



PRIVACY FOR PARENTS AND CAREGIVERS

Many family members and caregivers are surprised to hear that doctors and other service providers can't share information about their child's health. It can be a frustrating situation for everyone, and it can really affect the support that family members can offer. With good planning, you, your child, and your child's service providers can work together to make sure that everyone is included in a helpful way.

When is my child old enough to give their own consent?

The age when a young person can give their own consent is a judgement call. Anyone 19 years of age or older is considered by the law to be an adult and can, in most cases, make their own decisions around consent. It's not quite as clear for people under the age of 19. While the law technically sees anyone under the age of 19 as an "infant", a young child and a young adult have different capabilities when it comes to managing their care. Young people under the age of 19 can make their own care decisions when providers feel that the individual understands what's required of them, understands their own responsibilities, the health care choices and the consequences. At this point, care providers follow the young person's wishes—parents or caregivers can't change or take away the right to give consent or make decisions.

In some situations, people may not be able to give consent regardless of age. People are incapable of giving consent if it's believed that they don't understand what's happening or make sound decisions. For example, someone who is actively experiencing an episode of psychosis may not be able to provide their own consent to treatment.

A note on our words

When we say "**child**," we mean any young person that you care for.

When we say "**family**," we mean the person or people who care for a young person. This includes biological family, a legal guardian, foster parents, or any other adult that helps out.

When we say "**service provider**," we mean any person, organization, or agency that provides health care. This includes doctors, psychiatrists, psychologists, nurses, school counsellors, therapists, social workers, mental health teams, and more.

Who needs my child's information and what will they do with it?

Different service providers may share information related to your child's care. For example, your child's counsellor may share relevant information with your child's doctor. Even though this information can be shared without your consent in some situations, organizations usually have ethical guidelines around what kind of information they can disclose. Ideally, they should ask for permission whether it's legally required or not or explain their procedures before they begin sharing information.

Your child's service provider may share information with family members if the service provider believes it's in the best interest of the child's care. However, service providers may only share information that's relevant to care, such

Definitions

Personal information—information about an individual person. It includes your name and address, information about your health, information about your education, your cultural background, your religious beliefs, and more. Some information isn't very sensitive, like your name or birthday. Other information is sensitive, like your mental health history and the treatments you use.

Privacy—the right to decide who can access your personal information.

Confidentiality— the responsibility to protect someone else's personal information.

Consent—means that you agree to something. In this factsheet, consent means that the child or youth receiving care agrees to let service providers share information with family members.

Disclosure—another way of saying 'sharing.' When you disclose information, you're sharing information.

as information about a treatment and what your child needs at home. This can be a gray area for many people. It's true that family support is a very important part of recovery, but sharing information in a way that doesn't respect your child's wishes can really damage trust between your child and the service provider. Many service providers, organizations, and agencies have formal or informal policies that say they should have a conversation around consent to this kind of information sharing, even though it's not required by law.

Some information may be used without consent or notification, such as information for researchers and information for statistics or other data. In these cases, the information received will be stripped of anything that might identify an individual. In the very rare case that personal information needs to be collected for these purposes, they must seek written permission first. The individual has the right to refuse sharing.

Any provider must disclose information to authorities if they believe that your child is at risk of harm. This includes risk of suicide (ending your life) as well as acts of harm from someone else, such as abuse. Providers must also disclose information if they believe that your child may harm someone else.

Why should families be involved?

Mental health care is a team effort. Your child's team includes all of their service providers as well as important support people—like families. In addition to providing care and support, family members may also:

- Help a child monitor symptoms of illnesses and help them seek extra help when it's needed
- Help a child follow their treatment plan and monitor for side effects or other problems
- Act as advocates, explain challenges, and explain what care has been provided—this can be very helpful for service providers when the child who is ill has a hard time talking about their experiences or when they're seeing a new provider
- Give their perspectives of the illness, which can give service providers a better idea of what's happening

Families should feel supported and informed. Unfortunately, lack of information, confusion, or lack of communication can get in the way. But by including families as equal members of the team, families are informed and capable of providing the care and support that's needed. When a child begins to take charge of their own health and care, many family members find the transition challenging—they're no longer on the front line of their child's care, and many say that they feel like they're kept in the dark. The laws around sharing information with family members are not clear, and family members may not know what to ask for or what they're allowed to ask for. The best way to make sure that everyone is working together is to have a conversation with your child and their service providers.

What do the laws say? What does it mean for me and my family?

There are two main Acts or laws that say how information is protected and shared. One Act covers information that a private organization collects, like a private therapist you pay to see. Another Act covers information collected by a public body, like a hospital, health authority, or government ministry. There are some differences between the two, but they follow many of the same guidelines when it comes to the kind of information sharing we are covering in this factsheet. Here are examples of how these laws work:

Some personal information must be shared if:

- Someone believes that your child is in serious danger (such as immediate risk or suicide) or believes that your child may harm someone else.

Some personal information may be shared if:

- Your child works with more than one service provider, and they need to share information about your child's care. For example, your child's doctor may tell your child's counsellor about a new medication. Service providers can only share necessary information that's relevant to your child's care.
- Your child's service provider believes that family members need information about a child's care. Again, they can only share information that's necessary.
- Your child consents to share information with you or another person. Whoever gives consent can also say what information can be shared. For example, they may consent to share relevant treatment information with family, but keep other details private.
- Your child is sick or injured in a hospital on their own.
- A service provider believe that information sharing is critical to care, but can't obtain necessary consent. This may come up in emergency situations when people have to make decisions very quickly.

Personal information may not be shared if:

- Someone asks for more information than they need to care for your child.
- Someone who isn't providing care asks for your information.
- Your child doesn't allow one person to share their information with another person (they don't give consent)
- The reason for sharing information has changed, even if your child originally gave consent.

Learn more about laws

- Read the Guide to the Personal Information Protection Act at www.cio.gov.bc.ca/local/cio/priv_leg/documents/pipa/guidepipaview.pdf
- Read the Guide to the Freedom of Information and Protection of Privacy Act at www.cio.gov.bc.ca/cio/priv_leg/foipppa/foipppa_guide.page

When might family not have access to information?

Service providers can refuse to share information with family members, even if someone has given consent. This can happen when:

- A service provider believes that consent was not given freely (for example, someone was tricked or forced to give consent)A service provider believes that providing that information may harm their client or another person
- The information includes other people's personal information
- Information was provided by someone other than your child

How can I start the conversation with my child's health team? What can I ask for?

First, it's important to know that consent is an on-going process, not a one-time conversation. You can start the conversation at any time. Ideally, conversations around sharing information should start during intake or when someone begins to receive services. However, the conversation can (and should) come up regularly. It's important to pick up the conversation if you or your child are no longer happy or comfortable with the current situation or whenever your child's situation changes, such as changes in diagnosis, treatment, care team members, or family situations.

Service providers understand that family involvement is an important part of a child's care. In most cases, service providers are happy to help you and your child find an agreement that works for everyone.

- Ask about confidentiality and information sharing policies and procedures. Some providers may share information based on verbal consent, but most will ask your child to sign a form or agreement.
- Laws around information sharing are not always clear, so you and your child may have a lot of questions or concerns. Don't be afraid to ask questions to clarify any points you don't understand.
- Regularly check in with your child to make sure that they know what's happening and feel good about the current situation.

When your child lets a service provider share information with you or any other family member, it's important to remember that you have a responsibility to protect that information. Sharing health information takes a lot of trust, and it's important to respect your child's privacy. In addition, the stigma of mental illnesses mean that there may be consequences for your child if information is made public without their knowledge or consent.

What if my child doesn't want to share information with family members?

Understandably, many people would rather keep some information private between themselves and their care providers.

Information-sharing doesn't have to be all-or-nothing. A young person who is receiving treatment may feel more comfortable sharing information if they can set their own limits. For example, a young person may let a service provider share their diagnosis and information related to treatment with family members, but keep other information private. This kind of flexibility gives people control over their information but still keeps family members informed of what they need to know.

What about the *Mental Health Act*?

The *Mental Health Act* is a law that lets a service provider assess a person who is believed to be at risk of harming themselves or others due to a mental illness and admit them to a hospital, if needed. This assessment or hospitalization can happen voluntarily (with their consent) or involuntarily (against their wishes). The *Mental Health Act* can be complicated on its own, but there are a few important things to know about information sharing when someone is hospitalized under the Act:

- For the *Mental Health Act*, a person is considered an adult at the age of 16. As with other situations, a person can give their own consent when service providers feel that they understand what's happening, even if they're younger than 16.
- People who are admitted under the *Mental Health Act* have to give consent in writing by filling out a form.
- People can't give consent if providers feel that they are incapable of providing consent, regardless of age. People are also incapable of giving consent if they're believed to be intoxicated.
- The hospital must tell a family member in writing when someone is admitted under the *Mental Health Act*, when they apply for a Review Panel Hearing, and when they're discharged from the hospital. The person admitted can choose who the hospital notifies.
- Ideally, the hospital providing care should try to get consent to share an individual's information with family members. If this can't happen, service providers can still share relevant information about your child's ongoing care without their consent.

For more on the *Mental Health Act*, see the *Guide to the Mental Health Act* resource at www.health.gov.bc.ca/library/publications/year/2005/MentalHealthGuide.pdf

How do you request medical records?

If you want records from a doctor or someone that you see privately, you just need to ask for your records.

If you would like records from a hospital (like during time in hospital or an outpatient program), you usually make a request in writing, with a specific form. Look up the hospital's Privacy Officer for more information about the hospital's specific requirements. If you aren't sure what to do, check if the hospital has a patient advocate, patient navigator, or ombudsperson—they can help connect you with the right department.

How can I make a complaint?

If you have a complaint against a doctor's office, you can make a complaint to the College of Physicians and Surgeons of British Columbia. You'll find their website at www.cpsbc.ca. If you have a complaint about a hospital, you can contact the Patient Care Quality Office for your health authority. You'll find a list of health authorities at www.health.gov.bc.ca/socsec.

You can also make any privacy complaint to the Office of the Information and Privacy Commissioner. You'll find their website at www.oipc.bc.ca.

Where can I go for help?

The Office of the Information and Privacy Commissioner of British Columbia makes sure that everyone follows privacy laws. The 'For the Public' section of their website has a lot of information on your rights, how to make a complaint, and where to go for more help. Visit www.oipc.bc.ca

The People's Law School offers education and information on many different legal concerns. They can also refer you to other resources that can help. Visit www.publiclegaled.bc.ca

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