

Mental Disorders Toolkit

Information and Resources for Effective Self-Management of Mental Disorders

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**Mental Disorders Toolkit: Information and Resources for Effective Self-Management of Mental Disorders
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The Mental Health and Addictions Information Plan for Mental Health Literacy is a groundbreaking public information initiative driven by the Anxiety Disorders Association of BC (ADABC), Awareness and Networking around Disordered Eating (ANAD), British Columbia Schizophrenia Society (BCSS), Canadian Mental Health Association BC Division (CMHA), Kaiser Foundation, the Mental Health Evaluation & Community Consultation Unit at the University of British Columbia (Mheccu), and Mood Disorders Association of BC (MDA), working together in a collective known as the BC Partners for Mental Health and Addictions Information. The project is funded by the Ministry of Health Services, under the direction of Dr. Gulzar Cheema, Minister of State for Mental Health. Over three years, the project will create a permanent communications infrastructure, including a website and a series of practical toolkits developed to help individuals living with (or at risk for) mental health or substance use problems to manage their health conditions on a day-to-day basis. Combined, the groups have more than 100 years of service to British Columbians and regional branch networks or linkages throughout the province.

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Background

The Mental Disorders Toolkit is a resource designed to develop core self-management skills for people with a mental disorder. It has been designed to be helpful for an individual with any diagnosis, and to complement diagnosis-specific toolkits that have been developed for depression and anxiety disorders. If you have either of these conditions, you may wish to work through the Mental Disorders Toolkit together with the diagnosis-specific resource. This will contain more detailed information about your disorder, and about strategies for managing it.

If you are not sure what your diagnosis is, this toolkit will also be useful to you. Readers in this situation may want to skip directly to Module Two for information about the various mental disorders. If you suspect something is wrong, but have not yet received help, see the Sections entitled “How do I Know If I Need Help?” and “How do I Get the Help I Need?” on page 11 of Module Two.

Readers may also wish to enquire about other resources that will be available from the BC Partners for Mental Health and Addictions Information initiative explained on the inside cover, relating to caregiver issues, to mental health, and to addictions.

This toolkit, like the others in the series, takes an “evidence-based” approach, that is to say, the material is based on evidence from numerous, well-conducted research studies and attempts to include only information that this research suggests to be factual. It also means that the strategies and tips included in this toolkit have been shown by this evidence to help people manage their symptoms and live their lives in more fulfilling and healthy ways.

Disclaimer

The Mental Disorders Toolkit is not intended to replace the need for a trained mental health professional when diagnosing, treating and managing mental disorders. As noted, we have made efforts to only include evidence-based information or sources in this toolkit. However, please be aware that some of the recommended readings, websites and resources may occasionally contain information or recommendations that are not supported by the available evidence to date. For this reason, it is always recommended that you consult with an expert when seeking a diagnosis, evidence-based treatment options or an effective self-management plan.

Note about resources: As you work through this toolkit, you will note references to additional resources such as those found on the Internet or in books and videos. If you do not have internet access and/or do not know where to look for the books, manuals or videos suggested, please call us at 1 800 661 2121 so we can assist you in locating or borrowing these materials, or in the case of web resources, printing out and mailing you key pages of interest. As website addresses often change as well as phone numbers and even availability of books or videos, please let us know through the feedback form on the last page of this toolkit of any errors or updates.

Goals of the toolkit

When we designed this toolkit, we had some broad goals in mind. First of all, we wanted to create something that would help you develop core self-management abilities, in particular:

- making sense of information about your disorder and about the various treatments and strategies for managing it
- working with your doctor or other mental health professional to find a treatment that is as effective as possible
- learning your “early warning signs” and developing an “action plan” to avoid a relapse — that is, a return or worsening of symptoms leading to a repeat episode of the disorder

Overall, we wanted to create something that would serve as:

- an entry point to the path to self-management and recovery
- a basis for developing the knowledge, attitudes and skills for managing your disorder, managing your emotions and managing the roles that you value
- a basis for evaluating what other kinds of self-management resources may be appropriate for you

Achieving self-management

Self-management (known sometimes as illness management or as self-care) in simple terms is the ability to control your mental disorder and live a successful life *with* that disorder. Just as a person with diabetes or asthma can learn to go about his or her daily life without anyone really noticing that condition, you too can arrive at the point where mental disorder is not the defining part of your life.

This is easier said than done, you might be thinking. You may think of how much of a struggle it is to have a mental disorder. You may feel as well that nothing you try really makes a difference, and that the disorder controls *you*, rather than the other way around. If you are a family member of a person that struggles a great deal, and who may not even believe they *have* a disorder, you too may feel that self-management is a pipe dream.

In fact, with the right kind of support, self-management of mental disorder *can* be a reality, and research is now showing that even for people with the most serious forms of mental disorder, resources that support self-management need to be an essential part of the approach to mental health. The destination of successful self-management may take a while to reach, or it may take a while even to find the start of the trail, but you can find it and you can get to where you want to go. Or if you are a caregiver, you too can help someone find the path and keep making it down the road.

What does successful self-management look like in practice?

It may be easier to understand what self-management is by considering what it looks like in practice. Someone who is successful at self-management can:

- negotiate with their health professional to find a treatment that works for them, that is, a treatment that controls the symptoms of the disorder and still allows them to function effectively in their day-to-day lives
- monitor their symptoms (including medication side effects), their stress levels, and their early warning signs of trouble on a day-to-day basis
- cope effectively with stressful situations or with distressing symptoms so that they can lower the chances of a relapse occurring
- successfully enlist support from others, or from the mental health system when they do get into trouble
- think about their disorder as one part of their identity, not their *whole self*

In other words, a good self-manager not only finds a treatment that works for them, but also has an ongoing plan of attack for how to live with their disorder on a day-to-day basis and knows how to get help when needed before things get out of hand. A good self-manager also has a healthy attitude towards their disorder, and a sense that they *can* control their disorder, and that they can get the right kind of help when they need it, from the people around them and from the mental health system.

For more discussion on self-management including first-hand accounts of self-management and related issues in practice — from people with personal experience of mental health or substance use problems, family members and front-line service providers — please see *Visions: BC's Mental Health Journal*, Issue No. 18 on Self-Management. It's available online at www.heretohelp.bc.ca or call 1 800 661 2121 to enquire about a free subscription to the quarterly magazine.

What exactly do I manage? Illness management, emotion management and role management

Research about successful self-management shows that people don't just manage the symptoms of the disorder itself; symptom management is only one of three things that make up the full concept of self-management. The broader concept also involves things known as emotion management and role management.

In brief, emotion management involves dealing effectively with the feelings that are part and parcel of being diagnosed with an ongoing health condition, for instance, dealing with the negative attitudes that may go along with having a diagnosis — such as being “a mental patient” or “nuts” — or dealing with the idea that you have to live with the disorder the rest of your life. Successful emotion management involves reframing one's view of the disorder to a more positive, constructive view.

Self-management doesn't occur in a vacuum. Instead, it means being able to deal with the impact of your disorder in a number of different roles or settings. The final aspect of self-management — role management — involves developing strategies for managing your disorder in these situations; so for instance, your disorder doesn't get in the way of your job or schooling, or doesn't become a negative influence on your relationships, or doesn't get in the way of other important aspects of your life.

What resources do I need to self-manage?

Now that we've got a sense that self-management *is* possible, and we've got a picture of what successful self-management looks like, it's time to consider how to get there. The first thing you'll need is *information*. Information is the basis for making sense of your disorder, for understanding your symptoms, and for understanding potential treatment and support options. The next thing you'll need relates to your *attitudes*, and to the way you look at your disorder and your abilities to deal with it. For instance, you'll need *hope* that you *can* live successfully with a mental disorder and you'll need *motivation* to make the changes that may be necessary to help you live a healthier life. Finally, you'll need to develop certain skills. For instance, you'll need skills to make decisions about what kind of treatments and resources are right *for you*. And, you'll need skills to learn your unique set of early warning signs and to cope effectively with stress and with problem situations.

All of these things are related, and one thing leads to another. Information is the basis on which skills are built. Accurate information can also be part of the foundation of a hopeful attitude. And the knowledge that you *can* learn skills and that these skills can contribute to recovery is obviously also a powerful source of hope. Moreover, hope is a powerful motivator for someone to continue building skills and persevere in the face of adversity and setbacks.

Where do I find the resources I need to self-manage?

This toolkit has been designed as a starting point on the road to self-management. It will provide you with the basics of self-management, with ways of deciding for yourself just where you are on the road, and with a way for deciding what other resources may be available to help you down that road.

The following modules of the toolkit are designed to map out the core skills you will need on the path to self-management and provide some tools that will help you develop the skills and motivation to help you move down the path. Each of the following modules addresses a specific set of skills, as described in the outline below:

Module Two: *Psychoeducation*, or learning about the basics about your illness or disorder

Module Three: *Shared Decision-Making*, or working with your health professional to find a treatment approach and other strategies and resources that work for you

Module Four: *Developing an Early Warning System and Action Plan* to monitor and manage possible early warning signs of relapse on a day-to-day basis and seek help if necessary

Module Five: *Assessing Your Ability to Self-Manage*, and accessing further resources to strengthen your self-management skills

How do I use this toolkit?

As mentioned, each of the modules addresses a specific set of skills and is designed to provide the basic knowledge that you need to build and practice those skills. Each successive module is built on the one that comes before, so you should make sure you're comfortable with the material before you move from one to the next. However, you may find that you are already comfortable with some of the material in the beginning parts of the toolkit. Or you may find that a quick review of an earlier module is sufficient for you to begin addressing some of the more advanced concepts and skills.

There are several ways you can use the toolkit. If you are generally not confident with your current self-management abilities, you can work through the modules one at a time, from the very beginning. If you feel that your self-management abilities are strong already, you can simply use the toolkit as something you may want to dip into from time to time, as a way of refreshing your knowledge or skills. If you think you may be somewhere in the middle, you will probably need to think more carefully about where to start.

Whatever your abilities, we suggest that you do a quick run through of the material as a way to familiarize yourself with the contents, and to get a rough sense of your comfort level. After doing that, test yourself by doing the self-management pre-test in Appendix B, which measures your confidence with the concepts and skills dealt with in the previous modules. Your answers to these questions will give you a more specific sense of your self-management abilities, which will help you focus in on the areas you need to work on, and will give you an idea of where to start.

After finding your preferred starting point, we encourage you to go through the modules, in order, in a more focused way. As you do so, take the time to do the exercises within each module. They are designed to help you reflect on and build the necessary skills. Follow up on the links and the suggested resources as a way of becoming even more confident with the material.

Once you've worked your way back to the end of the toolkit, without looking at your previous results in the pre-test from Appendix B, do the post-test at the beginning of Module Five, and compare how you did before and after working through the modules by comparing your results from the two separate tests. See how much progress you've made, and then decide for yourself if you need to review some of the areas, or if you need to follow up on some of the suggested links.

Finally, we encourage you to seek out other self-management-related resources in your community. In order to help you do this, the last module outlines the types of group-based programs that may be available in your community. It also makes suggestions for some useful self-directed resources that anyone can benefit from. These may be especially useful if other self-management programs aren't accessible to you, or if you feel uncomfortable in a group situation.

Depending on a number of things — your diagnosis, the stage of the disorder, your age, or whether you have other health conditions you deal with — a certain kind of self-management resource might be a better fit for you. This toolkit is designed to help you get a sense of where you're at, to build up your self-management strengths, and then find the best fit between any further needs you may have, and the kind of resources that are available to you.

Self-management and the journey of recovery

We've talked about self-management as involving knowledge, skills, and attitudes. We've also talked about it as something that involves a set of tools — hence the idea of the toolkit. There's one other thing we'd like you to keep in mind, as we conclude this module, which is that no matter what diagnosis or diagnoses you may have, self-management is part of your journey of recovery.

Recovery has been defined as being control of your disorder, rather than having the disorder control you, and is a similar concept to self-management. But for the purposes of this toolkit, we'd like you to think about self-management as the set of tools that will help you on the journey to recovery. We wish you well on that journey. Now let's start taking the first steps.

PSYCHOEDUCATION: MAKING SENSE OF YOUR DISORDER

What is psychoeducation?

Psychoeducation in simple terms is the process of learning the basics about mental disorders, and learning the specifics of your own mental disorder. A part of this involves understanding general information about mental disorders and what causes or contributes to them. It also involves learning about your particular diagnosis, the symptoms that go along with it, and the impacts that the disorder and its symptoms may have on your life. Finally, psychoeducation involves learning about the different kinds of treatments and resources that may help you deal with the unique challenges that your disorder presents.

Learning about your disorder is a gradual process, as there is only so much information you can digest at once. It is best to consider the information in stages, ranging from the more basic and general, to the more specific and complex material. This module is designed to help you consider information about your disorder on a step-by-step basis. First, we will provide you with some general information about mental disorders and their various treatments, and then — by referring to other available resources — focus on helping you access high-quality information that is more detailed and relevant to your own situation.

Psychoeducation and making sense of your disorder

Psychoeducation is sometimes referred to simply as education; however, it is not just about taking in information, and learning facts about your particular disorder. More importantly, it is about helping you *make sense* of what has happened to you, and begin to make sense of experiences that may have been extremely puzzling or distressful for you. It is also a way to start gaining a sense of control over your disorder, and for finding hope that you will be able to live a healthy life with that disorder. And finally, psychoeducation should be about helping you to maintain your self-esteem, and to identify yourself not just in terms of your diagnosis — such as “a depressive,” an “obsessive-compulsive,” a “schizophrenic,” or an “anorexic” — but first and foremost as a person, who also happens to have a disorder.

Key messages in this module

- Psychoeducation involves learning “the basics” about mental disorders and about *your* disorder, on a step-by-step basis, ranging from general information to more specific practical information
- Information can come from different sources, including material of a more scientific variety, and from the experiences of others who have mental disorders
- It is about more than facts: it is about *making sense* of your disorder and what it means to your life
- It is also about achieving a sense of control over your disorder and building hope you can live successfully with your disorder
- Psychoeducation is a key building block to finding treatment options that work best for you, and to preventing relapses of your disorder (the topics of Modules Three and Four)

Deciding on your preferred learning style

As you learn more about your disorder, and delve into some of the resources recommended throughout this toolkit, you should consider your own preferred learning style; that is, whether you would prefer reading, or whether using additional formats — such as watching videos or listening to tapes — would help you learn better. It may be helpful to take in information using all of these channels, as that may help you remember and understand the material better. There are many different types of materials out there, and many different media that are available. So you should be able to find a way of learning that is flexible to your needs and preferences.

Knowledge as a building block

As we talked about in the last module, information is the foundation for building skills, and for applying them in your own situation. It is also the building block for the other modules in the toolkit; that is, on how to participate with your doctor or other health professionals in the decisions about your treatment (Module Three: Shared Decision-Making); on how to learn how to recognize and deal with the early warning signs of a potential relapse (Module Four: Part A: Developing an Early Warning System); and how to develop a plan that puts the material from all the modules together into an ongoing strategy for staying well (Module Four: Part B: Setting up an Action Plan).

Where do I find the kind of information I need and that I can trust?

Evidence-based information

Psychoeducation often starts within the relationship between you and your mental health professional, but it also can occur in other ways and from other sources. You can find a wealth of information in all sorts of places in addition to this toolkit: in your doctor’s office, at mental health centres, from provincial or local mental health agencies, from the local library or on the Internet. What many people find especially helpful is to learn from someone who has been through a similar situation, and has found successful ways of dealing with their disorder. This may be within a support group, through personal contact with a “peer mentor,” or with someone else you meet who happens to share a similar experience. You can also learn from personal stories that are collected in book format, or that may be posted on Internet websites or available in audiovisual format.

Whether you are looking for this kind of experiential information about your disorder, or information of a more scientific variety, your challenge is to find information that is accurate, or “evidence-based,” hopeful in tone, and applicable to your situation. As we noted, this toolkit is designed to give you the basics of what you need to know, and to help you to dig deeper and find valuable, accurate information that you can use to deal with your situation, in a format that meets your own needs and preferences.

Understanding mental disorders

What is a mental disorder?

Mental disorders (also known as mental illnesses) refer to a number of health conditions that affect an individual's emotions, thoughts and behaviours. Without intervention, they may prevent the individual from functioning effectively in their day-to-day life, and may even interfere with the person's connection to reality. They are conditions that, especially with early, appropriate intervention, can be managed effectively.

We sometimes speak about mental disorders and "mental health" as if they were opposites, and as if a mental disorder and a "mental health problem" were the same thing. But mental health is *not* the opposite of mental disorder. Generally speaking, having positive mental health means that you are able to meet the challenges of your daily life or that your personal resources are in balance with the demands of your environment. Having a mental disorder may make it harder for you to achieve this balance, but with the right kind of support, a person with mental disorder *can* be mentally healthy.

What are the causes and contributors to a mental disorder?

In broad terms, mental disorders generally involve an interaction between biological and environmental factors. For certain disorders, like schizophrenia and bipolar disorder, evidence suggests that the conditions are caused by an underlying neurological (brain-related) vulnerability, and may be brought out by factors in the individual's environment, or by substance use problems. While research on the role of genetics in mental disorder is ongoing, there is strong evidence for a genetic component to these two disorders in particular. This means they may appear over time in certain families, even when environmental factors aren't significant. Research is also emerging around the biology of depression and anxiety disorders.

Depending on the disorder in question, and on the individual's history, environmental influences may play an increased role in contributing to mental disorder. For example, research points to influences such as stressors and/or adverse circumstances in an individual's environment. For disorders such as depression and anxiety disorders, research also points to the role of learned patterns of thinking, behaviour or emotional response to situations. This includes learning that takes place in social situations, known as "modeling."

This overall framework of an interaction between environmental and biological factors is important to keep in mind, as it suggests different ways that you can develop some control over your disorder, regardless of the diagnosis. This is because some of the factors (or stressors) that may have contributed to bringing on your disorder in the first place may also act as contributors to relapse. As we'll discuss later on, you can develop strategies to deal more effectively with stress, and to identify and minimize the impact of other environmental influences that may otherwise lead to relapse. You can also make yourself less vulnerable to the biological aspects of your disorder by playing an active role in deciding on and following through on a treatment plan, and by avoiding substance use problems.

What are the common kinds of mental disorder diagnoses and what are some common forms they take?

The common categories or diagnoses of mental illness or mental disorder include:

- **Anxiety disorders** are the experience of an unusual degree of fearfulness or worry and are often accompanied by avoidance behaviours that can interfere with work, home, school and personal relationships. There are several different types of anxiety disorders, including:
 - *generalized anxiety disorder*: excessive and uncontrollable worry about more than one aspect of daily life
 - *social anxiety disorder or social phobia*: excessive fear of being judged or negatively evaluated by others
 - *agoraphobia*: excessive fear of experiencing symptoms of anxiety in situations where escape or access to help may be unavailable. *Phobias*, more broadly, are overwhelming fears in response to specific objects or situations
 - *panic disorder*: multiple, unexpected panic attacks and excessive fear of experiencing a future panic attack, that is, a sudden rush of intense anxiety symptoms that reach their peak within a few minutes
 - *obsessive-compulsive disorder*: repetitive actions are used to cope with recurring, unwanted thoughts
 - *post-traumatic stress disorder*: past traumatic experiences continue to cause excessive anxiety, intrusive memories, avoidance behaviours and other related symptoms, months or years after the event
- **Eating disorders** involve distorted body images that make it difficult for people to nourish themselves in a healthy way; these include:
 - *anorexia nervosa*: dramatic weight loss combined with an intense fear of gaining weight
 - *bulimia nervosa*: bouts of uncontrollable eating followed by vomiting or other forms of purging
 - *compulsive eating or "binge eating disorder"*: periodic episodes of controlled eating or bingeing
- **Mood disorders**, also known as affective disorders, affect how people feel and think about themselves, other people and life in general:
 - *depression* involves depressed mood, negative distortions of reality, and physical symptoms; subtypes include:
 - *seasonal affective disorder or SAD*: depression that comes on or is worsened by periods of dark weather occurring in winter months; occasionally also appears in summer months
 - *postpartum depression*: depression that is brought on or worsened by childbirth; very occasionally this can involve psychosis, or loss of contact with reality
 - *dysthymia*: less severe symptoms of depression that are ongoing
 - *psychotic depression*: depression involving loss of contact with reality
 - *bipolar disorder*: also known as manic depression, involves periods of intense activity, elation, grandiose thinking or behaviour, followed by periods of depression; subtypes of bipolar include:
 - *rapid-cycling bipolar*: mood shifts that occur in a matter of hours or a few days
 - *mixed states*: include both depression and mania at

- the same time; often includes feelings of agitation
- *suicidal behaviour or thinking*
- **Personality disorders** involve patterns of thinking, mood, social interaction and impulsiveness that cause distress to those experiencing them and others; may be associated with past trauma; a few subtypes include:
 - *borderline personality disorder*: difficulty maintaining positive relationships and dealing with often-intense moods
 - *paranoid personality disorder*: overwhelming distrust and suspiciousness of others
 - *antisocial personality disorder*: impulsive behaviour, aggression and violation of rights of others
- **Schizophrenia spectrum disorders** involve changes in the chemistry and structure of the brain, which may cause “negative symptoms” such as lethargy, “positive symptoms” such as hallucinations (e.g. hearing voices that aren’t real) and delusions (e.g. having supernatural powers), cognitive difficulties (e.g. problems with memory and concentration); and disorganized thinking (confused thoughts or jumbled speech). These disorders are not the same as multiple personality disorder, now called dissociative disorder, and include:
 - *schizophrenia*
 - *schizoaffective disorder*: the term used when the symptoms above are experienced along with significant disruptions in the person’s mood
- **Substance use problems disorders or addictions** are terms used in reference to people who use alcohol and/or legal and illegal drugs inappropriately, leading to significant social, occupational and medical problems.

Any of these disorders may appear alone or in combination (known as “concurrent disorders,” or you may also hear the terms “comorbid disorders,” or when only two disorders are present, “dual diagnosis.”). For instance, mental disorder and concurrent substance use is a very common example, as nearly 50 % of people with one mental disorder will also deal with problem substance use at some time or another. Depression and anxiety disorders are two conditions that also frequently go hand in hand.

Schizophrenia and some other mental disorders are sometimes spoken of using the term “psychosis.” While schizophrenia itself in its untreated form often involves a loss of contact with reality — the key component of psychosis — conditions such as depression and manic depression may also involve psychosis. The term “early psychosis” is used to describe a young person who has had an experience or “episode” involving psychosis, but who does not have a firm diagnosis.

If you have never sought help and you suspect that something is wrong, then you should seriously consider seeking out a mental health professional. The next sections of the module address the questions: how do I know if I need help? how do I find the help I need? what treatment and support is available? and who are the various types of mental health professionals?

Many of you will have already sought out help. For you, the important issues may be finding out more about your disorder, whether you are getting the kind of help you need, or whether this is working as well as it should be. We’ll address these questions later in this module starting on page 15. If this is the case for you, please skip ahead to the relevant sections.

How do I know if I need help?

In order to decide if you need help, there are a number of steps you can take. The first thing you can do is to become familiar with the signs of mental disorders. After considering the general descriptions of the various mental disorders in the previous sections, you may want to find more specific information about a certain condition and its early signs.

One option is to do a self-test, to evaluate whether you are experiencing the early signs of a particular disorder. Doing a self-test is not a substitute for receiving a diagnosis from a professional. However, it can help you understand if a particular diagnosis *may* apply to you, and help you take the next step to seek out a mental health professional for a thorough assessment. To access a self-test for anxiety disorders or depression, see the Anxiety Disorders Toolkit or the Depression Toolkit at www.heretohelp.bc.ca. The Addiction Toolkit also on this site will help you see if you have a substance use problem. Some warning signs of eating disorders can be found in the eating disorders section at this same website.

Here are some signs that you might be experiencing the early signs of psychosis, which may be related to disorders such as schizophrenia, bipolar disorder or psychotic depression:

- having unusual ideas or behaviours
- hearing voices that aren’t real (though they may *feel* real)
- feeling “changed” in some way
- withdrawing and losing interest in your usual activities
- losing energy or motivation
- becoming speeded up in your thinking or activities
- having problems with memory or concentration
- experiencing a deterioration in your ability to function at work or school, or in your normal role
- lack of emotional response, or having emotional responses that aren’t appropriate to the situation
- having problems with your sleep or your appetite

The signs of psychosis and other mental disorders may be similar to normal responses that anyone might have when they are confronted with difficult situations or events or symptoms of other physical conditions. However, if the signs are persistent, and if they are causing you significant disruption — or are worrying to the others around you — then you need to seek help. Seeking out help also helps rule out other explanations for the symptoms.

How do I find the help I need?

Most communities, especially cities and large towns, have a number of different options for seeking help:

- If you are in a crisis, you can call the local crisis hotline listed in the front inside cover of your phone book
- For information about the local crisis response or emergency mental health team in your area, or about other options, call the BC Mental Health Information Line at 1 800 661 2121 or 604 669 7600, or the BC Health Guide Nurse Line 1 866 215 4700 or 604 215 4700
- If you feel desperate or suicidal and need help immediately, you can phone or go to the emergency department of your local hospital

- See the blue pages of your telephone book under your local health authority for the phone number of the nearest mental health centre, or for the community service referral agency in your area
- Ask for your family doctor to help you find the professional help you need. First, he or she should start by giving you a thorough physical check-up to rule out an underlying medical cause to your symptoms
- For general information and advice about how to access the help you need, call one of the various provincial mental health agencies listed on page 41.

What treatment and support is available?

The appropriate combination of treatment and support varies according to the disorder and the individual. The following is a general outline of the types of treatment and supports that are available, and which are known to be effective for dealing with mental disorder. (For more specific information about evidence-based care for your diagnosis, see the section later in this module on Consumer and Family-Oriented Treatment and Recovery Guides.) The main alternatives include:

- **Medications**, including:
 - *antidepressants* for depression, certain types are sometimes also prescribed for other conditions, such as anxiety disorders.
 - *mood stabilizers* for bipolar disorder or unipolar depression
 - *anti-anxiety medications* including *minor tranquilizers* are used only for some anxiety disorders, where they are not recommended as a first-line treatment or for long-term use
 - *major tranquilizers* or *antipsychotics* (neuroleptics) for schizophrenia or other disorders where psychosis is present
 - for more information, including questions to ask your doctor, see *Medications*, published by the National Institute of Mental Health (US), and available online at www.nimh.nih.gov/publicat/medicate.cfm
- **Psychotherapy**, including:
 - *cognitive-behavioural therapy* (CBT): there are a number of variations of CBT that exist; in general, they help the person identify and manage disruptive thoughts, emotions and behaviours; can be effective by itself or in combination with medication, depending on the disorder and its stage or severity
 - *interpersonal therapy* helps the person develop specific skills in managing relationships such as assertiveness training or adjusting to transitions
 - *problem-solving therapy* uses a structured approach to identify and actively solve problems that contribute to depression or other mental disorders
 - *motivational interviewing* helps the person with the problem identify and achieve goals, especially related to lifestyle changes such as abstinence or dietary changes; used in treatment of substance use disorders, and also for depression
 - *supportive psychotherapy* where the therapist helps a person to understand and deal with problems and emotions through active listening and empathy
- for more about psychotherapy and how it works, and about cognitive-behavioural therapy (CBT), see www.changeways.com
- **Rehabilitation**, sometimes known as skills training, is effective for people with disorders like schizophrenia and bipolar disorder that are associated with cognitive difficulties, or with difficulty functioning in certain settings like jobs, school or housing situations. The approach helps individuals build strengths, modify settings, or develop accommodation strategies that help the person successfully function in roles or settings that are important to them. For more about rehabilitation, see www.bu.edu/cpr
- **Other Treatments**
 - *phototherapy*, commonly known as light therapy; research has shown that many patients with seasonal affective disorder (SAD) — clinical depression only during autumn and winter seasons — improve with light therapy which is exposure to bright, artificial light for as little as 30 minutes per day. Light therapy leads to significant improvement in 60% to 70% of SAD patients. For more information, visit the Society for Light Treatment and Biological Rhythms at www.sltr.org. Phototherapy is also being investigated for other kinds of depression.
 - *electroconvulsive therapy* (ECT) is available and effective under certain circumstances such as for suicidal depression that has not responded to other treatments. For more information about when ECT may be considered, see *Electroconvulsive Therapy: Guidelines for Health Authorities*, published by Mheccu, and available by going to www.mheccu.ubc.ca/publications
 - *alternative treatments* is a term used for a number of treatments that range from promising practices with some evidence for effectiveness, or which are effective in certain circumstances — for example, St. John's Wort for minor and moderate depression — to treatments that show little evidence for effectiveness, or which have not been studied enough to draw conclusions. For more information about alternative treatments and how to evaluate whether they may be appropriate for you, see some of the resources available on our website at www.heretohelp.bc.ca
- **Community Resources:** people whose disorders seriously affect their functioning on an ongoing basis may benefit from resources such as:
 - supported housing
 - supported employment (see Rehabilitation)
 - income supports (such as the Canada Pension Plan Disability Pension, or the provincial Disability Benefits Program)
 - self-help groups (available for many conditions)
 - information and resources in assisting in finding an appropriate support group and accessing other community resources are discussed further in Module Five

Who are the various types of mental health professionals?

There are a number of different types of mental health professionals, who may work in private practice, out of a publicly-funded mental health centre (also known as a mental health team in some communities), on a psychiatric inpatient ward, or within

a hospital outpatient program (day program or clinic) basis. The main types of mental health professionals are:

- **Family doctor:** has general training in medicine, though many may have a fair degree of specific experience in dealing with mental disorders; often the first step in accessing the mental health system and referral on to more specialized or intensive resources; usually works in private practice, though may also work within the formal mental health system; can prescribe medication and provide psychotherapy though counselling can be limited; may have some training in evidence-based psychotherapy
- **Psychiatrist:** a medical doctor with specialized training in psychiatry who is able to prescribe medications and provide psychotherapy, and who may be trained in evidence-based therapies such as CBT, interpersonal therapy, or motivational interviewing; may work in private practice, within the hospital system, or as part of a mental health centre or team.
- **Nurses:** Registered Nurses are medically trained care-givers employed throughout the mental health system, including on the hospital ward or within a mental health centre or team; they provide a wide variety of functions, including medication monitoring; Registered Psychiatric Nurses are educated specifically to take care of people with mental disorders, and work especially within hospital and mental health centre settings
- **Social Worker:** can have either a Bachelor's (BSW) or Masters degree (MSW); trained to assess, refer or provide counselling to people with mental disorder or difficulties with everyday living; often provide a "case manager" function within the mental health centre or team setting, providing counselling and helping people with serious, ongoing mental disorders such as schizophrenia and bipolar disorder solve problems and link with needed resources on a day-to-day basis; some also provide counselling to people with a range of mental health concerns on a fee-for-service basis, or to people covered by private insurance plans
- **Occupational Therapist:** university-trained professional who often works within mental health team setting to provide rehabilitation and help people improve their functioning in valued roles and settings
- **Registered Psychologist:** has a PhD in Clinical Psychology and can provide diagnosis and evidence-based psychotherapy, but does not prescribe medication; not covered by Medical Services Plan, but may be partially covered through private insurance plans
- **Registered Clinical Counsellor:** addresses clinical mental health issues through assessment, prevention, therapy and intervention; has a Masters degree or equivalent, usually in Counselling Psychology
- **Employee Assistance Plan (EAP) Professional:** may have various forms of training; provide counseling to employees with mental health concerns through workplace benefits plans

Finding information about your own diagnosis

A number of resources exist that can help you move beyond a basic level of understanding about mental disorders in general, and help you move towards a basic understanding of the diagnosis (or diagnoses) that may apply to *you*. Diagnosis-specific fact sheets in *The Primer*, produced by the BC Partners for Mental Health and Addictions Information at www.heretohelp.bc.ca offer more detail about the symptoms associated with specific disorders, and about the impacts of each diagnosis. Other diagnosis-specific information is also available from the BC Partners such as toolkits for anxiety disorders, depression, or addictions. All of these resources and additional information can be found by contacting any of the member agencies directly (contact information listed on page 39).

Other reliable evidence-based diagnosis-specific information is available that describes the various disorders, and that also describes the medications (and any side effects) that are used to treat each. Later on in the module, we'll discuss how to find more detailed information about the treatment options relevant to your own diagnosis.

- The Mental Health Information Line at 1800 661 2121 or 604 669 7600
- BC Health Guide Online at www.bchealthguide.org
- Internet Mental Health at www.mentalhealth.com. An exhaustive source of information about all mental disorders and their respective treatments; includes self-tests, as well as stories of recovery related to most disorders
- Multicultural Mental Health Australia which has translated brochures on mental disorders and mental health topics at www.mmha.org.au/library/brochures/brochures.html
- PsychDIRECT at www.psychdirect.com. Focuses on anxiety disorders, depression and other mood disorders (including depression in women, adolescents and seniors); early psychosis and women's mental health issues.
- Dual Diagnosis Pamphlet and Workbook Series, from the Dual Diagnosis Recovery Network (U.S.), produced by Hazelden, features material on understanding all the major mental disorders and their relationship to addiction. See www.dualdiagnosis.org

Moving towards a more thorough understanding of your disorder:

The initial diagnosis and beyond

You will probably find that once you have been given a diagnosis, and even after you have considered some basic information about the diagnosis, that this is not enough: either because you'd like to know more, or because the initial information has been confusing to you. Although for some people receiving a diagnosis and some basic information is a relief, for others, this can be extremely upsetting. It also might leave them puzzled, because they don't know how it applies to them, or it might conflict with their own ideas about what is going on, or with other information they've been given in the past.

Emotional reactions to the initial diagnosis

For some people, receiving a diagnosis in and of itself is a huge relief, because it offers an explanation for all the struggles they have been going through, and because it offers hope that something can be done. People who view the diagnosis as helpful are more likely to have had information about their disorder explained in a thorough, sensitive manner and to have been given practical information about what can be done and about other resources or interventions that may help.

For others, though, the diagnosis comes as a shock, because they see it as something that is highly stigmatizing, or believe that it means that their life as they know it is going to come to an end. Still others are somewhere in the middle: they are not quite sure what to make of the diagnosis, and they have trouble seeing just what it means, and how it applies to them. A final group of people may not receive a diagnosis, because it may be too early to know, which may lead to confusion or anxiety in some individuals who wish to know more about their situation and what they can do about it.

Making sense of different or conflicting diagnoses

Another potential challenge with making sense of a diagnosis is that you may have been given conflicting information about your diagnosis by different professionals, or by the person who has been treating you over time. If you are in either of these situations, you need to remember that many people *do* have more than one diagnosis, and that diagnoses may change over time, so there may in fact be more than one diagnosis that applies to you, at one time or another. It might also be that your doctor or other professional hasn't arrived at the correct diagnosis because he or she has not been able to take note of all the relevant symptoms that you are experiencing. Because of this, it is critical that you — with the help if someone close to you if necessary — are able to communicate the impact of your disorder to your doctor so that he or she has the full picture. Being able to do this is a skill discussed in the next module.

When the diagnosis doesn't fit your definition of the problem

For some people, the diagnosis they receive does not seem to fit with their own ideas of what the problem is. In some cases, this may be because they have been incorrectly diagnosed. For others though, despite the best efforts of all concerned to arrive at an accurate diagnosis, it just doesn't seem to fit. During the early stages of a disorder, and prior to receiving a diagnosis, many people develop their own interpretations of what's happening to them. For instance, they may interpret early signs of schizophrenia — such as depression and withdrawal — as just “being tired.” Or they might interpret the early phases of a manic episode — which are often a period of creativity — as meaning that they simply are “very productive people.” They might interpret the signs of a panic attack as meaning that they are having heart problems. Not only do people themselves develop such explanations, but these may have also been reinforced by their family members, or by members of whatever community or culture to which they belong.

Whatever the case, it can take a while to work through and accept a new explanation of what's going on, especially when a mental disorder diagnosis may be stigmatizing and threatening, and seen as a kind of a “life sentence”. Some people never become entirely comfortable with the terminology or explanations they are offered for their experience. For example, they may prefer the term “emotional vulnerability” (rather than mental disorder) to apply to their condition, or they may see their experience as being spiritual in nature rather than entirely disorder-related. If this is this case, the essential question to ask yourself is whether your definition works, that is regardless of what you choose to call it and whether you understand and are able to manage your condition in a way that allows you to live a healthy life in the community.

Going beyond the initial diagnosis

What you need to know

When you receive a diagnosis, of course you also need information about the disorder itself, such as what symptoms are involved. Beyond these basics, you also need to know about the various impacts the disorder might have on your life, and about the treatment and support alternatives available to you. Finally, you need to know what to expect about when you should be feeling better, and what kinds of things may speed up your journey on the road to self-management and recovery.

Receiving a diagnosis should be a starting point for learning more about your disorder and how to deal with it successfully. If you don't know what the diagnosis means, you need to find out more by asking questions and gathering more information. If you see a diagnosis as a life sentence, you need to know that this is not the case. Many people in similar situations *have* learned to deal successfully with similar conditions, and you need to find out more about their stories. You can do this by investigating the stories of recovery that are listed at the end of this module.

And if you are not sure how the diagnosis applies to you, then you need to find more specific information by asking or by exploring the resources that are suggested in this module. This will help you consider and decide for yourself whether the information about a particular diagnosis fits your situation.

When it's too soon for a diagnosis

Finally, if you are someone who hasn't yet received a diagnosis, you can still learn more about the specific symptoms that you experience and how to deal with them. For example, if you are a young person who has experienced psychosis, there is a fair amount of material that will help you understand what this means, and how to deal with your situation. Some information and resources related to early psychosis are listed below:

- Early Psychosis Information Sheets from the Early Psychosis Prevention and Intervention Centre in Australia (available in several languages) at www.eppic.org.au/infosheets.html
- HOPE (Helping Overcome Psychosis Early), the website of the Vancouver Coastal Health Authority's Early Psychosis Program, with information available in Chinese and Punjabi, at www.hopevancouver.com
- Psychosis Sucks, the website of the Early Psychosis Intervention Program of the Fraser Health Authority at www.psychosissucks.ca

Whatever the case, again you need to remember that the diagnosis is only a starting point. Along with the diagnosis, you need *hope* that you can learn to successfully manage the impact of the disorder on your life. Hope can be gained through the inspiration from the stories of others in similar situations who have learned to cope successfully with their disorder. Hope goes hand in hand with finding practical information about your disorder and ways you can deal with it. Hope also comes through your personal relationships with family and friends, especially by finding someone who believes in you.

With that in mind, the rest of this module outlines some resources that offer more detailed information about treatment alternatives, and about strategies for coping. The section immediately following outlines material known as Consumer-Oriented Treatment Guides. At the end of the module, we'll introduce you to some resources that further describe the idea of recovery from mental disorders, and that can help guide your own recovery.

Consumer (and family)-oriented treatment guidelines

Consumer-Oriented Treatment Guidelines contain comprehensive information about a particular disorder, its impact, and the various evidence-based alternatives that exist for the management of that condition. These are usually plain-language versions of guidelines that were initially created for health professionals, based on the best available evidence (or when experimental evidence is lacking, based on the consensus of the experts on the topic in question, based on their clinical experience). These are excellent resources for obtaining a more thorough understanding of your disorder, and for considering decisions about what basic treatment and support options are right for you.

The following is a list of evidence-based and consensus-based guides designed to help consumers and families understand more about the disorder and the various treatment options — including biological as well as psychosocial options — sorted into the different types of mental disorders.

Anxiety disorders

- *Expert Consensus Treatment Guidelines: A Guide for Patients and Families*, go to www.psychguides.com available for
 - Obsessive-compulsive disorder
 - Post-traumatic stress disorder
- BC Partners Anxiety Disorders Toolkit at www.heretohelp.bc.ca

Bipolar disorder (manic depression)

- *Expert Consensus Treatment Guidelines on Bipolar Illness: A Guide for Patients and Families*: go to www.psychguides.com
- *Bipolar Affective Disorder: A Guide to Recovery* (from the Alberta-based Organization for Bipolar Affective Disorders): go to www.obad.ca

Depression

- *Expert Consensus Treatment Guidelines for Depression: A Guide for Patients and Families*: go to www.psychguides.com — includes patient and family guides on the topics of:
 - Depression in older adults
 - Treatment of depression in women, including separate guides for premenstrual dysphoric disorder, major depression during conception and pregnancy, postpartum depression, and depression during the transition to menopause. Also see www.bcrmh.com, the website of the BC Reproductive Mental Health Program.
- PsychDIRECT Guides: go to www.psyhdirect.com — includes treatment guides on depression in women, adolescents and seniors
- BC Partners for Mental Health and Addictions Information Depression Toolkit at www.heretohelp.bc.ca

Eating disorders

- *Handbook of Treatment for Eating Disorders*, D.M. Garner & P. Garfinkel (Eds.) (1997). 2nd edition. Guilford Press.
- *Eating Disorders* (Seminar) published by *The Lancet*, Vol. 361 (February 2003). See www.thelancet.com

Personality disorders

- *New Hope for People with Borderline Personality Disorder: Your Friendly, Authoritative Guide to the Latest in Traditional and Complementary Solutions* (2002), N.R. Bockian et al. Prima Publishing.
- See www.mentalhealth.com for more information on other personality disorders.

Schizophrenia

- National Institute for Clinical Excellence, clinical guidelines for schizophrenia produced by the UK's National Health Service: www.nice.org.uk/pdf/CG1NICEguideline.pdf
- *Expert Consensus Treatment Guidelines for Schizophrenia: A Guide for Patients and Families*: go to www.psychguides.com
- *Dealing with Cognitive Dysfunction: A Handbook for Families and Friends of Individuals with Psychiatric Disorders* (2002), New York State Office of Mental Health. Also useful for mental health consumers. To download, go to: www.omh.state.ny.us/omhweb/resources

Early psychosis

- *Early Psychosis: A Care Guide* (2002), Mental Health Evaluation and Community Consultation Unit, University of British Columbia. See www.mheccu.ubc.ca/publications
- *Psychosocial Aspects of Recovery from Early Psychosis Fact Sheets* (2002), Canadian Mental Health Association, BC Division; topics include engagement in care, psychoeducation, and community integration. Go to www.cmha-bc.org to order

Resources featuring treatment guidelines for all mental disorders (including addictions)

- The National Electronic Library for Mental Health (of the National Health Services, UK): go to: www.nelmh.org
- Internet Mental Health: go to www.mentalhealth.com

Recovery-oriented information and resources

So far in this module, we've talked about the basics of mental disorders, moved on to talk about how to understand the basics of your own disorder, and then discussed how to access more specific information that describes the different alternatives to deal with the impact of your disorder. Before we go on to consider how to apply this information to your situation, there is one final source of valuable information to consider. This is material that describes the idea of recovery, and talks about how to achieve it.

Recovery can be looked at in different ways, both as a journey and as a destination. The word itself suggests a cure, but as we talked about in Module One, most people who are in recovery talk about it in terms of having control over their symptoms, so that they are able to live their life without the disorder constantly getting in the way. Research that looks at the recovery journey has found that there are similar patterns to the way recovery happens. This research also shows that despite these similarities, the process is unique to each individual, and may occur slowly, and in fits and starts. And even though you might have to be patient, especially in the first months or even years of your recovery, the important part to remember is that it *does* happen, and there are things you can do, and that others can help you with, that can speed your recovery journey along.

The other thing to realize is that there is a lot of material out there that designed to help you learn how to live successfully *with* your disorder, much of it based on the experiences of others who have been in similar situations to your own. The resources listed below contain two types of material: general advice and strategies based on the experiences of a number of individuals; and second, specific stories of coping and recovery.

While reading through individual stories you need to remember that the experiences and perspectives may not apply to you. Ideally, you need to find stories from people whose disorder and personal situation matches your own. To get a full picture, you then need to consider the “experiential” material together with the other kinds of information listed in this module. The listings below feature print-based or audio-visual resources where you can access a range of stories and experiences, from a range of mental disorders.

Recovery-oriented resources

- *The Recovery Workbook: Practical Coping and Empowerment Strategies for People with Psychiatric Disability* (1994), L. Spaniol, M. Koehler, and D. Hutchinson
- *The Experience of Recovery* (1994), Spaniol et als. (Eds.), features numerous case studies of coping and recovery. Can be used together with the *Recovery Workbook*. For ordering information on both titles published by the Center for Psychiatric Rehabilitation, see www.bu.edu/cpr/catalog/books
- *Recovery as a Journey of the Heart*, video by Patricia Deegan. For ordering information, see www.bu.edu/cpr
- *Reaching Out*, a video on the importance of early psychosis intervention, using the experiences of four individu-

als; produced by British Columbia Schizophrenia Society. To order, see www.bcscs.org

- *Consumer Empowerment and Recovery from Mental Disorder* (2001), video produced by Canadian Mental Health Association, BC Division
- *Storm Breaking*, CMHA BC Division, an anthology of first experiences with mental disorder, seeking help from the mental health system and achieving recovery. See www.cmha-bc.org
- *From Grief to Action*, an award-winning video, documenting one family's experience with addiction and mental disorders. See www.fromgriefftoaction.org
- *Strategies for Living: A Report of User-led Research into People's Strategies for Living with Mental Distress* (2000), U.K. Mental Health Foundation. For ordering information, see www.mentalhealth.org.uk and click on “Publications”
- *The Last Taboo* (2000), S. Simmie and J. Nunes
- *Beyond Crazy*, (2002), J. Nunes and S. Simmie. McLelland & Stewart. Both books by these authors feature case studies of the major mental disorders as well as information about how to access effective help
- For stories relating to all the major mental disorders, see www.mentalhealth.com; also see the websites of the various provincial mental health agencies listed in Module Five.

Moving on: applying knowledge to your own situation

Once you have had a chance to consider the information that we've talked about in this module and put some of the different types of information together, you are ready to go on to consider how to apply this knowledge in your own situation. The next module of this toolkit looks at how you can use your knowledge to develop the skills to play an active role in deciding on your treatment and support plan. The module after that will then consider how to use your knowledge to develop skills and strategies to maintain your health on a day-to-day basis, outside of your doctor's office.

MODULE THREE BECOMING AN ACTIVE PARTNER IN TREATMENT: SHARED DECISION-MAKING

Introduction

In the last module, we talked about how to find out information about mental disorders and how to begin learning about *your* mental disorder. The knowledge you have gained is the foundation for playing an active role in making decisions about what kinds of treatments will work *for you*, which is the topic of the present module.

Through this active involvement, you can make sure your health professional is aware of what you want to get out of your care, and also about what fears or concerns you might have about any treatment and support options recommended for your mental disorder. In general, the more involved you can become, the greater the chances that you will be satisfied with the treatment and its effectiveness in minimizing your symptoms and the impacts these have on your life.

What does playing an active role mean?

Playing an active role in your treatment means that you need to be able to communicate clearly to your doctor or other health professional in an informed way about what you think the problem is, about how it affects your daily life, and about what you expect to get out of treatment. This then puts you in a strong position to share in the key decisions about your treatment plan or strategy. Once you have developed an initial strategy, your next role is to help monitor whether it is successful. For example, once you make an initial decision to try a particular medication, you then need to be able to monitor whether in fact the medication is working as well as it should.

To take on this role, you need some benchmarks to measure success. For example, you need to know what to expect about how long the medication or other treatment will take before it works, and about what level of recovery it should bring. You also need a clear idea about what impact you hope the approach will have on your day-to-day life, so that you can measure success against these expectations.

Once you've got an idea about what you hope to achieve, you then need to be able to report on what's been happening between visits at your next appointment; and then, if necessary, you'll have to be able to negotiate some adjustments in the medication, or even a different medication or treatment

Key messages of module

- Playing an active role in your treatment can make you more satisfied with the results of the strategies you and your mental health professional choose to adopt
- Being active means being able to communicate and negotiate with your health professional about your expectations
- When you make a decision about your treatment plan, you need to reflect on a number of things: reliable information about the risks and benefits of potential treatment options, your own values and attitudes, and the experiences of others similar to you who have tried the options you are considering
- Playing an active role also means being able to monitor whether your treatment plan is working on a day-to-day basis, and being able to negotiate an adjustment to the strategy if necessary
- Once you've found an approach that works, you should follow through on your plan

approach altogether. It may take a while to find the approach or combination of approaches that works best for you. But taking an active role in this process will make you feel more like you're in the driver's seat, and less like a guinea pig.

Your ability to be active in this way may be different from other people — who may prefer more or less direct involvement in their care — and it may vary depending on what stage of the disorder you are currently in, or whether you have been recently diagnosed or have a fair amount of experience with your disorder. Regardless of your preferred level of involvement, you *do* need to be involved to some degree.

What resources do I need to play an active role in the decision-making process?

The process of active participation or “shared decision making” involves a series of steps that will eventually result in your individualized treatment plan. The steps are:

- 1) **problem definition:** also known as assessment, where your role is to explain the problem in your own terms
- 2) **goal-setting:** deciding what the goals of treatment will be, or deciding what you want to happen as a result of treatment
- 3) **decision-making:** developing and deciding on treatment strategies, which balance the advice of your mental health professional with your own expectations and priorities for treatment
- 4) **monitoring:** evaluating whether the strategies work properly, and if necessary reassessing the approach.

In the rest of this module, we'll look at the resources, skills and tools that will help you as you work through each of the stages.

Stage one: problem definition

When you first go to see a mental health professional, he or she will sit down with you to assess the problem. Your job at this stage is to do as much as you can to make sure that the doctor has the full picture of what's going on. So you need to be able to describe in your own words just what has happened to you, the kinds of problems you've experienced, and about what's happened with any other treatment approaches you've tried in the past.

Depending on the amount of experience you've had, or on the amount of knowledge you've gained about your condition in the past — or by working through Module 2 — you may or may not also be able to express your experience in terms of specific symptoms, or in relation to a particular diagnosis. Regardless of what you think the diagnosis may be, at this stage it is especially important to be able to think about how the mental health problem *impacts* you — that is, affects your emotions, thoughts, behaviours and the roles and relationships that you carry on in your daily life.

Then, after you've had a chance to reflect, talk to others and to do some relevant learning, you need to prepare for your visit to the health professional by writing down a brief, clear description of your problem in your own words, so that when you go to a health professional and ask for help, you can express your concerns as clearly as possible.

Tips for talking with your doctor or mental health professional

The average patient asks only two questions during an entire medical visit lasting an average of 15 minutes. However, studies demonstrate that patients who are actively involved in decision-making are more satisfied, have a better quality of life and have better health outcomes. Since most people's treatment path for a mental disorder begins in the family doctor's office, below are some tips for empowering yourself and starting a conversation about your mental health issue with your G.P. The material below is adapted from the Bayer Institute's PREPARE program (www.bayerinstitute.org/patient/index.htm):

- **Plan** — Think about what you want to tell your doctor or learn from your mental health professional today. Once you have a list, number the most important things.
- **Report** — When you see the doctor, tell him or her what you want to talk about during your visit.
- **Exchange Information** — Make sure you tell the doctor about what's wrong. Printing out an online screening tool, or bringing a diary you may have been keeping can help. Make sure to describe the impact your symptoms or side effects are having on your day-to-day life. Sometimes it can help to bring a friend or relative along for support and to help describe your behaviour and symptoms if you're unable to.
- **Participate** — Discuss with your doctor the different ways of handling your health problems. Make sure you understand the positive and negative features about each choice. Ask lots of questions.
- **Agree** — Be sure you and your doctor agree on a treatment plan you can live with.
- **Repeat** — Tell your doctor what you think you will need to take care of the problem.

Related resources:

- “Reclaiming Your Power During Medication Appointments with Your Psychiatrist” by Patricia Deegan, PhD at www.power2u.org/selfhep/reclaim.html
- an article about questions to ask your doctor by Mary Ellen Copeland at www.mentalhealthrecovery.com/medquestions.pdf

Stage two: goal-setting

Before you and your health professional can decide upon a treatment strategy, you need to think carefully about what you want to change. As we've just discussed, an essential part of explaining your problem to a health professional is not just talking about your symptoms or moods, but describing what impact your condition is having in your living or working environment, and on your day-to-day life. So your eventual satisfaction with your treatment strategy will depend on whether it helps you deal with these kinds of impacts. The goals you decide on should involve making change in these areas.

For instance, if you are feeling depressed, you need to be able to talk not just about your mood, but the problems that the mood might be causing in your relationships with those you care about, and the impacts it has on others who are important to you. You also need to consider the various impacts that the disorder might be having on all the various roles and settings such as school or work that are important to you, and where you spend most of your time.

At this point, you need to think carefully not just about what goals you have, but also about which goals are presently most important for you. When you consider which issues *are* priorities, you need to consider which issues you are currently ready or able to deal with. This will depend on your own personal skills and resources, and it will also depend on the resources that are available in your social support network, and from the health care system in your community. The key is to decide to deal with problems or issues that you *can* deal with presently, so that you get off on the right foot, and develop a sense of confidence.

Your sense of priorities may be different from your health professional's, so in this case you need to be able to explain what *your* priorities are, and why they are important. To take an example, imagine you are a student with agoraphobia who has trouble dealing with crowded classrooms. Your health professional suggests dealing with this issue directly by helping you build up your tolerance to crowds. However, you are preoccupied at the moment with studying for upcoming exams in the next two weeks. *Your* preferred goal then, at least temporarily, might be to arrange to write the exam in a quiet room so you can focus on studying and passing the course with a good grade. After the term ends, you can then reassess your treatment goals, and begin building up your tolerance to crowds.

When you're working these issues out, you need to be open to listening to advice from your health professional (or others in your support network), and to considering new information and perspectives that may lead you to change your ideas. The ideal situation is one where you can communicate your own concerns, listen to new information and perspectives, and then come together and agree on a strategy of which goals to address first.

Once you've decided on some issues that you feel you can realistically address, you then need to decide on some *specific* goals that you plan to achieve. For example, if you are depressed and have become socially isolated, a goal for you may be to become more socially active. At this point, it will be helpful to define for yourself in concrete terms what you'd like this to look like: for example, in the next week, you'd like to make contact with one friend who you haven't

talked to lately). Ideally a "change goal" should be described in SMART terms. That is, it should be *specific*, *measurable*, *achievable*, *realistic* and *timely*. That means you need a goal statement that says *what* you want to achieve and who's responsible, *how much* you are going to change, *by when* you're going to achieve it, and a way of measuring whether you have achieved it.

Stage three: decision-making around a treatment plan

The next step, after you've decided what you want to change, is to figure out *how* you're going to change it. In many cases, this will involve choosing a medication that is right for you, usually in combination with non-medical approaches such as counselling and, depending on your disorder, specific psychological approaches such as cognitive-behavioural therapy, interpersonal therapy or problem-solving therapy. You may also benefit from information or referral to community resources such as case management, supported housing, supported employment, and/or income support programs. Finally, you will need to decide on a self-management plan for dealing with your disorder outside the doctor's office.

Note: In the following section, we will be talking mostly about making the decision to try medication, and on finding one that is right for you. However, you can use the principles discussed to make decisions about any treatment or support alternative.

Making the decision about medication or other forms of treatment

Making a decision about starting or staying with a particular treatment involves a number of components. These include A) considering evidence about its effectiveness, B) considering your own preferences and values, and C) talking to others similar to you who have chosen the alternative you're considering. Below, we'll talk in more detail about each of these issues, so that you can be as sure as possible that the treatment strategy you decide on is the right one for you.

A) Considering "evidence"

When you consider an option for treatment, you need to know some basic facts about the treatment. When considering a particular medication, for instance, you need to find out what the medication does, how long it will take to work, its potential risks and benefits, and whether it is an appropriate choice for you. In the last module, we suggested some sources of information that will help you find out more detail about the medications that your doctor has suggested, and that you may be considering. A resource that can help you ask your doctor questions about medication can be found at www.mentalhealthrecovery.com/medquestions.pdf, by Mary Ellen Copeland.

In general, there are five questions you need to keep in mind when you consider evidence — whether this is from your mental health professional, or material you've come across on your own — to make an informed choice about a particular alternative. These are:

- **What are the intervention options?**
 - consider the assessments and treatment interventions for the condition or suspected condition
- **What are the benefits and harms of the intervention options?**
 - consider which benefits and harms might occur, and what they would look like in your life; also consider the chances that they might occur, when they might occur, and how long they would last
- **What would happen if I do nothing?**

- consider what negative outcomes would occur in this event, and how likely they are to occur
- **How do the benefits and harms weigh up for me?**
 - consider what you want to get out of the intervention, what you want to avoid, and what risks you are willing to take
- **Do I have enough information to make a choice?**
 - Consider whether you're satisfied with the information you've looked at and whether there are other treatment options you haven't considered.

For more information about these issues, see Part 5, Chapter 13 of *Smart Health Choices*, Irwig, L. www.health.usyd.edu.au/smarthealthchoices/contents.html.

As we've already mentioned, making a decision involves more than weighing information. It also involves considering your own attitudes — including your values and fears — and considering the experiences of others in your situation.

B) Considering attitudes, values, and fears about treatment

As you make a treatment decision, you need to consider all the things that may influence your thinking, including your personal values, emotions and attitudes about your disorder and potential treatments. For instance, there are a number of common fears and attitudes about medication or other therapies that you may want to reflect upon as you make up your mind about whether to take or continue to take a medication for your mental disorder. As listed in the following sections in this module, these issues include: fear and stigma about medication; concerns that there will be side effects, or that the medication is ineffective, or unnecessary; and beliefs about disorder and treatment specific to a certain community or cultural background.

Fear and stigma about illness and medication

One common feeling that may make you reluctant to take or continue taking medication is the association of medication with "being ill" or "mentally ill" — rather than "getting better" or "having a life." Some people may have fear or stigma associated with a particular medication treatment, because they know someone who was not doing well with it. Remember though, medications work differently for different people. Some people are reluctant to take medication or have mixed feelings because they fear they might become dependent on or addicted to a particular medication. They may even be reluctant to take *any* kind of medication, even aspirin, because they want to be able to do things for themselves or feel medication is a crutch.

If you hold any of these feelings or attitudes towards medication, there is another way of looking at things. Think about how the benefits of medication can help you reach the goals you'd like to achieve. Then think about this treatment plan itself as being *one part* of an overall self-management plan that will help you gain control over the disorder. Taking medication is not about you becoming being passive, and the pills doing all the work: they are a way for you to gain control over your life, and part of a treatment strategy where you ultimately are in charge. You can adopt the same mindset when considering other forms of treatment as well.

Ethnocultural beliefs

As you think through these issues, you may want to consider how your ethnic or cultural community — that is your family background — affects the way you feel about mental disorders, and the way you think about treatment options. Just as we talked about in the section above on assessment, it is important that you ensure your health professional understands your perspective. So you need to communicate clearly about your views on the disorder, what causes it, and what can help it. You may also want to talk about what kind of complementary practices — including those that are consistent with your particular background — you would like to try. It is important that you communicate with your mental health professional about alternatives, as there may be various risks and benefits when alternatives are combined with mainstream treatments.

Side effects and effectiveness

Another common fear is whether there will be distressing side effects associated with the medication. Many people are especially concerned with side effects that prevent them from functioning in the roles that they value. For example, they may worry about side effects that make it difficult for them to focus well enough to do their job, or be an effective parent. In order to address these fears and perceptions realistically, you first of all need information so that you can recognize potential side effects if they occur. Then you need to negotiate with your doctor about a way to minimize them. As we've talked about already, it is important to talk openly with your health professional from the outset about how the disorder impacts your day-to-day life so that you can find a treatment alternative that improves, rather than hinders, your ability to function.

A related barrier to taking medication is the perception that the medication simply doesn't work, or it doesn't achieve the goals you expected it to achieve. Later in this module we will talk about how you can evaluate the effects of your medication for yourself, so that, if necessary, you can negotiate with your doctor about finding an approach that works better.

C) Considering experiences of others

One final step you may want to take before you decide on a particular option is to consider the experiences of others who have tried a similar approach. This is helpful for many people, as it can provide valuable information about what to expect, and it can often provide reassurance. If you do this, you should talk to several people, not just one or two. You should also try as much as possible to consider the experiences of individuals who appear to be similar to yourself, so that the information you get is relevant to your own situation. As you are considering this type of information, or information from any source about a particular intervention, remember that your experience will be unique.

Summary: making a decision

Once you've had a chance to sit down and consider the information you've gathered from all the various possible sources — from your health professional, from material you've found yourself, from talking to others, and by reflecting on your own attitudes — you'll be in a much better position to make an informed decision. You will also be much more comfortable with that decision. In part, this will be because it is *your* decision, and you will have played a significant role in making it. The next challenge for you is to make sure that your decision works.

Stage four: monitoring

Once you start a particular treatment approach, you need to be able to monitor whether it works, in relation to the goals you and your doctor have set. The first step is evaluating the success that the medication or other strategy is having in eliminating or minimizing your symptoms. At the same time, you'll need to monitor any side effects, which means also that you'll need to be able to know the difference between a symptom and a side effect. For example, in some mental disorders, cognitive difficulties such as short-term memory or concentration difficulties are often part of the disorder, but may be due to the medication, or the particular dosage. You probably won't be able to decide which is which until you and your doctor experiment with different medications or dosages.

As we've a number of times, the success of your treatment should not be judged simply on the basis of symptoms and side effects. Ultimately, you need to evaluate the treatment in terms of its success in minimizing the impact of your disorder on your quality of life and your ability to function in the settings or roles that are important to you.

To play an active role in monitoring your treatment with respect to symptoms, side effects, and functioning, you need to have a sound knowledge of your own disorder. However, taking on this role can also be made easier by using the kind of resource we'll describe in the next section.

Tools and resources for monitoring and evaluating the effectiveness of a treatment approach

There are various tools that can help you systematically evaluate the success of your treatment strategy, including diaries, self-report charts, and side effect charts. Generally, these list symptoms and side effects to watch for, as well as indicators of functioning that should also be monitored. They also provide a place to record or chart whether any of these things are increasing or decreasing as you follow through on your treatment plan. Some useful examples that you can download and use on a daily basis include:

- symptom and side effect reporting charts for depression, bipolar disorder, and schizophrenia from the Texas Medication Algorithm Program (TMAP), available at www.mhmr.state.tx.us/centraloffice/medicaldirector/PtEd.html
- Harvard Bipolar Research Program self-report and mood chart for bipolar disorder, at www.manicdepressive.org/images/selfreport.pdf and www.manicdepressive.org/tools/moodchart.pdf
- bipolar disorder, depression and anxiety disorders personal diaries, which include symptom charts, side effect charts, as well as treatment goal charts, available from Okanagan Clinical Trials in Kelowna. Call 250 862 8141 to order these diaries and to enquire about diaries for other disorders.

In the short-term, the purpose of using these monitoring tools and approaches is to get a general sense of whether your treatment strategies are working as well as you think they should, and to communicate this back to your doctor so that, if need be, you can reassess the treatment strategies and attempt to figure out a better one. In the early stages of developing a treatment strategy, you should meet fairly frequently with your doctor to monitor your progress and come up with a different strategy if necessary. Remember to be patient, though, as sometimes it can take up to several weeks or more before the effects of treatment are apparent.

Just as you did for the initial assessment phase, you need to plan your approach for communicating with your mental health professional about whether your overall treatment goals — relating to impact on your quality of life as well as on symptoms — are being achieved. For instance, Patricia Deegan of the National Empowerment Center describes a concise, effective way of describing the success of a treatment strategy as follows: *“Well, doctor, before I began this medication trial I was so depressed that I missed seven days of work, spent 14 days in bed and lost 3 pounds. But during the last two months, since starting the drug and using the new coping strategies, I have only missed 2 days of work, have regained the weight I lost and I have only spent 4 days cooped up in my apartment.”*

In this scenario, you and your mental health professional might decide to “stay the course.” If the approach you tried was less successful, you and your therapist can jointly decide on the new approach you're going to take.

Once you've arrived at a treatment plan that works best for you, it is time to move to the next step, which is developing an early warning system, and setting up an action plan for dealing with your disorder on a day-to-day basis. These are the topics of Module Four.

Adherence: sticking with your treatment

One final point before we move on: once you've arrived an approach that works, you need to stick with it. This can be difficult for some people, especially in relation to taking medication, and there are a number of issues that you need to anticipate and think about in advance. For instance you may feel you are “better” and don't need to continue taking the medication, or you may feel reluctant to take medication in the long term.

Despite these feelings, you need to think carefully about your course of action. For instance, even though you may initially feel better in a few weeks after starting your medication, you still may be vulnerable to a relapse. And, depending on the nature of your disorder, you may need to stay on medication for months or even years.

As you consider these kinds of issues for yourself, it may be more helpful to think of them in terms of self-management, rather than “compliance.” That is, as we talked about earlier, you may want to think about how the medication can help you manage your disorder, rather than focusing on whether or not you'll need to take medication and on how long you might need to take it.

For many people, medication will be a necessary part of their illness management strategy for some time. But if you have doubts, you should talk these over frankly with your doctor. And, if you do decide to try things without medication, then make sure you inform your doctor of your decision. Maintain contact with him or her, so that you can monitor the success of your trial off the medication.

You should never attempt to go off your medication without knowing the early warning signs of a repeat episode. If you're not able to pick these up, you should stay in contact with someone else — such as a family member or friend — who does know your early warning signs of relapse. You also need to have a plan in place for what to do if these appear, which you should discuss with others close to you. Regardless, you need to be fully aware of the risks of coming off your medication, including your increased vulnerability to a repeat episode of your disorder, the possibility of being involuntarily hospitalized, or experiencing other serious consequences.

Introduction

In the last module, we talked about how to work with your doctor and/or other health professional to find a treatment approach that works best for you. Once you have done this, you can move to the next step on the path to self-management. In this module, we're going to talk about how to develop an early warning system for monitoring possible early warning signs of relapse, and for identifying situations that may trigger a relapse.

We'll also discuss how to develop and document a staged action plan that involves a continuum of preventive, proactive and crisis-based options. This, first of all, involves adopting a healthy lifestyle which ideally would prevent many problems from occurring. Moving along the continuum, it then involves learning to identify and manage stressful situations that inevitably do occur from time to time — including the types of situations that may have triggered your warning signs in the past. Finally your plan involves learning what to do if your early warning signs *do* occur, either by employing effective coping strategies or, in the event of a crisis, knowing how to seek the kind of outside help you need.

Before we move on, we should note that the idea of early warning signs may make some people nervous because it involves thinking about past experiences that may not be pleasant. This module is designed to help you think of early warning signs as a window of opportunity for doing something and for taking control. This is because there are usually a number of weeks before these early warning signs (or “illness prodrome”) progress into something more serious. This is also because it is possible to develop successful strategies for managing these situations before they turn into crises, and to strengthen the coping approaches you may have already tried in the past.

One final note: the topic discussed in this module — known sometimes as the early warning signs approach — has been found to be especially effective for people with psychotic disorders such as schizophrenia and bipolar disorder. Readers with other diagnoses, however, should find the material helpful. For a full discussion of related approaches that apply more specifically to depression and anxiety disorders, please see www.heretohelp.bc.ca for the relevant diagnosis-specific toolkits.

Key messages of module

- Setting up an early warning system involves knowing your early warning signs and identifying the situations or events that trigger them
- Early warning signs include specific symptoms as well as non-specific signs such as having difficulty sleeping
- Adopting a healthy lifestyle that moderates stress can help prevent warning signs from returning or worsening
- Identifying and managing challenging situations through effective strategies such as structured problem solving can help prevent warning signs of relapse from occurring, or can help you deal with them if they *do* occur
- By evaluating your past coping strategies and by considering the successful strategies adopted by others, you can enhance your own abilities for coping with distressing symptoms or situations that otherwise might lead to relapse
- A comprehensive action plan involves knowing when to adopt preventative strategies, when to try proactive coping strategies, and when to seek outside help

Part A: developing an early warning system

Becoming familiar with typical early warning signs

In general, there are a number of typical early warning signs that people with mental disorders may experience. These can be divided into “non-specific” signs — such as withdrawing from social contact, becoming suspicious, having your sleep patterns disrupted, or feeling overwhelmed — as well as more specific signs. Specific signs are usually less extreme versions of the acute symptoms of the disorder itself; for example, in schizophrenia, becoming preoccupied with unusual ideas; in bipolar disorder, becoming hypomanic (i.e., becoming considerably more active than usual). Early warning signs may relate to changes to your thoughts, feelings or behaviours.

Warning signs — both specific and non-specific — will depend on the diagnosis, but the important point to remember is that there is often a predictable pattern that is unique to each individual, known as the early warning “signature.” By thinking back to when you've had crises in the past, you will probably be able to recognize a specific pattern to what happens when you're not doing well, what things may stress you or set up a relapse, and whether that unique pattern happens fairly quickly or takes a long time.

Here's a hypothetical example: your first signs of trouble are to avoid social occasions, and to start listening to depressing music. This usually happens after you've been working hard on a project for an extended period of time, and not got the usual amount of sleep. In a couple of weeks, you begin staying up all night, and shortly after, you start losing contact with reality.

Learning your own early warning signs

When you experience a reoccurrence or a worsening of your symptoms, you need to know what it means and what to do. This kind of change may mean that something in your lifestyle needs to be altered, or that your treatment approach isn't working properly. However, it is sometimes difficult to tell what's going on. If you *have* found an approach that has been working well, it is more likely that a reoccurrence or worsening of symptoms may be early warning signs of a potential relapse, rather than problems with the medication.

To start developing an early warning system, you first need to have a general sense of what warning signs you've had in the past. So, you need to sit down and reflect on the last few times you went into the hospital, or on the times you had a crisis. Involve others close to you in this process, especially if they are familiar with your disorder. Ask yourself and your significant others: as your health got worse, what kind of things did you experience? What kinds of thoughts did you have? How did you behave? Is there a specific order to the way these signs occur? For example, you may first start to sleep less, then

Typical triggers

- Not enough sleep
- Overwork
- Interpersonal conflict
- Encountering feared or challenging situation
- Substance misuse (alcohol or drugs)
- Reproductive cycle
- Not following through on the treatment plan (non-adherence)

Part B: developing an action plan

After you've developed your own early warning signature, the next step is to decide on which strategies you're going to use to deal with your early warning signs in the future. There are three stages of strategies you can use, depending on how well things are going. In *stage one*, when things are going well you can adopt strategies to *prevent* warning signs from appearing in the first place. In *stage two*, if you are experiencing some early warning signs you can adopt *proactive* symptom-specific coping strategies that you can use to nip them in the bud. For *stage three*, you'll need to prepare a strategy in advance for how you'll look for help if and when things get out of hand and you experience a *crisis or emergency*.

Stage one: developing preventive coping strategies

Ideally, you want to keep things going well, and avoid experiencing your early warning signs. To improve your chances of doing this, you'll need to develop preventive strategies, such as adopting a healthy lifestyle, and learning to manage stressful events or situations. The next sections deal with these two issues, and with a strategy called the structured problem-solving approach that is effective for dealing with both.

Adopting a healthy lifestyle

One way of maintaining things on an even keel is by adopting a healthy lifestyle that moderates the amount of stress you experience. This means avoiding some of the general triggers that we identified earlier in the module, such as not getting enough sleep, misuse of alcohol or other drugs, and sticking to the treatment plan you've developed with your doctor or other health professional. Other strategies include eating wisely, getting enough exercise, socializing, and participating in meaningful activities, job-related or otherwise.

Adopting or maintaining a healthy lifestyle is something that is often easier said than done. For instance, some people may find it difficult to get enough sleep; others may find it difficult to curtail their alcohol intake, or they may have mixed feelings about sticking to their treatment plan. The first step in making your lifestyle healthier is to identify what aspects of your life may be causing you distress or problems, and then to concentrate on making a change to one area that is important to you, and that you feel is realistic to change. After doing so, you need to develop a strategy to make these changes. Since the approach we'll discuss — structured problem solving — is also relevant to the next section on dealing with stress, we'll discuss it at the end of that section.

Dealing with stress: identifying and managing stressful situations

Identifying signs of stress

The first step to coping proactively with specific distressing situations is to know just when you *are* experiencing stress, and to recognize the physiological, emotional, cognitive or behavioural signals your body is giving out that indicate that this is the case. The table below outlines some examples of the signs of different types of stress. You will see that some of these may be similar to the non-specific early warning signs, and may be looked at as *early* early warning signs. By being able to detect and deal with these earliest signs of stress, you may be able to avoid progressing into the early part of your early warning signature.

Your physiological signs may include:

- Shortness of breath
- Having tense muscles or tension headaches
- An upset stomach or digestion

Your emotional signs may include:

- Feeling overwhelmed
- Feeling angry
- Feeling down

Your cognitive signs might include:

- Thinking that you are not appreciated
- Thinking that everything is hopeless

- Thinking that other people are not being supportive
- Your behavioural signs may include:
- Becoming argumentative
 - Becoming aggressive
 - Developing tics, such as blinking, grimacing
 - Feeling the urge to self-medicate with alcohol

Identifying stressful life events and situations

Another aspect of managing stress is being able to identify difficult life events or situations that cause you stress. The two boxes below list some common stressful life events that you may encounter. Look through the boxes and consider whether they are relevant in your situation, and whether they have been associated with any of the specific signs of stress discussed above.

Stressful Life Events

- Moving house
- Accommodation problems
- Unemployment
- Money problems
- Marriage
- Divorce/relationship ending
- Relationship problem with partner
- Pregnancy
- Relationship problem with family
- Bereavement
- New job or college course
- Work or study problems
- Physical illness
- Legal problems

Stressful Situations

- Harassment/bullying/abuse
- Overwork
- Low self-esteem or confidence
- Boredom
- Isolation/loneliness
- Using 'street' drugs
- Changing or stopping medication
- Drinking heavily
- Keeping problems to yourself
- Not knowing how to get help

(source: *Coping with Setbacks and Staying Well* (2001), R. Siddle. York Health Services, National Health Service, United Kingdom)

Managing stressful or difficult situations: the structured problem solving approach

Once you've got a sense of which situations have caused you stress or are likely to challenge you in the future, you need to develop ways of managing them. As mentioned, the structured problem-solving approach is effective for making lifestyle changes, for dealing with the challenging and stressful situations that arise from time to time, or for dealing with difficult situations that occur on a more regular basis. This approach has been tested and found effective by people in all walks of life, and involves six steps that need to be followed in order for it to work for you. These are:

- 1) **problem definition:** deciding just what the difficult situation is about and how it's causing you trouble. The box above will help you identify potential problem areas.

- 2) **goal-setting:** describing in concrete, realistic terms what problem you'd like to solve and what you'd like to happen as a result of the strategies you develop. You may have more than one problem, but it is best to focus on one at a time, ideally one that you are able to solve in a relatively short time. After achieving success and building some confidence, you can then move on to dealing with the next issue you'd like to deal with

- 3) **generation of alternatives:** brainstorming all the possible solutions you can think of that would solve your problem. Remember that knowledge is power and that there is strength in numbers when it comes to thinking about solutions. Doing some research and/or consulting others you trust can significantly expand the range of solutions that you consider when you come to the next stages

- 4) **selection of alternatives:** weighing the pros and cons of each option, and then selecting the two or three strategies that you think might work the best

- 5) **selecting the preferred solution:** picking the most preferred option or options, defining it in concrete terms, specifying who does what, and testing out how it works

- 6) **evaluation of results:** seeing if it works and deciding whether you need to modify the approach or try another option

The case study on the next page will illustrate this process. The problem-solving worksheet in Appendix A will help you work through this exercise for yourself. If you would like more help working through this process, an excellent resource is the *Problem Solving: Service User Handbook* available at www.nyx.org.uk/modernprogrammes/mentalhealth/goodpractice/jan2002/carepathway.html

Case study

The problem-solving approach described in this case study is based on the Multi-Family Group model, developed by Dr. William McFarlane, which is now being implemented in London, Ontario by the Prevention and Early Intervention Program (PEPP) for early psychosis. This particular case study appeared in the Family to Family newsletter, Fall 2002, Issue No. 6:

My nineteen year old son and I belong to the Multi-Family Intervention Group...which meets every other week for an hour and a half...Each meeting begins with a bit of a 'go round' where we discuss the effects of the illness for us over the preceding two weeks. An individual's problem is then selected. Together, we define the problem and brainstorm possible solutions using a flip chart. The individual chooses the ideas from this list that are most likely to be successful and then develops new [strategies] to try out over the next two weeks. At the following group meeting, the individual reports on the success or failure of the various strategies and we discuss why some things succeeded and others did not.

*The trouble my son had of not having a sleep routine was a problem for both of us: too often, he would wake me at 3am to discuss the fact that he couldn't sleep (**problem definition**). The group worked on this with him/us (**generation of alternatives**) and a big list went up on our fridge detailing when he was to take his medication, what time he would go to bed at night and get up in the morning and even what kind of books he could read or what music he could listen to while in bed (**selection of alternatives**). He followed this new routine for two weeks. (My 'job' was not to nag) (**testing of alternatives**). Not surprisingly, his symptoms improved. He was proud to report his success back to the group. He continues this sleep routine even now because it works!...(**evaluation of results**). It was good for me to see my son do this problem-solving work on his own. The power of the group was greater than my parent power!*

The case study raises a few important points that need to be emphasized as we conclude our discussion on problem solving. First, when you *expect* success, often that breeds future success. That is, if you think of stressful situations as problems that *do* have solutions, you're more likely to think strategically and effectively about how to solve them. Secondly, success is not a one-shot deal, so even if you don't succeed at first, see this is a learning opportunity. If your first strategy doesn't work, take stock of what happened, and try again. And finally, don't always try to solve everything by yourself. Use the other people around you as a sounding board for ideas, and also to help you evaluate what works and what doesn't.

NOTES:

external force that can read your mind or steal your thoughts

- Realizing that despite what the voices are saying, they are a part of you, so you are in charge, and no harm will come to you when you don't listen to them
- Engaging in non-stressful, distracting activity such as gardening, listening to music and so on when the voices come on
- Making a contract with the voices, perhaps allotting a specific time when you will listen to them
- Experimenting with ways of diminishing the voices, for example by "shadowing" the voices, that is by whispering the content of the voices under your breath; or by humming when the voices come on
- Avoiding unhelpful strategies, such as
 - Passive activities (e.g., watching TV)
 - Arguing with the voices
 - Self-medication
 - Social isolation
- Making use of resources that suggest strategies and networks that connect voice hearers, such as those listed in the following resource list.

Related resources:

- www.schizophrenia.co.uk/background/Understanding_Voices/understanding_voices.html This site features a fact sheet called "Understanding Voices," developed by U.K. cognitive psychologist David Kingdon, based on his research in this area.
- www.mentalhealth.org.uk/page.cfm?pagecode=PMAMHV A very helpful fact sheet on dealing with voices, developed by the Mental Health Foundation in the U.K.
- *Accepting Voices* (1993) and *Making Sense of Voices: A Guide for Mental Health Professionals Working with Voice-Hearers* (2000). Books by M. Romme and S. Escher. To order, go to www.mind.org.uk/osb/showitem.cfm/Category/104 and www.mind.org.uk/osb/itemdetails.cfm/ID/138

Coping with delusions or unusual thoughts

Using ways of "testing" out your ideas/view of reality is another way of neutralizing your symptoms. One way of doing this is to make a list of alternative explanations for your idea, and consider the evidence for and against each of these possibilities. It may be possible to actually conduct an experiment to confirm which alternative is true. Another way of doing the same thing is to "check out" your perceptions of reality with another person you trust.

Related Resources:

- members.aol.com/DGKingdon/private/voice.htm#home "Understanding What Others Think," and "Cognitive Therapy of Psychosis," include strategies for dealing with delusions, hallucinations by researcher D. Kingdon
- R. K. Chapman. "Eliminating Paranoid Delusions and Telepathy-Like Ideas in Schizophrenia: A Personal Account," in Carol T. Mowbray, et al. *Consumers as Providers in Psychiatric Rehabilitation*. Columbia: International Association of Psychosocial Rehabilitation Services. (1997), p.201-208. Also see www.nas.net/~chapmanr
- D. Martyn. *The Experiences and Views of Self-Management of People with a Schizophrenia Diagnosis*. Self-Management Project: www.rethink.org/recovery/self-management

Stage three: getting outside help

So far in this module, we've talked about a staged approach to dealing with early warning signs, starting with a preventive approach to stress management, and then moving to a proactive approach to coping with specific distressing situations or symptoms. The final situation to consider is when your warning signs indicate that you are fairly far along in your early warning signature, and when you don't feel you can cope independently with your situation.

Before we talk about the various options you can consider, you may not be comfortable at all with your ability to respond to early warning signs. Some people, for instance, feel that they aren't able to respond to the warning signs themselves because they happen too rapidly. Others feel that their progression is so slow and gradual that they don't notice any change at all.

If this is the case, one option to consider is to enlist a trusted support person — such as a family member or friend — and sit down with him or her to draw up an early warning signature, and then talk about strategies for what to do when things start to go wrong and what you would like them to do. For instance, you might want them to strongly encourage you to seek help when they see certain signs, or you might even want them to do things like take away your credit cards (which might be necessary if you feel you lose your judgment when you start getting sick). You may even want to talk with them about circumstances under which you want to be hospitalized, and what kind of treatment you want if you do need to be hospitalized.

If for any reason, you don't feel comfortable with your own coping abilities in a given situation, you need to consider in advance some steps you can take, in the event that you experience early warning signs. These might include:

- scheduling more frequent visits with your doctor or key worker
- adjusting or adding to your medication as advised by your treating
- trying cognitive-behavioural therapy (CBT) techniques with your doctor or psychologist
- calling someone in your support network to talk things out
- calling your key worker or other mental health professional after-hours
- calling the crisis line or crisis outreach team
- going to a crisis clinic
- going to the emergency department of your local hospital

Documenting, rehearsing and formalizing your action plan

When you enlist the help of others, either in your informal or professional support network, the ideal situation is one where each of the people in your network is aware of your early warning signs, and is knowledgeable about what you want to happen — that is, when you prefer to cope with your own strategies, at what point you would like outside help, and about what kind of help you prefer.

One way of doing this is to develop something called a Ulysses Agreement or Treatment Contract, which is a document that describes your early warning signs, your plan for coping with them, and your preferences with respect to what kind of outside help you wish to receive, and under what circumstances. It also outlines the roles and responsibilities of each person that you would like to provide support to you.

You will need to sit down with all of the players, in advance, so that each person is clear on what you'd like them to do, and what signs you'd like them to consider. You should also regularly rehearse and review these strategies — by yourself, and with others — so that you are confident in your ability to carry your action plan out.

The next page is an example of a template that you can use to set up your own action plan, adapted from the New York Office of Mental Health. It is divided into two parts: a prevention plan, and a plan that comes into place in the event of a crisis. You can also see *Coping with Setbacks and Staying Well* (see page 25 of this toolkit) for an action plan or safety net template to use.

Personal relapse prevention plan (part one)

Signs that suggest I am doing well:

1.

2.

3.

Events or situations that triggered relapses in the past:

1.

2.

3.

Early warning signs that I experienced in the past:

1.

2.

3.

Effective ways I can cope if I experience early warning signs:

1.

2.

3.

What early warning signs indicate I need help from others:

1.

2.

3.

Who I would like to assist me:

Name(s)

What I would like them to do:

1.

2.

3.

Crisis plan (part two)

Name:

My crisis plan (what can be done if I am in crisis):

Ways I can manage stress, regain balance, or calm myself:

People I can call (include phone numbers of individuals – family, friends, counsellors, etc.):

Resources I can use (include phone numbers of agencies, support groups, etc.):

Things I or other people can do that I find helpful:

Medications that have helped in the past:

Medications that have not helped:

Medications I take (include types of medication, purpose/condition, and treating physician for your current medications; identify any adverse drug reaction or allergy history which you have):

Signatures: _____

MODULE 5 GOING FURTHER:

ASSESSING YOUR NEED FOR OTHER SELF-MANAGEMENT RESOURCES

Introduction

After working your way through all the modules, you may be feeling more confident about your skills and abilities, and you may feel that this self-management toolkit is all you need to put an ongoing action plan into place. You may feel, though, that you need some extra support in order to put into place some or all of the skills discussed in the various modules so far. And you may be wondering where to go from here to get that support.

Depending on your needs, the self-management toolkit can be used in different ways, so it is entirely fine if you feel you need more support. In fact, when we envisioned this toolkit, we saw it as something that would not be a be-all-and-end-all for most people, but rather would be a primer on self-management. We expected that it would be an entry point that would

first help you work on the basic self-management concepts. Secondly, we wanted it to help you connect with whatever other resources you need to support the process of self-management. This module helps you assess what further support you may need, and provides a resource guide to help you find it.

Assessing your self-management ability

When you think about what other kinds of self-management support you might need, first ask yourself how confident you are with the basic elements of self-management. Re-doing the self-management assessment scale below will help you decide how far you've come by comparing it with your test results from the beginning of this toolkit. You will then see and can decide what other support you should access.

Post-TEST

Module Two

1. My knowledge of my condition is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

2. My knowledge of the treatment options for my condition is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

Module Three

3. My ability to participate actively in decisions made about the treatment and management of my condition is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

4. My ability to monitor the effectiveness of my treatment plan is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

5. My ability to follow through on the treatment plan I've developed with my doctor or other professional is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

Module Four

6. My ability to monitor my early warning signs and their triggers is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

7. My progress towards adopting a mentally healthy lifestyle that minimizes the impact of my disorder is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

8. My progress towards coping with stressful or challenging situations is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

9. My progress towards coping with early warning signs and symptoms is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

10. My ability to get outside help when I need it is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

11. My ability to choose the right strategy when my disorder gets worse (that is, trying stress management, coping strategies, or seeking outside help) is:

0 1 2 3 4 5 6 7 8
Very Good Satisfactory Very Poor

Key messages in this module

- By doing the self-assessment in this module, you can decide what other self-management-related supports you may need
- A range of additional self-management resources may be available in your community, and include delivery formats such as self-directed manuals or workbooks, one-to-one options, group-based options, and peer-led or professionally-led options
- Other community resources — related to housing, employment, counselling — are available to help you live a fulfilling life in the community

Deciding where to go from here: considering other self-management resources

The answers to the self-management assessment scale will help you decide which skills you need to work on. For instance, you may find that your ability to participate in and follow through on a treatment plan is good, but you don't feel confident in your own day-to-day coping skills. Once you've got an idea just where you're at, there are a number of options to pursue that will help you strengthen your self-management abilities. First of all, review the recommended resources in the relevant module(s), since these are designed to bolster your knowledge and skill in the particular area. Then, should you want to go further in developing a particular skill, you can consider the other options that we'll describe below.

When you consider what resources might be relevant to you, you'll have to think about more than the kind of skills you want to build. The first issue to consider is availability. Assuming the program is available in your community, the next issue to consider is the delivery format you prefer, that is, whether you want something that is completely self-directed, or involves others; and if you do want others involved, whether this is on a one-to-one or group basis. Another delivery format consideration is whether you'd prefer something that is consumer-led or family-member led, professionally-led, or a combination of both.

Availability

There are a number of resources that are available in communities throughout British Columbia. Of course, which ones are accessible to you will depend on where you live, and how far you are able to travel to reasonably access that resource. Availability depends on how often the course or program is carried out, and may also depend on your particular diagnosis. While some resources are diagnosis-specific, others are designed for individuals with any form of mental disorder. Some are for people with *any* form of chronic health condition — mental, physical or both. Whether or not there is a course or group in your community that meets your needs, there are still options open to you that will allow you to build your self-management skills, such as working on your skills in the context of a one-to-one relationship between you and your health professional, or taking advantage of an entirely self-directed resource.

The next section of this module outlines the kinds of delivery formats that are available. The resource guide that follows describes specific examples of each format.

Self-directed options

Purely self-directed forms of self-management are something to consider in a range of situations: where few other resources exist, if you generally don't prefer to associate yourself with the mental health system, if you don't prefer group settings, if you are generally a self-motivated person, or if you have already achieved a fair degree of self-management ability. Examples include self-management workbooks — which may be downloadable from the Internet — or interactive web-based self-management programs.

Self-directed options may also be used in combination with other delivery formats, when those are consistent with your needs and preferences. A combination of approaches rather than a purely self-directed one will also be more valuable if your disorder is currently causing you a lot of problems. The *Self-Care Depression Guide* (described below) is designed for independent use or to be used with help from a mental health professional who is familiar with the approaches underlying the *Self-Care Guide*. Another example listed below is the WRAP program, which may be undertaken independently through the use of a workbook, or in an interactive group format.

One to one vs. group-based approaches

Many people wish to pursue their self-management abilities with the help of others, either on a one-to-one basis or group basis. One-to-one options include self-management-oriented support such as cognitive-behavioural therapy (CBT) and other ways of helping you develop coping and relapse prevention strategies. These may be available from your family doctor, psychiatrist, or other mental health professional. You may also be able to find a peer support worker, or a peer with a mental disorder in your area who is knowledgeable and helpful.

Within a one-to-one setting, you will usually be more able to discuss information and issues that are relevant to your own concerns, in comparison with your ability to do so in a group setting. A one-to-one setting may also be preferable for those who are uncomfortable sharing their experiences with others. Or, it may be a good lead-in for someone who is interested, but is not yet ready to be in a group situation. For instance, before discussing their disorder in a public setting, some people need to become somewhat familiar and comfortable with the idea of *having* a mental disorder; or, they may need time to become comfortable with the idea of being with *others* who have mental disorders before entering a group setting.

Those who do become comfortable with the group option often derive both emotional and practical support from others “who have been where they've been, and arrived at where they want to be.” The group setting may also a rich source of ideas and strategies for individuals facing problems with their disorder or their lives. The effectiveness of group-based self-management options is improved when they are skillfully facilitated. This ensures that individual members feel safe to speak freely without fear of criticism or ridicule. In addition, a good facilitator will ensure that attention is paid to the issues of all group members, rather than being taken up by the concerns of only a few people. Group-based options may also be more attractive when individuals are able to interact with others who they perceive as similar to themselves.

Group-based self-management

The following section contains both diagnosis-specific and non-diagnosis-specific group-based self-management resources.

Changeways

- Core Program has seven sessions providing “lifestyle-based treatment strategies for depression”
- professionally-led, group-based program, based on principles of CBT (cognitive-behavioural therapy)
- graduates of core program have options such as:
 - 8-session assertiveness training group
 - 6-session relaxation skills group
 - single evening lecture on recovery from depression
 - follow-up support group “Changeways continues”
- manuals associated with program components also available for ordering. See www.changeways.com
- available throughout most of B.C. Ask your health care provider about these groups, or for information about how to self-refer, see www.changeways.com/Referral.htm

LEAF program (Living Effectively with Anxiety and Fear)

- developed by the Anxiety Disorders Association of BC, with funding from the Ministry of Health Services
- run by recovered consumers
- based on 5 CBT principles for dealing with panic disorder: psychoeducation, management of physical symptoms related to panic, cognitive restructuring, exposure techniques for building tolerance to feared symptoms and situations, and relapse prevention
- 2-hour training sessions once weekly for 14 weeks
- cost of \$50 per participant (includes book and workbook for daily practice of skills)
- pilot program found to be effective in reducing symptoms of panic disorder, problems with avoidance and associated symptoms of depression
- plans to implement throughout BC
- contact ADABC for more information at 604 681 3400

B.R.I.D.G.E.S. program (Building Recovery of Individual Dreams and Goals through Education and Support)

- content applicable to any mental disorder
- developed in Tennessee, through the National Alliance for the Mentally Ill (NAMI) and currently the topic of a major multi-site evaluation
- program based on an extensive qualitative needs assessment of the experience of recovery and is sometimes run in parallel with a family-based program *Family to Family* also known as *Journey of Hope*
- led by 3 trained consumer facilitators
- 15-week program
- course addresses key topics including basic facts about the various diagnoses and medications, how to identify needs, how to communicate effectively and access relevant resources, and effective advocacy skills etc.
- available in most BC communities
- for more information about B.R.I.D.G.E.S. or Family to Family, call the BC Schizophrenia Society Provincial Office at 1 888 888 0029

Chronic Disease Self-Management Program groups

- group led by pairs of trained peer facilitators
- designed for people with co-occurring multiple health conditions such as arthritis and depression, diabetes and depression, etc.
- a six-week (2.5 hours per week) program
- between 10-15 consumers and significant others attend
- teaches lifestyle management, cognitive symptom management, breathing exercises, problem-solving, communication skills with families, friends and health providers, use of medication, and how to deal with emotions like anger or depression related to coming to terms with a chronic illness
- implemented in the former Vancouver/Richmond Health Board, now part of Vancouver Coastal Health Authority
- for more information or to check for availability in your area, see www.uvic.coag.org

Diagnosis-specific self-help groups

Self-help or support groups have a long-standing role in helping people cope with mental health problems, mental disorders and substance use problems. Many people find comfort in knowing they are not alone and benefit from the emotional support and practical tips that are often provided. It is important to keep in mind that some support groups are better than others. Problematic support groups are those that do not empower people and instead keep people trapped in old unhealthy coping patterns that do not help make things better. Some support groups only allow a place for members to vent without attempting to solve any ongoing problems. Although it is very important to feel heard and understood by others, a group should provide more than a venue for members to voice their concerns. The best support groups are those that provide members with reliable and accurate information that helps them better understand their mental health problem. A critical component is also the passing of knowledge about helpful resources and coping strategies that actually help a person make progress such as places to get treatment, effective self-management strategies, quality books and websites, and so on.

To find out about a support group in your area, look in your local community services directory, contact the Self-Help Resource Association of BC (www.vcn.bc.ca/shra or 604 733 6186), the BC Mental Health and Addictions Information Line at 1 800 661 2121 or contact one of the BC Partners agencies.

BC Partners agencies

Anxiety Disorders Association of BC
4438 West 10th Avenue, Suite 119
Vancouver, BC V6R 4R8
604 681 3400
www.anxietybc.com

Awareness and Networking Around Disordered Eating
109-2040 W. 12th Avenue
Vancouver, BC V6J 2G2
604 739 2070 or 1 877 288 0877
www.anad.bc.ca

BC Schizophrenia Society
201-6011 Westminster Hwy
Richmond, BC V7C 4V4
604 270 7841 or 1 888 888 0029
www.bcscs.org

Canadian Mental Health Association BC Division
1111 Melville St, Suite 1200
Vancouver, BC V6E 3V6
604 688 3234 or 1 800 555 8222
www.cmha-bc.org

Kaiser Foundation
1177 West Hastings Street, Suite 2210
Vancouver, BC V6E 2K3
604 681 1888
www.addictioninfo.ca

Mental Health Evaluation & Community Consultation Unit
University of British Columbia
2250 Wesbrook Mall
Vancouver, BC V6T 1W6
www.mheccu.ubc.ca

Mood Disorders Association of BC
#201 - 2730 Commercial Drive
Vancouver, BC V5N 5P4
604 873 0103
www.mdabc.ca

Other community-based mental health resources

There are a variety of other resources that may not use the term self-management, but can help you manage your mental disorder and live a fulfilling life in the community. Your area may have counselling, an ongoing community support worker program (sometimes known as case management), supported housing, supported employment, as well as income assistance programs. For more information about the resources available in your area, contact your local health authority. For additional information about housing, employment and income-related supports, you can also contact any of the BC Partners agencies listed above, or see the *Visions* journal issues produced on these and other related topics, by contacting Canadian Mental Health Association BC Division.

Vancouver Coastal Health Authority
www.vch.ca
1 866 884 0888 or 604 736 2033

Fraser Health Authority
www.fraserhealth.ca
1877 935 5669 or 604 587 4600

Interior Health Authority
www.interiorhealth.ca
250 862 4200

Northern Health Authority
www.northernhealth.ca
1 866 565 2999 or 250 565 2649

Vancouver Island Health Authority
www.viha.ca
1 877 370 8699 or 250 370 8699

Appendix A: Problem-solving worksheet

Use this worksheet to work through solving a current problem.

What is the problem?

What realistic goal would you like to meet?

What are possible solutions?

What are the best 3 possible solutions? (Use the notes section on page 28 to list pros/benefits and cons/costs of each possible solution and then make your ratings)

1.

2.

3.

Which strategy did you try? Did it work? What were the results?

If the results are not satisfactory after trying strategy #1 then repeat using strategy #2, #3 or another possible solution until the results are satisfactory. Otherwise, consider redefining your goal to make it more realistic and work through the steps again.

