

A Family Resource Guide:

**For family members with a
loved one involved with PACT**

**“Knowledge is a treasure,
but practice is the key to it.”**

-Thomas Fuller-

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**“Coming together is a beginning.
Keeping together is progress.
Working together is success.”**

-Henry Ford-

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Introduction

It is often difficult for family members of individuals diagnosed with a mental illness to access material that is program specific and also inclusive of multiple aspects of mental health. Often families do not know of all the available resources that exist or how many different types there are to meet a variety of needs.

The purpose of this guide is to provide families and caregivers of the clients of PACT information about the program, mental illness and available resources, in an easy to read format.

All of the information in this guide was gathered by Brandon University Psychiatric Nursing students, Lindsay and Uzoma.

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Chapter 1: PACT

“Family members and the PACT team members become something of a task force, in which experts from various sectors of the client’s total network share experiences, information, planning, and the creation of new ideas and opinions...The professional team’s job is then to take these possibilities and attempt to realize them”

-Bill McFarlane-

What is PACT?

PACT is an acronym for the Program of Assertive Community Treatment. In other areas around Canada and the United States, it is just referred to as Assertive Community Treatment (ACT).

PACT is a very unique program, based on the ACT model, in that it provides services to individuals in the community who are considered to have a severe and persistent mental illness. The clients of PACT typically have:

- A history of severe and persistent mental illness, particularly schizophrenia and bipolar disorder
- Major difficulties in functioning independently in the community
- A high use of hospital and crisis services
- An inability to successfully participate in other community-based mental health services
- Other complex needs related to addiction, homelessness and or/criminal activity

The long-term impairments characteristic of the clients of PACT includes:

- A high vulnerability to stress
- Difficulty with interpersonal relationships
- Deficiency in basic skills
- Marked dependency
- Poor transfer of learning

PACT Services

PACT services are available:

- 24 hours per day, seven days per week
- Without time limit
- Fluctuate in intensity
- Are fully mobile

PACT services are planned, implemented, and revised in accordance with the client's needs, strengths, and preferences. The team provides time-unlimited care, thus capitalizing on in-depth knowledge of the client and trust established over the long-term clinical relationships.

PACT services are “self-contained”, with the team serving as a fixed point of responsibility for the care of its clients. The team are the direct providers of all services and will respond to all needs rather than referring clients for specialized services to other agencies.

The “self-contained” strategy is directed toward the task of helping the client make a stable life of decent quality in the community. It accomplishes this through four functions:

- 1) The utilization of a broad approach
 - Focusing on any and all aspects that impact on the client's stability in the community, including those that interfere with or facilitate that stability
- 2) Acting as the fixed point of responsibility for all aspects of the client's life that affect his or her stability in the community
 - If a client needs a service, the PACT team is the responsible entity for making sure it is provided

3) Careful monitoring

- The PACT team must know what is going on in a client's life so that it can intervene promptly to help
- One critical function of careful monitoring is to be aware of impending relapse as early as possible, so that rapid intervention may be employed to prevent a full-blown psychotic episode

4) There are no set time limits on how long a client will be served by the team or on how long any specific service will be provided

When a client is in crisis, the team helps him or her resolve the crisis in the shortest time possible and in the least restrictive environment. When a client is hospitalized, the PACT team works closely with the hospital staff on treatment and discharge planning; keep the client's support system intact; and then get him or her back to the community as quickly as possible.

The PACT team attends to these barriers to recovery:

- Persistence of mental health symptoms
- Substance use
- Previously ineffective treatment
- Isolation and alienation
- Recurring trauma
- Hopelessness and helplessness
- Lack of valued roles
- Stigma and shame
- Financial insecurity
- Recurring relapse

PACT services include:

- Clinical assessments and treatments including:
 - Medication administration and monitoring
 - Education on medication side-effects
 - Counselling on mental health including symptoms control
 - Ongoing assessments on physical and mental health
 - Crisis services
 - Long-term clinical relationships
 - Psychotherapy
 - Motivational interviewing
 - Cognitive behavioural therapy

- Rehabilitation
 - Housing needs
 - Skills teaching
 - Nutrition
 - Social life
 - Family
 - Budgeting
 - Hygiene/self-care
 - Addictions
 - Behaviour
 - Vocational work
 - Meaningful activities

- Support
 - Daily visits (for some clients)
 - Emotional support
 - Transportation
 - Attending appointments
 - Food
 - Cigarettes

The PACT team also holds family meetings every 6 months, where family members have an opportunity discuss any issues of concern, pose suggestions, discuss things that they have enjoyed or appreciated now that their family member is a client with the PACT team, and talk with other families about their experiences with mental illness.

Who is on a PACT team?

PACT consists of a multi-disciplinary team of mental health professionals who provide treatment, support, and rehabilitation for people with severe and persistent mental health problems. The mental health professionals include:

- Psychiatrists
- Team leaders
- Administrative assistants
- Service coordinators
 - Psychiatric nurses
 - Social workers
 - Vocational rehabilitation specialists
 - Addictions specialists
 - Occupational therapists
- Support workers
- The clients, as the clients plays an active role in their recovery

Each client is assigned a mini-team, with one PACT team member serving as the primary contact person. Each mini-team consists of a designated number of PACT staff who each fulfill a function as outlined in the client's recovery plan.

However, the whole PACT team is ultimately responsible for the care of each client and every member of the team is involved, at one time or another, with virtually every client.

Frequency of Visits

The PACT team members usually meet with the clients on an "as-needed" basis in the community, that is, in the client's home or elsewhere.

- The intensity of the treatment depends on the needs of each client
- Initially, a client may be seen by a member of the PACT team on a daily basis. Over time, contact may only be needed on a bi-weekly basis, but ultimately it is based upon the needs of the individual client

The Benefits of PACT

The PACT team helps clients to achieve their goals, feel as well as possible and live and work in the community when they otherwise may not have been able to.

PACT allows families to be families, leaving the caregiver role responsibility to the PACT team.

The PACT mini-teams work with the clients to develop recovery plans which outline what goals the client would like to achieve during a 6 month period. Through this process of goal setting and developing life-long professional relationships with the clients, the outcomes of treatment can include:

- Increased stability of mental status and time out of hospital
- Reduced hospital costs
- Improvements in adherence to medication regimes
- Reduced unpleasant medication side effects
- Reduced symptom severity
- Enhanced residential stability
- Enhanced role functioning
- Improved overall quality of life

Personal accounts of PACT clients

When it comes to the benefits of working with the PACT program no one can give a better account than the clients themselves and fortunately enough, a few clients were kind enough to share their thoughts and feelings about the program for this guide.

Working with PACT...

- “It gives people direction in life; it keeps people out of hospital and gives them opportunity.”
- “My family says PACT is the best thing to happen to me in my entire psychiatric life.”
- “My symptoms are better managed; the psychiatrist is willing to experiment with medication dosages to find out which dose is most effective.”

Living with mental illness...

- “People treat you different when they find out you have mental illness. I don’t tell people when I meet them, because I don’t want to be judged on that.”
- “It’s not easy to be labeled with a mental illness. You don’t say someone is a mental illness, a person isn’t the illness. You don’t say to someone they are schizophrenia...you say they have schizophrenia.”

A Typical Day at PACT

8:00-9:00 Morning Meeting

- Review the previous day’s work
- Schedule tasks for the day

9:00-12:00 Clinical Work

1. Treatment

- Medication distribution
- Counselling on mental health including symptom control
- Education on medication side-effects
- Ongoing assessments on physical and mental health
- Psychotherapy
- Motivational interviewing
- Cognitive behavioural therapy

2. Rehabilitation

- Housing needs
- Skills teaching
- Nutrition
- Social life
- Family
- Budgeting
- Hygiene/self-care
- Addictions
- Behaviour
- Vocational work
- Meaningful activities

3. Support

- Daily visits (for some clients)
- Emotional support
- Transportation
- Attending appointments
- Food
- Cigarettes

12:00-12:45 Lunch

12:45- 16:00 Clinical Work (continued)

14:00- 22:00 Evening shift

- Concentrated for the most part on treatment and support

22:00- 8:00 On-call

- Crisis intervention
- Mostly over the phone intervention
- Psychiatrist-on-call, is available if needed

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Chapter 2:

Mental Illness Information:
Mental Illnesses Most Prevalent with PACT
Clients

“The concept of recovery is rooted in the simple and yet profound realization that people who have been diagnosed with mental illness are human beings... The goal is to become the unique, awesome, never to be repeated human being that we are called to be... one of the most essential challenges that face us is to ask *who can I become* and *why should I say yes to life.*”

-Patricia Deegan-

About Mental Illness

In Manitoba, about 1 in 10 physician visits was considered as being 'for' mental illness. It is important to realize that mental illness touches the lives of all Canadians, exerting a major effect on relationships, education, productivity and overall quality of life for those directly affected and their families.

Approximately 20% of individuals will experience some form of mental illness during their lifetime and the remaining 80% will be affected by an illness of a family member.

In this chapter you will find a summary of information for mental illnesses most commonly experienced by PACT clients, namely:

- Schizophrenia
- Bipolar disorder
- Depressive disorder
- Anxiety disorder
- Borderline Personality Disorder

Axis System

An interesting bit of information that may be beneficial to know is learning what the Axis system means, as you may hear the terms “Axis I disorder or Axis II disorder” or read that information from health care providers.

The *Diagnostic and Statistical Manual of Mental Disorders–IV (DSM IV)* uses a five axis system to help organize a complete diagnosis:

- Axis I: All mental health disorders (e.g. schizophrenia, bipolar disorder, substance dependence disorder) except personality disorders and mental retardation (also called intellectual disability)
- Axis II: Personality disorders and mental retardation
- Axis III: Medical conditions that may be contributing to psychological problems

- Axis IV: Psychosocial and environmental problems (e.g., housing problems)
- Axis V: Global assessment of functioning (GAF) (how well a person is coping with daily life)

An example of an axis system diagnosis could look like:

- Axis I: Schizophrenia
- Axis II: Borderline Personality Disorder
- Axis III: Diabetes
- Axis IV: Homelessness
Lack of social supports
- Axis V: GAF 23

Schizophrenia

Schizophrenia is a serious but treatable mental disorder. It affects an individual's ability to know what is real and what is not. It is a disorder that often develops among individuals 15-25 years of age, a critical developmental period in a young adult's life. Schizophrenia often starts slowly. When the symptoms first appear, usually in adolescence or early adulthood, they may seem more confusing than serious.

Symptoms of Schizophrenia

The symptoms of schizophrenia are thought to be caused by disturbances in the flow of information in the brain. Like other illnesses, symptoms may vary from individual to individual. For many families, there is a period of time when it is difficult to decide whether the individual is having a really rough time that will eventually improve, or whether there is something more serious happening.

For an individual developing schizophrenia there is a period of time before they have a psychotic episode. Individuals developing schizophrenia may find themselves losing the ability to relax, concentrate or sleep; they may start to shut long-time friends out of their lives; work or school may begin to suffer; and personal appearance may be neglected. During this time, there may be one or more episodes where the individual speaks in ways that may be difficult to understand and/or start having unusual perceptions.

Health professionals call this period the “prodromal” period. As the disorder develops, you may notice additional symptoms such as:

- Moodiness, suspicion, anxiety, fear, aggressiveness
- Changes in personal care and hygiene which cause concern
- Lack of interest and motivation
- Loss of feeling or emotions

“First episode” of psychosis

The first time someone shows clear signs of psychotic behavior is called the “first episode” or “first break”. The assessment process is similar to an acute episode assessment. The physician will need a detailed history about the time leading up to the first episode including:

- When changes in behavior were first noticed and how behavior has changed
- Duration of psychotic signs and symptoms
- Recent decline in level of functioning
- Presence of depression
- Impaired attention and concentration
- Substance use or abuse
- Any family history of psychosis
- How long the psychosis has gone untreated
- Social and academic functioning in childhood and adolescence

This assessment will be done at a very stressful time in the progression of the illness. Family support is extremely important. Having just one person who will take on the role of health advocate can make a significant difference to successful recovery. The more family support that is provided, the better.

Positive and Negative Symptoms

Positive symptoms – new behaviors – of schizophrenia include hallucinations, delusions and thought disorders

The positive symptoms include:

- **Hallucinations:** A hallucination occurs when an individual hears, sees, tastes or experiences something that is not really there. Hearing voices is the most common hallucination
- **Delusions:** A delusion is a fixed false or irrational personal belief. These can include feelings of being persecuted, cheated or harassed, as well as delusions of grandeur (a false idea of oneself, e.g., as being famous)
- **Disordered thoughts:** An individual's thoughts may become unconnected, so that conversations no longer make sense. Their thoughts may come and go and they may not be able to focus for long on one thought
- **Cognitive difficulties:** An individual may have problems with memory, concentration and understanding concepts
- **Decline in social or occupational functioning:** An individual may have problems with work or school, or have trouble taking care of him or herself
- **Disorganized behaviour:** An individual may seem agitated or disoriented for no particular reason

Negative symptoms – behaviors taken away – include:

- Lack of motivation, energy and interest
- Blunted or flattening (hard to show or express) of the emotions
- Reduced communication
- Social withdrawal
- Difficulty generating thoughts and speech

During this time, the individual's ability to think clearly and logically will get worse. Their thinking may appear unusually slow or too fast or they may not respond at all. Every individual is different. One individual may think people on the bus are talking about her (delusion); another may hear a voice in his or her head (hallucination); and another may laugh at a sad story while another may be unable to show any emotion at all.

As the symptoms worsen, the ill individual may deny anything is happening and try to keep their feelings inside. They may avoid people, places and situations where their symptoms might be noticed. They may feel panic, anxiety and fear as they try to hide the illness.

It's important to remember...

- Individuals with schizophrenia can experience extreme sensitivity as a result of their illness. Their brains are sending mixed messages from the eyes, ears, nose, skin and even taste buds. Until treatment begins and coping strategies are learned, they have limited control over their actions or reactions
- The sooner the symptoms are recognized and treatment is started, the sooner an individual living with schizophrenia can work at getting their life back on track
- Patience and reassurance is essential to help individuals with schizophrenia feel they will have support throughout their recovery
- It is important to understand that there may be times when an individual living with schizophrenia will need to avoid some situations, like crowded gatherings, noisy events, etc. Even family gatherings may be too much at times. Respecting someone's right to say "no" at times is important to their recovery

Stages of Schizophrenia

The medical and research communities have agreed that there are three distinct phases individuals go through when they have schizophrenia:

Phase 1: Acute- when major symptoms make it clear that the individual needs medical help. It may come on very gradually or quite suddenly.

Phase 2: Stabilization- when the illness is out of the acute stage and symptoms are reduced.

Phase 3: Stable or chronic- the acute symptoms are being managed but there may still be difficulty with ability to function and periodic relapses.

The Canadian Psychological Association principles for medication treatment for schizophrenia are:

Acute Phase

1. The assessment in the acute phase should be as comprehensive as possible under the circumstances.
2. Particular attention needs to be paid to the potential for danger to self or others.
3. During the acute phase, the individual's experiences need to be acknowledged. Communication should be clear, simple and include family and support persons where possible. Explaining the individual's rights and any legal process is essential.
4. Medication treatment should be started as soon as possible. The risks and benefits of medications should always be explained.
 - Antipsychotic medications are needed for nearly all patients experiencing an acute episode. The choice of medication should be tailored according to what is happening with the individual
5. All the above principles apply in emergency situations. Emergency medication strategies are available to contain the patient and maintain the safety of others.

Stabilization Phase

1. The goal in this phase is to reduce the intensity and duration of psychotic symptoms as much as possible, minimize side effects and encourage the individual to follow their treatment plan.
2. Medications used for short-term control of agitated behaviour during the acute psychotic phase may not be the best choice during the stabilization phase.
3. Adjust the dosage to the individual within the normal range for each medication. Try to get the individual's cooperation in following their medication plan completely and consistently.

4. Significant and sustained reduction in acute psychotic symptoms often takes 4 to 8 weeks. Improvements in other symptoms and functioning may take much longer. Improvement may continue over one year or more of uninterrupted treatment.

5. Stopping or reducing antipsychotic medication during this phase places the individual at high risk for relapse.

Stable Phase

1. Relapse prevention is one of the most important goals of medication treatment in this phase.

- Maintenance of medication is needed to avoid relapse in the stabilization and stable phases

2. Over the longer term, other goals include minimizing negative symptoms and other conditions and promoting improved functional ability.

3. There is a lot of variation in the dosage of antipsychotic medications needed for functional recovery with minimal side effects.

4. It is crucial to have the individual participate in their treatment plan and to address personal barriers and resistance to ongoing therapy.

- A long-acting injectable antipsychotic medication should be considered for people who do not follow their treatment program consistently or who have trouble taking oral medication regularly

5. Assessments should take place regularly to review dosages, choice of antipsychotic medications and to monitor for drug-induced side effects.

- A major depressive episode during the stable phase of schizophrenia may indicate the need for a trial of an antidepressant.

6. There are no predictive factors indicating which individuals can safely and permanently discontinue antipsychotic medication.

- Clozapine may be indicated for people who have tried two or more other antipsychotic medication without sufficient improvement in positive symptoms, have intolerable side effects or unremitting aggressive or suicidal behavior.

Chances of a relapse

It is an unfortunate fact that individuals with schizophrenia often relapse. However, like all individuals with a chronic condition, it is important to:

- Watch for a return of symptoms
- Take medications exactly as prescribed
- Learn ways to cope with stress
- Lead a healthy lifestyle

Stressors such as major family events, hassles at home or other illnesses may trigger a relapse. There is usually fair warning – a week or more – that an individual is relapsing into psychosis. Some warning signs are:

- Trouble sleeping
- Social withdrawal
- Anxiety
- Depression
- Decreased insight
- Agitation
- Increase in delusional beliefs or hallucinations

Preventing a relapse is most successful when medication is taken exactly as prescribed and distressing side effects are reported so that the medication can be changed or adjusted. In the words of health professionals, successful “adherence to treatment” also involves maintaining a good relationship with the PACT team and having a family who know about the illness and can watch for signs and symptoms.

Bipolar Disorder

Ordinarily, individuals experience a wide range of moods. They feel more or less in control of their moods. When the sense of control is lost, individuals experience distress.

Bipolar disorder is a type of mood disorder in which an individual's mood cycles from mania to depression (in the case of Bipolar I) or hypomania to depression (in the case of Bipolar II).

Symptoms

There are three major groups of mood symptoms related to bipolar disorder. These are mania, hypomania and depression. In addition to mood symptoms, individuals must have at least three of the following symptoms to a significant degree to be diagnosed with bipolar disorder:

- Exaggerated self-esteem or grandiosity
- Reduced need for sleep
- Increased talkativeness
- A flood of ideas or racing thoughts
- Speeding up of activities such as talking and thinking, which may be disorganized
- Poor judgment
- Psychotic symptoms such as delusions (false beliefs) and in some cases hallucinations (mainly hearing voices)

Mania

If an individual's mood is abnormally or persistently high for at least one week, he or she may be in the manic phase of the illness. Those with an elevated mood (mania) can experience:

- Expansiveness
- Racing thoughts
- Decreased need for sleep
- Exaggerated self-esteem
- Grandiose ideas

- Increased talkativeness (pressured speech)
- Hyper-sexuality
- Increased spending

However, not everyone who enters the manic phase feels euphoric. Some individual's may:

- Be extremely irritable
- Behave rudely
- Become angry
- Become disruptive
- Become aggressive
- Become impatient with others
- Make hurtful statements
- Behave impulsively or even dangerously

Mania causes individuals to be emotional and react strongly to situations. For individuals with poor anger management skills or with low tolerance for frustration, this can lead to violent behaviour.

Hypomania

Hypomania is a milder form of mania with less severe symptoms. However, symptoms can interfere with the individual's ability to function. We now recognize that hypomania has more of an impact on an individual's life and relationships than was previously recognized.

Depression

Individuals with a depressed mood (depression) can have symptoms such as:

- Loss of energy
- Loss of interest
- Feelings of guilt
- Difficulty concentrating

Course of illness

The mania/hypomania, depressive and mixed (both mania/hypomania and depressive) states usually do not occur in a particular order. How often they occur cannot be predicted. For many individuals, there are years between each episode, whereas others have episodes more often, i.e. they cycle between moods more often.

Over a lifetime, the average individual with bipolar disorder experiences about 10 episodes of depression and mania/hypomania or mixed states. As the individual ages, the episodes of illness can occur closer together. Untreated mania often lasts for two or three months. Untreated depression usually lasts longer, between four and six months.

One in five individuals with bipolar disorder have four or more—sometimes many more—episodes a year and have short phases without symptoms. This is called rapid cycling, and is a subtype of bipolar disorder for which individuals need specific treatment. The cause of rapid cycling is not known. Sometimes, it may be triggered by antidepressants, but how this happens is not clear. In some cases, stopping the antidepressant may help the individual return to a “normal” cycling pattern.

Major Depressive Disorder

Symptoms

An individual who is experiencing at least 5 of the following symptoms meets the criteria for a diagnosis of a major depressive episode:

- 1) Depressed mood: A depressed mood is much different from sadness. In fact, many individuals with depression say that they cannot feel sadness, and many individuals cannot cry when depressed. Being able to cry again often means the depression is improving.
- 2) Loss of interest or pleasure: At the start of depression or with mild depression, individuals can still enjoy and be distracted by pleasurable activities. When individuals are severely depressed, they lose these abilities.

- 3) **Weight loss or gain:** Many individuals lose weight when depressed, partly because they lose their appetite, others however, may gain weight due to increased appetite. Depending on the type of depression, an individual's metabolism may speed up or slow down. This can also cause weight loss or gain.
- 4) **Sleep problems:** Sleep problems are common in depression. Many individuals have insomnia. They have trouble falling asleep, wake up often during the night, or wake up very early in the morning. They do not find sleep to be restful and may wake up feeling exhausted. Others may find that they sleep too much, especially during the day.
- 5) **Physical changes:** For some individuals with depression, their movements, speech and/or thinking slow. In severe cases, they may be unable to move, speak or respond. With other individuals, the opposite happens. They become agitated and cannot sit still. They may pace, wring their hands or show their agitation in other ways.
- 6) **Loss of energy:** Individuals with depression find it difficult to complete everyday chores. It takes them much longer to perform tasks at work or home because they lack energy and drive.
- 7) **Feelings of worthlessness and guilt:** When depressed, individuals may lack self-confidence. They may not assert themselves and may be overwhelmed by feelings of worthlessness. Many individuals cannot stop thinking about past events. They obsess about having let others down or having said the wrong things, and they feel guilty. In severe cases, the guilt may cause delusions.
- 8) **Inability to concentrate or make decisions:** Individuals may not be able to do simple tasks or make decisions on simple matters.
- 9) **Suicidal thoughts:** Individuals with depression often think that life is not worth living or that they would be better off dead. There is a high risk that they will act on these thoughts. Many individuals do try to kill themselves when depressed.

10) Psychotic symptoms: These may include false beliefs, such as believing they are being punished for past sins. Individuals with psychotic symptoms may believe that they have a terminal illness, such as cancer. They may also hear voices that are not there (auditory hallucinations).

Other symptoms of depression may include:

- Oversensitivity and preoccupation with oneself
- Negative thinking
- Little response to reassurance, support, feedback or sympathy from others
- Less awareness of other's feelings because of one's own internal pain
- Feeling a need to control relationships
- Inability to function in a normal role

Course of illness

A first episode of depression can occur anytime in an individual's life. Most individual's struggle for long periods with the symptoms before seeking mental health intervention. They may have undergone several stressful events, and have tried to manage their mood fluctuations, only seeking help when they experience serious difficulties coping at home, at work or in important relationships.

An individual may be diagnosed as having had a "single episode" (meaning that this is the first time he or she has experienced a major depression) or "recurrent episode" (meaning that the individual has experienced at least one previous episode of major depression). Different episodes may vary in severity: some episodes may be minor and have less impact on an individual's ability to function, while others may be more severe and result in significant disruption to an individual's life.

Anxiety Disorders

Anxiety disorders take on several different forms, and are the most common type of mental health disorder. They have different causes and symptoms, but one thing individuals with anxiety disorders share is feelings of deep anxiety and fear that affect their mood, thinking and behaviour. When someone has an anxiety disorder, his or her thoughts and feelings may get in the way of taking the actions needed to be healthy and productive. These illnesses are chronic and can get worse over time if they are not treated.

In this resource we will discuss three common types of anxiety disorders:

Generalized anxiety disorder
Panic disorder
Social phobia

Generalized Anxiety Disorder

Individuals who have experienced at least six months of ongoing and excessive anxiety and tension in various types of situations may have generalized anxiety disorder. They usually expect the worst and worry about things, even when there is no sign of problems.

Symptoms

- Insomnia
- Fatigue
- Trembling
- Muscle tension
- Headaches
- Irritability
- Hot flashes

Panic Disorder

Panic disorder occurs when an individual has repeated panic attacks, which is the sudden onset of intense fear or terror. During these attacks, individuals may experience physical symptoms such as:

- Shortness of breath
- Heart palpitations
- Chest pain or discomfort
- Choking or smothering sensations
- Fear of losing control

Many individuals with panic disorder develop anxieties about places or situations in which they fear another attack, or where they might not be able to get help. Eventually this can develop into agoraphobia, a fear of going into open or public spaces. Women are twice as likely as men to develop panic disorder, which usually begins in young adulthood.

Social Phobia

Individuals with social phobia experience a significant amount of anxiety and self-consciousness in everyday social situations. They worry about being judged by others and embarrassed by their own actions. This anxiety can lead them to avoid potentially humiliating situations. Other symptoms such as blushing, sweating, trembling, problems talking or nausea can also occur. Women are twice as likely as men to develop social phobia, which typically begins in childhood and early adolescence.

Personality Disorders

Personality is a way of describing how an individual thinks, feels and behaves and the particular ways in which they understand and react to situations (e.g., their emotional response to an upsetting situation; their usual way of coping with stress; or how they understand and react to the external world).

Personality disorders can have symptoms that are similar to mood, anxiety, psychotic and impulsivity disorders. Diagnosing personality disorders is open to error. The diagnosis is often used to describe a set of symptoms that do not fit into any other category. The *DSM-IV* divides personality disorders into three clusters: psychosis, impulsivity and anxiety.

Cluster A - (psychosis dimension) consists of schizoid personality disorder, schizotypal personality disorder and paranoid personality disorder. It is characterized by disturbances in cognition and perceptual organization in ways that resemble psychotic processes, although are usually less severe.

Cluster B - (impulsivity dimension) includes antisocial personality disorder, borderline personality disorder, narcissistic personality disorder and histrionic personality disorder. This cluster is characterized by impulsive behaviours.

Cluster C - (anxiety dimension) includes avoidant personality disorder, dependent personality disorder and compulsive personality disorder.

The personality disorder that is experienced most often by clients of PACT is borderline personality disorder.

Borderline personality disorder

Borderline personality disorder is the most common personality disorder for which people seek treatment. The essential features of borderline personality disorder are a pervasive pattern of marked impulsivity and instability in interpersonal relationships, self-image and affects.

There is tendency to regress (i.e. to adopt childish behaviours and expectations) when placed in situations where what is expected of them is not clearly explained. In addition, individuals with borderline personality disorder can cling not only to people in real life, but also to objects that they associate with people.

The characteristics of borderline personality disorder can occur in various combinations. Individuals with the disorder have many, if not all, of the following traits:

- Fears of abandonment
 - Hate being alone, are intensely dependent on others
- Frequent feelings of boredom
 - Constantly seeking stimulation to overcome chronic feelings of boredom and emptiness
- Extreme mood swings
 - Intense anger or lack of control of anger
 - Moods are intense and brief
 - Marked shift in mood, irritability, or anxiety
 - Difficulty managing emotions
- Difficulty in relationships
 - Difficulty getting along with others
 - See people in black and white; extremes
 - Unique capacity for creating disagreements between other people (splitting)
- Unstable self-image
 - Confusion about who they are and what they believe in
- Suicidal ideation
 - Frequent threats of suicide or efforts to hurt themselves
- Transient psychotic episodes
- Impulsive behavior
 - Problems related to substance abuse, sexual behaviour, spending, shoplifting, reckless driving, or binge eating
 - Self-harming acts

Self-harm can be described as substituting physical pain, which is easier to tolerate and plainly visible, for emotional pain, which is experienced as intolerable and is mostly invisible to others. Many individuals with borderline personality disorder who self-injure report an immediate sense of relief from emotional pressure afterward.

It is important not to overreact by believing that every act of self-injury has suicidal intent. It is equally important not to underestimate the risk of suicide in individuals with borderline personality disorder. Self-mutilation in itself is a risk for suicide.

Because of their lability and manipulative histories, individuals with borderline personality disorder evoke attributions of deficits in character rather than brain chemistry.

It is very hard for families to see individuals with borderline personality disorder as sick when they are so functional in other ways and so disturbingly inconsistent in their interactions with other people. Yet families of individuals with borderline personality disorder excuse extreme behaviours by attributing such behaviour to the illness. It is a constant shift between accountability and non-accountability about the best way to behave, that makes life difficult for families and treatment teams, and feeds into the behaviour and attention seeking of the individual.

Suicide

Unfortunately the risk of suicide is higher in those diagnosed with a serious mental illness. It is important for the family of those who have been diagnosed with a mental illness to be aware of the warning signs of suicide and to act if and when they are present. There are several warning signs that an individual is considering suicide. He or she may:

- Discuss suicide and what it would be like to have things end
- Be concerned with providing for children, other family members or pets
- Give away possessions
- Express feelings of worthlessness, such as, “I’m no good to anybody”
- Feel hopeless about the future, reflected in comments such as, “What’s the use?”
- Talk about voices that tell him or her to do something dangerous

What to do if you find someone after a suicide attempt:

- Phone 911 immediately
- If you know first aid, administer it immediately
- Phone someone to accompany you to the hospital or to stay with you at home
- Phone PACT

Do not try to handle the crisis alone; contact a team member at PACT or a support group to help you with your immediate reactions and long-term feelings.

Winnipeg Suicide Statistics

The age- and sex-adjusted suicide rate is 1.2 per 10,000 Winnipeggers per year, just under the provincial average of 1.32 and on par with the Canadian average which is 1.2 per 10,000 deaths by suicide

In the community area data, Point Douglas has double the rate of suicide as Winnipeg (2.4 vs. 1.2 per 10,000)

The suicide-attempt rate is 5.5 per 10,000 Winnipeg residents per year, with females attempting twice as often as males (6.6 versus 4.3 per 10,000 per year)

The most common means of attempting suicide was by poisoning (usually a drug overdose) for both males (71.7%) and females (87.0%)

When risk factors are considered, the key factors predicting a suicide attempt are having a mental illness diagnosis in the previous year, poor health, being young, female, and living in a low income area

In general females are more likely to attempt or complete suicide up to the age of 65 when males are then more likely to attempt or complete suicide

All factors considered, being female, being young, being diagnosed with a mental illness in the previous year, and living in a low neighborhood income area are risk factors for attempting or completing suicide.

Medication Information

Here is a brief list of commonly dispensed psychotropic medications:

Antipsychotics:

- **Typical Antipsychotics:**
 - Chlorpromazine (Thorazine)
 - Methotrimeprazine (Nozinan)
 - Haloperidol (Haldol)
 - Zuclopenthixol (Clopixol)
 - Fluphenazine (Modecate)

- **Atypical Antipsychotics:**
 - Clozapine (Clozaril)
 - Olanzapine (Zyprexa, Zydys)
 - Quetiapine (Seroquel)
 - Risperidone (Risperdal)

Common antipsychotic medication side-effects:

- **Extrapyramidal symptoms**
 - Pseudoparkinsonism
 - Hypersalvation
 - Muscle rigidity
 - Fine tremors
 - Akinesia
 - Movement is slowed or difficult to initiate
 - Akathisia
 - Inability to sit still
 - Restlessness, pacing, fidgety
 - Dystonia
 - Painful spasms of major muscle groups in neck, back, eyes and face
 - Tardive dyskinesia
 - Impaired/abnormal muscle movement occurring after prolonged use of antipsychotic medications

- Neuroleptic Malignant Syndrome
 - Due to rapid increase in dosage when more than one antipsychotic is being taken
 - Fever
 - Muscle rigidity
 - Tachycardia (heart rate greater than 100 beats per minute)
 - Tachypnea (more than 20 breaths per minute)
 - Fluctuations in blood pressure
 - Profuse sweating
 - Shivering
 - Incontinence
 - Confusion

- Seizures

- Agranulocytosis
 - Deficiency in granulocytes
 - More common when taking Clozapine
 - Fever
 - Exhaustion
 - Chills
 - Sore throat
 - White blood cell count monitored via blood work and GENCAN every week initially, then every two weeks, then monthly

- Sedation

- Weight gain

Mood Stabilizers:

- Lithium
- Carbamazepine (Tegretol) -also an anticonvulsant
- Valproic Acid (Depakene, Valproate) -also an anticonvulsant
- Lamotrigine (Lamictal) -also an anticonvulsant
- Gabapentin (Neurontin) - also an anticonvulsant
- Topiramate (Topamax) - also an anticonvulsant

Common mood stabilizing medication side-effects:

- **Lithium:**
 - Fine hand tremor
 - Fatigue
 - Headache
 - Mild nausea
 - Toxicity
 - Nausea
 - Vomiting
 - Diarrhea
 - Diminished appetite
 - Course tremors
 - Confusion
 - Slurred speech
- **All others:**
 - Drowsiness
 - Dizziness
 - Blurred vision
 - Nausea
 - Vomiting
 - Diminished appetite

Antidepressants:

- **Cyclic antidepressants:**
 - Amitriptyline
 - Imipramine
 - Nortriptyline
 - Trazodone
- **Selective Serotonin Reuptake Inhibitors (SSRI's)**
 - Citalopram (Celexa)
 - Fluoxetine (Prozac)
 - Sertraline (Zoloft)
- **Serotonin-Norepinephrine Reuptake Inhibitor (SNRI)**
 - Venlafaxine (Effexor)
- **Norepinephrine-Dopamine Reuptake Inhibitor (NDRI)**
 - Bupropion (Wellbutrin)

Common antidepressant medication side-effects:

- Drowsiness or insomnia
- Dry mouth
- Constipation
- Blurred vision
- Orthostatic hypotension
- Headache

Anti-anxiety medication:

- Diazepam (Valium)
- Lorazepam (Ativan)
- Clonazepam (Klonopin)
- Alprazolam (Xanax)
- Buspirone (BuSpar)

Common medication side-effects:

- Drowsiness, sedation
- Dizziness
- Feelings of detachment
- Dependency

A successful recovery from mental illness should involve a number of approaches that go well beyond medication and hospitalization. Research and experience show that the best basis for recovery involves active participation of the individual and family in ongoing treatment. This includes education, training and skills development not only for coping with mental illness but with life in general. Knowledge is a powerful tool for the individual and family living with a mental illness. The more that is known about mental illness and how it can affect an individual's perceptions about the world around them and their internal world, the better those perceptions can be understood.

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Chapter 3: Substance Abuse

"The feeling of being valuable - 'I am a valuable person' - is essential to mental health and is a cornerstone of self-discipline."

-M. Scott Peck-

Substance use and Mental Illness

Severe mental health problems, such as schizophrenia or bipolar disorder, may leave an individual more vulnerable to developing substance use problems.

Individuals with mental illness generally abuse substances for three reasons:

- To temporarily reduce symptoms or side-effects of medication
- To enhance their social life and reduce feelings of isolation
- To increase pleasant feelings as an solution to the distress and loss associated with mental illness

This is called self-medication.

Substance use commonly seen within PACT:

- Tobacco
- Gravol
- Marijuana
- Alcohol
- Crack Cocaine
- Solvents
- Methamphetamines

In addition, individuals with a mental health problem tend to develop substance use problems with lower amounts of alcohol or other drug use than people who do not have mental health problems.

Effects of substance use

Substance use can induce psychiatric symptoms. For example, an individual using significant amounts of cocaine could become paranoid to the point of being psychotic. Substance use can not only induce psychiatric symptoms, but can also lead to psychosocial problems that may, in turn, lead to mental health problems. For instance, severe paranoia could lead to psychosocial problems such as trouble in family relationships, trouble at work and trouble with the law. These problems could lead to a mental health problem such as depression.

Co-occurring substance use and mental health problems affect individuals differently, and depend on factors such as the combination and severity of the problems. For example, individuals with severe mental illness who also have substance use problems tend to experience a wide range of serious problems. Common issues include:

- More severe psychiatric symptoms, such as depression and hallucinations
- More dramatic effects after using substances, including more blackouts
- A greater chance of not following treatment plans
- Physical health problems
- Increased experiences of stigma
- Financial problems
- Housing instability and homelessness
- Poorer management of personal affairs
- Serious relationship problems with family members
- More verbal hostility, tendency to argue, disruptive behaviour, and aggression
- Violence or crises that may end up involving the police
- A greater likelihood of ending up in jail
- Increased suicidal feelings and behaviours

Because of the overlap of symptoms between mental health and substance use disorders, it is often difficult to make a firm diagnosis in the early stages of treatment. The best way to tell the difference between the symptoms caused by substance-related and other mental health problems is to observe the individual when no substances are being used. Usually, the required period of abstinence depends on the substances being used and the suspected mental health problem.

For some individuals, getting substance use under control will produce immediate positive changes in mental health symptoms. For others, it can mean that their mental health symptoms become more active. Understanding the relationship between the substance use and mental health problems is crucial to working successfully with people to choose treatment strategies and anticipate outcomes.

CODI

In Winnipeg, the Winnipeg Regional Health Authority adopted an initiative to address the issue of co-occurring mental health problems and substance use. The initiative is called the Co-occurring Mental Health and Substance Use Disorders Initiative (CODI). Individuals with co-occurring mental health and substance use disorders have been identified as a distinct group with special service needs.

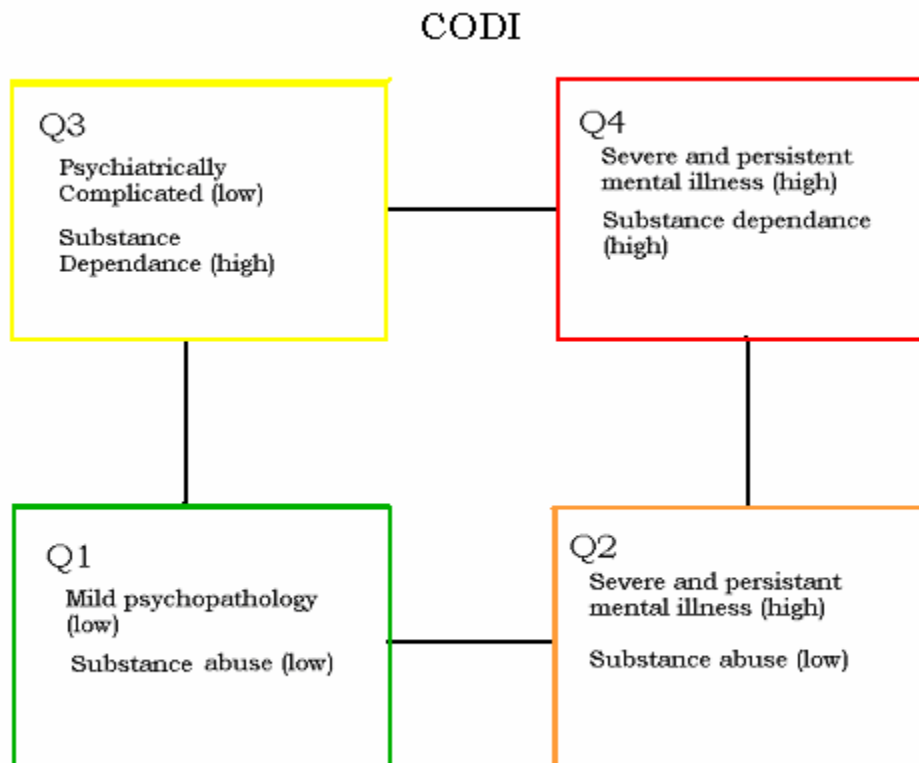
It is widely acknowledged that neither the mental health system nor the substance abuse system is well organized to address the special services needs of this group. These individuals often tend to fall through the cracks, resulting in an over-utilization of resources. There is growing research evidence that individuals with co-occurring disorders represent a significant proportion of individuals that appear in both mental and addiction service settings.

The needs of these individuals must be acknowledged and addressed across services settings in both systems. The combined system should offer a comprehensive array of services delivered in a coordinated and continuous fashion—a system where there would be NO WRONG DOOR.

In order to provide more accessible, integrated services to these individuals, the Initiative adopted the Comprehensive, Continuous, Integrated System of Care (CCISC) model developed by Dr. Kenneth Minkoff. This model is based on a

set of best practice principles. The following seven CCISC principles were adopted by Winnipeg CODI:

- 1) Co-occurring disorders as an expectation, not an exception
- 2) Empathetic, hopeful, clinical relationships
- 3) Four population subgroups
 - a. Quadrant IV-Severe and persistent mental illness (high)
- Substance dependence (high)
 - b. Quadrant III-Psychiatrically complicated (low)
- Substance dependence (high)
 - c. Quadrant II – Severe and persistent mental illness (high)
- Substance abuse (low)
 - d. Quadrant I- Mild psychopathology (low)
- Substance abuse (low)



The quadrant framework suggests that where an individual has:

- *Both substance use and mental health problems of low to moderate severity*, primary health care (e.g., family doctors) and community health resources are the core resources to draw on
- *A substance use problem of high severity, with a mental health problem of mild to moderate severity*, specialized substance use services, like Addictions Foundation of Manitoba (AFM), are the lead resources, with mental health services providing collaborative care
- *A mental health problem of high severity, with a substance use problem of mild to moderate severity*, specialized mental health services, such as PACT, are the lead resources, with substance use services providing collaborative care
- *Both substance use and mental health problems of high severity*, strong evidence suggests that integrated care by a single, multidisciplinary team, like PACT or the CODI Outreach Program, is the most effective way to provide continuing care and support

4) Balancing support with empathetic detachment

5) Addressing both conditions as primary disorders

6) Parallel phrases of recovery

7) Individualization of outcomes

- Harm reduction
- Stages of change

Motivation and Change

Motivational interviewing is an interviewing technique that the PACT team uses to discuss substance use (and other areas where clients would like to change). It is a client-centred, semi-directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence.

Motivational interviewing is non-judgemental, non-confrontational and non-adversarial. The approach attempts to increase clients' awareness of the potential problems caused, consequences experienced, and risks faced as a result of the behaviour in question.

Motivational interviewing seeks to help clients think differently about their behaviour and ultimately consider what might be gained through change.

Motivational interviewing is based upon four principles:

Expressing Empathy	It guides professionals to share with clients their understanding of the clients' perspective.
Developing Discrepancy	It guides professionals to help clients appreciate the value of change by exploring the discrepancy between how clients want their lives to be versus how their lives current are.
Rolling with Resistance	It guides professionals to accept client reluctance to change as natural rather than pathological
Supporting Self-Efficacy	It guides professionals to explicitly embrace client autonomy and help clients move toward change successfully and with confidence.

Stages of Change

Changes in behaviour in an individual takes time and can occur over a series of stages. The PACT team members have to recognizing what particular stage a client is at before they can help decide which interventions are more likely to be successful at a particular point in treatment and recovery.

There are five basic stages of change:

- Pre-contemplation
- Contemplation
- Preparation
- Action
- Maintenance

Some individuals move steadily through the stages toward recovery. Others move rapidly and then slow down or stop for a while. Individuals often relapse (return to problematic behaviours), that is, move backward through the stages, and then move forward again.

Stages of change examples

Stage	Example
Precontemplation	"I don't think I have a problem"
Contemplation	"I'm not sure, but I might have a problem"
Preparation	"I think I have a problem, but I am not sure what to do about it"
Action	"I have a problem, and I want to change it. I know where to get help with the change if I need it"
Maintenance	"I have already made changes and I want help to maintain them"

When people have co-occurring disorders, abstinence is often the best long-term substance use goal. Continued use of alcohol and/or other drugs may worsen emotional and mental health problems and threaten an individual's overall physical and psychological well-being. However, many individuals may, at least at first, lack the confidence and skills to decrease or stop their substance use.

When the PACT team works with someone who is struggling with both, major substance use and mental health problems, the short-term goal is often to reduce the most harmful effects of substance use while developing a strong working relationship with the client. This trusting relationship can help clients understand the negative effects of their substance use and develop the motivation to address it. This approach—not requiring the person to commit to abstinence as a condition for help—is called *harm reduction*.

Substance use and the family

When families learn that a relative has both a mental health disorder and a substance use disorder, they often feel shocked and scared. Mental health disorders on their own can overwhelm families. Families who once had a safe and comfortable daily routine may find themselves on an emotional roller coaster.

Some family members may find it almost impossible to soothe their own anxieties, and distract themselves from the strain of coping with their relative.

- You may feel unable or even guilty to take time for yourself, to relax, care for your own emotional and physical health, and rebuild your own coping resources
- Sometimes, you may even feel guilty if you experience resentment or anger. You should admit if you are extremely tired, worn out, angry or bitter. Denying these emotions can lead to exhaustion, depression, isolation and hopelessness
- Families may feel isolated from others who were once very good friends. You might feel that you do not have the time to maintain friendships, or you may be embarrassed or ashamed about the co-occurring disorder that affects your family member

Having a co-occurring disorder obviously affects the person experiencing the disorders directly, but they also have powerful effects on family members and friends. As problems become more complex, family members are often confused about which problems are causes, and which are outcomes. They are often puzzled and frustrated if their relative continues to use alcohol or other drugs when the consequences are so severe.

Family members may be concerned about leaving their family member alone because they are worried that he or she will take harmful drugs, forget to take medications, take part in dangerous or criminal behaviour to get illegal drugs, or harm him or herself during a serious episode of illness.

Substance use problems can interfere with an individual's ability to follow family routines and meet their responsibilities. They may:

- Spend more time getting and using substances, and less time or no time in their usual activities
- Have financial problems (the cost of using substances can become quite high; in some cases, substance use can lead to job loss, which can create further money problems)
- Act out physically

If your relative does not want you involved

Even if your relative has not agreed to share information with you about their substance use, the PACT team can still talk to you about:

- The nature of substance use and mental health problems
- How to respond to disturbing behaviours
- How to get help in an emergency
- How to get help for yourself

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Chapter 4: Supporting your family member

“Recovery involves a shift in consciousness of giving up the “sick” label, or seeing oneself, at core, as neither patient, nor even psychiatrically disabled, but as a unique individual with aspirations, strengths, and challenges, in short, a person in recovery”

-Paul Carling, 1995-

Family

Families can have a significant effect on the course of serious mental illness, in that their behavior toward their mentally ill relative can often facilitate or impede recovery. For example, family members may interfere with their relative with [mental illness] recuperation if in their natural enthusiasm to promote and support progress they create unattainable demands and expectations. Conversely, relatives who understand these disorders as medical conditions and adopt a more patient and tolerant approach and learn adaptive coping strategies, may achieve outcomes in their ill relative that exceed empirical expectations (Kuipers & Bebbington, 1988)

There is no replacement for the support a family can provide to a loved one who has a mental illness. The family's role in the treatment and recovery of clients of PACT is pertinent, as is how well family members take care of their own personal needs. This chapter discusses the role family member's play in supporting their diagnosed loved one, and what that role means to them.

Support

Family support means conveying to the individual that they are valued and loved, that their feelings are actually understood, and being a good listener. PACT provides support with housing, budgeting, vocational endeavours, and skill building, so that families can be families without taking on the extra responsibility.

In an effort to maintain commitment to their family member, families should consider ways to do this without subjecting other family members to too much fatigue and discouragement. If a family burns out, there is really no adequate replacement.

Families can help the individual with identifying goals that they would like to accomplish and help motivate them to achieve those goals; praise any achieved goals; encourage medication compliance and foster an environment of trust and consistency.

Creating a supportive environment

Individuals with mental illness experience an overwhelming number of painful and disorganizing effects on their lives:

- Sensory overload and confusion
- Difficulties in focusing attention and in concentration
- Strange and unpredictable perception
- Intense, changing, unpredictable moods
- Feelings of helplessness, incompetence and dependence
- Difficulty in accepting the mental illness and in coming to terms with the limitations it imposes

Families can help by:

- Reducing stimulation
 - Too many people around, too much activity, or too much noise can cause confusion and stress
 - Keep things calm and quiet
 - Some individuals have over-acute senses
 - Give the individual some time alone
- Creating a predictable environment
 - Be consistent and predictable in reactions to the individual's behaviour
- Using words carefully
 - Confusing or inconsistent statements should be avoided
 - Present ideas or explanations one at a time
 - Learn to recognize and avoid words that have a negative meaning for the individual to avoid agitation
 - Listen empathically without interrupting to correct mistakes or disagree
- Supporting the growth of confidence and self-esteem
 - Expectations should be gradually increased
 - Help the individual to identify short term goals that can contribute to long term ones
 - Try to be accepting of the often unconventional appearance and language

- Helping the individual come to terms with his or her illness
 - Do not be surprised if the individual denies they have a mental illness, as it may take years to come to term with this fact
 - Do not try to argue about delusional beliefs, they are real to the individual
- Facing the effects of mental illness on the family
 - Turn to others to express feelings of having someone with a mental illness in your family, like relatives, friends, or support groups
 - Families often need respite care from their family member

Recognizing, resisting and reconstructing

1) Recognizing- Learning to recognize behaviours that are purposeful and those that seem to be inherent and hard to control

2) Resisting- Resist being drawn into a vortex of dysregulation and irrationality.

- It can be hard to stay calm and avoid conflict when the family member is acting out
- A family's anger, criticism, and rejection can heighten the fragmentation of the individual's uncontrollable world
- Abusive language should not be answered the same way, but in a calm response
- staying calm, maintaining boundaries without rejection can be effective in defusing emotional storms

3) Reconstructing- Re-building a meaningful relationship with an individual who has seemed to be incapable to relating in meaningful ways

Communication Tips

- Avoid unnecessary criticisms and conflict and learn to express your concerns in a non-judgmental way
- Use “I messages” rather than “you messages”
- Listening attentively and responding empathically as mental illness sometimes makes it difficult for an individual to communicate effectively
- Speaking clearly and directly, and keeping messages brief and straightforward.

Instilling Hope for Recovery

Recovery is defined by a belief in one’s self. It is nurtured by the kindness, understanding, compassion and respect of friends, family and others who are significant in one’s life. Ultimately, recovery involves sharing and gaining support from others.

Recovery is a process of regaining lost skills, dreams and hopes, as well as renewed purpose and meaning

Recovery has been referred to as a process, an outlook, a vision and a guiding principle. Recovery has also been described as a process by which people recover their self-esteem, dreams, self-worth, empowerment, pride, dignity and meaning. For professionals and families, recovery is about treating the whole person; identifying their strengths, instilling hope, and helping them to function by helping them take responsibility for their lives.

Recovery is also about refusing to settle for less. A positive way of looking at recovery is to embrace the humanity of people and their potential for change. People are *people, family, and friends* before they are diagnoses, or cases, clients, clients, or consumers. They are not defined or controlled by their symptoms.

Individuals should be encouraged to:

- Have hope for change
- Form meaningful connections with others who understand their situation
- Set their own goals
- Nurture their interests and learn new skills
- Develop self-awareness about aspects of their own illness and behavior

Recovery...

- Does not necessarily move in one direction; recovery implies learning from setbacks and having the courage to move forward in spite of them
- May occur even when symptoms are present; recovery does not necessarily mean that people will never again experience symptoms, go through hard times or relapse
- Is facilitated by access to a support system, but it can occur without the intervention of mental health professionals
- Must also involve attending to other areas of life, such as work, leisure time, life goals and dealing with stigma
- Relapse can be part of the overall recovery process. It is important to use setbacks or relapses as valuable learning opportunities

Key Factors in Recovery

For people with mental disorders to achieve and maintain recovery, they need to:

- Be treated as unique and important
- Be treated as human being with goals and dreams
- Have the freedom to make choices and decisions about their lives
- Be treated with dignity and respect

- Accept that their unique journey through life has taken a different path
- Recognize that recovery is the potential to become free of symptoms by following an individualized treatment plan
- Have meaningful relationships with others who care and do not stigmatize
- Recognize that spirituality or religious beliefs and practices may be important.

Tips for families

- **Believe in the ability of people to change**
- **Be there**
- **Share your concerns—not your advice**
- **Accept that people are in-charge of their own lives**
- **Provide practical help**
- **Learn as much as you can**
- **Heal yourself**
- **Be patient**

The 3 R's of Family

Family plays a key role in the recovery of a loved one diagnosed with a mental illness. There are many elements considered important for your loved one's recovery that may overlap with your own journey of recovery. It is important for family to know their roles, rights, and responsibilities during the recovery process.

It is equally important for the family member diagnosed with a mental illness and for the professionals working with them to know their own rights and responsibilities.

Roles of Family

- Having hope about your own and your relative's future
- Being educated about your loved one's mental illness and substance use disorder and understanding how these problems interact
- Having supportive relationships with others in the family and community who are caring and do not judge or stigmatize
- Being considered a knowledgeable, engaged and respected part of your loved one's PACT team, and being kept informed by the PACT team
- Accepting that your loved one's journey through life has taken a new course
- Understanding that if relapses occur it does not mean that your relative has "failed" or lost previous gains
- Be positive and supportive. Encourage all positive efforts. Express appreciation for a job even half done
- Assist the ill person to set realistic goals. Encourage him or her to gradually regain former skills and interests
- Together, learn how to positively cope with stress.
- Learn from and enjoy the support of others who have similar problems

Rights of Families, Clients, and Professionals

- Family
 - Not be blamed or abused
 - To lead a normal family life
 - To be given information about the illness and how to help
 - To have information about the illness and ways to cope
 - To access information on advocacy and support

- Clients
 - To be provided with safety, security, and decreased stress while ill
 - To receive appropriate information about illness, treatment, and role

- PACT team
 - Not to be abused
 - Not to be expected to know it all
 - To be given honest, complete experiential information

Responsibilities of Families, clients, and professionals

- Family
 - To accept the illness and the ill person
 - To participate in treatment and rehabilitation
 - To learn as much as possible about the illness and family role
 - To share your experiences and observations of the patient with the professionals
 - To take good care of your own physical and emotional health
 - To seek out advocacy and support groups for yourself

- Clients
 - To accept the illness
 - To seek and cooperate with treatment
 - To learn as much as possible about the illness

- PACT
 - To accept the client and family as individuals
 - Give the most appropriate, current information as possible to client and family

Family Loss and Burden

When family learns that their child or sibling has a [mental illness], their emotions are similar to those experienced when a major illness, catastrophe, or accident occurs. They feel shocked, sad, angry, and dismayed.

Some affected families have described their feelings as follows:

- Sorrow- “We feel like we have lost a child”
- Anxiety- “We are afraid to leave him alone or hurt his feelings”
- Fear- “Will we be safe from physical harm?”
- Shame and Guilt- “Are we to blame? What will people think?”
- Feelings of Isolation- “ No one can understand”
- Depression- “We can’t talk without crying”
- Denial of the Illness- “This can’t happen in our family”
- Denial of the Severity of the Illness: “This is only a phase that will pass”
- Blaming- “If only you had been a better parent”

Unfortunately, a common tendency is for family members and the afflicted person to blame one another. Moreover, sisters and brothers often share shame and fears that their parents do. With time, a good understanding of the illness, and support from others who are experiencing the same challenges, family members can learn to share their feelings and stop destructive blame and shame.

Families need to give up “the wish to be blamed” and accept the reality that just as they did not cause the condition of their loved one, they cannot cure it.

It is important for family members to be able to recognize the feelings of burden associated that can arise when a family member has a mental illness. There are two types of burden: subjective and objective.

Subjective burden are feelings and emotions as described and felt by family members, such as: grief, loss, shock, disbelief, anger, despair, guilt, anxiety and shame.

- Grief - Mourn the relative they knew before that onset of the illness. The family experiences anguish and personal loss
- Symbolic loss- Hopes, dreams expectations one had for the individual

- Chronic sorrow- Continued feelings of grief and loss that increase and subside
- Emotional rollercoaster- Emotions changing by the periods of remission and relapse
- Empathic pain- Witness the family member's continued struggle with mental illness and impoverished life

Objective burden is the events that occur as a result of having a family member with a mental illness such as: the symptoms of mental illness, caregiving responsibilities, family disruption and stress, and social stigma

- Symptomatic behavior- Positive symptoms, negative symptoms, disturbances in mood, potentially harmful or self-destructive behavior, socially inappropriate or disruptive behavior and poor daily living habits
- Caregiving- Family members have to assume roles for which they are unprepared and untrained
- Family disruption and stress- Problems may include household disarray, financial difficulties, employment problems, strained marital and family relationships, impaired physical and mental health, and diminished social life
- Stigma- The most oppressive component of family. Families may feel lower self-esteem and damaged family relationships, risk of self-stigmatization, and feelings of isolation and shame.

Remember !

- Don't try to go it alone! People living with a mental illness need a strong care team
- Whether you have a mental illness or are close to someone who does you will need ongoing support with the challenges you will face
- The best recovery is made possible by combining effective treatment and strong support networks
- Family involvement and understanding are essential to recovery

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Chapter 5: Boundaries and Limit Setting

“Recovery is a process, a way of life, an attitude and a way of approaching the day’s challenges. It is not a perfect linear package. At times our course is erratic and we falter, slide back, regroup, and start again...The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution”

-Patricia Deegan-

Why set limits?

Setting limits is an important part of treatment for people with a mental illness. It not only establishes appropriate expectations for your family member, it allows families the right to say “no” in order to respect their own right to a decent life.

Family members may feel guilty when they set limits on their mentally ill family members’ behaviours or insist that he or she follow the rules and guidelines that everyone else in the family is expected to follow. By refusing to set limits, families may believe that they are being helpful in preventing their relative from becoming unnecessarily upset or angry; however by refusing to set limits, families are enabling the behaviours that they are unhappy with.

Examples of enabling behaviours that are best to avoid are:

- Making excuses
- Paying their bills
- Giving extra money, often over and over again, and being surprised when it’s used to buy more alcohol or other drugs
- Bailing the person out of jail
- Making excuses for irresponsible behaviour
- Ignoring problems caused by the person’s substance use
- Accepting excuses or believing lies

Consistent rules and boundaries can help to create a sense of predictability and security. Setting limits can also help to prevent conflicts from turning into crises. Conflicts can result from interpersonal or intrapersonal problems between the individual who is mentally ill and his or her family members, between the mentally ill individual and other people, or between the mentally ill individual and their internal stimuli.

How to set limits

Setting limits and being able to state expectations clearly and honestly is difficult and involves understanding the difference between supportive and enabling. Setting limits is important for the family, as no one should have to live in a dangerous or disturbing environment. Certain behaviors are not acceptable and should not be tolerated, such as behavior that is:

- Abusive
- Self-destructive
- Harmful to others
- Damaging to property
- Severely disruptive
- Projected rage- yelling, swearing
- Blaming
- Dangerous behaviour
- Stealing from family members or friends
- Misuse of money that is intended for rent or other basic needs

Families need to decide which behaviours are unacceptable, set clear limits, and impose consequences when those limits are exceeded. It is important to decide which behaviours can be ignored.

It may be helpful to have a list of unacceptable behaviours and the actions that will be taken by family members should those behaviours continue. Limits should be based on reasonable expectations for all family members. The expectations should reflect their age, their role in the family, and their strengths and limitations.

When objecting to unacceptable behaviour, be clear and request specific changes in the individual's behaviour. For instance:

- Identify problems
- Work on one problem at a time
- Avoid making demands or becoming confrontational
- Clearly state your expectations for the future in a positive, non-judgmental, and non-threatening manner

- Help the person to understand the consequences of ignoring a boundary or limit on a particular behaviour
- Be consistent in both limit-setting and following through with consequences
- Review the limits set on particular behaviours and re-design the plan as necessary

Family members must realize that they do not have absolute control to change things and cannot be responsible for all of their relative's actions.

Aggressiveness

Some individuals may be aggressive at times. They may harass, threaten, or actually assault other people. Since aggressiveness has a tendency to feed on itself, such behaviour should not be tolerated.

Careful plans should be made if such an occurrence arises. Families need to take a close look at the aggressive behaviour and the circumstances surrounding it. This gives a better understanding of the reasons for the aggression, the purpose it serves, and the factors that keep it going.

If your family member does lose control:

- Learn to pick up on cues that indicate that the individual is beginning to lose control
- Stay calm
- Give the individual a chance to calm down
- Preserve your own safety
- When things are calmer, discuss the issue with the individual

Questions to ask yourself during displays of aggressiveness

- Is this a real confrontation? Is there a real issue at stake?
 - Legitimate expressions of anger might be mistaken for verbal aggressiveness

- Remember, just because your family member has a mental illness does not mean that they cannot express regular emotions. He or she can feel angry, frustrated or sad just like everyone else
- Look at the behaviour; if the individual is calm but their words are hostile, the individual is likely not displaying aggressiveness, just irritability
- Is the violence related to distressing voices or delusional beliefs?
 - If so, then you may not be effective in trying to calm the individual. It is not helpful to argue with an individual about the reality of their hallucinations and delusions; the experience is real for them
 - Call the PACT team for support in this case

Afterwards:

- 1) During a period of calm, sit down as a family and plan a behaviour management strategy. Involve the PACT team. Decide which of the individual's behaviours will no longer be given it to.
- 2) Convey to the individual in a calm manner what you, as a family, will and will not tolerate and what consequences of the certain behaviours will be. The consequences are to be appropriate to the nature of the behaviour.
- 3) If threats of or actual behaviours occur, be prepared to carry out the consequences you have decided upon. Bluffing will not do.
- 4) Evaluate how well the plan is working and revise it as needed. Do not give up too easily, as it may take a number of attempts to find a strategy that works.

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Chapter 6: Stigma

**“Mental illness is nothing to be ashamed of, but
stigma and bias shame us all.”**

-Bill Clinton-

What is Stigma?

Many societies look down on people with a mental health or co-occurring substance use disorder. They—and their families—face negative attitudes, behaviours and comments. This is known as stigma.

When someone appears to be different, they may be viewed in a negative stereotyped manner. People who have identities that society values negatively are said to be stigmatized. Stigma is a reality for people with a mental illness, and they report that how others judge them is one of their greatest barriers to a complete and satisfying life.

Society feels uncomfortable about mental illness. Due to inaccuracies and misunderstandings, people have been led to believe that an individual with a mental illness has a weak character or is inevitably dangerous.

Mental illness can be called the invisible illness. Often, the only way to know whether someone has been diagnosed with a mental illness is if they tell you. The majority of the public is unaware of how many mentally ill people they know and encounter every day.

The Effects of Stigma

Stigma does more than make it more difficult to live with a mental health or substance use disorder. Stigma can:

- Shame, isolate and punish the individuals who need help
- Reduce the chances that an individual will get appropriate help
- Reduce social support
- Lead to lowered self-confidence
- Make individuals feel that they will never be accepted in society
- Increase social isolation

Words like “crazy,” “nuts,” “schizo,” and “psycho,” are just a few examples of words that keep the stigma of mental illness alive. These words belittle and offend individuals with mental health problems and their families. Many of us use them without intending any harm. Just as we would not mock someone for having a physical illness like cancer or heart disease, it is cruel to make fun of

someone with a mental illness. However, the use of discriminatory language distorts the public's view and reinforces inaccuracies about mental illness.

Many people try to protect themselves from stigma by avoiding certain people or situations. However, limiting social interactions can increase loneliness and psychological distress and lead to social isolation. As a result, people may start to think that they are incompetent, strange or otherwise flawed. A reduced social support network may actually lower your family members' self-confidence and self-esteem, and they may experience depression. In such cases, people are less likely to seek help.

When a person receives prompt treatment for mental disorders, the course of the illnesses may be changed for the better with greater hopes for recovery. But fear of stigma can discourage families from seeking care for their loved one as well as care and support for themselves.

Stigma and Families

Whether families actually experience discrimination or negative attitudes, or fear that they might, the experience can be stressful. Because of the fear of stigma, people tend to hide the diagnosis of their family member. They may start avoiding others and live in fear that the illness will be discovered. Families usually experience stigma in four stages:

- *Understanding stigma* refers to the ways in which family members understand and explain stigma to themselves and others
- *Experiencing stigma* refers to the ways that families experience the consequences of stigma
- *Surviving stigma* refers to the strategies family members use to cope with stigma
- *Combating stigma* refers to the decision by some families to fight stigma on a social and political level

Some family members have found ways to cope with stigma and discrimination. Strategies change, depending on the situation, their relative's stage of illness or recovery, and their own stage of self-discovery and healing. Strategies to survive stigma are unique to each family and its members:

- Turning to other families in similar situations for support
- Sharing their stories with the public
- Challenging negative attitudes
- Looking at the situation from a different perspective

Family support groups also provide the opportunity to develop friendships and social networks that can help build self-esteem and feelings of efficacy. When family members are in touch with others with the same problems, feelings and experiences, they are less likely to blame themselves for their relative's problems.

Strategies such as dismissing, downplaying or challenging negative attitudes and beliefs can help to enhance self-esteem and resilience. For many family members, accepting the idea that they can not control other people's attitudes, beliefs and behaviour is liberating.

Family groups are one of the best catalysts for change across the mental health and addiction services system. Members of family self-help support groups can:

- Argue for better treatment, planning and accountability
- Sponsor conferences
- Speak at professional meetings
- Lobby legislators and appointed officials

Mental Illness Myths

- *Mental illness is caused by poor parenting or weak family communication*
- *Mental illness does not exist*
- *Psychiatric disorders are not true medical illnesses like heart disease and diabetes. People who have a mental illness are just "crazy."*

- *People with mental illness are violent and dangerous.* The truth is that, as a group, mentally ill people are no more violent than any other group. In fact, they are far more likely to be the victims of violence than to be violent themselves.
- *People with mental illness are poor and/or less intelligent.* Many studies show that most mentally ill people have average or above-average intelligence. Mental illness, like physical illness, can affect anyone regardless of intelligence, social class or income level.
- *Mental illness is caused by a personal weakness.* A mental illness is not a character flaw. It is an illness, and it has nothing to do with being weak or lacking will-power. Although people with mental illness can play a big part in their own recovery, they did not choose to become ill, and they are not lazy because they cannot just "snap out of it."
- *Mental illness is a single, rare disorder.* Mental illness is not a single disease but a broad classification for many disorders. Anxiety, depression, schizophrenia, personality disorders, eating disorders and organic brain disorders can cause misery, tears and missed opportunities for thousands of Canadians. Statistics show that 1 in 5 Canadians will be affected by mental illness at some time in their lives.

Fighting Stigma

1. *Learn More About Mental Illness.* To the extent that you are better informed about mental illness, you will be better able to evaluate and resist the inaccurate negative stereotypes.

2. *Listen to People Who Have Experienced Mental Illness.*

These individuals can describe what they find stigmatizing, how stigma affects their lives and how they would like to be viewed and treated.

3. *Watch Your Language.*

Most of us, including mental health professionals and consumers, use terms and expressions related to mental illness that may perpetuate stigma.

4. *Monitor Media and Report Stigmatizing Material.* Protest such material by contacting the people--authors, editors, movie producers, advertisers--responsible for the material.

5. Respond to Stigmatizing Material in The Media.

Write, call or e-mail people who stigmatize yourself, expressing your concerns and providing more accurate information that they can use.

6. Speak Up About Stigma. When someone you know misuses a psychiatric term (such as referring to a person as a “schizophrenic”), let them know and educate them about the correct meaning. When someone disparages a person with mental illness, tells a joke that ridicules mental illness, or make disrespectful comments about mental illness, let them know that it is hurtful and that you find such comments offensive and unacceptable.

7. Talk Openly About Mental Illness. Don't be afraid to let others know of your mental illness or the mental illness of a loved one. The more mental illness remain hidden the more people continue to believe that it is a shameful thing to be concealed.

8. Demand Change from Your Elected Representatives

Policies that perpetuate stigma can be changed if enough people let their elected representatives know that they want such change.

9. Provide Support For Organizations that Fight Stigma. Join, volunteer, and donate money. The influence and effectiveness of the organizations fighting mental illness stigma depend, to some extent, on membership size and finances. They also rely heavily on the effort and passion of their volunteer members. You can make a contribution through them.

10. Contribute To Research Related To Mental Illness And Stigma. To the extent that mental illness can be understood and treated, stigma will be reduced. When we can be confident that mental illness can be treated quickly and effectively, it will be less frightening. When we know how stigma is perpetuated and better still, changed, we will be better able to assist those with mental illnesses to deal with it. Research will help us learn these things.

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Chapter 7: Resources

“It is what we think we know already that often prevents us from learning”

-Claude Bernard-

Families of those who have been diagnosed with a mental illness have to face many issues and concerns that other families do not. Having someone to talk to, connect with, and ask questions of is utmost importance during times of uncertainty, stress, and difficulty. There are variety of resources available for families of those who have a mental illness.

Local resources

- **FACES at 4 Fort Street**, in Winnipeg, includes the following organizations:

Manitoba Schizophrenia Society (MSS)

(204) 925-0600

www.mss.mb.ca

Mood Disorders Association of Manitoba (MDAM)

(204) 925-0600

www.depression.mb.ca

Anxiety Disorders Association of Manitoba (ADAM)

(204) 925-0600

www.adam.mb.ca

Eating Disorders Self-Help Program (EDSHP)

(204) 925-0600

www.manitoba.cmha.ca

Obsessive Compulsive Disorder Centre Manitoba (OCDC)

(204) 925-0600

www.ocdmanitoba.ca

Canadian Mental Health Association, Manitoba Division (CMHA)

(204) 925-0600

www.manitoba.cmha.ca

Partnership for Consumer Empowerment (PCE)

(204) 925-0600

www.manitoba.cmha.ca

Suicide Prevention Education Awareness Knowledge (SPEAK)
(204) 925-0600
www.speak-out.ca

Mental Health Education Resource Centre of Manitoba (MHERC)
(204) 925-0600 or (204) 953-2355
www.mherc.mb.ca

-MHERC provides materials (books, journals, pamphlets, CD-ROMs, presentation kits, videos, articles) on mental health and related issues to service providers, consumers, families, natural supports, caregivers, educators, and the general public.

- Addictions Foundation of Manitoba (AFM) at **1031 Portage Ave**, in Winnipeg.
Administration office: (204) 944-6200
Information requests via library email: library@afm.mb.ca or
call (204) 944-6233 www.afm.mb.ca

Videos

Here are 6 suggested videos that portray mental illness in a positive manner:

- 1) Shadow Voices: Finding Hope in Mental Illness (2005)
- 2) A Beautiful Mind (2002)
- 3) Shine (1996)
- 4) I'm still here (1996)
- 5) Angel Baby (1995)
- 6) Nobody's Child (1986)

Books

Here are some books that may be helpful in providing information about mental illness and families:

Beard, J., & Gillespie, P.N. (2002). *Nothing to hide: Mental illness in the family*. New York: New Press. First Person Accounts.

Gunderson, J.G., Hoffman, P.D. (2005). *Understanding and treating borderline personality disorder: A guide for professionals and families*. Virginia: American Psychiatric Publishing, Inc.

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Mason, P.T. & Kreger, R. (1998). *Stop walking on eggshells: Taking back your life when someone you care about has borderline personality disorder*. New York: New Harbinger Publications.

Miklowitz, D.J. (2002). *The Bipolar disorder survival guide: What you and your family need to know*. New York: Guilford Press.

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Spaniol, L., Zipple, A.M., Marsh, D.T., Finley, L.Y. (2000). *The role of the family in psychiatric rehabilitation*. Centre for Psychiatric Rehabilitation, Boston University.

Torrey, E.F. (2001). *Surviving schizophrenia: A manual for families, consumers, and providers* (4th ed.). New York: HarperCollins.

Woolis, R. (1992). *When someone you love has a mental illness*. New York: Tarcher.

Websites

For those who are computer savvy, here are some great online resources, in addition to the websites listed under local resources:

The Canadian Mental Health Association: www.cmha.ca

Canadian Association for the Mentally Ill: www.cami.org

The National Alliance on Mental Illness (NAMI): www.nami.org

The Canadian Health Network: www.canadian-health-network-.ca

National Institute on Mental Health: www.nimh.nih.gov

National Aboriginal Health Organization www.naho.ca

Schizophrenia Society of Canada: www.schizophrenia.ca

Schizophrenia Digest Magazine: www.schizophreniadigest.ca

The Canadian Network for Mood and Anxiety Treatments (CANMAT):
www.canmat.org

Mood Disorders Society of Canada: www.mooddisorderscanada.ca

Bp Canada magazine: www.bphope.ca

Depression and Bipolar Support Alliance: www.dbsalliance.org

Bipolar world: www.bipolarworld.net

Information about Borderline Personality Disorder: www.bpdworld.org

About Stigma and Discrimination: www.adscenter.org

The National Native Addictions Partnership Foundation www.nnapf.org

The Centre for Addiction and Mental Health: www.camh.net