Your Recovery Journey

meaning
management &
medication

Participant Workbook

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Your Recovery Journey: Meaning, Management, and Medication

The Schizophrenia Society of Canada is interested in hearing from you. If you find this resource helpful, or if you have any suggestions or questions, please let us know.

E-mail **info@schizophrenia.ca** or phone **1-800-263-5545**

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Contents

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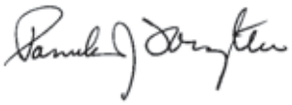

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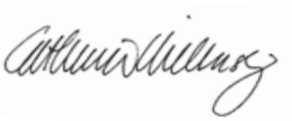

Catherine Willinsky, MHSc.
Manager, National Programs and Projects, member of the advisory committee

"Your Recovery Journey" is a valuable resource for those affected by mental illness who are looking for hopeful tools to assist them in their recovery. Recovery is a practical concept. It works in real life, with real people. I know this from first-hand experience.

A member of my family suffered from severe depression. Following an attempted suicide, with professional and spiritual help and medication, my sister was able to recover sufficiently to graduate from university and enjoy a meaningful and productive life for many years.

The national mental health strategy, which the Mental Health Commission of Canada is developing, will have as its cornerstone the principle of recovery.

(Michael Kirby, Chair, Mental Health Commission of Canada)

"We all have something to recover from, whether it is mental illness, addiction, physical disability, loss of loved ones, victimization or loneliness... Recovery creates a community that all can take part in as it erases the distinctions of position, age, skin colour, religion, language and education, and joins us in our common humanity."

(Sowers, W. 2007)

Foreword

"Don't tell me recovery is not evidence based! I am the evidence."

(Woman with a mental illness)

I love this quote! While there is no one definition that all agree on, recovery is all about hope, the hope that people can live lives of quality and dignity in spite of the limitations that come with mental illness.

For years it was thought that mental illnesses like schizophrenia were kiss-of-death diagnoses. Life was over. All hope evaporated. But we now have numerous long-term studies that indicate that up to two-thirds of people with mental illness can and do recover.

Recovery can have many different meanings. Some people will have one episode of psychosis or schizophrenia. Their recovery is much like that of a person recovering from a heart attack; though they are vulnerable, they may never have another episode again.

For others, the recovery or recovering process is much longer, perhaps even life-long. There may be intermittent relapses with mental illnesses like schizophrenia and bipolar disorder. Like people who live with asthma, people with schizophrenia can live a life of quality and purpose, but must pay special attention to self-care and to managing their illness.

Some people who have experienced unremitting mental illness seem to be beyond recovery. I understand this: one of my brothers lives with schizophrenia and another with bipolar disorder. Illness can be unremitting when people can't access recovery-oriented mental health services and systems. But we must still hope they can experience recovery.

Dr. Larry Davidson, professor of psychiatry at Yale University, says that 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. It is about self-determination, choice, hope, and empowerment.

Many who experience prolonged mental illness are not only recovering from the mental illness, but are also recovering from the losses associated with mental illness, and from its stigma and discrimination: loss of friends, income, safe and affordable housing, vocational and recreational opportunities, health, and hope of recovery.

We need to address the social injustices and lack of full citizenship opportunities experienced by people who live with mental illnesses.

Experts who work with young people experiencing early psychosis have said that recovery can be seen from three dimensions: personal, social, and illness-related. (Windell, D., et al., 2008)

- Personal recovery is about acceptance and regaining purpose and meaning in life as you come to terms with mental illness
- Social recovery is about living a safe, full, and dignified life in the community with appropriate supports and services
- Illness recovery is self-management and using your own *"personal medicine"* (Deegan, P. 2005), for example stress management, support groups, meditation, or yoga, as well as pharmaceutical medication

In the *Participant Guide*, we look at and discuss five topics.

- What is recovery?
- Quality of life
- Self-management
- Medication as a tool for recovery
- Moving forward: personal action planning

One of the best remembered television series from the 1950s was a show called *This Is Your Life*, broadcast from 1952 to 1961. The program was based on a simple principle: each guest was surprised with a presentation of his or her life.

Well, this is your life. You didn't ask for a mental illness. But a recovery journey is part of your life, too. It's a journey of meaning, management, and medication. We hope this resource helps you live life outside mental illness.

People who have experienced mental illness tell us recovery is possible. They say life can be lived beyond the illness.

The motto of Home Depot is *"You can do it. We can help."* The job of mental health service providers, family, and friends is to create environments in which recovery can take place. Only you can do the work of recovery. But we can help.

May this resource, *Your Recovery Journey*, inspire you; may your recovery be as much a reality as your mental illness.

I want to acknowledge the support of Janssen Inc. and our advisory board – consumers, family members, and service providers who assisted in the creation of this series. Our project coordinator, Catherine Willinsky, is to be congratulated and complimented on her leadership. She has kept us focused and on track with the project.

Finally, be assured we have endeavoured to be faithful to the literature written about recovery in the past twenty-five years.

I know as a Board Member of the Mental Health Commission of Canada that the Commission is committed to the development of a recovery-oriented mental health system in Canada. I trust that this program will contribute to the much-needed discussion in Canada about the recovery model.

Well, this is your life. Your journey of recovery!

Chris Summerville, D. Min., CPRP
Chief Executive Officer, member of the advisory committee

Schizophrenia Society of Canada

Introduction

Introduction

What's this program about?

Your Recovery Journey *is based on the premise that there is hope, that people with mental illness can get well, stay well for long periods of time, doing the things they want to do with their lives.*

The program 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 journey.

We have based the program on a peer-support model for a number of reasons: because peer support is an example of the kind of self-determination that occurs in recovery, and because peer support can transform lives. Hearing from others who have experienced similar struggles, and who understand how we are feeling, is an important factor in recovery.

The program is designed to be facilitated or co-facilitated by people who themselves have experience with mental illness and have also experienced recovery in their own lives. This "hope in action" approach is a fundamental principle of the program.

What will you learn in the program?

This program aims to increase your ability to meet your personal recovery goals. How?

By:

- providing an opportunity to explore the many aspects of recovery
- exploring the role of personal goals in the recovery journey
- sharing knowledge and tools that will help you take responsibility for your wellness and stability
- introducing a variety of self-help techniques so you can manage and reduce the symptoms of your illness
- helping you reflect on and plan *your recovery journey*
- finding effective ways to reach out for and use the support of a network of family members, friends, and service providers

Who is the program for?

Although some of the examples in this workbook relate to schizophrenia, ***Your Recovery Journey*** *is intended to serve the needs of all people who have had experience with mental illness, regardless of their diagnosis or the stage they are at in their recovery.* There are significant differences in the symptoms, course of illness, and treatment of different mental illnesses—but the recovery journey cuts across all of these. Almost everyone who is recovering from mental illness is striving to

- identify and reach personal goals
- find meaning and fulfillment in the face of a new reality
- deal with the effects of stigma
- establish a positive sense of self and a sense of belonging
- manage symptoms and medication
- stay well

What's this workbook about?

If you're reading the workbook, you're probably a participant in the program. The workbook covers the topics that are introduced in the group sessions, but it's yours to keep, and it provides additional tools and information for you to work through on your own.

It's best if you can work through the materials as you move through the program. During the week after a group session, you can reflect on what you learned and discussed in the group, read the information provided, and record your ideas, thoughts, and plans in these pages. Most important, you can use the workbook to chart your recovery journey.

"Instead of looking at recovery as relapse prevention, I see it as an active process of setting goals and working towards them."

(Manschreck, T.C. et. al. 2008)

"Schizophrenia is not a hopeless disease. Many, many people who are diagnosed go on to live full lives where they have a sense of happiness."

(Dr. Sonia Chehil)

Chapter 1: What is recovery?

Chapter 1: What is recovery?

What have we learned about recovery so far? Here are some key points.

- Recovery is a process built on hope, choice, self-determination, and empowerment.
- People with mental illness are resilient and have expertise about their own experience of recovery.
- Recovery is possible for all people living with mental illness.
- Recovery is more than reducing symptoms. Recovery happens when people with mental illness set and achieve their life goals and ambitions. The goals and the journey belong to you.
- People with mental illness 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 can involve many stages, with inevitable setbacks and uncertainty.

Tools in this chapter

❶ Defining your recovery
❷ Finding hope
❸ Building support systems
❹ Personal recovery strategies

What does "recovery" mean?

There is no one definition of recovery, because it means different things to different people. Here are a few definitions people have found helpful.

"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." (Anthony, W.A. 1993)

"Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again... The need is to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution." (Deegan, P.E. 1988)

"Recovery is a self-determined and holistic journey that people undertake to heal and grow. Recovery is facilitated by relationships and environments that provide hope, empowerment, choices and opportunities that promote people reaching their full potential as individuals and community members." (Pennsylvania Office of Substance Abuse Mental Health Services. 2005)

"Recovery is an uncharted, unpredictable and personal journey." (Sheehan, A. 2002)

What do these definitions have in common? They all

- emphasize a person's capacity to have hope and lead a meaningful life
- demonstrate that there is hope for recovery for every person with a mental illness
- acknowledge that just as the course of illness varies greatly from person to person, everyone's story and recovery are unique
- show that recovery is more than symptom management, and that personal recovery can happen even if a person continues to experience symptoms of their illness

❶ Defining your recovery

Often one of the first tasks in the recovery journey is to think about what we're recovering from – not only the effects of illness, but losses, trauma, stigma, dealing with the mental health system, and a lack of enriching opportunities as well.

Some of our losses may include loss of power, loss of valued roles, loss of meaning and purpose, and loss of hope.

➜ What are the losses you have experienced as a result of your illness that you need to recover from?

Many people have said that stigma, discrimination, and negative attitudes towards mental illness can be more difficult to deal with then the illness itself.

➜ How have you experienced stigma in your life?

➜ How have you dealt with it?

Mental health services and systems can devalue and disempower the people they are intended to serve.

➜ How did you experience the mental health services you received?

➜ What aspects of your experience do you need to recover from?

➜ What has helped you in your recovery journey?

➜ What has hindered your recovery journey?

"The power of the human spirit to sustain grief and loss and renew itself with hope and courage defies all description."

(Gottlieb, D. 1991)

"To hope under the most extreme circumstances is an act of defiance that permits a person to live his [her] life on his [her] own terms. It is part of the human spirit to endure and give a miracle a chance to happen."

(Groopman, J. 2003)

❷ Finding hope

Hope – a belief that we can get better – fuels the recovery process. Friends, family, and service providers can "hold the hope" for people who are ill in the early stages of recovery. But at some point each person much develop and internalize his or her own sense of hope. (Davidson, L. 2003)

Many people who have experienced recovery in their lives have said that the first step on their journey was having a sense of hope. Feeling the first glimmers of hope creates a source of energy that helps us move forward and see the possibilities ahead. We reclaim our identity as a whole, well individual and become self-directed. We begin to understand our preferences. As we advocate for ourselves, we begin to play an active role in our lives and our treatment. We make the choice to recover. (Holder, J. 2007)

Sharing hope

A helpful way to reinforce the hope we feel in our lives and to spread hope is to share our own personal stories. By reflecting on a time when we were faced with challenges and overcame them, we remind ourselves of our own personal power and encourage others that there is hope. (Holder, J. 2007)

"To me recovery means freedom, hope."
(Maritza)

➜ What does “hope” mean to you?

➜ When did you first feel hope that recovery was possible?

➜ What can you do to increase your feelings of hope?

➜ What/who are your key sources of hope (friends, family, spirituality, meaningful activities)?

❸ Building support systems

Support is an essential part of recovery, and having access to a wide range of supports is important in helping people celebrate their successes and get back on their feet when they experience a setback.

A support system is made up of people who care about you and spend time with you, listen to you and stand by your side. They can be friends, family members, service providers, community members, co-workers, members of peer-support groups, faith communities, and others.

➜ Who are the key members of your support system?

➜ Where are some places in your community you could meet and get to know potential members of your support team?

➜ What kinds of services and supports have you found most helpful in your recovery journey?

➜ What other services and supports are you interested in finding out about?

❹ Personal recovery strategies

Pat Deegan, an expert in the field of recovery and a person who has experienced mental illness, has created the useful concept of "personal medicine" to describe the things in people's lives that help build self-esteem, empowerment, and confidence.

In her own personal experiences as well as her research, Deegan found that there are many ways to change our body's biochemistry. This finding helped her come up with the notion of "personal medicine."

Personal medicine is not about medications prescribed by a doctor. It is a strategy for taking care of yourself that you can initiate yourself.

Like pharmaceutical medications, personal medicine can help reduce and even eliminate psychiatric symptoms. The goal of personal medicine is to improve mood, thinking, behaviour, and overall well-being.

> "Personal medicine' refers to the things we do that raise our self esteem and make life worth living. Fishing, meditating, exercising, having dinner with a friend, being a good mom – all of these things and more can be vital to our recovery."
>
> (Deegan, P. 2005)

What is your "personal medicine"?

➜ What do you do that helps comfort or soothe you?

➜ What kinds of activities challenge, and engage you?

➜ Are there things other than taking prescribed medication that you do to help reduce your symptoms?

➜ What other personal recovery strategies or activities have you found to be helpful?

"Mental illness is just one part of me, like I like music and writing poetry and I have family and friends, and all kinds of other things that make up me."

(Sherri)

Chapter 2: Quality of life

Chapter 2: Quality of Life

What have we learned about quality of life so far? Here are some key points.

- Having a positive quality of life is essential to recovery.
- The factors that contribute to quality of life are different for everyone, but usually include relationships with family and friends, work, housing, income, neighbourhood, community, health, education, and spirituality.
- Many people say that their personal tools for quality of life include an understanding of our personal mental health strengths and challenges; a positive sense of self, purpose, and meaning; a feeling of inclusion and belonging; and a sense of personal control and empowerment.
- Identifying the activities, relationships, and roles that promote quality of life can help us reach our recovery goals.

Tools in this chapter

❶ Understanding your personal mental health strengths and challenges
❷ Developing a positive sense of self
❸ Finding purpose and meaning
❹ Having a sense of inclusion and belonging
❺ Gaining personal empowerment and self-determination

What is quality of life?

In the first chapter we focused on recovery, what it means to us as individuals, and the things that have helped us in our journey of recovery.

In this chapter we are going to focus on the things that give our lives meaning, purpose, and "quality." We'll look at the things that support us and let us live a satisfying life.

A lot of research has been done measuring the quality of life of people with mental illness, but mostly from the service providers' point of view. Increasingly, though, there is an interest in looking at what quality of life means for people with mental illness, and how it is connected to recovery.

Many people with mental illness have described their basic mental health needs as "a home, a job, and a friend" or, as someone recently put it, "somewhere to live, something to do, and someone to love." People say that a decent quality of life depends on having access to these basic things, which are important for everyone.

"Quality of life means that you're in a place where you feel really good – about yourself, about what you're doing, who you are, where you live."

(Corey)

Knowing that we are valuable to ourselves and others, having a sense of why we are in this world and what we are striving for, and feeling that we have a clear role and a place to belong all contribute to our sense of control, our mental health, and quality of life. (Canadian Mental Health Association, 2004)

Let's take a closer look at the key components of quality of life, and what having a positive quality of life means to you.

❶ Understanding your personal mental health strengths and challenges

As individuals, we all need to develop an understanding of our strengths and challenges. For people with mental health problems, this can be a complex issue.

We need to understand how the illness affects our thinking, feelings, and behaviour before we can begin to take back control. The situation is even more complicated because we're not just dealing with our own symptoms and experiences, but also with the reactions of family, service providers, friends, and society.

Many people see recovery as a meaningful opportunity for positive transformation; they feel they have become a better person because of their illness experience, with an increased understanding of suffering and an expanded capacity for empathy.

The following questions look at how your experience has helped you develop an understanding of your personal mental health strengths and challenges. (There are more tools for understanding your mental health strengths and challenges in Chapter Three.)

➜ What are the biggest personal challenges your illness has posed?

➜ Think about your personal strengths and gifts. What positive traits and personal strengths do you have? For example, self-awareness, persistence, integrity, and patience.

➜ How can you use your strengths to deal with the effects of the illness on your life?

❷ Developing a positive sense of self

A positive sense of self is a basic tool for dealing with mental illness and promoting our mental health.

We need to be able to separate our illness from ourselves – the illness may be part of our life, but does not define who we are.

➜ How would you describe yourself as a person? Who are you other than your illness?

➜ How has your illness affected your sense of self?

➜ What has helped you put the illness in its place and develop a positive sense of self?

➜ How can you continue to nurture and develop a positive sense of self?

"Recovery is about having confidence and self-esteem. There are things I'm good at, and I have something positive to offer the world."

(Mueser, K.T. et. al. 2006)

❸ Finding purpose and meaning

All people strive to make sense of their lives and to develop a sense of purpose and meaning. In recovery, we need to develop a new purpose and meaning within and beyond the limitations imposed by our illness.

➜ How has your experience of illness changed the way you relate to the world?

➜ What kinds of activities and pursuits make you feel connected and give you a sense of meaning and purpose?

➜ What has your illness taught you about finding meaning and purpose in your life?

➜ Can you share what meaning or purpose you have or are searching for?

❹ Having a sense of inclusion and belonging

Mental illness can be a very alienating experience. Social rejection, in combination with an inner sense of isolation, can make the challenges posed by the illness even more difficult.

Having a sense of inclusion and belonging, on the other hand, can reduce the effects of illness and help people recover.

For most people, having a sense of inclusion and belonging comes from positive day-to-day interactions and involvement in different social contexts, for example work, family, and community groups.
(Canadian Mental Health Association, 2004)

➜ What are the key relationships or connections that give you a sense of mutual support and trust?

➜ How have stigma and discrimination affected you? How have you dealt with them?

➜ What are the settings or situations where you feel you belong?

➜ What kind of social/community involvement do you feel supports your recovery?

➜ What other community connections (employment, volunteering, leisure, participation in faith/religious groups, clubhouses) would you like to develop?

❺ Gaining personal empowerment and self-determination

All of the things we've just been talking about – understanding our personal mental health strengths and challenges, having a positive sense of self, being connected to a source of purpose and meaning, and feeling a sense of inclusion and belonging – contribute to our personal empowerment.

Having a feeling of personal empowerment, a sense that we are not at the mercy of factors beyond our control, is very important for mental health. People develop a sense of empowerment when they have meaningful choices and can implement those choices.

Mental illness can be a very disempowering experience, and many people have suffered the effects of a lack of choice and self-determination in many aspects of their lives.

The importance of personal empowerment and self-determination in the recovery journey cannot be overstated. Not everything in life is controllable, but having the right set of tools and resources can help you make choices and take action on your own behalf.

➜ What does "empowerment" mean to you?

➜ Have you ever felt like you did not have the power to decide or make choices? What was that like?

➜ Can you remember a time when making a choice strengthened your belief that recovery was possible?

➜ What kinds of resources (people, groups, beliefs, activities) in your life help strengthen your sense of control?

➜ What are some choices you could make to further your recovery and wellness?

"To be empowered, people need access to information and the opportunity to make their own choices."

(Ragins, M. 2000)

"Sometimes life is what you make it… I think to improve your quality of life you have to be the person behind that wheel saying 'Yes, this is where I'm going to go, this is what I think is good for me.'"

(Sherri)

"It's really empowering when you can learn all these things, and you say to yourself 'I have the power to change, I have the power to get better.'"

(Corey)

Chapter 3: Self-management

Chapter 3: Self-management

What have we learned about self-management so far?

Here are some key points.

- Studies show that self-management – a person's determination to get better, manage the illness, take action, face problems, and make choices – facilitates recovery from mental illness.
- Although the concept of recovery from mental illness is relatively new, people with mental health difficulties were self-managing and functioning in the community long before the idea of recovery became popular.
- Self-management means different things to different people, but generally includes: self-awareness and monitoring, coping strategies, personal goal setting, and relapse planning and management.
- Themes from earlier sessions – having a practical understanding of our mental health strengths and challenges, personal empowerment, developing our own personal resources for managing symptoms (the concept of personal medicine) – are also consistent with self-management.
- Effective communication with members of social support networks, including family, friends, service providers, and others, can help us manage symptoms, prevent relapse, and maintain recovery.

Tools in this chapter

What is self-management?

People may see their doctor several times a year, but as individuals, we have to manage our health on a daily basis. Whether or not we do well depends a lot on our own choices and behaviour.

"To me being in recovery means I try to stay in the driver's seat of my life. I don't let my illness run me. Over the years I have worked hard to become an expert in my own self-care. Being in recovery means I don't just take medication, rather I use medications as part of my recovery process. Over the years I have learned different ways of helping myself. Sometimes I use medications, therapy, self help and mutual support groups, my relationship with God, work, exercise, spending time in nature – all these measures help me remain whole and healthy, even though I have a disability."

(Deegan, P. 1993)

As we discussed as a group in our session on self-management, there are many things we can do to take an active role in staying well and managing our recovery. These include self-monitoring, stress management, identifying wellness tools, and creating a crisis plan and a post-crisis plan for getting back on the road to recovery.

"Self-management is not limited to managing symptoms. Self-management has to do with 'This is my life, and this is how I'll manage my life.'"

(Chris)

"Self management entails a positive mental attitude and positive actions that help you get on with living your life the way you want to. It includes knowing when to recognize the illness limitations and adjusting your way of life to accommodate them...and living your life to the full... The more you live your life and achieve goals, no matter how big or small, that is active self-management."

(Martyn, D. 2003)

There are tools, exercises, and samples in this chapter that you can use to develop your skills and express and communicate your wishes effectively. Before you begin working on your personal plan, have a look at the following tips, which address some of the issues involved in making an effective personal plan for managing your illness and maintaining wellness.

"Recovery is active coping rather than passive adjustment. It is important for the individual to take personal responsibility for his or her own well-being. To do so requires self awareness, including paying attention to sources of stress and positive reinforcement. People need to keep in touch with their own feelings and deal with difficulties as soon as possible."

(Ralph, R.O. et. al. 2004)

❶ Tips for effective self-management

(National Alliance on Mental Illness, 2007)

We know that:

- being aware of our symptoms, moods, habits, triggers, preferences, and early warning signs is the cornerstone of self-management
- writing down feelings that describe yourself when you are feeling well can act as a benchmark for knowing when you are not feeling well
- understanding emotional triggers (external events or influences), including relationships, social situations, and specific environments, can help us avoid doing things that will make us feel worse
- recognizing the early warning signs (including feeling more anxious, forgetful, or frustrated) and knowing how to deal with stress effectively can help keep us well

For more tips to help you manage your illness, please see the next 2 pages.

"You're always checking yourself and making sure that every day is a little better than the last."

(Ian)

◯ Build a support system

The important people in our lives play a vital role in our wellness. They can be a source of hope in difficult times, and can support, encourage, and challenge us to be our best.

Having a team of key support people involved in your wellness plan will help you keep on the right track with managing your illness and staying well. Support team members can be friends, family members, co-workers, community members, service providers, members of your faith community, and so on.

Besides providing social and emotional support, the people on your team can help you make sure you're doing what you need to do to take care of yourself, for example getting enough rest, eating well, exercising, maintaining a medication plan, and identifying early warning signs.

◯ Express yourself

Open and honest communication with your loved ones and support team can help you achieve your personal goals, manage your symptoms, prevent relapse, and stay on course with your recovery. Honest communication is also an important part of healthy relationships.

Expressing your feelings – both positive and negative – in a respectful manner is essential. When you keep your feelings and words inside, stress can build, and this can get in the way of your recovery.

◯ Attend your appointments

It's much easier for you and your support and treatment team to work together when you meet regularly. They can learn how you are feeling and work with you to achieve your personal goals, to make sure your medication is working as effectively as possible, and to minimize the effects of any side effects.

◯ Keep a journal

One way to communicate effectively with your treatment team is to keep a journal. Include information about how you are feeling, any symptoms you may be experiencing, your medication – missed doses, side effects – and your frustrations.

It is helpful to bring your journal with you to appointments, because the more information you can share with your treatment team, the better they can help you.

◯ Make a list of questions

If any questions come up between your appointments with service providers, write them down so you don't forget them. Bring your list of questions with you to your next appointment so you can get an answer.

◯ Communicate your wishes

Developing a wellness/relapse-prevention plan can help you negotiate bad periods. Share your plan with your support team and loved ones. You may even want to develop your plan in collaboration with members of your support team. We'll discuss this more thoroughly in Chapter Five.

◯ Know the difference between symptoms and side effects

To manage illness, you need to be able to differentiate between symptoms, side effects, and the kind of strong emotional reactions to life events and losses that everyone experiences sometimes.

"The support group really seemed to turn things around for me…just the level of understanding that other consumers have."

(Mia)

Things to consider

◯ Sometimes what appear to be symptoms may be side effects from medication.

◯ What may feel like symptoms could be strong, healthy emotional responses to things going on in your life.

◯ People can learn to manage strong emotions as well as they manage their symptoms.

(St. George, L. 2007)

"We are all different and what works for one person may be useless for another. Therefore, one has to discover one's own ways of improving. Also, it may take many years to become really good at it. But just starting is important: changing the attitude of 'passing the buck' and making the decision to take as full a role as possible in one's own treatment. Set yourself a different course with renewed hope."

(Jenner, A. *National Voices Forum Report*, 1998)

❷ Developing self-awareness

A big part of recovery involves reconnecting with ourselves, determining what is illness and what is self, discovering new and positive personal qualities, developing a belief in our own strength of character and potential.

When we look at ourselves and acknowledge the strengths and talents we have, we can put those positive qualities to work in helping us overcome the challenges we face.

Learning more about your personality, preferences, and tendencies can be a valuable part of developing greater self-awareness, which is a key element in your recovery journey. The information on the next few pages can help you think through some of the different aspects of your personality.

"I am more aware of what my strengths and weaknesses are...I'm more sensitive to other people, and I try to see other people's point of view. I understand myself more."

(Windell, D. et. al. 2008)

Personality traits and temperaments

(Dombeck, M. et. al., n.d.)

Your personality is that collection of behavioural, mental, and emotional tendencies you happen to have that makes you a unique person, distinct from all others. The starting place for personality is temperament, which is that set of biologically given behavioural, mental, and emotional tendencies you are born with. As people age, their base personality is deeply affected by their experiences and how they uniquely interpret those experiences.

Personality is usually described as a set of enduring tendencies or "traits" that tend to be stable over long periods of time. Though there are many competing voices, a sort of consensus has developed over the years that there are essentially five major normal personality factors. These factors are:

- **emotional stability**, which describes a person's tendency to be either calm and laid-back or else jumpy and prone to anxiousness and nervousness
- **extraversion/introversion**, which describes a person's preference for social interaction or solitary pursuits
- **agreeableness**, which describes a person's disposition to be friendly, emotional, and warm, or cold, cognitive, and detached
- **conscientiousness**, which describes a person's disposition to take on responsibility and avoid acting on impulse (or to avoid responsibility and act on impulse)
- **intellect/openness**, which describes a person's disposition towards opportunities to try out new ideas, attitudes, and sensations

There are psychological personality tests designed to measure personality on each of these five factors. Test scores provide a profile showing how the person ranks in comparison with an average score on each of the five factors. Average scores show up towards the middle of the graph; extreme scores show up as dramatic peaks or valleys far above or below the middle.

You may want to take a personality test to learn how your personality ranks against the average. Knowing that you score very high or low on a particular aspect of personality can help you understand how you differ from the average. Extreme personality tendencies can suggest particular vulnerabilities in your constitution; you can then be aware you are at risk. For example, low emotional stability scores are associated with a heightened risk for developing mood and anxiety disorders.

Understanding your basic personality profile also helps you understand what sorts of people you are likely to be compatible with. If you are highly extroverted and desire a lot of social stimulation, for example, you may have a hard time living with someone who is highly introverted, finds it difficult to socialize, and prefers solitary activities.

The more you know about your own personality, especially in relation to average personalities, the more information you have for understanding how you are likely to be perceived by others, what characteristics in other people you are likely to mesh well with, and what vulnerabilities you need to watch for. Knowledge of the ways in which you are extreme makes you capable of knowing what to work on and what to watch for.

Ask yourself the following questions.

- **Do you have a tendency to be anxious or depressed easily (low emotional stability), or do you have a more even, sunny disposition (high emotional stability)?**

  People who feel anxious and depressed have to take extra good care of themselves, and be sure their basic needs are met, so they can maintain a good mood and positive outlook during stressful times.

- **Are you impulsive (low conscientiousness) or more of a cautious and responsible person (high conscientiousness)?**

  Being too impulsive can cause you to jump into situations without thinking them through, which can sometimes cause problems. Too much caution can keep you from taking advantage of opportunities that might make your life better.

- **Is it easy for you to be with other people, or do you require time alone to recharge yourself?**

  Extroverted people get energy by being with others and generally find that they do better in work situations – such as sales – where they can interact with other people. Conversely, introverted people need more space to regroup when stressed and often find it easier to pursue work that can be done while alone, for example writing or engineering.

- **Are you stubborn and persistent, or are you more easygoing? Are you a generous person, or do you tend to watch out for yourself mostly?**

  Easygoing, generous people run the risk of letting other people take advantage of them. Conversely, stubborn, more disagreeable people run the risk of not fully respecting the needs of the people around them. Easygoing, generous people may find themselves becoming resentful of others, while stubborn, more self-centered people may find that people are resentful of them.

Generally, you are often best off working for a balance between extremes of personality attributes. When any given personality tendency causes you problems, a good solution is to work towards incorporating more of the opposite tendency into your personality, to balance yourself out.

❸ Your self-management plan

➜ What are the ways you already self manage?

➜ Thinking back to the list of "Tips for effective self management" (page 37–39), which tips do you use the most? Which tips do you think might be helpful in the future?

➜ How could other people support you in your self-management plan?

❹ Naming your personal goals

Goals are about where we want to go and how we can get there. The importance of setting and achieving personal goals has been emphasized throughout this program, because it's a key part of the recovery journey.

Most people have both long- and short-term goals. Short-term goals support recovery and can be achieved on a day-to-day basis. Our longer-term goals usually help us achieve the quality of life we want, and medium-term goals help us map out how we can get there using self-management and planning.

Remember to share your goals with members of your support team so they can help you reach them.

Examples of personal goals include:

- being able to stay awake during the day and not feeling "zombied-out"
- taking a university course
- holding down a part-time job
- going out on a date
- having an active sex life
- achieving good overall physical and mental health
- being a resilient person

"You need other things in your life to have that healthy balance, to make you feel good about yourself inside-out."

(Sherri)

What are the goals you would like to achieve?

➜ Short-term (within the next few months)

➜ Medium-term (over the next few years)

➜ Long-term (in five to ten years)

Chapter 4: Medication as a tool for recovery

Chapter 4: Using medication as a tool for recovery

What have we learned so far about using medication as a tool for recovery?

Here are some key points.

- Medication is one of the tools you can use to manage your illness.
- For most people with mental illness, medication is a necessary part of treatment.
- Although most people with mental illnesses (for example schizophrenia) usually find that medication is necessary, it should not be considered the only kind of therapy. Medication should be used in addition to other therapies, services, and supports.
- Sticking to a medication plan is a key factor in self-management and recovery.
- To be effective, people's treatment plans must support their ability to reach their personal goals.
- There are effective ways to deal with the issues and problems associated with medication (for example, side effects).

Tools in this chapter

Medication and recovery: What we know

For many of us with mental illness, medication may be a necessary and permanent part of our lives. In this chapter we'll explore ways we can use prescribed medication as a tool in our recovery.

We have learned a great deal in recent years about the different factors that influence the effectiveness of medication for people with mental illness. Much of the learning has come about because people with mental illness worked together with researchers to investigate the issue.

Here are some of their most important findings.

- Using medication is an active process that involves making complex decisions and working through problems and issues. People are faced with many choices in deciding the role of medications in their recovery process. (Deegan, P., Drake, R. 2006)
- People with mental illness can act in partnership with service providers by sharing information and collaborating to find the best treatment plan. This is called "shared decision-making."
- Medication can support recovery only when it enables people to effectively pursue activities that provide meaning and purpose – employment, education, relationships, and spirituality.
- When the side effects of medications interfere with the activities that are essential to recovery, it's difficult to stick to a treatment plan.
- Medication can create an environment in which recovery can take place and can open doors so people can find support.

"Using medications is a dynamic journey, not a static event, particularly for people with long-terms disorders."

(Deegan, P., Drake, R. 2006)

❶ Psychiatric medication and personal medicine

We talked a bit about the idea of "personal medicine" on page 21 and spent some time thinking about our own personal recovery strategies. But how does our personal medicine relate to prescribed psychiatric medication, and how can the two work together to facilitate recovery?

Pat Deegan argues that when prescribed medication supports people's personal medicine (their personal strategies for self-care), people tend to follow their treatment plan. She has identified three key principles for using prescribed medication successfully in the recovery process.

1. **The goal of using psychiatric medication is recovery.**
2. **Psychiatric medication must enable people to pursue their personal medicine, as well as the overarching goal of recovery.**
3. **The goal of the treatment team is to support people to achieve the best use of personal medicine and psychiatric medicine in the recovery process.**

"I have learned that psychiatric medicine is not the only type of medicine that is important to recovery. One of my major findings has been that people who are recovering do not simply swallow pills in a passive way. Instead they get active and they understand that recovery is about changing our lives, not just our biochemistry."

(Deegan, P. 2004)

Let's look at your relationship with medication.

➜ What is your treatment goal?

➜ What are some examples of your own personal recovery strategies or "personal medicine", things that give your life meaning and purpose, help you manage your symptoms, and raise your self-esteem?

➜ What do you see as the benefits of taking your prescribed medication?

➜ Are there any challenges with taking your prescribed medication (i.e., side effects, frequency of taking medication, compliance issues)?

➜ Does taking your medication help you manage your symptoms? How?

➜ When your symptoms are under control, does that help you do what you want? Does it help you achieve your own personal recovery strategies (personal medicine)? How?

➜ Have you had any bad experiences with medication? Describe them.

➜ What problems make it hard for you to stick with your medication routine?

"If you're on the wrong medication, you won't want to take it, and if you don't take it, you get sick again."

(Corey)

❷ Tips for using medication effectively

There is no one reliable method to help you stick with taking your medication, and no easy way to make the medication more effective. But here are some things to think about that may help you find what will work for you.

Get accurate information about medications.

- Get a clear understanding of why the medication is required, how long the medication is required, and what the benefits and side effects are.
- You may need different medications at different times, depending on what you're experiencing. Service providers need to be sensitive to stages of treatment and recovery, and provide information accordingly.
- Understand all of the possible treatment options so that you can make an informed choice.

Develop a partnership with service providers.

- Talk to your service providers about your recovery goals. Write them down.
- Tell them about your personal goals and preferences. This can help them put your medication into perspective.
- Describe your personal medicine and your other personal recovery strategies.
- Talk about the things that give your life meaning and purpose and the activities you would like to get back to doing.

Work with your service providers so you can agree on your treatments and goals.

➜ What are your problematic symptoms?
➜ What are your recovery and treatment goals?
➜ How can prescribed medication help you reach your recovery goals?
➜ How will you keep track of and deal with side effects of your medication?
➜ Do you have a treatment preference (i.e., once-a-day oral medication, long-acting injectable)?

"I have no shame in saying that I take medication to cope with everyday life, but I am not a walking prescription. I'm not just 300 milligrams of whatever."

(Batson Feuer, S. 2008)

Find the right medication and delivery method.

- All medications have their strengths and weaknesses, and different medications work for different people.
- Medication and doses are different for every individual. The rule of thumb is to find the lowest possible dose of medication that effectively reduces symptoms and prevents relapse.
- There are many more choices in medication available now than in the past. There are oral, injectable and long acting injectable medications available for various conditions. Each medication has its own benefits. It is important to understand the side effects and clinical significance of any medication you are taking. The majority of people with mental illness will be able to find a medication that will help.
- For many people, fewer doses during the day are more convenient and easier to remember.
- For other people, a long-acting injectable is preferable as it may improve adherence, and the frequent touch-points with healthcare providers may be beneficial. If you want to be on a different medication, such as a long-acting injectable, talk to your service provider and they can help you start the process.

"I remember within a day or two of taking medication, I knew I could get better. It just made me feel that well."

(Corey)

Understand what works for you.

Here is a list of strategies that have helped some people deal with their medications.

- Be aware of how your illness is affecting you at any given time, and the effect the medication has on your behaviour and functioning.
- Experience the positive role medication can play in your recovery goals. This may take some time, and often comes about through a lot of trial and error. Being persistent helps, because there are more and more treatment choices available, which increases the likelihood that there will be an effective approach for everyone.
- Get access to a range of different services and supports, for example housing and employment support.
- Practise! It's easier to stick to a medication plan over time if you're comfortable with your medication routine.
- Ask for reminders. Phone calls from the pharmacy or from friends and family can help you remember to take your medication. For some people, special packaging (blister packs, dosettes) simplifies a medication routine. Put a reminder into your mobile device.
- Talk about it. Use educational and peer-support groups, and share your ideas and concerns with people who have had similar experiences.

"The turning point was when my medications became not only stabilizing but energizing, and I suddenly had more ability to face everyday tasks."

(Manschreck, T.C. et. al. 2008)

Medication and relapse

- If people experience relapse because they're not taking the medication as prescribed, there are a few things to try. Lower the dosage. Take medication to control side effects. Switch to a medication with fewer side effects. Switch delivery methods; for example, change to a long-acting injection every two to four weeks. Talk to your doctor about your choices.
- Sometimes people experience relapse even when they're taking the medication as prescribed. Work with your service provider to try another medication, adjust the dose, or consider a different delivery method.
- Other factors in your life can lead to relapse, especially stress.

Following your treatment plan – Prevent relapse

- When you start a new medication, your body needs time to adjust. Taking a long-term treatment drug is not like taking an aspirin for a headache. It takes time for the drug to take effect – sometimes days or weeks. Try to be patient.
- It's important to remember that once your antipsychotic medication has started to work, it will only continue to work if it is taken correctly and regularly, according to your doctor's instructions.
- "Adherence" is a term that means taking your medication according to your doctor's instructions – and **staying with** your treatment. There are a number of reasons why people may have difficulty following their treatment plan, such as inconvenience, side effects, dosing issues, access to medication, lack of insight because of the illness – or simply forgetting.
- Keeping the treatment program as simple as possible may help with managing your medication schedule. For some people, that may mean an oral medication. For others, that may mean an injectable medication.
- If you do not follow your treatment plan, you could risk relapse, re-hospitalization, impaired functioning and a lower quality of life.

❸ Key questions and considerations about medication use

Here are a few questions you can ask your service provider.

- ➜ What is the desired effects of the medication?
- ➜ Why do I need it?
- ➜ How and when do I take it?
- ➜ What are the side effects?
- ➜ Does it have any special warnings or restrictions?
- ➜ Is there another medication I could take?
- ➜ Are there different delivery methods?
- ➜ Is the medication daily or long-acting?

Important considerations

- If you're taking psychiatric medications, avoid using illegal or street drugs, as they hinder recovery. Please see **www.schizophreniaandsubstanceuse.ca** for more information.
- You can have alcohol in very moderate amounts (one can of beer, one glass of wine). Large amounts of alcohol may encourage a return of symptoms.
- It can be tempting to stop taking medication, especially during the recovery phase or when side effects are distressing, but you need to understand the risks involved in doing so. Studies have concluded that four out of five people who stop taking their medications after a first episode of schizophrenia will relapse. Talk to your doctor before you decide to stop, change, or alter the dosage of your medication.

"I know that if I miss a dose of medication, certain things will start creeping back up on me."

(Corey)

❹ Information on common psychiatric medications and potential side effects

For definitions of terms, please refer to the glossary at the back of this workbook.

In Canada, types of medications commonly used to treat symptoms related to schizophrenia, mood disorders, and anxiety disorders include: antipsychotics, mood stabilizers and antidepressants.

Many psychiatric medications take a while to begin working, and some take six weeks before you feel the effect. With some medications you may notice an effect within two weeks.

Medications have two names: a generic or chemical name and a brand or trade name. The brand name is most commonly used. Different generic manufactures now make many of these medications, so the name on the label may be different than what you see in your list of medications, which shows the generic name first, then the brand name in brackets.

Antipsychotic therapy

Antipsychotic medication forms	
Oral medications	Injectable medications
Capsule or tablet (swallow with liquid)	Long-acting injection
Dispersible tablet (melts in your mouth)	Short-acting injection (used for acute treatment only)
Sublingual tablet (place under the tongue where it dissolves)	
Liquid (solution)	

- Can take up to several weeks (or months, in some cases) to show full benefits.
- Do not "cure" mental illness. Instead they treat the symptoms.
- Often prescribed over the long term to prevent relapse.
- May take a few tries to get the "best fit" in terms of response and side effects.

The fit is especially important when people take a medication over a long term. People who are ill often need much encouragement and support when they begin taking medication.

First-generation antipsychotics

The first-generation antipsychotics, also known as typical antipsychotics, were introduced back in the 1950s. At the time, they made a significant impact on the treatment of people with psychotic illnesses. Many people did well on these medications, but others experienced side effects. To eliminate the side effects, the second-generation antipsychotics (also called atypical antipsychotics) were developed.

Second-generation antipsychotics

The second-generation antipsychotics work differently than the first-generation do, and they are used much more commonly today. Their main advantage is that they cause fewer extrapyramidal side effects (for example, muscle stiffness and tremors) than the older agents.

The second-generation antipsychotics have benefited people with mood symptoms, and these drugs are increasingly being used to treat mood disorders such as bipolar affective disorder.

How it works

The action of antipsychotic drugs is very complex and not fully understood. One thing we do know is that these medicines decrease the amount of dopamine (a chemical found in the brain) in certain parts of the brain. Unfortunately, the older agents decreased the amount of dopamine in areas where it should not be decreased; thus the side effects. The second-generation agents work more selectively on the dopamine system, and troublesome side effects occur much less often. The antipsychotics also affect levels of serotonin (a chemical in the brain involved in mood), which can be helpful with other symptoms.

Antipsychotics

Uses

First-generation antipsychotics		
Medication	Oral	Injection
Clopixol (zuclopenthixol)	✔	✔
Chlorpromazine*	✔	✔
Fluanxol (flupentixol)	✔	✔
Fluphenazine*	✔	
Haloperidol*	✔	
Haloperidol deconoate*		✔
Loxapac (loxapine)	✔	
Modecate (fluphenazine)		✔
Navane (thiothixene)	✔	
Nozinan (methotrimeprazine)	✔	✔
Neuleptil (periciazine)	✔	
Orap (pimozide)	✔	
Piportil L4 (pipotiazine)		✔
Prochlorperazine*	✔	
Stelazine (trifluoperazine)	✔	
Trilafon (perphenazine)	✔	

*No brand name available in Canada.

Second-generation antipsychotics		
Medication	Oral	Injection
Abilify (aripiprazole)	✔	
Abilify Maintena (aripiprazole prolonged-release)		✔
Clozaril (clozapine)	✔	
Invega (paliperidone)	✔	
Invega Sustenna (paliperidone palmitate)		✔
Latuda (lurasidone)	✔	
Risperdal (risperidone)	✔	
Risperdal Consta (risperidone prolonged-release)		✔
Saphris (asenapine)	✔	
Seroquel (quetiapine)/Seroquel XR (quetiapine furamate)	✔	
Zeldox (ziprasidone)	✔	
Zyprexa (olanzapine)	✔	
Zyprexa IntraMuscular (olanzapine tartrate)		✔

Note that most oral therapies are taken daily, whereas the frequency of injection therapy could be weekly, monthly or less often, depending on the product. Talk to your healthcare provider about your preferences and what may work best for you.

Potential side effects

As with any medication, there are side effects. Discuss the pros and cons of all medications with your healthcare provider. Keep in mind that each person's reaction to a medication is unique.

Side Effect	Description
Akathisia or restlessness	Causes feelings of tension or restlessness on the inside, or makes a person feel fidgety and unable to stay still. This side effect usually happens in the first few months of treatment, or after an increase in dose. There are treatments to make a person more comfortable.
Blurred vision	Also a common early side effect that generally lasts no more than a couple of weeks. Most often noticed when people try to focus on objects that are close up, for example, reading.
Constipation	A common side effect of many psychiatric medications. Regular exercise, drinking plenty of fluids, and eating a diet rich in fibre will all help. Bran and fresh fruits and vegetables provide fibre. If constipation persists, medication may be needed; discuss the problem with the treatment team.
Dizziness	Occurs most often when the medicine is started or when the dose has been recently increased. People notice it when they get up too fast from sitting or lying down. To prevent dizziness: get up more slowly. Dangle your feet over the edge of the bed for a minute or so before you try to stand up. This side effect rarely lasts for more than a couple of weeks.
Dry mouth	A common side effect of many psychiatric medications. If it is bothersome, chewing sugarless gum or sucking on sugarless candy may help.
Dystonia	A muscle spasm that affects different muscles within the body. The most common dystonias involve the eyes, which roll backwards; the head and neck, which tilt backwards; the jaw, which locks into place; and the tongue, which feels fat or thick. Dystonia is most likely to happen very early in treatment – often in the first week – or when medications are increased. There is medication that makes the dystonia go away very quickly.
Elevated blood sugar	Atypical antipsychotic medications may cause an increase in blood sugar levels. People with diabetes report that the effects of the diabetes get worse; other people report new-onset diabetes after taking atypical antipsychotics. Check blood sugar levels frequently, especially if there is a family history of diabetes, and look for signs of the disease: increased thirst, increased need to urinate, and weight change, especially weight loss.
Elevated cholesterol	Appears to occur more frequently with the atypical antipsychotics. If you're taking antipsychotic medication, ask your family doctor to check your cholesterol levels.

Side Effect	Description
Excessive salivation	Flupentixol (Clozapine) can cause excessive salivation, usually when a person starts taking the drug or when the dosage is being adjusted.
Extrapyramidal side effects (EPS)	These occur much less frequently with the atypical antipsychotics than with the typical ones.
Neuroleptic malignant syndrome (NMS)	An extremely rare side effect of antipsychotic treatment. Symptoms include heart palpitations (the heart beats too fast or irregularly); confusion; a lot of sweating; unusual muscle stiffness; fever; and loss of bladder or bowel control. If you notice any of these signs, seek medical attention immediately.
Pseudoparkinsonism	Antipsychotic medication may cause a person to experience the symptoms of Parkinson's disease. These include: tremours, usually in the hands and fingers; stiffness in the joints; and slowed body movements. There are treatments for pseudoparkinsonism.
Sedation	Greatest during the first few weeks of therapy, and often lessens with continued treatment. If it continues or is bothersome, the dose or the times of medication may be changed. Be careful about driving and doing other activities that require alertness.
Tardive dyskinesia (TD)	A movement disorder that can occur in any part of the body. Common signs of TD include smacking of the lips, twitching, sticking out of the tongue, and movement of the jaw, fingers, and toes. It's important to prevent TD. Monitor for these signs; if they appear, discuss with your doctor.
Weight gain	Occurs more frequently with the atypical, or second-generation, antipsychotics. Not all people will gain weight, and the amount gained can vary greatly from person to person. The different kinds of antipsychotic medications have different effects on weight. If there is weight gain, it's usually very early in treatment. It's a good idea for you and your treatment team to monitor this side effect closely.

Mood stabilizers

Many of these medications are classified as anticonvulsants – they were designed to treat seizure disorders – but are beneficial in treating mood symptoms.

Generic	Brand name
carbamazepine	(Tegretol, Tegretol CR)
divalproex sodium	(Epival)
gabapentin	(Neurontin)
lamotrigine	(Lamictal)
lithium carbonate	(Lithane, Carbolith)
lithium carbonate slow release	(Lithmax)
oxcarbazepine	(Trileptil)
topiramate	(Topamax)
valproic acid	(Depakene)
lithium citrate	(PMS-Lithium Citrate) only available as an oral solution

Uses

There has been much research into the use of various anticonvulsants in the treatment of mood disorders. Some show more promise than others.

The ones most commonly used are divalproex, carbamazepine, and lamotrigine. Lithium also remains a mainstay in the treatment of bipolar disorder. (Lithium is the only medication in the list that is not an anticonvulsant.) The treatment of bipolar disorder is complex because some people have more "lows," or depressive phases, and others have more "highs," or mania. Different mood stabilizers are better at treating different phase. For example, lamotrigine appears to be better at treating depression than mania.

These medications are also used to treat other psychiatric illnesses. They are sometimes added to antipsychotic medication for people with schizophrenia and schizoaffective disorder; they improve symptom control, especially mood symptoms. Lithium is also used to boost the effect of antidepressants, especially for people who don't respond fully to antidepressants.

Potential side effects

Keep in mind that each person's reaction to a medication is unique.

Lithium

Side Effect	Description
Increased thirst, increased urination	Many people experience these side effects. It's important to maintain normal salt and water intake.
Nausea (stomach upset) and mild diarrhea	An early side effect that usually goes away as the body gets used to it. Taking lithium with food or milk may prevent the side effect. If nausea continues or is bothersome, consult the doctor.
Sedation, dazed feeling, sleepiness	Changing the time of day you take lithium – for example, closer to bedtime – may help. If the feelings persist or become bothersome, talk to your doctor.
Thyroid gland problems	The thyroid gland makes hormones that affect many body functions. From time to time, you might want to get a test to check on the levels of thyroid hormone. If a problem does develop, a thyroid hormone pill should correct it; no need to stop the lithium.
Tremor	Some people experience a slight shaking of the hands.
Weight gain	Some people may gain weight. Before you begin a diet or exercise plan, talk to your doctor.

Potential concerns with lithium

Lithium is unique in that the amount the body needs is very exact and can be measured in the blood. People taking lithium should have their levels checked regularly. When lithium is first started, the levels are checked more frequently.

Any illness that results in a loss of a large amount of salt or water from the body (fever, heavy sweating, vomiting, and diarrhea) can cause the body to have too much lithium. Diet and exercise programs can also affect the amount of lithium in the body. A person who takes lithium may still diet and exercise, under supervision of the treatment team.

Certain medications used for pain, heart conditions, and blood pressure can also affect the level of lithium. You can buy some of these medications without a prescription. It is very important that you tell all your doctors you are taking lithium. Always check with the pharmacist before taking any other medicine.

Teach your family members and friends the signs of too much lithium. Tell them to seek medical attention if they notice: unusual drowsiness, muscle weakness, sudden loss of appetite, confusion, slurred speech, unusual tremors, difficulty with balance, nausea (stomach upset), vomiting, or diarrhea. Pay special attention to these symptoms if they occur after the first few weeks of lithium therapy.

Anticonvulsant mood stabilizers

Potential side effects

Side Effect	Description
Difficulty with balance or gait, dizziness	Fairly common early side effect that occur as the body gets used to taking the medication. They usually lessen or go away as treatment continues.
Double or blurred vision	Early effects that lessen or go away as the body gets used to the medication.
Hair loss	In the vast majority of cases the hair will grow back even with continued treatment and will always grow back if the medication is stopped. Discuss with your doctor to decide on the best course of action.
Nausea (stomach upset)	Often an early side effect that goes away as the body gets used to the medication. Try taking the medication with food or milk.
Rash	If you get a rash, tell your doctor immediately. Rashes caused by lamotrigine and carbamazepine may be serious.
Sedation/dazed feeling/sleepiness	Often more noticeable when the medication is first started or when the dose has been increased. Sedation often lessens as the body adjusts to the medication. If it persists or is bothersome, discuss with the doctor, who may increase the dose or change the time(s) of day the medication is given. Caution is advised if you're driving or doing activities that require alertness.
Tremor	Some people experience a slight shaking of the hands.
Weight changes	Both weight loss and weight gain can occur.

Potential concerns

Serious side effects are very rare with anticonvulsant mood stabilizers. However, seek immediate medical attention if you experience: extreme nausea and vomiting, yellowing of the skin or eyes, easy bruising or bleeding, unexplained fever, or sign of infection (sore throat, mouth ulcers).

Antidepressant medication

Generic	Brand name
amitriptyline	(Elavil)
bupropion	(Wellbutrin SR, XL)
citalopram	(Celexa)
clomipramine	(Anafranil)
desipramine	(Norpramin)
doxepin	(Sinequan)
estalopram	(Ciprolex)
fluoxetine	(Prozac)
fluvoxamine	(Luvox)
imipramine	(Tofranil)
mirtazepine	(Remeron)
moclobemide	(Manerix)
nortriptyline	(Aventyl)
paroxetine	(Paxil)
phenelzine	(Nardil)
sertraline	(Zoloft)
tranylcypromine	(Parnate)
trazadone	(Desyrel)
trimipramine	(Surmontil)
venlafaxine	(Effexor XR)

Uses

Antidepressants are most commonly used to treat depression. However, they are also used to treat obsessive compulsive disorder (OCD); panic disorder; generalized anxiety disorder (GAD); phobias including social phobia; post-traumatic stress disorder (PTSD); and they are used to manage certain types of pain.

How it works

All antidepressants work by boosting the amount of certain neurotransmitters in the brain. These neurotransmitters (serotonin, norepinephrine, and dopamine) are naturally present, but may be reduced in individuals with depression. The difference in the many antidepressants lies in which neurotransmitter they increase and how they increase it. Studies have not shown one antidepressant to be more effective than another. Everyone responds differently to these medications. It may take a few tries to get the "best fit" – the best response and the fewest side effects. It takes several weeks to see the full benefit of an antidepressant, so people need encouragement and support until the medication begins its work.

Potential side effects

Side Effect	Description
Headache	Often an early side effect as the body is getting used to the medication. This side effect very often goes away on its own. Ask a doctor or pharmacist about pain relievers for short-term use.
Increased sweating	If bothersome, change in therapy may be needed.
Sedation (sleepiness) or insomnia (difficulty sleeping)	Certain antidepressants cause sleepiness and are better taken at night. Other medications, when taken close to bedtime, can interfere with a good night's rest. The doctor may wish to change the times of day you take the medication. Be careful driving or doing activities that require alertness.
Sexual side effects	Antidepressants can cause a decrease in the desire for sex. They can also interfere with the ability to have sex. Consult your doctor to determine the cause of the problem and discuss the best course of action. Certain antidepressants are less likely to cause sexual side effects, so changing medication may be one option.
Stomach upset (nausea)	Often an early effect that usually goes away. Try taking the medication with food or a glass of milk.
Weight changes	Both weight loss and weight gain can occur with antidepressants. Certain antidepressants are more likely to cause one than the other.

Potential concerns with antidepressants

Antidepressants are not addictive, but it's never a good idea to stop taking them "cold turkey." Always stop taking them very gradually, and under the advice of a doctor.

There is much talk about whether antidepressants increase suicidal thoughts and actions. These risks are being closely studied. If you notice an increase in agitation and/or suicidal or homicidal thoughts at any point during treatment, seek immediate medical attention.

Please note: The information on side effects in this workbook is not complete and lists only those most commonly experienced. For detailed information about a particular medication and its side effects, please consult a doctor or pharmacist. If you note any serious reaction to a medication, "we recommend you seek immediate medical assistance.

❺ Managing side effects

The goal is to find the medication that provides the greatest symptom relief with the fewest side effects. It's important to keep track of your response to the medications you're taking so you can work with your service provider to find the best possible response to symptoms with the fewest side effects. Keep in mind that each person's reaction to a medication is unique. Write down any side effect that you experience as this will help you make better use of your appointments.

"Sometimes you get a little leery because they have all the side effects listed, which makes you not want to take them. But you need to know how to weigh the pros and the cons."

(Sherri)

"It's better to deal with the side effects than to be ill."

(Mia)

General tips

- Often, mental illness goes hand in hand with other conditions for which you'll also have to take prescription medications.
- Because different medications are metabolized differently and can interact in potentially harmful ways, it's important that you tell your treatment team all the medications you're taking.
- Remember to list prescribed medications, herbs, over-the-counter medications, and vitamins.
- Be honest with your treatment team about your habits – smoking, drinking coffee, drinking alcohol, or using recreational drugs. Any of these habits can interact with your prescribed medication.
- Keep your physician up-to-date
- It's a good idea to fill all your prescriptions at the same drugstore or pharmacy – your pharmacist may be able to spot drug interactions or conflicts before they create problems.
- Keep a list of all medications that you take.

"Don't take a pill and sit back and wait for something to happen. Go out and get better. Go out and learn and make yourself healthy."

(Corey)

Keeping track

Use this section to help you keep track of the medications you're taking, the dosages, and the side effects you're experiencing. Completing it will help you prepare for your appointments with your service provider. You can take it with you to help guide your conversation and discussion of any concerns or questions you may have.

I am taking the following medications:

Name and number of milligrams	Dosage

Possible side effects

You may not experience any of the side effects listed here. Some side effects are bothersome but manageable; others may be intolerable. You can work with your treatment team to find medication that may provide similar benefits without the particular side effects, or to adjust your dosage so side effects are less pronounced.

- ◯ constipation
- ◯ urinary retention
- ◯ sleeplessness all the time
- ◯ dry mouth
- ◯ dizziness
- ◯ lightheadedness
- ◯ muscle cramping or tightness
- ◯ excessive blinking
- ◯ need to push tongue out of mouth
- ◯ shaky hands
- ◯ weakness or unsteadiness
- ◯ nausea
- ◯ headaches
- ◯ restless, need to move all the time
- ◯ craving for sweets or carbohydrates
- ◯ diarrhea
- ◯ stomach cramping
- ◯ sexual dysfunction
- ◯ lack of appetite
- ◯ loss of sense of smell
- ◯ drooling or excessive salivation
- ◯ difficulty controlling movements
- ◯ frequent bladder infections
- ◯ racing heart
- ◯ blurred vision
- ◯ other

Notes:

It is important to remember that this is a general list of possible side effects you may or may not find uncomfortable. You may not experience any side effects from your medications; you may have some side effects on this list, but find them not bothersome. Everyone is different.

Things to keep in mind

- All medications (even aspirin) have side effects.
- Many side effects go away with time.
- It's important to talk with your treatment team about any side effects you are experiencing.
- Everyone reacts differently to medication – even the same medication and dosage.
- Remember to update your list of medications and take it with you to appointments.
- Don't stop taking your medication, and don't change the dosage, without the support of your treatment team.

Things that may help manage side effects

- waiting a while to see whether they disappear on their own
- reducing the dosage of medication
- trying another medication
- taking medication to treat the side effects

➜ List and personal goals that you may be having trouble reaching because of the impact of side effects.

➜ Talk with your service provider about your concerns, question and personal goals.

Chapter 5: Moving forward: personal action planning

Chapter 5: Moving forward: personal action planning

What have we learned so far about personal action planning in recovery?

Some key points

- People can take an active role in staying well by creating and using personal wellness recovery and action plans.
- A strong community and social support system is important to maintaining recovery.
- Even with careful self-management, relapses can happen. If you prepare for them, you can get back to your recovery journey more quickly.
- There are tools that can help you maintain autonomy and facilitate recovery after a relapse.

Tools in this chapter

❶ Your Wellness Recovery Action Plan (Copeland, M.E. 1997)
❷ Information about Psychiatric Advance Directives
❸ Final reflections

Preventing relapse

Experiencing relapse is often an expected part of the recovery process for people with mental illness. Try not see relapse as a failure; view it as an opportunity to learn and improve. Remember that relapses can't always be avoided. Remember also managing them or preventing them is a key part of self management.

Spending less time and energy dealing with illness and symptoms gives us more time to pursue goals and develop the aspects of our lives that keep us well.

People with mental illnesses such as schizophrenia have often said that, over time, they can recognize when they are becoming unwell and learn what to do to avoid a psychotic episode. People become attuned to the "early signs," and many manage to think and reason even during complex, distressing, and delusional ideas. (Martyn, D. 2003)

Usually there are warning signs – a worsening of symptoms, a disturbance in daily routine and functioning, for example sleeping habits, or increased substance use. The warning signs are often apparent before a relapse happens. By keeping track and following a wellness plan, people may identify early warning signs and take action to prevent a relapse.

"The first step was to recognize when I was going downhill, and accept I needed to go into hospital before I lost too much control of my behaviour and thinking. A next step was to recognize problems at an even earlier stage and take additional medication, cut down on commitments, and seek medical advice."

"Nurses helped me to identify my 'relapse signature' and find ways of preventing a full-blown relapse."

(Martyn, D. 2003)

❶ Your Wellness Recovery Action Plan

(Copeland, M.E. 1997)

We've already discussed the importance of self-management in dealing with symptoms and taking an active role in our recovery. In this section we'll bring together information about preventing relapse, dealing with it when it happens, and planning for your recovery and wellness.

The **Wellness Recovery Action Plan** (WRAP) is a peer-based program intended to help you develop a personalized plan for managing your wellness and getting what you need, both individually and through supports from significant others and the mental health system. You design your own WRAP so you can stay well and know how to feel better when you're not well, increase your personal responsibility, control your own life, and make your life the way you want it to be.

Your plan can help you monitor and relieve uncomfortable and distressing feelings and behaviors and identify your best course of action.

We can't provide the whole program here, but we've included some tools that will get you started. To view the complete program, go to **www.mentalhealthrecovery.com**

Wellness toolbox

The first part of WRAP is developing your personal wellness toolbox – a collection of positive activities and lifestyle choices that increase your sense of balance and physical health and reduce stress.

These are activities you enjoy or that help you feel better. Include activities you've used in the past and those you would like to use in the future. Examples: contacting friends and supporters, peer counselling, relaxation and stress-reduction exercises, fun and affirming activities, exercise, diet, light, and getting a good night's sleep.

Identify the wellness tools that will most benefit you, then learn how to use them when you need them – every day or when you feel a certain way. Your list may be short to start and then get longer as you discover more and more things that help you feel better. Keep your tools handy to maintain your wellness and help you feel better when you are not feeling well.

Some common wellness tools

- ◯ asking for a medication check
- ◯ attending peer support groups
- ◯ doing something nice for someone else
- ◯ eating three healthy meals per day
- ◯ exercising
- ◯ going for a walk
- ◯ housework
- ◯ listening to music or making your own
- ◯ seeing a counsellor
- ◯ spending time with friends and family
- ◯ spending time with pets
- ◯ taking a nap
- ◯ watching a video
- ◯ writing in a journal

➜ What are your wellness tools?

Once you've identified some of your own wellness tools, you're ready to begin creating your WRAP.

Section 1 of WRAP is the **daily maintenance plan**. It includes three parts.

- a description of yourself when you are well
- the wellness tools you know you must use every day to maintain your wellness
- a list of things you might need on any particular day to feel well

➜ How would you describe yourself when you are feeling well? Think back to the questions you answered in Chapter Two, about developing a positive sense of self, and Chapter Three, about your personality and preferences.

➜ Which wellness tools do you need to use every day in order to feel well?

In Section 2 you identify the events or **triggers** that could make you feel bad. Potential triggers include:

- having an argument with a friend
- financial worries

➜ What external events or triggers could make you feel worse?

➜ How can you use your wellness tools to make sure you stay well even if these things happen?

To prepare Section 3, you'll identify **early warning signs**, those subtle signs that let you know you are beginning to feel worse – for example, being unable to sleep, or feeling irritable or anxious.

➜ What are the early warning signs that indicate you might be starting to feel bad?

➜ How can you use your wellness tools to get back to feeling good?

Section 4 looks at what happens **when things are breaking down**. In this section, you'll list the signs that let you know you're feeling much worse. Examples are:

- feeling very sad all the time
- hearing voices
- isolating yourself
- feeling agitated

➜ What are some of the signs that things have gotten much worse, and that you may be heading towards relapse?

➜ Which wellness tools will help you feel better quickly and prevent things from getting worse?

Section 5 is your **crisis plan**, where you list the signs that let others know they need to take over responsibility for your care and decision-making. State who you want to take over for you and support you through this time. List health-care information, and describe things you would like others to do or not do. Crisis planning gives you some control even when it seems that things are out of control. On the next page you will find more information about crisis planning, and a tool that many have used effectively, the **Psychiatric Advance Directive**.

Section 6 is the **post-crisis plan**. You may want to think about this part of the plan before anything goes wrong. It also makes sense to take notes as you are beginning to recover from a crisis, when you have a clear picture of what you need so you can feel well.

"I've gotten to a point where I'm in a pretty good place with my mental illness, but I still have symptoms. I've learned how to recognize them, I've learned to identify them, I've learned what my stressors are, and I've learned how to deal with the symptoms."

(Corey)

"It's so individual, and everyone's so different… If you're doing the right things and going about the right action plan, I don't think people have to relapse, and sometimes people don't."

(Sherri)

❷ Information about Psychiatric Advance Directives

- Many people 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 you want when you can't tell them yourself. 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 in a PAD, which we talk about below.
- 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 you 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, electroconvulsive therapy
2. **Health Care Power of Attorney (HCPA):**
   In this document, you appoint a proxy decision-maker to make treatment decisions for you when you're 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 (Kim, M.M. et. al. 2007)

How can you create a PAD?

- Generally, you fill out the form provided by your province. If your province does not have a specific form, you can create your own valid form. You can find a sample PAD online at **http://www.bazelon.org/publications/advanceddirectives/**
- PAD forms are usually witnessed and formally signed, and sometimes even notarized
- You must give a copy of your form to your attending physician, to the people you've named to act on your behalf, and to members of your treatment team

Things to keep in mind

- ◯ Keep your PAD up to date. If your information, preferences, or plans change, make sure you change your PAD
- ◯ Make sure you provide up to date information about the people who will act for you
- ◯ You have the right to revoke your PAD at any time

❸ Final Reflections

Throughout the program, and in the workbook, we have focused on the skills and practices necessary to your recovery journey.

These include:

- taking the time to look within yourself to understand who you are as an individual
- being able to challenge yourself to grow as an individual
- being self-reflective so you can recognize when you need to take action to manage your illness and adjust your course
- practising self-care so you can continually make room for new hope

"Dreams sometimes change, but dreams should always be there, and you should never stop dreaming… Sometimes you have to take baby steps…but know that you have the possibility of making that dream come true."

(Sherri)

Take a moment to answer a few questions below and reflect upon your learning experience.
(question adapted from Schultheis, G.M. 1998)

➜ What have you learned as you completed this program and your workbook?

➜ Name three or more new skills you've gained by taking part in the program and completing the workbook.

➜ How can you apply these skills in your life?

➜ How will these skills help you reach your personal goals?

➜ How has your participation in the program changed the way you see your recovery?

"I really believe that everyone with a mental illness can get better and that everyone with a mental illness deserves the opportunity to get better."

(Corey)

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Notes:

Appendix

Table of contents:

Additional Resources

Web sites

Recovery Innovations. **http://www.recoveryinnovations.org/**

Pennsylvania Recovery and Resiliency. **http://www.mhrecovery.org**

Mental Health Recovery. **http://www.mhrecovery.com**

Rethink. **http://www.rethink.org/**

Recovery Opportunity. **http://www.recoveryopportunity.com/**

Canadian Mental Health Association. **http://www.cmha.ca**

Journals

Psychiatric Rehabilitation Journal **http://www.bu.edu/cpr/prj/**

Videos

"Voices of Resiliency." Manitoba Schizophrenia Society. Order at **www.mss.mb.ca**

"Psychosis, Early Intervention and Recovery." British Columbia Schizophrenia Society, Victoria Chapter. Order at **www.bcssvictoria.ca**

Mental Illness Education Project has numerous excellent videos on recovery. Order at **http://www.miepvideos.org/shop/**

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Recovery in Mental Illness by Ruth O. Ralph and Patrick W. Corrigan. Washington, D.C: American Psychological Association, 2005.

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Glossary

You may find that medical professionals and other people use words you are not familiar with. This is a short glossary of some commonly used terms.

acute schizophrenia: The shortest and most intense period of schizophrenia, when the most serious symptoms are found.

affective disorder or mood disorder: A mental illness characterized by greatly exaggerated emotional reactions and mood swings from high elation to deep depression. Commonly used terms are manic depression (or bipolar 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.

affective flattening: Limited range and intensity of emotional expression. A negative symptom of schizophrenia. Also referred to as emotional blunting.

agranulocytosis: A serious condition in which white blood cells decrease in number or disappear altogether. This can be a side effect of an antipsychotic medication called clozapine (brand name Clozaril).

akathisia: The medical word for extreme restlessness. This may include rocking from foot to foot or back and forth, walking in place, pacing, or an inability to sit still. An extremely confused mental state generally accompanies akathisia.

akinesia: A state of reduced movement; lack of muscle movement.

alogia: The loss of ability to speak or understand spoken or written language due to disease or injury of the brain. A negative symptom of schizophrenia.

amenorrhea: Absence of menstrual periods. This can be a side effect of antipsychotic medications.

anhedonia: A lack of pleasure or interest in activities an individual previously enjoyed.

anosognosia: A symptom of several brain disorders. Anosognosia is a very severe lack of awareness. It is not simply denial of illness, but a lack of awareness of the illness. The individual cannot understand that he/she is ill.

anticholinergic: Blocking the action of acetylcholine, one of the chemicals the body makes to help nerve cells communicate with each other. This describes a group of the most common side effects of psychotropic medications, including dry mouth, blurry vision, palpitations, and constipation.

antidepressant: Medication used to treat depression. *See* medications.

antipsychotic: A group of medications used to treat psychosis. There are two types of antipsychotic medications: neuroleptics (also called "standard" or "typical" antipsychotics) and atypicals. Neuroleptics are older, first-generation medications used to treat serious mental illness. Neuroleptics have a tendency to cause neurological side effects (see extrapyramidal symptoms) such as akinesia (slowed movement), akathisia (restless limbs), and tardive dyskinesia (permanent, irreversible movement disorders). *See* medications, neuroleptics.

anxiolytics: Medications used to reduce serious anxiety, tension, and agitation. They used to be known as minor tranquilizers.

apathy: A lack of interest.

atypical antipsychotics: The atypical antipsychotics (also known as second generation antipsychotics) are a group of antipsychotic drugs used to treat psychiatric conditions. Some atypical antipsychotics are approved for use in the treatment of schizophrenia. Some carry indications for acute mania, bipolar mania, psychotic agitation, bipolar maintenance, and other indications. Atypicals are a group of unrelated drugs united by the fact that they work differently from typical antipsychotics. Most share a common attribute of working on serotonin receptors as well as dopamine receptors.

avolition: The individual lacks energy, spontaneity, and initiative. There is a loss of drive and interest. It's very difficult to begin a new task or to finish any assignment. A negative symptom of schizophrenia.

bipolar disorder: A serious affective disorder characterized by extreme changes in mood ranging from high elation to deep depression. An individual with bipolar disorder may feel extremely excited with boundless energy, and then suddenly feel very sad and depressed. Previously called manic depression.

blunted affect: Also called blunted emotions. An apparent lack of emotion. An individual's voice may become monotonous, and his or her facial expression may not change. This does not mean the individual cannot feel emotions, but that he/she appears emotionless.

catatonic behaviour: An extreme lack of reactivity to the surrounding environment. Symptoms include stupor, muscular rigidity, or excitement. A positive symptom of schizophrenia.

catatonic schizophrenia: Categorized by a marked disturbance in physical activity. The disturbance might be a long period of staying very still in a strange position, muteness, or uncontrolled excitement. This is one of the schizophrenia subtypes.

central nervous system (CNS): The brain and spinal cord. The CNS is responsible for coordinating the activities of all parts of the brain and spinal cord.

cognitive impairment: Cognitive abilities (also called "executive skills") include knowing, thinking, learning, and judging. Cognitive impairment means the individual is experiencing difficulty with memory, concentration, and decision-making.

compliance: "The extent to which the patient's behaviour (in terms of taking medications, following diets, or making other lifestyle changes) coincides with medical recommendations" – in other words, doing what health professionals want a person to do. People who don't follow the recommendations are called non-compliant. The definition is from F. McGregor in *Visions Journal* (vol. 4, no. 2, 2007).

concurrent diagnosis: Also called "dual diagnosis" or "co-occurring disorders." A concurrent diagnosis is made when an individual shows symptoms of both a mental illness and substance or alcohol abuse. The term is also used when a person is diagnosed with two or more mental disorders.

CT scanning, computerized tomography: A technique using X-rays or ultrasound waves to produce an image of interior parts of the body. These images can help with diagnosis.

delusion: A symptom of many mental illnesses, a delusion is a fixed belief that has no basis in reality. This belief is strongly held even in the face of evidence that it is false. Individuals suffering from this

type of thought disorder are often convinced they are famous people, are being persecuted, or are capable of extraordinary accomplishments.

depersonalization: Also known as "derealization." A feeling that a person is becoming unreal, or that a person's mind is being separated from his/her body.

depression: Feelings of sadness, hopelessness, helplessness, and worthlessness. In many cases the affected individual has a lack of energy and motivation. Sometimes there are physical symptoms, such as slow movement and speech.

diagnosis: Classification of a disease by studying its signs and symptoms. Schizophrenia is one of many possible diagnostic categories used in psychiatry.

disordered speech: Also known as "disorganized speech." Disorganized patterns of speech in which an individual shifts erratically from topic to topic. A positive symptom of schizophrenia.

disorganized type schizophrenia: Categorized by disorganized speech, disorganized behaviour, and flat or inappropriate affect. Severely disrupts the ability of the individual to perform simple tasks of daily living. This is one of the schizophrenia subtypes.

dopamine: A neurotransmitter found in high concentrations in the limbic system in the brain. Involved in the regulation of movement, thought, and behaviour.

dual diagnosis: Also called "concurrent diagnosis" or "co-occurring disorders." A dual diagnosis is made when an individual shows symptoms of both a mental illness and substance or alcohol abuse. The term is also used when a person is diagnosed with two or more mental disorders.

dyskinesia: Involuntary movements, usually of the head, face, neck, or limbs.

dyspnea: Shortness of breath or difficulty breathing.

dystonia: An extrapyramidal symptom (EPS) caused by some antipsychotic medicines. The main features are sticking out the tongue, abnormal head position, grimacing, neck spasms, and eyes rolling up. *See also* torticollis.

edema: The buildup of watery fluid in parts of the body.

electroconvulsive therapy (ECT): A treatment occasionally used for serious depression, catatonic schizophrenia, and mania. The individual is given a general anesthesia; then an electric current is passed through his or her brain, causing a convulsion. ECT is used primarily for patients suffering from extreme depression for long periods, who are suicidal, or who do not respond to medication or to changes in circumstances.

electroencephalogram (EEG): A recording of the electrical activity from various parts of the brain. An EEG is used to study the brain's electrical activity; the results may help make a diagnosis.

extrapyramidal symptoms (EPS): The medical term for neurological side effects, which include a disturbance of facial or body movements. These symptoms can be caused by antipsychotic medications. Common symptoms include muscle stiffness, tremors, and lack of arm movement when walking.

flight of ideas: Refers to a period where the individual's thoughts become very accelerated.

florid symptoms: Symptoms that are obviously worsening.

galactorrhea: An excessive flow of breast milk in men or women. This is sometimes a side effect of antipsychotic medications.

gradual-onset schizophrenia: Symptoms develop so slowly that it takes a long for time anyone to notice the illness.

grossly disorganized behaviour: Unusual behaviour, such as being silly and childlike or angry and aggressive. A positive symptom of schizophrenia.

hallucination: A false perception of something that is not really there. Hallucinations may be seen, heard, touched, tasted, or smelled by an ill individual.

hyperdopaminergia: A neurochemical condition of excess dopamine neurotransmission. This is thought to partly underlie the pathophysiology of schizophrenia.

hypertonicity: Excessive tension of muscles.

ideas of reference: The unfounded belief that objects, events, or people are of personal significance. For example, a person may think that a television program is all about him/her.

inappropriate affect: Reacting in an inappropriate manner, such as laughing when hearing bad news.

involuntary admission: The process of entering a hospital is called admission. Voluntary admission means the patient requests treatment, and is free to leave the hospital whenever he/she wishes. People who are very ill may be admitted to a mental health facility against their will, or involuntarily:

- under a medical admission certificate or renewal certificate;
- under special court order when they have been charged or convicted with a criminal offence. Under the court order, people may be held in a forensic facility.

Before someone can be admitted involuntarily, a physician must certify that the person is:

- suffering from a mental disorder and requiring care, protection, and medical treatment in hospital;
- likely to cause harm to self or others or to suffer substantial mental or physical deterioration if not hospitalized.

Involuntary admission varies from province to province. Contact your provincial health authorities or local mental health organization for specific details.

labile mood: An individual in a labile mood has alternating euphoria and irritability.

limbic system: Group of brain structures composed of the hippocampus and amygdala. The limbic system is associated with memory storage, the coordination of autonomic functions, and the control of mood and emotion.

major depression: A severe mental illness characterized by feelings of hopelessness, helplessness, and worthlessness; often accompanied by a loss of energy or motivation. Some individuals also experience suicidal thoughts.

mania: An emotional disorder characterized by euphoria or irritability, rapid speech, fleeting thoughts, insomnia, poor attention span, grandiosity, and poor judgment; usually a symptom of bipolar disorder. Positive symptoms of psychosis may also be present.

medications: In psychiatry, medication is usually prescribed in either pill or injectable form. Several different types of medications may be used, depending on the diagnosis. Ask your doctor or pharmacist to explain the names, dosages, and functions of all medications, and to separate generic names from brand names to reduce confusion.

- antidepressants: these are normally slow-acting drugs, but if no improvement is experienced after

six weeks, they may not be effective at all. Some side effects may occur, such as dry mouth, drowsiness, or headaches.
- antipsychotics: these reduce agitation, diminish hallucinations and destructive behaviour, and may bring about some correction of other thought disorders. Side effects include changes in the central nervous system, which can affect speech and movement, and reactions affecting the blood, skin, liver, and eyes. Periodic monitoring of blood and liver functions is advisable.
- mood stabilizers: one example is lithium carbonate, which is used in manic and manic-depressive states to help stabilize the wide mood swings that are part of the condition. Regular blood checks are necessary to ensure proper medication levels. There may be some side effects, such as thirst and burning sensations. Also called "mood normalizers."
- tranquilizers: generally referred to as benzodiazapines. These medications can help calm agitation and anxiety. Examples include Valium, Librium, Ativan, Xanax, Rivotril.

mental disorder: Also called "mental illness." Describes a variety of psychiatric (emotional, thinking, and behavioural) problems that vary in intensity and duration, and may recur from time to time. Major mental illnesses include anxiety, mood, eating, and psychotic disorders. Mental illnesses are diagnosable conditions that require medical treatment as well as other supports.

mental health: Describes a balance between the individual, his/her social group, and the larger environment. These three components combine to promote psychological and social harmony, a sense of well-being, self-actualization, and 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.

motor neuron: A nerve cell in the spinal chord that causes action in a muscle.

multifactorial: Multiple factors. Doctors use the term to describe the causes of some illnesses.

multiple personality disorder: A disorder categorized by the appearance of two or more distinct and separate personalities in one person. Many people confuse multiple personality disorder and schizophrenia.

negative symptoms: Symptoms that should be present in an individual but are not present. May include blunted affect (blunted emotions), apathy, a lack of energy or motivation, and emotional or social withdrawal.

neuroleptics: A group of medications used in the treatment of schizophrenia and other serious mental illnesses. *See* antipsychotics, medications.

neurotransmitters: Molecules that carry chemical messages between nerve cells.

non-compliant: Used to describe an ill individual who is not taking his/her medication or following the treatment plan. There are various reasons for non-compliance, including inability to remember to take medication, unpleasant side effects, or a lack of awareness about being ill.

obsessive compulsive disorder: An anxiety disorder in which individuals become trapped in repetitive patterns of thoughts (obsessions) and behaviours (compulsions). These patterns are potentially disabling, senseless, and extremely hard to overcome.

outpatient: An individual who goes to a hospital for medical or surgical care but does not have to stay after the treatment.

paranoia: A mental state that includes unreasonable suspicions of people and situations. A person who is paranoid may be suspicious, hostile, feel very important, or may become extremely sensitive to rejection by others. Paranoia falls within the category of delusional thinking.

paranoid type schizophrenia: Categorized by the presence of prominent delusions and auditory hallucinations in an individual whose cognitive functioning is otherwise well organized. This is one of the schizophrenia subtypes.

Parkinsonism: A group of symptoms including loss of movement, a lack of facial expression, stiff gait when walking, tremor, or stooped posture. These symptoms are sometimes side effects of older antipsychotic medications, for example, neuroleptics.

Parkinson's disease: A disease mostly affecting middle-aged and elderly people, characterized by tremors and rigid, slow movements.

personality disorder: A deeply ingrained and maladjusted pattern of behaviour that persists over many years. It is usually well-established in later adolescence or early adulthood. The abnormality of behaviour is serious enough to cause suffering to the person involved or to other people.

positive symptoms: Symptoms that are added to the individual's behaviour that should not be present. May include delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behaviour.

positron emission tomography (PET): A technique used to evaluate the activity of brain tissues. PET scanning is used as a research tool in schizophrenia and in cerebral palsy and similar types of brain damage.

postural hypotension: Also known as "orthostatic hypotension." Characterized by low blood pressure. Can cause dizziness and fainting when a person stands or sits up quickly. An early side effect when starting some psychotropic medicines.

poverty of speech: The inability to start or take part in a conversation, particularly small talk. This very common symptom in schizophrenia prevents people from taking part in many social activities.

prodromal phase: The first or early stage of an illness.

prolactin: A hormone produced by the pituitary gland. Stimulates lactation and ovarian function. Many older antipsychotic agents stimulate excess release of prolactin, resulting in abnormal menstrual cycles, abnormal breast milk production, gynecomastia (excessive development of the male mammary glands), and sexual dysfunction.

psychiatric advance directives: Legal documents that enable a person to maximize decision making about treatment and care when or if his/her capacity to fully participate in decision making may be compromised – for example during a crisis. Advance directives outline preferences for medication, treatment, and hospitalization. A person can also appoint an alternate decision maker. The creation and application of advance directives can help build an alliance between a person with mental illness and his/her care team.

psychosis: A group of symptoms of several major mental disorders. These symptoms include loss of contact with reality, breakdown of normal social functioning, and extreme personality changes. People affected with this condition usually experience delusions and/or hallucinations.

psychotherapy: Basically, "talk" therapy. Psychotherapy is a form of treatment that involves discussions between a patient and a mental health professional, and is often combined with prescribed medications. The many different types of psychotherapy have different aims and approaches.

psychotropics: Drugs used in the treatment of mental illnesses.

rapid schizophrenia: Also called sudden onset schizophrenia. The symptoms develop quickly, and the individual experiences dramatic behaviour changes within a few days or weeks.

receptor: A protein molecule that resides on the surface or in the nucleus of a cell. Receptors recognize and bind to specific molecules of appropriate size, shape, and charge.

recovery: Recovery is both a process and a goal. It is learning to successfully manage a disorder, control symptoms, and experience quality of life. Recovery is defined differently for each individual, but generally includes hopefulness, renewed meaning and purpose, managing the symptoms of schizophrenia, remission from substance abuse, living independently, having a job, having friends and social support, and experiencing quality of life.

residual schizophrenia: Signs of schizophrenia that may remain in some people after the most serious schizophrenic episode has passed.

schizoaffective disorder: The diagnosis of this illness is made when the clinical picture is not "typical" of either schizophrenia or a mood disorder, but the person shows symptoms of both psychosis and severe mood swings. Treatment usually consists of a combination of antipsychotic medications, antidepressants, and/or mood stabilizers.

schizoid: Sometimes used to describe a person who is unusually shy, aloof, sensitive, and withdrawn.

schizophrenia: A severe and often chronic brain disorder. Common symptoms include personality changes, withdrawal, severe thought and speech disturbances, hallucinations, delusions, and bizarre behaviours.

side effects: 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 side effects can be controlled with drugs. Side effects 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 caused by medication.

serotonin: A neurotransmitter that relays impulses between nerve cells (neurons) in the central nervous system. Functions regulated by nerve cells that use serotonin include mood and behaviour, physical coordination, appetite, body temperature, and sleep.

serotonin-dopamine antagonists (SDAs): Also known as "atypical" or "newer" antipsychotics. Unlike their predecessors, these medications treat both the positive and negative symptoms of schizophrenia and other serious mental illnesses, with fewer side effects. Examples include Seroquel (quetiapine fumarate), Clozaril (clozapine), Zyprexa (olanzapine), and Risperdal (risperidone).

split personality: *See* multiple personality disorder.

stereotypical behaviour: Repeated movements that have no obvious cause and are more complex than a tic. The movements, for example, rocking backwards and forwards or rotating the body, may be repeated in a regular sequence.

stupor: A condition that makes a person immobile, mute, and unresponsive, although the person appears to be fully conscious: the eyes are open and follow the movement of external objects.

tardive dyskinesia: An occasional reaction to medication, usually after prolonged usage. Characterized by abnormal, spasmodic, involuntary movements of the tongue, jaw, trunk, or limbs.

thought alienation: Also known as thought withdrawal. A belief that thoughts have been stolen from a person's mind.

thought broadcasting: A belief that a person's thoughts are being made known to others, usually through radio or television.

thought disorder: A symptom of severe mental illnesses. Thoughts may be slow to form, may come extra fast, or may not come at all. The person may jump from topic to topic, seem confused, or have difficulty making simple decisions. Thinking may be coloured by delusion – false beliefs with no logical basis. Some people also feel they are being persecuted or are convinced they are being spied on or plotted against. They may have grandiose delusions: they are all-powerful, capable of anything, and invulnerable to danger. They may also have a strong religious drive, or believe they have a personal mission to right the wrongs of the world.

thought insertion: A person's belief that thoughts are being put into his/her mind.

topectomy: Surgical removal of a small and specific part of the brain in the treatment of mental illness. Surgery is generally limited to cases where medications and other treatment methods have not been effective.

torticollis: A contraction of one or more of the neck muscles on one side, resulting in an abnormal position of the head. Also called wry neck. This sometimes occurs when a person is experiencing dystonia.

tranquilizer: A medicine that produces a calming effect. The "major tranquilizers" are used to treat serious mental disorders; the "minor tranquilizers" are often used to treat anxiety.

treatment: Remedies or therapy designed to cure a disease or relieve symptoms. In psychiatry, treatment is often a combination of medication, counselling (advice), and recommended activities. Together, these make up a person's treatment plan.

typical antipsychotics: Also called standard, or first-generation, antipsychotics. Typical antipsychotics seldom have an effect upon the negative symptoms and often result in greater incidences of neurological side effects – muscle stiffness, tremors, lack of arm movement when walking. Typical antipsychotics include haloperidol and chlopromazine.

undifferentiated type schizophrenia: Categorized by symptoms of schizophrenia in a person who does not meet criteria for specific schizophrenia types such as paranoid, disorganized, or catatonic. This is a subtype of schizophrenia.

ventricles: Four fluid-filled chambers in the brain, which form a network with the spinal cord.

Notes:

The Schizophrenia Society of Canada exists to improve the quality of life for those affected by schizophrenia and psychosis through education, support programs, public policy, and research.

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