Baycrest

Making Healthcare Decisions as a Substitute Decision Maker

UNIVERSITY OF TORONTO

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This document outlines some basic principles to help an individual who may be called upon to make future health care decisions on behalf of another individual. The information included here is meant to provide guidance as one fulfills the role of a substitute decision maker in making health care decisions for another.

Making Healthcare Decisions

Ask yourself:
Do I know what my wife would want if she could no longer speak for herself? As the SDM for my parents', do I know their wishes for future medical care should they become seriously ill?

In Ontario, less than 12% of the population have talked with those closest to them about what they would want if they were no longer able to make their own healthcare decisions. If you find yourself in the situation where you must make healthcare decisions for another, there is some important information in this guide that describes useful steps you can take that will help you. As the substitute decision maker, the healthcare team will turn to you for guidance in understanding the wishes of the client if she or he can no longer make their own healthcare decisions. This guide will help you to balance information from the health care team with the wishes of your family member or friend, to make the best healthcare decisions possible for the person.

The first step is to ask:

1. Does the person have an Advance Directive?

An Advance Directive is used to document a person's future care wishes when he or she can no longer make decisions. As the substitute decision maker, you can use what is written in the advance directive to inform whether or not you should accept or refuse the treatment being offered on behalf of your family member or friend.

Does the person have an Advance Directive?
☐ Yes ☐ No ☐ Unknown

If you answered yes, please provide a copy to the Nurse, so it can be placed on the person's electronic medical record.

2. Know Your Role as a Substitute Decision Maker (SDM)

In Ontario, everyone is presumed capable. Capable means that the person is able to understand and appreciate the foreseeable consequences of accepting or refusing a particular treatment. If for any reason the person is not able to understand and appreciate the information about the treatment being proposed by the doctor or other healthcare provider, the doctor or healthcare provider must contact the person's SDM(s) to obtain consent before a treatment can proceed.

However, in an emergency situation, where the delay to obtain consent from a substitute decision maker would prolong suffering or result in serious harm, the healthcare provider may provide treatment without consent. Please note that the treatment may be continued only for as long as it seems reasonable to locate and obtain consent from the incapable person's SDM.

You may be asked to attend meetings with the healthcare team to discuss your family member or friend's care wishes and Advance Care Plan. Please bring this booklet with you to the meeting.

How are SDMs chosen?
Everyone in Ontario has a default SDM under the Health Care Consent Act ranking. See Diagram 1. The doctor or person proposing the treatment for the incapable person will be obliged to follow the SDM Hierarchy, starting at the top, from a list of 8 possible persons or groups of persons legally permitted to make healthcare decisions on behalf of an incapable person. To serve as an SDM you must meet four criteria. First, you must be willing to accept the role. Second, you must be mentally capable to make treatment decisions on behalf of your incapable family member of friend. Third, you must make yourself available to speak with members of the healthcare team about your family member or friend's treatment and care. Lastly, you must be 16 years of age or older.

SDM Hierarchy

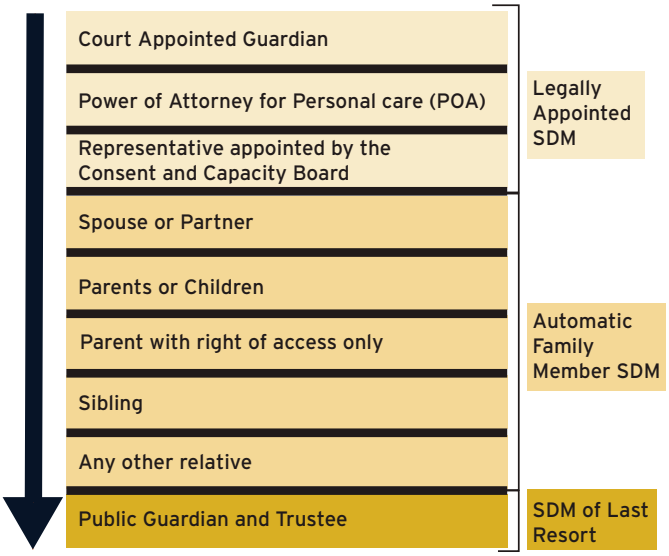

Diagram 1

Making health and personal care decisions for another person is not easy. If you do not want to serve as an SDM, you may refuse. The healthcare provider will move to the next person on the list. If you are the Power of Attorney for Personal Care (POA), this means that your family member or friend decided to appoint you to make their health and personal care decisions rather than rely on the default SDM. You can see that the POA is listed higher than family members in Diagram 1, though a POA may also be a family member. If you have decided that you want to serve as the SDM, you have a duty to follow the principles as outlined in the Health Care Consent Act (1996) and summarized below.

Principles the SDMs must follow

There are **Principles** for the SDM outlined in the Health Care Consent Act (1996) that can help guide you. Principles are guides to action. It is up to the health professional proposing the treatment to decide whether or not you are following the principles for substitute decision making.

The healthcare provider will provide the SDM with all the information that would be provided to a capable person and the SDM is expected to make the decision in accordance with these principles and what they believe the person would want.

Box 1: Example of a Prior Capable Wish

K told you that she would never want to live on a breathing machine – that would be a prior capable wish – but K had hip surgery and only needs the breathing machine for a short time – therefore her prior capable wish does not apply in this situation because it is anticipated that she will recover and be removed from the ventilator.

The first principle asks that you consider any wishes about treatment that the incapable person might have discussed with you while capable and at least 16 years of age. This is known as a prior capable wish and must be applicable to the given situation.
See Box 1 for an example of what a prior capable wish might look like.

If you do not know the incapable person's wishes, then you would turn to the best interest standard in deciding on behalf of the incapable person, which is described below. First, consider all you know about the values and beliefs of the person when capable and whether you believe the incapable person would still act on those beliefs today were she capable to make the decision herself.
See Box 2 for example.

In further trying to decide for your incapable family member or friend, consider what will happen **with** and **without** treatment?

Will the incapable person's condition or well-being improve, remain the same or get worse?

Will the expected benefit of the treatment to the incapable person outweigh the risk of harm?

Box 2:
Values and Beliefs of the Incapable Person

K loves her food, she was an excellent cook and always made sure that everything she fed her family was as fresh as she could find. Today, she has dementia and is having trouble swallowing. The health team spoke to you about inserting a "feeding tube", so that she can receive liquid food. You never talked to K about whether she would want a feeding tube. Knowing how she loves her food, you can't imagine that if she were able to decide for herself today that she would accept a feeding tube. But you're not sure.

Box 3: Other Factors to be considered under the Best Interest Standard

The doctor explains that in the case of inserting a feeding tube, we know that it will not cure K's dementia; there is some evidence that careful feeding by hand is as effective as tube feeding. The benefits and harms of inserting the feeding tube versus comfort feeding were explained to you. Knowing as you do, understanding what she would have wanted if she could still speak for herself today and weighing the benefits and harms of each option, you make your decision.

Is there a less restrictive or less intrusive treatment that would be as beneficial as the treatment that is proposed?
See Box 3 for an example.

What happens if no SDM can be found?

The legal framework includes an agency called The Office of the Public Guardian and Trustee that can be contacted by the doctor or other healthcare provider to make the treatment decision on behalf of the incapable person.

What if there is a conflict between two or more SDMs?

The Public Guardian and Trustee (PGT) is a provincial body that serves to ensure that when a person does not have an SDM or there is conflict amongst equally ranked SDMs there is a process in place to ensure timely decision-making. In other words, the PGT will make the decision.

Prior to contacting the PGT, efforts will be made to resolve the conflict. One of the SDMs may apply to become the person's legally appointed SDM.

For more information please see: http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/

Now that you know your role as the SDM and the way in which you should go about making decisions, it is time to think about your family member's or friend's values, beliefs and concerns in more detail.

3. THINK about the person's beliefs, values and concerns. Have they spoken to you about what gives their life meaning? For example, visiting with their grandchildren and being able to communicate with others. Has anything happened in their past that shaped their feelings about medical care? What religious commitments, family traditions, cultural values, or customs might influence your family member's or friend's decision making if they were able to decide for themselves in this situation?

You may wish to talk to family and trusted friends to help you further understand the person's beliefs and values.

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4. LEARN about your family member's or friend's existing medical conditions. Talk to the doctor and other health care providers. Ask about prognosis – what the person might expect to experience in the future as a result of those conditions. Learn about possible treatments for existing or future health conditions and about the type of care decisions you may be asked to make in the future. Learning about the person's medical condition and what to expect can help you to decide what medical care the person would accept or refuse.

What else would be helpful or important for you to know about your family member's or friend's health?

Questions to Ask:_____

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5. TALK with family and trusted friends - about the decisions you are being asked to make. Is this what the person would want? Are you comfortable making this decision or do you need more information? If there is more than one SDM, talk together about how each of you understands the person's values and beliefs as well as how your own values and beliefs may be affecting the decision making process. Are your values and beliefs in conflict with what the family member's or friend's expressed wishes were? If so, explore reasons, seek help in resolving any issues as needed.

What else would be helpful or important for you to know about your family member's or friend's life, in order for you to make healthcare decisions?
Who else should you talk to?

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6. Examples of Goals of Treatment

Now that you have reviewed the workbook, consider how your family member or friend has made health related decisions in the past and what beliefs or values may have guided him or her. Generally speaking, people fall into different groups when thinking about being seriously ill and what trade-offs they might be willing to make.

Here are some examples:

☐ Cure underlying disease
☐ Prolong life as long as possible
☐ Provide care aimed at comfort as opposed to cure
☐ Improve and/or maintain the person's ability to function and the person's quality of life
☐ Achieve the person's after and life goals (e.g. attend granddaughter's wedding)

Which group or groups do you believe your family member or friend would more strongly identify with? Be sure to share your thoughts and feelings with those closest to you and with those who know your family member or friend best. This will ease your burden in making healthcare decisions for your family member or friend.

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Thank you for taking the time to review and reflect upon the information provided here. When you attend meetings with the doctor and members of the healthcare team, you will be asked about some of this information. You will have an opportunity to ask questions. Based on your knowledge of the person you are being asked to make decisions for, you will have an opportunity to plan for the life sustaining treatment options that your family member/friend may need to have at some later date and whether they would be willing to accept the treatments or not.

Glossary of Terms

Mentally Capable: Used in the Health Care Consent Act to describe a person who is able to make their own health care decisions because they are able to understand, retain and appreciate the information regarding the benefits and risks of accepting or refusing a treatment or procedure.
Mentally Capable: Used in the Health Care Consent Act to describe a person who is unable to make their own health care decisions because they are unable to understand, retain and appreciate the information regarding the benefits and risks of accepting or refusing a treatment or procedure.
Substitue Decision Maker: The person who will make health care decisions on behalf of the incapable person.

Reference:

Health Care Consent Act (1996): https://www.ontario.ca/laws/statute/96h02
The Office of the Public Guardian and Trustee:
https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/
Power of Attorney for Personal Care (POA):
https://www.ontario.ca/page/make-power-attorney
Substitute Decisions Act (1992) http://www.canlii.org/en/on/laws/stat/so-1992-c-30/latest/

Acknowledgements:

Baycrest Advance Care Planning Brochure
Advance Care Planning Canada: http://www.advancecareplanning.ca/
East Toronto Health Link: My Health, My Wishes, My Plan: Advance Care Planning Workbook (2015)
"Advance Care Planning", (2014), Alberta Heath Services, Calgary Zone.