

A Guide to Substitute Decision-Making

A 7 year-old boy is diagnosed with leukemia. He is not capable of making treatment decisions on his own.

A 24 year-old woman is unconscious following a car accident and is unable to provide consent to surgery. Her parents do not speak English, but her two siblings do.

An 84 year-old woman with advanced Alzheimer's Dementia has developed pneumonia. She is unable to consent to treatment on her own behalf.

What is a substitute decision-maker (SDM)?

A person who is authorized to give or refuse consent to treatment, admission to a care facility, or personal assistant services, on behalf of an incapable individual is referred to as a substitute decision-maker.

What does incapable mean?

If an individual is unable to understand the nature of a proposed treatment or appreciate its foreseeable consequences, then the individual is considered incapable and is in need of a SDM(s).

Who determines incapacity?

The health practitioner who is proposing the treatment, admission to a care facility, or personal assistant service decides whether or not the individual has capacity or not.

What decisions can a SDM make?

A SDM can make decisions about treatment (e.g., medications, surgery, tests), admission to a care facility, or personal assistant services. If the SDM(s) is an Attorney for Personal Care, they may also make decisions related to nutrition, shelter, clothing, hygiene and safety.

How do we decide who is the SDM?

The *Health Care Consent Act (HCCA)* provides the list of SDMs as follows:

1. Guardian
2. Attorney for Personal Care
3. Representative appointed by the Consent and Capacity Board (CCB)*
4. Spouse or Partner
5. Child (>16 years) or Parent or Children's Aid Society (if applicable)
6. Parent with only right of access
7. Brother or sister
8. Any other relative

The person or persons who are highest on this list will be the SDM(s) provided they meet the necessary requirements as outlined later in this guide. If there is more than one person on the same line in the list (e.g., 3 siblings), they have equal decision-making authority.

If an SDM from the above list cannot be found, the Public Guardian and Trustee will make the decision to give or refuse consent.

* If there is no appointed guardian or attorney for personal care, any individual (e.g., family member, friend, neighbour) can apply to the CCB to be appointed as representative.

How are spouse/partner defined?

Two individuals are considered spouses if
a) they are married to each other; or
b) they are living in a conjugal relationship outside of marriage and have cohabitated for at least one year, are together the parents of a child, or have together entered into a cohabitation agreement.

Partner is defined as either of two persons who have lived together for at least one year and have a close personal relationship that is of primary importance in both persons' lives

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What are SDM requirements?

An SDM(s) must meet all of the following criteria:

- Capable;
- 16 years of age or older;
- Not prohibited by court order or separation agreement;
- Available; and
- Willing to assume the responsibility of giving or refusing consent.

According to the HCCA, a person is considered available if it is possible, within a time that is reasonable in the circumstances, to communicate with the person and obtain a consent or refusal. This communication can be done in person or through alternate means such as phone, fax, or e-mail.

If the person who is highest on the list of SDMs does not meet all of the requirements as outlined above, consent will be sought from the next highest person(s) on the list.

How does a SDM make decisions?

The Health Care Consent Act instructs the SDM(s) to make decisions based on the following principles:

- Previously expressed capable wishes of the individual (aged 16 or over) that are applicable to the situation; or
- If there are no previously expressed capable wishes as described above, best interests of the individual.

When making decisions, SDM(s) should consider: "Would the individual want the proposed treatment, admission to a care facility or personal assistance service?"

What does 'best interests' mean?

In determining best interests, the SDM(s) should take into account the following:

- (a) the individual's values and beliefs;
- (b) any other expressed wishes of the incapable individual; and
- (c) the following treatment-related factors:
 - i. will treatment likely improve the individual's condition, prevent or decrease rate of deterioration;
 - ii. is the individual's condition likely to improve, remain the same or deteriorate without treatment;
 - iii. do expected benefits of treatment outweigh risks of harm; and
 - iv. is there a less intrusive treatment that would be as beneficial as proposed treatment.

What if SDMs don't agree?

If two or more SDMs of equal ranking (e.g., 3 siblings) disagree about whether to give or refuse consent, there are several ways to resolve the conflict depending on the situation and its urgency.

1. Although the individual may not be capable of making the decision at hand, he/she may be capable of choosing a SDM by either creating or updating his/her Power Attorney for Personal Care.
2. If there is time, work with the SDMs to achieve consensus. Utilize additional resources as appropriate (e.g., ethicist, social worker, chaplain).
3. If there is time (a few days) and there is no Attorney for Personal Care, one or more of the SDMs or any other person can apply to be appointed the individual's representative by the Consent and Capacity Board.
4. If time is limited, SDMs should be informed that the Treatment Decisions Unit, Office of the Public Guardian and Trustee will give or refuse consent for the proposed treatment, admission to a care facility, or personal assistance service.
5. If the situation is an emergency and there is no reason to believe that the individual would not want to be treated, treatment may proceed without consent. An emergency exists if the person for whom the treatment is proposed is apparently experiencing severe suffering or is at risk, if the treatment is not administered promptly, of sustaining serious bodily harm.

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Additional Resources

More information about substitute decision-making can be found on the following websites:

Consent and Capacity Board of Ontario

www.ccboard.on.ca

Phone: (416) 327-4142

Office of Public Guardian and Trustee

<https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/>

Phone: (416) 327-6683

National Initiative for the Care of the Elderly—

Consent & Capacity Tool

www.nicenet.ca

Phone: (416) 978-0545

Substitute Decisions Act

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

Health Care Consent Act

<https://www.ontario.ca/laws/statute/96h02>