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family to family

FOR FIRST-EPISODE PSYCHOSIS FAMILIES

Conference Happenings

Reclaiming Our Roots

Partnering in Mental Health and Addictions Conference 2001

The Canadian Mental Health Association, Ontario Division and the Centre for Addiction and Mental Health, staged a very successful conference at the Toronto Airport Marriott Hotel, October 22-23, 2001.

Dr. Suzanne Archie, Director of the Psychotic Disorders Clinic at McMaster University Medical Centre (Hamilton, Ontario) hosted the First Episode Psychosis sessions over the two full conference days. Sessions were filled to capacity for presentations on current research in the field of early psychosis and innovative clinical programs, community and family supports.

Some of Canada's leading first-episode clinicians who participated in the *Reclaiming Our Roots* conference. From left: Dr. Jean Addington (Calgary, Alberta), Dr. Kola Oyewumi (Kingston, Ontario), Dr. Ross Norman (London, Ontario), Dr. Ashok Malla (London, Ontario), Dr. Robert Zipursky (Toronto, Ontario), Dr. Suzanne Archie (Hamilton, Ontario). Missing from photo: Dr. Paul Roy, (Ottawa, Ontario).

The conference provided first-episode families with an excellent opportunity to gain further knowledge of the illness and to connect with other first-episode families from across the province. Copies of *Family to Family* were made available to all who attended the First Episode Psychosis presentations.

Family to Family was on hand to interview one of the special guest speakers, Dr. Jean Addington, Program Manager of Calgary's Early Psychosis Treatment and Prevention Program. Our interview with Dr. Addington, along with a *Family to Family* "visit" to the Calgary program, will be featured in our next issue.

Advocacy In Action:

Manitoba Families Join Together and Push For First-Episode Services

By Sharon Scott

A dedicated early psychosis service does not yet exist anywhere in Manitoba. This situation not only creates an obvious treatment 'gap' for the young person with psychosis, but it means that first-episode families are likely to remain isolated from each other, and miss out on the powerful benefits gained through coming together with those who are living the same experience.

Despite this apparent obstacle, families in Manitoba found some creative ways to connect with each other. (More on "how we did it" in a future issue!) We formed the "Manitoba First-Episode Psychosis Family Support Group" in March 2000. We meet monthly to provide support to each other, share information, laugh and cry together and celebrate the achievements of our children. I can't begin to say how important the group has been to me. It's so helpful being with families who are in the same phase of the illness, families who listen and understand, who may be dealing with similar issues as yourself. When I don't know what to do, I call another group member and they're always ready to help.

We have also organized to lobby politically, steadily pushing our government to develop a comprehensive first-episode treatment program. We have been working hard to keep psychosis in the provincial spotlight! Our efforts have included visits to all of the members of the legislature during Mental Health Week. Our group is now being identified with the "red flag" pins which we wore and carried during our "Flag Psychosis Early" walk at the Legislature. We have met with the Minister of Health and other members in the governing NDP caucus; opposition members in the Liberal and Conservative parties; and Winnipeg Regional Health Authority staff. We are encouraged that various lobbying activities have generated some media response. We are learning much about the political process as we go (we never thought we'd be activists!!), and so far, we remain undaunted.

While we are first and foremost a support group, our advocacy work is important to us because we don't want other families to have to travel the same "rocky roads". It also helps to empower us in our own day to day struggles. I marvel at just how far we've come as families connected by common cause. But there's still a long way to go. And Manitoba families are prepared to go the distance - personally and politically. There is strength in numbers!

What's going on in your neck of the woods? Does your area need services? Do you want to find other families close to home? Let us know what's happening. The Manitoba First-Episode Psychosis Family Support group welcomes the opportunity to connect with other families across the country.

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Ask the TREATMENT TEAM

We are pleased to introduce our *Ask the Treatment Team* column in this issue. We have asked Canadian clinical sites to participate on a rotating basis – both to answer questions of concern to our readers and also to provide information about the services offered. Our guest site in this issue is the First Episode Psychosis Program, Centre for Addiction and Mental Health, Clarke Division, Toronto, Ontario. Dr. Robert Zipursky, Program Director, has answered two questions of concern and interest to our readers.

Thank you to Dr. Zipursky and his clinical team!

Q: How long does a person need to stay on medication after a first episode of psychosis?

A: I wish there were a short and simple answer to this one but it is not the case. First, it is necessary to clarify the underlying psychiatric diagnosis as recommendations will vary considerably between diagnoses. A first episode of psychosis might be a first episode of schizophrenia, bipolar disorder, depression or it might be due to drugs or an underlying medical condition. If we confine ourselves to talking about recommendations for medications after a first episode of schizophrenia, the question is a bit more manageable.

The major priority for ongoing treatment is to give the individual the best possible chance at staying well and experiencing as full a recovery as possible. We know from published studies that the chance of having a second episode after experiencing a first episode of schizophrenia is 80-90% over the first 5 years after the first episode. Those who stop their medications have at least five times the risk of relapsing as those who stay on their medication. While it is known that approximately 80-90 percent of patients will have a good response to treatment for their first episode, there is a real risk of having a less complete recovery after each additional episode. As a result, there is no guarantee that someone who has done well after their first episode will do as well after the second episode. The chances of staying well if one stays on medication are thought to be very high.

The other important consideration is the degree of improvement the person has had from their first episode. If the person has improved but is still having some psychotic symptoms (hallucination and/or delusions), it is not reasonable to stop medications and it is likely that medications will need to be taken indefinitely. The situation does get more complicated when the person has had a full remission of symptoms. It is probably the case that 10-20% of these individuals will not have a second episode even if they stop the medications. So there are a few people who could be well without ongoing medications. The trouble is, we don't know how to predict who these people are. That still leaves the person with an 80-90% chance of relapsing. For most people, relapses are associated with a lot of personal suffering and family suffering and tend to impair people for many

THE FIRST EPISODE PSYCHOSIS PROGRAM

The *First Episode Psychosis Program* was developed at the Clarke Institute of Psychiatry in Toronto in 1992 and continues to be located at the Clarke site of the Centre for Addiction and Mental Health in downtown Toronto. CAMH is an academic teaching hospital fully affiliated with the Department of Psychiatry of the University of Toronto.

Individuals are referred by their family doctors, psychiatrist, emergency room psychiatrist, or through family or self-referral. The program model includes: an outpatient assessment team that is available to provide rapid assessments of patients and families; a 12-bed inpatient research unit devoted solely to the needs of patients experiencing their first episode of psychosis; and a multidisciplinary outpatient case-management team consisting of psychiatrists, psychiatric nurses, psychiatric social workers and occupational therapists. Consultations are also provided by a clinical neuropsychologist and pharmacist. The *First Episode Psychosis Program* provides patients with comprehensive assessment and treatment including expert pharmacotherapy, individual supportive psychotherapy, family support and education and vocational assessment. An outpatient day program located adjacent to the clinic offers group activities with educational, social, vocational and recreational emphases. Approximately 150 new patients are assessed each year in the program with over 200 currently receiving ongoing outpatient care. It serves a target population of young people between the ages of 16 to 35 years. In the early years of the program, patients would typically be admitted to hospital for approximately one month for diagnostic evaluation and stabilization. With the advent of better tolerated medication strategies for the treatment of these young patients, it has become increasingly common to initiate treatment outside of the hospital and to avoid the hospital experience.

months and sometimes years. If the recovery from the first episode is excellent, the safest bet is to stay on medications. Psychiatrists around the world have been grappling with this dilemma. Many of the published treatment guidelines suggest that individuals should stay on medications for at least 2 years before considering the possibility of a medication-free period. My own thinking at this time is that after two years it would be safest for the majority of individuals to continue their medication indefinitely. That it might be best to stay on medications indefinitely underscores the importance of finding a medication for each individual that is free of significant ongoing side effects.

What are the common side effects of medication and how can a person best manage them?

With the recent shift to the new generation of antipsychotic medications (the atypical antipsychotics) and away from the older generation (typical antipsychotics) there has been a marked change in the types of side effects that can be expected. The most problematic side effects of the typical antipsychotics were neurological side effects such as muscle rigidity, muscle spasms, tremor and restlessness. These side effects were often extremely unpleasant. Fortunately, these side effects are much less common with the newer atypical medications. For individuals who had to remain on medications for many years, the older medications were associated with a high risk of developing a syndrome called tardive dyskinesia (TD). This is a neurological syndrome involving involuntary movements of muscles of the face, tongue, fingers, arms and sometimes other areas of the body. While many people with TD are not aware of these movements, they have the potential to be disfiguring. One of the new medications for schizophrenia, clozapine, is believed to carry little or no risk of TD. It is likely that the other new atypical medications also carry a greatly reduced risk of TD but further studies are required to establish this in a definitive way.

The newer medications are not, however, without side effects. Some of them may make people more sleepy or tired than the older medications. We are now aware that some of these new medications may be likely to cause quite a bit of weight gain. Weight gain can itself be a significant health concern as it may increase the person's chances of having other medical problems such as high blood pressure and diabetes. Each of the new medications seems to carry a different level of risk for weight gain. The best way to prevent and manage weight gain is through controlling diet and regular exercise. Although this can be a major challenge for people already coping with having schizophrenia, I have been very encouraged by the excellent progress many people I treat have made in losing weight.

family to family

Centre for Addiction and Mental Health, Clarke Division, Toronto, Ontario

We have recently received funding to develop a ***mobile home treatment team*** to facilitate rapid access to assessment and treatment and to provide care in the home for young patients experiencing a first episode of psychosis. The goals of the program are to improve the outcome from psychotic illnesses, reduce hospitalization and long-term treatment costs, to provide education and support to patients and families and to reduce the stigma and other barriers to accessing care. The mobile treatment team is composed of a multidisciplinary team made up of psychiatric nurses, social workers, an occupational therapist and a full-time psychiatrist. Detailed telephone screening of referrals takes place on the day of referral. Urgent assessments are completed within one working day while non-urgent assessments are seen within 3 working days. Patients and families are given the option of having the initial assessment in the community (typically at home) or at CAMH where they are seen by the assessment services of the *First Episode Psychosis Program*. The service provides care from 8AM to 9PM on weekdays and from 12 noon to 8PM on weekends. Nighttime emergency coverage is provided by a team case-worker together with a psychiatric consultant. Community-based treatment is offered by the Mobile Team for the first 3-4 months of care. During this time, the focus of care is on assessment, treatment and stabilization of the illness. Once this is achieved, clients and their families will then be referred to ongoing services either within the *First Episode Psychosis Program* or elsewhere if their needs are thought to be better met by another program.

For more information about our program, please contact:
April Collins, Manager – 416-535-8501 ext. 6865

Unravelling the Language of Psychosis

What is psychosis? Psychosis is a serious medical condition that affects the brain. It refers to a loss of contact with reality; a person has difficulty distinguishing between what is real and what is not real. When someone becomes ill in this way, it is called a psychotic episode. Psychosis is treatable. With prompt and appropriate treatment, most people will fully recover.

The involvement of our families and partners is extremely important in the overall plan toward recovery for our loved one. As we learn more about the nature of the illness, we find ourselves speaking a new language – the language of psychosis. Do you sometimes feel perplexed by the strange-sounding terms? To help navigate the language more easily, we're developing a mini-glossary of some commonly used terms. In this issue we cover the "language of symptoms".

The possible symptoms of psychosis are many, especially if you consider the pre-psychotic (prodromal) phase of illness. But this time, we will focus on "positive" and "negative" symptoms.

Positive Symptoms

Think of these symptoms as "added on". They are features that are present but should be absent.

Some examples of positive symptoms include:

Delusions
Fixed beliefs that have no basis in reality

Hallucinations
Unusual perceptions, for example, hearing sounds or voices that are not there

Thought disorder
Difficulty organizing and processing thoughts, thinking is blocked or jumbled, speech may appear fragmented and incoherent

NEW PROGRAM!

In April 2001, a new first episode psychosis clinic opened its doors in Kingston, Ontario, under the directorship of Dr. Kola Oyewumi. We'll have more on this program in coming months.

Negative Symptoms

Think of these symptoms as features that are "taken away" or "subtracted" from the individual. They refer to experiences that should be present, but are absent.

Some examples of negative symptoms include:

Blunted emotions or blunted affect
Appears less responsive on an emotional level to his surroundings

Emotional withdrawal
Becomes detached and uncommunicative

Poor rapport
Avoids eye contact, appears bored, indifferent, lacks warmth

Passivity
Lack of interest or concern for one's surroundings, lack of energy and drive, may do little more than eat and sleep

Social withdrawal
Wants to spend most time alone, absorbed in one's own thoughts and perceptions

Sources:

Early Recognition of Psychosis, from the brochure *Putting the Pieces Together. Prevention and Early Intervention Program for Psychoses (PEPP)*, London, Ontario.

First Episode Psychosis, A Guide for People with Psychosis and their Families, Czuchta, D. and Ryan, K. Centre for Addiction and Mental Health, Toronto, Ontario, 1999.

"Families can play a very important role in the treatment of psychotic disorders. Research has shown those with psychotic illness generally have a better recovery when their families are knowledgeable about psychotic illness and its treatment."

From: *Working Together, Things can get better; A Program for Families Dealing with Early Psychosis.* Prevention and Early Intervention Program for Psychoses, London, Ontario, 2000.

We would like to Hear From You!

We are very interested in your ideas, comments, stories and suggestions regarding what you would like to see here. So if you'd like to share with us please contact...

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PLEASE NOTE:
Brenda Wentzell has a new email address:
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This newsletter was compiled by Sharon Scott and Brenda Wentzell with the help from families across Canada.

This newsletter is intended as an additional source of information and support and does not replace the advice of your family's personal health practitioner. The views expressed in *Family to Family* are those of the writers.

Our resources are limited and we are looking for sites in each province to assist with distribution of this newsletter. If you are associated with an organization, agency or clinic that would find this newsletter useful for clients and could help by distributing a number of copies, please contact the Editor.

We also encourage everyone to photocopy and distribute this newsletter.

This issue of *Family to Family* has been produced through an unrestricted educational grant from Janssen-Ortho Inc. and the support of the Canadian Mental Health Association, National Office's early psychosis intervention project.

upcoming issues

- **The Early Psychosis Treatment and Prevention Program, Calgary, Alberta**
- **Talking about substance use**
- **A look at a Multi-Family Intervention Group**
- **"Accommodations" in Learning**
- **Laing House, Halifax, Nova Scotia**