

Obtaining and Providing Mental Health Information

A GUIDE FOR FAMILY MEMBERS



A REASON TO HOPE. THE MEANS TO COPE.
BRITISH COLUMBIA SCHIZOPHRENIA SOCIETY

BC SCHIZOPHRENIA SOCIETY FOUNDATION
SUPPORTING THE BC SCHIZOPHRENIA SOCIETY

**BC Schizophrenia Society
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A Guide for Family Members

Purpose

This Guide is designed to help family members and others playing a family-like role

- (i) Receive information from mental health care professionals; and
- (ii) Give information to mental health care professionals.

Information-sharing is important for continuity of patient care, as well as for the recovery and ongoing support of the ill person's health and well-being.

Guide for Whom?

This Guide is for families who:

- Are involved in caring for a person with a severe mental illness.
- Require information from clinicians (e.g. psychiatrist, physician, nurse, social worker, hospital or community mental health staff, residential facility staff, etc.)
- Wish to provide clinicians with information that would be helpful for the person's care (referred to as *collateral information*).

Confidentiality and the Law

The law and professional ethics require that doctors, nurses, and other clinicians keep everything a patient tells them confidential except:

- Where the patient gives permission or consent to release information OR
- Where the law allows or requires information sharing with others even if the person does *not* consent. The *Freedom of Information and Protection of Privacy Act*, which applies to Regional Health Authorities, is interpreted to mean that:

“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”

(see page 119 of Guide to the *Mental Health Act*, “Freedom of Information and Protection of Privacy Fact Sheet, Releasing Personal Health Information to Third Parties”, Ministry of Health, Information and Privacy Records Branch, effective 2004).

How to Obtain Relevant Information from a Clinician

Introduction

There are two ways a family member can obtain information relevant to the person's care:

1. By encouraging the ill person to provide consent to release necessary information to their family member. This is the preferred approach.
2. If the person does not consent, by providing clinicians with information so that they can use provisions in the *Freedom of Information and Protection of Privacy Act (FIPPA)* or the *Personal Information Protection Act* (in private practice) to justify information sharing without consent.

The decision to release information rests with the clinician. Such decisions — whether consented to or not — can be facilitated by families, who often know the ill person and their circumstances well.

This Guide applies to community and inpatient services and includes people under the *Mental Health Act*.

A. Tackling the Consent Issue

1. **Ask the Clinician to Obtain Consent.** Tell the clinician that you are helping care for the ill person and that you need relevant information necessary for their continuity of care. You do not want personal details that are not relevant to their care. Suggest that the clinician obtain consent from the ill person and have the consent information kept on the patient's file. This will also provide permission for other staff to give you needed information.

An approach to helping obtain consent is for you to ask the clinician how they obtain consent. If the response appears to be realistic for your relative, that should resolve the issue. If the clinician seems to need suggestions you might propose that the clinician say something like:

"For me and the people who work with me to be able to do our job to help you, we sometimes need to share information with or get information from others who care about you – for example, your mother, and other members of your support group. This does not include information about your personal life, but only things useful for your recovery. I assume that's ok?"

A positive response represents consent, and the clinician can make a file note that will cover all clinicians communicating with a family. The clinician assumes that the person is capable of consenting unless proven otherwise. Consent must be given freely and not obtained by coercion or threat.

If the clinician does not deal with consent in this fashion or the person does not consent in this situation, a consent form may be useful.

2. **Obtain Written Consent.** Complete a consent form for *Release of Information* (Appendix A), signed by the person and witnessed by someone other than you. If another clinician needs evidence of consent provide this completed form. The form is evidence of consent. Since the form was signed when the person was capable, its authority carries over if the person becomes incapable. (Of course, a capable person can withdraw consent at any time.)

A valid *Release of Information* form should be adequate for release of relevant information whether the person is capable of consenting or not. A more formal way of addressing consent to release information and decision making on additional issues is with a Representation Agreement.

3. **Prepare a Representation Agreement.** These agreements are the most powerful legal instrument available under the *Representation Agreement Act*. Representation Agreements exist so that if you are capable of understanding, you can name another person as your “representative” — usually a relative, but any adult can be named. Your representative can then make decisions on your behalf if you become incapable. Instructions can be given, for example, for a representative to give and receive mental health information and to make health-related judgments that a person may not be capable of if they become psychotic. The Representation Agreement comes into force when someone becomes incapable, but a signed Representation Agreement is also good evidence of consent for a clinician to release information.

Information on how to set up a Representation Agreement can be found here: https://www2.gov.bc.ca/assets/gov/health/managing-your-health/incapacity-planning/representation_agreement_s9.pdf

Nidus at <http://www.nidus.ca/?pageid=46> also provides information and a lawyer may be consulted.

B. If the Ill Person Does Not Agree to Release Information

1. Continue to try to discuss the benefits of consent with the person. Explain that personal or intimate details are not your business, that you have no interest in such information and that the clinician must keep all such information confidential.
2. If someone indicated when they were capable that they wanted their information shared if they become incapable (e.g., psychotic), that evidence should be acceptable to clinicians – even if the person subsequently becomes incapable and refuses. Evidence for this prior capable instruction would include a previously completed consent form, or statements the person has made and are known to the family member.
3. If the person has a Representative Agreement, it becomes effective if the person's illness worsens and they are not capable of making an information release decision. Information can then be released to the family on the authority of the Representative Agreement.
4. If consent is not available through verbal consent, a consent form, a Representation Agreement, or other evidence, the *Freedom of Information and Protection of Privacy Act* (FIPPA) can apply. FIPPA provides the clinician with authority to release information to you despite the ill person's objection provided certain conditions apply. The *Freedom of Information and Protection of Privacy: Fact Sheet* (Guide to the *Mental Health Act*, British Columbia Ministry of Health, 2005, Appendix 13, p. 120) states:

“If a client’s personal information was collected for health care purposes, public bodies [hospitals, regional health authority clinics, etc.] may release necessary information to third parties for “continuity of care”. This means public bodies may disclose personal information to healthcare professionals, family members, or to other persons, such as friends and relatives, involved in a client’s care for the purposes of that care. The release of the information must be in the best interests of the health of the client.”

The Guide to the *Mental Health Act*, Appendix 13, provides more detail, plus examples that show how clinicians can share important information with families despite the absence of consent. If clinicians involved are not familiar with this document, it may be helpful to provide them with a copy of Appendix 13. You should also inform the clinician of the reasons that you receiving the information is necessary for the continuity of the person's care and/or because it will reduce risk to the health and safety of the ill person or others, and it is in the patient's best interest. The Guide is available at:

<http://www.health.gov.bc.ca/library/publications/year/2005/MentalHealthGuide.pdf>

5. Regarding safety concerns, information may also be released without consent of the person if “compelling circumstances exist that affect anyone’s health or safety” (s. 31.1(m) FIPPA).

C. Mental Health Act Information Provided to Near Relatives

If the person is an involuntary patient under the *Mental Health Act*, the *Act* requires a near relative to be informed of the following: the involuntary admission and the patient’s right to Renewal Certificate examinations, to a second medical opinion on the appropriateness of the patient’s treatment, to apply to the Review Panel and the court. These applications may be made by the patient, a relative, or any other person on behalf of the patient. In addition, the near relative must be notified if the person applies to the Review Panel and also when the patient is discharged from involuntary status including from extended leave.

If the near relative does not receive these notifications or needs more information about the notification forms they should contact the patient’s nurse, social worker, physician or psychiatric unit director.

The “near relative” selected by the patient can be someone other than the nearest blood relative.

D. Valid Reasons for Not Releasing Information

Valid reasons for a clinician not releasing patient information to a family caregiver despite consent include the following:

- To do so would likely endanger the health or safety of the patient or another person
- The information names other people (in written form these can be blacked out)
- The information has been provided in confidence by another individual.

If, despite consent, clinicians refuse to provide information to caregivers, ask them under what provisions of the *Freedom of Information and Protection of Privacy Act* they are refusing.

E. If Information is Not Released by the Clinician

1. If clinicians are reluctant to give specific patient information, they may feel comfortable providing information about a hypothetical situation that you infer might apply to the person you are concerned about. For example, where a son has refused consent to talk to his mother about his prognosis, the clinician could respect that and say, for example, "If they don't take their medication, about X% of people with the kind of schizophrenia your son has are likely to relapse within a year."
2. If information is not forthcoming from a service provider then, to pursue the matter, ask to speak to the clinician's manager. If going up the management chain is not successful B.C. Health Authorities have formalized complaint procedures through their *Patient Care Quality Office*. If that office does not resolve the issue, an appeal can be made to the Patient Care Quality Review Board. The Health Authority can advise on how to contact the Board (see also <https://www.patientcarequalityreviewboard.ca/>). Assistance at any stage is often available through local mental health administration, mood disorder or schizophrenia advocacy organizations. The College of the profession of the clinician involved in withholding the information can be approached, as can the Ombudsman.

F. Providing Information to Clinicians

Families often have information that they believe would be helpful to clinicians. Examples might include noticeable improvement or worsening symptoms, side effects, new symptoms, not following treatment plan, etc. The relevant law in FIPPA is:

s. 27 (1) A public body must collect personal information directly from the individual the information is about unless (a.1) the collection of the information is necessary for the medical treatment of an individual and it is not possible (i) to collect the information directly from that individual ..."

If the ill person does not have the information or will not provide it, which means it is not possible for the information to be provided directly and hence the family may provide it to the clinician

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APPENDIX A: AUTHORIZATION TO RELEASE HEALTH CARE INFORMATION

Name _____ Date of Birth _____

I authorize the release of my health care information to and the provision of health care information from the following person or persons:

Name(s) _____

Relationship (*e.g., son, daughter, parent, friend, family physician, etc.*) _____

Signature: _____

Date Signed: _____

Witness: I testify that this is the signature of the above-named person and that the person understands and appreciates the effects of signing this release.

Witness (printed name): _____

Witness (signature): _____ Date: _____

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References

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