

FAQs on Substitute Decision-Making

Information for Patients, Caregivers, and the Sinai Health Community

The following information is for patients cared for in Ontario.

Prepared by the Department of Bioethics

What is a substitute decision maker?

When a health care professional finds a patient is not capable of making a health care decision, they ask another person to make decisions for the patient. This person is called a substitute decision maker.

What is decision-making capacity?

Decision-making capacity involves the process of decision-making, rather than the choice made.

A patient is capable with respect to a treatment, admission to a care facility or a personal assistance service if the patient is able to:

- understand the information that is relevant to making a decision about the treatment, admission or personal assistance service and
- appreciate the reasonably foreseeable consequences (what might happen as a result) of a decision or lack of decision.

Who is the substitute decision maker (SDM)?

The Health Care Consent Act lists the order in which substitute decision makers are asked to make decisions on behalf of the patient. If the highest ranking person is not willing or able to act as SDM, the next ranking person will be asked.

Being a SDM is an important role requiring patience, compassion, understanding and support. For many people, the SDM will be a family member.

Who can be a substitute decision maker?

A substitute decision maker must be:

- Capable with respect to the treatment decision
- At least 16 years old, unless he or she is the incapable person's parent
- Not prohibited by court order or separation agreement from having access to the incapable person or from giving or refusing consent on his or her behalf
- Available, and
- Willing to assume the responsibility of giving or refusing consent.

Specially Appointed

1. Guardian of the Person
2. Attorney for personal care
3. Rep. appointed by Consent and Capacity Board

Family

4. Spouse/Partner
5. Child/Parent
6. Sibling
7. Other relative by marriage or adoption

Other

8. Public Guardian and Trustee

This shows the hierarchy of possible Substitute Decision Makers from the Ontario Health Care Consent Act, 1996

■ What information do substitute decision makers (SDMs) receive before making a decision?

A SDM must make an “informed” decision on behalf of an incapable person. Therefore, a SDM is entitled to the same information the patient would have received. This includes:

- The nature of the treatment (what type of treatment is proposed)
- The expected benefits of the treatment (how it can help)
- The material risks of the treatment
- The material side effects of the treatment
- Alternative courses of action (other options) and
- The likely consequences of not having the treatment

■ What kinds of decisions do substitute decision makers (SDMs) make?

A SDM may be asked to provide consent on:

- Treatment (e.g. therapies or care options),
- Diagnostic procedures (e.g. colonoscopy or echocardiogram),
- Transferring the patient to another care setting, or
- Community care treatment plans.

■ How are family traditions considered in the process?

In some families the oldest brother or sister traditionally makes all decisions, rather than younger ones, or males rather than females.

While we will make every effort to respect family traditions, it is important to understand that in Ontario, under the Health Care Consent Act, all brothers and sisters have equal decision-making authority.

■ How should substitute decision makers (SDMs) make decisions? What are the principles for giving or refusing consent?

Your health care team will help you understand how these apply to your case. The Health Care Consent Act provides legal rules about making healthcare decisions for someone else. The SDM needs to make decisions based on:

1. Prior Expressed Capable Wishes;
2. Best Interest Standard.

■ How are prior expressed capable wishes applicable to current circumstance?

The substitute decision maker should make decisions on the basis of what the patient has expressed in the past that may be applicable in the current circumstances. Ask yourself:

- “Have we discussed this situation or similar situations in the past?”
- “Are there any values, beliefs or wishes they have shared that are applicable in this circumstance?”
- “What would the patient say if she could speak with us right now about this treatment choice?”
- “What would the patient want, under these circumstances?”
- “What is important to the patient in this type of situation?”

Your loved one may have told you in writing, speaking, with pictures or any other way what it is that he or she wants.

■ What is the best interest standard?

This standard is used in situations where the substitute decision maker does not know the patient’s wishes.

In assessing the patient’s best interest, the following factors should be taken into consideration:

1. the values and beliefs that the substitute decision maker knows the incapable person held when capable and believes would still act on if capable
2. any wishes expressed by the incapable person with respect to the treatment prior to attaining sixteen years of age
3. the following factors:
 - a. Whether the treatment is likely to:
 - i. Improve the patient’s condition or well-being
 - ii. Prevent the patient’s condition or well-being from deteriorating
 - iii. Reduce the extent to which, or rate at which, the patient’s condition or well-being is likely to deteriorate

- b. Whether the patient's condition or well-being is likely to improve or remain the same or deteriorate without the treatment
- c. Whether the benefit the patient is expected to obtain from the treatment outweighs the risk of harm
- d. Whether a less restrictive or less intrusive treatment would be as beneficial as the proposed treatment

■ What if the SDM disagrees with the patient's prior stated capable wish?

It is important for the SDM to focus on the wishes and values of the patient, rather than what the SDM would want for the patient. What did the patient say that he or she would want?

■ How should the incapable patient be involved?

Incapable patients should be involved in the decision-making process to the best of their ability. Although unable to act as the final decision-maker, the patient's feelings are important.

■ Can the SDM consult with others?

While the highest-ranking substitute decision maker in the hierarchy is the ultimate decision maker, the SDM may consult with others. Involving others in the decision-making process allows them to see firsthand how the decision was made. While they may not agree with the decision, many will appreciate that they were consulted. In some cases, consulting others may make it more difficult to reach a decision.

■ What if there are conflicts?

At the best of times it can be difficult to make decisions for an incapable person. End-of-life decisions are especially challenging. Conflicts often arise between well-meaning friends and family members.

Health care professionals will work with the appropriate SDMs to resolve disputes. A bioethics consult can help families walk through decision-making in a neutral, respectful environment.

■ What if there are two SDMs of equal rank?

Two or more equally ranked substitute decision makers (e.g., brothers and sisters) may disagree about treatment. If the conflict continues despite all efforts to resolve it, and if patient care is at risk, the Public Guardian and Trustee will be notified. The Health Care Consent Act gives the Public Guardian and Trustee the power to make decisions under these circumstances.

■ What if the SDM is not abiding by the Health Care Consent Act?

If the health care professional who proposed the treatment is of the opinion that the SDM did not comply with "Principles for giving or refusing consent" (see above), the health-care professional may ask the Consent and Capacity Board to determine whether the SDM complied with these principles.

■ Does the SDM have to make these decisions alone?

Substitute decision makers who face a difficult decision are encouraged to speak with those who can offer support:

- Members of the health care team (doctor, nurse, social worker or spiritual care/chaplain)
- Anyone of importance to the patient
- Religious or spiritual leaders.

The bioethicists at Sinai Healthare specially trained to support SDMs with difficult decisions.

Glossary

Consent and Capacity Board: An independent body created by the provincial government of Ontario under the Health Care Consent Act.

Guardian of the Person: Someone appointed by a court to make personal decisions for a child or an incapable adult.

Partner: Two people who have lived together for at least one year and have a close personal relationship that is of primary importance in both lives.

Public Guardian and Trustee (PGT): Appointed by the province to protect the legal, personal and financial interests of certain private individuals and estates.

Spouse: Two people are spouses if:

- a. They are married to each other; or
- b. They are living in a conjugal relationship outside marriage and,
 - i. have cohabited for at least one year,
 - ii. are together the parents of a child, or
 - iii. have together entered into a cohabitation agreement.

Substitute decision maker: A person given the authority to give or refuse consent on behalf of an incapable person.

Resources

Information about informed consent can be found on the following websites:

Health Care Consent Act

<https://www.ontario.ca/laws> (search Health Care Consent Act)

Consent and Capacity Board of Ontario

www.ccboard.on.ca

Substitute Decisions Act

<https://www.ontario.ca/laws/statute/92s30>

Power of Attorney Kit

www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp

References

Health Care Consent Act. 1996

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