

# Your Recovery Journey: Learning to live “outside the illness”

By Patricia Jane Teskey

“If you’ve shut the voices down and then you’ve got somebody sitting in a boarding house staring at the walls...is that better?”

This question is raised by psychiatrist Pam Forsythe, MN, FRCPC, in the video that accompanies Your Recovery Journey—a peer support program for people living with mental illness who would like to move beyond the walls and move their lives forward.

Forsythe was president of the Schizophrenia Society of Canada (SSC) in 2009 when the SSC, with funding from Janssen Inc., launched Your Recovery Journey. In the program materials she tells participants: “You’re so much more than just this illness. Yes, it may have a profound impact on you at the moment, but you’re a lot more than someone with schizophrenia.”

## The definition of recovery

Chris Summerville, chief executive officer of SSC, says the question he is most often asked is why some people don’t recover. He answers by defining two valid meanings for recovery: Clinical recovery means a complete remission of symptoms. Personal recovery means that, in spite of some continuing symptoms and limitations of the illness, people are able to regain a personal sense of identity, purpose, and meaning.

The reason some people do not experience personal recovery, Summerville says, is because they have been exposed to services limited to symptom reduction only. You need medication, he says, but personal recovery is about recovering from the



Chris Summerville, chief executive officer of the Schizophrenia Society of Canada

losses—sometimes profound losses—of severe mental illness, such as the loss of your home, income, family, and friends.

In the foreword to the program materials, Summerville quotes Larry Davidson, PhD, professor of psychiatry at Yale University: “Recovery means learning how to live outside the mental illness rather than inside it. To live inside the mental illness is to be lost in its downward spiral. Living outside schizophrenia is about reclaiming your life....”

A person living inside the illness is focussed on his or her symptoms, self-identifies as “a schizophrenic” or the illness, and doesn’t have a lot of hope, says Summerville.

He says he created the Your Recovery Journey program to promote the recovery philosophy, and to make a recovery-oriented program available

across Canada.

The program is based on the core principles of the recovery philosophy: choice, self-determination, hope, and empowerment. The premise is that the goals and journey belong to the recovering person, who is the expert on what works best for him or herself.

“It’s the people with lived experience of mental illness who recover,” explains Summerville. “It’s our task to create environments in which they can recover and achieve a quality of life.”

He says for some people with mental illness, social barriers—such as lack of housing and income—can hinder recovery more than the illness itself. Social barriers have their roots in stigma and discrimination, so “mental illness is not just a health issue, but a social injustice issue,” and “recovery is about restoring human rights.”

# What is recovery?

## Summary of key points:

- Recovery is a process built on hope, choice, self-determination, and empowerment.
  - People with mental illness are resilient and know their own experiences of recovery.
  - Recovery is possible for all people who live with mental illness.
  - Recovery is more than reducing symptoms; it happens when people with mental illness set and achieve their life goals and ambitions.
  - The goals and journey belong to the individual. Individuals must be encouraged and given the tools to direct their own recovery.
  - Taking responsibility for yourself and your own actions is part of recovery. So is seeking support from others.
  - Recovery is a process that may involve many stages, and will include inevitable setbacks and uncertainty.
- Source: Session 1, Your Recovery Journey

## Cuts across all diagnoses

The recovery philosophy maintains that recovery cuts across all diagnoses; therefore, Your Recovery Journey is designed for anyone who wants to recover from a mental illness, not just for those with schizophrenia. “While there are significant differences in the symptoms, course, and treatment of different mental illnesses, there are also many similarities in people’s experiences in working toward recovery,” the program materials state. “These include identifying and reaching personal goals; working to find meaning and fulfillment in the face of a new reality; dealing with the impact of stigma; and establishing a positive sense of self and belonging.”

The program is divided into five modules, or sessions, designed to be led by people who have experienced mental illness and recovery and who can model recovery for participants. Mental health professionals and family members can co-facilitate.

Each participant is given opportunities to develop a recovery plan based on personal experiences and preferences. For example, participants are encouraged to identify what helped and what hindered them during a previous relapse. Using this experience, they create personalized crisis plans or advance directives in case they relapse again.

In the module on self-management,

participants learn to recognize their symptoms and understand the role of medications in their recovery. They also learn ways to enhance physical and mental health, such as stress management and conflict management. They are encouraged to develop their strengths and take charge of their lives holistically, looking at the totality of who they are—body, mind, and spirit, and in relation to community.

The recovery philosophy promotes the recovering person’s right and responsibility to make an informed choice about medications. “Most people learn from trial and error that they need meds,” says Summerville. If someone decides not to take medication, “we have a responsibility to stay engaged, but not around trying to get them to take medications by instilling fear,” he says.

In the video, one mother whose son is recovering from mental illness says: “[People] can scare [parents] into saying [to their ill son or daughter]: ‘Well, if you don’t take your medication, you’re not going to get better.’ But it’s a matter of choice, and if you don’t give the person that choice, then how are you truly helping them?”

Her comment seems to overlook the plight of individuals with anosognosia, a symptom of several brain disorders, including schizophrenia, in which individuals cannot understand that they are ill and need help, and therefore

cannot make an informed choice about treatment. Research shows that 40 to 50 percent of people with psychosis suffer from anosognosia and that most can regain self-awareness when treated involuntarily with medications.

In light of this, Summerville says the Your Recovery Journey “is not meant for everyone. It is for people who are at the stage [of recovery] of wanting to live outside the illness.”

But the person who is too ill to make an informed choice is not abandoned, Summerville says. “The recovery philosophy is not just about self-determination. That’s just one pillar, and sometimes the goal of self-determination is compromised by the illness.”

For people living with severe mental illness, the recovery philosophy offers the possibility and hope of recovery. For those ready to reclaim their lives, the Your Recovery Journey program provides encouragement and some tools to help. In the video, Corey Maruca, who is now a college graduate and employed as a peer support worker, describes his journey across this spectrum in this way: “The first five years of my illness were hell. I was really sick and in a really dark place. I didn’t think I had any hope for the future.... [It’s] really empowering when you learn all these things, and you say to yourself, ‘I have the power to change, the power to get better.’” 🍁

The Your Recovery Journey program is free. If you would like more information, visit the Schizophrenia Society of Canada’s Website at [schizophrenia.ca](http://schizophrenia.ca) and click on the Your Recovery Journey logo at the bottom of the home page. Alternatively, contact Chris Summerville toll free at 1-800-263-5545 or by email at [chris@schizophrenia.ca](mailto:chris@schizophrenia.ca).