



**Understanding, Support and Self-Care**  
A Resource Manual for  
Family Members and Caregivers



**HONG FOOK  
MENTAL HEALTH ASSOCIATION**

**2008**

**MEMBER AGENCY OF UNITED WAY  
OF GREATER TORONTO**



# **Understanding, Support and Self-Care**

## **A Resource Manual for Family Members and Caregivers**

Developed & published by Hong Fook Mental Health Association

© 2008 Hong Fook Mental Health Association, All rights reserved.

**Contact information:**

**Telephone: 416-493-4242**

**Http://www.hongfook.ca**

**Email: info@hongfook.ca**



## Table of Contents

Introduction	3
Acknowledgements	4
Chapter 1 Understanding Mental Health	5
Chapter 2 Learning About Mental Illness	10
Chapter 3 Walking Toward Recovery	20
Chapter 4 The Role of Family and Coping With Challenges	24
Chapter 5 Self-Care	30
Chapter 6 Getting the Mental Health System to Work for You	35
Chapter 7 Community Resources	42
Appendix The Voices of Family Members	52

## Introduction

It is not at all easy to talk about mental illness in the family. I am sure that I am not the only family member who has tried, with little knowledge or resources for years, to support relatives with mental illnesses. I could write a book about all the well-meaning mistakes I made along the way. If only I'd had this resource manual years ago!

I am, therefore, proud to present this easy-to-read manual to family members\*, caregivers and friends of people with mental illness. In it, you will find reliable and up-to-date information, useful suggestions for developing coping skills, sympathetic supports for your role as a caregiver, and hope for your relatives and friends with mental illness.

When family members and caregivers acquire more knowledge and improve their skills, this should lead to improved relationships and more effective family support for individuals with mental illness. Supportive family members create an environment that is conducive to mental health, and we can be a very important factor in mental health recovery.

In this manual, I hope that family members and caregivers will find the power that comes with knowledge.

Marie Kwok  
President  
Hong Fook Mental Health Association

\* "Family members" refers to spouses, parents, children, siblings, other relatives and people perceived by the person with mental illness as family members. In some cases where the person doesn't have immediate family members or other relatives, friends could become like "family members" to him or her.

## **Acknowledgements**

Along with family members and caregivers, Hong Fook Mental Health Association would like to thank United Way of Greater Toronto for its funding support in the development of this resource manual.

This manual would not have been possible without the support of several individuals. We are grateful to Dr. Sam Law, a psychiatrist at the Asian Clinic at Hong Fook Mental Health Association, for reviewing the chapters “Learning About Mental Illness” and “Getting the Mental Health System to Work For You.” We also thank the family members and members from our family support groups who provided valuable input and shared their personal experiences.

Finally, we would like to express our appreciation to Alfred Lam, who co-ordinated and contributed to the writing, and Jaclyn Law, who edited the text.

## **Chapter 1: Understanding Mental Health**

What is mental health, and why is it important for family members to understand it when supporting their loved ones who have mental illness?

When we think of “health,” we often think of physical health. Most of us know that a sensible diet and exercise are important for good physical health. We read and hear about physical well-being and preventing physical illnesses in the media almost every day. While physical health is essential, it isn’t the whole picture. We also need to pay attention to our mental health. Good mental health enables us to lead fulfilling lives.

Focusing on “illness” and tackling its symptoms is only a piecemeal approach to addressing mental health needs. To promote mental well-being, we need to take a broader view of mental health. In this chapter, we’ll look at mental health, including early signs of problems and steps we can take to protect and promote our mental health.

Mental health is not a separate entity – it is one element of our health, and we should look at it in the context of “holistic health,” rather than think of it as simply an absence of mental illness.

### **What is holistic health?**

The World Health Organization defines health as a resource for everyday life. Holistic health embraces the interconnectedness of our body, mind and spirit, and encourages us to cultivate physical, mental and spiritual health.

There are key factors that we must consider when looking at holistic health, including social, environmental, economic and political factors. The Ottawa Charter\* states that health is not possible without peace, shelter, education, food, income, a healthy and sustainable physical environment, social justice and equity. In many cases, people face challenges in several of these areas, such as inadequate income, systemic barriers to employment, poor housing and a lack of services to meet their needs.

### **What is mental health?**

In the context of holistic health, mental health is about striking a balance in the physical, mental, spiritual, social and economic aspects of our lives. It’s connected to our ability to deal with day-to-day challenges, including making decisions; leading an independent life; feeling confident; enjoying life; and coping with and being able to recover from difficult situations. It includes engaging in meaningful, satisfying social relationships and activities. Reaching a balance is a unique experience for each individual.

This perspective involves looking at mental health beyond mental illness. It also promotes wellness and building on our strengths, such as developing healthy relationships with family and friends and exploring interests and talents.

---

\* In November, 1986, the Canadian Public Health Association, Health and Welfare Canada, and the World Health Organization co-sponsored an international conference on health promotion. The Ottawa Charter was written by the participants of that conference.

## **Mental health as a continuum**

We can also look at mental health as a continuum. Imagine that “wellness” is at one end and “illness” is at the other. We’re at different points on the continuum at different times, depending on what’s happening in our lives and related factors. We move back and forth along the continuum throughout our lives.

We should look not only at preventing or controlling mental illness, but also promoting wellness based on our resources, strengths and potential. We all have the right to live to our full potential regardless of where we are on the continuum at any time. Despite the influence of external factors, we have the ultimate responsibility for our own health.

### **Case example**

Mrs. G is the primary caregiver to her son, who has schizophrenia. She became very depressed in the first year of her son’s illness, and her anxiety level fluctuated frequently. When her son was doing better, she felt things were manageable and was able to enjoy quality time with her son and husband, but when her son was admitted to the hospital, Mrs. G was very anxious. She lost her appetite, slept very little, experienced stomach problems and headaches, cried easily and had trouble concentrating at work.

Mrs. G started seeing a counsellor for support. Since joining a mutual support group, where she met other family members in similar situations, she has been able to adjust and accept the fluctuations in her son’s condition. With the group’s support, she is also more attentive to her own needs, giving herself time to rest, re-energize and attend to her relationships with other family members. She also volunteers in the support group, sharing her experience with new members. She feels more hopeful and relaxed, and her physical problems have improved.

This example shows how an individual moves from one point to another along the mental health continuum. At times, Mrs. G is confronted with the challenges of mental health issues. She is able to turn the situation around by seeking support, taking care of herself and focusing on wellness.

## **Factors that shape our mental health: A holistic view**

Mental health is influenced by a range of factors. Understanding them helps us take control of our well-being.

- **Protective factors:** Factors associated with strengths and resources that protect an individual’s mental health
  - **Strong support network**, including family, friends and community/health service providers. Emotional and practical support from loved ones and peers can help an individual deal with a challenge or crisis, such as the death of a family member, loss of a job or caring for an aging parent.
  - **Positive attitude toward life challenges**, such as staying hopeful and positive when undesirable changes occur.
  - **Knowledge and skills in problem solving and coping**, such as familiarity with community resources and learning what to do in a crisis.

- **Healthy living practices**, including a nutritious diet, regular exercise, a positive approach to communicating with others, and effective stress management.
- **A social system that promotes social justice with a focus on equitable access to resources and opportunities**, such as employment, medical treatment, and educational and vocational training. (Example: An individual with depression enrolls in vocational training that matches her skills. This helps her find a new job, which helps her move toward recovery.)
- **Early identification of problems/issues and early intervention** prevents problems from getting worse. (Example: Parents should watch for problems in their relationships with teenage children and try to understand the issues facing young people today.)
- **Predisposing factors:** Factors that might make an individual more likely to develop mental health issues
  - **Biological factors**, including genetic factors and changes in body chemistry. (Example: A chemical imbalance in the brain may be associated with the development of schizophrenia.)
  - **Individual factors**, including negative attitudes and ways of coping, such as pessimism, lack of confidence, poor self-esteem, imbalanced living practices (such as smoking or drinking heavily), poor social skills, unhealthy relationships, social isolation and lack of social support.
  - **Social, economic, political and cultural factors**, including poverty, unemployment, inadequate housing, inadequate social and health services, political turmoil such as war, and certain health beliefs that might discourage a person from seeking help. An unhealthy and unsafe work environment can add stress. (Example: A woman whose son has an anxiety disorder is concerned that the noise level and hectic environment at the factory where he works will aggravate his illness.)
- **Precipitating factors:** Factors that trigger mental health problems
  - **Stress** is the response of our body and mind to change. Change is inevitable and ongoing. Stressors can be real or imagined, anticipated or unexpected. Negative stressors are usually associated with unexpected, undesired changes, such as bankruptcy, taking care of aging parents, or struggling with loss of mobility after a stroke. Some stressors are positive. These are usually anticipated, desired changes, such as being promoted at work or buying a new home. We're happy about these changes, but they can still be stressful.
  - **Trauma**, such as robbery, serious injury caused by a car accident, or a fire that leads to homelessness, can overwhelm the body, mind and spirit.



- **Perpetuating factors:** Factors that can prolong problems
  - **Systemic barriers and social injustice** can lead to inequitable access to opportunities, resources and services that affect an individual's physical and mental health. (Examples: Systemic discrimination toward those with mental illness, discriminatory practices in employment, and inequitable resource allocation to marginalized groups, such as homeless people and those struggling with developmental and physical challenges.)
  - **Chronic stress** (Example: The stress of struggling with chronic illness or disability.)

Awareness of these factors can help us take preventive or early action to protect and promote our mental health and that of our loved ones. It is also important to be familiar with the early signs and symptoms of mental health issues. The ability to recognize them enables us to seek support and prevent problems from escalating. Often, early signals are missed or not attended to, partly due to lack of awareness, and also possible denial of problems, given the stigma associated with mental illness. Often, people find it easier to express their problems as physical symptoms rather than mental health issues.

**Early signs and symptoms of mental health issues** (not an exhaustive list)

**Examples of physical symptoms that may indicate stress**

- Physical fatigue and low energy
- Restlessness
- Insomnia
- Panic attacks
- Loss of appetite
- Weight gain or loss
- Physical symptoms, such as headaches and stomach aches

**Other common symptoms**

- Increased irritability
- Racing thoughts
- Poor concentration
- Increased anxiety
- Anger
- Feelings of sadness
- Crying easily
- Changes in coping with stressors, such as feeling pessimistic or smoking or drinking heavily
- Changes in relationships with family members or peers, such as tension and communication difficulties between spouses, or family members blaming each other for challenges during the migration process
- Loss of interest or motivation at school or work
- Absenteeism from school or work

## **Taking action with our new understanding of mental health**

What can we do to promote wellness and positive mental health? While not all factors are within our control, there are areas in which we can make changes.

### **Examples of steps to promote positive mental health**

- Assume responsibility for our own health, rather than leaving it in the hands of medical professionals. We should seek treatment when needed, as well as promote wellness by paying attention to different aspects of our health (physical, mental and spiritual) and accessing available resources.
- Adopt a positive outlook and attitude toward taking care of our health.
- Develop positive ways of coping, such as problem-solving strategies and positive ways of communicating.
- Get to know both our physical and emotional responses to changes and stress.
- Learn the signals and symptoms of problems and take action to address these problems. (Examples: Learning stress management, working on relationship issues and taking time for ourselves if we are caregivers.)
- Take part in building a caring community. (Examples: Volunteering and providing input on the health care system.)

As family members or caregivers coping with the impact of mental illness, it's important to look at how we can stay healthy or restore our health as well as that of our loved ones.

### **Reflection questions**

- What factors presently play a role in shaping your mental health?
- With your understanding of holistic and mental health, what can you do to promote your own and your loved one's mental well-being?

### **References**

Journey to Promote Mental Health Training Manual, March 2006, Hong Fook Mental Health Association.

Carl D'Arcy, "Unemployment and health: Data and Implications," Canadian Journal of Public Health, 77, Supplement 1 (May/June 1996).

## **Chapter 2: Learning About Mental Illness**

In Chapter 1, we looked at the connection between mental health/illness and the factors that have an impact on our health. In this chapter, we'll look at mental illness and some of the approaches to recovery.

According to recent statistics from Health Canada (2002), 20% of Canadians will personally experience a mental illness. Those who don't might have a friend, colleague or family member who does.

To many, mental illness seems mysterious, and it's common for people to shy away from talking about it or avoid interacting with individuals who experience it. There are many misconceptions and myths about mental illness. Stigma associated with mental illness is a major issue in our society.

A "myth" is a commonly held belief that lacks basis in fact. Until people learn the facts, they may continue to be prejudiced against those with mental illness. They may behave in inappropriate ways, such as joking about mental illness or refusing to believe a person is ill because the problem is not physical.

"Stigma" is defined as a mark or sign of disgrace. It is also a complex idea that involves attitudes, feelings and behaviour. It is not just the use of an inappropriate or offensive word, such as "crazy," "cuckoo," "psycho" or "wacko." These are just a few examples of terms that keep the stigma surrounding mental illness alive by belittling and insulting people with mental health problems. Many of us use them without thinking that they will cause harm. We would not mock someone for having a physical illness such as cancer or heart disease; it is cruel to make fun of someone with a mental illness.

Stigma is also about disrespect. It is the use of negative labels to identify a person. It also emerges when difference is viewed as undesirable and shameful, which can result in people having negative attitudes and responses (prejudice and discrimination) toward another person.

Because of the stigma associated with mental illness, people are sometimes ashamed of their condition and are reluctant to seek help. When people know that they will not be discriminated against, they are much more likely to seek support. It would be unthinkable not to seek help for a broken leg – we need to develop the same attitude toward mental illness. Early treatment increases the chances of a quick recovery.

### **Common myths about mental illness**

#### People with mental illness are violent and dangerous.

In general, as a group, people with mental illness are no more violent than any other group. In fact, they are more likely to be victims of violence than perpetrators. Findings from a 2001 study indicated that about 3% of violent offences could be attributed to

mental illness and another 7% to substance abuse problems. Theoretically, only one in 10 crimes could be prevented if these disorders did not exist.

Other studies have shown that people who show symptoms of psychotic illness or substance abuse and are not in treatment can be more unpredictable and aggressive than average, but this is a relatively rare situation. People with mental illness are unfairly believed to be dangerous and violent.

People with mental illness are poor and/or less intelligent.

Like physical illness, mental illness can affect anyone regardless of intelligence, social class or income level. Many studies show that most people with mental illness have average or above-average intelligence.

Mental illness is caused by personal weakness.

Mental illness is not a character flaw. It is an illness, and not due to personal weakness or a lack of willpower. People with mental illness are not lazy just because they cannot “snap out of it.”

### **What is mental illness?**

Mental illness, also known as psychiatric disorder, is a medical condition that affects an individual's thinking, mood and behaviour. It can lead to distress and impaired functioning over an extended period of time. Mental illness can take many forms. The symptoms, severity and duration of mental illness vary among individuals. What's important and encouraging is that mental illness is treatable and recovery is possible.

Let's look at some types of mental illnesses that we commonly work with at Hong Fook: anxiety disorders, mood disorders and schizophrenia. It's important to remember that while the symptoms are classified under different diagnostic categories, they don't describe or represent who the person is. We must look beyond the “illness” when trying to understand and support an individual struggling with mental health problems.

### **ANXIETY DISORDERS**

Anxiety disorders are among the most common mental illnesses. People can become anxious in stressful situations, such as a job interview or exam. Everyone experiences anxiety at some point. However, if someone becomes preoccupied with fear, distress and worries that are out of proportion to the actual threat or danger, and these intense feelings of anxiety continue to the extent that they affect the individual's daily life, he or she may have an anxiety disorder.

Anxiety disorder affects about 12% of Canadians. It is more common in women than in men (Health Canada, 2002). Without treatment, an individual's physical, mental and emotional health may be in jeopardy. Anxiety disorders are also associated with alcohol and/or drug abuse, family problems, depression and, in some cases, suicide.

Due to stigma, individuals who suffer from anxiety disorders might be afraid of being labeled “weak.” This may cause them to delay or resist seeking support and treatment. The good news is that anxiety disorders are treatable, and we encourage people to seek early intervention.

### **What causes anxiety disorders?**

While research is ongoing, it is believed that multiple factors are usually involved.

- **Biological factors**, including genetic factors, that make a person more vulnerable to certain illnesses and influence their reaction to external stressors.
- **Psychological, social and environmental factors**, including a wide range of stressors and experiences. Negative childhood experiences, traumatic events involving actual or threats of death or serious injury to oneself or others, sexual abuse or assault, war, a car or plane accident, industrial accidents and natural disasters, or the endangerment of a close friend or family member, can all have long-lasting negative effects and contribute to the development of mental illness, such as anxiety disorders. Examples of social and environmental stressors include poverty, unemployment, social uprooting and poor immigration experiences.

Let’s look at some types of anxiety disorders that we often encounter at Hong Fook: obsessive-compulsive disorder, panic disorder and post-traumatic stress disorder.

### **Obsessive-compulsive disorder (OCD)**

People with OCD experience persistent, intrusive, unwanted thoughts (obsession) that can make them feel extremely anxious. Examples include concerns about hygiene or contamination with dirt or germs, and worries about religion, safety, sex, symmetry or certain numbers. Individuals respond to their obsessive thoughts by performing certain compulsive acts/rituals, such as repetitive hand washing, counting or checking to make themselves feel better. In addition to the mental strain of the obsessions, the compulsive acts may take hours to perform each day, interfering with the person’s life.

OCD has a strong genetic component. A traumatic event can trigger obsessive thoughts or behaviour. People who are described as perfectionists may be more prone to developing obsessions. This doesn’t mean that all people who have an obsessive-compulsive personality style have OCD – it occurs in about 2% to 3% of the population. If untreated, OCD can result in severe difficulties in many areas of functioning, such as an individual’s social relationships, education and career.

### **Panic disorder**

People who have panic disorder have frequent, intense panic attacks, during which they experience sensations such as sweating, nausea, trembling and numbness in the legs or hands, dizziness, hot or cold flashes, a feeling of tightness or pressure in the chest, hyperventilation, “jelly” legs or blurred vision. They may even feel like they are going to die of a heart attack or lose control of bodily functions.

These intense feelings of panic usually do not last long. The symptoms come on suddenly and peak within 10 minutes, and attacks end within a few hours. However, some people become very worried and agitated, and fear that it will happen again. Individuals who are susceptible to panic attacks are more likely to be concerned with illness, death or losing control.

Panic disorders usually begin between the ages of 20 and 30. They occur in 2-5% of the population, and they are two to three times more common in women than in men.

### **Post-traumatic stress disorder (PTSD)**

This is an anxiety reaction to an actual or threatened traumatic event, such as a car accident, sexual assault or war. Such events can be devastating and unexpected, and may continue to have serious effects on a person long after the danger has passed. Symptoms of PTSD include:

- Feelings of extreme fear and helplessness after the initial trauma
- Re-experiencing the event through upsetting memories, nightmares, flashbacks or a severe reaction whenever the person is exposed to anything that reminds him or her of the event
- Avoidance of things associated with the traumatic event; inability to recall the details of what happened, and feelings of detachment from everyday life
- Feeling jumpy, trouble sleeping, angry outbursts or problems with concentration

Children and adults can develop PTSD, and it can begin as soon as one week and as long as several years after the traumatic event. Effective treatments are available.

## **MOOD DISORDERS**

Another common type of mental illness is mood disorders. There are different types of mood disorders, including major depression and bipolar disorder, the two we come across quite often at Hong Fook. Approximately 8% of adults will experience depression, and approximately 1% will experience bipolar disorder.

### **Major depression**

Major depression is more than simply being unhappy. It is a clinical term used by psychiatrists to describe a condition that causes a person to feel very sad, worthless, hopeless and helpless for a period of time longer than two weeks. It impairs a person's performance at work or school, and can damage his or her social relationships.

Everyone experiences unhappiness, and many people become depressed temporarily when things do not go as they would like. When a depressed mood persists and begins to interfere with daily life, it may be a sign of serious depression that requires professional help.

## **Causes of depression**

Multiple factors are usually involved:

- Biological factors and neurochemistry
- Genetic disposition: Studies of identical twins show that if one twin has depression, there is a 65-75% chance that the twin sibling also does; the incident rate among fraternal twins is 14-19%
- Hormonal changes
- Chemical imbalance in the brain: Research has pointed to problems with neurotransmitters, chemicals that pass signals from one brain cell to another
- Psychological: Problems may include poor self-esteem or negative thinking
- Psychosocial and socio-economic: Stress can come from the loss of a job, financial problems, relationship difficulties, the death or illness of a family member or friend, inequitable opportunities in society and other hardships
- Seasonal changes

## **Symptoms of depression**

Depression can change the way a person thinks and behaves, and how his or her body functions. Signs include:

- Feelings of despair and hopelessness
- Feeling detached from life and other people
- Continued fatigue or loss of energy
- Feelings of sadness; crying for no apparent reason
- Inability to concentrate or make decisions
- Thoughts of suicide
- Changes in eating or sleeping patterns
- Persistent or recurring headaches or frequent digestive problems
- Excessive guilty feelings

## **Bipolar disorder**

Bipolar mood disorder (formerly known as manic depression) is characterized by extreme highs (manic stage) and extreme lows (depressive stage) in mood. Bipolar disorder often begins with depression in adolescence or early adulthood, although the first manic episode may not occur until several years later. It can be debilitating, and professional help is essential.

## **Causes of bipolar disorder**

There is no single cause of bipolar disorder. Researchers believe that biological factors such as genetics and the brain's chemistry play a major role in producing the illness. One's personality, along with stressors in the environment, may also play a part in bringing on an acute episode of mania or depression. Stress management along with medication can be very helpful in controlling manic and depressive episodes.

## **Symptoms of bipolar disorder**

Attacks of mania may come on very quickly, sometimes within a single day, or can build slowly. Manic episodes can last for hours, weeks or months.

### Symptoms of the manic phase (some or all may be present)

- The individual's mood seems excessively high
- Unreasonable optimism or poor judgment
- Grandiose (very inflated) ideas about himself or herself that can become bizarre delusions, including beliefs of having a special connection with a higher power, special powers and skills, etc. The individual may think that he or she can do the impossible, such as jumping off a building or out of a moving car without being hurt.
- Hyperactivity
- Racing thoughts
- Rapid shifts to rage or sadness
- High-risk behaviours as part of poor judgment and an inflated sense of self, such as reckless driving, spending sprees, excessive intake of alcohol or other drugs, inappropriate business investments, unusual sexual behaviour, etc.

### Symptoms of the depressive phase (see "Major depression," pages 13-14; some or all symptoms may be present)

- Feelings of worthlessness, hopelessness, helplessness, total indifference and/or guilt
- Prolonged sadness or unexplained crying spells
- Jumpiness, irritability
- Withdrawal from formerly enjoyable activities, social contacts, work and sex
- Inability to concentrate or remember things
- Thoughts of death or suicide
- Changes in appetite

## **SCHIZOPHRENIA**

Schizophrenia is a form of psychotic disorder. Psychotic disorders are characterized by a number of things, the most noticeable being changes in perception. A person may hear, see or feel things that other people do not (hallucinations). Other characteristics include delusional thinking around fixed ideas that are not based on reality, and very disorganized, bizarre behaviour.

The causes of schizophrenia are complex. Most researchers and clinicians agree that it has a bio-psychosocial basis. One theory is the "two hit" concept, in which the individual develops the illness because of a genetic/biological predisposition (one hit), and also as a result of experiencing psychosocial stressors (second hit).



Schizophrenia occurs in all societies. One in 100 people will be diagnosed with it. Typically, it begins in the late teens and early 20s for males, and the mid- to late 20s for females.

### **Causes of schizophrenia**

The following factors have been identified:

- **Genetics:** Among identical twins, if one twin has schizophrenia, there is a 50% chance that the other also has it. The genetically linked rate is 10% among fraternal twins, siblings and children, and 40% among children whose parents both have schizophrenia.
- **Neurochemistry:** Illness may be related to problems with neurotransmitters, chemicals that pass signals from one brain cell to another. An excess of dopamine in specific regions of the brain is a factor.

### **Symptoms of schizophrenia**

There are two main types of symptoms: positive and negative. Below is a list (not exhaustive). A person with schizophrenia won't necessarily have all of these symptoms.

#### Positive symptoms ("positive" means extra/added symptoms)

- **Delusions:** Fixed, false beliefs that are firmly held by the individual, such as grandiose ideation and paranoid beliefs. (Examples: "I am God" or "Someone is trying to kill me.")
- **Hallucinations:** False sensory perceptions without external stimuli. This can involve the senses (seeing, hearing, tasting, smelling). (Examples: "I see the queen talking to me in my room" or "I hear a male voice asking me to jump from the bridge.")

#### Negative symptoms ("negative" means lacking/deficit symptoms)

- Lack of emotional response
- Less talkative than normal
- Lack of motivation
- Social withdrawal

Other symptoms can include being disorganized, mood-type symptoms such as depression, and subtle cognitive-type symptoms, such as memory and concentration difficulties.

## Approaches to treating mental illness and facilitating recovery

If you think that you or a relative may have a mental health issue, seek consultation/assessment from a family doctor or a mental health professional, including mental health workers. They can suggest treatment options and, if needed, provide a referral to a psychiatrist. Mental illness can be treated effectively with medication in combination with other therapies and supports. Regular follow-up treatment from medical doctors and/or mental health professionals can be a key factor in facilitating recovery. Family, community and peer support are also important.

### Psychiatric medications

Medication plays an important part in recovery. It can be taken orally or administered as an injection (needle) depending on the person's situation. Taking medication as directed (compliance) is essential. It's also important to be patient and set realistic expectations. It may be several weeks before medication takes effect. Family members can support their loved ones by helping them attend medical appointments to monitor progress.

There are various types of psychiatric drugs. We'll look at some key categories. (The list is not exhaustive, and while some of the more common drugs are included as examples, this does not imply that they are better than others not listed.)

Antipsychotics, also called neuroleptics, treat symptoms of acute or chronic psychosis, including schizophrenia, mania and organic disorders. Examples include risperidone (Risperdal), olanzapine (Zyprexa), haloperidol (Haldol) and clozapine (Clozaril). (It is important for people who take clozapine to have regular blood tests because it can lower white blood cell counts, which might weaken the immune system if not detected.)

Antidepressants are most commonly used to treat depression. They are also for anxiety, severe premenstrual mood changes and bulimia. One type that is commonly used are selective serotonin reuptake inhibitors (SSRIs), including fluoxetine (Prozac), sertraline (Zoloft) and citalopram (Celexa). Other antidepressants include venlafaxine (Effexor), bupropion (Wellbutrin) and mirtazapine (Remeron).

Mood stabilizers help control mood swings (extreme highs and lows) connected with bipolar disorder. They include lithium (Lithane, Duralith) and divalproex (Epival).

Anti-anxiety medications, previously known as anxiolytics or minor tranquilizers, are used to help calm and relieve anxiety. Commonly used anti-anxiety drugs are the SSRIs listed above and lorazepam (Ativan), clonazepam (Rivotril) and diazepam (Valium).

#### Side effects of psychiatric medication

Side effects can be minor or serious, and vary greatly. Often, people stop taking drugs because they fear side effects. Don't discontinue or change the dose on your own – talk to your doctor and keep your health care team informed about other health issues and medications you're taking.

Possible side effects of psychiatric drugs include restlessness, weight gain, minor stomach problems (nausea, constipation, diarrhea), dizziness, dry mouth, blurred vision, fatigue, difficulty getting to sleep, twitching and trembling, and sexual difficulties. Side effects vary depending on the medication and from person to person.

### **Electro-convulsive therapy (ECT)**

There are many misconceptions about ECT. In general, it is a safe, effective option for severe depression and mania, especially when medication is ineffective or causes serious side effects. The commonly identified side effect of ECT is temporary loss of memory for a short duration. If you have concerns regarding ECT, learn more about it and consult your treatment team.

### **Hospital inpatient treatment**

Over the course of their illness, individuals might go through ups and downs. At times, it may be necessary to consider hospital inpatient treatment to handle a crisis or adjust medication.

### **Assertive Community Treatment Teams (ACTTs)**

ACTTs consist of multidisciplinary staff who provide psychiatric treatment to individuals with chronic and serious mental illness who can benefit from intensive, ongoing community support.

### **Herbal treatment**

Some individuals believe in traditional healing and alternative treatments, and might consult herbalists. It's important to talk to a medical doctor about the use of herbal medicine and alternative treatments. Patients should not discontinue or change the dose of prescribed medication on their own.

### **Other forms of treatment and psychosocial support**

Medical treatment is only one part of the recovery process. There are other forms of treatment and support that can also play a significant role. Recovery is about hope and making the most of life given each person's unique situation. Identifying appropriate forms of support and treatment helps individuals move on in positive ways. We'll look at this in the next chapter.

The following are some approaches to consider. (This is not an exhaustive list.) It is important to involve the individual and health care professionals when making choices.

- **Psychotherapy** builds a trusting relationship between the counsellor and the person with mental illness. Goals include identifying problems, problem solving and “blowing off steam” through talking. It also helps modify inappropriate behaviours and enhances personal growth. Therapy can be one-on-one or in a group.
- **Community support** can be valuable in the recovery process. Case management services involve one-on-one support provided by mental health professionals, who can connect the individual to community resources, advocacy and educational resources, as well as counselling for the individual and his or her family.

- **Group support** can promote recovery and personal growth as individuals benefit from mutual support, acquire life skills and learn to relate to each other. Types of group support include self-help, mutual support, interests and skill development groups. Some treatment programs also provide group therapy.
- **Day programs** with meaningful activities gradually build structure into a person's life. Programs can have different forms as mentioned under "Group support."
- **Vocational (employment) programs and education** can have a positive impact on an individual's self-confidence and sense of self-worth, and can give hope and meaning.

While there can be many challenges in coping with mental illness, it is encouraging that there are different types of treatment and support available to individuals and family members. Talk to your doctor and other mental health professionals to help make appropriate choices.

There is no single formula to treating mental illness. Keeping an open mind, learning about the illness and treatment options and, most importantly, maintaining a healthy attitude – such as looking beyond a person's diagnosis and seeing the whole person, not simply a label – are all important to recovery. Each individual is unique despite the illness he or she might have, and should be treated with respect and optimism.

### Reflection questions

- Has your understanding and attitude toward mental illness changed? In what ways?
- What approaches other than medication do you think are relevant in supporting your loved one in recovery?

### References

A Report on Mental Illnesses in Canada. Health Canada, October 2002.

Mental health for life. Canadian Mental Health Association brochure, 1993.

About Mental Illness – "Stigma and Discrimination" (2004), [www.ontario.cmha.ca](http://www.ontario.cmha.ca).

Mental illnesses. Canadian Mental Health Association brochure, 1993.

Bipolar Disorder, What's the balance? Canadian Mental Health Association – Alberta Division, 1996.

## Chapter 3: Walking Toward Recovery

In Chapter 1, we discussed mental health as a continuum and a component of overall health. The continuum suggests that the condition of a person with mental illness isn't constant, and the impact of the illness can change. The person can have a meaningful life and take responsibility for his or her wellness, rather than the illness being in control.

### What is recovery?

While it's common to talk about recovery from physical illness, people often question whether individuals with mental illness can "get better," and may have low expectations for their future. How recovery is defined can have an impact on how individuals live their lives and influence how family members interact with their loved ones.

In the past, people believed that mental illness was a long-term disorder and that the most one could hope to do was stabilize it. Over the past 20 years, a new philosophy has emerged, one that believes that people with mental illness can lead meaningful lives in the community. There has been a gradual movement toward rehabilitation and treatment outside of institutions. Individuals with mental illness, family members and mental health professionals have successfully challenged the belief that the most that can be done with mental illness is to get the symptoms under control.

Research shows that people with mental illness do make progress and can recover, although the illness may not be "cured." What does "recovery" mean? Dr. William Anthony, Director of the Center for Psychiatric Rehabilitation at Boston University, says that recovery is "a way of living a satisfying, hopeful, and contributing life even with limitations caused by the 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, 1993)

Recovery has become the guiding principle in service delivery and practices in the mental health field. It challenges service providers to shift from a custodian role to developing goals and structures geared to the needs of individuals. It affirms and supports the crucial roles of people with illness and their families in recovery.

### Recovery in action: What does recovery involve?

**Taking a new perspective of illness and staying hopeful:** The recovery process calls for those involved to change their view and approach to mental health and illness. Having a mental illness does not mean that life will be empty of hope and satisfaction. Taking a new perspective may inspire hope and optimism and open up new possibilities for a person with mental illness. Recovery has different meanings to different people, and it is the individual who defines what recovery means for him or her.

**Building on strengths:** To move forward, it's important to explore and mobilize a person's strengths, talents and potential rather than focus on symptoms and problems.

**Living a meaningful and fulfilling life:** Recovery is a personal and unique experience. It involves making a commitment to live a fruitful, meaningful life according to one's values, capacity, readiness and pace, and with the limitations caused by illness.

#### **Examples of meaningful participation**

**Re-establishing relationships with family and friends:** Reconnecting with friends and establishing new friendships; building or restoring bonds with family members.

**Engaging in activities that bring satisfaction and enjoyment:** Pursuing new interests and hobbies, such as yoga, Tai Chi, dancing, reading and watching movies.

**Community participation:** Having a mental illness doesn't mean that one cannot help improve the community. Opportunities to contribute include volunteering (for example, helping at a charity event; teaching skills to others; or joining a service organization committee) and educating others by sharing one's experience of mental illness. Another way to become engaged is to exercise one's rights as a citizen (for example, voting or voicing an opinion on community issues such as health care).

**Vocational or academic training:** People can learn new skills at their own pace.

**Working toward employment:** Participating in meaningful activities can promote a positive sense of self, increase self-confidence and cultivate a sense of purpose in life.

**Being active participants in recovery:** People with mental illness and their families or caregivers become active partners in managing their mental health. Recovery is not something planned by service providers; rather, the individual plays a key role.

**Taking control and responsibility for health and choices in one's life:** Believing in recovery helps people change their focus from illness to wellness, from emphasis on symptoms of illness to holistic health, and from preoccupation with their diagnosis, medication or therapy to pursuing other life experiences.

#### **Examples of taking control and responsibility**

**Balancing the focus between illness and wellness:** Recovery means gaining control and taking responsibility for the wellness of one's mind, body and spirit rather than viewing oneself primarily in terms of illness. A person with heart disease would manage their condition with the help of medication, a sensible diet and exercise. A person with mental illness can also manage with medication and healthy living practices, such as relaxation techniques and positive ways of communicating.

**Making informed decisions and choices:** This is an important aspect of establishing or regaining control of one's life. It includes decisions about medical and alternative treatments.

**Active learning:** This involves taking the initiative to learn about services, options, one's rights and responsibilities, and accessing community resources, as well as advocating for positive changes in service delivery and the health system.

### **What facilitates recovery?**

Recovery is not only an individual matter – others can help by cultivating a supportive environment. The individual and his or her family and friends, service providers and the community all have roles to play. These factors help facilitate recovery:

- Building hope to get better
- Promoting a positive attitude, looking at strengths and seeing an individual as a whole person, beyond the label of mental illness
- Striking a balance in the focus on treatment, wellness and health promotion, such as building relationships with family and friends and improving eating habits
- Focusing on the rights, needs and choices of individuals dealing with illness
- Advocating for changes to the design and delivery of services
- Advocating for equitable access to resources, services and employment, which lead to meaningful activities that give people an identity, self-confidence, self-esteem and a recognized social role
- Creating partnerships between the individual, family and service providers

### **What might interfere with recovery?**

An individual may encounter challenges and barriers along the path to recovery, partly because of the prejudice and stigma surrounding mental illness. These factors can interfere with recovery:

- The belief that recovery is only possible with a medical model instead of the holistic health model
- Stigma attached to mental illness
- Focusing on symptoms, but not strengths
- The individual is uninterested, unwilling or not ready to make changes
- Fear of change and the unknown
- Feeling hopeless about the future
- Feeling helpless about the illness
- Inequitable access to community resources and employment opportunities
- Absence of a social support network
- The individual's dreams and aspirations are constantly put down by others
- Family members or caregivers are overprotective and/or controlling
- Social isolation from family, peers and the community

This is an example of how one family supported their loved one on the path to recovery:

#### **Case example**

E.Y. is a 40-year-old male who was diagnosed with schizophrenia 15 years ago. He was an engineer, but since he developed the illness, he has not been able to work. E.Y. lives on his own and receives disability benefits. His parents are in their 70s and he has no siblings.

In the first few years of his illness, E.Y. and his parents felt devastated and ashamed. They isolated themselves. The parents became very protective. Thinking that E.Y. couldn't make sound decisions, they took greater control of his life. Then, during one of E.Y.'s stays in the hospital, his parents were introduced to a family support group. From there, changes slowly took place. *(Continued)*

E.Y.'s parents started to understand his illness. With the mentoring and support of family members in the group, they gradually learned to take care of their emotional needs and give E.Y. space. They encouraged their son to try new things. At first, E.Y. lacked confidence and was reluctant to make changes. It took patience from his parents to stay hopeful and optimistic. They didn't impose their wishes, but let him go at his own pace, beginning with some chores at home when he didn't want to go out.

As their relationship strengthened, E.Y. agreed to go out with his parents. With their encouragement, he began to meet regularly with a mental health professional, who helps him set goals. As E.Y.'s sense of hope grew, he explored what "recovery" means to him, and he and his parents identified his needs and goals.

Now, E.Y. volunteers at a community centre teaching English, and he is learning Tai Chi. He also does community outreach and education, sharing his experiences at workshops on mental illness and at mutual support groups. His parents have also become mentors in the family support group.

Despite the many struggles of mental illness, recovery is possible. It takes commitment and effort to shape one's recovery path, which is unique for each individual. In the next chapter, we'll look at how family members can support their loved ones.

### **Reflection questions**

- How has this chapter affected the way you look at recovery?
- How might you take part in your family member's recovery plan?

### **References**

Anthony, W.A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal* 16(4), p 11-23.

Onken, S., Dumont, J., Ridgeway, P., Dornan, D. and Ralph, R. (2002). *Mental Health Recovery: What Helps and What Hinders?* NASMHPD and NTAC.

Carpenter, J. Mental Health Recovery Paradigm: Implications for Social Workers, *Health & Social Work*; May 2002; 27, 2; ProQuest Nursing Journals, p 86.

Our Lives in 2014, A Recovery Vision, June 2004, New Zealand.



## **Chapter 4: The Role of Family and Coping With Challenges**

While the individual with mental illness plays the key role in his or her recovery journey, there are many ways that family members can contribute their support. Here are key principles of facilitating support, based on what we discussed in earlier chapters.

### **Keep a positive attitude toward mental illness and recovery.**

**Respect the individual as unique and don't compare:** Our role is not to change our loved one in ways we would like him or her to be. Sometimes, family members judge and make comparisons with others, which could cause frustration, jealousy and resentment.

**Respect the person's right to have wishes and choices:** Well-intentioned family members trying to care for or protect a person with mental illness might be tempted to take control of their loved one's decisions and plans. While we want our loved ones to be healthy and safe, we also need to see that each of us, whether we have an illness or not, has unique wishes and desires. We should respect the wishes of individuals with mental illness as much as possible.

**Build on positives:** It's easy to find fault with what the individual is not doing rather than what he or she is capable of doing. This could discourage the person while reinforcing the notion "I am no good because I have an illness." Building on and recognizing abilities and positives fosters optimism and hope. It also facilitates the growth of self-confidence and self-esteem.

**Cultivate rather than take away ownership of responsibilities:** Family members might become overly protective and inadvertently foster dependence. They often experience a strong sense of guilt, which leads them to yield to inappropriate requests and demands made by their loved one. We need to set appropriate boundaries and provide opportunities for the individual to take ownership of his or her affairs as well as responsibility for his or her actions. An important part of recovery is building the person's skills.

**Working in partnership with others:** Family members who try to provide support to their loved ones on their own face a lonely journey with many challenges. The individual with mental illness and family members can benefit from other sources of support. It's important for family members to have their own support network and to work with health care professionals, such as psychiatrists, social workers, and vocational and rehabilitation counsellors. Learning about the mental health system, community resources and how to get the system to work for us is also critical. We'll discuss these in Chapters 6 and 7. For now, let's examine how family members can facilitate support.

## Enhancing communication with our loved ones

It's common to hear family members express concerns about communication difficulties, such as, "I want to help Mom get better, but she's so angry every time I tell her what to do – she says I'm in no position to give her instructions as she is the mother" or "My husband ignores me when I tell him to go out rather than sit at home doing nothing." Often, family members have good intentions, but their messages might be perceived differently, and this results in conflict.

### Keys points on effective communication

**Active listening:** Listen to what our loved ones want to tell us, not what we want to hear.

**Be non-judgmental and aware of our assumptions:** We all have standards, attitudes and values that come across in our speech. For example, we might say "Don't be so lazy" or "Why don't you go to yoga class rather than stay home and read? Reading doesn't get your mind stronger, but yoga does." Imposing our beliefs creates distance. Our loved ones might feel they're being criticized or pushed to do something they aren't ready for. Sometimes, family members make assumptions, such as a mother telling her son he shouldn't go to art class because he has no talent, or a brother telling his sister that he paid for her to attend Tai Chi class (without asking first) and he'll drive her. What would the son and sister think? They might feel that their family members are trying to control what they do. Clarifying and asking can help our loved ones feel respected and accepted, and open up communication.

**Address needs through communication:** One of the goals of communication is to address needs that we have. Sometimes, there are unmet needs that people have trouble expressing directly, and this can create communication problems. For example, a 40-year-old male complains that his sister has ignored him since he became ill. He feels angry and finds fault with his sister, creating more distance between them. His wife supports him to find ways to express to his sister that he misses the bond they shared and needs her support.

Here is an example of how these principles translate into practice.

### Case example: Building skills, fostering independence and facilitating recovery

J.J. is a 25-year-old male whose 30-year-old sister, M.G., has depression. Since their parents died, J.J. has taken on the responsibility of supporting M.G.'s recovery. Their parents were overprotective, so M.G. lacked opportunities to develop independent living skills. Her self-confidence and self-esteem are low, and J.J. is her only social support. Because J.J. is younger, he feels that it's inappropriate for him to tell M.G. what to do. His approach is to continue respecting her as his older sister, and to involve her in decisions that affect her. For example, he shops for groceries with her, but she decides what to buy. He also supports her in learning cooking skills, enjoys her meals and acknowledges that she lets him do this with her. He gives credit to M.G. for all the positive steps she takes. J.J. also introduces her to his friends when they go out for dinner. Gradually, M.G.'s self-confidence improves as she feels respected and accepted, learns new skills and makes friends. As J.J. gains his sister's trust, he encourages her to use professional support and introduces her to a mental health agency where she can join activities to help facilitate her recovery.

This example shows that patience, combined with support that takes into account a loved one's readiness to change and is communicated in a non-judgmental way, can have a positive impact. By adopting an appropriate communication approach, family members also act as role models to their loved ones in terms of interpersonal skills.

Facilitating support is not a straightforward process. Individuals can go through ups and downs in the course of their illness. They might go off medication against professional advice. Family members might have to deal with crises, such as their loved one's thoughts of suicide or a suicide attempt. The person's responses may be difficult for families to manage, or he or she might pose a risk to himself/herself and others. Let's look at some challenges.

### **Planning ahead with our loved ones**

The example brings up another issue: What happens when elderly parents who care for their children with mental illness pass away or are no longer able to take care of their loved ones? It's important that they plan for the future, and that the person with mental illness is involved in planning.

Questions to address include whether the individual would stay with other family members or live on his or her own; what life skills the individual needs to build; whether any estates are involved and what financial plans are needed. (Consult outside help, such as a lawyer, where needed.) Planning can reduce the stresses that fall on individuals with the illness and their siblings when the parents are no longer there. Peer support groups can be a source of support for parents who are preparing for the future.

### **Early identification and intervention**

Individuals experience fluctuations in their illness, and problems do not just escalate suddenly. There are signs and symptoms we should be aware of. In Chapters 1 and 2, we discussed early identification of mental health issues and the different types of illness. By becoming familiar with symptoms, conditions and intervention approaches, we're better prepared to identify problems and stop them from getting worse.

#### **Highlights of early identification**

Take note of small or gradual **changes in the individual's mood and behaviour**. Take into consideration what the individual is usually like.

Often, family members make assumptions about their loved ones' **unusual behaviour**. For example, parents may interpret early psychotic symptoms or schizophrenia in a teenager as laziness, or think that they are experiencing an adolescent identity crisis. Instead of assuming, family members should talk to their loved ones about their concerns using the positive communication approach discussed earlier in this handbook.

Family members can **seek professional consultation** and communicate with the treatment team while respecting confidentiality, which will be discussed in Chapter 6.

### **Dealing with resistance to or non-compliance with treatment**

There may be times when individuals want to stop taking medication or refuse to start although they have an illness. Some people are afraid of side effects. Others want to test whether they can manage without medication, especially if the illness has been under control for a while.

While it seems counterproductive to not follow directions, people with mental illness aren't the only ones who resist taking medication. People often don't follow directions for many health problems, minor and serious. More important, the stigma associated with mental illness makes many people want to avoid being labeled a "patient."

Family members might encounter these scenarios and sometimes end up in a power struggle with their loved ones. Rather than arguing, be supportive by listening to your loved one's concerns about treatment. Showing understanding facilitates trust and encourages discussion about options, consulting the doctor on side effects, the pros and cons of stopping medication, and alternatives in working toward recovery.

### **Signs of suicidal ideation and intervention**

There might be times when a person with mental illness has suicidal thoughts (suicidal ideation) and loses interest in living. Family members should be aware of certain signs.

#### **Warning signs**

- Talks about committing suicide
- Is preoccupied with death and dying
- Shows signs of depression
- Has trouble eating and sleeping
- Experiences drastic changes in behaviour, for example, from feelings of depression to a sudden and unexpected cheerful attitude
- Takes unnecessary risks
- Loses interest in personal appearance
- Withdraws from friends and/or social activities
- Loses interest in hobbies, work, school, etc.
- Prepares for death by making out a will and final arrangements, such as taking out insurance, and expressing final wishes to someone close
- Gives away prized or valuable possessions
- Has attempted suicide before
- Has had recent severe losses
- Increases use of alcohol or drugs

Family members might be afraid to deal with suicidal ideation because they're concerned that opening up the subject could trigger suicidal behaviour. Here are some general pointers.

#### **Do's**

- Be direct. Talk openly about suicide. This gives room and permission for the person to express his or her thoughts and challenges.
- Be willing to listen. Allow expressions of feelings. Accept the feelings.
- Be non-judgmental. Don't debate whether suicide is right or wrong, or whether feelings are good or bad.
- Get involved. Become available. Show interest and support.
- Offer hope that alternatives are available, but do not offer glib reassurance.

### **Do's**

- Take action. Remove dangerous items, such as guns or stockpiled pills.
- Maintain contact with the person.
- Work with the person to plan what he or she can do for the next few hours or days.
- Encourage the person to seek help.
- Work with the person to identify resources and services that may ease his or her situation. If possible, go with the person to get help.
- Obtain advice/support from agencies specializing in crisis intervention and suicide prevention.

### **Don'ts**

- Don't dare him or her to do it.
- Don't be judgmental and criticize the person.
- Don't minimize the person's feelings.
- Don't lecture that he or she shouldn't have these thoughts as things cannot be that bad.
- Don't act shocked. This will create distance between you and the person.
- Don't uphold secrecy if a life is clearly in danger, even if you promised. Seek support.

## **Handling disruptive moods and behaviour**

At times when the individual has fluctuations in his or her mental condition and experiences mood changes, his or her behaviour can become disruptive, such as verbal or physical agitation, or the person experiences delusions or hallucinations to the point that others cannot communicate with him or her. These conditions can escalate into a crisis that poses challenges for family members.

### **General principles in handling a crisis**

- Remain calm and do not confront or argue with the individual.
- Allow space for the individual and yourself.
- Pay attention to your own and the individual's safety.
- Be attentive to what the individual tries to express and do not judge.
- Provide assurance and show understanding of the feelings and needs expressed.
- Call crisis support services or 911 in case of emergency.
- Connect with the psychiatrist or mental health professionals involved to seek consultation.

It is not uncommon for family members to hesitate to call the police or a crisis line because they're worried about upsetting their loved ones and breaking their trust. Family members can also feel guilt and shame for seeking help. It is important that family members have their own sources of support, and when safety becomes a concern, this takes priority. In Chapter 6, we'll discuss the mental health system and options that families may have to consider as they facilitate support for their loved ones, such as involuntary hospital admissions.

Handling a crisis can be demanding and stressful. If you need to work with the police or call a crisis line, it's helpful to have information on the individual's present state and immediate concerns about safety or risks, as well as background information about his

or her history of illness and treatment. Keep contact information for crisis lines and the individual's health care professionals handy.

### **Addressing stigma**

Stigma associated with mental illness adds to the challenges faced by both the person with the illness and his or her family members. It is important that family members work together to combat stigma at the system level, such as participating in mental health education through personal sharing with the media and taking part in advocacy at the system level.

Coping with mental illness and walking alongside our loved ones in their recovery journey is complicated and challenging, but it can also be fruitful and rewarding. Engaging in a supportive role can take a lot out of family members, and some people find the pressure rather heavy. Self-care is important, and family members need to be aware of their own health and personal needs to minimize the risk of burnout. In the next chapter, we'll focus on self-care for family members.

### **Reflection questions**

- What do you see as your key role in your loved one's recovery journey, and how can you fulfill it?
- Having read this chapter, what could you do differently in communicating your support to your loved one?

### **References**

Selected Caregiver Statistics (Fact Sheet), Family Caregiver Alliance. (2001). San Francisco, California.

CARE for the FAMILY CAREGIVER: A place to start. The White House Conference On Aging, December 2005. National Alliance For Caregiving & Health Plan of New York.

Journey to Promote Mental Health Training Manual, March 2006, Hong Fook Mental Health Association.

## Chapter 5: Self-Care

Supporting our loved ones in their recovery can be very challenging and often stressful. A family member may put in a great deal of time, energy and effort as a caregiver in addition to other responsibilities, including a full-time or part-time job and household chores. It's very common for family members to neglect their needs or those of other family members while devoting attention to the loved one with mental illness.

Family members face a greater risk of developing depression and chronic physical illnesses. The Family Caregiver Alliance says that about 30-59% of families report depressive disorders or symptoms (2001). Depression is also associated with common chronic physical problems, such as coronary heart disease, cancer and diabetes.<sup>1</sup>

A participant in Hong Fook's Cantonese family support group shares her experience:

*"As a family member, stress often goes beyond what one can handle. Our loved one who is struggling with illness becomes our priority, and we forget our own needs. The daily tasks involved in caring for the person with the illness, handling sudden crises, financial problems, searching for community resources, as well as caring for other family members can drain us of energy. With these stresses, we might end up with exhaustion, and this can lead to depression, anxiety, burnout and physical illnesses."*

Self-care is critical when addressing the challenges associated with the caregiver's role. Benefits of self-care for family members and caregivers include:

- Reducing the chances of physical and mental health problems
- Restoring one's health and improving overall well-being
- Improving relationships with our loved ones – if our own needs aren't met, we're more likely to be irritable, short-tempered, judgmental and resentful, which can have a negative impact on interpersonal relationships (Voit, S. 2002)
- Enhanced effectiveness of care provided to our loved ones – we have more energy and a greater capacity to provide support when we're healthy
- Setting an example for our loved ones by staying healthy and active as we walk alongside them in the recovery journey

### What does self-care involve?

Self-care takes different forms and routes. Next, we'll take a look at some key areas, including ways to take care of our mental health needs.

---

<sup>1</sup> Cannuscio, Jones, Kawachi, Colditz, Berkman, 2002; National Institute of Mental Health, 2001.

## Taking care of our body, mind and spirit

In Chapter 1, we examined health in a holistic context and learned that our body, mind and spirit are interconnected. As we attend to the needs of our loved ones, it is essential that we find ways to recharge and re-energize. Building holistic health practices into our lives can be very beneficial.

### Holistic health practices

Holistic health practices are strategies that can help us manage stress and promote the health of our body, mind and spirit. Here are some examples:

#### Adequate and regular rest, and sufficient sleep

**A balanced diet** helps the immune system and repairs our cells. It gives us nutrients to nourish our body and mind. Strive for a balanced diet of grain products (especially whole grains), vegetables, fruit, dairy products and meat or alternatives that provide similar nutrients. Choose foods low in fat, salt and sugar, and avoid eating too many spicy dishes. Avoid or reduce the intake of alcohol, caffeine and nicotine.

**An annual medical checkup** to help keep you healthy and identify any problems early.

**Regular exercise and stretching** improve our physical strength and endurance, enhance oxygen and blood flow, nourish our body and brain, and reduce the risk of certain diseases.

**Time and space for ourselves** relax both the body and mind.

**Deep breathing, relaxation exercises and massage** help improve blood circulation, relax tense muscles and remove body wastes, rejuvenate the mind and improve brain function.

## Taking care of our mental health needs

**Listen to ourselves and what our body tells us:** Early identification of signs and symptoms can help prevent problems from developing or escalating. Prevention is better than treatment.

**Recognize and build on our strengths and potential:** We should know what we're good at and develop our talents and interests by building on them.

**Give and receive support:** As caregivers, we are used to giving to and caring for our loved ones. Receiving support from others, such as family or friends, is as satisfying and important as giving. For example, if a friend offers to help with grocery shopping or child care, take him or her up on it.

Building a social support network provides us with friendship, encouragement, practical support and also fun, joy and intimacy. Due to the stigma attached to mental illness, family members aren't always willing to share their struggles with relatives and friends. In mutual support groups, family members can obtain support, learn about mental illness, and find ways to cope. We'll look at family support programs in Chapter 7.



At times, family members feel helpless in the face of crises or certain situations, or they're unable to "bounce back" from a stressful situation despite support from friends and family. Professional help is an option. Seeking it doesn't mean we're incapable or that we've failed. Sometimes, we need someone to walk alongside us to move forward.

**Pursue things we like to do:** While supporting others, it's important to engage in activities we find meaningful and enjoyable. Taking care of our loved ones doesn't mean that we have to give up what we like to do. Nurturing ourselves doesn't make us selfish. Instead, we should try to strike a balance between caring for ourselves and others. Re-energize yourself by trying a new activity or spending time with friends.

**Prioritize and set limits:** Knowing our limits and the limits of others helps us set realistic expectations and achievable goals, thus making life more satisfying and less frustrating. Identify the tasks that are most important and work on those first.

**Example 1:** Jane has been spending most of her time with her daughter, who has mental illness, so that she won't be isolated. Jane drives her daughter everywhere she needs or wants to go. Jane recognizes that she is ignoring her son and husband. She gradually notices that this is causing tension and poor communication at home. She begins to balance her attention among the others and her daughter while letting her daughter learn to take more responsibility in caring for herself.

**Example 2:** Michael is the father of three children. When he develops schizophrenia, his employment capacity is affected and his income decreases. Michael isn't able to sustain his family's standard of living. His wife supports him as the family readjusts their expectations and lifestyle, and they move to a more affordable place, which reduces their financial stress.

**Give ourselves credit:** Acknowledge yourself for taking on responsibilities and making efforts.

**Develop positive thinking and be open to new perspectives:** Positive, flexible thinking promotes constructive responses to our circumstances and problems and facilitates effective coping, as we are open to more options. Negative thinking drains us physically and emotionally, and creates barriers to moving on. For example, thinking that there is no hope for our loved one and ourselves in the future might discourage us from making efforts to change. Thinking that others won't want to befriend us could stop us from starting relationships. Learn to deal with negative thoughts as they arise.

**Take care of our emotions:** Promoting emotional wellness is an important part of self-care. The National Wellness Institute defines "wellness" as an interactive process of becoming aware of and practising healthy choices to create a more balanced lifestyle. Emotional wellness comes with awareness and acceptance of our feelings and the ways we respond to specific situations (stressors). Our experiences and the meaning we attach to them influence our emotional responses, which include feelings, facial and other forms of outer expression, and changes inside our body.

A person may have a mixture of feelings – such as anger, fear, anxiety, hatred, jealousy and happiness – at the same time. When life is going smoothly, it is easy to feel secure and calm. When things are difficult, our feelings may be disturbed. There is no right or wrong regarding feelings, but we can promote emotional wellness.

#### **Promoting emotional wellness**

- Be aware of and accept your positive and negative emotions. It's crucial that we do not run away from our feelings.
- Cultivate positive emotions while confronting and dealing with negative ones. The following are areas that need to be addressed:
  - What causes my emotions? When?
  - What do I do when I have emotions?
  - What impact does my behaviour have on myself and others?
  - What do my emotions tell me about myself and my needs?
  - What steps could I take to attend to my needs?
- Focus on what you can do to promote your emotional well-being, not what others do and don't do. Also, don't dwell on "What I didn't do" or "What I shouldn't have done."
- Learn to forgive yourself and others.
- Avoid blaming others, as this is self-destructive and emotionally draining.
- Develop positive thinking as discussed earlier.
- Recognize what's within your control and what isn't, learn to let go and move on.
- Allow time and space for yourself to heal and bounce back from negative emotions.
- Ask for support from those you trust and if necessary seek professional help

The next example addresses feelings that family members often experience when a loved one has mental illness: grief, anger and guilt.

#### **Case example**

**Stress caused by mental illness and changes in family circumstances:** Ms. M. is a 50-year-old lawyer. She has a son who was diagnosed with schizophrenia two years ago at age 26, just as he established his accounting practice. Ms. M's marriage ended in divorce when her husband's business went bankrupt and he decided to leave the country. Her daughter, who is 22 and has just finished university, has moved out, because she doesn't feel attached to home and wants to live her own life.

**A mixture of negative emotions:** Ms. M was grieving several losses: the changes in her son's health and career, the end of her marriage and separation from her daughter. She was angry with her husband for leaving when support was most needed. She blamed him for their marital conflicts, which she believed contributed to their son's illness. She also felt guilty and angry at herself for not spending more time with her children. She believed she had been selfish for focusing on her career when they were young, and associated her daughter's departure and son's illness with lack of parental love.

**Problems coping:** Ms. M initially denied her feelings and suppressed her need for support and understanding. She devoted her time to her son and gave up her legal practice. She became overprotective of him; at the same time, her son was turning away from her. (*Continued*)

Ms. M started to develop sleeping problems. She gradually recognized that the stresses were beyond what she could handle. Her doctor referred her to a mental health agency. Ms. M joined a support group for family members.

**Strategies to manage negative emotions and promote positive coping:** With the support of the mental health professional and mutual support group, Ms. M is gradually recovering and developing alternative coping strategies. Her new friends encourage her to explore different ways of looking at her challenges. She recognizes when she feels sad and angry, acknowledges these feelings and deals with them, sharing with friends she trusts and engaging in relaxation exercises. Instead of dwelling on what her husband did not do in their marriage, she deals with the “here and now,” looking at how to re-establish relationships with her son and daughter. Ms. M gives her children personal space instead of being controlling. She gives herself credit for standing by them at a difficult time when the family is going through various changes. Having learned more about mental illness and recovery, she learns to accept her son’s condition while supporting him to do what he can manage. She also finds time to nurture herself, enjoying photography and jogging. She is gradually gaining control of her well-being and is content with her progress.

As this example shows, self-care is possible and positive change can happen. Caring for our loved ones shouldn’t stop us from caring for and nurturing ourselves. Self-care is an ongoing process. We’re change agents in promoting health, not only for ourselves, but also for our loved ones. By practising self-care, we are role models.

When applying the knowledge and strategies in this chapter, consider the uniqueness of your loved one with mental illness, who knows what suits him or her most and whose wishes should be respected.

Community resources can play an important role in self-care. In the next two chapters, we’ll explore our mental health system and community resources.

### Reflection questions

- What aspects of self-care in this chapter can you apply to your situation?
- Are family support programs relevant to you? Why or why not?

### References

Cannuscio, C.C., Jones, C., Kawachi, I., Colditz, G.A. and Berkman, L. (2002). Reverberations of family illness: A longitudinal assessment of informal caregiving and mental health status in the Nurse’s Health Study, *American Journal of Public Health*, 92, 1305–13.

Definition of Wellness. National Wellness Institute.

Vijai P. Sharma. *Watch negative thinking*. MIND Publications, 2000.

Women’s Holistic Health Peer Leadership Training Manual, March 2002. Hong Fook Mental Health Association.

Journey to Promote Mental Health Training Manual, March 2006. Hong Fook Mental Health Association.

Voit, S. (2002). Seminar Offers Help on Avoiding Caregiver Burnout. *NIH Record*, Vol. LIV, No.4.

## **Chapter 6: Getting the Mental Health System to Work for You**

In previous chapters, we learned that family members play a key role in the recovery of individuals with mental illness. We also learned the importance of self-care for family members. Another essential aspect is equipping ourselves with knowledge of the mental health system, including legislation related to mental health, the rights of individuals with mental illness and family members, and the overall health care system.

Why do we need to know about the mental health system? There is a saying that “knowledge is power.” With knowledge, family members will be able to access and make use of the system, as well as go one step further by advocating for changes in the system where there are service gaps and limitations.

### **Ontario’s health care framework**

Under Ontario’s health care system, individuals covered by the Ontario Health Insurance Program (OHIP) have access to free medical treatment. Traditionally, the majority of our health care programs have been funded directly by the Ministry of Health and Long Term Care (MOHLTC). In March 2006, with new legislation titled The Local Health System Integration Act, the Ontario government delegated the planning of health care services and funding allocation to 14 local boards. The services include hospital care and community programs for mental health and addiction. The official transition took place on April 1, 2007.

The LHINs have expressed strong commitments to engage local communities in shaping their health care system. As family members who are trying to make positive changes in services for our loved ones with mental illness, it is crucial for us to learn about health care in our communities. It is both our right and responsibility to give constructive input.

### **Mental health legislation**

There is legislation relevant to an individual’s rights, choices, treatment decisions, and access to treatment and other support services. The Acts that will be highlighted in this chapter include the Mental Health Act, Health Care Consent Act, Substitute Decisions Act, and the Personal Health Information Protection Act (PHIPA). First, we need to look at an individual’s rights regarding treatment decisions.

### **Right to choose treatment and decide to accept services**

A challenge identified by family members is the difficulty of getting treatment for their loved ones when they are reluctant or unwilling to receive it.

#### **Case example**

A mother is frustrated that her son’s psychiatrist won’t make him go to the hospital although his symptoms are coming back after stopping medication for a few months. He has had schizophrenia for many years with numerous admissions to different hospitals. His mother predicts that he will get sicker if the situation stays the same, but he refuses to go to the hospital. She feels that he should not make his own decisions.

Many family members can relate to this example. The issue is respecting the individual's rights and choices regarding treatment.

When choosing treatment for physical illnesses, an individual has the right to make decisions unless he or she is deemed mentally incompetent to do so. Does an individual with mental illness also have that right?

As discussed earlier, a key element of recovery from mental illness is that the individual takes an active part in his or her life. This includes making decisions and choices, assuming ownership and the responsibility of looking after himself or herself, accepting the consequences of choices, and growing through learning from experiences.

Balancing the individual's right to refuse treatment and the risk of further deterioration is challenging. The law provides guidance on treatment decisions, as well as voluntary and involuntary hospital admissions. Rather than engaging in a conflict or power struggle with our loved ones, family members can learn about the different laws. This helps us identify feasible, realistic options, as well as build trust and a stronger relationship with our loved ones as we support them through the illness.

### **Psychiatric assessment on an involuntary basis**

In the example, under what conditions could the son be brought to the hospital even if he refuses? Under the Mental Health Act, there are three venues to facilitate an individual to get a psychiatric assessment at a hospital if he or she won't go voluntarily.

- By order of a *medical doctor* (does not have to be a psychiatrist) through issuing a Form 1, which authorizes the individual to be sent to a hospital for an assessment and kept at the facility for up to 72 hours for such an assessment. Within that time, the attending doctor must decide whether there are adequate grounds to keep the individual for involuntary admission if he or she refuses to be admitted voluntarily, or if the individual can be discharged. In order for a medical doctor to issue a Form 1, he or she must have examined the individual in the past seven days.
- By order of a *Justice of the Peace* through a Form 2, which authorizes the individual to stay in the hospital for a doctor to make an assessment. The process that follows is the same as in Form 1.
- By a *police officer* acting on his or her own authority under the Mental Health Act. An individual can be taken to the hospital for an assessment if the officer believes that he or she poses a safety risk to himself or herself and/or others.

## Grounds for consideration when applying one of the above measures

- Threats to cause bodily harm to self
- Attempts to cause bodily harm to self
- Behaviour that is violent toward another person
- Behaviour that causes another person to fear bodily harm
- Lack of competence to care for self
- Serious physical impairment of self
- Substantial mental deterioration
- Substantial physical deterioration

There must be evidence that an involuntary assessment is necessary. For example, when was the person threatening to kill himself? What did he do or say he would do in his attempt to kill himself? Family members may also be asked about the person's history, including the number of suicide attempts, aggression toward others, hospital admissions and non-compliance. Human rights are taken seriously, and it is important that there is concrete evidence that the individual meets the above ground(s) for involuntary assessment.

If the son in our example doesn't meet any of the above grounds, it would not be possible to force him to go to the hospital even though his mother is concerned. Threatening or lecturing him would only lead to further resistance and more conflicts between mother and son. The mother needs to explore alternate ways to encourage her son to seek support.

### Involuntary hospital admissions

Assessment does not guarantee hospital admission and treatment. The medical doctor must assess whether there are adequate grounds according to the list above.

#### **Example of involuntary admission**

A young woman who has depression had just attempted suicide with a knife, and her father was afraid that she would try again. The daughter refused to go to the hospital, so her father called 911 and the police came to take her there. At the emergency department, she was assessed by a psychiatrist, who believed that she was in danger of harming herself. The daughter was admitted to an inpatient unit involuntarily.

Family members sometimes think that the individual will be able to stay "long" in the hospital for treatment. Frustration can occur when there are unrealistic expectations or misunderstandings of the legislation. There are certain processes that must take place and conditions that must be met as part of the legal provisions under the Mental Health Act.

After the initial assessment, if involuntary admission is necessary, a Form 3 (Certificate of Involuntary Admission) is issued. It is valid for up to two weeks. Whether the individual will stay in the hospital on an involuntary status when the Form 3 expires will

depend on the doctor's assessment. If required, the doctor can prolong the involuntary admission by issuing a Form 4. It is also possible that under a Form 3 or 4, upon the psychiatrist's assessment, the individual could be discharged if he or she improves enough. The doctor can also change the admission status to voluntary when the grounds for an involuntary stay no longer apply.

### **Individuals' entitlement to rights advice**

The offer of rights advice to individuals during their involuntary admission ties into protecting their rights. This is something family members may find difficult to comprehend. In some cases, tension between family members and the treatment team arises because of the provision of rights advice to the individual. The individual always has the right to challenge and appeal the doctor's decision to admit him or her.

#### **Case example**

A concerned mother went through a Justice of the Peace to facilitate the hospital admission of her son, who has bipolar affective disorder and has been denying that he needs treatment. The son was admitted involuntarily under Form 3. The son received rights advice, which indicated that he could appeal the doctor's decision by getting a lawyer from Legal Aid. The son applied for an appeal, meaning that a Review Board hearing would be held. If he wins the appeal, he will be discharged from the hospital. His mother is angry at the hospital and does not understand why her son was admitted involuntarily, yet the doctor gave him an opportunity to get rights advice.

Rights advice provision is one of the legal requirements that protect an individual's rights. Balancing rights and the benefits of treatment is always challenging. The doctor must comply with the legal requirement even if a family member has concerns.

### **What can family members do?**

In this example, rather than entering into a dispute with the doctor, the mother could learn about the Mental Health Act, explore how she and the treatment team could work together to promote trust between her son and the staff, and explore strategies to help him understand the value of treatment. The family could also advocate treatment at the Review Board hearing, where the Board hears evidence from the patient, treatment team and family, and decides whether the person must stay in the hospital.

### **Community Treatment Order (CTO)**

Another situation that family members might find challenging is when their loved ones have frequent admissions to hospitals due to non-compliance with follow-up treatment in the community. CTO is a provision under the Mental Health Act that requires the individual to follow treatment while residing in the community or he or she will be brought back to the hospital for treatment. Grounds for a CTO include:

a) The doctor's opinion that the individual has a mental illness and that he or she needs continuing treatment or care and continuing supervision while living in the community. Without these, the individual is likely to cause serious bodily harm to himself or herself or another person, or suffer substantial mental or physical deterioration or serious physical impairment.

b) The individual has been an inpatient in a psychiatric unit two or more times, or for at least 30 days in the past three years.

c) The individual or, when the individual is not competent to make treatment decisions, the Substitute Decision Maker (details below), would need to consent to the CTO.

### **What can family members do?**

Family members and individuals interested in knowing more about CTO can consult the mental health professionals and psychiatrist in charge to explore the eligibility, appropriateness and feasibility of such an arrangement.

### **Consent to treatment**

Family members may assume that admission to an inpatient unit means that the individual will receive medication and/or other forms of treatment. They are sometimes alarmed and upset to see that while their loved ones are inpatients, they still aren't taking medication. How could this happen?

#### **Case example**

A woman whose mother was an inpatient was upset that her mother's condition had not improved. The daughter blamed the treatment team for not forcing her mother to take medication while in the hospital. The mother was declared incompetent to consent to treatment by the psychiatrist, and treatment decisions would be made by her daughter, who is the Substitute Decision Maker. The mother was angry, and upon receiving rights advice, decided to appeal. Before the appeal process, she continued to refuse medication.

An individual may refuse treatment while he or she is in the hospital. This is frustrating to family members, but again, there are legal provisions governing individuals' rights that must be followed. Under the Health Care Consent Act, with the exception of certain emergency situations, all treatment requires informed, capable and voluntary consent. If an individual is capable (mentally competent to make decisions to consent), he or she makes the decision to accept treatment.

If the individual is not capable, the decision is made on his or her behalf by a Substitute Decision Maker (SDM). Again, if the individual is declared incompetent to consent to treatment, rights advice must be given and, except in an emergency, treatment may not begin if the individual has indicated his or her intention to appeal the doctor's decision.

### **What can family members do?**

We encourage family members to work with their loved ones to resolve their reluctance and/or fear of getting treatment. Rather than get upset with the hospital treatment team, we need to identify ways to collaborate and encourage the individual to work with the team in supporting his or her recovery.



## **Substitute Decision Makers (SDMs)**

Below is a list of potential SDMs in descending order (the list is not exhaustive).

- Individual designated with Power of Attorney for Personal Care (Power of Attorney is a legal document written and signed by a person while mentally competent)
- A spouse
- Children and parents
- Brothers and sisters
- Any other relatives by blood, marriage or adoption

The Substitute Decisions Act has rules that the SDM must follow: a) respect prior capable wishes of the individual; b) act in the individual's best interests.

### Family members should note:

- Being SDM for personal care and/or treatment does not necessarily give the right to make substitute decisions for property.
- Power of Attorney for Personal Care is not the same as Continuing Power of Attorney for Property.

There are situations where the individual's capacity to manage his or her finances might be affected by illness.

#### **Case example**

A man with bipolar affective disorder is having problems with overspending, giving away his money and selling the house he shares with his daughter. A psychiatrist declares that the man is not competent to manage his properties, based on an assessment and the facts he obtained. The psychiatrist notifies the Public Guardian and Trustee in accordance with legal requirements. Although the daughter is the SDM for the man's treatment decisions, this does not automatically give her the right to take charge of his finances and property. She must apply at the Public Trustee's office.

This situation can frustrate family members, and some find it intrusive to have the Public Trustee notified. It is important for family members to become familiar with the relevant laws and make plans with their loved ones while they have the capacity to make decisions. Individuals might want to consider putting in place a Power of Attorney for Property when they are mentally competent.

## **Accessing personal health information of individuals with mental illness**

Family members often ask why they can't access information about their loved one's illness, issues he or she brought up with the treatment team, and the treatment plan.

While it's positive that family members want to be involved in the recovery process, confidentiality and respect for privacy are key principles that health care providers must adhere to by law. The Personal Health Information Protection Act (PHIPA) governs the conditions for releasing health information and the protection of confidentiality. The fact

that you are a mother, father or spouse does not give you the right to access your loved one's health information – the individual must give consent.

Family members sometimes end up in conflict over confidentiality issues with both the service providers and the individual. A more positive approach is to explore ways of building a trusting relationship with the individual. When there is trust, the individual may be more open to sharing information.

### **Where do we go from here?**

This chapter provides some highlights of our overall health care framework and mental health system, with reference to key legislation. We looked at the rights of individuals with mental illness regarding treatment decisions and personal information, and what happens when family members are genuinely concerned and struggling to support their loved ones along the recovery journey.

Individual rights must be protected, regardless of illness, while considering risks and other factors. With enhanced knowledge, family members are encouraged to stay active in their loved one's recovery and provide constructive input, either as individuals or part of a group, to resolve gaps and limitations in the health care system. Venues where we can contribute include the LHINs' community consultation forums, family support groups, meeting with Members of Parliament and politicians where appropriate, and participation in board and committee work at the system level when opportunities arise.

Through constant learning and working with both individuals with mental illness and service providers, family members can make positive differences in the mental health system that will benefit our loved ones, ourselves and our communities.

### **Reflection questions**

- Having learned about the mental health system and relevant legislation, what might you consider in facilitating support if your loved one refuses treatment?
- How would you work with a treatment team in facilitating your loved one's recovery process?

### **References**

Psychiatric Patient Advocate Office: [www.ppao.gov.on.ca](http://www.ppao.gov.on.ca)

Ministry of Health and Long-term Care:  
[www.health.gov.on.ca/english/public/pub/pub\\_menus/pub\\_mental.html](http://www.health.gov.on.ca/english/public/pub/pub_menus/pub_mental.html)

Consent and Capacity Board: [www.ccboard.on.ca](http://www.ccboard.on.ca)

Community Legal Education Ontario: [www.cleo.on.ca](http://www.cleo.on.ca)

Mental Health Service Information Ontario: [www.mhsio.on.ca](http://www.mhsio.on.ca)

Office of the Public Guardian and Trustee: [www.attorneygeneral.jus.gov.on.ca/english/family/pgt/](http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/)

Legal Aid Ontario: [www.legalaid.on.ca](http://www.legalaid.on.ca)

## Chapter 7: Community Resources

Learning about and accessing community resources plays an important role in promoting your own mental health and facilitating your loved one's recovery.

Choosing resources means more than just getting a phone number and address – we must consider several factors. Each individual is unique, and people who have the same diagnosis may not necessarily benefit from the same treatment or support services.

In our chapter on recovery, we discussed hope, choice and participation. Family members should respect the needs, interests and readiness of their loved ones, and to explore jointly with them what they would like to pursue and which programs will address their needs and goals. Participation in programs requires consent from the individual and it's important that he or she is involved in planning.

Services vary in method of delivery and eligibility requirements. It's a good idea to do some preparation before contacting the agencies that provide the services. Here are some examples:

List relevant questions, such as:

- Where is your service available?
- What types of services do you offer?
- Are services targeted to groups (for example, by age, gender or functioning level)?
- What language and cultural provisions are available? For example, can you arrange interpreter services?
- Is there a fee for your services? How much?
- Is the service available now, or is there a waiting list? How long is the wait?
- How do we apply? What is the deadline?

Prepare relevant documents, such as a health card, financial information, and history of illness and hospitalization.

The next several pages offer examples of different types of community resources. Please note that the list is not exhaustive, and not all social and health services are included. Also, many services are provided in English, and culture and language differences may make them difficult to use.

## **Overview of community resources available to facilitate recovery**

### **Community information and referral lines**

There are telephone services that provide information on a wide range of community, social, health and government services. Services are free and confidential.

211 Toronto.ca	If dialing from 416 area code, call 211 for nearest office; if dialing from outside 416 area, call 416-397-4636 or 416-392-3778 (TTY)
Connex Ontario <ul style="list-style-type: none"><li>• Health Services Information</li></ul>	1-866-531-2600 (Mental Health) 1-800-565-8603 (Drug & Alcohol) 1-800-230-3505 (Problem Gambling) www.connexontario.ca
Community Information Markham	905-415-7500
Helpmate Community Information and Volunteer Bureau (York Region)	905-884-3000 or 1-800-363-2412

### **Crisis intervention services**

In crisis situations, individuals and families can approach these services as appropriate.

Distress Centre (GTA)	416-408-4357
Emergency (police, fire, ambulance) <ul style="list-style-type: none"><li>• To request an interpreter, indicate your preferred language by saying, for example, “Korean” or “Chinese”</li></ul>	911
Gerstein Centre <ul style="list-style-type: none"><li>• Crisis intervention for adults with mental health problems</li></ul>	416-929-5200
Scarborough Hospital Regional Mobile Crisis Program <ul style="list-style-type: none"><li>• Serves East York and Scarborough</li></ul>	416-289-2434
St. Elizabeth Health Care Integrated Community Mental Health Crisis Response Program <ul style="list-style-type: none"><li>• Serves Etobicoke and North York</li></ul>	416-498-0043

Emergency department

- An individual who is experiencing a psychiatric crisis can go to a hospital emergency department.

## **Family support programs**

Family support programs offer mutual support groups, workshops, resource materials and other services to help families learn about mental illness, the mental health system, community resources and coping strategies. Some programs also assist with advocacy.

Across Boundaries	416-787-3007
Family Association for Mental Health (FAME)	416-207-5032
Hong Fook Mental Health Association	416-493-4242
Mood Disorders Association of Toronto	416-486-8046 or 1-888-486-8236
Schizophrenia Society of Ontario	416-449-6830 or 1-800-449-0367

## **Psychiatrists**

Individuals who need psychiatric assessment and follow-up treatment can be referred to a psychiatrist by his or her family doctor or a general practitioner. For information on psychiatric treatment in Cantonese, Mandarin, Korean and Vietnamese, please call Hong Fook Mental Health Association at 416-493-4242.

## **Case management services**

Case management services provide one-on-one support to individuals with mental health problems who live in the community to facilitate recovery by empowering them to work on identified needs and goals. Services may include psychosocial assessment, co-ordination of resources, advocacy, supportive counselling on coping, and education on illness. To determine if a person is eligible, his or her diagnosis, duration of illness and disability as a result of the illness will be considered.

Hong Fook Mental Health Association	416-493-4242
<ul style="list-style-type: none"><li>• Languages: Cambodian, Cantonese, Korean, Mandarin and Vietnamese</li></ul>	

Across Boundaries	416-787-3007
Community Resource Connections of Toronto	416-482-4103
Central Toronto Youth Services – New Outlook <ul style="list-style-type: none"> <li>• For people 16 to 24 years old</li> </ul>	416-504-6100
York Support Services Network	1-888-695-0070

### **Assertive Community Treatment Teams (ACTTs)**

ACTTs provide intensive community treatment and support services for people with serious mental illness. Below are a few examples.

Mount Sinai Hospital ACTT	416-586-9900
North York Hospital ACTT	416-632-8708
Scarborough Hospital ACTT	416-431-8230
Canadian Mental Health Association <ul style="list-style-type: none"> <li>• East Metro ACTT and New Dimensions ACTT</li> </ul>	416-289-6285

### **Substance abuse rehabilitation and support services**

These provide referrals to substance abuse rehabilitation and support services.

Drug & Addiction Registry of Treatment (DART)	1-800-565-8603
Metro Addiction Assessment & Referral Service (MAARS)	416-599-1448

### **Home care**

Community Care Access Centres (CCACs) are access points to health and community support services, such as visiting nurses, personal support and occupational therapy, to help people live independently or transition to long-term care. Call 211 for information.

### **Financial assistance**

When an individual loses his or her work capacity due to illness and has financial hardship as a result, he or she can apply for financial assistance. Below are key types.

**Ontario Works** provides financial and employment assistance to people in temporary and emergency financial need. A doctor must give details about health issues. Call 1-888-465-4478.

For the **Ontario Disability Support Program (ODSP)**, Ministry of Community & Social Services, call 211 for the nearest office. A doctor must give details about health issues.

For **Employment Insurance (EI) Sickness Benefits** from Human Resources & Development Canada (HRDC), call 1-800-206-7218.

The **Income Security Program: Canada Pension Plan (CPP) Disability Benefits** is available to people who have made the required contribution to CPP and whose disability prevents them from working at any job on a regular basis. Call 1-800-277-9914.

The **Trillium Drug Program** is for Ontario residents who have a valid Ontario Health Card and high prescription drug costs relative to their net household income. Call 416-326-1558. You can also pick up an application form at a drugstore.

### **Emergency food services**

Free meals are available to those in need. Here are some examples.

Good Shepherd Ministries	416-869-3619
Salvation Army	416-366-2733
Scott Mission	416-923-8872
Food banks	Call 211 for nearest location
<ul style="list-style-type: none"><li>• Provide food to individuals and families who cannot afford groceries</li></ul>	

### **Counselling and family services**

Assaulted Women's Helpline	416-863-0511; outside 416 area, call 1-866-863-0511 1-866-863-7868 (TTY)
Living Water Counselling Centre	416-754-0470
Chinese Family Services of Ontario	416-979-8299
KCWA Family & Social Services	416-340-1234
The Lighthouse	416-535-6262

## **Psychosocial rehabilitation programs with education and/or vocational components**

These programs facilitate recovery by providing a daytime structure for the individual. They focus on enhancing participants' social, vocational and other life skills. Below are several examples.

### Programs in a school environment

George Brown College

- Redirection Through Education – For You 416-415-5000 x 4570

Seneca College

- Redirection Through Education 416-491-5050 x 2920

### Vocational programs

Salvation Army – PLUS Program 416-693-2116

Progress Place – Transitional Employment Program 416-323-0223

Trinity Square Café Incorporated – Training in Food Service 416-599-9315

Goodwill Toronto 416-362-4711

Jewish Vocational Services of Metro Toronto (JVS) 416-787-1151

### Shelter workshops

Salvation Army – PLUS Program 416-693-2116

Salvation Army – Booth Industries 416-255-7070

Centre of Opportunities, Respect and Empowerment (CORE) 416-340-7929

## **Self-help programs**

Self-help programs provide venues for individuals to develop a support network and learn from their peers. Through group and mutual support, individuals acquire independent living skills, confidence in relating to others, and other coping strategies.



The friendship and fun that evolve from participation in the social and recreational activities offered in these programs also add to quality of life.

Opportunities to engage in meaningful activities and supportive employment (offered through some self-help programs) facilitate individuals to regain hope as they see that they can make contributions. Below are examples of agencies that provide self-help programs.

Hong Fook Mental Health Association	416-493-4242
Mood Disorders Association of Ontario	416-486-8046
Progress Place	416-323-0223
Self-Help Resource Centre	416-487-4355 (Toronto) 1-888-283-8806 (Ontario)

## **Legal services**

Legal Aid, legal clinics and some statutory programs provide services for legal matters.

Legal Aid certificate application	Call 211 for nearest office
Lawyer referral services	416-947-3380 or 1-800-268-8326
Community legal clinics	Call 211 for nearest office
• Example: Metro Toronto Chinese & Southeast Asian Legal Clinic	416-971-9674
ARCH Disability Law Centre	416-482-8255
Justice of the Peace	Apply in person at a court or City Hall
Mental Health Court Support Services	Call 211 for the nearest office
Office of the Public Guardian and Trustee	416-314-2477
• Deals with substitute decision-making in financial, placement and treatment matters	

## **Housing services**

There are housing programs with varying levels of support that cater to the functioning level and needs of individuals. Below are some examples (the list is not exhaustive).

### Independent housing

Housing Connections 416-981-6111

- Offers housing with rent geared to income
- Co-ordinates applications for subsidized housing

### Low level of support

Hong Fook Mental Health Association 416-493-4242

- Supportive housing with case management services for individuals with mental health problems in Toronto
- Target communities include Cambodian, Chinese, Korean and Vietnamese

Houselink Community Homes 416-539-0690

- Co-op and independent housing for adults with mental health problems

Mainstay Housing 416-703-9266

- Provides and promotes affordable housing with support for individuals with mental illness

St. Jude Community Homes 416-359-9241

- Provides supportive housing for individuals who have mental health problems
- Individual, self-contained units with group activities and communal dining

### Medium level of support

Bayview Community Services Inc. 416-495-7778

- Supportive housing in a group home setting with life skills training

Salvation Army – The Dufferin Residence 416-531-3523

- Supportive housing in a group home setting for people aged 21 to 64 who have mental health problems
- Collaborative housing and structured programs

### High level of support

24-hour group home or residential support for individuals with mental health problems

Margaret Frazer House 416-463-1481  
• Residence for women with psychiatric issues

Scarborough Hospital Manse Road Residential Support Services 416-286-0766

### Other levels of support

Habitat Services 416-537-2721  
• Habitat-funded boarding homes with meals and 24-hour staffing  
• Targeted to individuals with mental health problems

### Services for homeless people

Street Helpline 1-866-392-3777  
• Information on services including emergency shelters and transportation to shelters or 211 after midnight

Out of the Cold Program 416-699-6682  
• Emergency shelter spaces, mid-April to mid-November

### Shelters with support for people with mental health problems

Salvation Army - Maxwell Meighen Centre Primary Support Unit 416-366-2733

Salvation Army - Evangeline Residence Primary Support Unit 416-762-9636

Here is an example of how community resources can facilitate an individual's recovery and support family members.

#### **Case example**

K.T. is a 28-year-old Mandarin-speaking male. He immigrated to Toronto from China with his parents eight years ago. He was diagnosed with schizophrenia seven years ago while at university. K.T. dropped out of school after his first psychiatric hospital admission at age 20. K.T.'s parents are both in their 60s and retired. They've had difficulty coping with K.T.'s illness, as he sometimes stops his medication and has had numerous hospital admissions.

While K.T. has ups and downs in his illness, he has made progress since last year. A friend referred him to Hong Fook's case management program, which assigned him a Mandarin-speaking mental health worker. They've been working together to identify K.T.'s needs and goals. K.T. was also referred to the Ontario Disability Support Program (ODSP), which enabled him to get a drug card and support himself without burdening his parents. He was also referred to Hong Fook Self Help, where he receives peer support and learning. He volunteers in the program and has built bonds with others.

K.T. has gradually built up his confidence at his own pace. Now, he is able to join the Redirection Through Education program at Seneca College. He also socializes with friends, and is gradually able to manage his symptoms as he continues to receive support from his case manager and develop a better understanding of his illness and ways of coping. He says that he is happier with his life. K.T.'s parents have also felt more at ease since joining a Hong Fook family support group, as suggested by K.T.'s case manager. The group enables them to learn coping strategies and talk about their worries in a safe environment. They're gradually able to accept K.T.'s illness, take better care of their own needs, and stay hopeful about their son's recovery.

You may find it challenging to identify and access appropriate services, and there is still a lack of culturally competent services. You can play a role in improving the health care system. We encourage individuals and families to become familiar with available resources, but it's also important to raise our collective voice to advocate for system change, with the goal of enhancing service provision to facilitate recovery.

### **Reflection questions**

- How can you apply what you've learned about community resources to support your loved one's recovery?
- What factors will you consider when choosing programs to apply for?

### **Reference**

Journey to Promote Mental Health Training Manual, March 2006. Hong Fook Mental Health Association.

## **Appendix: The Voices of Family Members**

As discussed in this handbook, mutual support can play an important role in the journey of family members as they support loved ones in the recovery process. Encouraging words and the sharing of experiences can make challenges and struggles more bearable. We thank our family support group members who opened their hearts to share their feelings and stories.

### **A Mother's Story**

When I first found out that my son was diagnosed with schizophrenia, I was very unhappy because our society has always shunned people with mental illness. I thought that there would not be a future for my son, who was only 14 at the time of his first episode. No future for me as a mother. My dream of my son becoming an architect will no longer come true. Through the support of Hong Fook, I have changed the way I think and feel about myself. I don't look at myself as a victim, but rather feel empowered with hope! I have changed my whole perspective and attitude about mental illness, and I think there is a bright future ahead of us. My son is now in his second year of obtaining his Master's degree in architecture. I'm really proud of him.

### **A Single Father's Story**

Having a daughter with mental illness who does not take medication can be very stressful and challenging. My daughter has been admitted to the hospital on an involuntary basis numerous times because of her mood swings and aggressive behaviour. It has been quite a struggle to cope with her illness.

When I first came to Hong Fook's Family Support Group two and a half years ago, I wasn't sure if it could really help my daughter and me. I had nowhere else to turn, so I decided to give it a try, thinking that there was nothing to lose since I was already in bad shape. I had no idea how it would change my life.

I'm glad that I made the choice to join. The group provided a lot of helpful tips and information that went beyond my expectations. The education and mutual support were very helpful in understanding my daughter's illness. Lessons on compassionate communication were very helpful in improving my relationship with my daughter. Also, I had neglected self-care before coming to the support group. I was not aware of the importance of my own mental and holistic health. Learning the skills to handle crisis situations made me realize that the things I did before were right, but not wise. I also learned that each and every one of us has a unique recovery experience.

I have gained a lot of confidence in myself through the mutual support and sharing of other group members. We solve problems together. We go through thick and thin as a family in the group. I no longer feel alone and isolated, even if my daughter is not feeling well and needs to be in the hospital again.

To me, recovery means living life to the fullest and facing the future without any fear.

## **A Sister's Story**

My sister immigrated to Canada in 1997 under my persuasion. Like most new immigrants, she experienced difficulties in finding a job, learning the language, and adjusting to the culture of a new country. Eventually, she settled down. She got a job that she could manage with ease and took night courses at a college. Everything seemed to go well, except she had few friends and could not get along with my husband. Then one day, she was arrested for assaulting a classmate in the classroom. That incident did not result in any charges, but she was arrested a second time for another assault. Only then did it dawn on me that there was something not quite right. I took my sister to see a psychiatrist and I was told that she has schizophrenia.

I was my sister's only family member in Canada. I felt responsible for her care, which posed many challenges on me. She refused to keep appointments with the psychiatrist and did not follow through with taking medication. She got into fights with my husband and parents. She lost her job. I found myself spending a lot of time and energy on her, to the point that my marriage was at the brink of breaking down. I was under tremendous pressure and I, too, was at risk of mental health difficulties. I had to see a psychiatrist for myself.

As someone who has learned to cope with caring for a family member with mental illness, my tips would be to learn about mental illness and what it means to the individual. We need to realize that the recovery journey can be long and slow. Don't get discouraged too early. We need to be aware of our limits, and that we are only human – not "superman" or "superwoman." We do not have the control or power to change another individual. However, what we can change is our own attitude. We should be positive about seeking support. From time to time, other family members might complain and blame us. Do not feel bad about it. Always keep the communication open. Stay positive and do not give up hope.

– *Linda*

## **From the mother of a son with bipolar affective disorder**

A poem dedicated to all the parents who are walking with their children in their recovery journey.

### **To My Loving Son, My World, My Blessing**

When I think about you I'm filled with so much joy  
It fills up my heart and makes me feel as if it would burst  
Through you I see that I can never love too much.  
I was selfish, self-centered, and didn't know  
I was capable of loving so intensely.  
But then you came along and you proved me wrong,  
I'm capable of loving deep  
My love brings tears to my eyes like a beautiful song.  
You're so young, yet smart, and it gives me great satisfaction to know  
I'm responsible for guiding and helping you grow.  
Don't ever feel you are too small or insignificant  
You are a strong man with pride and confidence.  
Don't let anyone fool you, the world is yours to explore,  
Set your goals at a pace you can handle;  
Do remember it doesn't matter what you do,  
As long as you try your best, I will always be proud of you.  
Life is full of obstacles and roadblocks, yes indeed.  
Things will not always go your way.  
I will always be there for you to walk through difficult times  
If you can't come to me, you can turn to your Bible  
And if one day I cannot be with you, our bond will still remain  
I only hope that you will forever  
Keep me in your heart.  
Fill your heart with love and forgiveness  
I personally know you are destined to be great.  
You mean the world to me and  
You mean more to me than all the power, jewelry and wealth.  
You have truly been a blessing in my life  
Take this with you forever, and remember it's true.  
Take these words to heart my son.  
I LOVE YOU!!

*– From a Loving Mother of Christian Faith*