

Initiative canadienne de collaboration en santé mentale

# Working together towards recovery: Consumers, families, caregivers and providers.

A TOOLKIT FOR CONSUMERS, FAMILIES AND CAREGIVERS

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# Working together towards recovery: Consumers, families, caregivers and providers

A Toolkit

# OUR GOAL

The Canadian Collaborative Mental Health Initiative (CCMHI) aims to improve the mental health and well-being of Canadians by enhancing the relationships and improving collaboration among health care providers, consumers, families and caregivers; and improving consumer access to prevention, health promotion, treatment/intervention and rehabilitation services in a primary health care setting.

# **Table of contents**

Preface	i
Introduction	1
A word about the Internet	3
Section 1: Getting the facts straight	
Some terms General information Suicide, suicidal thoughts and attempts.  Resources to help.  Resources for those who have lost a loved one to suicide.  Recommended books:  Getting help early. Other resources to consider	9 10 12 13 13
Section 2: You are not alone	15
Self-help and peer support	16 16 17 18
Section 3: Your team	19
Community mental health professionals  Other professionals who can help you  For people who are working  Registered health professionals and what they can do for you  What to expect from team members  Questions a mental health professional may ask you	22 22 22 26
Questions you can ask your mental health professional and/or teal	m
members Some additional things to look for when working with your team Advocating for yourself or someone you love Some information about medication issues: What to do when things go wrong Finding a new team Getting a second opinion	31 32 33 35 36
When things have gone really wrong	37
Section 4: Recovery	39
Consumers and recovery.  Families and recovery  Recovery resources  Trauma recovery resources	40 40 41
Thinking about work	

Section 5 - Complementary therapies and self-care	45
Complementary therapies	45
Self Care	
Looking out for yourself	
To tell or not to tell	
Spirituality	
Section 6 – Culturally competent care	49
Respect for diversity	50
Some resources offered in other languages	
Resources for gay, lesbian, bisexual and transgendered people	(GLBT)
Some resources especially for Aboriginal peoples	
Section 7: Caregivers' contributions and their needs	55
Families' and caregivers' contributions	55
Signs you need to support yourself:	
Information and self care resources	56
Recommended books:	58
Section 8: Making a difference	59
Things you will need to know	59
How government works	
How Boards of Directors work	
Why consumers, families and caregivers should participate	60
"Big picture" issues (for those who don't mind a little heavy read	
Appendix 1: Charter principles	63
Appendix 2: Crisis plan	67

# **Preface**

# Welcome to the CCMHI Toolkit Series!

The Canadian Collaborative Mental Health Initiative (CCMHI) is led by 12 national organizations representing community services; consumers, families and caregivers; self-help groups; dietitians; family physicians; nurses; occupational therapists; pharmacists; psychiatrists; psychologists; and social workers. Funded through Health Canada's Primary Health Care Transition Fund, the goal of the CCMHI is to improve the mental health and well-being of Canadians by increasing collaboration among primary health care and mental health care providers, consumers, families and caregivers.

The CCMHI toolkits contain practical tools to:

- Help mental health consumers and their family members understand mental illness and work with other members of the care team
- Assist providers and planners in the implementation of collaborative initiatives
- Inform educators of the benefits of interprofessional education (IPE) and provide tools to teach about collaborative mental health care.

Each toolkit was developed with an interprofessional expert panel and guided by a working group representing a number of key stakeholder groups. We hope that readers of any of the toolkits in the series will recommend them to others (e.g., consumers referring toolkits to their providers and vice versa).

In addition to this series of 12 toolkits, the CCMHI has developed a Charter of principles and commitments that will influence the future of mental health care in Canada and a series of reports that capture the current state of collaborative mental health care. The reports highlight health human resource issues, provide an annotated bibliography, summarize best practices, review initiatives from across the nation and summarize provincial and territorial mental health and primary care reform. These documents guided the development of the toolkits and are available at <a href="https://www.ccmhi.ca.">www.ccmhi.ca.</a>.

# Consumer, family and caregiver toolkits

Consumers, families and caregivers developed both of these toolkits for consumers and their loved ones.

Working together towards recovery: Consumers, families, caregivers and providers is intended for all consumers, families and caregivers wishing to know more about mental health and mental illness, how to access services and the type of professionals that can assist them in their recovery. This toolkit also offers an outline of complementary therapies and self-care as well as the contributions and needs of caregivers. Finally, this toolkit includes a guide to "getting involved", describing how government and boards of directors work, and why consumers and families should participate.

Pathways to healing: A mental health guide for First Nations people is a toolkit that offers a basic overview of mental health and mental illness along with a contextual section outlining the impact of history, social, economic and political conditions on the mental health of these peoples. There are tools in this toolkit to foster holistic care.

# Implementation toolkits

Collaboration between mental health and primary care services. A planning and implementation toolkit for health care providers and planners is a guide for providers wishing to establish or enhance the mental health services they provide through collaboration. This general toolkit offers readers a guide to all aspects of planning, implementing and evaluating a collaborative mental health care initiative, including assessing need, setting goals and objectives, developing a budget, building a team, maintaining a well-functioning team, managing change and monitoring the initiative.

Eight population-specific toolkits, entitled Establishing collaborative initiatives between mental health and primary care services, are designed to be used in conjunction with the general toolkit. They offer tips on adapting the general toolkit for Aboriginal Peoples, children and adolescents, ethnocultural populations, rural and isolated populations, seniors, individuals with serious mental illness, individuals with substance use disorders and urban marginalized

populations. There is some overlap in the toolkits; for example, information about collaborative mental heath care and the homeless may be found in at least three toolkits: individuals with serious mental illness, individuals with substance use disorders and urban marginalized populations. Readers are encouraged to consider all the toolkits that may be relevant to their needs.

The general and population-specific toolkits are not intended as clinical practice guides but offer practical advice on different aspects of establishing successful collaborative initiatives.

# **Education toolkit**

Strengthening collaboration through interprofessional education: A resource for collaborative mental health care educators serves as an educational resource to assist in the implementation of educational initiatives and programs that promote collaborative mental health care in primary health care settings. The toolkit is targeted to education program developers in regulatory agencies, professional associations, regional health authorities, family health teams, governmental departments, and educators within both academic (universities and colleges) and care delivery settings.

This toolkit highlights the importance of interprofessional education in promoting collaborative care. It offers four case studies and several activities accompanied by a sample lesson plan and other useful tools to aid educators in the implementation of educational events.

# Introduction

When you first recognized that you, or someone you love, might have a mental illness, you probably felt a lot of emotions; shock, fear, sadness, anger. You also likely felt all alone. You are not. In any given year, one in five Canadians will experience a mental illness.

A team of experts (people who've experienced mental illness themselves, family members and caregivers) have come together to provide you with this toolkit so you won't feel so alone. It is intended to offer you the information they wished they'd had right from the beginning.

Recovery from mental illness is the guiding light of this toolkit. Recovery is living life to the fullest – despite a mental illness. At first, recovery may seem like just too BIG of a mountain to climb – but it is really about finding hope and holding onto it.

Working together towards recovery describes the best sources of information we could find. Many are on the internet because it is accessible – from the privacy of your home - whenever you want and the resources are free. If you don't have a computer – or access to one - your local library has free internet service. If available, we have included the addresses and phone numbers of organizations who host the recommended sites. We have also recommended books and pamphlets but they have to be ordered at a cost.

For those of you who prefer a human voice and people with a known location in the real, as opposed to the cyber world, the following organizations are there to help answer your questions:

**Canadian Mental Health Association** 

8 King Street East, Suite 810 Toronto, ON

M5C 1B5

Phone: (416) 484-7750 Fax: (416) 484-4617 E-mail: <u>info@cmha.ca</u>

"When I was first diagnosed, the idea that I could recover was the furthest thing from my mind. I thought I had dropped into a deep pit and would never get out. But I did bit by bit by bit with a lot of help. My life is not all roses now, but it's a whole lot better than I ever thought it could be."

# **Mood Disorders Society of Canada**

3 – 304 Stone Road West Guelph, ON

N1G 4W4 Phone: (519) 824-5565 Fax: (519) 824-9569

E-mail: mooddisorderscanada@rogers.com

# **National Network for Mental Health (NNMH)**

Suite 604 - 55 King Street St. Catharines, ON L2R 3H5

Phone: (905) 682-2423 Toll-Free: (888) 406-4663 Fax: (905) 682-7469 E-mail: info@nnmh.ca

# Schizophrenia Society of Canada

50 Acadia Avenue - Suite 205

Markham, ON L3R 0B3

Phone: (905) 415-2007 Fax: (905) 415-2337

E-mail: info@schizophrenia.ca

# AMI-Québec

5253 Décarie, Suite 150 Montreal, QC H3W 3C3

Phone: (514) 486-1448 Fax: (514) 486-6157

# The goals of *Working together towards recovery* are:

- 1. To provide easy to find information you can trust so you and your family can be effective partners in your treatment and recovery.
- 2. To make sure you know it is OK to ask that the professionals you see work as a team if this would work best for you.
- 3. To assure you that the most important members of the team are you and those who love you.
- 4. To help you or your family become involved, if ready and interested, in creating a collaborative care initiative or other mental health service in your community.

We have tried to give you the most up-to-date information possible – noting that new resources are being published daily. Overtime, there will be new and useful books and websites for you to find.

And finally, the biggest concern of the hundreds of people that were consulted by the Canadian Collaborative Mental Health Initiative was that they plan, *in advance*, for crises. If this is your concern as well, please go to Appendix 2 for a Crisis Plan.

# A word about the Internet

The Internet used to be considered the way of the future but it is now the reality of today. Canadians use the Internet most often to find health information.

The Canadian Health Network (<a href="http://www.canadian-health-network.ca">http://www.canadian-health-network.ca</a>) offers advice on what to look for when you are deciding whether or not a health website is trustworthy.

Is the source credible?

- Is the organization who hosts the site well-known and reputable?
- If it is an individual, do they identify themselves and do they have the appropriate credentials to provide mental health and mental illness information?
- If the site is hosted by someone who has had a mental illness or who is a family member, is this clearly stated? Experiential information is valuable but it is different than medical information or information from other professional sources.

Is the information relevant?

- Does the site have Canadian content? A lot of health information is borderless - it remains the same no matter what country hosts the website. But there can be substantial differences in medication names, legislation and other facts if the site is not from Canada.
- Does the information appear superficial or seem like someone's individual opinion? It may still be helpful but it is not the same as scientific research or information from an organization known to specialize in mental health and mental illness information.

# Is the information timely?

- Has the site recently been updated?
- Is the information it provides identified by the date so that you know it is current?
- Are the links to other sites active?

# Is there disclosure?

- If the site wants to sell you something, has that been made clear? Can you still access valuable information without purchasing?
- Are both sides of an issue presented or do the site authors seem to be trying to convince you to believe only what they believe?
- If the site is sponsored, is it clear who the sponsor is? For example, one source of information on mental health and mental illness are pharmaceutical manufacturers' sites. The information may be helpful but you must be aware that the host is selling a product.
- If you have to register to use the site, is it clear why, and how your privacy will be preserved?

"My greatest need was information – plain, basic stuff. What is this? What can I do about it? How can my family and friends help? Information helped me make better decisions about my treatment. Hey, when you get diagnosed with cancer – you get information, right? Why not with mental illness."

"Knowledge is power and to be without power is to be a victim. No one wants that."

# Section 1: Getting the facts straight

Your family doctor may be the first person you turn to when you have a health problem. Your doctor is in an excellent position to help because he or she knows you, knows what other health problems you may have and knows your family and your community (this is less so in big cities). When there is no doctor in your community (or you have to wait a long time for an appointment), you may talk first to a nurse, social worker, psychologist or community mental health worker. People who work may have an Employee Assistance Program – and this may be the first place you visit. Family, friends, a neighbour, clergy or Elders are people you can turn to – if you feel comfortable talking with them.

Often, people have trouble describing their symptoms. They may even be unsure or frightened to talk to a professional. Getting the facts will help you talk more easily about your problems to your doctor (or other health professional) so they can understand what's wrong – and you can begin the process of building trust.

Professionals are most effective when you, your family and friends have as much information as possible and are able to ask questions. Recovering your mental health depends, in large part, on you and the people who love you, becoming fully informed about what mental illness is and what your choices are.

# Some terms

Just to be sure we all understand what we are talking about in this toolkit.....

*Mental health* (or well being) is an ideal we all strive for. It is a balance of mental, emotional, physical and spiritual health. Caring relationships, a place to call home, a supportive community, and work and leisure all contribute to mental health. However, no one's life is perfect, so mental health is also about learning the coping skills to deal with life's ups and downs the best we can.

*Mental illness* is a serious disturbance in thoughts, feelings and perceptions that is severe enough to affect day-to-day functioning. Some names for mental illnesses are:

- schizophrenia seeing, smelling or hearing things that aren't there or holding firm beliefs that make no sense to anyone else but you – symptoms that are often called psychosis, noting that psychosis can be associated with other disorders such as depression or in relation to drug abuse,
- depression intense feelings of sadness and worthlessness
   so bad that you have lost interest in life,
- *bi-polar disorder* cycles of feeling intensely happy and invincible followed by depression,
- anxiety disorders panic attacks, phobias, obsessions or post traumatic stress disorder,
- eating disorders anorexia (not eating), bulimia (eating too much and then vomiting), or binge eating disorder (eating too much and not purging – often leading to obesity), and
- borderline personality disorder severe difficulty with relationships, placing yourself in danger, making decisions that turn out to be very bad for you – most often as a result of a history of child abuse, abandonment or neglect.

*Disability:* Limitations and difficulties in performing the basic activities of daily life as a result of health conditions, including mental health problems. For example, limitations in social and family relationships, self-care, being part of your community and in functioning well at work.

**Note:** Research shows that many people with a mental illness also have substance abuse problems.

Substance abuse: Substance abuse is defined in behavioural terms – the effect it is having on an individual's life – poor attendance at work or school, problems in relationships (violence, neglect of children, marital breakdown), dangerous use of substance (for example, while driving) and continued

use of substance despite obvious negative consequences (job loss, trouble with the law).

*Addiction:* Addiction is defined in two ways: psychological dependence (the individual believes the substance is necessary for social functioning) and physiological dependence (increased consumption over longer periods of time, increased tolerance, withdrawal symptoms and health problems related to substance intake).<sup>1</sup>

Assessment: A mental health professional will ask a number of questions about what you (or your family member) are experiencing (symptoms and behaviours) to help determine the diagnosis. Time (how long has this been going on?) and severity (how bad is it?) are factors.

*Diagnosis*: While receiving a diagnosis of mental illness can be frightening, many say that just knowing what they are experiencing has a name is a form of comfort. Your doctor and other professionals need to get to know you as a whole person in order to make an accurate diagnosis. Getting the correct diagnosis can be difficult with 50% of families reporting that, at first, their loved one received the wrong diagnosis. An accurate diagnosis is crucial because it leads to a set of actions you can take to begin your journey of recovery.

*Medication:* There are dozens of psychiatric medications. Your family doctor or psychiatrist will select one for you to try. People react differently so it may be necessary to try a number of medications before you are satisfied with the results. Some people choose not to take medication at all. For some, this may be the right choice. For others, it can be disastrous, leading to repeated episodes of illness and hospitalization.

**Therapy**: Therapy helps you learn emotional and relationship skills so that you can make healthier choices for yourself. While therapy can seem just like a conversation, you should

<sup>&</sup>lt;sup>1</sup> American Psychiatric Association, (2004). Practice guidelines for the treatment of patients with substance abuse disorders: Alcohol, cocaine, opioids. <a href="http://www.psych.org">http://www.psych.org</a>.

feel that you are growing and learning each time you visit. Family and friends may also choose therapy to help them support themselves and you. Different kinds of health professionals provide psychotherapy (for example, medical doctors, psychiatrists, psychologists and social workers). If you see someone for psychotherapy, it is important to be sure that they have the proper training. The advantage of seeing a registered health professional is that they are accountable to a regulatory body for the services they provide. Note that only family physicians or psychiatrists have their fees paid by Medicare. Other health professionals will charge fees (unless they work for a hospital, school or community agency). See Section 3 for a list of registered health professionals and a description of what they do.

Rehabilitation services: These services are concerned with preventing disability that can be associated with mental illness. They are designed to ensure that you receive the supports you need to fully and successfully participate in life. Rehabilitation services providers are trained to identify (with you) problems (along with solutions) that might arise in a broad range of activities, from home, to school, to workplace, to your ability to participate in the wider community.

Other supports and treatments: Some people want to try other avenues such as self-help groups, a change in lifestyle (diet and exercise), traditional medicines (Chinese, Aboriginal) or herbal remedies. You have to be careful that other medicines do not interact badly with psychiatric medications.

Consumers: People with mental illness are not always happy with being called a "patient" or "client" because these terms do not acknowledge the importance of their role in their own recovery. "Consumer" is intended to highlight a more empowered role in the treatment partnership.<sup>2</sup>

*Family members and caregivers*: Your family may be relatives – in the way we mostly think of families. But your family also may be close friends, a same sex partner or a whole

<sup>&</sup>lt;sup>2</sup> Those who are most unhappy with formal treatment call themselves psychiatric survivors.

community. A caregiver is anyone who cares enough about you to involve themselves positively in your treatment and recovery. *Special note:* Not all families are helpful and supportive. Some have been abusive and rejecting. This is why the definition of family is broad – people who care about you even though you may not be related *are* family.

The following resources offer trustworthy information that will help you, your family members and caregivers get the facts - and become informed partners in your care and recovery.

# **General information**

# http://www.canadian-health-network.ca (bilingual)

Sponsored by the Public Health Agency of Canada, this site partners with many health organizations which are responsible for content. It is easy to search. The information is jargon-free and accessible. Topics can range from **definitions** (for example, what is depression) to **coping strategies** (tips on how to get the most out of life despite your diagnosis) to **where to find services and self-help groups**.

# http://www.mediresources.sympatico.ca (bilingual)

This site offers information in the form of definitions and frequently asked questions. It has a partnership with PharmAssist which has provided an **online library** that describes first, **major diagnoses** in easy to understand language (the facts, the causes, symptoms and complications, treatment and prevention) and second, **medications** (the drug's generic and brand name, what it is supposed to do, how long it will take to work, usual dosage levels, who should *not* take it and why, side effects and precautions).

# http://www.healthcanada.gc.ca/medeffect (bilingual)

This website includes the Canadian Adverse Reaction database that lists the types of problems people may have had with certain medications. It also lists **warnings**, **recalls and advisories** regarding all sorts of health products including drugs and natural health remedies.

# http://www.cmha.ca (bilingual)

This is the site of the Canadian Mental Health Association and it includes **frequently asked questions and information on specific disorders.** It also includes policy papers on the need for affordable housing, employment, homecare and other relevant topics for people living with a mental illness. It has a **wellbeing section** that challenges visitors to respect their mental health as much as their physical health. It also **lists a CMHA in your area** and provides information on how to contact them.

# http://www.mentalhealth.com

This online encyclopedia offers the latest research, information on diagnosis, medication and therapy along with criteria for various diagnoses of mental illness. It also has discussion groups and magazine articles.

# http://www.psychdirect.com

This site is sponsored by McMaster University in Hamilton Ontario and features a **women's mental health** section and **fact sheets on mental disorders**. It reports on new research and offers a section on how to assess whether or not current research is credible. This information is aimed at students but it is also useful for the general public.

# http://www.camh.net/about\_addiction\_mental\_health

This web site is sponsored by the Centre for Addiction and Mental Health in Toronto and offers numerous **fact sheets on mental disorders and addiction** – most have been translated into **many languages**.

# http://www.cwhn.ca (bilingual)

This is the website of the Canadian Women's Health Network. While mainly dedicated to women's reproductive health, a quick search using the words "mental health" or "santé mentale" offers a resource list on dozens of topics related to women's mental health.

# http://www.mentalhealth.samhsa.gov

This is a US site sponsored by the Substance Abuse and Mental Health Services Administration and offers an **online library with research articles**, **fact sheets and booklets** to assist consumers and families. Its **focus is wellness and recovery**.

# http://www.nimh.nih.gov

This is the site of the National Institute for Mental health in the US. It offers a wealth of information including descriptions of diagnoses and medications, and fact sheets and frequently asked questions. It hosts the Real Men, Real Depression campaign to raise awareness among men of the incidence of depression.

# http://www.dietitians.ca

This is the site for registered dietitians in Canada. It offers a variety of nutritional resources and an online "Find a Dietitian" database.

# Suicide, suicidal thoughts and attempts

Many mental illnesses are accompanied by feelings of deep despair. People may feel worthless and unable to experience any pleasure. People with mental illness are at higher risk of committing suicide than the general population with 90% of suicide victims having a diagnosable psychiatric disorder.

# Worrying signs:<sup>3</sup>

- Hints or outright statements such as, "The world would be better off without me," "I don't want to live anymore," "There is no future for me."
- Making preparations like getting one's affairs in order and giving away prized possessions.
- Storing up medications.
- Social isolation.
- A recent catastrophic loss such as the death of a loved one, loss of a job, significant financial loses.

It is a common myth that just raising the subject of suicide with a friend or loved one who is suffering will put the idea in their head or drive them to take action. In fact, talking about suicidal thoughts or feelings may actually help them to get help and avoid an attempt. Some strategies to use if you fear someone is feeling suicidal:

- Take it very seriously but don't panic. Talk with them in a straightforward manner about suicide.
- Stay connected. People who are suicidal feel utterly alone.
   Offer the message "you matter" even if they can't respond at the time.
- Listen. Hearing people's deepest feelings is life-affirming.
- Don't keep it a secret. Contact the person's significant others (family, friends or doctor) and begin to build a support network and a support plan that answers questions such as: How can I help? Who (and when) can you call for support? What, even in a small way, makes you feel better?
- Is it time to go to the hospital? Hospitalization is a *last resort* but if people communicate clearly that they intend to make an attempt on their life, do not hesitate to call the

Canadian Collaborative Mental Health Initiative

<sup>&</sup>lt;sup>3</sup> Special note: Self-harm (cutting, burning or otherwise violating one's own body) used to be considered a form of suicide attempt. People who self-harm do so for a variety of reasons. Some to restore control over uncontrollable situations or feelings, to actually prevent a suicide attempt, to feel an adrenalin rush, or to communicate emotional pain in a visible way. Some people hurt themselves for all of these reasons. People who self-harm need help to change their coping mechanisms but these behaviours are not, in themselves, suicide attempts. In cases where you suspect someone is self-harming, let them know you care and support them in finding professional help.

police or go to the hospital. Accompany them as their support and advocate.

People who are most at risk:

- Those who are also abusing drugs or alcohol.
- Those who have made past attempts especially involving lethal means.
- Those who have a plan and the means to attempt or complete suicide (for example, a store of pills, possession of weapons).
- Those experiencing major life-altering developmental changes (for example, teenagers and the elderly).

Families, caregivers and friends can be terrified for the safety of their loved one with mental illness. They know all too well that their fears are real because people who express suicidal thoughts may actually die. The grief after losing someone to suicide is especially painful because of the complexity and power of the emotional reaction: guilt (should I have done more?), anger (why did she leave us?) and sadness (he is never coming back again). Talking with other survivors of suicide will show that they experienced similar feelings – even while knowing there was absolutely nothing they could have done to change things.

# Resources to help

http://www.cmha.ca/bins/content\_page.asp?cid=3-101102&lang=1

This is a fact sheet about preventing suicide that offers **practical advice** on how to support and help someone who is suicidal. It talks about the **warning signs** and what to do after an attempt. It also talks about **what you can do if you, yourself, are feeling suicidal.** 

# http://www3.sympatico.ca/masecard/help.htm

A HELP resource published by Sympatico that offers a **listing of crisis lines** and **survivor groups in Canada**. It has **brochures for someone who is living with a person** who is suicidal, for people who are "losing hope" and for people who have experienced the suicide of a loved one.

# http://www.befrienders.org/index.php

This is a worldwide **multi-lingual** site of volunteers who are **online 24 hours a day, seven days a week** to talk with people who are feeling suicidal. They listen. They don't judge and they don't tell people what to do.

# Resources for those who have lost a loved one to suicide

# http://www.sharegrief.com

This Canadian site offers 24 hour a day, seven day a week **online support for people who are grieving the loss of someone close**. It does not specialize in helping people who have lost someone to suicide but the counsellors understand this especially difficult form of grief.

http://www.thesupportnetwork.com/CASP/supportgroups.html
This national site (Canadian Association for Suicide Prevention) lists support groups in your local area for survivors of suicide.

# **Recommended books:**

Healing after the suicide of a loved one by Ann Smolin. Published by Fireside Press. It costs \$21.00.

*No time to say goodbye* by Carla Fine. Published by Main Street Books. It costs \$21.00.

Both available at: <a href="http://www.chapters.indigo.ca/Default.asp">http://www.chapters.indigo.ca/Default.asp</a>

# **Getting help early**

People often say that they wish they had been able to figure out what was wrong sooner. Research supports them in that the course of mental illness is much more positive if diagnosed and treated early. These following resources will help you spot the signs and get help.

*Note*: Sometimes websites try to be helpful by offering short self-diagnosis tests. These are to be taken with a grain of salt only a family doctor, psychiatrist or psychologist can give you an accurate diagnosis.

# http://www.ssoAware.com

The onset of schizophrenia is often in the late teens or early adulthood. This Ontario site offers the facts on schizophrenia and tells visitors why getting help early matters. Early intervention in psychosis is a new area of specialized treatment that helps young adults stabilize as quickly as possible, on lower doses of medication, often without hospitalization (if at all possible) and with the least interruption in their schooling or relationships.

# http://www.psychosissucks.ca

This British Columbia site offers information about the **signs and symptoms of schizophrenia**, **treatment and recovery**. It talks about substance abuse and its role in precipitating symptoms or making them worse.

# http://www.bpkids.org

Sponsored by the American Child and Adolescent Bipolar Foundation, this site offers full description of bipolar symptoms in children, a library, message board, chat room and "ask an expert" feature.

A Sibling's Guide to Psychosis: Information Ideas and Resources and What can Communities do? Available at <a href="http://www.cmha.ca">http://www.cmha.ca</a>. This resource offers **basic information on psychosis**, what to look for and how to help.

# http://www.cmha.ca/english/intrvent/

This site offers three pamphlets: What is psychosis? Youth and psychosis: What parents should know, and Early intervention: Time is of the essence – available in English, French and Chinese.

# Other resources to consider

The Self Care Depression Patient Guide – available at <a href="http://www.mheccu.ubc.ca">http://www.mheccu.ubc.ca</a>. This easy to read resource talks about what depression is, how it is treated, the causes and ways to take control: Reactivate your life, challenge negative thinking habits, and solve problems effectively.

Dealing with Depression: Antidepressant Skills for Teens – available at <a href="http://www.mheccu.ubc.ca">http://www.mheccu.ubc.ca</a>. This booklet begins with a chapter that helps readers find out if they are depressed or just sad. Its "antidepressant skills" include realistic thinking, handling difficult situations and setting goals you can reach. It also discusses drugs and alcohol, diet and exercise and how to deal with relapse.

Reaching Out – for schools and community health (with French sub-titles). This is a youth-oriented early intervention resource kit designed to educate young people about schizophrenia and provide real tools to help. It also offers a 20-minute video where five young people with schizophrenia educate viewers so that people can be more understanding. It is available from the Schizophrenia Society of Canada for free <a href="http://www.schizophrenia.ca">http://www.schizophrenia.ca</a>. The video can also be viewed online if you have up-to-date software.

Surviving schizophrenia: A manual for families, consumers and providers (4<sup>th</sup> edition) by E. Fuller Torrey. Published by Harper Collins, it costs \$22.95. You can order by calling 1 800 361 6120 or visiting <a href="http://www.cavershambooksellers.com">http://www.cavershambooksellers.com</a>

Surviving manic depression: A manual of bi-polar disorder patients, families and providers by E. Fuller Torrey. Published by Basic Books, it costs \$22.50. You can order by calling 1 800 361 6120 or visiting http://www.cavershambooksellers.com

"Been there, done that! Having mental illness - or having someone you love have a mental illness - is not a fun experience - but no one understands it better than those who've been there."

# Section 2: You are not alone

Consumers, families and caregivers value professional help but they have found they also need to tell their stories among people who have "been there" – those who understand exactly what they are going through.

The professional and scientific views of mental health and mental illness are one part of the picture. Another part is the knowledge and wisdom that comes from living everyday with a mental illness.

Consumer and family groups offer their own stories, suggest coping strategies, develop self-help manuals, host chat rooms, provide links to local resources, and offer practical tips about all the things they wish they'd known when they, or a loved one, was first diagnosed. But above all, they offer messages of hope. "You are not alone." "I went through it and I'm doing fine now." "My son just got a job!"

# Self-help and peer support

Self-help is people helping people. Its primary benefit is connection – learning that you are not alone. Peer support is self-help but it includes one-to-one help where people who have "been there" help others who are newly diagnosed, in crisis or just discharged from hospital. Peers provide everyday practical advice because they have been through similar experiences. Peer support workers can be volunteers but more and more, they are being hired as paid paraprofessionals attached to mental health services or self-help organizations. In this more formal role, they may provide counselling, advice on resources, and referrals to services that will be helpful to you.

Some self-help and peer support groups are advocates, reaching out to politicians and government policy workers on issues that affect their members' quality of life. They may also speak at schools and community groups or hold information and resource fairs to help educate the general public on mental health and mental illness. As part of your recovery, you might like to get involved and make a difference (see Section 8).

Here are some places you can turn to for information developed for - and by - people who have "been there":

# National Canadian self-help groups with provincial affiliates and local chapters

http://www.mooddisorderscanada.ca (Babel Fish Translator on site)
This is the site of the Mood Disorders Society of Canada. It offers the latest policy papers and Canadian surveys, links to local self-help resources and many fact sheets on mood disorders and other mental illnesses. There is a forum for discussion and an easy-to-read pamphlet entitled Beyond the Depths of Depression.

# http://www.schizophrenia.ca (bilingual)

The Schizophrenia Society of Canada's site offers an array of detailed information on schizophrenia but also many other mental disorders. It reviews current research, publishes policy papers, answers frequently asked questions, offers links to other sites and resources, and hosts a message board. Its online publication, *Learning about schizophrenia: Rays of hope* is valued and is available in French, Latvian and Serbian. The English version can be downloaded for free. The site also publishes inspirational personal stories.

http://www.nnmh.ca (Babel Fish Translator on site)
The National Network for Mental Health's site has a chat room,
discussion forum and newsletter. It has published a paper called *Model for Community Inclusion* available in both English and French. The NNMH does not have local chapters.

# Self-help, peer support and peer advocacy

# http://www.selfhelpnetwork.org

This Alberta site publishes an **events calendar**, **news and links to helpful resources**. It lists support groups across the province and publishes a newsletter called *Thinking Allowed*.

# http://www.heretohelp.bc.ca

This British Columbia site is sponsored by the BC Partners for Mental Health and Addictions. It offers many helpful publications such as a toolkit for families, state of knowledge papers, links to resources, stories of hope and recovery, help for children and adolescents, and a message board. Visitors can subscribe to *Visions Journal*, published four times per year.

# http://www.selfhelp.on.ca

This Ontario site promotes **self-help and mutual aid for many health problems** but offers numerous resources for people with mental health and addiction problems. There are listings for groups throughout the province and **tips on how to start your own self-help group**.

# http://www.dbsalliance.org

This is the site of the Depression and Bipolar Support Alliance. It offers a peer-to-peer resource centre, "ask and expert" section and general information on mood disorders. Support groups are listed only for the US.

# http://www.amiquebec.org

Sponsored by the Alliance for the Mentally III Inc/Alliance pour les Malades Mentaux Inc. this site is **dedicated to the needs of families**. It includes topics such as associations in Montreal, knowing the system, after hospitalization, taking care of yourself, if a family member refuses treatment, where to find legal services, and dealing with the Public Curator. It also publishes **Out There Newsletter**. The site is in English.

# http://www.cmha-bc.org

This Canadian Mental Health Association, BC Division site offers a **Mental Health Survival Kit** that tells you about the symptoms of mental illness, the roles of various professionals and what questions to ask.

# Other resources to consider

# http://www.ourvoice-notrevoix.com.

Founded 18 years ago, there are now **20 Activity Centres (French and English) throughout New Brunswick**. In addition to regular meetings, twice a year, the groups publish a newsletter called *Our Voice/Notre Voix* that can be received in hard copy or accessed online.

# channal@nl.rogers.com.

Established in 1989, CHANNAL (Consumers' Health Awareness Network Newfoundland and Labrador) serves the needs of consumers through self-help groups in many locations in the province. Its goals are to combat isolation, to educate the public, to provide social and emotional support, to provide a safe forum for consumers to voice their concerns and to provide skill building opportunities.

# http://www.thedreamteam.ca.

The Dream Team is made up of consumers and families who tell their personal stories in three minute speeches to politicians, community groups and universities. **Their message: Safe, affordable housing saves lives.** The group books presentations for a fee and its goal is to **validate consumers' and families' life stories.** 

# http://www.selfhelpconnection.ca

This site originates in Nova Scotia and offers a manual on how to start your own self-help group.

Alcoholics Anonymous (<a href="http://www.alcoholics-anonymous.ca">http://www.alcoholics-anonymous.ca</a>),
Al-Anon and Alateen (<a href="http://www.al-anon.alateen.org">http://www.al-anon.alateen.org</a>), Narcotics

Anonymous (<a href="http://www.narcoticsanonymous.net">http://www.narcoticsanonymous.net</a>), Emotions Anonymous and Women for Sobriety (reached through a Google search only – no website). These self-help groups hold meetings in every province and territory in Canada. Al-Anon and Alateen help family members of people with substance abuse problems. **Women for Sobriety** does not encourage reliance on a higher power, but instead promotes self-sufficiency and empowerment.

# http://www.cmha-bc.org

The Canadian Mental Health Association in British Columbia has published a **Peer Support Training Manual**. The Manual provides a lot of general information about mental illness, medication, coping skills and recovery. It also covers such topics as spirituality and mental illness, anger management, medication and suicide prevention.

*Note:* There are self-help organizations in every province in territory. Please see <a href="http://www.cmha.ca">http://www.cmha.ca</a> for a listing of Canadian Mental health Associations and their phone numbers. If you call, you can get information on self-help group in your area.

# Magazines

# http://www.moodsmag.com

This magazine offers information and stories of hope. It is available by subscription but the site offers many other resources such as mood disorders and addiction self-help group listings, a glossary of mental health terms and a self test for depression.

# http://www.schizophreniadigest.ca/

The digest is available by subscription. The site offers articles on research and news, healthy living, family issues, faith and spirituality and stories of inspiration. Some articles are available online. The Digest is also beginning a new publication for people with bi-polar disorder called *BP Digest*.

# http://www.bphope.com

This is the online home of the **US based bp Magazine** that publishes **inspirational stories**, practical **coping strategies** and articles of general interest. You can subscribe and have the magazine sent to you or you can read the articles online.

# Section 3: Your team

"Believe me, to recover from mental illness, you need all the help you can get. Just remember, you are the most important member of your team. And another thing, the people who love you your family and friends - are just as important as professionals. No, they are more important in the long run, even though you've got to have professional help. No one's going to argue about that."

"I finally found help and this was from a family doctor. When I see her, I feel welcome. When I tell her my story, she takes time to listen. For the first time, I feel respected and I'm getting real help." Many people, but not all, want to work with a team. Some people relate well to only one professional and want to keep it that way. Others live in areas where health care professionals are so scarce, there is only one or two people available to help. Team members don't have to be health care professionals – they can be your minister, Elder, boss, neighbour, landlord/lady, teacher – anyone who wants to support you in your recovery. Some mental illnesses go on for many years and this is an instance when good treatment really needs a team: the consumer, family and caregivers, and professionals.

People with mental illness and their families say that they need a much broader range of help than just diagnosis and medication. They want help finding housing and employment, filling out forms for social assistance, counselling and support. Some want therapy and others want help with the tasks of living on their own.

This broader approach can be called the *biopsychosocial* model, meaning that biology (your genetic family history, brain function and chemistry), psychology (your personality, relationships and beliefs) and sociology (life experiences, social environment and cultural background) are all important when recovering from mental illness. (Information from a fact sheet, Strengthening Families Program).

When there are a lot of professionals involved, consumers, families and caregivers want them to work as a team so they don't have to coordinate their own services, go through multiple assessments, and so that their plan for recovery is shared by all.

For more information on teamwork visit <a href="http://www.cpa-apc.org/MIAW/pamphlets/Teamwork.asp">http://www.cpa-apc.org/MIAW/pamphlets/Teamwork.asp</a>

Also see <a href="http://www.schizophrenia.on.ca/files/23036-CNSu-treat.pdf">http://www.schizophrenia.on.ca/files/23036-CNSu-treat.pdf</a> for a pamphlet entitled *Schizophrenia facts for families:* You and the treatment team.

There are many ways to look at professionals and what they do – sometimes they are named for the role they fulfill – for example, case manager. Sometimes they are named by their professional designation – for example, nurse or social worker. It can be confusing. The main things to consider are:

- Do the professionals involved in your (or a loved one's) care tell you what their role is and what they can do for you?
- Do they listen to you and treat you with respect?
- Are they helpful? Are they making a difference?
- Do you feel you can trust them?
- Does their training or practice include the "voice" of consumers, family, and their representative groups?
- Do you know where to take comments or complaints if you feel you need to? Is there good information about these mechanisms, and are they welcoming and effective?

# **Community mental health professionals**

Assertive Community Treatment Teams (ACT Teams): The members of ACT Teams are psychiatrists, nurses and social workers. If you have a severe mental illness, you may be referred to an ACT Team so that you can live comfortably and safely outside of hospital and as independently as possible. ACT Teams help monitor your medication, refer you to other services and stay closely in touch with you through regular visits for as long as you, the team and your family agree that you need them.

Case managers: Case managers will also work with you on a long term basis. Some provide counselling. Others will help you find housing and community support services – and coordinate these services so everyone is working as a team. They will help you stay out of hospital by working with you to prevent a recurrence of your illness. You will likely see your case manager weekly – and they will often be able to visit you in your home rather than you having to go to their office. Case managers also work in mental health law courts and help people get treatment if the charges are minor and directly related to mental illness.

Crisis workers: Not all communities have crisis services but for those that do, crisis workers (not always but most often) work with a mobile team that will go to your home in an emergency. Sometimes, the police may be the first people to arrive but, if the crisis is related to your mental illness, they will call a crisis worker (or one will come with them) who is specially trained to help. Some communities have crisis programs that you or your family can call directly. This approach is less upsetting than having the police in your home. The crisis worker stays with you until you feel better and then follows-up in the next several days or weeks to see that you are referred to services so you can avoid a crisis in the future.

Housing workers: If you live in supportive housing, there may be staff working there to help you settle in and get to know your neighbours. Housing workers often organize tenants' meetings, social events or work-parties to do common chores (if the tenants are required to help out). Some housing situations have staff 24 hours a day, 7 days a week. In other cases, the staff are available on call or at specified hours.

*Peer support workers:* People who have had a mental illness or who are a family member may volunteer to help others, or they may be paid para-professionals. They work in consumer or family organizations or in professionally managed mental health services. They may be called by different titles such as Peer Advocate, Peer Counselor or Peer Outreach Worker but they all have one thing in common – they've "been there."

*Vocational counsellors:* Some programs help you to finish your education and/or to develop the skills to work. Then, they support you through the process of finding and keeping a job. Vocational counsellors also work with employers to find jobs for people and ensure that they are educated about mental illness.

Some other names for professionals who perform these roles, as described above, are National Native Alcohol and Drug Abuse Prevention Worker (NNADAP Worker), mental health therapist, wellness worker, community and social development worker, addiction worker or alternative worker

– the main thing is to ask what they do, not what they are called.

# Other professionals who can help you

Art and music therapists: Some people find that their recovery is aided by creative expression. Art therapy allows people to deal with overwhelming emotions in ways other than talking about them. They also help people find their creative side and relate it to their psychological and mental well being. Some sponsor art shows where work is exhibited and sold. Music therapists know that the heart is touched by music. Creating or listening to music is healing.

Psychotherapists: Psychotherapists may have many professional backgrounds. Psychotherapy is not a registered health profession (there is no formal regulatory body) so you need to be sure that the person you are seeing has proper training. Psychotherapists work from a wide variety of approaches. Note that only family physicians or psychiatrists have their fees paid by Medicare – other psychotherapists will charge fees (unless they work for a hospital or community agency). Visit <a href="http://www.aboutpsychotherapy.com">http://www.aboutpsychotherapy.com</a>, a British site that offers information on the models of psychotherapy and what they can do for you.

# For people who are working

Employee Assistance Programs (EAPs): Many workplaces now offer employees, as part of their health benefits package, confidential counselling for emotional, marital, mental health and addiction problems. While sessions are limited (approximately six per employee), EAP counsellors can provide referrals to community services and longer term counselling. Some EAPs offer workplace training on subjects such as wellness, recognizing the signs of mental illness and accommodation.

# Registered health professionals and what they can do for you

"Registered" means that these professionals must belong to a college that oversees ethics, practice standards, complaints and discipline. The following are short descriptions of what these professionals can do for you, but be sure to ask questions as many may offer services which can be broader in

scope than what is described here. Some, such as registered nurses, registered psychiatric nurses, social workers, and occupational therapists may fulfill many of the roles listed under the previous section.

Family physicians: Your family doctor is your personal physician and your health advocate from birth to old age. After obtaining a medical degree, your family doctor received additional training in the diagnosis and treatment of a wide range of health problems, and learned to provide care in different settings (hospital, clinic, home) with other healthcare providers. This expertise enables your family doctor to see you through the little problems as well as the bigger health problems that relate to both your physical and emotional health, which may afflict you over time. Your family doctor can also work with you to minimize your risk of becoming ill and advise you on the best ways to stay healthy. Your family doctor is part of a network of health care professionals and can help you access the care that you need. For more information see <a href="http://www.cfpc.ca">http://www.cfpc.ca</a>.

*Dietitians (RDs):* Nutrition plays a key role in mental health, including recovery from substance abuse, in mood and eating disorders and in combating the side effects of certain psychiatric medications. Weight management, diabetes, blood levels affecting heart disease, high blood pressure, heartburn/reflux, food allergies, swallowing problems and access to good food are just a few of the issues dietitians can address. Dietitians may be available through outpatient clinics, homecare centers and through mental health programs. You will need to check with your family physician or case manager to find about this service in your community. The Dietitians of Canada has a consumer friendly web site http://www.dietitians.ca (bilingual) that has resources for healthy eating and instructions on how to find a nutrition professional. The Consulting Dietitians Network's toll free line (1-888-901-7776) is also available to provide referral to dietitians in private practice. In British Columbia there is a Dial-A-Dietitian line (1-800-667-3438) that provides answers to nutrition-related questions.

Occupational therapists: Occupational therapists help you identify the daily activities in your life that are important to you - but are causing you difficulty. They work closely with you to develop ways of overcoming these difficulties. They address a broad range of activities such as self-care and community living, to education, work, parenting, recreation and leisure. They evaluate why problems are occurring and suggest approaches to compensate for these difficulties. Some problems you might have are trouble with concentration or memory, difficulties getting organized, a hard time making plans to return to work or difficulty negotiating workplace accommodations with your employer. Another thing an occupational therapist might do is develop (with you) an activity schedule that promotes success in tackling your dayto-day challenges but which also supports your mental health and well-being. For more information, see <a href="http://www.caot.ca">http://www.caot.ca</a>

Pharmacists: Pharmacists work to ensure that you are taking the right dose for the right reason and are not taking any unnecessary medications. Working in drug stores and hospitals, pharmacists dispense medication and are there to answer your questions. Some pharmacies have private counselling rooms where you can ask questions in confidence. If there is no special space, you are still entitled to your privacy. It is important that your pharmacist is aware of all your medications. Work with your pharmacist to get your questions answered in a confidential manner – perhaps over the phone. For more information, see <a href="http://www.pharmacists.ca">http://www.pharmacists.ca</a>

Psychiatrists: Your family doctor may refer you to a psychiatrist to help with diagnosis and finding the right medication for you. Your psychiatrist will involve your family or caregiver at your request and recommend your treatment plan. Psychiatrists also provide consultations to family physicians and to community mental health services. In the case of consultation, you may not actually see the psychiatrist, yourself, but they will be working on your behalf in the background. For more information, see <a href="http://www.cpa-apc.org">http://www.cpa-apc.org</a>

*Psychologists:* Psychologists assess and diagnose psychological problems, sometimes with the use of

psychological tests. They are also offer psychotherapy which can help you understand why you think, feel and behave the way you do – and, if you are in distress, help you figure out what you can do to make changes in your life. Some psychologists work for hospitals, clinics, jails or school boards where their services are covered by public health insurance. Others work in private practice where they charge a fee for their services. If you are employed and have a health benefits plan, it may offer from \$500 to \$1000 per year for the services of a registered psychologist. Visit <a href="http://www.cpa.ca/Psychologist/psychologist.htm">http://www.cpa.ca/Psychologist/psychologist.htm</a> where you can learn more about what psychologists do.

Registered nurses (RNs): RNs work in many locations throughout the entire health care system. They will help you with all your health needs – some of which will relate to your mental illness. Nurses can provide counselling, help you monitor your medication, make referrals and advocate for you, and provide teaching about healthy living. Some nurses work in community roles such as case managers or crisis workers. Others have advance training and are called Nurse Practitioners. Working in consultation with a physician, these nurses offer a broader range of health services including diagnosis and the prescription of some medications - things that only doctors used to be able to do. For more information, see <a href="http://www.cna-nurses.ca">http://www.cna-nurses.ca</a>

Registered psychiatric nurses: Registered Psychiatric Nurses provide health care to persons in a variety of settings. Their focus is on the mental and developmental health of persons within the context of their overall health and life situation. Their education provides a special focus on mental health and mental illnesses. Their knowledge and skills include needs assessment, program planning and therapeutic interventions. They practice where people live, work and play as well as in hospitals and community clinics/services. They are often the only mental health resource available to a rural or remote community and therefore work closely with other members of the community to meet the diverse mental health needs of its people.

These are nurses specially trained to help people with mental illness. They work in mental health services, both in hospitals and in the community. They can provide you, your family or caregiver with education, advice and counselling – and they are skilled at helping you monitor your medication. For more information, see <a href="http://www.psychiatricnurse.ca">http://www.psychiatricnurse.ca</a> or <a href="http://www.cfmhn.org">http://www.cfmhn.org</a>

Social workers: Social workers help with personal problems in the context of your relationships, family, community and life circumstances (poverty, childhood trauma, domestic violence, marginalization, cultural heritage – and many other situations that are unique to you). Some social workers provide counselling or psychotherapy. Many work in positions where their job is to get to know the services in your community and, with your input, refer you to the ones that will help you live independently. Their roles in mental health agencies or hospitals include health teaching, treatment and rehabilitation services and they will work with individuals, couples, families and/or community groups. For more information, see <a href="http://www.casw-acts.ca">http://www.casw-acts.ca</a>

# What to expect from team members

There are many efforts to bring professionals together to begin to work in a collaborative manner but many, like you, are learning new ways. Having a team working with you should allow professionals to:

- have time for you,
- listen to you,
- work with you in an atmosphere of compassion, respect and dignity,
- make a great deal of effort to understand you and your life,
- are up-to-date in their area of expertise,
- are holistic in their approach,
- explain things to you and answer your questions,
- communicate options from which you can choose,
- be culturally competent this means your team is respectful of and responsive to your history, culture and language. In fact, they should have had training that helps them in this goal.

# Questions a mental health professional may ask you<sup>4</sup>

In order to get to know you, understand your problems and develop an effective treatment plan, professionals will ask you questions over a number of introductory sessions. The questions are designed to assess your own views about what is troubling you and, if possible, what those close to you are observing. They are also aimed at understanding your life circumstances (home, work, culture, relationships) and ongoing, past or recent stressors in your life. Professionals also know that there is a statistical probability that people with mental health problems might also have other, more sensitive issues they are dealing with such as a substance abuse problem, experiences of violence in their past or present lives or suicidal thoughts. If you have had these experiences, you may feel uncomfortable talking about them. You are being asked these things so that the professional can be more helpful but the bottom line is that you don't have to talk about sensitive topics until you are ready to do so.

The following are some of the subjects a mental health professional may explore with you:

- 1. What has brought you here today? This is a question designed to help you begin to describe what is troubling you in whatever words you can find.
- **2.** Can you describe to me how you are feeling? The professional will be looking for symptoms that will help them understand what's wrong. They will also try to understand how much you understand about your illness.
- 3. Can you describe what you are doing to cope with these symptoms? Here, the professional will be making the distinction between a symptom (for example, intense feelings of sadness), thoughts (it's all hopeless), and behaviours (staying in bed all day long).
- **4.** *Tell me what other people in your life are noticing.* The first few questions are looking at how you see your

<sup>&</sup>lt;sup>4</sup> These interview questions assume you are seeking help voluntarily and are not in crisis.

problems. This question is aimed at finding out what others are observing. Often people with mental illness minimize their suffering or have symptoms that they deny (such as hearing voices, seeing things or expressing bizarre beliefs). Asking you what others are observing can provide very important information. If you are comfortable, a friend or family member can be called upon to answer this question.

- 5. What is your living situation? The professional wants to know about your culture and community, whether or not you are living and working in positive circumstances, if you have supportive relationships in your life and if you are exercising and eating well. Professionals will explore these areas in different ways including asking questions about your family, your job, and your connection to community, cultural heritage or traditional healing practices (if relevant). They may also ask about previous or present involvement with other service providers and whether or not it has been helpful. These types of questions are looking for past or ongoing stressors that may be affecting your mental health either positively or negatively.
- 6. What is going on in your life right now? Here, the professional is looking for recent or sudden stressors that may have affected your mental health for example, the onset of a physical illness, job loss, marriage break-up, death of someone close or relocating to a new community.
- 7. Having learned much more about you by now, and, hopefully, having made you comfortable talking about your problems, the professional may go on to more sensitive life issues such as:
  - a. Do you drink alcohol? How often and how much?
    This question is not to accuse you most people drink it's to find out if you or your family are at all worried about the level of your drinking.
  - b. Are you taking anything? (prescription, over-the-counter, herbal or traditional medicines or street drugs)? If so, what are they? How much are you (taking) using and how often?

- c. Have you experienced violence in your past? In your present?
- d. Are you feeling suicidal? Have you attempted suicide in the past?
- 8. What is going right in your life? What helps you over the hard times (coping mechanisms)? What do you excel at (talents and abilities)? What are you most proud of (accomplishments)?

Mental illness can seem to overwhelm the whole of a person's identity and everyone, including you or your family, can forget that you have strengths that can be built upon. These questions are designed to find out what's good in your life.

All of these questions are aimed at getting to know you as a whole person so that your professional team and you have a shared understanding of your problems, are clear on where to start to solve them, and are able to jointly develop an overall treatment plan that fits your circumstances.

## Questions you can ask your mental health professional and/or team members

Your encounter with your team is not a one-way street. You get to ask questions as well as answer them. Some questions to consider:

#### For the person who is ill:

- Do you work as part of a team? If so, what types of professionals are on the team?
- Do you have a particular treatment philosophy or model that will guide how you help me?
- How will you use the information I have given you to develop my treatment plan? In what ways do you ensure my confidentiality?
- How often will you see me? Can I call you if I am in distress? If I can't call you (because you only work during the week or certain hours), who can I call?
- In what ways are you going to ensure that I (and my family or caregivers if I want them involved) are full

partners in my healing and recovery?

- If I ask you to, will you share information with my family or caregivers so that they can know what's going on? If I do not give permission for my information to be shared, will you follow my wishes?
- What, exactly, is my diagnosis? Where can I find more information about it?
- What medications are you prescribing and how are they expected to help? How long will it take before they begin to work? What are the side effects?
- Will you tell me about all the options available to me and will you involve me in decisions regarding my treatment and referrals to other programs?
- If something we've decided to try (a treatment, therapy or program) is not working, will you respect my experiences and work with me to change approaches?
- If there are parts of my clinical file that are inaccurate, how can I have them changed?
- If I don't agree with aspects of my treatment plan, will you listen to my opinions with respect?
- Will you respect the traditions and beliefs of my culture? Are you willing to consider involving alternative healing practitioners as part of my treatment team? Will you consider my cultural ceremonies and practices as an integral and viable method in my healing and recovery?

## For families or caregivers who you have asked to be involved:

- Many times people with mental illness are very ill when they first encounter their treatment team. In these cases, supportive family or caregivers may have the responsibility for asking questions. The questions listed above may be of use to families and caregivers as well, but they may have some specific questions of their own:
- When I observe the first signs that my loved one is getting ill, will you respect my views and take action?

- When I tell you that my loved one is disguising or denying his or her symptoms or suicidal thoughts, will you take my observations seriously?
- What is your policy regarding sharing of information with families and caregivers? How can you ensure my continued involvement in my loved one's treatment plan?
- Will you let me know when you are changing my loved one's medication, treatment plan, appointment times, community program or therapist so that I can be supportive?

#### For inpatient teams:

• Will you involve me in discharge plans and let me know the date when you are discharging my loved one?

#### **Another resource:**

http://www.bcss.org/information centre/questions to ask psychiat rist.html offers a list of questions you, your family member or caregiver might want to ask your psychiatrist when you visit.

## Some additional things to look for when working with your team

1. Good communication – Professionals in community and in hospital need to talk with one another so that when you are discharged from hospital, people are there to help you with the transition. You may also be on higher doses of medication meant for crisis management but your community team has to see that the dosage is lowered so that you can concentrate on getting your life back on track. People who've "been there" want you to know that good collaborative care means that your hospital and community teams work together.

There are no easy solutions to problems of communication but if you (family member or caregiver) keep the names and numbers of your community team and supportive caregivers and see that they are posted on your inpatient chart, it becomes easier for the inpatient team to communicate.

**2.** Consistent goal setting – Members of your team may focus too closely on their own specialty and not recognize that the goals they set with you are in opposition to the goals another professional has set. For example, your

psychiatrist may increase you medication to address your symptoms - making you tired and listless - while your case manager is working with you to find a job. Both goals are important but they are working against one another.

As a solution, keep a record of your recovery goals and share them with all members of your team and caregivers. This way, everyone is on the same page.

### Advocating for yourself or someone you love

You and your family or caregiver, (if you chose to have them involved) are equal members of your team but people are often intimidated by professional know-how and feel that their job is just to follow orders. The system is very complicated; some providers may not have all the answers. You have to ask questions about professionals' plans for you to be sure that you are getting what you need.

One tip is to keep your own notes. If you (or your family member) has notes about what medications you've tried and their effectiveness, including any negative reactions – you won't have to go through experimenting with something that didn't work. You may also want to keep track of the number of visits you make to professionals and what you discussed, what programs you've been referred to and whether they worked for you, and when you've been in hospital and for how long. Having this information will prevent you from having to tell your story over and over again – and will help you "manage" your professional team by doing your part to communicate.

The following websites provide a wealth of information on how best to work with professionals to get the help you, a friend or a family member needs.

#### http://www.mhselfhelp.org/techassist/selfadvocacv.pdf

This guide talks in practical ways about how to do your own research, how to make calls to professionals and how to be persistent in getting an appointment for yourself or a family member. It offers tips on how to prepare for your visit so that you have your information ready. It also offers sample letters of complaint if you feel you haven't been treated fairly.

#### http://www.mentalhealth.samhsa.gov

This US site offers self-help booklets on recovery, one of which is **Speaking out for yourself**. The site is a little difficult to navigate but if you type in *speaking out yourself* (do not include "for") in the search box, you will have success.

#### Some information about medication issues:

http://www.ontario.cmha.ca/content/reading\_room/factsheets.asp?
cID+4282\_This link will take you to a discussion of marijuana, its
effects on mental illness and potential interaction with psychiatric medications.

 $\underline{\text{http://www.bcss.org/information\_centre/resource\_materials/index.h}}\underline{\text{tml}}$ 

This link discusses the use of street drugs and their effects if you have schizophrenia.

http://www.ontario.cmha.ca/content/about\_mental\_illness/women. asp for a free brochure on psychiatric medication and weight gain.

http://www.rrasmq.com/publications (site is French only but booklet is available in both English and French).

This site offers (for order at no charge), **Taking back control: Self management of psychiatric medications** or **Guide personnel sur la gestion autonome de la medication.** It is for people who, with the support of their doctor, want to find the right dosage of medication so they aren't suffering difficult side effects that make them want to stop all together – which may not be good for their health. To order by mail, write to ERASME/RRASMQ, 2439 rue de Rouen, 4e étage, Montreal, Qc, H2K 1L8.

## What to do when things go wrong

Professionals are there to help and most people are satisfied with the care they receive. But things can go wrong. It can be a matter of poor fit. You or your family and caregivers just don't relate to the professional (or team) - as a people. I can be a question of approach or the team's treatment philosophy just isn't for you. Other concerns can be:

- You don't feel you've received the correct diagnosis.
- Your medication is not working and you can't convince the team to try a new one.
- You feel disregarded the team is not hearing your ideas about your own treatment and recovery.
- As a family or caregiver, the team seems to ignore your perspective.
- Appointments are canceled with no explanation.

- The team has no understanding of your culture and does not see its importance to you.
- The team is so overloaded with clients that they have very little time for you – yet you need to discuss important matters with them.
- You can't reach your team by phone and they don't respond to your messages.

Many of the issues listed above are about poor communication. In fact, poor communication between professionals, their clients and family members is a common source of dissatisfaction with health care. For example, *poor communication between a physician and patient is the reason for doctors being sued in* 70 -80% *of cases* (http://www.cfpc.ca/cfp/2005/Jan/vol51-jan-clinical-3.asp).

The common characteristics among doctors who are sued by their patients were:

- They were not prepared for their meeting with their patient.
- They made it clear to the patient that they had little time for them.
- They failed to understand the seriousness of the patient's health problems.
- They showed little regard for the patient's or the family's views.

Bringing up your concerns with the team (or individual professional) is *not* easy. It is likely that you and your family had a hard time finding help in the first place. You may be afraid that you will lose them if you complain. However, if you are unhappy and don't say anything, your relationship with the team is going to deteriorate further, your treatment is going to be less effective and you are, quite naturally, going to experience frustration. Here are some thoughts:

Has your team developed and published a *complaints process* that you (your family or caregiver) can follow? If a team has this process already in place, it is reassuring. They are saying – we know complaints occur and there is a way to get your concerns heard.

- Professionals are people too. They have feelings. If you allow your frustration to build to the point you explode, they won't be able to hear what you have to say and your legitimate concerns might be labeled "unreasonable."
- There is a certain amount of frustration everyone experiences with the health care system. Write down your concerns and check them out with a friend who can give an objective opinion. Is the team ignoring your views? Are you being treated badly? Or, are you over-reacting?
- Having confirmed that your concerns are justified, rehearse ways of bringing matters before the team. Try to think not only of problems, but also of solutions. If your phone calls are not being returned – is there a time frame that would be acceptable to you (within 48 hours, for example). Is there one team member you feel more comfortable with where you can begin your conversation?
- Is there someone who can go with you for support? Having someone who is aware of your concerns and is prepared to help you tell your story balances the powerdifferential between you and your team. This person can also listen for potential points of compromise that you might miss as you may be nervous.

The following resource offers practical advice on ways to start these difficult conversations.

#### http://www.psych.uic.edu/uicnrtc/raisingissues.pdf

This booklet walks you through the steps to take to raise difficult issues with your own or a loved one's service provider (prepare, stay calm, and bring a friend with you). It offers "conversation door-openers" – suggested scripts - on all sorts of topics such as wanting more respect, feeling unheard, how the professional can be a better partner, and how you can be more involved in your own life and treatment decisions.

#### Finding a new team

If you and your family and caregivers are unable to resolve things to your satisfaction with your present professional or team, you may decide to leave. However, the reality is that there are many areas in Canada where mental health services are so scarce that there is no other team you can turn to. If this is your circumstance, you will have to work especially hard to resolve things with your present team.

When there *are* other services to turn to, people are still nervous about making a change. Some options for you to consider:

- Most community mental health services accept selfreferrals. You may encounter a waiting list, but you can research a new agency, call and ask about their services and place yourself on their list without needing a referral from another professional.
- Convene a "self-designed" team this will take time and energy to build but you may choose members according to your needs and preferences. The team may have anyone on it that you feel will contribute to your recovery: Friends, clergy, a homeopath, Elders, co-workers, a massage therapist, a case manager, a physician, a dietician, a practitioner of traditional Chinese medicine – all chosen according to your own wishes.
- Turn to the traditional healing ways of your culture. Western approaches to medicine and helping are only one way of assisting people in their recovery from mental illness. You may find that re-activating your sense of cultural history and belonging, along with the medicines and practices of your community, are affirming, empowering and healing.
- Find a self-help group. Some people supplement professional treatment with self-help. Others find selfhelp sufficient, in and of itself. Section 2 of this toolkit will help you find and choose a group in your area.

And finally, you may decide to maintain some form of contact with your professional or team – even if it is not that satisfactory – but also choose one or more of the options listed above.

#### Getting a second opinion

You may feel that you have not received the correct psychiatric diagnosis. If you want a second opinion, you must ask your physician to refer you to another diagnosing professional (psychiatrists, general practitioner or psychologist). It would be rare for you or your family to be able to call directly and make your own appointment – except in the case of a psychologist who is in private practice.

#### When things have gone really wrong

If your experiences with a professional or professional team are *extremely* troubling and efforts to resolve issues have not resulted in change, you may consider making a complaint to the relevant college. The point of being a "registered health professional" is that it is mandatory to belong to a professional college in order to practice. The college's role is to protect the public. You do not have this protection if the professional you are seeing is un-registered.

Complaints to professional colleges are of a very serious nature and include:

- Negligence or malpractice.
- A breach of ethics, conduct or communication.<sup>5</sup>
- Concerns of an intimate or sexual nature.

The following websites list the contact information for all regulatory colleges of registered health professionals in Canada.

#### Physicians and psychiatrists:

http://www.cpsbc.ca/cps/physician\_resources/registration/importantlinks/canadianmedicalreg

Dietitians: <a href="http://www.dietitians.ca/find/i\_1.htm">http://www.dietitians.ca/find/i\_1.htm</a>

#### Occupational therapists:

http://www.caot.ca/default.asp?ChangeID=63&pageID=50

#### Pharmacists:

http://www.pharmacists.ca/content/about\_cpha/about\_pharmacy\_i n\_can/directory/associations.cfm?main\_heading=Provincial\$Regulat ory\$Authorities

Psychologists: <a href="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showPage.asp?id=2057&fr="http://206.75.45.181/showpage.asp?id=2057&fr="http://206.75.45.181/showpage.asp."http

#### Registered nurses:

http://www.cna-

nurses.ca/CNA/nursing/regulation/regbodies/default\_e.aspx

<sup>&</sup>lt;sup>5</sup> This means a serious failure in communication – as one example only, failing to warn you about potentially dangerous side effects related to a certain procedure or medication.

Registered psychiatric nurses: Note that psychiatric nurses have their own regulatory colleges in only four provinces: British Columbia, Alberta, Saskatchewan and Manitoba. In other parts of the country, they are regulated through registered nurses' colleges (as above). <a href="http://www.crpnbc.ca/">http://www.crpnbc.ca/</a>

**Social workers:** <a href="http://www.casw-acts.ca">http://www.casw-acts.ca</a> Go to "What is Social Work?" and click on Regulation of Social Work in Canada

"Recovery is a journey that helps us gain some control over our lives and our illness - by finding our own way to deal with it. Recovery includes hope, encouragement and support. It is also about being honest and learning to take responsibility for yourself"

## **Section 4: Recovery**

Recovery defines consumers, not as passive objects of treatment, but as active participants – along with their families and caregivers - in creating and maintaining their own mental health. Recovery focuses on wellness rather than illness.

Recovery is not a cure. There is no timeline. It is living life to the fullest despite challenges.

### **Consumers and recovery**

Consumers say that recovery is much more than just dealing with the symptoms of mental illness. People have other life experiences that have affected their mental health. Recovery acknowledges and validates all these experiences and opens the door to a broader base of coping mechanisms than simply diagnosis, medication or therapy.

These are some questions to ask yourself when making a recovery plan – noting that no one is aiming for perfection:

- Can you manage your symptoms, rather than your symptoms managing you?
- Have you begun to make healthier choices for yourself and your life?
- Do you have more positive relationships in your life?
- Is your home comfortable and safe?
- Do you have something to do during the day that makes you feel valued and useful?
- Have you found the right medication at the right dose level – for you?
- Do you eat well, exercise a bit and get a good night's sleep?
- Do you have strategies to calm yourself down when you are overcome by worries?
- Do you have someone to call when you are lonely?
- Do you have a shoulder to cry on when you are sad?
- Do you do things now and then that simply soothe your soul?
- Can you comfortably say "no" to a suggestion or plan that just doesn't suit you?

For those consumers who are severely ill and struggle with delusions or hallucinations, recovery may have to begin with the tiniest of steps. For a time, supportive others: professionals, families and caregivers, may be leading recovery planning because the consumer is simply too ill to make choices. Here, the contribution of recovery is that it provides hope. Even those who have the severest forms of mental illness can do better and the most important ingredient in their recovery is to be surrounded by people who believe in them and their future.

#### **Families and recovery**

Families and caregivers are central to consumers' recovery. Their presence and support is valued above all else. While consumers are only all too aware of the trauma of mental illness, families and caregivers may minimize the fact that they have suffered too. As their loved one gets better, they rejoice. But they may, themselves, need to recover – from months, and sometimes years of frantic worry, from the terror of a suicide attempt, from trips to the emergency room and from financial burdens. Some families have had to endure the horror of seeing their loved one homeless. Others have been worn down by their struggles with the health care system which can be hard to understand and frustratingly hard to access – even though individual professionals try hard.

It is important that families and caregivers recognize that they may have to take a recovery journey of their own – and make plans for it – just like their loved one is doing.

While the recovery resources in this chapter often speak directly to the consumer's experience, a close reading will show that the tips and coping skills they offer will work just as well for family members and caregivers.

## **Recovery resources**

#### http://www.nnmh.ca

This site offers the *Lexicon of recovery: Defining and language of self-directed citizenship,* a document for and by consumers that explores in full, the definitions and the struggles of recovery.

#### http://www.mentalhealthrecovery.com

The Wellness Recovery Action Plan (WRAP) program offers a **series of educational seminars** – **for a fee** - covering topics such as: Essential recovery values such as hope, personal responsibility, education, self-advocacy and support; medical care and health management; how to develop and use various support systems; developing a healthy lifestyle; suicide prevention; beginning steps to dealing with trauma; and the development of your own personal wellness plan.

#### http://www.bu.edu/cpr/recovery

This website is a rich source of **articles**, **films and videos on recovery**. Most are free but the many books listed have to be ordered from the publisher.

#### http://www.power2u.org

The National Empowerment Centre has many **articles that will help you learn about recovery**. Most of its pamphlets and manuals are available for free.

#### http://www.mentalhealth.samhsa.gov

This is a US site that offers **self-help booklets focused on recovery:** Building Self-Esteem, Making and Keeping Friends, Dealing with the Effects of Trauma, Developing a Recovery and Wellness Lifestyle, Speaking Out for Yourself, and Action Planning for Prevention and Recovery. The site is difficult to navigate when looking for these specific booklets, but if you type the title of the booklet in the search box, you will have success.

#### Trauma recovery resources

Many, many families are committed to helping their loved ones recover from mental illness but there are instances when families hurt. Consumers have experienced rejection, denial and blaming from families. Some are survivors of child abuse and family violence. While consumers say that, above all else, the support of a loving family is most important, some simply cannot be with family because the relationships are harmful to their recovery. In some cases, they are able to establish relationships with an aunt, a cousin – or someone who has not been part of the abuse or present-day hurt. In other instances, they build their own family circle with friends, other consumers and partners. "Family" is anyone who loves you.

For those who have had experiences of childhood trauma (physical, sexual or emotional abuse), the following resources are for you:

#### http://www.heretohelp.bc.ca/publications/factsheets/child\_sexualabuse.pdf

This is a fact sheet entitled, *Childhood sexual abuse: A mental health issue*. It offers facts and figures and discusses the types of symptoms survivors of sexual abuse may experience.

## http://www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/html/nfntsxsensi\_e.html

This is the location of a resource called the *Handbook on sensitive practice for health professionals: Lessons learned from women survivors of childhood sexual abuse.* If you feel your professional team needs to better understand your experiences, this resource may help them help you more effectively.

#### http://www.vansondesign.com/RecoveryCanada

Recovery Canada – the Wellness Network is a **virtual network for self-help**, **electronic support and wellness information**. People from all over the world form their own discussion groups to help them through bad times. Healing and recovery from child abuse is one of the most visited discussion sites.

## http://www.uofaweb.ualberta.ca/SAC/pdfs/TheMaleExperienceofSexualViolence.PDF

This pamphlet talks about the myths surrounding **male survivors** (for example, that it was their own fault, that sexual assault doesn't hurt men as much as women) and provides the real facts. It also talks about paths to recovery.

### Thinking about work

Many people feel getting a job, or returning to work, is central to their recovery. Work builds self-confidence and an income provides financial stability. The following resources offer practical advice and help:

#### http://www.builtnetwork.ca

This site is sponsored by the federal Ministry of Social Development. It brings together **people with disabilities to work as a team to increase their workplace skills**. People deal with issues such as low self-esteem, poor self-confidence and mental health problems such as depression, anxiety disorders, schizophrenia and bi-polar disorder.

#### http://www.cmha.ca.

Hangin' in there: Strategies for job retention by persons with a psychiatric disability talks about what employees and employers need to know so that you can retain your job. It also offers a list of resources available across Canada.

#### http://www.mentalhealthworks.ca

This site offers practical information on mental illness in the workplace. It has a special section for employees and another for employers. It publishes a newsletter with coping strategies and the

latest information to help both employers and employees deal effectively with mental illness in the workplace.

#### http://www.workandstress.ca

This site offers three booklets on mental health, mental illness and the workplace: 1.Scope of the problem: How workforce stress is shown; 2.What causes the problem: The sources of workplace stress; and 3.Solving the problem: Preventing stress in the workplace.

#### Letting professionals know about recovery

The professionals who are involved in your own, or a loved one's care, may not be as knowledgeable about the recovery approach as you would want. The websites listed in this chapter are for professionals too. The following site is mainly for professionals:

 $\frac{http://www.mentalhealth.samhsa.gov/cmhs/communitysupport/tool}{kits/illness/IMRculturalcompetence.asp}$ 

This site publishes a series of six toolkits intended to help professionals change their practice approaches to include goals of recovery. Topics are: Illness management and recovery, medication management – approaches in psychiatry, assertive community treatment, family psychoeducation, supported employment and co-occurring disorders.

"Recovery in not just about medical diagnosis and psychiatric medication. It's about taking control of your life. Sometimes choosing an alternative therapy can work wonders... so why not? And certainly, learning

how to care for

yourself means you

charge of your ups and

are much more in

downs"

# Section 5: Complementary therapies and self-care

More and more, people are taking an active interest in their own health. Western culture is very aware of physical health but it pays less attention to mental health. Emotional and mental well-being are just as important. Mental and physical health are also inter-related – mental illness can make you more vulnerable to physical illness and a physical illness can bring on a mental illness – for example, depression is commonly associated with many physical illnesses.

In supporting your own mental health, you may want to turn to help that is non-medical or non-Western. These ways of helping often connect physical, mental and spiritual health in ways that people feel are respectful of the whole person. They can include herbal remedies, massage, homeopathy, naturopathy, acupuncture and many more. Many cultures have ancient traditions and medicines that they do not think of as "complimentary" – even thought this is what they are called in the Western world. Their traditions are a time-honoured way of promoting health and dealing with illness.

## **Complementary therapies**

Some resources that will help you learn about these complementary therapies are:

#### http://www.ccmadoctors.ca

This is the website of the Canadian Complimentary Medicine Association which is a network of physicians, residents and medical students who are dedicated to bringing together conventional and alternative medicine. It has a **listing of websites that provide information on alternative therapies**.

#### http://www.nccam.nih.gov

This is the US version of the complimentary medicine site described above. It has a useful section dedicated to **alternative therapies and mental health**, for example a full discussion of **St. John's Wort** (an herbal remedy for depression) offering the scientific evidence on its effectiveness and possible interactions with psychiatric medications.

#### http://www.medicinechinese.com

This site **lists practitioners** of traditional Chinese medicine (TCM) and acupuncture in Canada, **frequently asked questions**, **and tips on how to choose a credible practitioner**. It also offers information on how to combine Western and Chinese medicine in a responsible manner.

#### **Self Care**

#### Looking out for yourself

People with mental illness have special vulnerabilities to relapse. It can be a struggle to learn the skills of self care but adopting a broad range of coping strategies is the best insulation against relapse. In addition to the many recovery sites listed in Section 4, the following sites have some wise advice:

## $\underline{\text{http://www.heretohelp.bc.ca/publications/factsheets/positivemental}}\\ \text{health.shtml}$

This **fact sheet offers tips** on finding relaxation time, saying "no," and challenging negative thoughts.

#### http://www.namiontario.ca/courses.html

The Family-to-Family education program consists of **12 free sessions**. The course follows a set curriculum that balances education with self-care, emotional support and empowerment. Presently, courses are only offered in BC and Ontario. This site will tell you times and locations of the next courses.

#### http://www.heretohelp.bc.ca/helpmewith/wellness.shtml

This location on the "heretohelp" site offers **eight practical worksheets**. Subjects covered are: Mental health matters, stress and wellbeing, social support, problem-solving, anger management, getting a good night's sleep, eating and living well and healthy thinking.

#### http://www.mindvourmind.ca

This site is **aimed at youth** who are looking for information on mental health and ways of coping with stress. It offers young people resources both to get help and to give help. It provides information through art and film projects, stress busters and a newsletter called Lip Service.

http://www.psych.uic.edu/uicnrtc/self-determination.htm#tools
This is a link from the US National Consumer Supporters Technical
Assistance Center (http://www.ncstac.org). It offers pamphlets on
learning to express yourself and how to pinpoint areas in
your life you'd like to change. It also has a workbook on
creating your own self-directed life plan.

http://www.rrasmq.com/publications (this site is French only but the booklet is available in English and French)

Taking back control: Self management of psychiatric medications or Guide personnel sur la gestion autonome de la medication. It is for people who want to find the right dosage of medication so they aren't suffering difficult side effects.

#### To tell or not to tell

Stigma and discrimination are the greatest burdens attached to mental illness. People feel that the minute someone knows they (or a family member) have a mental illness, they are treated differently. However, keeping the secret of mental illness is a burden in itself, particularly when the support of others is central to recovery – and it may only add to stigma and discrimination if you are not willing to speak out. But it's a risk that requires careful thought. It may help to prepare an answer in advance so that you are not caught off guard.

Some things to think about before talking about your own, or a family member's illness:

- 1. Illness is a private matter most people you meet don't need to know.
- 2. If you want to tell, ask yourself, do I know this person well enough? Do I trust them?
- 3. How much will you tell? You may not want or need to be too detailed.
- 4. Is it really important that they know? You may need to take time off work to attend appointments, or you may have to ask for accommodation to continue in your job, for example. In these cases, your employer has to have some information although you do not have to reveal the diagnosis.
- 5. Is this relationship serious? When to tell, what to tell all are important decisions as intimacy deepens.

#### http://www.mentalhealthworks.ca

This site offers information on mental illness in the workplace, including a **section on how to talk with your employer and co-workers**. It makes it clear that you don't have to tell. It also offers practical scenarios that tell stories of how people can talk about their mental illness in a practical manner. The site makes it clear that you are entitled to accommodations in your workplace to help you be productive regardless of a mental illness.

#### **Spirituality**

Honouring your spiritual side is important in recovery. Spirituality is defined broadly – as those things that lift your spirits – nature, art, music, worship, and writing – as only a few examples.

Spirituality in First Nations communities is closely tied to the land. It is an essential part of well-being. Identity is built on connection to ancestry, family and community and "mental health" (for example Ojibwe people use the term *biimadziwin*) is defined as living in harmony with nature. Spirituality offers a sense of belonging and a collective sense of self (Source: Acting on what we know: Preventing youth suicide in First Nations, Chapter 4 Spirituality - available at: <a href="http://www.hc-sc.gc.ca/fnib-spni/pubs/suicide/prev\_yout-jeunes/index\_e.html">http://www.hc-sc.gc.ca/fnib-spni/pubs/suicide/prev\_yout-jeunes/index\_e.html</a>)

#### http://www.embarque.org (bilingual)

This site is **especially for people with mental illness**. It acknowledges the central role spirituality plays in recovery. It offers an events calendar, advertises conferences and has a section for **links to other sites that celebrate spirituality**.

#### http://www.crossroads.ca/resources/mentalill.htm

This site offers advice and support **for families of faith coping with mental illness**. It lists books and resources that you may find helpful, noting that some of the addresses for the organizations are out of date.

"I was born in Canada but my parents weren't. When my mother got sick – she cried all the time and didn't seem able to get out of bed, day after day - we didn't know what was wrong. When we finally took her to the doctor, it was hard to talk about my fears – and my mother couldn't speak English. We were upset and *crying* – *but the nurse* heard us. She was from our country! We felt rescued. She was able to talk with us and then tell the doctor- in a way he could understand about my mother's problems. He gave us some medicine for her. She's little better now. The nurse calls us once a week. Now that I know more about depression, I fear what might have happened if she hadn't helped us."

## **Section 6: Culturally competent care**

Special note: Aboriginal people speak of culturally safe care, meaning that everyone must acknowledge unequal power relationships in providing health services, along with the social and historical factors that affect these relationships. The idea of safety also helps professionals focus on results - are Aboriginal people benefiting from the mental health and addictions care system as it currently exists, or does it place them at risk? And does research, itself, benefit the Aboriginal peoples who are being studied? Sometimes, the answer to these questions is, "No, it is not helpful unless the people themselves are involved." The need of Aboriginal peoples is a special topic, and while touched upon here, is dealt with more fully in its own toolkit.

Canada is now a culturally diverse nation. Refugees and immigrants can bring with them their own vulnerabilities related to experiences of war, civil unrest, natural disasters, torture or losing family. The wrench of immigration itself, along with adapting to a new country, can place a strain on families. Employment may be hard to find – or, if found, may not acknowledge the educational backgrounds of new immigrants. Sometimes, the honoured traditions of the "old country" have little recognition in Canada. Children, either very young when coming to Canada or who are born here, can shock their parents with their Canadian ways. It is not surprising that new Canadians can experience mental illness which can become more complicated as a result of the additional challenges they face.

Access to mental health services is important for recovery. Generally, mental health treatment is based on Western views of mental health and mental illness. In fact, research investigating the newest or best practices has most often been conducted on white populations. Since treatment is based on the beliefs of the majority (white) culture, there are barriers to accessing services for people from minority groups. These barriers are related to language, different values and belief

systems, inadequate funding, inadequate resources, lack of cultural understanding, or a form of institutionalized racism that devalues people from minority cultures. Marginalized groups may have very few services in their communities that recognize their unique cultural experience and the effect it has had on their mental health. A goal of the mental health system is to offer services that respect a person's cultural beliefs; known as *culturally competent* care.

Culturally competent care means that the professional team acknowledges diversity. Diversity can include your ethnic, cultural and racial roots, and your gender, age or sexual orientation. The team also openly demonstrates respect for your unique experiences. The professional team must show an appreciation of your beliefs and traditions by incorporating them into your treatment plan. It is the responsibility of your team to gain an awareness and understanding of your culture's traditional healing methods, its medicines, its views of health and illness, and the role of the family, community and religion in your recovery goals.

### Respect for diversity

Professionals may not understand *everything* about your culture but they can create an atmosphere of respect.

Some signs that your team respects diversity are:

- The agency or clinic has posters and signs that welcome diversity.
- Members of the team, themselves, come from a variety of cultures.
- Pamphlets and educational materials are available in other languages.
- Although budgets are tight, there is an interpreting service available even if it is limited.
- Professionals understand that "mental illness and mental health" is not a common language. Some cultures have no words for these ideas – or they have other terms.
- The team is visible in your community and doesn't confine its activities to the office only.
- Your need to involve family and community in your recovery plans is respected.

 You are encouraged to learn about and, if you choose, use traditional and alternative healing practices and medicines. Your team makes you aware of how Western and traditional medicines can interact.

### Some resources offered in other languages

http://www.mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/illness/IMRculturalcompetence.asp

This is the site of an American toolkit on cultural competence aimed at professionals who need to learn more. It offers practical examples and talks about culturally competent care from the point of view of managers, administrators and clinicians.

The following websites offer information on mental health and mental illness in many different languages. Unless stated otherwise, the sites below are bilingual, as well as offering the other languages listed.

#### http://www.schizophrenia.com/ami

This is an American site that offers an extensive online library. Its fact sheets have been translated into: Spanish, Punjabi, Bengali, Urdu, Serbian, Croatian, German, Greek, Japanese and Arabic. It does not offer French versions.

http://www.camh.net/about\_addiction\_mental\_health/multilingualre sources.html (bilingual)

This site offers **fact sheets** on topics such as *About Mental Health, Asking for Help When Things are Not Right, Understanding Addiction, and Coping with Stress.* These resources are available in **Farsi, Polish, Somali, Urdu, Greek, Portuguese, Amharic, Hindi, Punjabi, Tagalog, Chinese, Italian, Serbian and Tamil.** 

#### http://www.cwhn.ca

The Canadian Women's Health Network offers a publication called *Alone in Canada: 21 ways to make it better* in Chinese, Farsi, Somali, Spanish, Tamil and Urdu.

#### http://www.cmha.ca/bins/content\_page.asp?cid=4-42-211

The Canadian Mental Health Association has published a variety of brochures on mental health and mental illness offered in Farsi, Hindi, Greek, Italian, Polish, Portuguese, Somali, Serbo-Croatian, Tamil and Urdu.

#### http://www.bcss.org/information\_centre/translation

The British Columbia Schizophrenia Society has fact sheets on schizophrenia (signs and symptoms, treatment, brain factors, nutrition, how to find help and many other useful topics) in Bengali, traditional Chinese and simplified Chinese, Hindi, Punjabi, Urdu and Spanish.

## Resources for gay, lesbian, bisexual and transgendered people (GLBT)

#### http://www.rainbowhealth.ca

This is the web site of the Rainbow Coalition, a project designed to improve access to primary health care for GLBT and two-spirited people. The Rainbow Coalition can also be reached at 1 800 955 5129.

#### Some resources especially for Aboriginal peoples

First Nations peoples define mental health as a "good life" - living according to the seven grandfather teachings of respect, wisdom, truth, humility, love, bravery and honesty. A good life is achieved by balancing the mental, physical, emotional, spiritual parts of one's self with mother earth.

The following websites are devoted to Aboriginal health and use the medicine wheel as a way of explaining health and illness:

#### http://www.turtleisland.org

This site is sponsored exclusively by Aboriginal peoples and offers a variety of health information, including healing and wellness for mental health and addiction problems. It gives instruction to visitors who want to engage in traditional treatment and explains the many facets (based on the number four) of the Medicine Wheel.

#### http://www.visions.ab.ca

This is a directory of **online Aboriginal health resources mainly in Alberta**, including mental health. It is jointly sponsored by Health Canada and the Nechi Training Centre in Edmonton.

#### http://www.redwiremag.com/mentalhealth.htm

This Aboriginal **online magazine** offers a story of hope where the medicine wheel and traditional healing helped a young Anishnaabeg women deal with depression.

#### http://www.hc-sc.qc.ca/fnihb-dgspni/fnihb/cp/irs.htm

This site is sponsored by the First Nations and Inuit Health Branch of Health Canada. It is **for people who experienced abuse in residential schools** and who are claiming damages from the Canadian government as a result. The site points people to available mainstream counselling and/or traditional healers that you may visit for free if you qualify. The site tells you who to call in order to determine if you are eligible for these services.

## http://www.hc-sc.gc.ca/fnih-spni/pubs/suicide/prev\_youth-jeunes/reference4\_e.html

Suicide rates among First Nations people are the highest in the world. The whole of the First Nations community mourns for the loss of their children. *Acting on what we know: Preventing youth suicide in First Nations* is a comprehensive manual that describes the roots of the problem, and offers a model for an effective suicide prevention program that involves youth in all aspects.

#### http://www.suicideinfo.ca/csp/go.aspx?tabid=144

This site is sponsored by the Centre for Suicide Prevention and offers a manual of promising suicide prevention strategies. It is a practical resource developed with the support of the RCMP Aboriginal Policing Services.

#### http://www.cine.mcgill.ca/

This site is sponsored by the Centre for Indigenous Peoples' Nutrition and Environment (CINE), McGill University. CINE was created to address Aboriginal people's concerns about the safety of their traditional food systems. Environmental changes and pollution have had a negative effect on the health and lifestyles of indigenous peoples, in particular food.

# Section 7: Caregivers' contributions and their needs

Family is one of the most sensitive topics there can be. Many consumers live with, or near their families. Others are not in touch at all and this is a source of great sadness. This chapter is especially dedicated to families who remain involved with their loved one who has a mental illness.

Families' and caregivers' contributions

Families and caregivers want to be members of the treatment team. They want to have information about diagnosis and treatment plans as their loved one does so that they can support follow-through on the recommended actions. They need to be notified of medication changes along with what to expect, and they certainly want to know about discharge dates. Families and caregivers recognize that confidentiality is legislated and are willing to work within those rules – but they want to be informed of what they are.

The benefits of having families and caregivers involved are numerous. They:

- Support treatment plans so that the possibility of relapse is lessened.
- Offer emotional and financial support and they often provide a home.
- Provide needed history of the progress of the illness and can describe the earliest signs of relapse so that action can be taken.
- Often have records of previous treatments, medications and hospitalizations.
- Provide information on the context of the loved ones' life so that they can be understood as a whole person.
- Are strong advocates for improving the health care system as a whole.

"As a mother of three young men, I was so relieved to realize I was not alone in supporting my son when he got ill. Without asking them, his two brothers came to the hospital with me every Sunday. When he got out of hospital, they included him with their friends in their soccer games and parties. He gained more and more confidence and now he has his own friends and his own job. We cannot say it's never going to happen again, but it has been six years since his first episode of psychosis of schizophrenia."

Families and friends of people with mental illness say that they need information and education – about the illness, symptoms, medication, signs of relapse, what forms of treatment are available and where to get help.

But the information that is most welcome comes from others who have "been there." They offer messages that say, "This is not your fault. Take some time for yourself. Your health matters too."

### Signs you need to support yourself:

- Isolation you just don't see your friends anymore.
- Tears you cry a lot or are constantly trying not to cry.
- Lack of concentration you're overwhelmed and can't think straight.
- Bad temper you lose it and you can't remember why.
- Bouts of physical illness you seem susceptible to whatever is going around.
- Pessimism you've lost hope that things will ever get better.
- Everyone seems to want a piece of you you are overloaded with others' needs to the point of exhaustion.
- You're missing work your care giving role is starting to take over your whole life.
- Depression you've begun to experience the symptoms of a mental illness yourself.

Sometimes families, in their efforts to cope with the illness of a loved one, try to help in ways that simply don't work. Or they worry themselves to the point of exhaustion. They can benefit from self-help groups where others share education and coping tips. Here, they learn that it is natural to grieve as some of the hopes and dreams for the future are gone.

#### Information and self care resources

The following resources balance basic information with coping and self-care strategies for families, friends and caregivers.

#### http://www.schizophrenia.ca (bilingual)

The Strengthening Families Together 10-session educational program is offered free of charge. Examples of topics covered are schizophrenia and mood disorders, treatment options, living with mental illness and coping as a family. Email

info@schizophrenia.ca to ask if sessions are available in your area.

Also, if you need someone to talk to now, call 1 888 772 4673 or 1 888 772 HOPE to speak with someone who's "been there."

#### http://www.mentalhealth.com/book/p40-sc01.html

**Schizophrenia:** A Handbook for Families offers definitions and early warning signs. It talks about stigma and how to get help. Other topics are signs of relapse, refusal to take medication, trouble with the law and fears of suicide. It also has a reading list at the conclusion.

#### http://www.amiguebec.org

Sponsored by the Alliance for the Mentally III Inc/Alliance pour les Malades Mentaux Inc. this site is **dedicated to the needs of families**. It includes topics such as associations in Montreal, knowing the system, after hospitalization, taking care of yourself, if a family member refuses treatment, where to find legal services, and dealing with the Public Curator. It also publishes <u>Out There</u> newsletter.

#### http://www.heretohelp.bc.ca/helpmewith/ftoolkit.shtml

This site publishes information on mental illness and substance use problems. This points to a helpful **toolkit for families** that is divided into five modules:

- 1. Understanding mental and substance uses disorders
- 2. Supporting recovery from a mental or substance use disorder
- 3. Communication and problem-solving
- 4. Caring for yourself and other family members
- 5. Children and youth in the school system.

#### http://www.heretohelp.bc.ca/publications/factsheets/families.shtml

This **fact sheet** gives families dealing with loved ones with a mental illness all sorts of information and coping strategies.

## http://www.bcss.org/support\_centre/information\_for\_families/spouses\_handbook.html

This handbook discusses topics such as what it's like to be mentally ill, tips for living with the illness, problem management, limit setting with a partner, financial issues and helping children cope.

## http://www.bcss.org/information\_centre/resource\_materials/index.h tml

Here you can find three booklets for children who have parents with mental illness: When things are sad and gloomy (depression); When moods go up and down (bipolar disorder); When things get really weird (schizophrenia).

## http://www.ontario.cmha.ca/content/about\_mental\_illness/family\_resources.asp

This portion of CMHA, Ontario's website offers a listing of helpful **links** for families, along with reviews of many **books and articles** 

that **families and spouses** will find useful (topics such as education, stigma, and research on the experience of caregivers, siblings, children, teens, adult children, parents and partners).

#### http://www.schizophrenia.ca/english/support.php

This is a reference manual for families and caregivers called *Learning about Schizophrenia: Rays of Hope* (also available in Latvian and Serbian) now in its third edition, chapters include: What is schizophrenia, recognizing schizophrenia, diagnosing schizophrenia, early intervention, dealing with crisis situations, acute episodes, treatment, related illnesses, living with schizophrenia, coping with schizophrenia, impaired cognition, relapse and chronic illness, and best practices in rehabilitation.

http://www.phac-aspc.gc.ca/mh-sm/mentalhealth/mhp/pub/together/index.html

This is the location of *All together now: How families are affected by depression and manic depression.* Available in free PDF format.

#### Recommended books:

What hurts – What helps: A guide to what families of the mentally ill need from mental health professionals by Joyce Burland (first edition – about 20 pages). You can order it from NAMI c/o Lynne Saunders, Colonial Place Three, 2107 Wilson Blvd. Ste 300, Arlington, VA 22202-3042 or call 1 888 999 6264 or 1 703 524 7600. The cost is nominal.

*Taming bipolar disorder* by Lori Oliwenstein ISBN 1-59257-285-5. It includes a chapter called a *survival guide for families*. You can order the book at <a href="http://www.chapters.indigo.ca">http://www.chapters.indigo.ca</a>. It's price is \$18.20 plus shipping.

The bipolar disorder survival guide: What you and your family need to know by David J. Miklowitz. ISBN 1-57230-712-9. Available at http://www.amazon.ca. The price is \$27.00 plus shipping.

How you can survive when they're depressed by Anne Sheffield. ISBN 0-609-80415-4. Available at <a href="http://www.chapters.indigo.ca">http://www.chapters.indigo.ca</a>. The price is \$22.95 plus shipping.

Loving someone with bipolar disorder by Julie Fast and John Preston. ISBN 1-577224-342-2. Available at <a href="http://www.amazon.ca">http://www.amazon.ca</a>. The price is \$15.96 plus shipping.

<u>Surviving schizophrenia: A manual for families, consumers and providers</u> (4<sup>th</sup> edition) by E. Fuller Torrey. Published by Harper Collins, it costs \$22.95. You can order by calling 1 800 361 6120 or visiting http://www.cavershambooksellers.com

"When you're going through your own pain, you see so many things you'd like to change. So I asked myself, what's the use of complaining and doing nothing about it? Get involved and push for change. I have ... and I feel that, even if it's small, I'm making a difference."

## Section 8: Making a difference

As part of recovery, people may feel that the time has come to get involved in their community – to make a difference.

One of the criteria for establishing a collaborative care team practice is to have consumers and families involved right from the outset.

In fact, it is now common for consumers and families to be involved in *all sorts of activities* related to improving the services in their community, advocating for more responsive government policy, and educating the public. Some of the options for involvement available to you are sitting on a non-profit board of directors, becoming a member of a committee, planning body or task force, or participating in a research project.

This sort of involvement is not for everyone, but for those who are interested (and many people in recovery – and their families - are), the following websites will help you acquire the knowledge to become an informed and effective participant.

## Things you will need to know

How the health care system is funded, how boards of directors work and the many complicated debates regarding health care in Canada can be daunting topics. You, like everyone else, can become informed and engaged. Your opinion counts. Here are some websites to begin (or continue) the process of your education.

#### How government works

Most mental health care funding comes from government – it's important to figure out how government makes decisions.

#### http://www.canadainfolink.ca/government.htm

This site tells you about the **different levels of government**, their various **duties and how bills get passed into law**. It offers links to all provincial and territorial government websites. The booklet, *How Canadians Govern Themselves* is available here.

#### **How Boards of Directors work**

Mental health care organizations are non-profit and they are lead by a Board of Directors.

#### http://www.mhselfhelp.org/techassist/serving.pdf

This is, overall, a helpful site for consumer and family training needs but this particular address leads to a **manual that helps inform consumers and families who sit on boards**. Subjects covered include: Understanding boards and committees, deciding if a board or committee is right for you, being an effective contributor, knowing the rules, knowing the unwritten rules, over coming tokenism, and getting along without giving in.

#### http://www.boarddevelopment.org (bilingual)

This site is a comprehensive "one-stop" resource on accountability for members of Boards of Directors – called governance. It has been created, hosted and managed by the United Way. The site does not specifically speak to consumer and family participation but it is an excellent overall reference to help you become knowledgeable and informed about all sorts of issues related to governance.

## Why consumers, families and caregivers should participate

You have valuable experience to offer that will make things better for other people. While you may hope that things will change all on their own, the reality is that they often don't unless people get involved and speak out.

#### http://www.nmha.org/position/ps3.cfm

This is the US National Mental Health Association's policy position on Stakeholder Participation in Mental Health Planning, Advisory and Governance Boards. The document provides twelve essential components in participation that could be adapted for local use.

#### http://www.nnmh.ca

This site is sponsored by the National Network for Mental Health. The organization offers training and occasional workshops on topics such as why, how and where consumers can get involved, the roles and responsibilities of boards and committees, and techniques for maximizing participation. The intended audience is primarily consumers but families would benefit as well.

## "Big picture" issues (for those who don't mind a little heavy reading)

Mental health care is complicated and there are many points of view on what should be done, how much it should cost and who should make decisions.

#### http://www.marketingisland.com/mi/tmm/en/cataloguemanager/CM HA/CMHA\_Framework3rdEd\_EN.pdf

The newly released *Framework for Support* document (Third Edition) from the Canadian Mental Health Association is a more general resource on consumer and family participation. Among other things, the document defines the concept of "knowledge base" and makes the case that moving forward in understanding mental health and mental illness requires experiential knowledge and the accumulated wisdom derived from custom, tradition and history – in addition to medical science and human services research. This is exactly the contribution that consumers and families bring to the Board table.

#### http://www.ontario.cmha.ca

This site has a number of resources that will help you understand the larger issues. Every week, it publishes *Mental Health Notes*, a newsletter that describes recent developments in mental health in Ontario, Canada and the world. You will find *Network*, a magazine published three times a year that examines a particular topic indepth each issue. You can subscribe for free or download articles from the website.

## http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-e/socie/rep-e/repintnov04-e.htm

For the really serious student of mental health issues in Canada, the Standing Committee on Social Affairs, Science and Technology, chaired by Senator Michael Kirby and Senator Keon, most recent activities have involved a national study of the mental health and addiction care systems resulting in three reports (with a final set of recommendations due in 2006).

http://www.ccmhi.ca (English) or http://www.iccsm.ca (French)
This is the website of the Canadian Collaborative Mental
Health Initiative which will give a full explanation of the group's aims and the research it has engaged it. This and other toolkits are also published here.

Working together towards recovery:

Consumers, families, caregivers and providers

## **Appendix 1: Charter principles**

The *Canadian Collaborative Mental Health Charter*<sup>6</sup> reflects the commitment of national consumer and provider organizations of mental health services to improving the mental health of persons in Canada. These organizations, who are signatories to the *Charter*, agree to promote and support the *Charter* through their membership.

The signatory organizations agree that the following seven principles form the foundation of collaborative mental health care and agree to promote these principles among their members and stakeholders.

### Principle 1: Promotion and Prevention

All Canadian residents have the right to live in a society that promotes health and provides for the prevention and early detection of mental health problems.

This principle acknowledges that health has many biological, psychological and social determinants. It outlines the responsibility of Canadian society to adopt a population health approach to attend to the social determinants of health of its residents.

## Principle 2: Holistic

All Canadian residents have the right to health services that promote a healthy mind, body and spirit.

This principle supports the view that health is more than the absence of disease. It also recognizes the links between physical and emotional well-being.

## Principle 3: Access to Collaboration

All Canadian residents have the right to collaborative, effective and timely mental health services.

This principle acknowledges the importance of appropriateness and accessibility to mental health care, at or

<sup>&</sup>lt;sup>6</sup> These principles were being adopted by each CCMHI association during the release of this toolkit. Please visit <a href="www.ccmhi.ca">www.ccmhi.ca</a> for the final approved charter principles.

through the individual's first point of contact with a health care provider or system. Collaboration supports this by involving working partnerships among consumers and professionals at the levels of policy and program planning, evaluation and training, as well as front-line care and practice.

### Principle 4: Partnership

Consumers\*, along with their social supports\*\*, have the right and responsibility to be full partners in their recovery.

This principle acknowledges that collaborative care depends on consumer participation in all aspects of self-care including assessment, intervention, decision-making and management.

## Principle 5: Respect

All Canadian residents have the right to receive mental health services and supports in a manner that respects their diverse needs.

Diverse needs may pertain to age, gender, culture, language, creed, race, economic standing, accommodation status, education, sexual orientation, and spiritual beliefs.

Those people that are most marginalized in society (homeless, minority ethnic groups, elderly, gay/lesbian/bisexual) often experience higher levels of mental and physical health problems and the most difficulty accessing services appropriate to their needs.

This principle emphasizes the importance of flexible and responsive mental health services designed to fit the needs of the individual – not expecting the individual to "fit" into a prescribed program. As people's needs and goals change over time, individualized services and supports must also change to remain responsive.

<sup>\* &</sup>quot;Consumer" refers to a person who uses mental health services; other terms such as "patient", "client" or "person with a mental illness" may also be used in reference to a consumer.

Social supports include people that play a significant support role such as family members, caregivers, friends, clergy or community agencies as identified by the consumer.

## Principle 6: Informed

All Canadian residents have the right to be informed about the range of mental health services and supports that can meet their needs.

This principle expects the health care provider(s) to present and discuss the risks and benefits of treatment options. Treatment alternatives need not be limited to those that are publicly funded.

### Principle 7: Resourced

Mental health services must be supported by policy and provided with adequate financial and human resources.

Effective collaboration takes time and resources to be successful. The availability of mental health and addiction services (from prevention and early intervention through to treatment, rehabilitation and recovery) and access to an integrated team of health professionals requires clear policy direction and innovative funding models to sustain collaborative mental health care.

Working together towards recovery:

Consumers, families, caregivers and providers

## Appendix 2: Crisis plan

This toolkit has been designed for when you or your family member are *not* in crisis – when you have time to reflect and learn about mental illness. But crises do occur. The following is a *crisis plan* adapted from Mary Ellen Copeland's Wellness Recovery Action Program. Writing down the answers to these questions (with the knowledge and support of your family or caregiver) will help you through the tough times.

When I am feeling well, I am (describe yourself when you are feeling well):	Preferred medications and why:
The following symptoms indicate that I am no longer able to make decisions for myself,	Acceptable medications and why:
that I am no longer able to be responsible for myself or to make appropriate decisions:	Unacceptable medications and why:
When I clearly have some of the above symptoms, I want the following people to make decisions for me, see that I get appropriate treatment and to give me care	Acceptable treatments and why:
and support:	Unacceptable treatments and why:
I do not want the following people involved in any way in my care or treatment. List names and (optionally) why you do not want them involved:	Preferred treatment facilities and why:
	Unacceptable treatment facilities and why:

	What sympt	I want from my supporters when I am experiencing these oms:	
		I don't want from my supporters when I am experiencing symptoms:	
		What I want my supporters to do if I'm a danger to myself or others:	
	Things	s I need others to do for me and who I want to do it:	
	How I	want disagreements between my supporters settled:	
	Things	s I can do for myself:	
I developed this document mys the help and support of:	elf with	I (give, do not give) permission for my supporters to talk with each other about my symptoms and to make plans on how to assist me:	
Signed	Date		
Supporter	Date	Indicators that supporters no longer need to use this plan:	
Supporter	Date		
Witness	Date		

### **Toolkit Series**

### This toolkit belongs to a series of twelve toolkits.

#### Implementation toolkits for providers and planners

1. Collaboration between mental health and primary care services. A planning and implementation toolkit for health care providers and planners

A series of companion documents to the CCMHI planning and implementation toolkit for health care providers and planners. Establishing collaborative initiatives between mental health primary care services for

- 2. Aboriginal Peoples
- 3. Children and adolescents
- 4. Ethnocultural populations
- 5. Individuals with serious mental illness
- 6. Individuals with substance use disorders
- 7. Rural and isolated populations
- 8. | Seniors
- 9. Urban and marginalized populations

#### Toolkits for consumers, families and caregivers

- 10. Working together towards recovery: consumers, families, caregivers, and providers
- 11. Pathways to healing: A mental health guide for First Nations People

#### A toolkit for educators

12. Strengthening collaboration through interprofessional education: A resource for collaborative mental health care and educators.

#### A series of documents examining aspects of collaborative mental health care support these toolkits:

1.	Barriers and strategies	7.	International initiatives [unpublished]
2.	A framework	8.	Health human resources
3.	Annotated bibliography	9.	Mental health prevalence and utilization
4.	Better practices	10.	Interprofessional education
5.	Canadian initiatives	11.	Aboriginal mental health [unpublished]
6.	A policy review	12.	The state of collaborative mental health care

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