



The Role of the Substitute Decision-Maker

Making Healthcare Decisions for Others

What does it mean to be a Substitute Decision-Maker?

This may be a difficult time for you, when a family member or friend is ill and no longer capable of making decisions about his or her treatment and the kind of care he or she might want. Someone else must make those decisions for him or her. That person is the Substitute Decision-Maker. But who will that be? And how does the substitute decision-maker get to make decisions for a loved one?

This brochure, which is a summary of the Legislation that guides decision-making for people who are not able to make treatment decisions for themselves, is designed to answer those and other questions.

See back page for information on available resources.

What does it mean to be incapable?

People are considered incapable if they do not understand:

- The information they need to know to give consent for treatment:

OR

- What might happen or not happen as a result of making a decision.

In Ontario, according to the *Health Care Consent Act (1996)*, every person can make his/her own decisions about healthcare and treatment when they are capable of doing so.

- A person is assumed to be capable unless there is a reason to believe otherwise.
- Being capable is specific to the medical treatment

Form #: 845931

Revised: Dec 2010

Department: Ethics

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proposed, which means that a person may be capable of making certain decisions, but incapable of making others.

- A person may be incapable with respect to a treatment at one time and capable at another.
- A capable person has the right to change his/her mind at any time.

If a person is not capable of making a treatment or care decision (for example; if they are unconscious), the responsibility is given to the substitute decision-maker.

Who will be the Substitute Decision-Maker?

If a patient while capable did not appoint someone to be his/her Attorney for personal care, the law provides a list of people who can act as the substitute decision-maker, arranged in order of legal priority as shown below. For example, an Attorney for personal care ranks higher than a spouse or partner; parent or child ranks higher than brother or sister. The law allows a child, or sibling or other relative of the incapable person who is present or has been contacted when the health practitioner proposes a treatment, to consent for the incapable person if no other higher ranking person is available or fulfils the criteria listed on page 3. The substitute decision-maker is then asked to make treatment or care decisions for the incapable person. Healthcare practitioners may be asking about documents to clarify the appointed substitute decision-maker (for example, they will ask for Power of Attorney (POA) for personal care, where one exists; for their records.

Rank of Substitute Decision-Makers from the Health Care Consent Act, (1996).

1. A guardian with the authority to give or refuse consent to treatment;
2. An attorney for personal care with the authority to give or refuse consent to treatment;
3. A representative appointed by the Consent and Capacity Board;
4. A spouse or partner;
5. A child or parent or Children's Aid Society;
6. A parent who has only a right of access;
7. A brother or sister;
8. Any other relative (related by blood, marriage or adoption);
9. The Public Guardian and Trustee is the decision-maker of last resort if no other person is capable, available or willing to give or refuse consent.

Criteria to be a Substitute Decision-Maker

A person may give or refuse consent only if he or she is the highest-ranking substitute decision-maker and is:

- Capable with respect to the treatment;
- At least 16 years old, unless the parent of the incapable person;
- Is not prohibited by a court order or separation agreement;
- Is available within a time that is reasonable; and
- Willing to assume the responsibility of giving and refusing consent.

What kinds of decisions might the Substitute Decision-Maker have to make?

The substitute decision-maker might have to make decisions about:

- Treatment and care;
- Diagnostic procedures;
- Placement or transfer to other healthcare organizations;
- End of life wishes.

What information does the Substitute Decision-Maker receive before making a decision?

The substitute decision-maker will receive all information that the person deemed incapable (patient) is entitled to before making any decisions. Except in specific cases of emergency, the substitute decision-maker must give or refuse consent to treatment on behalf of a person who is incapable in respect to treatment.

What is informed consent?

Informed consent means the healthcare practitioners proposing the treatment must give all information that a “reasonable person” needs to make a decision about treatment regarding:

- What the treatment is;
- Benefits of the treatment;
- Risks of the treatment;

- Side effects of the treatment;
- Other possible courses of action;
- What happens as a result of not having the treatment.

How does the Substitute Decision-Maker make a decision?

There are rules in law about making healthcare decisions for someone else. A substitute decision-maker is asked to make decisions for an incapable person (patient) when the patient is no longer capable of doing so. It is important to understand that the substitute decision-maker is not being asked to make the decision he/she feels best, but what he/she feels the incapable person would want. The important question to ask is, "What would my loved one want if he or she could decide for himself or herself?"

What if I don't know what my loved one would want?

Knowing the values and beliefs the patient held while capable and/or prior expressed wishes usually helps in knowing what he/she would want.

If the substitute decision-maker does not know the wishes of the incapable person that is applicable to the situation, or it is impossible to follow, then the substitute decision maker must make the decision about treatment according to the patient's best interest.

Determining best interests involves considering:

- The values and beliefs the patient held while capable;
- If those treatment decisions will improve or change the patient's condition for the better.

The substitute decision-maker must make decisions based on prior expressed wishes of the patient. If the substitute decision-maker does not know of a wish applicable in the situation, or it is impossible to follow the wish, the substitute decision-maker must act in the patient's best interests.

What are prior expressed wishes?

A prior expressed wish is a direction or instruction a person gave about the treatment while capable and at least 16 years old. The wish may be:

- Written in a Power of Attorney (POA) document;
- Written in another document such as a living will or advance directive;
- What the patient said verbally.

It is important to realize that the most recently expressed wishes trump any earlier wishes. If, for example, your loved one said that he/she would “want everything done to be kept alive,” but now says, “I’m done fighting and just want to die peacefully,” it is this second wish that you must consider when making decisions on his/her behalf.

What happens if there are disagreements?

Sometimes, when there is more than one substitute decision-maker, they disagree. In such situations, our staff will help them to work it through. If there is still no agreement, there are two choices:

1. The public official in the office of the Public Guardian and Trustee will make a decision; or
2. The Consent and Capacity Board, a third party provided in the Health Care Consent Act (1996) to assist Substitute decision-makers in making appropriate decision, will appoint one person to make the decision. That person may or may not be one of the prior substitute decision makers.

Can the treatment team have a concern about the Substitute Decision-Maker’s decision?

Sometimes, members of the patient’s treatment team think the substitute decision-maker is not making a decision based on patient’s prior expressed wishes or best interests. In this case, the team may apply to the Consent and Capacity Board to see if the treatment decision was the right one according to the law. This almost never happens. When it does, it is only after extended discussions between substitute decision-maker and members of the treatment team have not produced a result that is satisfactory to everyone.

Who can provide further help and support?

At The Scarborough Hospital, our mission is “To provide an outstanding care experience that meets the unique needs of each and every patient.” We recognize the importance of serving a diverse community whose customs, traditions and beliefs might play a role in decision-making. As a result, the hospital staff is available to provide further assistance.

If you have any concerns about making the best decision for your loved one, please feel free to talk to the doctors, nurses, social worker, patient relations officer, chaplains and clinical ethicist.

Helpful Contacts:

- Social Work Department (General)..... (416) 438-2911 ext.8109
- Social Work Department (Birchmount) (416) 495-2461
- Spiritual Care Department (General) (416) 438-2911 ext.6270
- Spiritual Care Department (Birchmount)..... (416) 495-2535
- Patient Relations Office (General) (416) 431-8200 ext. 6433
- Patient Relations Office (Birchmount)..... (416) 495-2701 ext.5424
- Clinical Ethicist..... (416) 438-2911 ext. 8026
- General Campus Main Phone Number (416) 438-2911
- Birchmount Campus Main Phone Number (416) 495-2400

Patient Care Manager of the unit... Please have unit clerk contact for you.

Notes



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This information is based on the Health Care Consent Act (1996). To view this Act, go to www.e-laws.gov.on.ca

Under Consolidated Law (includes Historical Versions) Statutes and Associated Regulations.
You can obtain a copy of the Power of Attorney for Personal Care Form from the
Ministry of Attorney General, Ontario at:
<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>