Acts. There are two key objectives to these laws:

1. To help provide treatment to a person with severe mental illness who refuses needed treatment, and who is likely to suffer harm or cause harm to others or suffer significant mental or physical deterioration.
2. To protect the legal rights of a person with a severe mental illness.

Since mental health legislation differs from province to province, the information provided here is general. The degree and type of harm or deterioration criterion that a person must meet before becoming an involuntary patient is specific to each province. A few provinces restrict the definition of harm to mean physical bodily harm. Most provinces, however, include serious non-physical harms in their criterion for involuntary patients. Some provinces have an alternative to the harm criterion that includes significant mental or physical deterioration of the person. It is a good idea to consult your provincial Schizophrenia Society or similar organization and a knowledgeable mental health or legal professional about the law in your province.

<sup>75</sup> The LEAP Method. NAMI Pierce County; <https://namipierce.org/the-leap-method/>: 14 March 2021.

<sup>76</sup> The LEAP Method. NAMI Pierce County; <https://namipierce.org/the-leap-method/>: 14 March 2021.

## Involuntary Admission Procedures

### (i) Physician Certificates

If the person will not go to the hospital voluntarily, but a medical examination performed by a physician determines he/she meets the criterion for involuntary admission, then this is the preferable method to enforce hospitalization. In most provinces one physician can, upon examination, issue a certificate that authorizes the transportation and admission to hospital for a short period of time (e.g., 1-3 days). A few Canadian provinces require two physician's certification to enforce hospital admission. A second certificate is required to hospitalize the person for an additional period of time (e.g., two weeks to one month), and this may be granted upon examination in the hospital.

### (ii) Judge's Order

If the person refuses to allow a physician to examine him/her, then any person can go to a judge and apply for the compulsory psychiatric examination of another person. Mental health laws require that if such an order is requested, it must be accompanied by evidence that shows the person is suffering from a mental disorder, is refusing to see a physician, and meets criteria for harm or deterioration concerns as specified by the provincial legislation. If the judge is satisfied that the criterion for involuntary examination are met, the court can order the transportation and physical examination of the person. The results of the medical examination may then lead to involuntary hospitalization.

### (iii) Police Apprehension

There are times such as emergency situations, when it is not practical to use a physician or judge to initiate hospitalization of the person. The police may be your only resort in a time of crisis. Mental health legislation does give the police the authority to apprehend a person if the person meets the criterion for police enforcement (e.g., appear to be ill and in danger). The police may take the person to have a medical examination, which in turn may lead to involuntary hospitalization.

## Legal Rights and Protections While in Hospital

When a person is involuntarily detained in accordance with provincial mental health laws, the Charter of Rights and Freedoms (of Canada) requires that the person be informed of certain rights. For example, the right to be told of the reason for his/her detention, and the right to consult a lawyer. In addition, Mental Health Acts provide further rights such as the right to a review board to determine if the person can be released; the right to have regular examinations (renewal certificates), and in some cases, the right to have second medical opinions on the appropriateness of the medical treatment.

## Family Involvement

In this book, we emphasize the importance of family involvement to help the person during acute episodes, and throughout the course of the illness. We have also talked about the importance of working closely with the treatment team. Specific opportunities for family involvement are provided by most provincial mental health legislation. They include:

- The family's right to provide information to a judge to facilitate admission to hospital.
- The family or next of kin are supposed to be notified that the person has been involuntarily admitted to hospital and given information about family and the individual's rights.

- In some provinces, treatment can be authorized by the hospital, but in the majority of provinces it is a family member or next of kin who must authorize treatment. Some provinces (e.g., Alberta) dictate that the family member who authorizes the treatment must act in the person's best interests. In Ontario, this is also the practice with the exception that the substitute decision maker must make the decision in accordance with the person's competent wish applicable to the circumstances. If these are not known the decision maker makes the decision in the person's best interests. Families should be aware that if they refuse to authorize treatment as recommended by the hospital, then the person may continue to suffer and be detained in hospital unnecessarily.
- Most provincial mental health legislation provides that families must be informed when an involuntary patient applies to medical review board (tribunal, or panel) to be released from hospital, or to change or review some other treatment decision. Families are usually given the opportunity to give evidence to the board that will be considered in the decision process.
- Provinces that have conditional leave or community treatment order provisions allow the families to be involved in the development of the plan. In Ontario, a next of kin must consent to the order if the person is not capable.

### **Mandatory Outpatient Treatment**

Despite the efforts of family and caregivers, some people with schizophrenia discontinue their treatment once they are discharged from hospital. There are various reasons for persons to stop medication and other interventions, but once they have, they are often subjected to relapses and readmissions to hospital. This disrupts their lives considerably, and if there are numerous re-admissions, other alternatives may be appropriate.

Mandatory outpatient treatment measures, such as conditional leaves or community treatment orders are available in most provinces to address this problem. These alternatives ensure that individuals adhere to their treatment plan while living in the community. In most Canadian jurisdictions, conditional leave provisions are time limited, but there are a few jurisdictions where the leave can be renewed indefinitely under certain circumstances. Various studies when considered together support the view that Mandatory Outpatient Treatment "provides various benefits for a subgroup of patients with serious and persistent mental illness."<sup>77</sup>

## **Confidentiality**

Sooner or later families run up against the legal and ethical issue of confidentiality. It is a basic principle in the practice of medicine. Information about an individual cannot usually be released, except to members of the treatment team, unless that individual has given written consent. The exceptions are when a person is under-age or is deemed to be mentally incompetent. Under the law of some jurisdictions, a priority list of those who may act on behalf of a mentally incompetent person has been established. It often comes as a surprise to family members that they are not first on such lists. In the case of a spouse in Ontario, if the person who is ill has appointed someone else while still mentally competent, that person ranks before the spouse.

It is natural for family caregivers to want to know as much as they can about the person's health in order to help as much as possible. Health care professionals recognize this, but their hands may be tied because no

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<sup>77</sup> O'Reilly, Richard L. Community Treatment Orders and Other Forms of Mandatory Outpatient Treatment, Canadian Psychoatric Association Position Paper, Revised, July 2018.

individual's consent has been given. Ideally, written authorization for the doctor to talk to the family should be obtained when the individual is well. However, if the person is unwilling to give consent, try asking the physician whether there is anything that you can do to help obtain it. Note that a physician can disclose where this is required or authorized by law (e.g. where there is an imminent and significant risk of harm).

Legal requirements on the release of medical information vary between provinces and territories. You can ask a health care professional what is needed in your particular province or territory. It may be worth seeing if it is possible to attend some of the health care team meetings or consultations with the person. The person may be more willing to accept this than to sign a consent form for the release of information.

Physicians and other health care professionals will normally look to family members to supply information about the person. At the doctor's discretion, this information may be passed on to the individual. You may wish to consider, therefore, the effects of telling the person directly about the information that you share with a member of the treatment team. Family members often find that this enhances their relationship with the person.

## Involvement With the Criminal Justice System

Unfortunately, some people with schizophrenia get in trouble with the law. Offences may range from minor altercations like shoplifting, mischief, assault, or ordering a meal from a restaurant and refusing to pay for it, to much more serious charges such as aggravated assault, arson, or even murder. It is important to remember, as the Canadian Mental Health Association website notes, that people with mental illness are more likely to be victims of violence rather than perpetrators.

According to the Centre for Addiction and Mental Health's website, there are several reasons why people with mental illness may end up involved with the criminal justice system:

- Some of the difficulties in a person's development that are associated with coming in contact with the law (for example poverty, physical and emotional abuse), are the same problems that can increase the risk of developing a serious mental illness.
- People with serious mental health problems may have higher rates of unemployment and may struggle financially and may live in neighborhoods with for example, more crime or substance use problems. Crimes of poverty or crimes related to problematic substance use may lead to issue with the law.
- Sometimes symptoms of a mental illness itself will cause conflict with the law. Paranoid delusions or certain hallucinations may in some instances result in aggressive or unusual behavior.

When persons with schizophrenia have to face criminal charges, their illness may mean they are unfit to stand trial or are not criminally responsible. These are legal concepts that relate to the state of mind of an accused person. Fitness to stand trial is based on the accused's mental capacity to understand the trial process, for example, the ability to instruct a lawyer, understand the role of the Crown Attorney (or Prosecutor), and understand the applicable penalties. Criminal responsibility applies to the accused's state of mind at the time of the offense. The state of mind is tested by his/her awareness of the consequences of his/her actions, and whether or not he/she appreciates the act is morally wrong. For example, could the accused's illness be affecting him/her in such a manner that he/she believes he/she is tickling someone, when in fact he/she is

stabbing a person. Or could it be that voices convince the individual to believe that by killing a person, he/she is saving the world from a terrible evil.

If the charge is serious, and the person goes through the court process, and is found either unfit to stand trial or not criminally responsible, the subsequent outcome will be determined by a provincial Review Board. The Board includes professionals in the legal field and psychiatric field. If the accused is found unfit to stand trial, this is a temporary status, meaning that he/she must return to court when he/she becomes fit. In the case of either finding, the Board imposes conditions on the individual that is accused such as where and under what circumstances he/she may reside; whether or not he/she must be hospitalized, for what duration, and under what conditions the accused may be released from the hospital. If the Board permits the individual that is accused to reside in the community, and the individual does not follow the conditions of the court, he/she may be detained. The Board normally reviews the status of the accused once a year at a formal hearing, and family members and caregivers may attend these hearings and give evidence. If the accused was found not criminally responsible, and the Board concludes that he/she is not a significant threat to the safety of the public, the Board may grant him/her an absolute discharge, thereby ending its jurisdiction over the person.

Just because a person has schizophrenia does not mean he/she will automatically be declared unfit to stand trial, or not criminally responsible. It is not the diagnosis that determines his/her status, but to what extent the disorder was affecting him/her at the time of the offense (in the case of criminal responsibility), or at the time of trial (in the issue of fitness to stand trial). Presumably if he/she is not taking his/her medication, he/she is likely being very strongly affected by his/her illness.

If the offense is minor, and the accused is not a risk to public safety, it is feasible – and most preferable – to keep the person out of the criminal justice system. This goal may be achieved through a process known as diversion. Diverting the case means to have the criminal charge stayed or withdrawn by the Prosecutor, so that the person will not be tried. The decision to divert the case rests with the Crown Attorney's office (or Crown Prosecutor's office), and depends upon a number of factors including the availability of community programs, the extent of family support, the nature of the offense, the effects of the illness, and the disposition of the offender.

Families are advised to explore community programs that support the person's case for diversion. For example, there are sponsored court outreach workers in some municipalities who help the accused find an arrangement that will comply with the conditions for diverting his/her criminal charges.

Individuals with mental illness are disproportionately affected by homelessness and are over-represented in the criminal justice system. If you find yourself faced with legal issues involving your family member, consider the following suggestions:

- Seek a lawyer (or legal aid lawyer) who is familiar with the law and with mental illness. Your local legal aid office, the Canadian Mental Health Association, a psychiatric hospital's forensic department, or police headquarters may be able to provide a list of lawyers who specialize in this area. Be warned that there are not many attorneys with this experience, so your search may require some patience.
- If you're hopeful on having the accused released on bail, you should be sure to have a lawyer represent the accused at a Bail Hearing pending his/her trial, or while diversion options are being explored. Also, be prepared to assure the judge that the person will be supervised if released.
- If you are seeking to get the case diverted, speak to a lawyer or legal aid duty counsel, if at all possible. If

necessary, speak to the Crown Attorney (Prosecutor) or prosecutor handling the case.

- The lawyer representing the individual who is accused or the Crown Attorney (Prosecutor) may ask the court to make an Assessment Order. This order is applicable where there are reasons to believe a person may have a mental disorder and needs to be assessed in order to determine whether or not he/she is fit to stand trial or he/she was criminally responsible at the time of the offense. The order is set for a specific number of days. How the accused is then dealt with depends on your jurisdiction. Problems such as bed shortages and waiting lists for psychiatrists could mean that the person ends up sitting in a detention centre instead of being assessed in a hospital or being cared for at home. It is therefore preferable for the accused to be remanded out of custody while complying with the assessment order.
- Get in touch with a Schizophrenia Society (local chapter, provincial office, or national office) or a similar organization. They may be able to direct you to an information centre, or provide you with literature, or recommend resources.
- Some cities have Mental Health Courts where the court works very closely with the mental health system in order to provide better service for those with a mental illness who have also become involved with the law. A lawyer, mental health clinic or the Schizophrenia Society could advise if such a court is available in your area.

## Wills

Here are some legal and financial tips from families who are experienced in these matters:

- Appoint a trustee for administration of your family member's inheritance.
- Bequeath only financial assets – no real estate or portable items.
- You may decide to have a condition attached on provisions for access to income from investments for your family member such that the trustee can withhold and/or administer sufficient money to ensure medications, housing, food, and other basic necessities are provided to the beneficiary. Even if the person is managing on his/her own, this provision protects him/her in the event of relapse.
- Provision should be made that the trustee is to access the capital of the trust only if it is deemed necessary for the welfare of your family member.
- Provision should be made to allow for control of the trust to be relinquished to the person should a cure be found for schizophrenia, and psychiatric experts have determined that the person has achieved permanent stabilization and is competent to manage the assets on his/her own.
- When the person dies, a provision should be made so that the rest and residue of the trust can be passed on to a specified next of kin. If this person predeceases the individual, provision could be made to pass on the balance of the trust to another individual of your choosing or to your choice of charities.

## Finances

### Managing Money

Some people with schizophrenia have trouble handling money matters. This can present families with some awkward situations, some of which may be beyond an immediate solution.

Individuals who are entitled to disability benefits can get help to apply for them while still in hospital or they may apply for them while in the community with the support of a family member or a health professional working with them.

Disability benefits are typically paid on a monthly basis. Most recipients will need a good deal of help learning how to budget properly to meet basic needs such as rent, food, and transportation. They may find it difficult to make the money last for the whole month. When a substantial sum is available (for example, on receipt of a disability cheque), some individuals tend to blow all or a large part on impulse spending, or to give their money away to friends – even to strangers. Families find that they are then called upon to pay for basic living expenses.

Behaviour of this sort, although not surprising for someone with few chances to enjoy life, is disconcerting for families, and requires that they exercise a good deal of patience. For the individual, managing money well is an important step toward the achievement of greater independence. By linking behaviour that demonstrates responsibility (e.g., successful completion of chores) to autonomy in handling money, you may be able to help the person learn to manage his/her finances.

While trying to support someone who is having challenges in managing their money, it is important to try to also affirm a person's right to make decisions and to exercise personal control. Sometimes it is finding a balance. In situations where financial management is significantly challenging, here are some ideas on how to make life a little easier on the family while giving the person a sense of independence:

- Investigate the possibility of assisting the person to look into pre-paying landlords, utility companies etc. so that the person's rent, heat, hydro, and phone bills are covered.
- If necessary, your local grocer may be asked to create vouchers for the person, paid for by the family in advance, and redeemable on a weekly basis by the holder.
- Arrange with a local restaurant to pay for meals on the person's behalf.
- It may be possible that provisions could be made with a local pharmacy, smoke shop, bookstore, etc. so that a debit/credit system for goods is in place for the person (e.g., you pay so many dollars which credits his/her account, and purchases made by the person are debits against the account). You should, of course, be sure to make your instructions clear as to overdrawn or zero balance accounts.
- Consider discussing with your family member the possibility of arranging for the disability cheque to be delivered to a parent or guardian.
- Some provinces have personal planning resources (such as NIDUS in BC) that can assist with financial options related to health care issues, or your family member's bank may have further information or options related to helping to manage finances.

In the event that your family member outlives you, you may want to make plans and preparations to provide for him/her. The first and most important piece of advice is to **SEEK ASSISTANCE FROM PROFESSIONALS** who understand your situation and who know the rules about disability benefits in your province.

Efforts should continue to be made to assist your family member to learn how to better manage their finances as independently as possible.

## Canadian Disability Tax Credit

The Canadian federal government may allow a tax credit for the benefit of persons disabled by schizophrenia. In order to prove eligibility for the tax credit a doctor, who is familiar with the person's medical status, must complete the appropriate tax forms (e.g., Form T2201, Disability Tax Credit Certificate). The family member may also claim an amount for an infirm dependent on his/her income tax return. These claims may apply even if the relative is not living in the family home. The disability credit is fully transferable. Therefore, the amount claimed may be divided, for example, between two parents filing tax returns. For further information, refer to the Government of Canada website on Disability Tax Credit.

## Disability Benefits

The provision for disability benefits or allowances comes from provincial governments. Terminology and criteria for financial assistance may vary from province to province. The general concept, however, is based on the level of disability, the age of the disabled person, and the ability of the person to work.

The following link is a guide that gives some information about how to talk with one's doctor, and also has a brief handout for giving to the doctor:

<https://www.getsmarteraboutmoney.ca/invest/savings-plans/rdsp/rdsp-how-rdsp-work/>

Another source is Planned Lifetime Advocacy Network.

<http://rdspresource.ca/index.php/how-to-contact-us/>

For further information, please contact your provincial office of the Schizophrenia Society (or similar organization) or your provincial government.

## Support For and From Within the Family

Evidence has demonstrated that social support among persons experiencing psychosis is minimal, and for the most part consists of immediate family members as compared with the general population.<sup>78</sup> Family members therefore play a critical role in their family member's recovery and are often under a great deal of stress every day.

"Personal stress is something that often goes unacknowledged. The sick person becomes a priority, and we forget our own needs. The day-to-day tasks involved in caring for a dependent – sudden crises, worry, financial problems, searching for community services, coping with

78 Amaresha, Anekal C. et al. Needs of Siblings of Persons with Psychosis: A Systematic Descriptive Review. *Clinical Psychopharmacology and Neuroscience*, 2014 Aug; 12(2): 111-123.

bureaucracy, becoming an advocate, squeezing out precious moments for our other family members – depletes and robs us of our energy. Eventually we end up with stress exhaustion, and this can lead to depression, anxiety, burnout, and psychosomatic illness.”

Families and health care professionals caution that the strain of having a family member with schizophrenia can begin in the very early days, when that person first behaves unusually. Normally, when we see someone who is visibly physically impaired – for example, using a wheelchair or white cane – we are inclined to offer that person our support. With mental illness, however, often the only way we realize that something is wrong is to actually see the person exhibit abnormal behaviour. It is natural to be disturbed by such behaviour, and to tend to withdraw from it. When unusual behaviour occurs within our own family, the reaction is not much different. In the early days, family members may be bewildered and resentful, and often blame and criticize the individual. Members may blame other members of the family as their fear and frustration grows.

Families caution that one of the most important things to watch for are the possible feelings of resentment and other feelings in siblings. When you are spending all of your time and energy supporting and seeking help for your family member, it is very easy to neglect other children. You may also have to accept that a sibling may never have any feeling of affection for his/her brother or sister. As one woman said,

“My brother was several years older than me. I never had a relationship with him when he wasn’t ill. When he first got sick, I was very young, and his behaviour scared me. Then, as I got older, the things he did embarrassed me. It’s very hard for my parents to accept, but I don’t feel any connection to this ill man.”

Many parents cannot understand this lack of empathy and find that they resent their other children for not feeling the same way they do about the individual. Some families believe that one way to prevent resentment is to include siblings in family discussions about the relative, and to ask for their support and/or advice regarding care. Parents often try to protect children by keeping the truth from them, but ignorance can be very frightening. Children should be given as much information as is appropriate for their age.

One woman, whose parents always included her in the support of her brother, stated,

“My brother is only one year older than me. I don’t remember a time when he wasn’t there. I love him dearly, and I am the only person he can really talk to about what is happening to him.”

One father remarked that now that his daughter is on medication and doing well, his other three daughters are willing to be supportive. In the past, they were afraid of, and embarrassed by, their sister. But now all four girls go out once a week and have strong family ties.

Some research has been done to identify the needs of siblings of persons with psychosis. The top need identified in one study is for more info on illness and symptoms. This was followed by the need to be part of a support group and help in managing their own negative impact on their emotions, family issues, etc. These

needs need to be met in order for them to play their much-needed role in supporting their family member.<sup>79</sup> Because different relationships within a family can be strained during the very early days, families of those with schizophrenia stress again the importance of joining a support group as soon as the diagnosis has been determined. Listening to others who have been through the experience will help family members to acknowledge feelings of anger, confusion, guilt, shame, and so on, and to realize that this is normal. Normal as these feelings are, however, they are painful and will worsen if the family members are uninformed and unsupported. The sooner a family comes to an understanding of the illness and finds appropriate ways of relating to the individual, the greater chance a family has of remaining a healthy, functioning, supportive unit.

Another reason to join a support group early is to find ways of avoiding the burnout that so often comes with caring for someone with schizophrenia. Feelings of chronic fatigue, a lack of interest in life, a lack of self-esteem, and a loss of empathy for the person with schizophrenia are common to people who have been coping alone for a number of years. These people can experience headaches, insomnia, drug and alcohol abuse, depression, and stress-related illnesses.

### **Families offer the following ideas for avoiding burnout:**

Chapter 17 offers further information about self-care, but families who informed this book suggest the following ideas to avoid burnout:

- Be aware of your health on a day-to-day basis. Eat nutritiously. Join an exercise club. Go for walks as often as possible. Get enough sleep. Visit your own doctor for regular check-ups. Let him/her know that you are the caregiver of a person with schizophrenia.

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- Learn about, and practice, relaxation techniques.

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- Schedule a break for yourself every day.

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- Take regular vacations if you can. Try to get a day or a night to yourself every now and then. If your family member lives with you, perhaps a friend or a relative could stay overnight while you go to a hotel.

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- Avoid self-blame and destructive self-criticism.

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- Take a course – give yourself a few hours when you have to concentrate on something else.

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- If the person with schizophrenia lives away from home, don't visit more than three times a week after the initial transition, and limit phone calls.

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- Try not to neglect the other relationships in your family.

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- Share your grief and problems with supportive people.

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- Aim for teamwork in your family.

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- Recognize that successful treatment and workable after-care programs require the coordinated and shared efforts of several groups of caregivers.

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- Realize that life must go on for you and for others in the family. This attitude may benefit the individual. He/she may be strengthened by the realization that life goes on.

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- Keep on top of developments in the person's illness that may indicate that a change of lifestyle is

79 Amaresha, Anekal C. et al. Needs of Siblings of Persons with Psychosis: A Systematic Descriptive Review. *Clinical Psychopharmacology and Neuroscience*, 2014 Aug; 12(2): 111-123.

necessary. For example, many families find that although their relative lived at home successfully for a number of years, at some point a change occurred that lowered the quality of life for everyone. Do not insist on keeping the person at home if different housing is required.

- Keep your religious or spiritual beliefs and family traditions. This may be important to the person's sense of continuity and quality of life.
- Keep a sense of humour.
- Never lose hope.

Burnout may also be caused by a lack of acceptance on the family's part. Some people are unable to recognize the illness for what it is. They never let go. They never get on with their own lives. They wear themselves out. Those with experience advise that once you let go, once you say, "This is it", life becomes simpler. One father stated,

"You work through fear, anger, grief, and finally come to acceptance. Acceptance is like adopting someone new – the other person is no longer there."

Acceptance means that you have learned to look at the person as he/she is now. Then there is room for hope, and you can begin to work for those things that will really make a difference in his/her life.

## A Note on the Role of Educators

Educators can play an important role in the lives of those living with schizophrenia. Here are some facts that educators should be aware of:

- Schizophrenia is a common illness which strikes many young people in their mid to late teens and early twenties.
- Most people with schizophrenia have normal intelligence and many have high IQ's.
- In very rare instances, children between the age of five and adolescence can develop schizophrenia. At this early age, these children are frequently described only as being different from other children; they are unlikely to display psychotic symptoms until adolescence or adulthood.
- Recovery and living a life of quality are possible.

"Professionals ...must help the person set realistic goals. I would entreat them not to be devastated by our illnesses and transmit this hopeless attitude to us. I would urge them never to lose hope, for we will not strive if we believe the effort is futile."

Esso Leete (who has lived with schizophrenia for more than 20 years) now commits herself to educating others about mental illness.

### Here are some suggestions on how educators can help those living with schizophrenia:

- Wherever possible, bring the illness into the open. Openly discuss the issues with students in classes such as Health and the Sciences. Such action can help to dispel some of the myths and reduce the stigma associated with the illness.

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- Provide preventive information on precipitating factors such as drug abuse.

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- Be alert to the early warning signs of schizophrenia. Young people often have mood swings, become apathetic, and experience a drop in athletic or academic performance, among other things; but if such behaviour persists, an educator may wish to consult with the student's family and assist the young person to receive an assessment.

### If an educator has a student in their classroom who has been diagnosed as having schizophrenia, they can:

- Reduce stress for the young person by slowing their pace when explaining situations that are new to the student.

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- Help the young person to set realistic goals for academic achievement and for extracurricular activities.

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- Establish ongoing communication with the student's family for feedback on his/her progress. As a result, in order to optimize the learning situation, their learning objectives, content of curricula, teaching methodology, student evaluation format, and other educational concerns may need to be modified.

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- Encourage other students to extend their friendship. Some may wish to act as peer supports when illness occurs, perhaps helping the student to catch-up on missed lessons.

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- Get to know the person, rather than "seeing an illness".

### In the school environment, an educator can assist families dealing with schizophrenia in the following ways:

- If there is a peer counseling program in the school, the illness of schizophrenia, as it affects young people and their families, should be one of the areas addressed by the program.

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- Ask education directors to provide training on schizophrenia at professional development sessions.

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- Run informational sessions on the illness for parent nights and student assemblies and set up displays (ask a mental health organization to help you) for special occasions in the school library and counseling office.

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- Order print and audiovisual resource materials for your library. Just as you have reference and instructional materials available on other subjects, so you should have materials on schizophrenia.

Educators have an excellent opportunity to foster understanding and compassion for people with brain disorders.



## Missing Persons

Some people with schizophrenia decide that a new location will provide an answer to the problems that the illness has imposed on them – or they may be directed by voices to leave. They simply disappear. When someone you are close to goes missing, it can affect your own mental health as you worry about their safety and where they are. It is important to keep a sense of hope to the greatest degree possible that the person will be found in order to keep moving forward.

If the person is a minor, you should contact the Missing Persons Bureau of the local police department.

Adults can choose to leave home and cut off all contact which means the police may be limited as to what they do in these situations. They have no authority to return the person, or to inform you of his/her actions or whereabouts without specific permission from that person. It is still reasonable to contact missing persons in your area if you are concerned for your family member's well-being.

However, it may happen that the person leaves the hospital before treatment has been completed. If the person is an involuntary patient, the hospital is responsible for notifying the police to look for and return the individual to the hospital. In some jurisdictions, if the police have been unable to find a missing involuntary patient within a certain period, the hospital then has the right to discharge the person.

When a person with schizophrenia has disappeared from the hospital, the option of changing the patient's voluntary status to involuntary is open to the attending physician(s). The police can then be asked to look for the individual.

Often, relatives and caregivers may simply have to wait until the person surfaces. When this happens, (unless the police have been involved) you may make arrangements for the person to return home or consider other options.

### **Here are some tips on preparing yourself for a possible disappearance of the person:**

- If the person mentions places he/she is interested in, or would like to visit sometime, jot it down. It could be a useful clue as to where to look should he/she disappear.
- If he/she decides to travel, try to think of some effective way of staying in touch. For example, one father arranged with his son that he would keep his son's money for him while the son was away. Then, whenever the son needed some funds, the father would send him some, but not too much. This was an effective way of maintaining contact.

### **Some ideas to consider if the person disappears:**

- If you have lost touch with him/her for a period of time, it is wise not to wait too long before you begin checking. Although the police may have no basis for active involvement, it is definitely worth speaking to Missing Persons and telling them your story. They may be able to help by doing some checking or offering some practical advice.
- If you have an idea where an individual may have gone, get in touch with your provincial Schizophrenia Society or the national office. They may be able to help you through a provincial association or chapter in the area where you think the person may be.

- If travel to the United States is a possibility, contact the National Alliance for the Mentally Ill (NAMI) directly or through SSC.
- Check with local voluntary agencies such as the Salvation Army. Sometimes a missing person will show up in one of their hostels. Also, your place of worship may be able to help, particularly if the individual took a keen interest in religion.

If you decide to use the services of a firm of private investigators, determine if the firm you select is well connected with the police (they may be able to get help from this source that you cannot.) Discuss with the firm a reasonable limit on its expenses, including the fee, to undertake a realistic search on your behalf.



## Chapter 12

# Impaired Cognition in Schizophrenia

Traditionally, functioning of the mind is described under four headings – perception, emotion, cognition, and conation. Perception refers to awareness of surroundings, usually through sensory functions such as seeing, hearing, smelling, tasting, or touching. Emotion refers to feelings such as happiness, sadness, anger, etc. Cognition is derived from the Latin word *Cognitio*, which means to know. In modern psychology and psychiatry, the phrase “cognitive functions” is used to describe various aspects of thinking such as attention, concentration, comprehension, memory, orientation, abstraction, and judgment. Cognitive functions range from simple abilities such as counting change from a dollar, to complex tasks requiring concentration and coordination such as playing chess, driving a car or writing poetry. Conation refers to behaviour or actions, e.g., walking, cooking etc.

### Is Cognition Impaired in Schizophrenia?

The simple answer is yes. However, there are some controversies and caveats about it. The controversies become evident from a historical review of the concept of schizophrenia. At first, pioneering psychiatrists such as Krapelin and Bleuler believed that schizophrenia, over a period of time, causes a cognitive decline. In the intervening years, others viewed schizophrenia from a narrower perspective, and described it in terms of distorted thoughts (delusions) and perceptual problems (hallucinations) without the involvement of cognitive functions. These views have again changed over the past two decades, and we have now come to believe that cognitive impairment is commonly associated with schizophrenia. In fact, one research study suggests that approximately 61-78% of people with schizophrenia demonstrate significant cognitive impairment.<sup>80</sup> Another study suggests it could be as high as 98%.<sup>81</sup>

Schizophrenia is now considered to have four sets of symptoms: positive symptoms, negative symptoms, disorganization symptoms, and cognitive impairment. The relationship between cognitive disturbances and other symptoms of schizophrenia is not clearly understood at present. It has been observed that some people experience cognitive problems before they develop positive symptoms, while others experience cognitive deterioration after the first episode and with subsequent relapses. The emergence of cognitive deficits, generally speaking, results in an unfavourable outcome in the long term.

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80 Green MF. Cognitive impairment and functional outcome in schizophrenia and bipolar disorder. *The Journal of Clinical Psychiatry*. 2006 Oct; 67(10): e12

81 Tripathi, Adarsh et al. Cognitive Deficits in Schizophrenia: Understanding the Biological Correlates and Remediation Strategies. *Clinical Psychopharmacology and Neuroscience*. 2018 Feb; 16(1): 7-17

There are two caveats though, to remember. First, there is a great variability in the occurrence of these different sets of symptoms. Some people experience positive symptoms only, while others may have more negative symptoms, and a proportion of affected individuals develop cognitive difficulties. Second, the extent of cognitive involvement may also vary between different individuals. The majority of people diagnosed with schizophrenia experience only subtle difficulties, while a smaller group (about 1 in 5) seem to show more striking cognitive deficits.

## How Do Cognitive Problems Affect Daily Routine in Schizophrenia?

The Merck Manual describes cognitive impairment in schizophrenia as “difficulty concentrating, remembering, organizing, planning, and problem solving.” Further, it states that “some people (with schizophrenia) are unable to concentrate sufficiently to read, follow the story line of a movie or television show, or follow directions. Others are unable to ignore distractions or remain focused on a task. Consequently, work that involves attention to detail, involvement in complicated procedures, decision making, and understanding of social interactions may be impossible.”<sup>82</sup>

The person experiencing cognitive difficulties often complains of speeded-up thinking, racing thoughts, feeling mixed up, and having poor concentration or being forgetful (memory problems). When these problems are mild, the person will have difficulties with reading, writing, or watching TV. People with a greater degree of cognitive problems will be unable to carry out tasks (e.g., cooking, shopping, etc.), manage their money, and look after themselves. This may result in poor hygiene, malnutrition, and self-neglect. The worst type of cognitive impairment results in potentially dangerous behaviours such as walking into traffic, leaving the stove on, or mixing up medications. Over time, for some people with schizophrenia, cognitive difficulties can lead to consequences such as unemployment, disability, poverty, debts, and excess dependency. Two of the common and frustrating problems are forgetting to take medications and neglecting to keep medical appointments.

## What Causes Cognitive Deficits in Schizophrenia?

It is now generally believed that schizophrenia is a brain disorder, and the variety of symptoms experienced is the result of impaired functioning in different areas of the brain. It is possible that abnormalities in neurodevelopment, with influences from genetic factors, might be responsible for the cognitive impairment seen in schizophrenia.<sup>83</sup>

## How to Get Cognitive Problems Assessed?

There are three possible methods of identifying, assessing, and monitoring cognitive problems. These include periodical reviews by a psychiatrist, specialized testing by a psychologist, and diagnostic brain scans. Of these,

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82 Tamminga, Carol. Schizophrenia. The Merck Manual; May 2020.

83 Tripathi, Adarsh, et al. Cognitive Deficits in Schizophrenia: Understanding the Biological Correlates and Remediation Strategies. *Clinical Psychopharmacology and Neuroscience*. 2018 Feb; 16(1): 7-17

regular monitoring in a clinical setting is often the only feasible option. Psychological testing to assess the cognitive problems in schizophrenia is a sophisticated procedure and is not readily available everywhere. There are a few psychologists who have the required training and expertise to perform such tests. Brain scanning techniques such as MRI hold the promise of precisely identifying and monitoring cognitive problems. But these techniques are still being developed and are not easily accessible in all places.

## What Can Be Done About Impaired Cognitive Functions in Schizophrenia?

There are two ways of dealing with cognitive problems: treatment and prevention. Treatment strategies include the use of appropriate medications, maintaining an active daily routine, and participating in cognitive remedial therapy programs. One study proposed that “newer antipsychotics, including paliperidone, lurasidone, aripiprazole, ziprasidone, and perphenazine, have been reported to exert cognitive benefits in patients with schizophrenia.”<sup>84</sup> It is also important to remember that using inappropriately higher doses of medication may actually worsen, instead of improving certain aspects of cognition. Distinguishing frequently associated symptoms such as anxiety, depression or obsessions, and treating them with appropriate medications such as antidepressants, also makes a big difference in improving cognitive functioning.

Cognitive remedial therapy is a relatively new approach that is not widely available for routine use. It involves a set of techniques or tasks designed to improve cognitive abilities and social functioning. It is individualized but may involve for example practicing various mental exercises, usually with the help of a computer. Other simple steps include the use of various memory aids (e.g., using a dosing box to take medications regularly, and a calendar to note appointments), and generally maintaining an active structured routine.

### **Like many other things in life, the principle with cognition is, “Use it or lose it.”**

In the small proportion of individuals who are prone to develop a progressive type of cognitive deterioration, prevention is more critical. Initiation of antipsychotic medications early, soon after the first symptoms of illness appear, may have some value in limiting the deterioration in later years. Strict adherence to the recommended dose of medication over a period of time is also essential in lessening the degree of deterioration. Keeping symptoms under control and avoiding relapses of illness is perhaps the best approach to prevent cognitive deterioration. It is important to note that the indiscriminate use of recreational (street) drugs can worsen cognitive functions in vulnerable individuals.

## Current Limitations

While a lot has been learned from research over the past two decades, several questions still remain unanswered. First of all, it is not known if there are certain cognitive disturbances that are unique to schizophrenia. Cognitive problems of different sorts are seen in a number of other disorders such as Alzheimer’s disease, and the type of difficulties that are specific to schizophrenia are yet to be clearly identified. Second, there is a continuing debate about the progression of cognitive problems: whether they get worse

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84 Hsu, Wen-Yu, et al. Medications Used for Cognitive Enhancement in Patients With Schizophrenia, Bipolar Disorder, Alzheimer’s Disease and Parkinson’s Disease; *Frontiers in Psychiatry*; 04 April 2018.

over a period of time or not. Third, there is a need to develop a method of identifying individuals who are more prone to develop cognitive problems than others. Having such a predictive strategy will help with early recognition and possible prevention. Fourth, the areas of the brain that are involved in cognitive deficits need to be further pinpointed. Lastly, there is a need to develop new treatment strategies. Cognitive deterioration is one aspect of schizophrenia for which we do not have an effective treatment strategy at present.

## Research in Progress

Cognitive aspects of schizophrenia have become an active area of research. Researchers are working on identifying the exact nature of cognitive problems experienced by people with schizophrenia and have developed appropriate tests to measure and monitor them. Functional imaging has been another active area of research. Scanning devices such as the MRI and PET imaging are being used to study the brain mechanisms involved in causing cognitive problems. Also, major pharmaceutical companies are actively investing in the development and testing of newer medications that are likely to offer greater benefits in improving cognitive problems. Psychologists, occupational therapists, and specialists in education are involved in developing various cognitive remedial strategies that could be incorporated into day treatment programs and daily routine.

## Conclusion

Our efforts to understand schizophrenia seem to unfold as if we were peeling the layers of an onion. At first, it appeared that positive symptoms were the only problem. Antipsychotic medications have been greatly helpful in controlling these symptoms. As these medications became widely available, the problem of negative symptoms became apparent. The new second generation antipsychotic drugs offer some hope that negative symptoms can also be conquered. Cognitive problems are the next ones to tackle in the ongoing battle with this devastating disorder. Solving them presents a significant challenge. Understanding the origins of cognition and brain mechanisms is likely to help us not only in dealing with schizophrenia, but also in unraveling the mysteries surrounding other mental illnesses.

The reader is encouraged to see:

[http://www.ncbi.nlm.nih.gov/  
pubmed/21914252](http://www.ncbi.nlm.nih.gov/pubmed/21914252)



## Chapter 13

# Relapse and Chronic Illnesses

### Relapse

The nature of schizophrenia is such that the positive symptoms (hallucinations, delusions, etc.) tend to reoccur. It is important, therefore, to be aware that the person is likely to experience a relapse, and to watch for the early warning signs that their condition is getting out of control again. Each individual's early warning signs of relapse will be different and over time, you will get to know your family member's "signature" relapse signs. However, often the behaviours that indicate a relapse are usually the same as those that occurred prior to the first episode, for example:

- Sleeplessness
- Increased social withdrawal
- Deterioration of personal hygiene
- Thought and speech disorder
- Signs of visual and auditory hallucinations (e.g., listening excessively to loud music, usually with headphones, perhaps in an attempt to drown out the voices).

Relapse can occur for a number of reasons, as well as for no apparent reason. Some potential clues are listed below:

- Stopping medication for a long enough period of time that acute symptoms may reappear
- Insufficient dosage of medication to prevent the return of acute symptoms
- Lack of support, either at home or from community services
- Severe emotional stress, e.g., the death of a loved one, the loss of a job, the move to a new home
- Physical exhaustion
- Usage of alcohol or street drugs

Sometimes the cause may be something that can be dealt with quite easily. For example, medication can be increased, a brief hospital stay can be arranged, or more support can be found.

Health care professionals warn that relapse can occur during a period called self-cure. (This also occurs in other illnesses, such as diabetes and arthritis.) Usually, such an attempt occurs three to five years after a diagnosis of schizophrenia has been made. It is a time when the individuals, tired of the illness, decide to take matters into their own hands. They may stop taking prescribed medication, may join a cult, may try to exorcize the illness out of the body, may do strenuous exercise to get rid of it, may consume vast quantities of vitamins or herbal medicines, and so on.

A relapse is very disappointing but is common among people with various chronic diseases. Whether the person goes through a period of carelessness, forgetfulness, or rebelliousness, he/she is simply being human. Unfortunately, however, this makes a person with schizophrenia vulnerable to relapse.

The best way to prevent relapses, and deal with them when they happen, is to plan ahead by developing strategies both for avoidance and occurrence. Discuss these plans with the individual while he/she is in a

stable phase, and also with the attending physician(s).

By knowing the illness, you and the person with schizophrenia can be prepared to watch for signs of relapse and seek immediate medical attention when they appear. Try to establish an agreement with the individual that, for example, will deter him/her from stopping medication, or that will encourage him/her to advise you or the doctor when the feeling of losing control returns. Allow the person to have as much input as possible into the plan. Assure the person that he/she will not be abandoned should a relapse occur, but also make it clear as to what behaviours will not be tolerated, e.g., extreme aggression or violence.

Awareness and readiness can help your family prevent or minimize relapses. A plan is your weapon in the battle against schizophrenia.

While every effort must be made to persuade people with schizophrenia to take their medication voluntarily, most provincial mental health laws provide some form of assisted community treatment. When a person has a severe illness, has a history of not taking prescribed treatment, and has frequent relapses, he/she may be required by law to receive treatment in the community (as opposed to a hospital environment). If he/she refuses to comply with the treatment order, then he/she may be involuntarily admitted to a hospital. This can be a very helpful measure to those (relatively few) families who experience this problem. For more information on assisted community treatment orders, consult your provincial Schizophrenia Society, and a mental health or legal professional with expertise in this area.

## Risk of Suicide

With schizophrenia the possibility of suicide is an ever-present fact. The illness involves depression, delusions, and sometimes command hallucinations that may tell the person to attempt suicide. There is a tendency to act impulsively. E. Fuller Torrey, notes in *Surviving Schizophrenia: A Family Manual* that an estimated ten percent of

all people with schizophrenia die by suicide. As in the general population, men are more likely to die by suicide, while women attempt it more often. Suicide, when it happens, occurs most commonly during the first five years of illness. After this, the risk drops considerably. Torrey suggests that, “Those at highest risk have a remitting and lapsing course, good insight (e.g., they know they are sick), have a poor response to medication, are socially isolated, hopeless about the future, and have a gross discrepancy between their earlier achievements and their current level of function.”<sup>85</sup>

Sometimes a suicide is methodically planned and deliberately completed. At other times, a suicide may be accidental — that is, the victim is acting out a hallucination or delusion when in a psychotic state. In either of the above situations there are some preventive measures you can take, although you can never guard completely against the possibility of suicide.

Here is a list of behaviours that may indicate suicide is being contemplated:

- The person talks about suicide: what it would be like to die, how to go about it, or makes comments such as, “When I’m gone...,” and so on. He/she is concerned about having a will, and about the distribution of possessions. He/she may begin giving away treasured belongings.
- The individual expresses feelings of worthlessness, for example, “I’m no good to anybody”.
- They show signs of hopelessness about the future, making comments like, “What’s the use?”
- The person is showing signs of hearing voices or seeing visions that may be instructing him/her to do something dangerous.

All talk of suicide or self-harm must be taken seriously. It is not true that someone who talks about suicide rarely does it. If the person begins to talk about suicide or inflict wounds — no matter how superficial — upon him/herself, it is vital that you reach his/her therapist immediately. If this isn’t possible, take the person to a mental health crisis response centre or the hospital where he/she was previously admitted, or to the nearest emergency department. In many communities, there is a suicide hotline available.

If suicide is attempted, and you are the one who discovers the individual during the act or soon thereafter, the following steps should be taken:

- Phone 911 immediately. (If this service is not available in your area, call the emergency number of the nearest hospital.)
- If appropriate, and if you are fully trained, perform

<sup>85</sup> Torrey E. Fuller, *Surviving Schizophrenia: A Manual for Consumers, Families, and Providers*. 3rd edition Harper Collins, NY, 2001.

Often, when someone dies by suicide, family members stop going to support group meetings. The relatives of suicide victims may believe that their presence is too depressing for other members of the group.

Families in support groups urge these people to keep attending meetings. As one father stated: “When a relative develops schizophrenia, the support group becomes your family, because so often you lose family and friends. Now, when you’ve lost your relative, you need your new family more than ever.”

CPR (cardiopulmonary resuscitation).

- Phone someone to come and be with you, whether it is at the hospital as you wait for news, or at home to take care of you.
- Although it is not likely, be prepared for the possibility that the hospital may not admit the person, even after a suicide attempt.
- Get in contact with your local support group, if there is one, and let them know what has happened.
- Do not try to handle the crisis alone.
- Do not hesitate to contact other support groups that deal specifically with grief and bereavement.

## Treatment-Resistant (Refractory) Schizophrenia

### What is Treatment-Resistant Schizophrenia?

As we have noted in earlier chapters, schizophrenia is an illness characterized by onset relatively early in life, most frequently during late adolescence or early adulthood. Its course is variable. Many people show a rapid and effective response to antipsychotic medications. However, some individuals treated with antipsychotic medications, particularly older individuals, do not respond well to the treatment.

These individuals are frequently referred to as having treatment-resistant or refractory forms of the illness. Treatment resistant schizophrenia occurs in up to 34% of individuals with schizophrenia.<sup>86</sup> At present, there are no specific tests or measures that allow us to distinguish who will respond well to treatment or who will do poorly. There are certain factors which seem to increase the risk of doing poorly (e.g., male, early onset) but these are by no means absolute predictors. Some individuals fail to show effective response even in the earliest stages of the illness, while others may only show treatment resistance over time.

### Evaluating Treatment-Resistant Schizophrenia

In those who are not responding effectively to treatment, various factors must be considered. It is important to review the diagnosis, because schizophrenia-like symptoms are seen in other conditions, and this may influence treatment. Antipsychotic medication remains a key cornerstone of treatment in schizophrenia. Therefore, if a person is failing to take the prescribed medication, this may explain why they have persistent symptoms that can mimic treatment resistance. There is variability in responses to antipsychotic medications, with individuals showing response to certain medications and not to others. For this reason, it is important to try various medications with people who have not responded to one or more medications. Other behaviours, such as problematic substance use, can exacerbate or diminish symptom control, and this too can result in an individual appearing to be refractory to treatment.

It is important to know that having treatment-resistant schizophrenia does not mean that the individual will have the worse manifestations of this illness. Individuals may have a mild, moderate, or severe form of schizophrenia.

86 Lally, J. et al. Two distinct patterns of treatment resistance: clinical predictors of treatment resistance in first-episode schizophrenia spectrum psychoses. *Psychol. Med*46, 3231–3240 (2016).

## Defining Outcome Measures

Not so long ago, it was common to evaluate response to treatment along a single dimension, e.g., dealing only with positive symptoms such as hallucinations and delusions. However, it is now more common to see schizophrenia defined as an illness that can affect a number of dimensions, and therefore have different outcome measures. For example, it is now more common to look at not only positive and negative symptom outcome measures but functional outcome measures, that is how an individual is able to carry out the normal daily activities required of all of us.

With these numerous measures now being evaluated, the scope of treatment response, or conversely treatment-resistance, has broadened. More specifically, individuals may show improvement in some of these measures, while failing to show the same degree of change in others. In this sense, treatment resistance is not seen as a single entity any longer, but rather a multi-dimensional process.

## A Systematic Approach to Treatment-Resistant Schizophrenia

In order to optimize treatment outcome, it is absolutely essential that a systematic approach be taken to treatment. This includes not only trying different types of medications, but also combining medical treatment with psychosocial approaches.

In terms of medical treatment, it is important to ensure that different antipsychotics have been tried, and that this has been done in a way that maximizes the chance of success, for example, adequate doses for a sufficient duration of time. Among the newer antipsychotics, there is evidence that clozapine seems to work best in those individuals who have truly proven resistant to treatment with other first and second generation anti-psychotics. As has been mentioned, unfortunately clozapine is associated with a particular side effect that requires ongoing blood monitoring, and for this reason some individuals choose not to take it. However, it is generally recommended that all individuals who have not demonstrated a good response to other antipsychotics have a trial of clozapine at some point. As a rule, this trial is often left until various other antipsychotic agents have been tried because of the need for the ongoing blood monitoring.

Even with those who have tried clozapine, it is possible to see only a partial response. Research indicates that up to 60% of individuals with treatment resistance will not respond even to clozapine.<sup>87, 88</sup> At that point, what are called augmentation strategies are frequently invoked in order to further improve response. This involves the addition of other medications, or even electroconvulsive therapy (ECT), to the existing antipsychotic, once again in an effort to maximize clinical response. Agents that might be used as augmentation strategies include antidepressants, mood stabilizers, benzodiazepines, and even other antipsychotic medications in combination.

In treating persons, including those who seem to be treatment resistant, it is essential that the approach include more than just medication. While medication is a key factor in recovery for those with schizophrenia, some of the elements that contribute to a good quality of life (for example, a sense of purpose, a positive sense of self, connection to community) can be bolstered by non-medical means as well. To this end, the best response seems to occur in those individuals who receive medication in addition to non-pharmacological interventions

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87 Farooq, S., Agid, O., Foussias, G. & Remington, G. Using treatment response to subtype schizophrenia: proposal for a new paradigm in classification. *Schizophr. Bull.* 39, 1169–1172 (2013).

88 Siskind, D., Siskind, V. & Kisely, S. Clozapine response rates among people with treatment-resistant schizophrenia: data from a systematic review and meta-analysis. *Can. J. Psychiatry* 62, 772–777 (2017).

such as psycho-education programs regarding the illness, rehabilitation programs, informal supports and relationships, and ongoing individual and social therapeutic interventions. This often involves the coordination of a number of different health and social profession and seems most successful when the treatment team can work collaboratively with the individual and his or her social supports e.g., a spouse or other family members.

## Conclusion

In general, there is a sense that medical treatments for schizophrenia are improving, particularly more recently. It is a clinical reality that at present there are individuals who remain resistant to existing therapies, but ongoing developments and improvements in treatment serve to hold hope even for this particular group.

With all these options available, it is crucial that persons be evaluated and re-evaluated by their physician(s) on a regular and timely basis. Every effort should be made to bring people to the best level of functioning possible, for example, trials of newer medications.

New drugs provide better opportunities than ever for better stability and functional recovery. It is, therefore, advisable to keep abreast of the most up-to-date developments in drug therapy. New medications bring new hope for all who experience schizophrenia.

Another key avenue for hope lies in the potential for recovery, in which medication plays a major role, as do other factors as well. People who have experienced schizophrenia see recovery as a personal and unique individual process, built on each person's own meaning in life. Those of us who are in relationships with people with schizophrenia foster their recovery when we support their need for hope, their capacity to help themselves and each other, and their ability to change and grow. The topic of psychosocial rehabilitation and recovery is discussed extensively in Chapter 14.

## Prevention of Relapse

### Definition

Relapse in the older psychiatric literature was always synonymous with re-admission to hospital. Outcome studies used rates of re-admission (relapse) as measures of outcome even though for families, and frequently for individuals, re-hospitalizations were good things in that they offered respite from constant worry, or a chance at a re-assessment or better treatment, or a roof over one's head and nutritious meals.

More recently, relapse means a change of score on a symptom scale. At the beginning of a treatment program, for instance, the person may be given a symptom questionnaire. As they improve the score changes (goes either up or down depending on the questionnaire). A relapse is subsequently defined as a certain percentage change back to the pre-treatment value. This is a useful and measurable definition, but it is not foolproof. The questionnaire may not include questions that address the behaviour that, to the family and caregivers, signals imminent worsening of the individual. For example, sleepless nights or sudden aggression may alert people who know the person well that something is changing, however, this change in behaviour may not be reflected in the questions asked or answers given in the questionnaire.

In the future, relapse may be defined with respect to function: losing a job for instance; losing a friend or failing a class. Functioning is probably more important to families and to the person than symptoms. For the purpose of the following section, relapse will simply mean general worsening as perceived by the family and caregivers.

## How To Prevent Relapse

Tried and true ways to prevent relapse are the reduction of stress, the provision of structure, the modulation of stimulation, and the maintenance of support. Daily life will be different for each individual. Not everything will be within your control and it is important to encourage autonomy, but the following are some general thoughts about how to support your family member to prevent relapse.

### Relapse Prevention Plan/Crisis Plan

Identifying early warning signs of and triggers of a relapse are important first steps as knowing these help an individual to take action early.

A relapse prevention plan/crisis plan is something that can be created when an individual is not in crisis. Such a plan typically includes things like triggers, early warning signs of a relapse, what the individual will do if they have any of the early warning signs, phone numbers of health professionals they are working with and of support persons (such as a parent, a sibling, or a friend), and who they will call in case of a crisis/emergency.

Everyone will have their own triggers, but the following are some examples of common triggers:<sup>89</sup>

- Poor sleep or not getting enough sleep
- Loss or grief
- Conflict among loved ones
- An unpleasant event such as a perceived failure, disappointment or criticism
- Other stressful events
- Alcohol and other drug use
- Not following through on treatment and recovery plan (such as not taking prescribed medications)
- Other health problems or concerns

A relapse prevention plan can also include a list of things that help the individual when they are feeling overwhelmed or start to notice their warning signs. A list of things that don't help can be added to the plan, too.

You can encourage your family member to create their own personal relapse prevention/crisis plan or if your family member needs help with this and is agreeable, you can help support him or her in creating their own personal relapse prevention plan. Individuals can be encouraged to print a copy of this and keep it in their wallet, purse, etc. and provide a copy to their health care provider and a family member if they are agreeable so that their support system can watch for signs of relapse, too.

The wellness recovery action plan (WRAP) is an example of a recovery/crisis prevention plan which individuals can create for themselves.<sup>90</sup>

89 heretohelp website. Preventing Relapse of Mental illnesses. <https://www.heretohelp.bc.ca/infosheet/preventing-relapse-of-mental-illnesses>

90 <https://www.fraserhealth.ca>

### **Taking Action to Prevent Relapse**

Once your family member has a relapse prevention plan in place, it is time to consider how to take action if the warning signs show up. Identifying stressful situations, managing those stressful situations, and building healthy coping skills are all important.

### **Identifying and Managing Stress**

Reducing the chance of being overstressed is like reducing the chance of being infected. You try to avoid possible sources of stress (just as you would avoid people who sneeze); you try to develop habits that counter the effects of stress (just as you would regularly wash your hands); you try to fortify your defenses against stress (just as you would eat a healthy diet with lots of vitamins), and you try to immunize yourself against stress (just as you would get a flu shot).

We have already talked about the importance of identifying triggers of stress and warnings of potential relapse. Good counter stress habits include getting lots of sleep, good food, exercise, having friends you can talk to, and avoiding alcohol, drugs, caffeine, and nicotine. Individuals can fortify their defenses against stress and it is good to encourage your family member to speak to a therapist about this important issue. You can also help your family member find other healthy ways to relax, such as doing deep breathing exercises, meditation or mindfulness, art or writing.

There are some practical ways to approach situations or events that may be coming up, such as for example, going back to school.<sup>91</sup> In these situations, it is advisable for an individual to start slowly, rather than all at once. So, for example, it may be possible to take part-time courses instead of a full course load. It is also important to take time for self-care. It is also okay for individuals to cut back on some responsibilities if they are taking on something new.

### **Building Healthy Coping Skills**

Healthy coping skills overlaps with some of the ways we manage stress. It involves things like eating well, exercising regularly, getting enough sleep, practicing relaxation skills, and developing healthy thinking skills. It also involves learning good problem-solving skills.<sup>92</sup>

You can support your family member in understanding the importance of healthy coping skills and ways in which they can learn and practice them.

### **When Structure is Needed**

If your family member is not currently active or keeping busy, it may be important to help or support them in making up a schedule for each day. It is important that the individual take a lead in identifying his or her own interests in a daily schedule. An appointment calendar serves as an organizer and memory tool; using it can also give the individual a sense of accomplishment at the end of each day.

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91 heretohelp website. Mental Health; Preventing Relapse of Mental Illness.

92 heretohelp website. Mental Health; Preventing Relapse of Mental Illness.

A sample schedule could look something like this:

Time	Task
8:00am	Wake up, shower, dress
9:00am	Prepare and eat breakfast, (take medications)
9:30am	Clean breakfast dishes and make bed
10:00am	Walk around the block, mail letter, buy newspaper
10:30am	Write in diary
11:00am	Read newspaper and rest
12:00pm	Prepare a salad, eat it, clean up
12:30pm	Listen to music
1:00pm	Errands, laundry, sewing, ironing, cleaning
2:00pm	Write a letter, call a friend

2:30pm	Have a piece of fruit, relax
3:00pm	Watch TV
4:00pm	Read a book
5:00pm	Start preparing for supper, prepare vegetables, cook main dish, set the table
6:00pm	Supper (with family)
7:00pm	(Help) Clean up
7:30pm	TV
9:00pm	Call friends, talk to family
10:00pm	Prepare for bed, take medications

While too much stimulation can cause stress, too little may result in apathy and boredom. The task of the family and caregivers is to support the individual to find the right balance. This is not easy but comes with practice. Generally, some people find that activities that involve fewer people are easier. A walk around the block together could be a start. Introducing something new now and again is good, but novelty can also be stressful. It is important to support the establishment of a routine, then encourage slight variations on the routine if that seems necessary.

### Maintaining Support

Maintaining support refers mainly to emotional support but may include financial support as well. No matter what the person with schizophrenia says or how he/she behaves, the family needs to maintain a supportive stance. This can be at a distance if necessary. Support does not necessarily mean closeness. It means that the person knows that the family is always there for him/her no matter what. Ideally, this is accompanied by encouragement, praise, recognition of even minor accomplishments, and optimism.

If you notice behavioural changes in the person that you suspect may coincide with the onset of a relapse, talk to the individual and encourage them to bring it to the attention of a member of the treatment team immediately. In some instances, you will have to bring it to someone's attention yourself. Remember, relapse is a natural phase of the illness. With strength, courage, and lots of support, the person can recover again!

### Use of Psychiatric Advanced Directives

Many people with a mental illness choose to express their crisis plan in the form of a legal document called a Psychiatric Advance Directive (PAD). During a crisis, people may lose their autonomy and their ability to choose. They may need help making their preferences known and having them followed. A PAD is a statement of rights and preferences and tells others what the individual as the patient wants when they can't tell them themselves. Several research studies have found that individuals with mental illness have a high interest in

PADs, with one study demonstrating that “between 66% and 77% of respondents would want to complete a PAD if provided assistance”.<sup>93</sup>

PADs are only used temporarily and only when the individual is incapable of making or communicating treatment decisions.

The exact form and use of PADs will vary from one province to another depending on the provincial Mental Health Act, but there are a number of basic elements covered below in a PAD (written from the perspective of the individual).

- A PAD lets you plan for, consent to, or refuse treatment, such as hospital admission, administration of medication, or electroconvulsive treatment (ECT).
- A PAD anticipates that your family member may experience crisis at some future time and that you may not be able to make decisions or communicate your wishes about treatment.

### There are Generally Two Components to a PAD:

1. Advance Instructions (AI): A statement of consent or refusal of treatment, listing specific medical interventions during a crisis, for example, medications, or electroconvulsive therapy.
2. Health Care Power of Attorney (HCPA): In this document, your family member appoints a proxy decision-maker to make treatment decisions for them when they are not able to make or communicate decisions.

### What are the benefits of creating a PAD?

Research has shown that creating a PAD can support the recovery process by:

- Empowering the person who is experiencing a psychiatric crisis.
- Helping people maintain their autonomy during periods of psychiatric crisis.
- Providing a way to clearly express wishes for the treatment a person knows is most effective during a crisis.
- Making people more aware of what treatments they need.
- Using experience as a learning tool by identifying preventive actions, coping skills, and self-management techniques.
- Recognizing people’s expertise in their own treatment.
- Facilitating stronger patient-provider relationships by creating a more informed and open dialogue<sup>94</sup>

93 Scholten, Matthe et al. Psychiztric Advance Directives Under the Convention of Persons with Disabilities: Why Advance Instructions Should be able to override current Preferences: *Frontiers in Psychiatry*: 11 September 2019.

94 Kim, M. M., Scheyett, A. M., Elbogen, E. B., Van Dorn, R. A., McDaniel, L. A., Swartz, M. S., et al. (2008). Front line workers’ attitudes towards psychiatric advance directives. *Community Mental Health Journal*, 44(1), 28–46.

**How Can Your Family Member Create a PAD?**

- Generally, your family member fills out the form provided by your province. If your family member's province does not have a specific form, they can create your own valid form.
- PAD forms are usually witnessed and formally signed, and sometimes even notarized.
- Your family member must give a copy of their form to their attending physician, to the people they've named to act on their behalf, and to members of their treatment team.

**Things to Keep in Mind:**

- Keep the PAD up to date. If your family member's information, preferences, or plans change, make sure they make changes to their PAD.
- Make sure your family member provides up to date information about the people who will act for them.
- Your family member has the right to revoke their PAD at any time.

This section on Advanced Psychiatric Directives is taken from the SSC's resource material: Your Recovery Journey found at: <http://www.your-recovery-journey.ca>

Your Recovery Journey is important for several reasons. It builds on the now well-established literature and evidence base for recovery from mental illness and contributes to the growing number of programs that focus on empowering people to manage their own treatment and recovery. Chapter 14 expands on the definitions, principles, and the values associated with the recovery model.



## Chapter 14

# Psychosocial Rehabilitation and Recovery

### Psychosocial Rehabilitation And Reintegration

Some of the most hopeful news in schizophrenia research is emerging from studies in the field of psychosocial rehabilitation and recovery, concepts that are threaded throughout this document. Psychosocial intervention for schizophrenia is based upon best practices of psychiatric rehabilitation. By intervening with persons, significant improvements in their recovery and quality of life can be achieved. This proven philosophy has led to the development of renowned concepts and programs in rehabilitation.

One of the goals of early intervention is to facilitate the person's return to his/her regular activities as soon as possible. The person must be ready to face the challenge of returning to his/her life in the community, and thus the timing and pace of reintegration must be handled carefully. Readiness will depend on the rate of recovery from positive symptoms, which could take days or weeks. The treatment team can assist by providing psychoeducation and psychosocial rehabilitation from a recovery-oriented philosophy. Working with the individual, these service providers will help assess the person's ability to maintain his/her pre-illness academic or career goals; explore together with the individual his or her interests and strengths to see if new activities are more suitable; examine with the individual his/her living conditions and ability to live independently, and help the person make suitable living arrangements. They will also support the individual in setting goals for returning to social settings.

The purpose of psychosocial rehabilitation is to teach the person how to negotiate his/her need for support within the various environments in his/her life. For example, if returning to school, the person may require some modifications to his/her curriculum, and/or some study aids. If returning to a job, the individual may need to negotiate some changes in responsibilities, accommodations such as a quiet workspace, or a change from full-time to part-time working hours. If financial assistance and/or disability benefits are necessary, the person may need to be educated on how to obtain them. He/she may also need help with day-to-day living skills. The longer the person is removed from a near normal lifestyle, the more difficult it will likely be to reintegrate. It is to

“Myth: Rehabilitation can be provided only after stabilization. Reality: Rehabilitation should begin on Day One.”

— Dr. Courtenay Harding,  
University of Colorado School of  
Medicine

the person's advantage to receive early interventions (e.g. psychoeducation and psychosocial rehabilitation) to help him/her participate as fully as possible in community life. Family members should strive to obtain the appropriate services for their relative as soon as he/she is stable.

## Principles of Psychosocial Rehabilitation (PSR)

According to PSR CANADA, psychosocial rehabilitation “promotes resilience, personal recovery, full community integration, and a sense of purpose and meaning” for individuals living with a mental illness and/or problematic substance use issue. Not only does PSR support individuals but its approaches also offer practitioners and organizations an ability to provide recovery-oriented services.

Psychosocial rehabilitation services and supports are collaborative, person directed, and individualized, and an essential element of the human services spectrum. They focus on helping individuals develop skills and access resources needed to increase their capacity to be successful and satisfied in the living, working, learning and social environments of their choice and include a wide continuum of services and supports.

The following PSR Core Principles and Values are meant to further describe key elements of Psychosocial Rehabilitation practice.<sup>95</sup>

1. Psychosocial rehabilitation practitioners convey hope and respect and believe that all individuals have the capacity for learning and growth.
2. Psychosocial rehabilitation practitioners recognize that culture and diversity are central to recovery and strive to ensure that all services and supports are culturally relevant to individuals receiving services and supports.
3. Psychosocial rehabilitation practitioners engage in the processes of informed and shared decision-making and facilitate partnerships with other persons identified by the individual receiving services and supports.
4. Psychosocial rehabilitation practices build on strengths and capacities of individuals receiving services and supports.
5. Psychosocial rehabilitation practices are person-centered; they are designed to address the distinct needs of individuals, consistent with their values, hopes and aspirations.
6. Psychosocial rehabilitation practices support full integration of people in recovery into their communities, where they can exercise their rights of citizenship, accept the responsibilities and explore the opportunities that come with being a member of a community and a larger society.
7. Psychosocial rehabilitation practices promote self-determination and empowerment. All individuals have the right to make their own decisions, including decisions about the types of services and supports they receive.
8. Psychosocial rehabilitation practices facilitate the development of personal support networks by utilizing natural supports within communities, family members as defined by the individual, peer

95 PSR Canada website. Psychosocial Rehabilitation and Recovery Resources.

support initiatives, and self-help and mutual-help groups.

9. Psychosocial rehabilitation practices strive to help individuals improve the quality of all aspects of their lives, including social, occupational, educational, residential, intellectual, spiritual and financial.
10. Psychosocial rehabilitation practices promote health and wellness, encouraging individuals to develop and use individualized wellness plans.
11. Psychosocial rehabilitation services and supports emphasize evidence-based, promising, and emerging best practices that produce outcomes congruent with personal recovery. Psychosocial rehabilitation programs include program evaluation and continuous quality improvements that actively involve persons receiving services and supports.
12. Psychosocial rehabilitation services and supports must be readily accessible to all individuals whenever they need them; these services and supports should be well coordinated and integrated as needed with other psychiatric, medical, and holistic treatments and practices. 33

## Recovery

Clinicians who investigate the long-term course and prognosis (a forecast of the course of the disorder) of schizophrenia are now presenting a very different picture of the illness from the gloomy scenario painted in the past. Research now challenge several long-held myths in psychiatry about the inability of people with schizophrenia to recover from their illness. It now appears that such myths, by maintaining an overall pessimism about outcomes, may significantly reduce people's opportunities for improvement and/or recovery. In fact, the long-term perspective on schizophrenia should give everyone a renewed sense of hope and optimism. As a result of this knowledge we now possess, rehabilitation programs have evolved dramatically to improve the quality of life and functional recovery of people with schizophrenia, focusing less on reducing symptoms and more on meaningful engagement and the potential for growth.

Recovery from schizophrenia does not imply a cure. While some view it as cessation of symptoms, many people with mental illness see recovery as a sense of mastery over their life and illness. Recovery in this context can occur while symptoms are still present. One article describes how recovery from serious mental illness can be understood in these two different ways: disease oriented, focusing on remission of symptoms, or a personal and social process or journey that is characterized by positive changes in views of oneself, purpose in life relationships and ways of growing beyond the illness. The authors suggest that this process view of recovery is compatible with positive mental health, an ideal state for all people regardless of whether or not we have a diagnosis of mental illness.<sup>96</sup>

Writings by people with mental illness support this view of recovery as a process or a journey. They suggest that the process is based on a sense of hope and renewed optimism and that it is unique to each individual. It may involve changing one's attitudes, values, feelings, goals, and/or roles to develop a new purpose and meaning. Most important, it can lead to a satisfying life that is not controlled by the illness.

96 34Provencher, H. and Keyes, C. (2011) Complete mental health recovery: bridging mental illness with positive mental health. *Journal of Public Mental Health*. Vol. 10 No. 1:57-69.

The course to recovery may well be marked by setbacks. For some people, or at some periods, managing the illness will be the priority consideration. But a recovery orientation is based on a belief in resilience or the ability to bounce back from challenges. It takes a long-term view that it is possible to grow beyond the catastrophic effects of mental illness or its devastating social consequences, and to have a meaningful life despite the challenges. The experience of recovery involves a personal sense of this possibility, and faith in a future where things may be expected to work out reasonably well.

Service providers who understand the promise of recovery are learning from individuals about how to support their recovery. As they spread the word about recovery-oriented practice amongst their colleagues, increasing numbers of providers are working with individuals in partnerships to support their informed decision-making, encouraging their pursuit of their own independent goals and aspirations, acknowledging their strengths, educating them about their medications, and giving them room to make mistakes.

There is more and more reason for hope. Alongside these psychosocial rehabilitation and recovery-oriented approaches, new and better drug therapies continue to be produced. Also, studies show that schizophrenia is not a disorder that progresses with age. And the longer a person is free from acute episodes, the better the chances for a full recovery.

The importance of family input for treatment, and the benefits of good relationships between clinicians and families, is now well established. Families need and want education, information, coping and communication skills, emotional support, and to be treated as collaborators. The recovery journey is in fact a shared one; families need to recover as well. For this reason, knowledgeable clinicians will make a special effort to solicit involvement of family members and caregivers. Clinicians, individuals with the disorder, and families should work together to identify needs and appropriate interventions to help the person. Everyone involved should be able to have realistic yet optimistic expectations about improvement and possible recovery.

Many countries such as Australia, New Zealand, the United States, and many jurisdictions in Canada have adopted a recovery-oriented mental health system that is individualized, respectful, allows people to exercise personal choice and autonomy whenever possible, but also has the capacity to intervene and provide humane, compassionate assistance to people when they most need it.

The SSC recognizes the important role families play in helping adults living with mental illness and that the guidelines should emphasize that recovery means different things for different people. There are many different pathways to recovery.

The rest of this chapter will attempt to define recovery more clearly as it is understood from narrative stories of those with lived experience of mental illness like the ones in Chapter 10.

## Defining Recovery and Understanding its History

Recovery is a concept that was introduced in the writings of people with lived experience of mental illness beginning in the 1980s. It was inspired by such people who had themselves recovered to the extent that they were able to write about their experiences of coping with symptoms, getting better, and gaining an identity (such as Dr. Patricia Deegan, 1988, and Esso Leete, 1989). Recovery is variously called a process, an outlook, a vision, and a guiding principle. While there is no agreed-upon definition of recovery nor a single way to

measure it, experts like Dr. Deegan and Dr. William Anthony from the beginning of the recovery movement have referenced the overarching message of hope and restoration of a meaningful life are possible, despite serious mental illness.

Instead of focusing primarily on symptom relief, recovery casts a much wider spotlight on restoration of self-esteem and identity, on social inclusion, and on attaining meaningful roles in society. Deinstitutionalization, the emergence of community supports and psychosocial rehabilitation, and the growth of the individual with lived experience and family advocacy movements all paved the way for recovery to take hold.<sup>97</sup>

While there are various definitions, few imply full recovery in which full functioning is restored and no medications are needed. Instead, they suggest a journey or process, not a destination or cure. One of the most prominent professional proponents of recovery, Dr. William A. Anthony with the Center for Psychiatric Rehabilitation of Boston University, crystallized individuals with mental illness writings on recovery with the following definition:

... a person with mental illness can recover even though the illness is not cured ... [Recovery] is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.<sup>98</sup>

According to the writings of pioneering psychologist Dr. Patricia Deegan who lives with schizophrenia, recovery refers to the lived experience of gaining a new and valued sense of self and of purpose.

The Ohio Department of Mental Health defines recovery as: "A personal process of overcoming the negative impact of a psychiatric disability despite its continued presence". Some refer to this as recovery in that people are in a state of recovery from the losses associated with social prejudice and discrimination. The Social Model of Disability insists that people with mental illnesses face the disabling effects of the lack of accommodation by society: lack of housing, employment, educational opportunities, etc. Recovery as such is a recovery of "full citizenship" privileges.

Many writers assert that the recovery process is governed by internal factors (one's psychological perceptions and expectations), external factors (social and community supports), and the ability to self-manage care, all of which interact to give them mastery over their lives.

The Substance Abuse and Mental Health Services Administration (SAMHSA) in the United States has defined recovery from mental disorders and substance use disorders as: A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential. SAMHSA articulates four major dimensions that support a life in recovery:

- **Health:** overcoming or managing one's disorder(s) as well as living in a physically and emotionally healthy way;

97 Anthony, William A. Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s. *Psychosocial Rehabilitation Journal*: 1993, (16)4, 11-23.

98 Ibid.

- **Home:** a stable and safe place to live;
- **Purpose:** meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavours, and the independence, income and resources to participate in society; and
- **Community:** relationships and social networks that provide support, friendship, love, and hope.<sup>99</sup>

Champions of recovery argue that its greatest impact will be on mental health providers and the future design of the service system. They envision services being structured to be recovery-oriented to ensure that recovery takes place. They envision mental health professionals believing in and supporting individuals in their quest to recover.

As stated above, recovery is not the same thing as being cured. Recovery is a process not an endpoint or a destination. Recovery is an attitude, a way of approaching the day and facing the challenges. Being in recovery means recognizing limitations in order to see the limitless possibilities. Recovery means being in control. Recovery is the urge, the wrestle, and the resurrection. Recovery is not a linear process marked by successive accomplishments. The recovery process is more accurately described as a series of small beginnings and very small steps. Professionals cannot manufacture the spirit of recovery and give it to individuals. Recovery cannot be forced or willed. However, environments can be created in which the recovery process can be nurtured like a tender and precious seedling.<sup>100</sup>

Recovery is not tied to symptom relief. Re-hospitalization and relapse are part of the recovery process. Recovery includes recovering from stigma, institutionalization, the effects of poor or wrong treatment and interventions, lack of opportunities for self-determination, inadequate social and community access and interactions, lack of safe and affordable housing of choice, the effects of unemployment, misunderstandings about mental illness, and crushed dreams.

## Assumptions and Principles of Recovery

The basic assumptions of a recovery-focused mental health system according to Dr. William A. Anthony are:<sup>101</sup>

1. **“Recovery can occur without professional intervention.”** Professionals do not hold the key to recovery; people with lived experience of mental illness do. The role of professionals is to facilitate recovery; the task of individuals is to recover. Recovery may be facilitated by the individual’s natural support system. People who are in touch with their own recovery can help others through the process. Self-help groups, families, and friends are the best examples of this.

It is important for mental health providers to understand that recovery is not simply promoted by a variety of mental health services. Integrated community activities and organizations, e.g., sports, clubs, adult education, and places of worship are also essential to recovery.

99 SAMSHA website. Recovery and Recovery Support.

100 Deegan, Patricia E. The Lived Experience of Rehabilitation; Psychosocial Rehabilitation Journal: Volume 11, Number 4: April 1988.

101 Anthony, William A. Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s. Psychosocial Rehabilitation Journal: 1993, (16)4, 11-23.

2. **“A common denominator of recovery is the presence of people who believe in and stand by the person in need of recovery.”** Critical to one’s recovery is having a person or persons that one can trust to “be there” in times of need. People who are recovering talk about the people who believed in them when they did not even believe in themselves, who encouraged their recovery but did not force it, who tried to listen and understand when nothing seemed to be making sense. Recovery can be everybody’s business.

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3. **“A recovery vision is not a function of one’s theory about the causes of mental illness.”** Adopting a recovery vision does not commit one to any particular theory about the cause of mental illness, nor on the use or nonuse of medical interventions. Recovery may occur whether one views the illness as biological or not.

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4. **“Recovery can occur even though symptoms reoccur.”** Individuals who experience significant psychiatric symptoms can also recover.

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5. **“Recovery changes the frequency and duration of symptoms”.** People who are recovering and experience heightened symptoms may have a level of symptom intensity as bad as or even worse than previously experienced. However, as an individual recovers, the symptom frequency and duration appear to have been changed for the better. That is, symptoms interfere with functioning less often and for briefer periods of time. More of one’s life is lived symptom-free. Symptom recurrence becomes less of a threat to one’s recovery and return to previous function occurs more quickly after exacerbation.

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6. **“Recovery involves growth and setbacks, periods of rapid change and little change.”** The overall trend may be upward, but the day to day experience may not feel that way. Intense feelings may happen unexpectedly and periods of insight or growth also happen unexpectedly.

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7. **“Recovery from the consequences of the illness is sometimes more difficult than recovering from the illness itself.”** Issues of dysfunction and disadvantage are often more difficult than impairment issues. Not being able to perform treasured tasks and roles, and the resultant loss of self-esteem, are significant barriers to recovery. The barriers and stigma brought about by being placed in the category of “mentally ill” can be overwhelming. Disabilities and disadvantages can combine to limit a person’s recovery even though one has become predominantly asymptomatic.

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8. **“Recovery from mental illness does not mean that one was “not really mentally ill.”** At times people who have successfully recovered from severe mental illness have been discounted as not “really” having a mental illness. Their successful recovery is not seen as a model, as a beacon of hope for those beginning the recovery process, but rather as an aberration, or worse yet as a fraud. People who have or are recovering from mental illness are sources of knowledge about the recovery process and how people can be helpful to those who are recovering.

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There are a number of possible stimulants to recovery. These may include other people with lived experience known as peer support specialists who are recovering effectively. Books, films, and groups may cause serendipitous insights to occur about possible life options. Visiting new places and talking to various people are other ways in which the recovery process might be triggered. Critical to recovery is regaining the belief that there are options from which one can choose—a belief perhaps even more important to recovery than the particular option one initially chooses.

Recovery-oriented mental health systems must structure their settings so that recovery “triggers” are present. The mental health system must help sow and nurture the seeds of recovery through creative programming. In essence, the goal of mental health services is to create environments in which recovery can take place!

Mental health clinician, Laurie Davidson delineates the practical principles of recovery for those service providers working with clients and individuals:<sup>102</sup>

- Recovery is about building a meaningful and satisfying life, as defined by the person themselves, whether or not there are ongoing symptoms or problems.

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- Recovery represents a movement away from focusing solely on pathology, illness and symptoms to focusing on health, strengths and wellness.

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- Hope is central to recovery and can be enhanced by people discovering how they can have more active control over their lives and by seeing how others have found a way forward.

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- People are encouraged to develop their skills in self-care and self-management in whatever way works for them. There is no ‘one size fits all’.

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- The helping relationship between clinicians and individuals with mental illness moves away from being expert/patient to mentoring, coaching or partnership on a journey of personal discovery. Clinicians are there to be ‘on tap, not on top’.

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- Recovery is about discovering and often re-discovering a sense of personal identity, separate from illness or disability.

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- People do not often recover in isolation. Recovery is closely associated with being able to take on meaningful and satisfying social roles and participating in local communities on a basis of equality.

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- Words are important. The language we use and the stories we tell have great significance to all involved. They can carry a sense of hope and possibility or be associated with a sense of pessimism and low expectations, both of which can influence personal outcomes.

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- The development of recovery-based services emphasizes the personal qualities of staff as much as their formal qualifications or professional skills. Training support and supervision aim to cultivate their capacity for hope, creativity, compassion, realism and resilience.

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- Family and other supporters are often crucial to recovery and they should be included as partners wherever possible. However, peer support is central for many people in their recovery.

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- There will be no more ‘them and us’, only ‘us’ - sharing struggles and challenges as part of being human.

102 Adapted from “Recovery-Concepts and Applications” by Laurie Davidson, the Devon Recovery Group, 2008

## Guiding Principles of Recovery By Substance Abuse and Mental Health Services Administration (SAMHSA)

### Recovery Emerges from Hope:

The belief that recovery is real provides the essential and motivating message of a better future – that people can and do overcome the internal and external challenges, barriers, and obstacles that confront them. Hope is internalized and can be fostered by peers, families, providers, allies, and others. Hope is the catalyst of the recovery process.

### Recovery is Person-Driven:

Self-determination and self-direction are the foundations for recovery as individuals define their own life goals and design their unique path(s) towards those goals. Individuals optimize their autonomy and independence to the greatest extent possible by leading, controlling, and exercising choice over the services and supports that assist their recovery and resilience. In so doing, they are empowered and provided the resources to make informed decisions, initiate recovery, build on their strengths, and gain or regain control over their lives.

### Recovery Occurs via Many Pathways:

Individuals are unique with distinct needs, strengths, preferences, goals, culture, and backgrounds (including trauma experiences) that affect and determine their pathway(s) to recovery. Recovery is built on the multiple capacities, strengths, talents, coping abilities, resources, and inherent value of each individual. Recovery pathways are highly personalized. They may include professional clinical treatment; use of medications; support from families and in schools; faith-based approaches; peer support; and other approaches. Recovery is non-linear, characterized by continual growth and improved functioning that may involve setbacks. Because setbacks are a natural, though not inevitable, part of the recovery process, it is essential to foster resilience for all individuals and families.

### Recovery is Holistic:

Recovery encompasses an individual's whole life, including mind, body, spirit, and community. This includes addressing: self-care practices, family, housing, employment, education, clinical treatment for mental disorders and substance use disorders, services and supports, primary healthcare, dental care, complementary and alternative services, faith, spirituality, creativity, social networks, transportation, and community participation. The array of services and supports available should be integrated and coordinated.

### Recovery is Supported by Peers and Allies:

Mutual support and mutual aid groups, including the sharing of experiential knowledge and skills, as well as social learning, play an invaluable role in recovery. Peers encourage and engage other peers and provide each other with a vital sense of belonging, supportive relationships, valued roles, and community. Through helping others and giving back to the community, one helps oneself. Peer-operated supports and services provide important resources to assist people along their journeys of recovery and wellness. Professionals can also

play an important role in the recovery process by providing clinical treatment and other services that support individuals in their chosen recovery paths. Peer supports for families are very important for children with behavioural health problems and can also play a supportive role for youth in recovery.

#### **Recovery is Supported Through Relationship and Social Networks:**

An important factor in the recovery process is the presence and involvement of people who believe in the person's ability to recover; who offer hope, support, and encouragement; and who also suggest strategies and resources for change. Family members, peers, providers, faith groups, community members, and other allies form vital support networks. Through these relationships, people leave unhealthy and/or unfulfilling life roles behind and engage in new roles (e.g., partner, caregiver, friend, student, employee) that lead to a greater sense of belonging, personhood, empowerment, autonomy, social inclusion, and community participation.

#### **Recovery is Culturally-Based and Influenced:**

Culture and cultural background in all of its diverse representations, including values, traditions, and beliefs, is important to a person's journey and unique pathway to recovery. Services should be culturally grounded and culturally safe, attuned, sensitive, congruent, and competent, as well as personalized to meet each individual's unique needs.

#### **Recovery is Supported by Addressing Trauma:**

The experience of trauma (such as physical or sexual abuse, domestic violence, war, disaster, and others) is often a precursor to or associated with alcohol and drug use, mental health problems, and related issues. Services and supports should be trauma-informed to foster physical and emotional safety and trust, as well as to promote choice, empowerment, and collaboration.

#### **Recovery Involves Individual, Family, and Community Strengths and Responsibility:**

Individuals, families, and communities have strengths and resources that serve as a foundation for recovery. In addition, individuals have a personal responsibility for their own self-care and journeys of recovery. Individuals should be supported in speaking for themselves. Families and significant others have responsibilities to support their loved ones, especially for children and youth in recovery. Communities have responsibilities to provide opportunities and resources to address discrimination and to foster social inclusion and recovery. Individuals in recovery also have a social responsibility and should have the ability to join with peers to speak collectively about their strengths, needs, wants, desires, and aspirations.

**Recovery is Based on Respect:**

Community, systems, and societal acceptance and appreciation for people affected by mental health and substance use problems – including protecting their rights and eliminating discrimination – are crucial in achieving recovery. There is a need to acknowledge that taking steps towards recovery may require great courage. Self-acceptance, developing a positive and meaningful sense of identity, and regaining belief in oneself are particularly important.

**How can Family Members Support Recovery?**

BC Partners for Mental Health and Substance Use suggest that with an understanding of the above values and principles of recovery, family members can be better equipped to:<sup>103</sup>

- Nurture hopefulness, with high expectations!
- Aim for recovery – a full life beginning with clear, attainable, smaller goals
- Foster self-determination and critical thinking
- Value healthy independence
- Support their family member with schizophrenia to take risks and exercise their right to try
- Emphasize opportunities for community connections and rebuilding a meaningful life

**Family Recovery**

It is important to note that families embark on their own process of recovery alongside their family member. A family's journey will not be straightforward either and will involve successes and setbacks as well. Each family's experience will be unique. Acceptance of the illness, developing coping strategies, and building on successes, will be present for both the person with schizophrenia and the family. Some challenges will be faced simultaneously while others will be different in their timing and severity.

Some family members think of recovery as meaning that the illness is no longer front and centre in their lives. They expressed a sense of moving away from living and breathing mental illness toward focusing on getting their own lives back on track.<sup>104</sup>

**The values which support recovery are:**

<b>Hope</b>	<b>Choice</b>
<b>Acceptance</b>	<b>Citizenship</b>
<b>Mutual respect</b>	<b>Person-centred</b>
<b>Diversity</b>	<b>Meaningfulness</b>
<b>Inclusion</b>	<b>Partnership working</b>
<b>Empowerment</b>	<b>Believing in people</b>

103 heretohelp. BC Partners for Mental Health and Substance Use: <https://www.heretohelp.bc.ca/sites/default/files/family-self-care-and-recovery.pdf>: 14 March 2021.

104 heretohelp. BC Partners for Mental Health and Substance Use: <https://www.heretohelp.bc.ca/sites/default/files/family-self-care-and-recovery.pdf>: 14 March 2021.

## Chapter 15

# Multiculturalism, Cultural Safety & Schizophrenia

Some migrant groups and their direct descendants face a substantially increased risk of schizophrenia and other psychotic disorders.<sup>105</sup> This risk may be even greater among refugees. This, of course, has implications in terms of the need for adequate and culturally safe mental health resources.

Culture influences how people with schizophrenia and their families respond to the disorder as well. For example, some immigrant Canadians with schizophrenia may try to ignore the illness, accept it as fate, or seek advice from a religious or spiritual leader. The person may not seek treatment from a physician about mental health and emotional problems.

In some cultures, it is unacceptable to complain to a health professional about feelings such as despondency, loneliness, or the desire to die. It is more probable that physical symptoms such as sleeplessness, change in appetite, or weight loss will be relayed. In other words, some immigrant people with schizophrenia may translate their emotions into physical ailments when talking to a physician.

## Isolation

SSC recognizes the additional challenges and difficulties imposed upon some families from ethnically diverse backgrounds. They may be isolated from mainstream Canadian social support systems and health care systems. The key reasons for this are:

- Histories of trauma from colonization and Residential School experiences
- Racism and oppression
- Language barriers which interfere with assessment and treatment of people
- In some cultures, schizophrenia is viewed as a punishment of the person — the stigma associated with it is therefore formidable, and families and individuals may try to hide in shame from the illness
- A reliance on family members to deal with the illness
- A lack of sensitivity and cultural safety awareness by professionals in diagnosing and treating people with schizophrenia from different cultures

105 Bourque F, van der Ven E, Malla A. A meta-analysis of the risk for psychotic disorders among first- and second-generation immigrants. *Psychol Med* 2011;41:897–910.

- A lack of collaboration between community organizations, agencies, and institutions to increase accessibility to treatment
- A lack of ability, particularly for new immigrants, to pay for psychological or psychiatric services.

## The Need for Awareness and Education

Outreach to multicultural groups is required to promote an awareness and understanding of schizophrenia as well as gaining an understanding of their worldview. There is, at times, a lack of knowledge about the disorder and how it can be recognized, about our mental health care system and how it can treat schizophrenia, and about how to gain access to drug therapy and psychosocial services.

SSC, and the contributing families, have identified areas where work is needed to support Canadians of diverse cultures, to understand their worldview of schizophrenia, and understand their ways of healing. They include:

- Promoting “culturally safe” standards of practice in which the person’s worldview is respected, in which his/her ways of knowing as a cultural group is honoured and, in which traditional ways of healing are incorporated into western treatment responses.
- Translation of information and educational materials into various languages, so as to support multicultural families’ access to knowledge.
- Work with ethnic press, radio and TV stations to promote awareness of schizophrenia.
- Dissemination of materials on schizophrenia through immigrant service agencies and ethnic community associations.
- Increased coordination and joint efforts among community and mental health organizations that serve the multicultural community.
- Gathering and dissemination of research data pertaining to various ethnicity response levels to drug therapies amongst the medical professions.
- Promotion of awareness of the different values diverse cultures hold, which impact their attitudes toward mental illness, amongst health caregivers.
- Invitation of members of ethno-cultural-specific communities as guest speakers to meetings of support groups and associations involved in helping those who live with schizophrenia.
- Development of culture brokers (persons who help to bridge the gap between the person’s culture and that of the health caregivers by translating professional jargon and attitudes to people and his/her families, and by helping the professionals understand how the person’s culture impacts their problems) and promotion of their involvement with schizophrenia organizations.
- Advocacy in the area of ethno-cultural-specific housing, social support, and employment programs, and integration of mental health services and immigration services.
- Work with colleges, universities, and professional accreditation bodies to encourage the adoption of culturally sensitive and safe training in the curriculum for health caregivers.



Having a culturally diverse mental health workforce is also a key priority. Some jurisdictions have specialized cultural mental health workers so be sure to contact your local health authority or mental health organization to determine if there are specialized services in your area.

**Some key points:**

- Immigration does not cause schizophrenia; however, the stress surrounding it can trigger or compound the problem.
- A physician cannot accurately diagnose the individual unless the emotional symptoms the person has experienced are revealed, along with the physical ones.
- It is incumbent upon family members to help the person by making physicians and health caregivers aware of your family's and culture's attitudes toward mental illness.
- Although schizophrenia does not differentiate between races and cultures, drug treatment may affect some cultures differently than others.
- Be sure to use all the federal and provincial government services, and ethno-specific community association programs available to you. They may be able to provide interpreters and other assistance you require to get diagnosis and treatment for the individual.

## Schizophrenia and Indigenous Peoples

National statistics about the use of mental health services by Indigenous people, particularly First Nations people who live on reserves, are lacking. One health report released by Statistics Canada in 2018 indicates that First Nations people living on reserve were about twice as likely as non-Aboriginal people to be hospitalized for schizophrenic/psychotic disorders.<sup>106</sup>

Jacqueline McPherson, a health director for the Osoyoos Indian Band suggests that schizophrenia and other mental illness is largely misunderstood among First Nations. She explains that “it is often perceived as behavioural problems or an individual's lack of self-discipline; there is a tendency to blame the individual experiencing the symptoms. Often, symptoms of mental illness are addressed through ceremony and guidance to resolve the “behaviour” rather than through medical intervention. Although these actions are critical to the overall well-being of the individual, such cultural perceptions of mental illness may impede medical treatment.”<sup>107</sup>

Ms. McPherson has worked to help people find the right balance between cultural perception and medical treatment. She notes that with the availability of mental health educational programs, misperceptions about mental illness are changing. She adds that “in an attempt to further reduce the stigma associated with mental illness, some First Nations patients may choose to explore their cultural belief systems, including spiritual and ceremonial designations such as shape shifting, in order to explain their illness and educate their families and communities. Unfortunately, the medical system is not

106 Carriere, Gisele et al. Acute Care Hospitalizations for Mental and Behavioral Disorders among First Nations People; Statistics Canada: Release Date 20 June 2018.

107 McPherson, Jacqueline. heretohelp; Shape shifter or Schizophrenic? Reprinted from “Indigenous People” issue of Visions journal, 2016, 11 (4), p. 26.

designed to support this paradigm, which involves sacred ritual and private designations.”<sup>108</sup>

For Indigenous cultures, there are limitations to the medical model. Further work must be done to make community-based and hospital-based services culturally relevant and culturally safe for all Indigenous cultures.

Among Canadians who are homeless and have a mental illness, those who are Indigenous have unique histories and current needs that are consistent with the legacy of colonisation. The context of reconciliation between Indigenous and non-Indigenous Canadians must be considered in the responses to Indigenous homelessness and mental illness. Responses must also consider trauma, substance use and family separations.<sup>109</sup>

## Help for Indigenous and Ethnocultural or Racialized Families

### Cultural Interpretation Services (CIS)

Hospitals and health care facilities across Canada are becoming more aware of their responsibility to provide culturally safe interpretation services for individuals who are not proficient in English or French. It is becoming widely recognized that language barriers result in poor quality care, which adds to the burden of costs to the health care system. Research has proven that clear and understandable communication between health professionals and their patients leads to better results.

An example of a CIS service can be found at the Centre for Addiction and Mental Health in Toronto. The Centre provides this service to individuals with mental illness and families who have specific language and/or translation requirements. A trained interpreter is available for clinical visits to ensure the individual's concerns are understood, thereby enabling the treatment process. The CIS also works to help the Centre identify areas of service that are not sensitive to race, culture, ethnicity, gender, age, abilities, religion, and sexual orientation, and develop strategies to address these gaps in service.

The role of an interpreter in a clinical setting is to:

- Provide a safe, welcoming environment in which the principles of cultural safety are practiced.
- Ensure the individual understands his/her rights with respect to treatment.
- Provide accurate interpretation of the meaning and content of information given by the individual.
- Facilitate communication between the individual and clinician.
- Respect the integrity and right to confidentiality of all parties involved.
- Try to establish a rapport with the individual.
- Avoid situations where there may be a conflict of interest.
- Reveal and correct errors in communication or misunderstandings that occur.

108 McPherson, Jacqueline. heretohelp; Shape shifter or Schizophrenic? Reprinted from “Indigenous People” issue of Visions journal, 2016, 11 (4), p. 26.

109 Bingham, Brittany et al. Indigenous and non-indigenous people experiencing homelessness and mental illness in two Canadian cities: A retrospective analysis and implications for culturally informed action; PMC published online 2019 April 8.

- Respect the families they help by not interfering with conversations between individuals and family members.
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Often a CIS service can be accessed through the Special Services department of the hospital or clinic you are attending. Please be sure to ask if interpreters are available at your health facility, or if provisions for this type of service have been established within your community. Where available, make arrangements to have an interpreter accompany you on clinical visits. The better you are understood, the better able the health care system is to treat you appropriately and effectively.

For additional reading on Cultural Safety see:

[http://www.mooddisorderscanada.ca/documents/Publications/CULTURAL%20SAFETY%20AN%20OVERVIEW%20\(draft%20mar%202010\).pdf](http://www.mooddisorderscanada.ca/documents/Publications/CULTURAL%20SAFETY%20AN%20OVERVIEW%20(draft%20mar%202010).pdf)



## Chapter 16

# Stigma and Discrimination– Misunderstanding Schizophrenia

### Public Perception

“One thing I find really hard about my illness is the stigma.”

– Shawna, a person with schizophrenia

What is the biggest problem people who have been treated for mental illness face when trying to resume a normal life? Most will say it is simply that others do not accept them. They have difficulty in finding friends, housing, and work. They feel the sting of discrimination in almost everything they attempt. Many times, people with this disorder feel that even old friends and family are uncomfortable in their presence. Overall, they experience a feeling of being cut off from society. The social prejudice that still surrounds mental illness can sometimes be the most disabling component of schizophrenia. The Social Model of Disability proposes that it is society’s attitude and lack of accommodation that disables people who live with physical and mental health challenges.

In 2012, the Centre for Addiction and Mental Health released the following statistics:<sup>108</sup>



110 Centre for Addiction and Mental Health. (2012). Mental illness and addictions: Facts and statistics. Retrieved from: [http://www.camh.ca/en/hospital/about\\_camh/newsroom/for\\_reporters/Pages/addictionmentalhealthstatistics.aspx](http://www.camh.ca/en/hospital/about_camh/newsroom/for_reporters/Pages/addictionmentalhealthstatistics.aspx)

Being “in recovery” for many people with schizophrenia or any mental illness is about recovering from the losses associated with societies prejudice towards those viewed as “abnormal” who live with a mental illness. Recovery is about regaining the full privileges of citizenship.

Public perception of mental illness is partly driven by fear: fear of the illness itself, fear of the unknown, and fear of violence as well as lack of association with people living with a mental illness. When people do not understand, they often make wild guesses. Some cultures believe mental illness is the work of evil spirits, while other cultures feel bad blood, poisons, or a lack of moral integrity causes it. As we learn more about the biological causes of mental illness, many of these wrong beliefs will, hopefully, fade. But the best way to reduce stigma and discrimination is through what is called “contact education” where a person with schizophrenia stands before a group and tells his/her story of schizophrenia and recovery: what helped and what hindered his/her recovery process.

Such “contact education” programs can help to correct these myths and misunderstandings. To the greatest degree possible, providing treatment in individuals’ own communities with the necessary supports, will also help to overcome the prejudice against persons with mental illness.

The devastating reality of the public’s wrong perception is its impact on those who have the illness, along with their families. Public fears keep those with schizophrenia marginalized and isolated from community. Stigma is self-perpetuating; people avoid what they fear, and as a result they do not get to know the people behind the label. It is a vicious circle in which everyone loses.

Self-stigma is when a person with a mental illness accepts and agrees with negative stereotypes. They end up feeling ashamed and try to conceal their illness from others.

In addition, stigma has caused families to shy away from public involvement for fear of creating further hurt or embarrassment for the person and other family members. As a result of these years of silence about the illness, the general public sees no evidence of an unmet need. Without powerful advocates and government recognition and support, funds necessary to carry research forward have fallen far behind those of other illnesses.

## Myths About Violence and Split Personality

Schizophrenia is one of the most misunderstood disorders of our day. A common myth about mental illness is based on the Hollywood portrayal of a mad person. The public has impressions of people with mental illness being institutionalized behind locked doors and barred windows; being physically restrained by cuffs or straight-jackets; and being committed by the courts due to their behaviour. There is a common fear that persons with mental illness are dangerous, unpredictable, and violent. The myth of danger is perpetuated by 1) social prejudice in one’s family of origin 2) lack of understanding of the recovery process, 3) the media and 4) Hollywood movies. Television and movie dramas frequently portray persons with mental illness as violent, homicidal objects of dread. Newspapers and magazines also exaggerate events where mental disorders are involved.

The truth is that persons with mental illness are usually anxious, fearful of others, and passive. There are situations in which people with mental illness may become violent and aggressive, such as if they are acting out

as a result of a delusion or hallucination. This small group is typically characterized by the following:

1. They have a severe form of schizophrenia and are not taking medication,

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2. They have a history of substance use and abuse, and

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3. They have a volatile personality and history of violence.

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The second common misconception about schizophrenia comes from the notion that, by definition, it means having a split personality. Schizophrenia is not a splitting of the personality into multiple parts, not a Jekyll and Hyde phenomenon, despite the popular hold of the Robert Louis Stevenson story. Most people with chronic schizophrenia are much too ill to carry off double lives. Nevertheless, the idea that schizophrenia equals split personality is pervasive. When people in everyday life describe something as “schizophrenic”, they mean split into two separate parts. But that is an incorrect reference. How did the confusion arise?

In 1911, the psychiatrist Eugen Bleuler invented the term schizophrenia to describe the disorder. (Schizophrenia comes from the Greek “schizo” meaning split, and “phrenia” which means mind.) What Bleuler was trying to convey by the term was the split between perception and reality. Today many psychiatrists regret the existence of the term because it is misunderstood.

Misunderstanding can cause serious and unnecessary grief. It is important that we all take responsibility for sharing our knowledge about schizophrenia and recovery with others: for their sake, for our sake, and most importantly, for the sake of those who have this disorder.

The Centre for Addictions and Mental Health suggests there are things that you can do to reduce stigma, including:

- Educate yourself about mental illness.

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- Be aware of your own attitudes and behaviors.

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- Choose your words carefully.

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- Educate others.

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- Focus on the positive.

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- Support people and treat them with dignity and respect.

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- Include everyone.

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## Chapter 17

# Self-Care for Family Caregivers

Family caregivers put a lot of energy into caring for and supporting family members with schizophrenia. As a family caregiver, you work extremely hard and perhaps without any or much apparent appreciation. Caring for your own mental health, physical health, and spiritual health is as important as caring for that of your loved one. This chapter offers some ways to be watchful about your own needs as well as those of your family member. The Here to Help project (BC) suggests the following considerations related to what they refer to as “healthy altruism”:<sup>111</sup>

## Healthy Altruism

### Healthy Boundaries

It is important to have some space between yourself and your family member who is ill. This should occur on a regular basis. Boundaries related to how much time you spend doing something for and thinking about your ill family member are important to protect your own health. While it is true that during crisis or certain points of concern, a high level of involvement may be necessary, this should not be the constant. Sometimes this is easier said than done, but you need to make a conscious effort to establish and maintain healthy boundaries.

### From Helping to Supporting

As your family member’s recovery journey proceeds, it is healthy to move from a “helping” role to a “supporting” role. You can do this by allowing your family member to make choices about their life rather than making them for him or her; by reducing the amount of conversation that focuses on “illness”; and by taking advantage of having more “free time” that you can use to focus on hobbies or activities of your own.

### Natural Supports

It can be helpful to reach out to family, extended family, and friends for support, particularly those who understand your situation and are willing to lend a hand. While it might be tempting to isolate yourself, build a support system instead. Support is the number one need identified by families living with mental illness.

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111 heretohelp.BC Partners for Mental Health and Substance Use Information; <https://www.heretohelp.bc.ca/sites/default/files/family-self-care-and-recovery.pdf>; 13 March 2021.

## Formal Supports

If you feel overwhelmed, consider formal counselling, whether it be individual or family counselling, grief counselling, marital counselling, etc. Access to counselling may be available through your mental health service system, your extended health benefits, or privately if you can afford them. Counselling is not a sign of “weakness”, rather it is a sign of self-awareness and strength.

## Caring for Yourself!

Treating yourself well every day and focusing on your health and wellness will help you to be better able to cope with the demands of being a caregiver, as well as all the other demands that are made of you in life. It will also help you to maintain your own identity outside of your caregiving role.

Some of the things you can do to take care of yourself include:

- **Set aside time to exercise.** Anything from a short walk, some stretches, a game of golf, or time at the gym – whatever suits your interest and time best.

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- **Maintain good nutrition.** Feed your body the healthy things it needs, such as fruits and vegetables, grains, water, etc.

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- **Maintain healthy sleep habits.** Unwind before bed and follow a consistent sleep routine for a good night's sleep.

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- **Stay connected to friends.** Commit to stay socially connected by talking to or visiting with friends and relatives, going out to a movie, shopping, or other activities that you enjoy.

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- **Consider your spiritual health.** However you think about life and its meaning, continue to spend time to find peace and hopefulness within your heart. If you belong to a specific religious denomination, you may want to consider attending worship services.

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- **Find time for calming activities.** Yoga, meditation, mindfulness practice, reading books, and listening to music are all activities that promote calmness and support emotional health.

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- **Attend family support groups.** Support from others that have been through or are going through some of the same experiences as you can be very helpful and may offer new ways to problem solve, cope, and care for yourself.

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## Creating a Self-Care Plan

Creating a self-care plan for yourself can confirm your commitment to take good care of your mental, physical and spiritual health. A self-care plan can be developed by:

- Continuing to do those things that you are already doing that rejuvenate you and positively contribute to your health and quality of life.
- Starting to do new activities or accessing services that will enable you to recharge and achieve better balance in your life.
- Stopping those things which are optional and add to your current responsibilities and stresses, and/or those things for which you can enlist the help of others to lighten your load.

Take a few minutes to create your individualized self-care plan, one that considers your needs, and the activities and experiences that you enjoy, and one that can improve the emotional, spiritual, physical and mental health aspects of your life. Commit to a lifestyle that very deliberately considers YOU, as well as the family member that you are supporting.



# Chapter 18

## Coping with Schizophrenia During COVID-19

### Introduction

On March 11, 2020, the World Health Organization (WHO) declared COVID-19 a global pandemic. This new virus has had unprecedented impacts on populations globally. In a pandemic, people living with severe mental illness, such as schizophrenia, and their family caregivers, can be faced with additional issues and problems. Therefore, it is important to stay educated, to stay vigilant, and to implement strategies that will keep us to be healthy and hopeful.

To this end, information within the context of the COVID-19 pandemic this chapter has been added to Rays of Hope. It is hoped that this information will help people to feel better equipped to manage challenges that are being faced during this unprecedented time.

Public health restrictions and public health orders across jurisdictions vary and they will continue to vary as provincial and territorial governments make the best possible decisions based on data such as local virus transmission, number of cases, etc. Because of this, it is always important to connect with your local public health authority for local information regarding access to services/service delivery changes.

The information in this chapter has been gathered from reliable sources, but the content is not intended to be a substitute for professional medical advice or treatment. For answers to specific questions regarding a family member's health issues, always seek the advice of your health care provider.

### Impacts of COVID-19 on People with Schizophrenia

One needs only look at history to see the effects that pandemics and the associated circumstances have on the mental health of populations across the world. A current review of literature suggests that people with schizophrenia or psychosis or at risk of psychotic disorder may be disproportionately affected by the effects of COVID-19.

There is some evidence to suggest that individuals living with schizophrenia are at **increased risk for transmission** of COVID-19, due to many factors. They typically have a higher prevalence of residing in shelters, group housing, other housing, or homelessness that may put them at risk of transmission. In addition, challenges associated with symptoms of psychosis (including disorganized thinking, poor insight and decision-

making) may make it more difficult for someone to recognize the severity of the situation and take the steps necessary to protect themselves against COVID-19.<sup>112, 113</sup>

Individuals living with schizophrenia may also be at **increased risk for adverse symptoms or treatment outcomes** of COVID-19 due to a very high prevalence of co-occurring medical conditions (such as type II diabetes, respiratory illness, heart disease), which have been known to increase mortality rates among COVID-19 patients.<sup>114</sup> As well, ongoing stigma in health care services may prevent them from pursuing required health care<sup>115</sup>, or prevent them from being taken seriously and properly assessed if they report symptoms. Social isolation and physical distancing also make symptoms more difficult for family members to recognize, resulting in delays in seeking care.

**Psychosocial impacts** of COVID-19 such as social isolation, unemployment, homelessness, relationship breakdown, domestic violence, worsening physical health and isolation also put individuals with schizophrenia at increased risk.<sup>116</sup>

## The Mental Health System During COVID-19

Due to increased guidelines around social distancing during the COVID-19 pandemic, the ways that people are able to access mental health services has changed.

Many provinces have quickly transitioned and established greater access to **online/virtual mental health services** in response to the COVID-19 pandemic. It is known that telemental health services are evidence based and comparable in effectiveness to in person services<sup>117</sup>, however some challenges to accessing virtual services may exist. Some individuals with schizophrenia lack access to technology, such as a computer or cell phone. In some situations, an onsite care provider may be able to assist in accessing these.<sup>118</sup> As well, privacy may be an issue. For example, it is hard to have privacy when receiving services online if you live in an accommodation with other people. It is important to connect to your local health authority and organizations for help in locating virtual services and supports in your area.

112 Morgan VA, Waterreus A, Carr V, et al. . Responding to challenges for people with psychotic illness: updated evidence from the Survey of High Impact Psychosis.

Aust N Z J Psychiatry. 2017;51(2):124–140.

113 Nicole Kozloff et al., The COVID-19 Global Pandemic: Implications for People with Schizophrenia and Related Disorders. Schizophrenia Bulletin, 2020 Jul; 46(4): 752–757.

114 (Wu Z, McGoogan, 2020) (Guan WJ, Liang WH, Zhao Y, et al. 2020) (Correll CU, Solmi M, Veronese N, et al. 2017) (Ward M, Druss B. 2015) (Zareifopoulos N, Bellou A, Spiropoulou A, Spiropoulos K.2018) all cited in Nicole Kozloff et al., 2020

115 (Thornicroft G, Mehta N, Clement S, et al. 2016) (Clement S, Schauman O, Graham T, et al. 2015) as cited in Nicole Kozloff et al., 2020

116 (Anglin et al., 2020) as cited in Brown et al., The potential impact of COVID-19 on psychosis: A rapid review of contemporary epidemic and pandemic research. 2020

117 Gratzner et al, 2020

118 Firth et al., 2015

In terms of **emergency and crisis services**, as in pre-COVID-19 times, if a family member is in immediate danger or requires immediate medical response, call 911 or present to your local emergency department. Crisis response (walk in) centres, crisis stabilization units (CSUs), and mobile crisis services are typically the types of crisis services that are available across jurisdictions in Canada. These services continue to operate however in some instances, variations may be in place depending on local public health requirements. It is expected that individuals who are in crisis seeking or needing a mental health assessment would typically be screened for COVID-19 risk factors. Depending on the screening outcome, an appropriate means of assessment would be determined (i.e., in-person vs virtual).

Crisis services that are already operating remotely should continue to be available. As well, some new phone lines or online crisis supports may be available. For example, the federal government has partnered with other organizations to establish Wellness Together Canada, which offers online resources as well as a number to text for immediate crisis support. (The portal can be found at <https://ca.portal.gs>)

While **emergency rooms** are still open, there may be additional safety measures that have to be followed, such as mandatory mask wearing and hand sanitizing. Some emergency rooms may put limits on non-essential visitors, or visitors that do not pass the screening questions. Though these extra measures can provide added stress in an emergency situation, it is important to keep in mind that these measures are in place for safety purposes.

## Accessing Medication

It is important for individuals to continue to regularly take any prescribed medications. However, there may be additional factors to consider when accessing medication during COVID-19.

Due to supply shortages, some pharmacies may have limits in place on how much they are able to dispense of certain medications at one time. For instance, some provinces implemented a 30-day limit on dispensing some medications at earlier points in the pandemic. It is important to speak to your pharmacist to stay updated on changes to pharmacy policies and restrictions. It should be noted that with 30-day limits on some medications comes an overall increase in dispensing fees.

Processing times may also be longer than normal and doctor availability may be affected, so it is important to give as much notice as possible to the pharmacy if a prescription renewal or refill is required. A pharmacist can assist in contacting a doctor to obtain a prescription renewal (at the doctor's discretion). If a family member is sheltering in place, some pharmacies will deliver medications for free to at-risk or quarantining individuals.

If a family member requires blood testing for clozapine, additional information on clozapine treatment during COVID-19 can be found at: <https://www.bcsc.org/what-you-need-to-know-if-youre-on-clozapineduring-covid-19/>

## How to Provide Support During COVID-19

Providing support and care for a family member who has schizophrenia or psychosis is an important role, but it can also be challenging. Supporting and encouraging your loved one and collaborating with treatment may be more difficult during COVID-19 for many reasons:

- Routines may be disrupted
- Usual ways of communication and support might not be possible
- Physical distancing requirements may hinder ability to provide both practical (doing laundry, preparing meals, etc.) and emotional support
- A family member's psychotic symptoms may exacerbate
- Access to mental health services for a family member may have changed
- There may be uncertainty about the availability of mental health services and supports and/or temporary disruptions to services, and
- Inpatient units may have reduced or suspended visiting hours or may only permit essential visitors.

Even in these circumstances, it is important to consider strategies for encouraging collaboration with treatment, such as becoming knowledgeable about how supports and services will change or have changed during COVID-19. It may also be helpful to assist your family member to make alternative arrangements to access medication if necessary or to help them make alternative arrangements to access required services and supports.

Social withdrawal and isolation can be very challenging for individuals with schizophrenia. It may be helpful to agree to connect at certain times with your family member, either over the phone or via a video call. Encouraging your family member to take part in online social activities, such as online peer support, or suggesting other online activities for you to do together can be helpful. When safe to do so, certain in-person physical distancing activities may be appropriate, such as meeting outside in an open space or going for a walk (while maintaining a safe distance).

Family caregivers often need to anticipate the level of assistance and encouragement their family member will need to take care of themselves and to keep themselves safe, especially during COVID-19. Listening, empathizing, and partnering can be an effective approach to discussing the benefits of taking safety precautions. Reminding your family member to wear a mask, wash their hands, and physical distance when appropriate, and providing support for accessing the equipment required to stay safe (mask supply, hand sanitizer) is also important. In some situations, you may have to provide these to your family member yourself.

As a family caregiver, you can also work to maintain a calm atmosphere. Due to the additional tensions and anxieties associated with COVID-19, it may be difficult to maintain a calm atmosphere at home. Try to avoid acquiring habits that may increase that level of anxiety, such as excessively playing negative news coverage on the television, or constantly discussing what is going wrong or what could go wrong in the world. Continue to practice calming activities together and draw up a self-care plan to help yourself stay calm.

Be sure to recognize your limits as a caregiver. Due to the additional stress that you may be feeling due to COVID-19, take some time to reassess the level of care and support you can reasonably provide. If you need to temporarily step back from providing some type of support, explain this to your family member and the health professionals involved in their care so that alternative supports can be arranged.



## Strategies For Encouraging and Supporting Recovery During COVID-19

It is important to remember especially during this challenging time that hope is essential to recovery! The University of Michigan Department of Psychiatry suggests three things to emphasize during COVID-19 to promote and support recovery.

- **Support regular recovery activities of our loved ones.** It is easy for our family members to fall away from healthy habits when they are stressed, however keeping up with their routines and focusing on their recovery goals puts them in a better position to manage the stresses they are experiencing. You can encourage your family member to keep in contact with those involved in their recovery plan by telephone, face to face technology, or even in person if public health guidelines permit.
- **Support coping skills.** Part of a recovery plan often includes practicing healthy coping and relaxation skills. Because even small stresses can affect a person with psychosis it is important that your family member engage in activities that they enjoy to the greatest degree possible while following public health guidelines. This could include a safe physical distance walk, deep breathing, reading, listening to music, etc. Perhaps now is a time where you could help your family member discover new interests as well, such as taking an online yoga class or learning a new skill on the computer.
- **Encourage connections.** While there are times when face to face connections will not be possible, it is still important for your family member to maintain connections. These may be connections with people that they have already established in their lives, and/or it may be new connections that may be available in your community such as online groups, peer supports, etc. It may also be an opportunity for you to encourage your family member to connect with other family members that they may not have connected with in a while. As well, you can encourage your family member to have a “check in” buddy to connect with every day.

## Relapse and Warning Signs During COVID-19

There is a relationship between psychosis and stress and people who experience psychosis can be particularly sensitive to stress. Within the context of COVID-19, individuals with schizophrenia or psychosis may be vulnerable to relapse due to fear of COVID-19, increased stresses generally, or even the “boredom” of social isolation.<sup>119</sup> As such, it is important to be able to anticipate your family member’s reactions to stress and look out for warning signs that may indicate that your family member is at risk of a relapse.

The warning signs of a psychosis relapse vary between individuals. A family caregiver is often aware of their family member’s relapse “signature” which is a personal set of early warning signs. During COVID-19, due to social isolation and not being able to have face to face contact at some points, it may be more challenging for family caregivers to recognize or notice some of these signs. It is important to remember that you can only do what you can do right now...that some things are not within your control. Continue to connect as best you can through phone calls or online venues such as Facetime or Skype.

It is important to take time to encourage your family member to develop and/or review a personal relapse prevention program, to ensure it is feasible to follow during COVID-19. If there are any items that are not feasible,

119 Lais Fonseca, Schizophrenia and COVID-19: risks and recommendations, Brazilian Journal of Psychiatry, April 2020

you can support your family member to come up with alternative strategies. If a crisis does occur, refer back to your family crisis plan and follow the additional measures that you outlined to account for the COVID-19 context. (Further information about a family crisis plan during COVID-19 appears below.)

## The Impacts of COVID-19 on Substance Use

There is evidence to suggest that the risks associated with substance use have increased during the COVID-19 pandemic. The Centre for Disease Control outlines some additional risk factors associated with substance use during COVID-19. For example, an inability to obtain drugs due to supply shortages or social distancing can lead to withdrawal symptoms. As well, illicit drug supply disruptions could also lead individuals to consume drugs they are not used to, which might increase risk of overdose or other adverse reactions. Reduced access to harm reduction services and in-person treatment options may also increase risk, and physical distancing guidance and stay-at-home orders may lead to higher numbers of people using substances alone, without others around to administer naloxone, perform life-saving measures, or call for help in case of overdose. People may also be afraid to seek medical attention in the Emergency Department (ED) or from other healthcare professionals for fear of infection. (Centre for Disease Control, 2020)

### Helping Your Family Member with Problematic Substance Use During COVID-19

At any time, it is important to communicate with your family member about alcohol and substance use by listening, empathizing, agreeing, and partnering. However, you may notice some additional challenges relating to helping your family member manage their substance use challenges such as disruptions to service. It is important to talk to a healthcare provider to learn more about what services will be available during COVID-19. As some in-person treatment options may not be available, you may also consider encouraging your family member to connect with available virtual recovery meetings or local treatment services and supports.

As you may not be having as much in person contact with your family member, it may be more challenging to identify if an increase in substance use is occurring. Through your regular virtual check ins with your family member, it is important to keep the lines of communication open regarding this, especially if your family member has experienced problematic substance use in the past, and/or if they are in a recovery program.

People in Canada who are staying at home more because of COVID-19 and consuming more alcohol indicated that they are doing so because of having no regular schedule, boredom, and stress, followed by loneliness.<sup>120</sup> For these reasons, it is important to encourage your family member to maintain their regular schedule as much as possible, and to tap into their coping skills and healthy stress management options, such as hobbies, exercise, and connecting with support systems.

The resources included below provide further information about COVID-19 and some key points to keep in mind in relation to different substances.

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120 Canadian Centre on Substance Use and Addiction, April 2020.

### General

Centre for Disease Control's FAQ about drug use and COVID-19:

<https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/other-at-risk-populations/people-who-use-drugs/QA.html>

### Alcohol

Drinking alcohol does not protect individuals from COVID-19 and can decrease the body's ability to fight off infections.

### Marijuana

The Canadian Centre on Substance Use and Addiction (CCSA) notes that there is current evidence that smoking cannabis can negatively affect people's respiratory and immune systems. Further, CCSA notes that "there is no evidence that smoking or vaping cannabis can prevent, alleviate or treat COVID-19 symptoms", and in fact that "cannabis smoking or vaping could worsen the respiratory symptoms of COVID-19".

### Cocaine and Methamphetamines

Using drugs such as cocaine and methamphetamines affects health and puts users at a greater risk of COVID-19.

[https://www.ccsa.ca/sites/default/files/2020-05/CCSA-COVID-19-Methamphetamine-Cocaine-Health-Risks-Infographic-2020-en\\_0.pdf](https://www.ccsa.ca/sites/default/files/2020-05/CCSA-COVID-19-Methamphetamine-Cocaine-Health-Risks-Infographic-2020-en_0.pdf)

### Opioids

The intersection between COVID-19 and the "opioid epidemic" has been noted by various medical personnel and academics. Several urgent actions have been called for.

<https://www.acpjournals.org/doi/10.7326/M20-1210>



## Suicide Risk of People With Psychosis During COVID-19

During the COVID-19 pandemic, people with mental illness or mental health challenges may be at increased risk of suicide. There is some evidence that more suicides occur after previous pandemics<sup>121</sup>, which means there is a possibility for this to occur after COVID-19. Additional stressors can lead to feelings of hopelessness despair<sup>122</sup> and social isolation may increase the risk of suicide in people with schizophrenia.<sup>123</sup> Family members who are already receiving treatment for suicide risk including those who are having suicidal thoughts and those who have had recent suicidal thoughts or a suicide attempt, may need additional support.<sup>124</sup>

During the COVID-19 pandemic, people with mental illness or mental health challenges may be at increased risk of suicide. There is some evidence that more suicides occur after previous pandemics, which means there is a possibility for this to occur after COVID-19. Additional stressors can lead to feelings of hopelessness despair and social isolation may increase the risk of suicide in people with schizophrenia. Family members who are already receiving treatment for suicide risk including those who are having suicidal thoughts and those who have had recent suicidal thoughts or a suicide attempt, may need additional support.

Crisis supports, emergency departments and 911 lines are still operating. Again, don't hesitate to call or visit your nearest crisis response centre or emergency departments when necessary. As well, it is important to review your family member's personal safety plan with them and adapt any information that needs to reflect the COVID-19 context. For example, have them brainstorm ideas about how to stay connected with supports and how to reach out to supports when physical distancing is at play. Discuss the new crisis lines that have been established due to COVID-19. Encourage them to add these additional ideas to their safety plan. As in pre-COVID-19 times, this should be done when your family member is not experiencing suicidal thoughts.

**Stay Connected!** Having open lines of communication with your family member is more important than ever during the COVID-19 pandemic. Create a network of family and friends who can stay connected with your family member especially during times of social isolation. Surround yourself with support. The support of



121 (Chan et al., 2006)

122 <https://medicine.umich.edu/dept/psychiatry/michigan-psychiatry-resources-covid-19/specific-mental-health-conditions/suicide-risk-recognizing-responding-riskduring-covid-19-pandemic>

123 Montross LP, Zisook S, Kasckow J. Suicide among patients with schizophrenia: a consideration of risk and protective factors. *Ann Clin Psychiatry*. 2005;17(3):173–182.

124 University of Michigan, Department of Psychiatry, 2020

other family caregivers can make a huge difference in terms of how you cope with the stresses and worry of a suicidal family member. Seek out virtual family caregiver communities/peer support groups that may have been established with the onset of COVID-19, or which may have existed pre-COVID-19.

## A Note on Aggressive Behaviors

Among people with schizophrenia, stress has been associated with aggressive behavior.<sup>125</sup> Coexisting problematic substance use can exacerbate aggressive behavior in people diagnosed with schizophrenia as well.<sup>126</sup> Maintaining treatment and recovery routines are important for reducing potential triggers of aggressive behaviors in people with schizophrenia or psychosis.

## Completing a Family Crisis Plan For COVID-19

Having a family crisis plan will help everyone to manage whatever crisis may occur. It is important to review your family crisis plan with your family member and consider if any aspect of that plan needs to be adapted to the COVID-19 context.

As well, it is important that your family crisis plan includes a plan should you become ill with COVID-19. If you are a primary caregiver for your family member, the adapted plan should identify who would play the roles you currently play if you become ill for an extended period of time.

### A Word About “Normal” Reactions

When faced with an “abnormal” situation such as the COVID-19 pandemic, it is important to remember that feeling anxious, sad, or afraid are all “normal” physiological responses. Some common feelings may include:

- Fear of getting COVID-19 or infecting others,
- Fear of being apart from family members, or
- Boredom or loneliness related to having to isolate or physical distance.

As well, a sense of loss that comes from the COVID-19 pandemic may be experienced. This may include losing a loved one, a job, a routine, a hobby or anything else that we have “lost” during this time.<sup>127</sup> Grief is a normal experience following loss, but it can be very difficult. Your family member may experience these feelings, as may you. It is important to respond to their COVID-19 related concerns in a supportive way by listening, reassuring them, and again, encouraging them to maintain their recovery routine to the greatest degree possible.

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125 (Volavka J, Citrome L. Pathways to aggression in schizophrenia affect results of treatment. *Schizophr Bull.*2011;37(5):921–929).

126 Volavka, John, *Aggression in Psychosis*, February 2014

127 Centre for Addiction and Mental Health, 2020

## Self Care During COVID-19: Tips For Family Caregivers

With the addition of extra stressors, it is even more important to ensure that family caregivers pay attention to their own mental health and self-care. Now is the time to develop or adapt a self-care plan!

It is important to try to limit the amount of COVID-19 news that is consumed, only seek information from trusted sources, and avoid inaccurate or overly sensational news stories and outlets. As much as possible, it is important to try to keep to the pre-COVID-19 routines or if some daily routines have been disrupted, try to find alternatives or develop a new routine. Generally, it is also important to continue to try as much as possible to keep a regular exercise routine and maintain healthy eating habits. Try to take time to engage in activities that are relaxing and enjoyable. Though at times sharing the same physical space may not be possible, staying connected and in regular contact with people in your social network is important.

Reach out to your support network if you are feeling overwhelmed. Though it is perfectly normal to feel anxious or overwhelmed during this challenging time, try to be mindful of your thoughts and mental states, and challenge unhelpful thinking. If you feel that you are not doing enough or operating at your usual capacity, remind yourself that you are doing your best in this uncertain and difficult time! Celebrate your resilience and what you have been able to accomplish and give yourself space to adjust to this new and unpredictable situation.

Contact your regional health authority and local organizations to understand what supports are available to you!

### Building on Internal and External Strengths During COVID-19

There are six strengths that families can continue to be practiced during times of COVID-19:

- **Appreciation and Affection:** While we may not always be able to physically hug our loved ones during COVID-19, things like smiles and jokes are easy to offer over the phone or during facetime. Even sending small notes to loved ones through the mail can demonstrate that you are thinking of them.
- **Positive Communication:** It is easy to focus communication on COVID-19 and the stress and worry that it brings, but it is also important to talk about other things that we can feel positive and hopeful about. What are some of the things you enjoyed talking about before COVID-19 came to be? Recall fun memories, talk about something new you learned today, or about some of your dreams you have for when this is all over.
- **Adaptability (flexibility):** In these times of COVID-19 our ability to adapt to change and to be flexible are certainly challenging. And this can be even more challenging for people who don't like change to begin with.
  - > The following nine tips from the New Zealand Department of Health can help you adjust to our "new normal":
  - > Be accepting of the situation
  - > Respond instead of reacting
  - > Give yourself time to process new information
  - > Allow yourself time to adapt to change. Everyone reacts to new things differently

- › Be flexible and open to relinquishing control over the situation
  - › Go easy on yourself and manage expectations at work and at home
  - › Focus on what you can do, not on what you can't
  - › Set new routines that work for you and don't pressure yourself
  - › Practice mindfulness. Be in the moment and focus on what you can achieve today<sup>128</sup>
- **Unity:** while there are times during COVID-19 when we cannot come together physically to do the things we used to do, we can still endeavor to do those things "virtually". We can still have a meal together or play a favorite game via Skype. Do not forgo some of your traditional and favorite family times altogether. Try to use your imagination and creativity to continue to do some things together!
  - **Spiritual Well Being:** However, you think about life and its meaning, continue to spend time to find peace and hopefulness within your heart. You can do this with your family member, or you may find solace in being a part of a family caregiver community. Find solace in your traditional ways, or perhaps a new possibility to find solace will emerge as part of your personal COVID-19 experience. If you belong to a specific religious denomination, you may want to look into available live stream worship services.
  - **Commitment:** Commitment to stay emotionally connected when you may not be able to be physically connected can be a challenge. COVID-19 has forced us to be even more committed to staying connected than before COVID-19. But we also need to be committed to self-care even more than previously.

During times of self-isolation and social distancing during COVID-19, social support becomes even more important for family caregivers as anxieties and stresses increase. It is still important to reach out to family and friends by whatever means are possible to tell them what kind of support you need from them. From providing a listening ear, to assisting with grocery shopping for your loved one, there are many things that you may need help with from time to time so don't be reluctant to ask!

In many areas of the country, support groups have gone virtual. Search out your local health authority and mental health organizations to determine what online family caregiver support groups/communities are available and make connections if this is something that you find helpful. Many family therapists offer sessions either over the phone or via facetime or Skype. Virtual therapy is still a very effective way of getting support if needed.

## Housing and Financial Support During COVID-19

Information related to housing and financial support during COVID-19 can change from month to month and differs according to region. Be sure to reach out for specific information about what supports are available in your region during COVID-19.

Since COVID-19, governments have responded quickly by providing rent, income and employment relief to those who are struggling.<sup>129</sup> For example, the federal government announced the Canada Emergency

<sup>128</sup> <https://www.health.nsw.gov.au/Infectious/covid-19/update/Pages/adapt.aspx>

<sup>129</sup> CMHC, 2020; Government of Canada, 2020; Government of Ontario, 2020

Response Benefit (CERB) in the early months of COVID-19. CERB is a benefit of \$2000 per month over four months for workers who lost their employment, or who are ill or quarantined due to COVID-19. As well, people who were looking after someone with COVID-19 or who couldn't work because they had to stay home with their children were also eligible for CERB. CERB has been widely applauded. Unfortunately, however, it has not been accessible to some vulnerable people. To keep up to date on CERB, please see the following link:

<https://www.canada.ca/en/services/benefits/ei/cerb-application.html>

As another example, the federal government announced a one-time \$600 payment in recognition of the extraordinary expenses faced by persons with disabilities during COVID-19.

To address the risk of homelessness during COVID-19, some new housing initiatives have been put in place very quickly.

## Advocacy For Your Family Member During COVID-19

COVID-19 raises many opportunities to advocate generally for better mental health services and supports, as well as improved income and housing programs. Some areas to consider focusing advocacy efforts on include:<sup>130</sup>

The relative success of CERB has led to calls to make this a permanent replacement to the antiquated income support programs. You may want to advocate for a basic income guarantee with your local government which can improve social and health outcomes.

You may also want to advocate for making the recent expansion of virtual mental health services permanent following COVID-19. Tele-mental health and other virtual supports are effective, convenient, and particularly relevant for people living in rural, northern, and remote communities, not just during COVID-19 but always.

Continued advocacy for increased housing options (particularly supported housing options) needs to occur. The response to COVID-19 in this regard has demonstrated that enhancements can occur quickly when needed, and this needs to be continued.

The response to COVID-19 in general has demonstrated both the need for drastic improvements to our health and social support systems, and that enhancements to programs and services can occur quickly when needed. Though many new additional supports may be phased out, the impact of the pandemic will not go away so quickly. The energy for change needs to be maintained as we move beyond COVID-19.

## Chapter 19

# About the Schizophrenia Society of Canada

Founded in 1979, the Schizophrenia Society of Canada (SSC) is a national registered charity. Our mission is, Build a Canada where people living with early psychosis and schizophrenia achieve their potential. The SSC works with existing provincial schizophrenia societies and other mental health organizations to improve the lives of individuals living with early psychosis and schizophrenia, as well as their families.

### SSC is committed to:

- Raising awareness and educating the public to help reduce social prejudice and discrimination towards those living with mental illness.
- Supporting families and individuals
- Advocating for legislative change and improved recovery-oriented treatment and services, and
- Supporting research through the SSC Foundation and other independent efforts

The SSC web site offers effective tools and programs in raising the profile of schizophrenia and recovery at the local, provincial, national and even international level. [www.schizophrenia.ca](http://www.schizophrenia.ca)

Also see:

- Family Recovery Journey: <https://schizophrenia.ca/family-recovery-journey>
- Your Recovery Journey: [www.your-recovery-journey.ca](http://www.your-recovery-journey.ca)
- Schizophrenia and Substance Use: [www.schizophreniaandsubstanceuse.ca](http://www.schizophreniaandsubstanceuse.ca)
- Cannabis and Psychosis: Exploring the Link: [www.cannabisandpsychosis.ca](http://www.cannabisandpsychosis.ca)



## Canadian Alliance on Mental Illness and Mental Health

Advocacy is another key area of involvement for SSC. We are founding members of the Canadian Alliance for Mental Illness and Mental Health (CAMIMH)

<http://camimh.ca> and remain active core members, firmly committed to advocating for a national action plan for mental health and mental illness, working through the Mental Health Commission of Canada. <http://www.mentalhealthcommission.ca>

## Schizophrenia Society of Canada Foundation (SSCF)

SSC is also committed to supporting research through our foundation. The SSCF's main focus is to fund fellowships particularly in the areas of molecular genetics, genetics, imaging, and biochemistry of the central nervous system with special emphasis on schizophrenia.

### In all of our work, SSC's philosophy is based on the following core values:

- Schizophrenia and early psychosis are medical illnesses that, like other medical illnesses, have variable expression/effects on symptoms, function and response to treatments.

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- Schizophrenia and early psychosis are caused by a number of different factors; from multiple genetic or environmental factors or from a combination of both.

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- The SSC fully supports the important role of research in all areas related to schizophrenia and early psychosis (biological, psychological, spiritual, and social determinants of health)

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- Persons with schizophrenia and early psychosis are entitled to efficient multi-disciplinary and integrated evidence-informed treatment and community support services.

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- Persons at the early phases of their illness are entitled to real secondary prevention (early intervention and treatment) through specialized first episode early psychosis clinics and their collaborators.

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- Persons with schizophrenia and early psychosis are to be included as full citizens in accessing education, employment, housing, medical services, recreation and social supports.

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- Whenever possible families are essential partners in the care and the treatment and recovery plans of persons with schizophrenia and early psychosis, and deserve respect and support

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- Persons with schizophrenia and early psychosis must be included in their treatment planning, care and recovery plans.

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- Persons with schizophrenia and early psychosis and their families are not to be blamed for this illness.

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- The SSC values collaboration at all levels to ensure that caring, compassion, hope, and recovery remain at the heart of our movement.

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For more information visit our web site at

[www.schizophrenia.ca](http://www.schizophrenia.ca)



# Appendix A

## Glossary – Understanding the Language of Mental Illness

If you have a relative, friend or student with schizophrenia, you may find medical professionals and others using words you are not familiar with. This is a short glossary of some of the most commonly used terms.

### Acute Dystonia

An extra pyramidal side effect, its symptoms include contraction of muscle groups, particularly the neck, eyes, and those muscles affecting posture. The individual may also experience discomfort, and an inability to think. Acute dystonia usually occurs within the first few hours of drug therapy.

### Affective Disorders or Mood Disorders

Mental illness characterized by greatly exaggerated emotional reactions and mood swings from high elation to deep depression. Commonly used terms are manic-depression, bi-polar disorder and depression – although some people experience only mania and others only depression. These extreme mood changes are unrelated to changes in the person's environment.

### Antipsychotics

Also referred to as neuroleptics or psychotropics, these are specific medications used in the treatment of mental illness, like schizophrenia. They are used to control psychotic symptoms such as delusions and hallucinations.

### Delusion

A fixed belief that has no basis in reality. People experiencing delusions are often convinced that they are famous people, are being persecuted, or are capable of extraordinary accomplishments.

### Diagnosis

Classification of an illness by studying its signs and symptoms. Schizophrenia is one of many possible diagnostic categories used in psychiatry.

### Dyskinesia

This extra pyramidal side effect causes abnormal movements, such as: irregular blinking, grimacing, tongue movements and protrusion of the tongue, and worm-like movements of fingers and toes.

### Electroconvulsive Therapy (ECT)

Used primarily for people who are experiencing extreme depression for long periods, who are suicidal, and who do not respond to medication or changes in circumstances.

### Extrapyramidal Symptoms (EPS)

Side effects caused by antipsychotics. They include uncontrollable movements in the face, arms and legs. Parkinsonism, Acute dystonia, Dyskinesia, and Tardive dystonia are included in this group of symptoms. They can usually be managed by lowering the dose of the neuroleptic drug, adding or increasing the dose of an antiparkinsonian medication, or introducing other blocking drugs.

### Hallucination

An abnormal experience in perception. Seeing, hearing, smelling, tasting or feeling things that are not there.

### Involuntary Admission

The process of entering a hospital is called admission. Voluntary admission means a person request treatment or agrees to treatment and are free to leave the hospital whenever they wish.

People who are very ill may be admitted to a mental health facility against their will, or involuntarily. There are two ways this can occur:

- Under medical admission certificates or renewal certificates
- Under special court orders when the person has been charged or convicted with a criminal offence. In this case, they may be held in a forensic facility

In some provinces, before someone can be admitted involuntarily under certificates, two physicians – one of whom is a psychiatrist – must certify that the person is: suffering from a mental disorder and requiring care, protection and medical treatment in hospital; unable to fully understand and make an informed decision regarding treatment, care and supervision; and/or likely to cause harm to self or others or to suffer substantial mental or physical deterioration if not hospitalized.

### Mental Illness/Mental Disorder

Physiological abnormality and/or biochemical irregularity in the brain causing substantial disorder of thought, mood, perception, orientation, or memory – grossly impairing judgment, behaviour, capacity to reason, or ability to meet the ordinary demands of life.

### Mental Health

Describes an appropriate balance between the individual, their social group, and the larger environment. These three components combine to promote psychological and social harmony, a sense of well-being, self-actualization, and environmental mastery.

### Mental Health Act

Provincial legislation for the medical care and protection of people who have a mental illness. The Mental Health Act also ensures the rights of patients who are involuntarily admitted to hospital and describes advocacy and review procedures.

### Paranoia

A tendency toward unwarranted suspicions of people and situations. People with paranoia may think others are ridiculing them or plotting against them. Paranoia falls within the category of delusional thinking.

### Parkinsonism

Another extrapyramidal effect, Parkinsonism is divided into two categories: hypokinetic and hyperkinetic. Hypokinetic symptoms include decreased muscular movement, rigidity, awkward and stiff facial movements, and possibly depression and apathy. Hyperkinetic symptoms are agitation of lower extremities, agitation, tenseness, tremors, rapid rhythmic movements of the upper extremities. These symptoms commonly occur between a few days and a few weeks of treatment for an acute phase.

### Psychiatrist

A physician that specializes in treating mental and emotional disorders.

### Psychosis

Hallucinations, delusions, and loss of contact with reality.

### Recovery

A process in which a person with lived experience of mental illness comes to live beyond the limitations of the illness in spite of on-going symptoms. "Recovery is being able to live a meaningful and satisfying life, as defined by each person, in the presence or absence of symptoms. It is about having control over and input into your own life. Each individual's recovery, like his or her experience of the mental health problems or illness, is a unique and deeply personal process." (Scottish Recovery Network) From the perspective of the individual with mental illness, recovery means gaining and retaining hope, understanding of one's abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self.

### Recovery Oriented Care and Services

Recovery oriented care refers to what psychiatric treatment, rehabilitation and community support practitioners offer in support of a person's recovery (Larry Davidson, Yale University, Program on Recovery and Community Health).

Recovery oriented system is a system in which the person, not the program, is the centre of all choices, plans and activities. The focus is on healing and growing, not maintenance. Hopes and dreams are discussed, encouraged and supported. (Adapted from Farkas and Gagne, 2002)

### Rehabilitation

Programs designed to help individuals return to normal functioning after a disabling illness, injury or addiction. They are designed to help people with mental illness live as independently as is possible in the community.

### Receptor

Neurotransmitter receptors are structures (usually proteins) on the surfaces of cells that recognize and bind to specific neurotransmitters. Once bound, the receptor often changes shape, causing a cascade of chemical events within the cell. These events can alter which genes are turned on or off and can make the cell more or less likely to release its own neurotransmitters. Each type of neurotransmitter might have multiple receptors, each with a different role to play.

### Schizophrenia

Severe and often chronic brain disorder. Common symptoms – personality changes, withdrawal, severe thought and speech disturbances, hallucinations, delusions, and bizarre behaviour.

### Side Effects

Side effects occur when there is drug reaction that goes beyond, or is unrelated to, the drug's therapeutic effect. Some side effects are tolerable but, some are so disturbing that the medication must be stopped. Less severe side effects include dry mouth, restlessness, stiffness, and constipation. More severe side effects include blurred vision, excess salivation, body tremors, nervousness, sleeplessness, tardive dyskinesia, and blood disorders.

Some drugs are available to control side effects. Learning to recognize side effects is important because they are sometimes confused with symptoms of the illness. A doctor, pharmacist, or mental health worker can explain the difference between symptoms of the illness and side effects due to medication.

**Social Worker**

A person specially trained to help individuals with social adjustment. A social worker would counsel persons with schizophrenia and their family on the social and emotional issues that arise from the disorder. In the community this person may be called a “mental health worker.”

**Tardive Dystonia**

One of the extrapyramidal side effects recognized by unusual posture and dysarthria (difficulty in speech articulation).

**Recovery/Treatment Plan**

Refers to therapy or remedies designed to cure a disorder or relieve symptoms. In psychiatry, treatment is often a combination of medication, psychosocial rehabilitation, psychological support services and recommended activities to promote recovery. Together, these make up the individual’s recovery/treatment plan.

**Treatment Team (or Care Team)**

Refers to the attending mental health professionals, case workers, etc. who work to provide collaborative care services to the person in accordance with the treatment plan.



## Appendix B

### Further Resource Materials

SSC maintains a library of up-to-date pamphlets, books, and videos. For complete information on library resource materials, please contact us at:

#### **Schizophrenia Society of Canada**

1-204-320-3188

Email: [info@schizophrenia.ca](mailto:info@schizophrenia.ca)

Web site: [www.schizophrenia.ca](http://www.schizophrenia.ca)

Suggested Reading. The following books are highly recommended and should be available through your local library or bookstore.

#### **Books on Schizophrenia and the Family**

- | Amador, Xavier. *I Am Not Sick I Don't Need Help*. (2000). Vida Press Peconic, New York.
- | Delisi, Lynn E. (2006). *100 Questions and Answers About Schizophrenia: Painful Minds*. Jones and Barlett Publishers, Massachusetts.
- | Doherty, Susan. (2019). *The Ghost Garden*. Random House Canada.
- | Johnson, Julie Tallard. (1994). *Hidden Victims Hidden Healers: An Eight-Stage Healing Process For Families And Friends Of The Mentally Ill*. PEMA Publications.
- | Lafond, Virginia. (1994). *Grieving Mental Illness: A Guide for Patients and Their Caregivers*. University of Toronto Press, Toronto.
- | Mueser, Kim T., & Gingerich, Susan. (2006). *The Complete Family Guide to Schizophrenia*. New York: The Guilford Press.



- | Turkington, Douglas, & Spencer, Helen M. (2009). Cambridge University.
- | Mueser, Kim T., & Jeste, Dilip V. (2008) Clinical Handbook of Schizophrenia. Guilford Press.

### **Books on Recovery**

- | Corrigan, Patrick W., & Ralph, Ruth O. (2005). Recovery in Mental Illness. Washington DC.: American Psychological Association.
- | Davidson, Larry. (2005). Living Outside Mental Illness: Qualitative Studies of Recovery in Schizophrenia. New York: New York University.
- | Davidson, L., & Harding, C. & Spaniol, L. (2005). Recovery from Severe Mental Illnesses: Research Evidence and Implications for Practice. (Vol. 1). Boston: Center for Psychiatric Rehabilitation for Boston University.
- | Davidson, L., & Harding, C. & Spaniol, L. (2006). Recovery from Severe Mental Illnesses: Research Evidence and Implications for Practice. (Vol. 2). Boston: Center for Psychiatric Rehabilitation for Boston University.
- | Repper, Julie & Perkins, Rachel. (2003). Bailliere Tindall.
- | Slade, Mike. (2009). Personal Recovery and Mental Illness: A Guide for Mental Health Professionals. Cambridge University Press.

### **Suggested Web Sites:**

Canadian Mental Health Association

[www.cmha.ca](http://www.cmha.ca)

Institute for Recovery & Community Integration

[www.mhrecovery.org](http://www.mhrecovery.org)

Recovery Opportunity

[www.recoveryopportunity.com](http://www.recoveryopportunity.com)

Rethink

[www.rethink.org](http://www.rethink.org)

Schizophrenia.com

[www.schizophrenia.com/index.php](http://www.schizophrenia.com/index.php)

Scottish Recovery Network

[www.scottishrecovery.net](http://www.scottishrecovery.net)



## Appendix C

### The Schizophrenia Societies Across Canada: National and Provincial

#### **Schizophrenia Society of Canada**

103 Harvest Drive  
Steinbach, MB R5G 2C6

Phone: (204) 320-3188  
Fax: (204) 320-5441  
E-mail: [chris@schizophrenia.ca](mailto:chris@schizophrenia.ca)  
Web site: [www.schizophrenia.ca](http://www.schizophrenia.ca)

#### **Mental Health Recovery Partners, South Island**

941 King's Road,  
Victoria, BC V8T 1W7

Phone: (250) 384-4225  
Fax: (250) 388-4391  
E-mail: [admin@mhrp.ca](mailto:admin@mhrp.ca)  
Web site: [mhrp.ca](http://mhrp.ca)

#### **Société Québécoise de la Schizophrénie**

7401, rue Hochelaga  
Montreal, QC H1N 3M5

Phone: (514) 251-4125 or Toll Free 1-866-888-2323  
(Quebec only)  
Fax: (514) 251-6347  
E-mail: [info@schizophrenie.qc.ca](mailto:info@schizophrenie.qc.ca)  
Web site: [www.schizophrenie.qc.ca](http://www.schizophrenie.qc.ca)

#### **Peer Connections (Previously Manitoba Schizophrenia Society Inc.)**

100-4 Fort St  
Winnipeg, MB R3C 1C4

Phone: (204) 786-1616 or 1-800-263-5545  
Fax: (204) 783-4898  
E-mail: [info@mss.mb.ca](mailto:info@mss.mb.ca)  
Web site: [www.mss.mb.ca](http://www.mss.mb.ca)

#### **British Columbia Schizophrenia Society**

110-1200 West 73rd Avenue,  
Vancouver, BC V6P 6G5

Phone: (604) 270-7841 or Toll free: 1-888-888-0029  
E-mail: [info@bcss.org](mailto:info@bcss.org)  
Web site: [www.bcss.org](http://www.bcss.org)

#### **Schizophrenia Society of Alberta**

4809-48th Avenue  
Red Deer, AB T4N 3T2

Phone: (403) 986-9440  
Fax: (403) 986-9442  
E-mail: [info@schizophrenia.ab.ca](mailto:info@schizophrenia.ab.ca)  
Web site: [www.schizophrenia.ab.ca](http://www.schizophrenia.ab.ca)



**Schizophrenia Society of New Brunswick**

1756 Water Street Suite 103  
P.O. Box 562  
Miramichi, NB E1N 1B5

Phone: (506) 622-1595  
Fax: (506) 352-0180  
E-mail: [ssnbmiramichi@gmail.com](mailto:ssnbmiramichi@gmail.com)  
Web site: [www.schizophreniasociety.nb.ca](http://www.schizophreniasociety.nb.ca)

**Institute for Advancements in Mental Health  
(Previously Schizophrenia Society of Ontario)**

300-95 King Street  
Toronto, ON M5C 1G4

Phone: (416) 449-6830 or Toll Free 1-800-449-9949  
Fax: (416) 449-8434  
E-mail: [support@iamentalhealth.ca](mailto:support@iamentalhealth.ca)  
Web site: [www.iamentalhealth.ca](http://www.iamentalhealth.ca)

**Schizophrenia Society of Newfoundland &  
Labrador**

18A-18B UB Waterford Hospital  
48 Kenmount Road  
PO Box 28029  
St. John's, NL A1B 4J8

Phone: (709) 777-3335  
Fax: (709) 777-3524  
E-mail: [info@ssnl.org](mailto:info@ssnl.org)  
Website: [www.ssnl.org](http://www.ssnl.org)

**Schizophrenia Society of Saskatchewan**

131 Saskatchewan Drive,  
Box 305 Station Main  
Regina, SK S4P 0C9

Phone: (306) 584-2620 or Toll Free 1-877-584-2620  
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