



# FAQS: ON PRIVACY AND CONSENT FOR CAREGIVERS OF CHILDREN AND YOUTH

## ACKNOWLEDGEMENTS

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## DISCLAIMER

This resource document is meant to provide general information to family caregivers and care providers on the privacy and health care consent requirements in Ontario. This resource is not intended to provide a comprehensive description of the privacy and consent legislation, nor to serve as a decision tool, or as legal or clinical guidance. For advice on particular situations—especially those that are complex—caregivers and providers should consult with privacy staff in local health or community care organizations or seek their own legal advice.

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Please refer to [Understanding Health Privacy and Consent in Ontario: A Guide for Caregivers and Care Providers](#) for information on privacy law in Ontario, consent, capacity, and substitute decision-making, and how caregivers and providers can support patients within the framework of privacy law.

We also offer three other FAQ resources:

[FAQs on Privacy and Consent for Caregivers Supporting Someone Capable of Making Their Own Decisions](#)

[FAQs on Privacy and Consent for Caregivers Supporting Someone Incapable of Making Their Own Decisions](#)

[FAQs on Privacy and Consent for Caregivers Supporting Someone in the Mental Health and Addiction System](#)

These FAQs address common questions of caregivers of children of any age (but specifically under the age of 16). If the child is over the age of 16, you may find our other FAQ resources are also of interest to you. This resource includes addressing decision-making authority after divorce or with split families.

There is no specific age at which a child automatically starts to make their own health care and privacy decisions. Just like adults, children may make their own decisions if they are capable. This includes with whom information is shared and who can have a copy of their health record.

Babies and very young children are never capable of making their own decisions. But as children mature they usually become more capable of making their own choices. Children may start making simple health care decisions for themselves (such as participating in counseling) around age 10, 11 or 12. They may be able to make most health care decisions for themselves at age 14, 15 or 16. If a child is making their own treatment or counseling decisions, only the child is able to make privacy decisions about that treatment or counseling.

Some children will never become capable to make their own decisions because of injury, developmental issues, or mental abilities.

If a child or young adult is incapable, they need a substitute decision-maker (“SDM”) who will make decisions about privacy.

### Special Rules for Children Under the Age of 16

If a child is under the age of 16 and capable of making their own decisions, the child can make their own decisions. The child’s parents may also authorize the collection, use or disclosure health information except:

- If the information relates to information about treatment or counseling where the child made their own decisions, only the child gets to make the decision
- If the child is capable to make health record decisions and objects to the release of the health record (to the parent or anyone else), the child’s decision trumps the parents’ decision.

Age	Capacity	Decision Maker
Person of any age	If capable	Can make their own privacy decisions
Person of any age	If incapable	Needs a substitute decision-maker to make privacy decisions
Person under the age of 16	If capable	Can make privacy decisions and a custodial parent can also make privacy decisions about treatment or counseling the child did not consent on their own (but not if the capable child objects to parent making those decisions)

### Incapable Children

Parents are usually the SDMs if their child is incapable, except:

- If the parents are separated or divorced, there may be a court document that grants one parent custody or decision-making responsibility and one parent access rights only. Parents may have to produce court documents or separation agreements to prove to a provider who has custody/decision-making authority.
- If the child is in the care and custody of a children’s aid society or Indigenous child well-being agency.
- If the parents are deceased, the person who has custody of the child becomes the SDM.
- If the parents are not available (for any reason such as they are out of town and cannot be reached or are in detention, or unconscious), the child’s sibling can be the SDM (as long as the sibling is over the age of 16), and if there is no sibling, then any other relative can be the SDM.

### Q: Is it true that providers can provide health services without a parent even knowing?

Yes. If a child is capable, they can consent to health care treatment or counseling on their own. This commonly happens with health interventions like counseling, birth control, sexual health services, and smoking cessation. If a child is capable and asks that their parents not be told, the provider cannot share information with the parents. In many scenarios, patients will be encouraged to have support from their family. But there are scenarios where young patients choose their health care and parents are not involved or told.

**Q: Are children allowed to have a copy of their own health records?**

Yes, if a child is capable they can ask for and be given a copy of their own health record. If a child is incapable, their SDM may share the child's health records with the child.

**Q: What happens if a child does not want information released to their parents?**

If a child is capable and does not want information released to their parents – the child's decision trumps the parents' request. However, the provider should discuss this decision with the child (among other purposes, to determine whether the child is interested in sharing some information with their parents in order to provide a safe and supportive environment for the child if living at home).

If a child is incapable, the child's SDM makes decisions for the child (even against the child's objections). If the parents are the child's SDM – the parents get the information they need to make treatment decisions. The provider may talk to the child about the child's objections.

**Q: If a provider cannot provide a parent with a copy of a child's health record, can they receive a verbal summary of a child's diagnosis or care or other health information?**

Health information is protected whether it is written in a health record or summarized verbally. So the same rules apply as above.

**Q: Can parents make appointments for their children?**

Yes, in most situations. If the child is incapable, their parents will make their appointments. Capable children can agree to having their parents make appointments for them.

**Q: Can parents have information about the health care their child received for insurance companies or school reports?**

If a child is incapable of making their own decisions, their SDMs (in most cases, their parents) can have their information for any purpose including to share with insurance companies or schools.

If a child is capable, the child can authorize the provider to share their information with their parents to give to insurance companies or schools.

If a child is under the age of 16 and capable, the parents can also authorize the release of information about health care or counseling the child did not decide on their own (which might include their immunization records when they were babies and very young children), but not records about health care or counseling they decided on their own.

**Q: If a parent is in the room with a child during a medical appointment, can the parent know about the test results from that appointment?**

If the child is incapable of making their own treatment and information decisions, and the parent is the SDM, then yes.

If the child is capable of making their own decisions, providers should ask the child with whom they want their test results shared. If for some reason the provider does not know what the child wants, the provider must ask for the child's permission to share the results with a parent, even if the parent was there when the test was ordered.

**Q: When a child is incapable, do parents have to make information decisions together? What if they disagree?**

If two parents are both SDMs for their incapable child, they make information decisions together. If they cannot agree, then they should be encouraged to try to agree. If they cannot agree they may lose the right to make information decisions and the provider must ask the Public Guardian and Trustee for decisions on the child's behalf.

**Q: What happens if a child's parents are separated or divorced? Who makes information decisions for the child?**

In cases of separation or divorce there may be a separation agreement or court order relating to decision-making and sharing information about a child. If a parent says there is such a document – the provider should be given a copy and should read it carefully.

If the child is capable – the child makes information decisions even if there is a court order that says one or both parents have custody or decision-making responsibility.

If the child is incapable (and there are no higher ranking SDMs):

- If both parents have custody or decision-making responsibility, they both make information decisions.
- If one parent has custody/decision-making responsibility and the other parent has only access/parenting time, the custodial/decision-making parent makes information decisions.

**Q: How do I continue to be involved in my child's care as they transition to adult care?**

If an incapable child is transitioning into adult care, the parent will still be the SDM and will have continued rights to information (unless the child has a spouse or partner or there is some other higher ranking SDM). These transitions can be bumpy and you may have to advocate for yourself to stay involved, though as SDM you have rights to be involved.

If the child is capable, the child can ask for their providers to include their parents in appointments or share information with their parents.

**Q: As the parent of a child with a complex health condition, it's frustrating that I don't have online access to my child's information. I am left having to get copies of all the information and bring it with me to their appointments. Is there an online alternative where a patient's information is stored electronically?**

Some providers have portals where patients and their SDMs can have easy online access to patient information. An example of this is lab results. Ontario Health is developing a provincial electronic health record that will eventually give patients and their SDMs online access to information – but that is not yet widely available. Providers have to make sure to transition parental access to a child's health records online when the child is capable and starts making their own decisions.