

# How You Can Help



A TOOLKIT FOR FAMILIES A Resource for Families Supporting Children, Youth and Adults with a Mental or Substance Use Disorder



# The F.O.R.C.E.

Families Organized for Recognition and Care Equality Society for Kids' Mental Health



### About Us

The BC Schizophrenia Society and F.O.R.C.E. Society for Kids Mental Health are members of the BC Partners for Mental Health and Addictions Information. The BC Partners for Mental Health and Addictions Information are a group of seven leading provincial mental health and addictions nonprofit agencies. The seven partners are Anxiety BC, BC Schizophrenia Society, Centre for Addictions Research of BC, Canadian Mental Health Association's BC Division, F.O.R.C.E. Society for Kids Mental Health, Jessie's Hope Society, and Mood Disorder's Association of BC. Since 2003, we've been working together to help individuals and families better prevent, recognize and manage mental health and substance use problems. BC Partners work is funded by BC Mental Health and Addiction Services, an agency of the Provincial Health Services Authority. We also receive some additional support from the Ministry of Children and Family Development. The BC Partners are behind the acclaimed HeretoHelp website. Visit us at www.heretohelp.bc.ca.



A REASON TO HOPE. THE MEANS TO COPE. BRITISH COLUMBIA SCHIZOPHRENIA SOCIETY The F.O.R.C.E.

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## INTRODUCTION

### **Managing a Mental Illness**

Learning how to cope with any ongoing illness is no easy task. Learning how to manage a mental illness and make the most out of life can be challenging. However, with information and the support of their family and friends, most people (children, youth and adults) can take an active role in managing the symptoms of their disorder and in living a fulfilling and productive life. Illness management (also referred to as self-management) is a set of strategies designed to help individuals with a mental or substance use disorder to cope effectively with various aspects of their illness. An important part of illness management involves working collaboratively with the person's mental health professionals involved in the person's care. In addition, there are various strategies a person can use to help reduce the impact of the illness on their lives. These strategies are not intended to replace professional medical care for mental or substance use disorders but should be viewed as strategies individuals and families can use on a day-to-day basis.

Illness management involves both understanding the particular illness or disorder and using techniques to live successfully with the illness. Living successfully with one's illness is often referred to as recovery. Recovery is not necessarily an absence of symptoms, but rather is often personally defined—discovering strengths, pursuing personal goals and developing a sense of identity that goes beyond the mental illness. It is probably best thought of as a journey rather than a desired end state.

Although there can never be a guarantee that a person will stay well, research shows that the information in this toolkit can help people to be more prepared, take action to get help when needed, and reduce the likelihood of a relapse occurring.

# Why Do We Need a Toolkit for Families and Friends?

Illness management is typically presented as a set of self-management tools and strategies that patients or people with a diagnosed mental illness can

# You may benefit from reading this toolkit if:

- You are seeing your family member engage in behaviours that you instinctively know are not quite right
- You've noticed that quirks or behaviours haven't improved despite your child getting older
- Your adolescent or teenager is showing unusual behaviours that are interfering with their school, social life or relation-ship with the rest of the family
- Your family member (child, youth, or adult) has been recently diagnosed with a mental or substance use disorder
- Your family member is struggling with their mental health problem and you would like to know how you can help them to have a better quality of life
- You are seeking general information about how you can support a family member who has an ongoing mental illness

use to manage their illness. However people with mental illness or substance use problems are not ill in isolation. Families and friends, no matter what they think of the illness, are involved in the lives of those they care for.

Families play a major role in supporting a person with a mental illness. Children and youth depend greatly on their families to help them deal with mental health problems. Spouses provide much needed support to their partners. As adults, we also rely on those who care about us to help us deal with problems that affect our lives.

Research shows that adults with chronic illness do much better when they have a strong social network. Research has also shown that peo-



#### note:

For the purposes of this toolkit, we use the terms "mental illness" and "mental and substance use disorders" to refer to the set of disorders included in this toolkit. They include anxiety disorders, eating disorders, mood disorders (bipolar disorder and depression), schizophrenia, and substance use disorders (e.g., alcohol or other drug addiction).

### INTRODUCTION

ple who have major health problems recover more quickly and stay well longer when they have family members around to help them solve problems and deal with stressors in their lives. It is estimated that 40-65% of adults with a serious mental illness live with their families and many more have ongoing contact with their family. Family and friends are often the first to notice that "things are not quite right." They are often called upon when help is needed. In order to best help a person, families also need information on how to support a person to manage their illness effectively.

When a person is diagnosed with a mental or substance use disorder, their health care provider will work with the person to determine the best method(s) of treating the disorder.

### How Do I Use This Toolkit?

For the purposes of this toolkit, the term "family" is defined as an extended network of parents, spouses, siblings, children, other relatives and close friends. Regardless of who makes up the social support network, these individuals can play a crucial role in helping a person to manage their illness effectively.

This toolkit was designed to be used by families who have a family member with one (or more) of the following disorders: anxiety disorders, eating disorders, mood disorders (bipolar disorder and depression), schizophrenia, or substance use disorders (alcohol or other drug addiction). Families who have a family member who has symptoms but has not yet received a diagnosis may also find the information contained in this toolkit helpful. Families should always ensure that they obtain medical or professional advice in addition to reading this toolkit.

The aim of this resource is to highlight some of the more common issues that arise for families who have a family member who is faced with managing a mental illness. Coping effectively often involves learning new skills and making lifestyle adjustments. There are many things you can do to help your family member stay mentally well. For example, learning early warning signs can help prevent a relapse. Finding ways to reduce stress can help a person cope more effectively.

Learning as much as you can about mental illness is critical to providing effective support. All members of the family, including the person or child with the illness will benefit from increased understanding about symptoms, preventing relapse and ways to increase quality of life. This knowledge will help everyone involved be informed decision-makers about the support they can provide.

**Module I** provides a very brief overview of the various mental and substance use disorders and the more commonly-seen symptoms. We strongly encourage families to seek additional information relevant to their family member's diagnosis as it is not possible to provide a comprehensive overview in this toolkit.

In **Module 2**, we explore the main features of illness management—identifying risk factors and early signs of possible relapse, developing a crisis plan and managing emergencies. Gaining mastery over symptoms and relapses is an important component of illness management. Not everyone will experience a re-occurrence of symptoms, however, the course of a mental or substance use disorder is often unpredictable. Watching out for early signs or problems and having a plan to cope will greatly assist in preventing a setback or worsening of symptoms.



Families may also benefit from reading the toolkits produced by the BC Partners for Mental Health and Additions Information.

#### These include:

- Anxiety Disorders Toolkit
- Depression Toolkit
- Mental Disorders Toolkit
- Problem Substance Use Workbook
- Wellness Modules

These toolkits are available through the BC Partners. Please call 1-800-661-2121 or visit us online at www. HereToHelp.bc.ca We have attempted to provide information and strategies that are relevant for adults as well as children and youth. It is important to keep in mind that there will be features of illness management that are unique to the person or child. Not all strategies will be applicable to everyone.

A good treatment plan is essential to managing an ongoing mental health problem. In order to provide the best support, families need basic information about their family member's treatment plan. Families who are providing ongoing, day-to-day care should be involved in treatment planning and monitoring. This will require developing a collaborative relationship with both your family member and the professionals involved in your family member's care. Families can help by providing information about how well their family member is doing (e.g., symptom management) and by encouraging their family member to work together with their mental health provider so that treatment is maximized.

Good communication and problem-solving skills will aid greatly in dealing with the challenges that mental illness presents to families. **Module 3** focuses on basic communication skills that all of us use in our day-to-day interactions. These include providing respectful feedback about behaviours and activities your family member engages in and conveying concerns or requests to change a behaviour in a respectful considerate way.

Positive feedback helps to build self-esteem and enables your family member to feel good about him or herself. Providing constructive feedback about difficult or problematic behaviours allows families to give negative information in a non-critical way.

In the last part of the module, we have provided a step-by-step approach to working through problems that arise in day-to-day coping with a mental or substance use disorder. These steps include defining the problem, exploring alternatives, deciding on a solution, implementing the solution and then evaluating the success of that solution.

In **Module 4** you will find tips and suggestions to help families to care for themselves. When mental illness strikes in a family, everyone is affected. How the person and their support network (families, friends, co-workers, etc.) cope on a daily basis plays a critical role in determining the quality of life for everyone. Having a family member diagnosed brings on many emotions and creates stresses in most relationships. Learning how to manage these feelings and relationships is essential to successful coping.

When a child or youth develops a mental health problem, it will likely have implications for how well they do in school. In some situations, additional support from the education system will be needed. **Module 5** presents some useful tips and tools for parents and teachers to help ensure that children are supported to do the best they can in school.

Whenever possible, we encourage families to work together with their family member to develop a plan for managing a mental or substance use disorder. For some families this may require helping your family member better understand how support from the family will help them achieve a higher quality of life. It is important to create a safe climate to talk about your family member's problem and negotiate a level of family involvement that meets everyone's needs. Each family will be unique as the degree to which the ill family member can make their own decisions about their health and



For more information about how you can become a better judge of health research findings and for summaries of mental health topics especially written for people diagnosed with a mental disorder and their families see www. cochraneconsumer.com manage their illness in their day-to-day lives. The family member's age, level of maturity, type and severity of the disorder, and the resources of the family are factors which will influence the extent to which the family will be involved in the care of the person.

Most people are able to make decisions regarding the medical care of their disorder and can take care of themselves on a day-to-day basis. However, in some situations (or at some points in their life), a person may need some help to make decisions or may need a certain amount of decision-making done for them. Examples would include a young child, a person who does not believe they are ill, or someone who becomes acutely ill and unable to make decisions for themselves. There is a wealth of information contained in this toolkit, so we advise that you take your time and read it at your pace. Feel free to read the sections in any order. Your starting point (the first steps you may want to take) will likely depend on how well your family member or friend is doing and how long they have been dealing with a mental disorder. It may be helpful to re-read sections as it can be difficult to take in a lot of information at any one time. Although the idea of managing a mental illness may appear overwhelming at first, most people find they feel empowered by the information and strategies contained in this toolkit. Be kind to yourself—caring for someone with a disorder can be challenging. Go slow. Celebrate the small successes.

We strongly recommend that you consult additional resources and have listed some useful books and websites as a starting point. In your search for other resources, please be aware that the quality and accuracy of information can vary greatly. An important component of illness management is being able to evaluate the quality of the information. The information that is available is not always supported by evidence to date and caution is advised.

### Disclaimer

The *How You Can Help Toolkit* is not intended to replace the need for a trained mental health professional when diagnosing, treating or managing a mental or substance use disorder. While BC Partners for Mental Health and Addictions Information makes every effort to provide reliable and accurate information, BCPMHAI does not guarantee the accuracy of its materials. The information provided through BCPMHAI is not intended to provide, nor is it a substitute for, professional medical advice or other professional services. Decisions regarding specific interventions for individuals remain the responsibility of the person who has the illness, in collaboration with their health care professional and support network.

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For a complete list of references used in developing the Family Toolkit, please see Family Toolkit: References at www.heretohelp.bc.ca/