What Can Communities Do?
A Community Action Guide to Early Psychosis Intervention Strategies
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Visit CMHA’s web site (www.cmha.ca) to find this guide and other materials produced by CMHA’s early psychosis intervention initiatives.

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# TABLE OF CONTENTS

**Preface** | 1

**Introduction** | 2-3

**What Can the Community Do?**
- Get the Facts | 4
- Know the Signs and Symptoms | 5-6
- The Roads to Recovery | 7-8
- Appreciate the Importance of Early Psychosis Intervention | 9
- Understand the Elements of a Comprehensive Early Psychosis Intervention Service | 9-10
- Get Together with Others: Develop a Community of Interest and Build Working Partnerships | 11-12
- Understand the Community’s EPI Needs | 13
- Raise Public Awareness | 14
- Raise Awareness among Gatekeepers and Stakeholders | 15-16
- Promote Ongoing Recovery, Normalization and Integration | 17
- Advocate for Access to Services and/or for Improved Services | 18
- Put It All Together!
  - Newfoundland and Labrador’s “Travelling Road Show”: Reaching Out | 19
  - Prince Edward Island Workshop and “Report Card”: Covering the Bases | 20
  - Manitoba’s “Flag Psychosis Early” Family Campaign: Advocacy in Action | 21

**Sources** | 22

**Suggested Resources**
- Web Sources | 22
  - Psychosis | 22
  - Community Action | 23
  - Supporting Success in Education | 23
  - Self-Help Resources | 24
  - Mental Health Resources for Youth | 24
- Recent Books | 25
- Videos | 25

**Canadian Early Psychosis Intervention Clinical Programs** | 26-27

**Template for Laminated Handout** | 28-29
Since 1999, with project funding from the Population Health Fund of the Public Health Agency of Canada, the national office of the Canadian Mental Health Association has pursued a number of activities with a goal of increasing awareness, understanding and action across Canada regarding the principles and practices of early psychosis intervention (EPI).

Over this time, the evolution of our understanding of the complexities of the EPI paradigm has been accompanied by a growing appreciation of the critical role of the community to the success of EPI. This role is crucial regardless of the availability of dedicated EPI clinical services and is relevant to each step along the continuum of early identification, treatment, and recovery – including the return to school/work.

CMHA’s project activities have reflected this community focus by promoting “ownership” of the issue and the capacity for action by a range of community-based constituencies.

The project has:
• promoted awareness and provided information to key national stakeholder organizations by preparing articles for publications in journals and newsletters
• produced and widely disseminated a range of educational resource materials
• developed a strategic planning framework to assist policy makers to move forward effectively
• facilitated first-episode family action and mutual support, and
• raised awareness and improved access to services through working directly with various groups and organizations across Canada.

This community guide represents one of the last resources to be produced by the project, and essentially reflects six years of community capacity building experience around the issue of early psychosis.
WHAT IS COMMUNITY?

“What often when we think of community, we think in geographic terms. Our community is the location (i.e., city, town or village) where we live. When community is defined through physical location, it can be defined by precise boundaries that are readily understood and accepted by others.

“Defining communities in terms of geography, however, is only one way of looking at them. Communities can also be defined by common cultural heritage, language, and beliefs or shared interests. These are sometimes called communities of interest.”


We live in communities within communities, within communities...

In the end, it is hoped that this guide will inspire individuals and groups to build capacity within their communities – large and small – for successfully addressing the issue of first-episode psychosis. The information is relevant to all communities regardless of whether or not early psychosis services are currently available.
INTRODUCTION

Does Your Community Offer EPI Services? The Truth Is... Most Don’t

Canada has numerous well-established early psychosis clinical programs and a variety of community-based initiatives. Spurred on by the hopeful outcomes suggested by EPI, more and more centres across Canada are keen to provide early intervention services. Still, the majority of communities in Canada lack ready access to comprehensive EPI services. But, in these cases, it is just as important for the community to understand the issues, build awareness and educate stakeholders in order to lay the foundation for efforts to improve access to services and create brighter futures for young people and their families.

This guide has been written with community-based groups and organizations in mind. It is assumed that groups focused on mental health and/or the general well-being of youth and young adults are the primary audience. Interested individuals, such as first-episode psychosis family members, would be well-advised to connect with others who have a stake in the health and well-being of young people as an important first step. Community capacity building depends on partnership and collaborative action.

Regardless of whether or not a community has access to EPI services, the process required to create positive change at the community level is essentially an exercise in community capacity building. Community capacity building is an ongoing, evolving process of development that encompasses several components and can be applied to community issues, large and small. In the particular context of building EPI capacity, communities can:

- Get The Facts And Know The Signs And Symptoms
- Appreciate The Importance Of Early Intervention
- Understand The Elements Of A Comprehensive Early Psychosis Intervention Service
- Get Together With Others: Develop A Community Of Interest And Build Working Partnerships
- Understand The Community’s EPI Needs
- Raise Public Awareness
- Raise Awareness Among Gatekeepers And Stakeholders
- Promote Ongoing Recovery, Normalization And Integration
- Advocate For Access To Services And/Or For Improved Services
- Put It All Together!

What can the community do? Build capacity for local EPI action

BROADLY SPEAKING...WHAT IS COMMUNITY CAPACITY BUILDING?

Capacity is simply the ways and means needed to do what has to be done. It is much broader than simply skills, people and plans. It includes commitment, resources and all that is brought to bear on a process to make it successful. Most often capacity is referred to as including the following components:

- people who are willing to be involved
- skills, knowledge and abilities
- wellness and community health
- ability to identify and access opportunities
- motivation and the wherewithal to carry out initiatives
- infrastructure, supportive institutions and physical resources
- leadership and the structures needed for participation
- economic and financial resources; and
- enabling policies and systems.

It was hard to believe. My son had been so spontaneous, funny, bright. He seemed to have everything going. Then the picture just changed so drastically. At first, the illness was overwhelming.

“We thought our daughter was just lazy. She wouldn’t do anything. So we’d get annoyed and get on her case. If we’d known she was ill, we wouldn’t have pushed her. The stress just probably made it worse.”

Psychosis is a serious but treatable medical condition affecting the brain. It is characterized by some loss of contact with reality and can dramatically change a person’s thoughts, beliefs, perceptions and/or behaviours. Psychosis is estimated to affect up to 3% of the population. Males and females are affected equally.

It is difficult to know the cause of psychosis the first time it occurs. Psychosis is associated with a number of medical conditions including schizophrenia, depression, bipolar (manic depressive) disorder, and substance abuse, among others. As well, members of families with a history of psychotic illness are at increased risk for developing psychosis themselves.

While psychosis can happen to anyone, symptoms of psychosis most often develop during adolescence and early adulthood. It can be an extremely distressing condition for the individuals affected, and for their families and friends. Without prompt and effective treatment, psychosis can derail young lives.

Many young people who develop psychosis are still residing with their families; they’re attending school; they’re hanging out with friends. Because of this, family members, friends, teachers and others in the community play a crucial role in helping to identify the signs of psychosis.

In large part, the sections “Get the Facts” and “Signs and Symptoms” were taken from existing CMHA resource materials. See Sources.

WHAT CAN THE COMMUNITY DO?

GET THE FACTS*

What is psychosis?

“It was like I was having a million thoughts all at once and yet I was so disorganized, nothing was getting done. I was frightened and anxious because I felt someone was trying to harm me. Increasingly, I spent most of my time alone in my room doing nothing. I didn’t want to be bothered with friends or family. The television started having special messages meant only for me and I was hearing voices commenting on what I was doing. Looking back, I realize things just weren’t making sense anymore. At the time though, it seemed normal and I didn’t mention what was happening with me to anyone. Since getting treatment, I understand that I was experiencing a health problem called psychosis.”

EARLY PSYCHOSIS INTERVENTION

It’s Everybody’s Business!

*In large part, the sections “Get the Facts” and “Signs and Symptoms” were taken from existing CMHA resource materials. See Sources.
WHAT CAN THE COMMUNITY DO?

KNOW THE SIGNS AND SYMPTOMS

Sometimes symptoms appear suddenly and are very obvious to everyone. But, psychosis can also emerge gradually, making it difficult to spot early signs and symptoms. Early identification can also be difficult because the teen years typically are marked by upheavals in behaviour, motivation and mood. And there are other conditions that can cause similar symptoms. But in fact, parents of youth with psychosis often remark in hindsight that they knew “something wasn’t quite right”; that their child “just wasn’t himself”. Noticeable, persistent changes to who your son, sister or friend ‘usually is’ may be important signs of psychosis.

Family members, friends or others might notice changes such as:
- withdrawal and loss of interest in socializing
- loss of energy or motivation
- deterioration in work or study
- lack of attention to personal hygiene
- confused speech or difficulty communicating
- lack of emotional response or inappropriate emotional display
- general suspiciousness
- sleep or appetite disturbances
- unusual behaviours.

“We saw things happening. His friends did. His brothers did. They thought it was drugs and thought “we’d better keep it from mum and dad, we don’t want them to get upset”. But when I started seeing things happening - the monotone voice, the way he walked – just so much was happening within a six month period, I thought there is something wrong here.”

A person with psychosis may experience one or more of the following symptoms:
- hear voices that no one else hears
- see things that aren’t there
- believe that others can influence their thoughts, or that they can influence the thoughts of others
- believe that they are being watched, followed or persecuted by others
- feel their thoughts have sped up or slowed down.

“We met with Jan’s teacher, school guidance counselor and school psychologist. Then our family doctor referred her to a private counselor for her depression. No one realized that it was psychosis.”

Consequences of delayed treatment can include:
- serious disruption of life course
- deterioration of family and social relationships
- increased likelihood of substance abuse
- increased risk of depression and suicide
- loss of self-esteem and self-identity
- increased likelihood of hospitalization
- slower and less complete recovery
- poorer overall prognosis.
“We struggled to understand and help our son. He began to withdraw from longtime friends and the support of his family. For 1 1/2 years we couldn’t find appropriate treatment and support for our son and family.”

Delays in seeking and finding appropriate treatment can be devastating. Social isolation, resulting from symptoms that interfere with peer and family relationships is common. Declines in school and work performances can also lead to a profound loss of social and economic potential. Secondary problems such as unemployment, substance abuse, depression, self-harm and illegal behaviour can occur or intensify. While the personal costs to the individuals and their families are immeasurable, the economic and societal costs to the community are immense.

“Our daughter had to drop out of high school. She wonders if she will ever be able to work. She’d like to contribute too.”

Reasons for treatment delays include:
• inability of the individual, family or professional to recognize the signs and symptoms of psychosis, especially if symptoms emerge gradually
• inability of persons experiencing psychosis to perceive themselves as ill
• fear and stigma associated with mental illness
• limited access to appropriate services.

In most cases, psychosis will not go away on its own. But, psychosis responds well to treatment...especially when it is caught early.

GET MORE FACTS

The information presented here provides an introduction to the topic, but the issues are complex and there are now many useful resources available. Some are listed at the end of this guide, and they can lead to many more. Knowledge is power.

Knowing the early signs and symptoms of psychosis is just the beginning. Then what? In a best case scenario, one would find easy access to expert clinical services and ongoing support from family, friends and others in the community. This is surely the preferred road to recovery. But for many, the road to recovery is still a rocky one. Following is an illustration of both the “smooth” and “rocky” roads to recovery, accompanied by stories that depict the journeys associated with each.
THE ROADS TO RECOVERY

THE SMOOTH ROAD

- Early detection
- Treatment started rapidly

- Short duration of untreated psychosis
- Continual treatment

- Optimal treatment: medication, individual counselling, family support, psychosocial treatment, information

- Supportive social network
- Stable living environment
- Structure and calm

- Meaningful occupations: study, work, hobby
- Someone to share experiences and feelings with
- Good physical health

- Rapid disappearance of symptoms
- Lasting absence of symptoms
- Realistic expectations and hope for the future

THE ROCKY ROAD

- Late detection
- Treatment started late

- Long duration of untreated psychosis
- Interrupted treatment

- Fragmented, inaccessible, or incomplete care
- Little support from patient’s immediate environment

- Too much stress and tension
- Conflictual personal relationships

- Idle times filled up by worrying
- Isolation and loneliness

- Neglect of physical health and abuse of street drugs

- Persistent symptoms of psychosis and long-lasting disability, persistent depressive symptoms

- Relapse of psychosis and recurrence of positive symptoms
- Inadequate understanding of the illness plus hopelessness

Which one is the “road less travelled?” The answer is: the smooth one.

These stories provide readers with real life examples of the very different experiences encountered by youth and their families. Perhaps it’s no accident that the accounts from the smoother road come mainly from the youths themselves, while the trip down the rocky road is described by the parents.

The Smooth Road

“Fortunately, early treatment of the disease resolved symptoms before they interfered with her ability to function and participate in her own care. My daughter was diagnosed and treated at the onset of the disease before psychotic symptoms fully developed.”

“The first year after my diagnosis was the most difficult. No eating junk food, no staying up late, and most importantly, no stimulants. I had to adopt a low-key life style that most teenagers aggressively avoid. I have taken up many quiet hobbies such as quilting and embroidery in an effort to remain stimulated yet not overly so.”

“The group program became very important to me because I was learning about myself and my experiences from other patients.”

“What has helped me the most is talking to select family and friends about what I am going through.”

“I’ve been able to work part-time and earn my own income. That’s been so important. I took one computer course and got a grade of 95%! ”

“Because I am taking responsibility for myself I believe that the outcome is positive. It will take me more time to accomplish all of my goals than most people, but I look forward to the challenge an uncertain future presents.”

The Rocky Road

“For 1 1/2 years we searched for appropriate treatment and support for our son and family as we struggled to understand and help our son. Our son began to withdraw from longtime friends and the support of his family.”

“Our son asks if he is ever going to be able to work. He wants to contribute too.”

“Our daughter had to drop out of high school. Her community mental health worker’s suggestion was that we pay to have her employed in a sheltered workshop for the mentally challenged.”

“Once a promising athlete, a competitive swimmer, soccer player, student of Tai Kwan Do and an avid skateboarder, our son retreated from a world that once was safe and known to him and into a lifestyle fraught with risk, abuse, criminal activity and exploitation.”

“We live in a sometimes bizarre home. Tensions run high with anticipation of what might happen next and the police have been called several times.”

“Our son has dropped out of mainstream life and lives a marginalized life while homeless, living on the street. He has found acceptance for his distracted and quiet manner and his excessive drug use with other street people.”

“He sleeps in a park and lives minute to minute. I, his mother, pray for him and others like him.”

“Our daughter told us that if she died that we would be the only ones to grieve. She has lost all her friends.”

WHAT CAN THE COMMUNITY DO?

APPRECIATE THE IMPORTANCE OF EARLY PSYCHOSIS INTERVENTION

“Early psychosis intervention” (EPI) refers to best practice approaches to the treatment of psychosis that emphasize the importance of both the timing and types of intervention provided to persons experiencing a first episode of psychosis. “Early” is as early as possible following the onset of psychotic symptoms; the “intervention” is comprehensive, intensive, phase specific and individualized. The psychosis itself is the target of intervention since at the time of the first episode, the course of illness is not yet known. Effective early psychosis intervention consists of multiple components that progress in sequence from recognition, to referral, to assessment and treatment, and ultimately to recovery of the individual.

The goal of early intervention is to improve outcomes by promoting as full a recovery as possible thereby reducing the long term disability and costs – both human and economic – associated with serious mental illness. To achieve this, early intervention strategies are designed to limit the duration of the psychosis – prior to and during treatment – and prevent relapse.

Early identification followed by comprehensive, individualized treatment strategies that incorporate the use of low-dose anti-psychotic medications with education and psychosocial interventions can promote full recovery from early psychosis. And research indicates that the sooner psychosis is appropriately treated, the better the outcomes.

"The earlier that an intervention occurs, the sooner that person will be able to recognize that they have an illness and can get better and can get on with their life."

Benefits of early intervention can include:
• improved capacity to maintain self-identity and self-esteem
• faster and more complete recovery
• improved capacity to maintain life course
• reduced disruption of family and social relationships
• reduced likelihood of hospitalization
• reduced disability and fewer relapses
• reduced risk of suicide.

WHAT CAN THE COMMUNITY DO?

UNDERSTAND THE ELEMENTS OF A COMPREHENSIVE EARLY PSYCHOSIS INTERVENTION SERVICE

With the growing interest in EPI as best practice, there is a risk that services provided in the name of EPI may lack fundamental components. This is a serious concern. The implementation of well intentioned but piecemeal interventions may be counterproductive. The evolving research on early psychosis intervention suggests that the whole is potentially much greater than the sum of its parts.
WHAT CAN THE COMMUNITY DO?
UNDERSTAND THE ELEMENTS OF A COMPREHENSIVE
EARLY PSYCHOSIS INTERVENTION SERVICE

Key Elements of an Early Psychosis Intervention Service*

Timely Access

• The program provides timely access to appropriate clinical services. Both the number of steps needed for a person to receive appropriate care and the time spent seeking treatment should be minimized.
• Referrals can be from anyone in the community such as family members, physicians, teachers, peers and the young people themselves who are experiencing psychosis.

Rapid and Comprehensive Assessment

• The assessment is timely, depending on urgency, and flexible in terms of location.
• The assessment incorporates strategies to promote engagement and the formation of a therapeutic relationship with the client and family.
• It includes a thorough medical and neurological examination as well as a psychosocial assessment.
• The assessment identifies the status of social relationships, school or work performance, recreational pursuits, ability to manage money, housing and clothing, self-care and community involvement.
• It identifies comorbid conditions, such as depression and substance abuse and pays particular attention to any risk factors for suicide, violence, or victimization.

Appropriate Treatment

• Treatment is phase-specific, individualized and includes medication, education and psychosocial interventions.
• It provides a multidisciplinary team approach to care.
• An approach of “start low, go slow” is adopted in administering medication to clients experiencing their first episode in psychosis.
• The emphases of treatment are on managing symptoms and role fulfillment rather than diagnosis.
• Care is provided in the least restrictive environment.
• Services and support are provided on an on-going basis in order to consolidate and sustain gains.

Family Engagement

• Family engagement is early, intensive and sustained.
• The involvement of the family is part of a specific treatment plan rather than informal and as needed.
• Work with the family includes supportive counseling, education, relapse prevention, stress management and enhancement of coping skills.

Normalized Recovery Context

• Reintegration into school and work activities is supported.

Awareness and Education

• Community outreach initiatives and education programs are implemented to reduce the duration of untreated psychosis and support recovery.
• Opportunities for ongoing professional development for health care workers are provided.

Evaluation and research constitute additional key elements in order to ensure that care corresponds to best practices, is continuously improving, and is based on our continuously expanding knowledge.

*Some of the information provided in this section is from T. Ehmann and L. Hanson. See Sources.
In order to move towards increasing awareness and improving access to early psychosis services, an important early step is to connect with others who have a stake in the issue. Stakeholders are likely to be those who have an interest in the mental health and well-being of young people. Of course, if there is an early psychosis clinic in the community it would be central to this process.

Who Might Be Involved?

1. **Mental Health Organizations**
   - Canadian Mental Health Association?
   - Schizophrenia Society?
   - Mood Disorders Association?

2. **Education**
   - School teachers?
   - School guidance counselors?
   - University and college counselors?

3. **Health**
   - Mental health agencies?
   - Family physicians?
   - Emergency room physicians/nurses?

4. **Youth Programs**
   - Community centres?
   - Youth shelters?
   - Employment programs for youth?

5. **First Episode Psychosis Families**

6. **Addictions**
   - Youth counselors?

7. **Police/Justice**
   - Local police?
   - R.C.M.P?
   - Corrections?

8. **Government Departments**
   - Provincial Health Ministry?
   - Regional Health Authority?

Illustration adapted from The Community Development Handbook, page 28.
WHAT CAN THE COMMUNITY DO?
GET TOGETHER WITH OTHERS: DEVELOP A COMMUNITY OF INTEREST AND BUILD WORKING PARTNERSHIPS

**Some Experiences**
- In 1999, Manitoba began pursuing EPI activities. There were no specialized EPI clinical services available in Manitoba at that time. A CMHA project brought together people to form an EPI steering committee. There were representatives from a number of institutions and agencies interested in the mental health of youth: the provincial addictions organization, a local hospital, regional health authority, provincial health department, and a First Nations disability group. Members were added as additional stakeholders were identified and brought on board. There were also rural “corresponding” representatives.

- Unlike Manitoba, EPI clinical services in Ontario have been present and growing for over a decade. In 1999, the Ontario Working Group (OWG) on Early Intervention in Psychosis was formed with a commitment to bring the benefits of early treatment to all citizens of Ontario experiencing the onset of psychosis. Given the context, the make-up of the Ontario group was more institutionally based than that of Manitoba but also included individuals and organizations reflecting a variety of mental health disciplines, families, and consumers.

**Some Tips**
- At first, stakeholders may not recognize themselves as stakeholders in this context. This is where raising awareness begins.
- Getting buy-in from a diverse group of stakeholders can be challenging. Don’t wait for perfection before moving ahead.
- The exact make up of the working group will vary depending upon community size, location and extent of services and experience with EPI.
- The community of interest will grow. Networks work!
- The process is organic. It will snowball.
- Don’t reinvent the wheel. Connect with other communities who’ve already been involved in EPI.

**FIRST-EPISODE FAMILIES ARE A SIGNIFICANT FORCE**

First-episode families are a significant force in the context of EPI:
- They are valued as active partners in care by the treatment team; they sit on many EPI working groups and steering committees.
- They are recognized as having important educational and support needs of their own, needs that EPI programs help to address.
- They are on the vanguard of a new generation – living with new hopes for the future.
- They are passionate first-episode advocates on behalf of their children.

“An established first-episode psychosis group walked us through the steps of forming a family support group. That group was able to put a notice up in the waiting room of their first episode clinic, but since we didn’t have a clinic, our challenge was finding other families! We distributed a letter that introduced who we were and asked interested families to contact us to a number of organizations, agencies and hospitals where we thought we might find families. It worked! Twelve people attended our first meeting and we agreed that “it felt good” and decided to meet monthly.”
WHAT CAN THE COMMUNITY DO?
UNDERSTAND THE COMMUNITY’S EPI NEEDS

It’s important to know exactly what’s going on in the community in relation to EPI. There may be activities happening in a number of arenas, for example: service provision, education and awareness raising, first-episode family activities, and advocacy activities.

Initial guiding questions could include the following:
• What happens in your community now when a young person experiences a first episode of psychosis?
• What types of treatment services are available?
• How accessible are they?
• To what extent do existing services resemble EPI services as described earlier?
• Which community-based organizations and agencies are dealing with issues of EPI?
• Is there evidence of information/education being made available to the community? If so, who’s responsible for it?
• Are first-episode families involved in activities and services related to EPI?

Some Experiences
• There’s no widespread awareness of mental illness in general or psychosis in particular, so no awareness of the importance of early psychosis intervention.
• There’s a lack of psychiatrists and other mental health professionals in the region.
• Family doctors may not give appropriate treatment or referrals and there is a long wait for psychiatrists.
• Service depends upon which hospital and which psychiatrist you may end up seeing.
• Bridging child and adolescent mental health services to adult mental health services is a challenge.
• Health and other youth-related service systems are disconnected.
• There are complex pathways to reach appropriate services.
• Situation now is reactive — there is usually a crisis before service is available.
• No family support exists in the region.
• No money!

Some Tips
• Most communities find themselves at the same starting point, which can seem discouraging but success is still possible.
• Some of the challenges are actually opportunities in disguise!
• Investigating the community’s EPI resources is a learning experience in itself and ends up creating new communication and resource networks. And so it grows...
Initiatives to raise awareness should aim to educate the public about the nature of early psychosis intervention, the signs and symptoms of psychosis and the importance of receiving timely treatment. Public education should provide accurate information about psychosis and aim to dispel misconceptions. Education should specifically target persons at increased risk for developing the illness, i.e. youth and young adults. Schools and Boards of Education should be encouraged to incorporate psychosis into school programs and curricula.

Some Experiences

- In communities where an EPI service is established, public awareness campaigns may be spearheaded by the EPI program itself. For example, in British Columbia, the Fraser Health Authority's Early Psychosis Intervention Program launched a “Psychosis Sucks” public awareness campaign. This campaign targeted physicians, other health care providers, schools and the general public through the distribution of brochures, posters, and a six-month bus and newspaper ad campaign to promote a new web-site called www.psychosissucks.ca.

- Similarly, the London, Ontario Prevention and Early Intervention Program for Psychoses (PEPP) and the PEPP Parent Support Group partnered to raise community awareness of psychosis and promote early identification and referral. “Putting the Pieces Together” was a large-scale initiative, using brochures, posters, a desk calendar, bookmarks in student admission packages, local radio, bus and shelter advertising, public forums, community fund-raising events and a 30-second television commercial on the early signs of psychosis. PEPP parents and clients were involved in the planning and dissemination of these materials.

- In Newfoundland and Labrador, where EPI clinical services were only available in St. John’s, travelling EPI forums and open meetings for family and friends raised public awareness throughout the province. Leading up to this, a provincial advisory committee had identified key stakeholders within each region and information had been distributed to these groups prior to the EPI forum. Media releases and public service announcements about EPI were issued and newspaper and radio interviews were given in local communities.

Some Tips

- Watch for media opportunities to get the message out. Build relationships with your local media. Keep them in the loop.
- Seek out appropriate local events and venues for the distribution of information.
- Develop an electronic information network: build an EPI email list.
- Create an EPI community awareness opportunity such as an EPI information evening for the whole community.
WHAT CAN THE COMMUNITY DO?
RAISE AWARENESS AMONG GATEKEEPERS AND STAKEHOLDERS

BUILDING CAPACITY

When communities are building capacity, there is a significant impact on many aspects of community life. Capacity building places the emphasis on existing strengths and abilities, rather than being overwhelmed by problems or feelings of powerlessness. An indication that capacity is developing within a community is that people are active, interested and participating in what is going on.

Practical and small projects can be a great experience that demonstrates the power of collective community development. Starting small and building on strengths is a good strategy for building awareness and motivation.

*The Community Development Handbook, pages 11, 15.*

The professionals who are in a position to interact with individuals who may experience psychosis should be trained to recognize symptoms of psychosis and understand the importance of early intervention. This “gatekeeper” training should include groups such as teachers, school counselors, and family physicians. While formal training should be introduced as part of a professional educational curriculum, community-based groups and agencies can seek out opportunities to raise awareness among these groups at the local level. One or more of these gatekeepers may well emerge as a vocal advocate.

Gatekeepers, young people and the general public should be informed of available and appropriate clinical resources if early psychosis is suspected. Information should be provided on access to these services.

A GREAT OPPORTUNITY

“A University Health Fair provided a great opportunity to distribute information about EPI to students, faculty and staff. We set up a display table with pamphlets, posters and a quiz about psychosis... and even offered a prize! An advertised evening event was an ‘EPI Coffee House’ which was held in the student lounge. Students read poetry, played musical instruments and a young man who had experienced psychosis spoke about his experiences.”
WHAT CAN THE COMMUNITY DO?

RAISE AWARENESS AMONG GATEKEEPERS AND STAKEHOLDERS

Some Experiences

• In Calgary, a partnership between the Canadian Mental Health Association, Alberta South Central Region, the Alberta Mental Health Board and the Early Psychosis Treatment and Prevention Program provided educational workshops to teachers and guidance counselors at the secondary and post-secondary level, as well as to community-based health and social service agencies to improve their ability to identify the early signs of psychosis.

• A stakeholder group invited a well-known EPI specialist as a keynote conference speaker and decided to use his time in their community to full advantage. He presented at the conference, participated in Grand Rounds at the hospital, lunched with a number of clinicians and spent the afternoon in an interactive session with key service providers.

• First-episode parents in a rural community decided to target the family doctors in their community. They developed EPI information packages from available web resources and personally visited local doctors’ offices to leave the information and speak with staff.

• A local EPI steering committee targeted school guidance counselors at an annual training event. A half-day training session “A Workshop to Help Identify Psychosis Early” was so successful that it had to be offered again in the afternoon. Seventy-five school guidance counselors participated.

GETTING THE WORD OUT

“We provided information about early psychosis intervention for three consecutive issues of the School Guidance Counselor newsletter. This information reached over 350 counselors province-wide.”

“The family doctor on our EPI Committee wrote and successfully submitted an EPI article for the College of Family Physician’s newsletter. This newsletter is distributed to 1000 family physicians throughout our province!”

“We were able to piggy-back with the distribution of an Addictions annual provincial resource package. We prepared a one-page EPI handout and 1,750 copies were distributed to all provincial junior and senior high schools.”

Some Tips

• Become aware of relevant organizations and professional associations and the ways to reach them – newsletters, web sites, etc.

• Watch for conference opportunities and look for opportunities to piggy-back on existing events or activities.

• Create simple messages in an easy to use format. The template included at the end of this guide has been very useful as a double-sided, laminated handout for doctors, counselors, etc.
WHAT CAN THE COMMUNITY DO?

PROMOTE ONGOING RECOVERY, NORMALIZATION AND INTEGRATION

The issue is bigger than psychosis. To many, mental illness is a frightening thought and unfortunately, this fear can discourage people from seeking help early. Much of the fear surrounding mental illness is based on myths and misunderstandings. Mental illness should not be feared. Like other medical conditions, mental illness needs to be treated. And for treatment to succeed, there need to be broad supports for recovery.

To be most effective, a holistic approach to programs and services is needed. Services must be comprehensive and involve multiple sectors (e.g. vocational, economic, physical health, educational and recreational). Communities need to ensure there are broad mechanisms to assist individuals through acceptance and support. This includes peer support, family support networks and appropriate community-based resources.

Some Experiences

• Through a partnership between an EPI working group, the local EPI service, and the local university’s counseling service, an EPI presentation was made at a national conference of the Canadian Association of College and University Student Services (CACUSS).

• A first-episode parent returned to his son’s former high school with EPI resource materials. He discussed their family experience of psychosis and the importance of early identification with teachers and the school guidance counselor. Working together they added information about psychosis to the school’s web site.

DISABILITY SERVICES

“Our EPI service worked with my son and the Disability Services Department at my son’s college to figure out how he could be successful in returning to his studies. He decided to start slow and only took two courses the first semester. They provided a private tutor and a tape recorder so he could tape his classes.”

Some Tips

• Learn about and encourage appropriate accommodation policies and practices in your schools and workplaces. CMHA has produced guides that can help students in high school and post-secondary institutions. See Web Sources.

• Work to dispel the myths about mental illness and reduce the fear and stigma that can deter people from seeking help. Psychosis is a medical condition. It can happen to anyone. It can be successfully treated.
WHAT CAN THE COMMUNITY DO?

ADVOCATE FOR ACCESS TO SERVICES AND/OR FOR IMPROVED SERVICES

Advocacy typically refers to activities that are used to raise the profile of an issue and mobilize the forces necessary to change public opinion, policy and practice. Advocacy works best when focused on something specific.

A lot of advocacy is just a matter of seeing a need and finding a way to address it. People advocate or “plead the cause of another” all the time – for our families, friends and neighbours. Advocacy is often necessary – generally at the level of government or service providers – in order to access sufficient resources to create or enhance mental health services such as services for EPI.

• In Manitoba, as a result of the advocacy efforts of “The Manitoba First-Episode Psychosis Family Support Group” and local mental health organizations, a specialized EPI clinical service was announced in July 2002. The Early Psychosis Prevention and Intervention Service (EPPIS) opened its doors in Winnipeg in January 2003.

• Province-wide funding for early intervention was announced in Ontario in June 2004 as a result of the advocacy efforts of the Ontario Working Group. The Ministry of Health adopted early psychosis intervention as one of four top mental health priorities for the province. Funding for a multi-site research project was also secured.

• An EPI coordinator/case manager was hired in the western region of Newfoundland to work in partnership with the St. John’s Early Psychosis Program as a result of the advocacy efforts of first-episode families and local organizations.

Some Tips

• Nothing happens overnight! Pace yourself and never give up.
• Being positive and persistent can pay off.
• Pay attention to small details. A lot of advocacy turns on small details and basic courtesies such as personal thank you’s.
• It’s often awkward for service providers to be associated with advocacy efforts; family members know the issues first-hand and are passionate advocates.
• Don’t be afraid to start small. Most advocacy efforts begin with and are sustained by small groups of dedicated people. You don’t have to start with big numbers, you just have to start with big commitment.

CHANGING THE WORLD

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”

Margaret Mead
WHAT CAN THE COMMUNITY DO?
PUT IT ALL TOGETHER!

Through the lens of peoples’ experiences, this guide has described many of the ways in which the community is central to the development and success of early psychosis initiatives. But behind each quote and case example lurks a fuller story. Following is a sample of these stories that illustrates various communities’ attempts to “put it all together”. There are always more stories to be told. Perhaps the next story will be yours!

**Newfoundland and Labrador’s “Travelling Road Show”: Reaching Out**

**Purpose**
To raise awareness of early psychosis so that young people experiencing a first episode of psychosis can be connected as quickly as possible to sources of help and be supported in their home communities.

**Who**
First-episode families, community organizations, the Canadian Mental Health Association – Newfoundland Division and the Early Psychosis Program (St. John’s).

**When**

**Where**
Corner Brook, Clarenville, Grand Falls, and St. John’s in Newfoundland; Labrador City, Happy Valley-Goose Bay in Labrador.

**Approach**
A Provincial Advisory Network was formed to assist in identifying key regional gatekeepers at the start of this EPI Community Outreach Project. First-episode family members, CMHA staff and St. John’s Early Psychosis Program staff provided one-day EPI workshops throughout the province. Local first-episode families were invited to an informal family meeting the evening prior to the work-shop day to foster mutual support networks for family members.

**Outcomes**
- There were 500 forum participants province-wide.
- In the West Region of Newfoundland, a regional EPI position was funded by the provincial government, in part through the successful advocacy efforts of family members and local community groups.
- The family support group is offering monthly teleconferences that include one hour of education and then another one and one-half hours to talk among themselves. First-episode families from every corner of the province are talking to other families from their homes.
The Prince Edward Island Workshop and “Report Card”: Covering the Bases

**Purpose**
To raise awareness of the importance of EPI and mobilize action among community stakeholders in Prince Edward Island.

**Who**
Fourteen participants from across Prince Edward Island representing education, mental health, health, social services, youth services, corrections and families.

**When**
November 2004.

**Where**
Charlottetown, Prince Edward Island.

**Approach**
The CMHA National early psychosis project and CMHA – PEI Division hosted a one-day EPI community training workshop to provide key provincial stakeholders with information about psychosis, raise awareness of the role of the community in early psychosis intervention, and identify the potential for community action.

Three categories of strategies were chosen:
- Building General Awareness
- Promoting Early Identification through Education of Gatekeepers
- Working for Enhanced Services

Action plans were developed and participants identified specific roles for themselves in follow-up within the categories.

**Outcomes**
Participants reported their activities and a January 2005 “Report Card” was produced. Activities included:
- EPI information sheet from the CMHA Manitoba EPI project updated and customized for PEI
- EPI article for CMHA provincial Winter Newsletter
- EPI information sheet, pamphlets provided to CMHA resource libraries, displays
- EPI pamphlets distributed to addiction offices waiting rooms and addictions youth/family counselors
- Information packages developed and distributed to school counselors across PEI
- Information distributed to staff at mental health clinics in PEI
- PEI Teachers’ Federation Annual Conference, Oct. 2005 – display table booked
- EPI information distributed to Holland College and Student Services, University of Prince Edward Island
- EPI information distributed to the RCMP, Youth Probation Workers, Community Youth Workers, and Alternative Residency Providers
- EPI discussed at Crisis Response Planning Group
- EPI discussed with Health and Social Services
- Email list of EPI Community Training participants compiled and distributed
- EPI discussed at Schizophrenia Society monthly meeting, also EPI discussions with consumers and carers
- A second meeting of the stakeholders is being considered to discuss the next steps.
Manitoba’s “Flag Psychosis Early” Family Campaign: Advocacy in Action

**Purpose**
To advocate for a comprehensive early psychosis intervention service in the province of Manitoba.

**Who**

**When**
May 2000 – Present

**Where**
Winnipeg, Manitoba

**Approach**
Frustrated by the lack of a dedicated early psychosis intervention service in Manitoba, this family support group decided to forge ahead and advocate. They met with Manitoba Health staff and Winnipeg Regional Health Authority staff on numerous occasions. A sympathetic elected Member of the Legislative Assembly (MLA) guided them through the political process and they began by presenting information to members of the governing party caucus, and to the opposition parties. They met with the Minister of Health on two occasions. Another sympathetic MLA assisted the group by bringing their questions and concerns forward in the house during “Question Period”.

**Outcomes**
- In July, 2002, the Health Minister announced funds of $500,000 would be available for an early psychosis intervention program in Winnipeg! “It’s a huge issue,” he said. “They (family group) came to us and said, “We want a first-episode program, we want a seamless program, we want a province-wide program.”
- Families were members of the steering committee created to establish a new service and helped name the service. The Early Psychosis Prevention and Intervention Service (EPPIS) opened in January 2003.
- The family support group now holds their monthly meetings at EPPIS and assists in family education sessions offered by the service.
- A number of parents participate in the EPPIS Community Advisory Committee.
- The family group continues to advocate for expanded EPI services in Winnipeg and throughout Manitoba.
WEB SOURCES

Psychosis

www.cmha.ca
Canadian Mental Health Association, National Office
The psychosis pages on this site offer information about a number of topics including: early psychosis intervention; Canadian early psychosis initiatives; resources for families and communities; a framework for strategic planning; and a number of links. Resource materials are available for download or order.

www.psychosissucks.ca
Early Psychosis Intervention Program (EPI)
This site offers easily accessible information on psychosis, treatment, associated problems, substance use and recovery. The downloadable PDF files include fifteen excellent handouts that range from “What is psychosis?” to “Goal Setting” and “Problem Solving”.

www.pepp.ca
The Prevention and Early Intervention Program for Psychoses (PEPP)
Of interest to clinicians, families and other community members, this site includes manuals for screening, assessment, treatment; information about a well-established family support group; family stories and excellent links. The downloadable PDF files include a “Screening and Assessment” Manual (Part One) and a “Treatment” Manual (Part Two).
Also, see “Self Help Resources” for a first-episode psychosis family newsletter.

SOURCES


CMHA early psychosis resource materials:
“Early Psychosis Intervention, A Framework for Strategic Planning”
The pamphlets “Youth and Psychosis”, “Early Psychosis Intervention”, and “What is Psychosis?”

SUGGESTED RESOURCES
SUGGESTED RESOURCES

Community Action

Mental Health Promotion Tool Kit: A Practical Resource for Community Initiatives
Produced in 1999, this kit is a comprehensive guide for communities that wish to undertake mental health promotion initiatives. It contains everything anyone would need to know about implementing a mental health promotion program, including examples, strategies, tips and tools.

Mental Health Promotion-Train the Trainers Manual
This manual is the companion piece to the Mental Health Promotion Tool Kit. It is an ideal resource for groups or organizations interested in further enhancing their capacity to undertake mental health promotion initiatives.

Produced by the Canadian Mental Health Association, National Office.
Available online at www.cmha.ca.

The Community Development Handbook: A Tool to Build Community Capacity
An introductory guide to community development and capacity building. This handbook provides information, tips and questions about the basics of community development.

The Community Development Facilitator’s Guide: A Tool to Support the Community Development Handbook
Designed to support the understanding and effective application of community development.

Produced by Social Development Canada (SDC) www.sdc.gc.ca
Free PDF download available from http://publications.gc.ca or call 1-800-635-7943.

Supporting Success in Education

Mental Health and High School
An online resource for students that includes information on how mental health problems can affect life at high school and ways of coping with the challenges and issues students may be experiencing. Real-life, personal experiences are expressed throughout this resource by teens, parents and school staff. The guide for students includes tips on recognizing signs and symptoms, learning how to cope, and knowing when and where to get help.

Your Education – Your Future: A guide to college and university for students with psychiatric disabilities
A comprehensive resource for Canadian students providing information on all aspects of post-secondary education. It includes checklists to help students make decisions, and also features the experiences and advice of students with psychiatric disabilities from across the country.

Both resources were produced by the Canadian Mental Health Association, National Office.
Available as on-line resources at www.cmha.ca.
Self-Help Resources

www.selfhelp.on.ca
Self-Help Resource Centre
Promoting self-help, the site offers excellent information about how to start and maintain a self-help group.

Family to Family: A Newsletter for First-Episode Psychosis Families
Developed and produced by first-episode families, this newsletter is sent to families across Canada and provides a venue for sharing information and support.
Three issues annually, available as PDF downloads at www.cmha.ca.
Inquiries, contact the Editor at slsm@rainyday.ca.

Mental Health Resources For Youth

www.beyondblue.org.au/ybblue
A youth depression awareness web site from Australia
This site is about getting the message out there that it’s ok to talk about depression, and to encourage young people, their families and friends to get help when needed. The site hosts a whole range of new fact sheets, e-cards, depression and anxiety checklists and stories from young people.

www.getontop.org
Get on top - a guide to mental health
The site looks at depression, bipolar disorder, psychosis, substance use and other mental health concerns. There is also a personal experiences section with stories from young people who have dealt with a mental health problem.

www.cyberisle.org
Teen Net – University of Toronto
This youth site was developed with teens for teens. It is an interactive site all about young people and health issues, in a fun graphic style. Lots of links are provided to other sites about youth issues and health.
RECENT BOOKS

**Implementing Early Intervention in Psychosis: A Guide to Establishing Early Psychosis Services**
ISBN: 184184053X
Ordering Information: Tel 1-215-625-8900.
A practical book for mental health professionals establishing an early intervention program.

**Best Care in Early Psychosis Intervention: Global Perspectives**
ISBN: 1841844039
Ordering information: [www.dunitz.co.uk](http://www.dunitz.co.uk).
This book presents the “Early Psychosis Care Manual” – a comprehensive review of best practices. The book seeks to assist widespread implementation by presenting views on best practices from around the world.

**Psychological Interventions in Early Psychosis: A Treatment Handbook**
ISBN: 0-470-84436-1
Ordering information: Tel 1-800-665-1148
Drawing on the expertise of international experts, this practical treatment manual guides mental health professionals in helping first-episode clients. Chapters are organized according to phase of illness, starting with the pre-psychotic “at risk” phase and extending to protracted recovery from psychotic symptoms.

VIDEOS

**A Map of the Mind Fields: Managing Adolescent Psychosis**
National Film Board of Canada
2004. 56 minutes 30 seconds.
From EPI South Fraser, British Columbia this video is part of a three part series which also includes “Beyond the Blues: Child and Youth Depression” and “Fighting Their Fears: Child and Youth Anxiety.” To order: Tel 1-800-267-7710 or [www.nfb.ca](http://www.nfb.ca).
Identification #: 113C9104260

**One Day At A Time**
Canadian Mental Health Association, National Office
2001. 28 minutes.
Several members of a first-episode psychosis parent support group describe their experiences as parents of young people with psychosis.
Order through [www.cmha.ca](http://www.cmha.ca).
CANADIAN EARLY PSYCHOSIS INTERVENTION CLINICAL PROGRAMS

Since 1999, CMHA has witnessed the emergence and/or evolution of these clinical programs. Certainly, other programs exist. Clearly, the momentum continues to grow.

BRITISH COLUMBIA

**Port Moody:** Fraser North Early Psychosis Intervention (EPI) Program
Eagle Ridge Hospital, Tel: 604-469-5152

**Vancouver:** Early Psychosis Intervention Program (EPI)
Vancouver Community Mental Health Services, Tel: 604-225-2211

**Victoria:** Victoria Schizophrenia Service/Early Psychosis Intervention
Victoria Mental Health Centre, Tel: 250-370-8175

**White Rock:** Fraser South Early Psychosis Intervention (EPI) Program
Peace Arch Hospital, Tel: 604-538-4241

ALBERTA

**Calgary:** Early Psychosis Treatment Service
Calgary Health Region and University of Calgary, Foothills Medical Centre,
Tel: 403-944-4836

**Edmonton:** Edmonton Early Psychosis Intervention Clinic (EEPIC)
Edmonton Mental Health Clinic, Tel: 780-429-7890

SASKATCHEWAN

**Saskatoon:** Early Intervention Program in Psychosis and Schizophrenia
Saskatchewan District Health and University of Saskatchewan, Tel: 306-655-6686

MANITOBA

**Winnipeg:** Early Psychosis Prevention and Intervention Service (EPPIS)
Manitoba Adolescent Treatment Centre, Tel: 204-958-9677

ONTARIO

**Hamilton:** Psychotic Disorders Clinic
Hamilton Health Sciences, McMaster Site, Tel: 905-521-5018

**Kingston:** Southeastern Ontario District Early Intervention in Psychosis Program
Hotel Dieu Hospital and Queen’s University, Tel: 613-544-3400 ext. 2550

**London:** Prevention and Early Intervention Program for Psychoses (PEPP)
London Health Sciences Centre and University of Western Ontario, Tel: 519-667-6777

**Ottawa:** Champlain District First Episode Psychosis Program
Ottawa Hospital and University of Ottawa, Tel: 613-737-8899 ext. 73062

**Toronto:** First Episode Psychosis Program
Centre for Addiction and Mental Health, Clarke Site, Tel: 416-535-8501 ext. 4745

**Windsor:** Schizophrenia and First Episode Psychosis Program
Windsor Regional Hospital-Western Campus, Tel: 519-257-5111 ext. 76945
CANADIAN EARLY PSYCHOSIS INTERVENTION CLINICAL PROGRAMS

QUEBEC
Montreal: Early Psychosis Intervention Clinic (EPIC)
Royal Victoria Hospital, Allan Memorial Institute, Tel 514-934-1934 ext. 34530
Verdun: Prevention and Early Intervention Program for Psychoses (PEPP-Montreal)
Douglas Hospital, Tel: 514-761-6131 ext. 4121

NEW BRUNSWICK
Fredericton: Fredericton Early Psychosis Program
Victoria Health Centre, Tel: 506-444-5337

NEWFOUNDLAND & LABRADOR
St. John’s: Early Psychosis Program
Health Care Corporation of St. John’s, Tel: 709-777-3614

NOVA SCOTIA
Dartmouth: Nova Scotia Early Psychosis Program
Capital District Mental Health Program and Dalhousie University, Tel: 902-464-5997
KNOW THE SIGNS AND SYMPTOMS OF PSYCHOSIS

Know what to look for – Intervene Early

Symptoms of psychosis reflect a distorted view of reality and include hallucinations, delusions and/or disorganized thinking. But there can be many signs that something is not quite right.

Social

- Dropping out of activities – or out of life in general
- Social withdrawal, isolation and reclusiveness
- Severe deterioration of social relationships
- Unexpected aggression
- Suspiciousness
- Sensitivity or irritability when touched by others

Thinking and Speech

- Irrational statements
- Hallucinations
- Belief that one possesses special powers
- Extreme preoccupation with religion or the occult
- Belief that things have changed around them
- Memory problems
- Severe distractibility
- Peculiar use of words, odd language structures

Emotional

- Inability to cry or feel joy, or excessive crying
- Feelings of depression and anxiety
- Inappropriate laughter
- Emotions not in keeping with a situation or thought
- Euphoric mood

Behaviour

- Deterioration of personal hygiene
- Excessive writing without meaning
- Excessive or very diminished energy
- Bizarre behaviour
- Strange posturing
- Severe sleep disturbance
- Agitation
- Staring without blinking or blinking incessantly
- Feeling refreshed after much less sleep than normal

Personality

- Shift in basic personality
- Reckless behaviours that are out of character
- Significantly prolonged decrease in motivation

These signs may mean many things, particularly when exhibited during adolescence or young adulthood. If they are persistent they may indicate psychosis. A thorough assessment by a medical professional is necessary to determine whether or not psychosis is present.

Acknowledgements: Mheccu (Mental Health Evaluation and Community Consultation Unit), University of British Columbia; CMHA National pamphlets, “What is Psychosis?” and “Time is of the Essence…” April 2000.
PSYCHOSIS – KNOW THE SIGNS – INTERVENE EARLY

What is psychosis?
The word “psychosis” is used to describe conditions which affect the mind, where there has been some loss of contact with reality. When someone becomes ill in this way it is called a psychotic episode. “First-episode” psychosis means that an individual is experiencing psychosis for the first time.

Psychosis is associated with a number of medical conditions including schizophrenia, depression, bipolar (manic depressive) disorder and substance abuse.

Who can be affected?
Psychosis affects males and females in equal numbers and most often begins during adolescence or young adulthood. Psychosis is a challenging condition to face at any point in life and its effects can be particularly disruptive during this important period of development. It can seriously damage a young person’s sense of self, the ability to relate to others and the capacity to create a meaningful and productive future.

Can it be treated?
Psychosis responds well to treatment... especially when it is caught early. Early identification followed by comprehensive, individualized treatment strategies that incorporate the use of low dose anti-psychotic medications combined with education and psychosocial interventions can promote full recovery from psychosis. Research indicates that the sooner the psychosis is appropriately treated, the better the outcome.

The benefits of early intervention can include:
• Reduced disruption of activities
• Reduced disruption of family and social relationships
• Reduced likelihood of hospitalization
• Reduced risk of suicide
• Faster and more complete recovery

Who should I call?
• For more information on early psychosis intervention, call:

• For more urgent information or assessment call:

• If there is an emergency or crisis, call:

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PSYCHOSIS – KNOW THE SIGNS

Psychosis can happen to anyone. Early detection and effective treatment can promote full recovery.

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Canadian Mental Health Association, Manitoba Division, March 2001.