



In this Issue

In this issue we're pleased to hear from three family groups - the Nova Scotia Family Support Group, the Manitoba First-Episode Psychosis Family Support Group and the Multi-Family Intervention Group, PEPP, London, Ontario. The Multi-Family Intervention Group is thought to be the first of its kind in Canada and we're sure that our readers will be interested in the problem-solving strategy used by this group. Not only is this approach successful - everyone seems to have fun!

Announcements

Announcing a new national early psychosis project! Over the summer, *Family to Family* was very pleased to hear that the Canadian Mental Health Association's Early Psychosis Project proposal was approved by Health Canada! As you may recall, *Family to Family* was born through the course of a similar CMHA project and it is with its support that we have been able to offer the newsletter in French, maintain a web presence and ensure full mailing distribution. This time, the project continues to support families and strengthen family networks across Canada through the development of a resource guide for siblings and by convening a national level meeting of first-episode families. We'll keep you posted. Thanks to CMHA for the ongoing support!

Calling all families!! Especially brothers and sisters!!

CMHA needs your help. CMHA's new national early psychosis project is in the process of compiling a resource guide created "by and for" the siblings of young people with psychosis. Siblings are often the forgotten ones, though when psychosis strikes, it affects all family members and family dynamics. So, the project is looking for brothers and sisters, around 16 to 25 years of age, who would be willing to share some of their stories and insights in order to help others like themselves. Hopefully, it will prove to be a very positive, empowering experience for all. Confidentiality is assured.

To find out more, please contact:

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or

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family to family

FOR FIRST-EPIISODE PSYCHOSIS FAMILIES

Funds flow in Manitoba, thanks to families!

By Sharon Scott

The Manitoba First-Episode Psychosis Family Support Group was formed in March 2000 when first-episode families came together to provide support to each other. In Issue 3 of *Family to Family* we shared the story of our group and our advocacy efforts. We have continued to lobby politically, working hard to keep psychosis in our provincial spotlight. Our efforts have been rewarded! In July, Health Minister Dave Chomiak announced a \$500,000 early psychosis program for Manitoba!

"It's a huge issue," Chomiak said. "They (the family group) came to us and said, "we want a first-episode psychosis program, we want a seamless

program, we want a province wide program. It will be a modest beginning but will probably expand." (Winnipeg Free Press, July 27, 2002).

Our group is now eager to work in partnership with this new service - whether it is in the role of family support, public education, fundraising for the service, or advocacy (Yes! It will need to expand to meet the needs of the entire province!) We look forward to being involved in the creation of an early intervention service that we will be proud to "feature" in an upcoming issue of *Family to Family*.

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Families Supporting Families: The Nova Scotia Early Psychosis Family Support Group

Our family support group evolved from our participation in the Early Psychosis Family Education Program, offered by the Nova Scotia Early Psychosis Program.

This education program, which is offered to family members, including siblings of person's recovering from a first episode of psychosis was offered once a week for six weeks. Because most of us knew very little about psychosis before this illness affected our family member, it was a tremendous help to learn about psychosis, available treatments, and how we could work with the early psychosis team to support our family member's recovery. Through attendance at the sessions, gradually our shock, fear and worry became replaced by hope, optimism and increasing confidence in our ability to provide the best support to our relative. In addition to the information that we got from the clinical team, we were happy to meet with other family members "in the same boat," who understood our experiences and concerns. It made us feel like "we were not alone."

When the family education program ended, we felt a sense of loss as we felt we had formed a bond with other family members and had looked forward to the weekly sessions. With the assistance of Margie Crown, the NSEPP Education Coordinator, we arranged a reunion meeting of family members who had participated in the education program to determine if there was interest in formation of a support group. Twenty-two people turned out on a stormy winter night to say, "Yes, we need such a group."

Family members suggested having two aspects to each support group meeting:

- an educational component on a topic of interest to families
- meeting time for families to discuss issues of concern, share and give support to other family members

We formed a small committee to plan the schedule and content of meetings. We surveyed family members to find out what they wanted for educational presentations. Some of the topics which have been covered in our meetings to

date include: relapse and recovery, getting on with life, financial planning: wills and estates, getting to know community supports, cognition and psychosis and medication adherence. Some nights we simply have open agendas where people can just discuss issues and concerns or we watch a video. Some families travel as far as 200 kilometres to attend support group meetings so it is clear how much this kind of support is needed.

We maintain a strong linkage to the NSEPP particularly through the Education Coordinator, who has been instrumental in getting a small amount of funding for our group. We actively participate in the evaluation of the NSEPP family education program, and at present some of our members participate in delivery of the program. As a result of our feedback, the family education sessions were increased from six weekly sessions to nine.

The need to share experiences, ideas on how we can handle problems that arise, ways to cope, and the need for a safe place to express our concerns and feelings were just some of the reasons why we formed a support group.

Our plans for the Fall/Winter include reviewing and providing feedback on education materials being developed by NSEPP, developing a brochure for the support group, and planning joint evening education sessions which include participation of our recovering relatives. We welcome the opportunity to connect with relatives across the country. You can contact me at anneobrien@hfx.eastlink.ca.

Anne O'Brien, Parent

Nova Scotia Early Psychosis Family Support Group



Ask the **TREATMENT**

Q What is medication non-adherence?

A Medication non-adherence is a term used to describe a number of behaviours including refusal to take medication, taking less than the prescribed amount of medication, taking medication erratically or discontinuing medication against the advice of the treatment team.

Medication non-adherence can be a serious problem for persons with first episode psychosis. Reported estimates of medication non-adherence in psychotic disorders vary from 11%-80%. Medication non-adherence has been clearly demonstrated to have negative effects on rates of relapse, length of time to relapse, rates of rehospitalization, length of hospital stay, length of time to recovery from relapse and extent of recovery from relapse.^{1,2}

Q What are the key factors that influence a person's adherence to a prescribed medication regimen?

A Many factors can be involved and they may vary from one person to another. Common factors associated with medication non-adherence include:⁴

Aspects of the illness itself:

- Lack of insight. The young person may not appreciate that they have an illness for which they require treatment and/or may not perceive any benefit from taking medication.

Nova Scotia Early Psychosis Program (NSEPP)

When Dr. Lili Kopala founded the Nova Scotia Early Psychosis Program (NSEPP) in 1995, the idea of a specialized program to care for young people who were first being treated for psychosis was a relatively new idea.

In the past seven years, we and others involved in the field of Early Psychosis, have made considerable progress in learning how to optimize care for young people first experiencing psychosis. Yet funding limitations remain a challenge.

Because the NSEPP has not been funded as a full clinical program by our local health authority, we have relied on grants, contracts and our linkage to Dalhousie University, to develop an infra-structure of staff and equipment.

The NSEPP Today

From the start, the NSEPP has operated with three interlinked components: clinical care, education and research.

Clinical Care: The NSEPP operates as an outpatient clinic within the Capital District Mental Health Program. Clinical care is provided by a multidisciplinary team including physicians, nurses and an occupational therapist. The care is based on the following principles:

- Partnership and mutual respect among the client, the family and health care professionals.
- Treatment with atypical antipsychotic medications in conjunction with anti-anxiety or antidepressant medications as needed.
- Formal education sessions for clients and families.
- Linkage to community programs supporting a return to social and occupational activities.
- Realistic optimism.

Referrals come from clients themselves, families, schools and health care professionals.

- **Cognitive and disorganized symptoms.** The person may be overwhelmed by the details of the medication regimen. These individuals, unless supervised, are likely to miss doses and/or take the medication erratically.
- **Negative symptoms.** The experience of low motivation or low energy may make it difficult for individuals with psychosis to take their medication as they should.
- **Positive symptoms.** Delusional thinking and hallucinations may impair a person's ability to understand and appreciate the nature of the illness, the benefits and risks of medication and the consequences of refusing to take medication.
- **Side effects of the medication.** Side effects of antipsychotic medications such as tremor, muscle stiffness, restlessness (EPS) involuntary movements (tardive dyskinesia), sedation and weight gain can be very unpleasant and of great concern to clients and have been found to be a frequent cause of medication non-adherence.³ One of the major advantages of the novel atypical antipsychotics is their reduced risk of EPS and tardive dyskinesia compared to the older conventional antipsychotics. Weight gain, however, can occur to varying degrees with the novel atypical antipsychotics.
- **Substance abuse.** Use of alcohol or street drugs in any quantity can impair the person's judgment and ability to follow their medication regimen. Many persons, having been told not to mix street drugs and alcohol with their antipsychotic medication, will choose to stop the antipsychotic medication. It is important to

advise people with first-episode psychosis to take their antipsychotic medication even if they continue to use alcohol or street drugs.

- **Stigma.** Having a mental illness, like psychosis, can be very stigmatizing. Having to take medication is a daily reminder of having a mental illness and of being "different" from one's peer group.
- **The complexity of the medication regimen.** The more complicated the medication regimen is, the greater the likelihood that a person will miss doses.
- **The duration of treatment.** Understandably a young person wants to feel well and "get on with their life". It can be difficult for them to accept that they have an illness which may require long-term treatment.
- **Belief that one is cured and no longer needs medication.** After recovering from a first episode of psychosis a person may feel that there is no need for maintenance medication.
- **Cost of medication.** While the newer atypical antipsychotics such as olanzapine and risperidone tend to be the treatment of choice, the costs can run to several hundred dollars per month. Sometimes a parent's employee benefit plan or a government drug program will cover the costs. But sometimes not.

Medication cost is a large and important topic that will be discussed more fully in a future issue.

See back page for references.

It is important to understand the reason(s) for non-adherence so that successful solutions can be found.

Halifax, Nova Scotia

Education. An active program of educational initiatives has been a major focus of the NSEPP. This has included:

- The annual Atlantic Psychosis Conference
- A multi-module professional education series
- Multifamily education sessions
- A client education series
- Development of videotape and written educational materials including a recently developed package "The Sooner the Better". (When it becomes available, we'll let you know.)

Research. Research is an integral part of the NSEPP. Clients are provided with information about research studies they may wish to consider. Involvement in research is voluntary. Among the variety of studies being conducted, most clients are interested in one or more of the following three areas:

- Clinical trials of each of the atypical antipsychotic agents with the goal of understanding how these medications can best be used in the early stages of psychotic disorders.
- Systematic measurement of clinical outcomes in early psychosis.
- Participatory Action Research (PAR) involving clients in the design and implementation of research and evaluation.

Future Developments:

The NSEPP is developing partnerships with both public and private organizations that share our concern for the well being of young people with psychosis. To these partnerships we bring our unique expertise in clinical care, education and research. For program information contact: david.whitehorn@cdha.nshealth.ca

Multi-Family Intervention Group

Multi-Family Intervention Group, PEPP (Prevention and Early Intervention Program for Psychoses), London, Ontario

An introductory note from Terry McLean R.N., B.A., M.Ed., PEPP Clinical Leader: The purpose of our Multi-Family Intervention Group is to provide continuing psychosocial treatment after the completion of the two year core program with the goal of helping families solve the problems that psychosis can continue to bring to family life. Clients and their families want and need ongoing education and support, not only from professionals, but from their peers, as old problems related to psychosis are solved and new problems emerge.

Families would previously have attended the PEPP Family Psychoeducation Workshop and the majority will have established a good knowledge of psychosis and a positive working relationship with professionals by the time they participate in this group.

The first meeting was on June 26, 2001. The intervention itself is based on a problem-solving strategy. It's like a recipe. The following steps are applied to each problem: define the problem, brainstorm, consider the pros and cons of each idea, choose 1 or 2 or 5 strategies, and finally, do it. We have had near perfect attendance! The meetings have been fun, very productive and rewarding for clinicians. It is great to see teens and parents working things out together and making new friends!

We are grateful to Dr. William McFarlane and Margaret Newmark of Portland, Maine for their ideas and support in our preparation for this group.

A Parent's Reflections

My nineteen year old son and I belong to the "Multi Family Intervention Group", which is made up of PEPP clients and their families. Our group consists of about 13 members: four pairs of mothers and sons; one father and son; one set of parents without their son and one older man with the illness; plus three professionals. We believe that this is the first such group in Canada.

Our group meets every other week for about an hour and a half and uses a "brainstorming" approach to problem solving. Each meeting begins with a bit of social time, followed by a "go round" where we discuss the affects of the illness on us over the preceding two weeks. An individual's problem is then selected. Together, we define the problem and brainstorm possible solutions using a flip chart. The individual chooses the ideas from this list which are most likely to be successful and then develops new routines and schedules, as necessary, to try out over the next two weeks. At the following group meeting, the individual reports on the success or failure of the various strategies and we discuss why some things succeeded and others did not.

I like the way the young people relate easily to one another and how the issues seem so common to them. Their own solutions and suggestions often have the most insight and compassion and being present to observe them commiserating and trying to motivate one another is heart warming and refreshing.

The trouble my son had of not having a sleep routine was a problem for both of us: too often, he would wake me at 3 AM to discuss the fact that he couldn't sleep. The group worked on this with him (us) and a big list went up on our fridge detailing when he was to take his medication; what time he would go to bed at night and get up in the morning; and even what kind of books he could read or what music he could listen to while in bed. He followed this new routine for two weeks. (My "job" was not to nag). Not surprisingly, his symptoms improved. He was proud to report his success back to the group. He continues this sleep routine even now because it works!

For me, the group has eased my sense of isolation. Hearing the stories of others and sharing my own stories feels most healthy when my son is with me. It was good for me to see my son do this problem-solving work on his own. The power of the group was greater than my parent power!

The group has helped my son to improve his life. He, alone, did the work of following a new routine, but he accomplished this with the support and encouragement of the group. And we both had fun.

For more information contact: info@pepp.ca.

References from "Ask the Treatment Team":

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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...

Family to Family

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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 health care team. 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.

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