



Interested in Creating an Advance Directive? (Living Will)

With the attention focused on the Terri Schiavo case in the media, many people are wondering: **What can I do to prevent this from happening in my family?**

Terri Schiavo is the severely brain-damaged woman in Florida who is at the heart of the battle over whether a feeding tube that has kept her alive for 15 years should be re-inserted. Terri's husband, Michael, believes that Terri would never want to go on living in the condition she is in. Terri's parents and siblings feel that Terri should be kept alive at all costs, and that by not allowing a feeding tube to keep her fed and hydrated, she is being "killed".

The best way to avoid a similar acrimonious battle is to put your wishes in writing, and then to have a heart-to-heart talk with your loved ones about what you would like to happen and what kind of health care choices you wish to have made should you no longer be able to do so.

In Ontario, the Health Care Consent Act (1996) says that when people are no longer able to make decisions for themselves, a Substitute Decision Maker is authorized to make decisions on their behalf. Most often this person will be a family member, as outlined according to a hierarchy in the Act. Substitute decision makers are required to follow two principles in their decision-making:

1. Prior capable wishes
2. Best Interests

While capable, a person may express wishes in respect to treatment, admission to care facilities, personal assistance services and so on. The Substitute Decision Maker must follow these expressed wishes wherever possible. The manner in which these wishes are expressed can be in any format: by making out a power of attorney for personal care, by completing an advance directive (living will), or in any other written form. They can also be expressed verbally. For

example, a person may have told family members that she would never want any tubes put in for feeding if she became unable to make decisions for herself.

Many Advance Directive forms have been developed to assist people to express their wishes for future care. While not intended to be used in the absence of specific medical and legal advice, they can help people determine what their wishes might be and help them to communicate to others. The following are some examples that are readily available:

The **CareWish Advance Directive for Personal Care** was developed here in London. It contains instructions, a form, a fridge magnet and a card to put in your wallet/purse. It is available for \$6.00 from the [Hospital Gift Shops](#) or by mail for \$8.00 from the [Communications & Public Affairs Offices](#)

The **University of Toronto Joint Centre for Bioethics Living Will**. This was developed by Dr. Peter A Singer, and is a guide to help you think about and express your wishes about future health and personal care decisions. Information about living wills and forms are available for downloading free at http://www.utoronto.ca/jcb/outreach/living_wills.htm

Your Life Your Choices: Planning for Future Medical Decisions: How to Prepare a Personalized Living Will. This is an American document that explains, in plain language, the process of **advance care planning**. It discusses all of the important components of advance care planning and resources to help you examine your values and communicate them to your family/loved ones. This can be found at: <http://www.hsrdr.research.va.gov/publications/internal/ylyc.htm>

Making Decisions for Others: The Principles of Substitute Decision-Making Brochure is available from Social Workers at all sites, or below, next page.

A Guide to Advance Care Planning is available from the Ontario Senior's Secretariat on line at www.gov.on.ca/mczcr/seniors or by phoning the Seniors INFOline at 1-888-910-1999.

Making Substitute Health Care Decisions is available from the Office of the Public Guardian and Trustee, online at www.attorneygeneral.jus.gov.on.ca or by phoning 1-800-366-0335

ST. JOSEPH'S HEALTH CARE, LONDON

Making Decisions for Others: The Principles of Substitute Decision-Making

Decisions about quality of life and end-of-life care can be difficult for residents, families and the health care teams who care for them. Although these subjects are often not easy to talk about, it is very important that we understand our obligations when we make decisions for others. When people are **no longer capable of making decisions for themselves**, someone else needs to make decisions for them. The obligations of that someone else, known as a "Substitute Decision Maker", are outlined in the Substitute Decision Makers Act, according to the Health Care Consent Act, which establishes a set of rules for consent to treatment and personal care decisions.

What is capacity?

According to the Health Care Consent Act, a person is capable of consenting or refusing a treatment if he/she is able to:

1. Understand the information that is relevant to making a decision about the proposed treatment, and
2. Appreciate the reasonably foreseeable consequences of a decision or lack of a decision.

Capacity is specific to the treatment proposed, which means that a person may be capable of making certain decisions, but incapable of making others. Also, a person may be incapable with respect to a treatment at one time and capable at another. As well, a capable person has the right to change his/her mind *at any time*.

It is important to understand that whenever a resident has the capacity to make a decision, the decision of the resident must be respected. Substitute decision makers make decisions only for those determined incapable of making the decision.

What capacity is not...

Capacity does not refer to the person's

- Physical status

- Psychiatric status
- Cognitive/mental status
- Ability to make a decision with a “rational” or “reasonable” outcome
- Ability to make a decision in accord with “best interests”

We are evaluating the decision-making process, not the actual decision made.

What happens when residents lack decision-making capacity?

When people are unable to make decisions for themselves, a person termed the Substitute Decision Maker is authorized to make decisions on their behalf. Most often this person will be a family member, as outlined according to a hierarchy in the Health Care Consent Act, where there is a list of people in order of priority who are the legal substitute decision maker (see box – Hierarchy of Substitute Decision-Makers).

What rules should guide Substitute Decision Makers?

Substitute Decision Makers must follow two principles:

1. Prior capable wishes
2. Best Interests

Prior Wishes

While capable, a person may express wishes in respect to treatment, admission to care facilities, personal assistance services and so on. The Substitute Decision Maker must follow these expressed wishes wherever possible, once the person is no longer capable. The manner in which these wishes are expressed can be in any format: by making out a Power Of Attorney for Personal Care, by completing an Advance Directive (living will), or in any other written form. Prior wishes can also be expressed verbally. For example, a person may have told family members that she would never want any tubes put in for feeding if she became unable to make decisions for herself.

As the Substitute Decision Maker, ask yourself “What would my _____ (father, mother, loved one) have wanted to do in this instance?”

It is also important to realize that later wishes expressed while capable prevail over earlier wishes, for example, “I said before that I would want everything done to keep

me alive, but now, I think that if I can't talk to and enjoy my family, I would just like to be allowed to go peacefully."

Best Interests

If there are no known prior expressed wishes, or the wishes are impossible to follow, then the Substitute Decision Maker must act in the resident's best interest. This can be determined by considering:

- ◆ Whether treatment is likely to:
 - i. Improve the person's condition or well-being
 - ii. Prevent the condition or well-being from deteriorating
 - iii. Reduce the extent or rate of deterioration of the person's condition or well-being
- ◆ Whether condition or well-being is likely to improve or remain the same or deteriorate without the treatment
- ◆ If benefit outweighs risk of harm
- ◆ Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment proposed

When deciding about best interests, **the Substitute Decision Maker must also consider the values and beliefs that he or she knows that the incapable person held when capable, and believes that the person would still act on.** One must also consider other wishes of the incapable person with respect to treatment, admission, personal assistance services that are not required to be followed (i.e. those wishes expressed AFTER the person became incapable).

Supports and Resources

Deciding for others is often difficult to do, but there are many resources to help Substitute Decision Makers follow the law and make the best decisions possible.

The following are supports that SDM's may refer to:

- ✓ Family physician
- ✓ Health Care Team members (e.g. Social Worker, Nurse)
- ✓ The Ethics Education and Consultation Committee at your site (Parkwood Hospital, Regional Mental Health or St. Joseph's Hospital/Mt. Hope). (have unit staff contact for you)
- ✓ Spiritual Care at your site OR Chaplain-on-Call – reach via Switchboard)

- ✓ Patient Relations at St. Joseph's Hospital or Parkwood Hospital (have unit staff contact for you)
- ✓ Clinical Ethicist (have unit staff contact for you)

For more information:

A Guide to Advance Care Planning is available from the Ontario Senior's Secretariat on line at www.gov.on.ca/mczcr/seniors or by phoning the Seniors INFOLine at 1-888-910-1999.

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HIERARCHY OF SUBSTITUTE DECISION-MAKERS

(Health Care Consent Act, 1996)

1. The incapable person's guardian (if one exists)
2. The incapable person's Attorney for Personal Care (if one exists)
3. The incapable person's representative appointed by the Consent and Capacity Board (if one exists)
4. The incapable person's spouse or partner
5. A child or parent of the incapable person
6. A parent of the incapable person who has only a right of access
7. A brother or sister of the incapable person
8. Any other relative of the incapable person _____

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