

## CONFIDENTIALITY VS “THE NEED TO KNOW”

*Public bodies may release necessary personal information to third parties without the consent of the client where disclosure is required for continuity of care or for compelling reasons if someone's health or safety is at risk.*

- BC Freedom of Information & Protection of Privacy Fact Sheet:  
Nov.. 98: Releasing Personal Health Information to Third Parties

Families coping with schizophrenia need to be effective in getting medical help for someone who is seriously ill. The BC Ministry of Health *Fact Sheet* quoted above can be a tool for families who need information to help a relative with a serious mental illness.

Health care providers must regularly make decisions on disclosure of information relevant to a person's health. This is considered “personal health information”. However, there *are* circumstances when providers need to disclose patient information to third parties.

The Ministry of Health Fact Sheet quoted above provides clear guidelines for sharing patient information with third parties, such as family or friends, and to other health care providers, such as the family physician. It sets out exactly how and when the *Freedom of Information and Protection of Privacy Act* allows for disclosure of personal information to third parties, and provides several useful examples.

*Copies of the above-mentioned Fact Sheet are available from the Ministry of Health or the BC Schizophrenia Society.*

## FAMILY CHARTER OF RIGHTS

Families have a right:

- To explicit information that families do not cause schizophrenia.
- To basic information about diagnosis, specific cognitive difficulties, treatment plan, options, and prognosis.
- To information about behaviour management, advice and guidance about resources in the community, and the availability of peer support.
- To education that can assist them in coping with mental illness.
- To respect from professionals for the expertise of the family, as well as the sharing of power in the therapeutic process.
- To become appropriately assertive and to overcome traditional socialization that teaches families not to question authority.
- To have a social ethic that is more concerned about the welfare of the person with mental illness than about cost effectiveness.
- To a mandated role on governance or advisory boards and a clear voice in mental health planning that directly affects their lives.
- To a non-adversarial legal system that is understanding of potential tragedy and helpful in attempts to prevent disaster from occurring.


— British Columbia Provincial Mental Health  
Family Advisory Council, 1995

## WHERE CAN WE GET MORE HELP?

The British Columbia Schizophrenia Society (BCSS) is a family-based organization. We understand what it's like to live with schizophrenia.

FOR MORE INFORMATION, CONTACT:

**British Columbia Schizophrenia Society**

 201 - 6011 Westminster Hwy.  
Richmond, BC V7C 4V4  
Tel: 604-270-7841 Fax: 604-270-9861  
Toll Free: 1-888-888-0029  
bcss.prov@telus.net www.bcss.org

## OUR MISSION:

*“To alleviate the suffering caused by schizophrenia”*

## OUR MANDATE:

- Family support and education
- Public education, awareness and understanding
- Advocacy for better services for people with schizophrenia and their families
- Promote research into the treatment and cure for schizophrenia

Partners in Care



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[www.janssen-ortho.com](http://www.janssen-ortho.com)

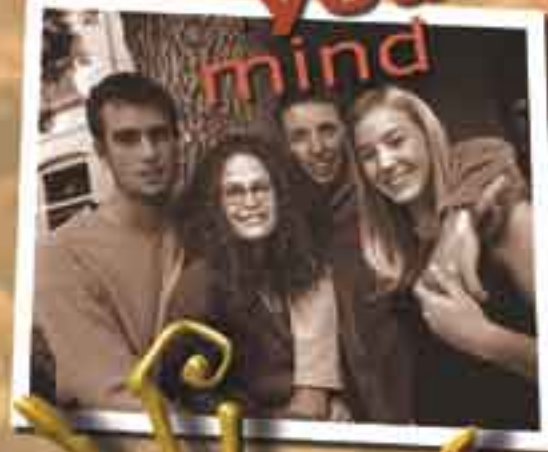
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*This information not to be substituted for the advice of a professional.  
Always consult a physician regarding individual circumstances.*

# SCHIZOPHRENIA

## FAMILIES WORKING WITH PROFESSIONALS

We'd like to  
change  
your  
mind





## FAMILIES WORKING WITH PROFESSIONALS

### WHAT CAN I DO TO HELP?

Studies show that outcomes for people with schizophrenia are much better when the family is included as part of the treatment team.

Families coping with schizophrenia need to learn:

- How to be *effective* in getting help for someone who is seriously ill
- What questions to ask
- Who to see and where to go
- How “the system” works and how best to interact with it.

### KEEPING RECORDS

Try to keep a record of everything. Nothing is unimportant.

- Keep a list of names, addresses, phone/fax numbers, emails, etc.
- Keep a notebook or diary so you can be precise about dates and times, who said what, and what subsequently happened.
- Keep all notices and letters you receive, and copies of everything you mail.

### COMMUNICATING EFFECTIVELY

When someone is ill with schizophrenia, patients and families may be so overwhelmed by the experience that they may accept vague information or jargon they don't really understand.

Families need honest, direct information. They also need specific, practical suggestions about how to cope during acute and stable phases of the illness.

#### To get positive results:

Be polite. Keep all conversations short and to the point. Ask for specific information and write it down.

- Get the name of the primary case manager — the person who knows the most about the patient.
- Make an appointment with this person.
- Request that the doctor in charge also attend the meeting.
- Ask to participate in the development of the plan.
- Help keep meetings short. Come with a list of specific questions about:
  - > Symptoms and how you can help the person deal with them
  - > What medications are prescribed, how they are monitored
- If the ill person is in hospital, ask about discharge planning.
- Educate yourself about the mental health system, starting now. Learn about the chain of command relevant to your relative's needs.

- Familiarize yourself with services and resources outside the mental health centre.
- Write letters of appreciation when warranted. Write letters of criticism if necessary. Send these to the head of Mental Health Services or to the hospital concerned.

#### REMEMBER...

- Some actions are effective — others are counter-productive
  - Most professionals are trying their best to do a good job
  - Many direct-service staff are over scheduled. Try to be as organized and as prepared as possible.
- These points hold true throughout the system. Social workers, therapists, nurses, doctors and supportive care workers sometimes have unreasonable case loads.

Always start by assuming that professionals care and want to help your relative. The following will help:

- Do not be late for appointments
- Do not make excessive demands on staff, or harass them with special requests
- Do not call all the time, or have long phone conversations filled with elaborate details.

### AVOID THINGS THAT DON'T WORK!

- Dealing with people because they are easily accessible (secretaries, receptionists) — but who have little or no power to act
- Always criticizing and never acknowledging mental health professionals for their good intentions and hard work
- Only calling when there is a crisis, rather than establishing and maintaining good relationships as a partner in care
- Expecting immediate attention and being rude or angry if you don't get it.

Courtesy is something we all aim for. But being polite should not prevent you from getting the information you need.

Specifically:

- Don't feel you should know the meaning of technical terms or phrases
- Don't hesitate to ask for clarification in plain language if you are unsure of specific issues
- Don't be afraid to ask for an explanation of procedures. Try to understand what is being done, how it is documented, and what you can do to assist.
- Don't allow yourself to be intimidated. And don't try to intimidate others.

Your goal is to help obtain proper care and resources for someone who is suffering from a serious brain disorder.

