



Making Care Decisions When a Patient is Incapable:

*The Role & Responsibilities of a
Substitute Decision-Maker*



Sunnybrook

THE ETHICS CENTRE

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Information contained in this brochure 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.

This material was adapted from:

- Humber River Regional Hospital “*Substitute Decision-Makers*” brochure.

Note: In this booklet, the term “patient” also refers to residents who live in the Sunnybrook Veterans Centre.



Sunnybrook

HEALTH SCIENCES CENTRE

This brochure has been produced by:

The Ethics Centre

Department of Quality and Patient Safety

Revised July 2013

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Being a Substitute Decision-Maker (SDM)

You may be asked to help with decision-making for a patient in hospital who is considered mentally incapable to make care or treatment decisions. This brochure has been developed to provide you with information about the role of Substitute Decision-Maker and the duties and challenges you may face.

In general, people who are capable of understanding and communicating their care wishes are supported to make their own decisions about their health care. It is the right of a mentally capable person to direct health care choices for him/herself.

In most cases, a Substitute Decision-Maker (also known as an “SDM”), is needed only when a person is mentally incapable. However, there are situations in which a person who is mentally capable requests that a family member receive all health information and assist in making treatment decisions.

In situations where the patient is mentally incapable, there is guidance in the Health Care Consent Act (1996) to identify the legally authorized SDM. This guide is in the form of a list of people, or a hierarchy. The highest-ranking person on the hierarchy who is willing and able to make decisions regarding health care for the patient becomes the SDM. If that person is not willing or able to do this, the next ranking person on the hierarchy becomes the SDM. Being the SDM for a person who is mentally incapable is an important role requiring patience, compassion, understanding and support.

The terms “capable” and “incapable” as used in this brochure refer to mental capacity.

1 When is a Person Considered Incapable?

People may have special disabilities, injuries, or serious illnesses that make them incapable to provide consent or make treatment choices.

In assessing whether a patient is capable of making his/her own treatment decisions, health care professionals must determine whether the person is capable or incapable to do the following:

- **Understand** the relevant proposed **treatment** information **AND**
- **Appreciate** the reasonably foreseeable **consequences** of giving or refusing consent.

Possible Scenario

Mr. R's son Jonathan had a serious motorcycle accident and suffered many injuries including a trauma to his head. While in the intensive care unit, members of the health care team continued to speak with Jonathan about his condition and his care. Mr. R asked the nurse, "Why are you bothering him? Jonathan is badly injured. Please speak to me about his care." The nurse explained that although Jonathan's injuries were extensive, his physician found Jonathan able to understand health information and to appreciate the likely consequences of the treatments being proposed. The nurse explained to Mr. R that the treatment team considered Jonathan capable of giving informed consent and should therefore be involved in directing his own plan of care.

Question: What is meant by "informed consent"?

Answer: Before any medical treatment can begin (except under emergency conditions), the patient or SDM must give informed consent to that treatment.

Informed consent means that a doctor must provide the patient or the patient's SDM with all the information that he or she needs in order to make a decision about treatment regarding:

- what the treatment is meant to do
- the likely benefits of the treatment
- the possible risks of the treatment
- side effects of the treatment
- options (if any) other than the treatment being proposed
- what is likely to happen to the patient if treatment is not received

② Who is a “Substitute Decision-Maker” (SDM)?

A substitute decision-maker or SDM is a person with the legal right to make a decision about treatment options on behalf of someone who has been found incapable to make decisions about his/her own treatment.

In some cases, while a person was still capable, he/she may have completed a Power of Attorney for Personal Care form. In this form, the person identifies someone to be his/her SDM in the event he/she becomes incapable to make treatment decisions. A Power of Attorney for Personal Care form is ***valid only if completed while the person is still capable.***

If a patient did not complete a Power of Attorney for Personal Care form while he/she was still capable, health care providers use the hierarchy of people found in The Health Care Consent Act (1996) to determine who the SDM will be.

The following is a list of people who can act as a person’s SDM. It is listed according to priority and was retrieved from the Health Care Consent Act (1996):

1. A court appointed 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 (i.e. a person named to be SDM on a Power of Attorney for Personal Care form)
3. A representative appointed by the Consent and Capacity Board (CCB) with the authority to give or refuse consent to treatment
4. A spouse or partner
5. An adult child (16 years or older) or parent or a Children’s Aid Society representative
6. A parent who has only a right of access (parent does not hold custody)
7. An adult sibling (16 years or older)
8. Any other relative (biological, marital or related by adoption)
9. The Public Guardian and Trustee* (PGT) is the decision-maker of last resort if no other person is capable, available or willing to give or refuse consent. *PGT is a government appointed representative (PGT office 416.314.2800)

3 Can a Patient's Capacity to Make Decisions Change or Improve? Can a Person be Capable to Make Certain Treatment Decisions But Not Others?

Possible Scenario

Mrs. M has early dementia and requires surgery for a fractured hip. The SDM (her daughter) was asked to make a treatment decision for Mrs. M because her physician found her unable to understand the medical reasons for surgery. At the same time, Mrs. M was found capable to make a choice about medication for her pain symptoms.

People can be found to be incapable of making certain decisions about care or treatment, but capable of making other decisions about care or treatment.

Because the patient is still considered capable of participating in care or treatment decisions to a certain degree, as the SDM, you may be asked to help with certain care decisions and not others.

Very often, a patient's health will change while in hospital. Some days the patient's health may improve while on other days the patient's health may get worse. The changes that can occur in a patient's health status could affect the patient's capacity to make decisions about his/her health care. A patient may be capable to make a treatment decision at one time, and not capable at another time.

Unfortunately, for some patients, capacity to make treatment decisions is not possible due to severe disabilities or illness. Other patients may either permanently or temporarily lose capacity due to illness or injury. That is why it is very important for the health care team and the SDM to engage in regular communication and to reach a common understanding about the patient's capacity as well as treatment options, and to reassess the patient's capacity to make decisions, when appropriate.

4 I am an SDM. What Are My Duties?

Possible Scenario

Karl, who lived in Toronto, asked his niece Sally to be his SDM should he become incapable to make decisions for himself. Years later, after Karl suffered a devastating stroke, leaving him paralyzed and incapable, Sally was living in Windsor with young children and unable to commute to Toronto. When Karl's doctor phoned her, Sally asked, "Can I be my Uncle Karl's SDM if I now live in Windsor?" The doctor explained, "Yes you can be an SDM providing you are:

- Willing to take on this role and all the responsibilities it involves (having the time, energy and interest it will require to assist with decisions that need to be made regarding care);
- Capable of understanding health information;
- Age 16 years or older;
- Able to appreciate the consequences of the health care options for Karl;
- Available and willing to receive information and discuss matters concerning Karl's health status and the care plan."

Sally and the doctor planned regular telephone meetings so that she could serve as Karl's SDM.

Question: Can the role of the SDM be shared with another person?

Answer: Yes. In some circumstances an individual may appoint more than one SDM to act independently or jointly. If there is no Power of Attorney for Personal Care and there is more than one person on the hierarchy with equal ranking (i.e. if the patient has more than one child), then these parties have equal rights as SDM.

Question: What happens if a disagreement occurs between two or more SDMs of equal ranking regarding the patient's care?

Answer: Whenever possible, the health care team will assist the SDMs in providing information and support and will suggest available resources to assist them in addressing the conflict.

5 What Kinds of Decisions Will I Need to Make?

The health care team is responsible for outlining treatment or care options. As SDM you provide input about what the patient may have wanted, based on wishes the patient expressed previously when he/she was capable, or based on what you think would be in his/her best interests. You may be asked to provide informed consent on:

- Therapies and/or care options
- Diagnostic procedures, e.g. colonoscopy or an echocardiogram
- Transferring patient's care to another care setting

6 How am I Expected to Make Treatment Decisions as the Patient's SDM?

The way an SDM makes treatment decisions depends on whether or not the patient's wishes from a time when he/she was capable are known.

Making decisions when the patient's prior capable wishes are known:

If the SDM knows that the patient has (when capable) indicated a wish with regard to medical treatment, then this wish should guide treatment decisions.

As the SDM, you are expected to follow the patient's wishes as much as possible. The patient, while still capable, may have told you the form of care or treatment he/she preferred. In addition, you may be certain, based on your personal relationship with the patient, what care or treatment he/she would want in these circumstances. This knowledge or information must guide the care or treatment decisions. **Question:** What is meant by the person's "prior capable wishes"?

Answer: A prior capable wish is a direction or instruction a person over 16 years old gave about his/her care while still capable. These wishes may be:

- written in a Power of Attorney for Personal Care document
- written in another document such as a living will or advance care directive
- stated verbally

Question: What if I don't agree with the patient's prior capable wishes?

Answer: The Health Care Consent Act directs the SDM to honour the patient's capable wishes. However, these wishes are not always reflective or applicable to the patient's health situation. It is important that you as the SDM receive as much information, support and guidance from the health care team as needed to help with decision-making.

If you feel you cannot follow the patient's wishes, you may prefer to find another family member who can act as SDM.

Question: According to the doctor, the patient's prior capable wishes for a particular treatment are not medically indicated or recommended. What happens in this case?

Answer: The physician most involved in the patient's care, in consultation with the health care team, will determine what treatments, therapies, or care options, are recommended and available for the patient. Whenever possible the wishes of the patient, the family and the SDM are considered in making treatment decisions. However, if a treatment desired by the patient when capable is not medically indicated or recommended, it will likely not be offered as part of the care plan.

Making decisions when the prior capable wishes of the patient are not known:

If you do not know the patient's wishes, then you must make care or treatment decisions in the person's "best interests" in consultation with other family members and the health care team.

Consider the following to determine a patient's best interests:

- The person's values and beliefs
- If the treatment is likely to improve the person's condition or prevent the condition from getting worse
- If the benefit to the patient outweighs the risk of harm
- If a less restrictive or intrusive treatment would be as helpful

7 As the SDM, What if I Don't Agree With the Care Plan?

Possible Scenario

As the SDM, Ali had struggled with the health care team's proposed plan to discontinue his father, Mr. M's, chemotherapy. Mr. M had been ill for some time with colon cancer, and halfway through his current round of chemo he became very sick and was now approaching the late stages of his illness. Mr. M's treating physician, along with other members of the treatment team, explained to Ali what could be done to ensure Mr. M remains comfortable and the family supported during the final phase of Mr. M's life. Ali was quite certain that based on his father's religious values and the way he lived his life, his best interests would be served if all measures of life prolonging therapy were provided. Therefore, Ali disagreed with the plan of care for his father.

Mr. M's health care team met with Ali and other members of the family to discuss Mr. M's condition and care options, as well as the wishes, values and beliefs Mr. M held when he was still capable to make his own health care decisions. Unfortunately, no agreement could be reached on the matter of chemotherapy. The health care team requested a clinical ethics consultation and provided Ali with the phone number for the Office of the Patient Experience/Office of the Resident & Family Experience. To help them cope with their father's condition the family agreed to meet with a social worker. As attempts were being made to address the differences in opinion about the goals of care, members of Mr. M's care team expressed their continued support for the family and their commitment to providing the best possible care for Mr. M.

Question: What happens if the SDM and the doctor or health care team cannot agree about the plan of care?

Answer: Hospital guidelines for addressing conflict stress the importance of using a collaborative approach. This means that, wherever possible, the health care team will continue to discuss the patient's health and the care provided, and will try to negotiate a plan that is satisfactory to the SDM. This approach is dependent upon effective, respectful and timely communication, and upon attempting to understand and address the needs of the SDM and family. In such circumstances, the SDM can:

seek help from the Office of the Patient Experience/Office of the Resident & Family Experience; request a second opinion; or try to locate another health care setting willing to offer the preferred level of care or treatment.

When agreement cannot be reached despite efforts to resolve the conflict over the care plan further consultation on the ethical considerations, as well as, suitable clinical or legal options can be provided. This may entail one or more of the following: referral to Clinical Ethics, application to the Consent and Capacity Board, and/or a recommendation to the SDM to consult a lawyer. Throughout this process, the health care team remains committed to providing the acknowledged professional standard of care to the patient, despite any differences of opinion that may exist.

8 Where Can I Get Help and Support?

As the SDM for an incapable patient, you face important responsibilities at a time when you may also be dealing with difficult feelings like loss, worry and disappointment. The health care teams at Sunnybrook are made up of experienced health professionals who are there to provide support and information to you. These health care professionals will also know about other resources within the hospital that are available to assist you including social workers, chaplains, patient relations consultants and clinical ethicists. These resources can provide you with information, support and opportunities to share some of the concerns you may be facing as the SDM.

Helpful Contacts:

Social Work Office: 416.480.4477

Office of the Patient Experience:

Sunnybrook Bayview Campus: 416.480.4940

Holland Centre Campus: 416.967.8558

Office of the Resident & Family Experience

Veterans Centre: 416.480.6107

Spiritual Care: 416.480.4421

The Ethics Centre: 416.480.4818

Feedback



Please assist us by providing your feedback. Indicate your response with X.

1. The information contained in this brochure was easy to read and understand.
Agree Disagree No opinion
2. After reading this information, I have a better understanding about the role and duties of a substitute decision-maker.
Agree Disagree No opinion
3. It is important for Sunnybrook patients/residents and their families to receive this information.
Agree Disagree No opinion

Additional comments:

I am a:

- | | |
|--|---|
| <input type="checkbox"/> Patient | <input type="checkbox"/> Resident |
| <input type="checkbox"/> Spouse or partner of a patient | <input type="checkbox"/> Spouse or partner of a resident |
| <input type="checkbox"/> Relative or friend of a patient | <input type="checkbox"/> Relative or friend of a resident |
| <input type="checkbox"/> Hospital staff or volunteer | |
| <input type="checkbox"/> Other: _____ | |

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