

Communicating with Health Care Providers

How you can be a health care communication champion for your family member

Before the appointment:

Explore and understand any worries the person has about the appointment:

- Ask about their fears - don't avoid this topic. Validate how important their feelings are to you.
- Help them to overcome their fears and worries. Discuss and review strategies that might be helpful:
Preparing a social story? Doing a site tour? Watching a demonstration video? Role playing and practicing? Making note of a favourite item to bring?
- Record information in the **About My Health** tool, and bring it to the appointment.

Did you know?
[Easyhealth.org.uk](https://www.easyhealth.org.uk)
has loads of health care videos made with and for people with IDD.

Help the person to understand what will happen at the health care appointment:

- Be truthful, *but supportive*. ('I'm sorry this might hurt. We will try to be quick.')
- If you minimize what will happen (for example, saying 'it won't hurt much' to have blood taken), this tells a person that you can't be trusted, or that they are weak because it did hurt for them, but not you. This may impact your relationship, while also making your family member even *more* afraid about health care visits in the future. This may seem helpful for a moment, but when we think about it, it is not helpful at all.
- Review with the provider if there are ways to make things more comfortable.
- When booking the health care appointment, ask if it's possible to have extra time booked for the appointment.

During the appointment:

Help promote positive communication with the provider:

- Encourage and support the person to express their feelings: any questions, pains, worries. You may need to initiate this during the appointment. Ask your loved one's permission before you share any sensitive information.

Role model ideal communication to the provider:

- As a caregiver, you have expert knowledge about how to enhance communication. Techniques you can demonstrate to the health care provider may include:
 - If a question is posed to you, redirect it to your loved one: make eye contact, ask the person directly, modify your language if needed.
 - Pause and give enough time for a response before repeating or trying again.
 - Rephrase difficult concepts or medical jargon (and don't be afraid to ask the health care provider to explain it to you too).
 - Use the **My Health Care Visit tool** to record information.
 - Suggest concrete wording instead of abstract/open ended questions.(e.g. "Are you happy? Mad? Sad?" - instead of "How's your mood?").
 - Use visual aids, gestures or written information if that will foster understanding.

After the appointment:

Reflect and Review

*See the [Health Care Decision Making tool](#) for more information.

- Review how the visit went.
- If it went well reinforce your family member's great efforts at being their own self advocate.
- If there were problems debrief about what can be done next time.

Appointment Preparation

Summary Checklist

The following is a summary of the things to discuss to help increase the success of the medical appointment.



Stages of the appointment to plan for:

Before

- Practice running through the appointment and what can be expected
- Track the health care issue/symptoms using a tracking sheet.
- Bring preferred items to help with waiting.
- Have “**About My Health**” and “**My Health Care Visit**” tools and any other data you were tracking, ready to show the doctor.
- Arrive on time.
- Ask about a quiet waiting space.
- Have up-to-date contact information for yourself as a caregiver and the substitute decision maker (see “**About My Health**”) in case the doctor needs to contact them for any health care decisions.
- Other ideas:
- Ask your family member before sharing information.

Start

- Give the health care provider the “**About My Health**” tool and “**My Health Care Visit**” tool and any other data you were tracking.
- Model the best way to communicate.
- Involve your family member.
- Support the communication process.
- Other ideas:

Exam

- Check in with your family member during the appointment.
- Ask the health care provider to explain what will happen before they start.
- Ask for a demonstration when possible.
- Ask the health care provider to deliver one instruction at a time and to slow down.
- Other ideas:

Summary

- Ask if your family member wants you to be present to hear what the doctor says.
- If health care decisions require a substitute decision maker, have their contact information available.
- Make sure the information is understood as best as possible
- Other ideas:

Wrap up

- Make a note of what happened and what was decided in the “**My Health Care Visit**” tool.
- Make sure instructions are understood.
- Other ideas:



“Be my microphone, not my voice.”

- Dave Hingsburger

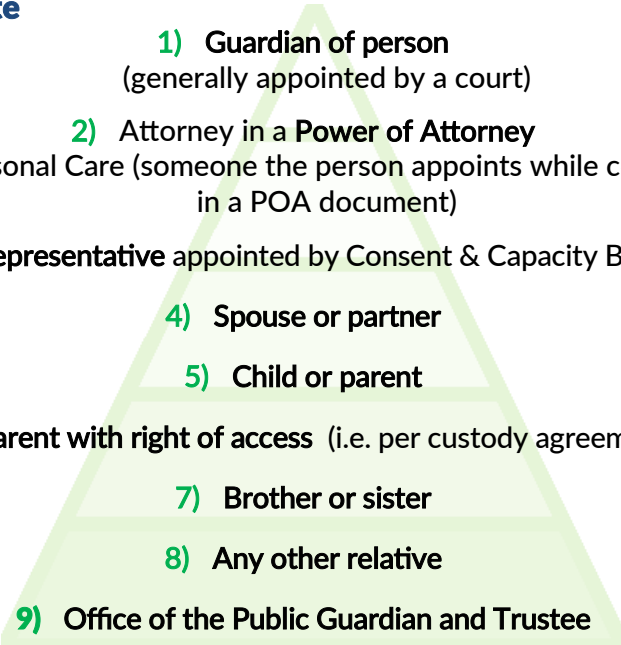
Health Care Decision Making

The ability to make decisions for ourselves is a human right. This is part of the ethical principle known as autonomy. When it comes to making a health care decision, current laws state that people can make their own decisions—unless there are grounds to think a person does not have the capacity or mental ability to do so. This can happen if a person is temporarily incapacitated (e.g. in a coma), or if someone has a more chronic disability that affects decision making.

People with intellectual and developmental disabilities (IDD) can participate in decision making and planning, even if they might need some extra support and accommodations from family, caregivers, and health care professionals. This person-centred approach puts the person with IDD at the centre of communication, planning, and decisions regarding their care.

There may be times when, even if information is explained clearly or repeated, the decision may be too complex given the person's abilities, and someone else is needed to make the decision. This follows the current laws in Ontario which are based around a concept known as *substitute decision making*. When a person is found to be incapable of making decisions, a substitute decision maker (SDM) is appointed to make the decision. The SDM is guided by knowledge of the person, gained from those closest to her or him. The laws in Ontario are very specific on who can be a SDM. In order, they are:

The “hierarchy” of substitute decision making in Ontario

- 
- 1) **Guardian of person**
(generally appointed by a court)
 - 2) **Attorney in a Power of Attorney**
for Personal Care (someone the person appoints while competent, in a POA document)
 - 3) **Representative** appointed by Consent & Capacity Board
 - 4) **Spouse or partner**
 - 5) **Child or parent**
 - 6) **Parent with right of access** (i.e. per custody agreement)
 - 7) **Brother or sister**
 - 8) **Any other relative**
 - 9) **Office of the Public Guardian and Trustee**

Health Care Consent Act (1996)

When the SDM does not know the person well, trusted family members and other caregivers can help to inform decision making. You can also be helpful by ensuring that up-to-date contact information for the SDM is shared with the health care provider, in case this is needed. You can also discuss with your loved one the benefit of keeping their SDM informed of any health care appointments, in the event there is a decision the health care provider will call upon them to make.

What does capacity mean?

Legal capacity means having the ability to **understand the information** that is being presented (for example, knowing the risks and benefits of the decision), and to **appreciate how it relates to you** (for example, being able to explain what happens if you agree to treatment, but also understand the consequences if you refuse treatment). If a person understands and appreciates the information, they have the right to say no, or to make a bad or foolish decision. In fact, people do this all the time!

What health care decisions are included?

In Ontario, the law specifies that health care decisions include **medical treatment**. This is anything done for a *“therapeutic, preventive, palliative, diagnostic, cosmetic or health related purpose and includes a course of treatment”*. Examples could include things like having a pap test, starting new medications, having a biopsy, going for surgery, or getting physiotherapy. It also includes decisions about going into a long-term care home and personal support services. It does not include asking questions about your health history.

Who determines if a person is capable to make the health care decision?

The person proposing the treatment (the doctor, therapist, etc.) is the one to determine a person’s capacity to decide whether or not they wish to proceed. Usually, capacity is presumed – meaning, it is only questioned if the health care provider feels there are significant grounds to think a person can’t make the decision. Having an intellectual or developmental disability (IDD) may be a situation where the health care provider takes some extra time to explain and assess the person’s decision making abilities. Capacity needs to be assessed for each decision. This means that people may be able to make some decisions, but not other decisions AND that people may be able to make a decision at one point in time, but not at another time.

What is your role as a caregiver?

As a caregiver, whether you are the SDM or not, your role could include:

- Role modelling and encouraging effective communication and accommodations, so that your family member can be provided with the best opportunity to participate in the decision making process. If there are any specialist reports (e.g. psychology or speech and language pathology) that provide strategies for how best to communicate with the person, encourage that these be shared and reviewed by the health care provider.
- Ensuring that your family member has familiar, positive faces around them who can be trusted allies and support them through any big decisions.
- Make sure the SDM’s contact information is up-to-date and clear at every appointment, and on hospital information sheets in emergencies.
- The SDM needs to know about every appointment before it happens, so they are aware that they may be contacted, if the doctor feels it is necessary (i.e. if the doctor feels the patient is not capable to make a health care decision).
- If you are the SDM, be prepared and available to help the care team know about decisions being made. Help your loved one understand what is happening and involve them to get their input (“assent”).



SURREY PLACE

If you would like more resources on this topic, please visit the Developmental Disabilities Primary Care Program at Surrey Place:

- [Capacity for Decision Making Guidelines](#)
- [Communicate CARE: Guidance for person-centred care of adults with IDD](#)
- [Decision Making in Health Care Tool](#)