

Talking About Confidentiality

Mental health professionals are often caught between their desires to be supportive of families and their legal and ethical obligations to protect the confidences of their clients. To learn more about privacy rights, and by implication, the sharing of personal health information across Canada, we visited Health Canada's "Office of Health and the Information Highway (OHIH)" at www.hc-sc.gc.ca/ohih, go to "Key Topics", go to "Protection of Personal Health Information".

Currently, the protection of personal health information in Canada is shared among federal, provincial, and territorial governments with a "patchwork" of legislation, policies, regulations, and voluntary codes of practice.

Protection of personal health information involves:

- **Privacy:** The right of individuals to determine when, how, and to what extent they share information about themselves with others.
- **Confidentiality:** The obligations of one person to preserve the secrecy of another's personal information.
- **Security:** The procedures and systems used to restrict access and maintain the integrity of information.

There are four federal acts listed on the site. As well, many provinces/territories have legislation protecting personal information in the public sector. If you are interested in learning more about your province's legislation, this site also provides links to all provincial documents.

I'm very pleased to introduce you to the Early Psychosis Prevention and Intervention Service (EPPIS) of Winnipeg, Manitoba. In Issues 3 and 6 of *Family to Family* we shared the story of our Manitoba First-Episode Psychosis Family Support Group and our advocacy work.

In July 2002, Health Minister Dave Chomiak, in announcing a \$500,000 early psychosis program for Manitoba, credited the family support group for its advocacy efforts. Our family group was invited to serve on the Steering Committee for the new program and participate in naming the new service! We are now co-facilitating family education sessions and holding our monthly meetings at EPPIS.
It is a true partnership of families and professionals.

An outstanding characteristic of Manitoba's service has been the extension of this spirit of partnership into the actual treatment and support of the young person experiencing psychosis. At EPPIS, families, clients and professionals work together as effective members of the treatment team.

In our "Ask the Treatment Team Q & A" column, we asked EPPIS professionals how they maintained respect for an individual's rights of privacy while ensuring that essential information is shared among team members to the benefit of the client. We were delighted with their thoughtful responses and hope that you will find the information helpful.

*Hope that summer is bringing the best to your family. See you in the fall.
Families can make a difference!*

Sharon Scott, Editor

upcoming

International Early Psychosis Association (IEPA)
4th International Conference on Early Psychosis "Translating the Evidence"
Vancouver, British Columbia
September 28th – October 1, 2004.

For the first time ever (as far as we know), families will be presenting to an international audience at the International Early Psychosis Association Conference!

Our National First Episode Psychosis Family Network together with the Prevention and Early Intervention Program for Psychoses (PEPP) of London, Ontario will present a two hour symposium titled "The Family as a Potent Force in Early Intervention for Psychosis".

For more information about this conference and to become a member (free of charge) of this association visit: www.iepa.org.au

We'll be reporting about this conference in the next issue of *Family to Family*.

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Talking About Confidentiality

Ask the Treatment Team Q & A

Early Psychosis Prevention and Intervention Service (EPPIS), Winnipeg, Manitoba

Weather Alert

IEPA Conference-Vancouver, B.C



By: *Ian Hughes with contributions by Dano Demare, Elliot Chan, Shannon McGunigal, Ian Krochak and Linda Nash*

Q *What does EPPIS see as the key issues regarding family/professional confidentiality?*

A One of the most subtle and insidious aspects of the onset of psychosis is its timing. Typically striking for the first time in late adolescence or early adulthood, the illness enters the lives of an individual and his or her family just at the point when they should be preparing for independence. Instead of celebrating the move from dependent child to autonomous adult, family members can find themselves in a whirlwind that alternates between complete reliance on family and forceful rejection of their attention and interest.

▶ Part of the challenge in treatment lies in the young person's absolutely normal wish to be independent of his or her parents. A key component of mental health recovery and a major aspect of early intervention is the focus on the early and rapid return to "normal" functioning. For someone in their early twenties, normal functioning means school or work and independently assuming responsibility for himself or herself. The struggle for anyone trying to work with a young person experiencing an early psychotic episode is to reconcile the age appropriate desire for autonomy with the knowledge that many will face a far greater challenge for recovery without the active support of family.

▶ A health care professional cannot share any personal health information without obtaining permission from a client. Typically many professionals only think to ask for that permission at the time they want information from family members. As a result, it can be well into treatment before family members are involved and they may have a sense of being somewhat of an afterthought.

▶ Canadian law dictates that, except under strictly determined circumstances, a person who has reached the age of majority* is judged able to direct his or her medical treatment and to own and control medical information specific to it. In Manitoba for example, a person over 16 (and younger in some instances) is deemed competent to make medical decisions. He or she can choose who has access to their medical information and can deny their parents any input into the treatment they are receiving. This is regardless of whether he or she is living with or dependent upon parents.

*Age of majority is determined by provincial and territorial legislation and varies across Canada.

Q *How does EPPIS deal with these issues?*

A In EPPIS, we believe family to be the primary social support of the individual clients we work with. We know there are not sufficient programs available in the community to meet client needs so we work with parents to support their adult child. A partnership like this can only succeed if all parties are open with and equal to one another.

▶ EPPIS enters each treatment relationship with the expectation we must be able to communicate fully with the parents/family of our clients. We make this clear from our first contact with new clients and ask up front to have this type of involvement. In the 18 months EPPIS has been in operation, we have had only three instances of a client denying us permission to share treatment information with other family members. In these cases, we have agreed not to reveal details of treatment but have provided general information to family members about the symptoms and effects of psychosis and offered support through our family education group and the Manitoba First-Episode Psychosis Family Support Group. We did so with the knowledge and approval of the clients involved, who were satisfied by the assurance that we were not going to disclose confidential information about them. In these situations, we continually stress the value of open relationships with parents and gently encourage the client to accept the support that family members are offering.

Q *What suggestions would you make to families who experience barriers in obtaining information and providing information to professionals who serve/support their family member?*

A We encourage families to become active members of the treatment team.

▶ It can be very difficult for family members to challenge the secrecy surrounding their loved one's medical care, regardless of which aspects of the health care system they are involved with. I was talking with my wife about this the other day as she recounted another story about having to advocate for proper attention for her mother from the staff of her personal care centre. We find the best way to ensure you are kept "in the loop" is to become an advocate, be a little bit pushy and ask questions.

“Going right to the top” with concerns is one possibility, however, it is not always the most effective route. The physicians involved in your child’s care often have the least amount of time available. It is certainly important to connect with them, but talking with other team members such as nurses, social workers or psychologists is just as likely to provide you with the information you are looking for.

It is important to educate yourself about the illness and your rights and then politely but clearly make the professionals involved aware that you know what you are talking about. Ask to be kept aware of treatment progress. Often there will be “conferences” involving your child and the treatment team; you can be present. If you have your family member’s permission, politely insist that you are invited to any such conferences.

Find support from others who have been through a similar experience. There is nothing like first hand knowledge. Someone who has already “been there” will know the tricks of the trade and may be willing to walk you through it. It is also very good to hear from a survivor that you will get through it too, especially when it really doesn’t feel like that to you.

If all else fails, most, if not all, hospital or health care systems have an advocate or ombudsperson’s office or ethics panel to which you can appeal. These services are part of the healthcare network but are sufficiently removed to be impartial. They may be able to mediate between you and the system when you have hit an impasse on your own.

The Early Psychosis Prevention and Intervention Service

(EPPIS), Winnipeg, Manitoba

A Community-Based Early Intervention Program

The Early Psychosis Prevention and Intervention Service, a program of the Winnipeg Regional Health Authority (WRHA), was developed to identify, support and treat individuals experiencing a psychotic disorder for the first time. Active involvement of family members, including support and education, is a key component of the service. The service began in January 2003 and is open to residents of Winnipeg between 13 and 35 years of age. The program is unique in that it is operated by the Manitoba Adolescent Treatment Centre, a child and adolescent mental health program. EPPIS is the first program of its kind in Canada not run as part of an adult-focused program.

EPPIS works with individuals who have just begun to display signs of psychosis or who have not previously received extensive treatment of psychosis. Those who have been treated for psychosis for more than one month are directed to other services. Individuals experiencing a first episode of psychosis and who also have problems with drugs or alcohol are welcome in the program.

The EPPIS model calls for community-based care with a strong emphasis on psychosocial interventions and family involvement. A clinical team of four mental health clinicians, two psychiatrists and a psychologist provides support, treatment, education and advocacy in all areas of life affected by psychosis. To help prevent deterioration in cognitive, emotional, family, social, and academic or occupational functioning, EPPIS tries to intervene as soon as possible after the initial onset of psychosis.

Group sessions are used to look at a wide range of issues. Although group approaches are important, clients and families may choose not to participate. Ongoing support is available on a one-to-one basis for both clients and families.

If, at any point in treatment, an EPPIS client needs to enter hospital, the EPPIS team helps arrange admission to an appropriate facility and will remain involved while the client is in the hospital and after they return home. The support is continuous; clients and families don’t have to build bridges between services by themselves.

The average length of involvement with EPPIS is anticipated to be about 2 years. Some individuals may be ready to move on earlier while others may need a longer period of support. Moving on from EPPIS is a decision that will be discussed with the clinician, the client, and family.

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Weather Alert!!

Many young people experiencing a first episode of psychosis take anti-psychotic medications such as olanzapine, quetiapine, risperidone and clozapine so it is important that young people and their families know that antipsychotic medications may impair the body's ability to regulate its own temperature.

During hot and humid weather, individuals taking these medications are at risk of developing excessive body temperature which can cause serious illnesses, such as heat exhaustion and heat stroke.

Symptoms of heat exhaustion include:

- Irritability or change in behaviour
- Low or normal temperature
- Rapid, full pulse and heartbeat
- Rapid breathing
- Cold, pale skin (may be ashen-grey)
- Profuse perspiration
- Dizziness, headache, and weakness
- Nausea, vomiting
- Cramps in the abdominal area or in the extremities.

If a person displays symptoms of heat exhaustion, he or she should be moved to a cooler place as soon as possible, given water or other liquid immediately and encouraged to rest for a short period.

Heat stroke most often occurs during heat waves. Symptoms of heat stroke include:

- Agitation, confusion, seizures, lethargy, or coma (all may be the first symptoms)
- High temperature (105 Fahrenheit or above)
- Rapid pulse and heartbeat
- Rapid shallow breathing if the person is moving about; slow and deep breathing if the person is still
- Hot, dry, flushed skin.

As soon as you recognize the signs of heat stroke, get professional help immediately.

Heat stroke is the most serious of the heat-related illnesses and, if left untreated, may even result in death.

To prevent heat-related illnesses, there are a number of things that people can do:

• TRY TO KEEP COOL

- Keep windows shut, drapes, blinds, or shades drawn during the heat of the day. Open windows in the evening or night hours when the air outside is cooler.
- Avoid overexertion, particularly during the warmer periods of the day.
- Drink plenty of fluids (avoid coffee, tea, and alcohol).
- Dress in loose fitting, light-colored clothing.
- Eat regular meals to insure that you have adequate salt and fluids.
- Seek the shade outside.
- Use a sun hat or other head covering.
- Apply sun screen (minimum SPF 30).



BRIGHT IDEAS



The London, Ontario, PEPP Parent Support Group is entertaining the idea of purchasing fanny packs (with hat/cap, sunscreen, and drinking bottle) for PEPP clients! Clinicians could then distribute them to the clients who needed them. *Please share your ideas!*

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. **Please note that we have a new mailing address and a new e-mail address** 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 help from families across Canada. The information in this issue came from many sources including materials from Health Canada's web site "Office of Health and the Information Highway" (OHII), "The Role of the Family in Psychiatric Rehabilitation" (Boston University), the pamphlet "Summer Heat and Sun Risks for Antipsychotic Medication Users" (State of New Jersey, Mental Health Services) and numerous other web sites. A special thank you to Dr. Michael Eleff who is our "behind the scenes" proof-reader.

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 contributors.

Our resources are limited and we are looking for sites in each province to assist with the 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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We thank all of you who make this newsletter happen!