Planning for Future Care:

A Guide for Patients and Their Families

Sunnybrook
THE ETHICS CENTRE
when it matters MOST

Commonly used terms:

Advance Care Plan (ACP), Living Will, Advance Directive:
These terms refer to a document completed by a person or wishes he/she has stated about care and medical treatments made in advance of a serious illness or injury that renders the person incapable. For the purpose of this brochure the term **Advance Care Plan or ACP** will be used.

Power of Attorney (POA) for Personal Care:
A document that may contain a person's advance care planning wishes and identifies who she/he would choose as the substitute decision maker to provide consent if he/she becomes incapable of making care decisions.

Substitute Decision Maker (SDM):
A substitute decision maker or SDM is a person with the legal authority to make decisions about treatment options on behalf of someone who has been found incapable of making decisions about his/her own treatment.

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This brochure was developed by the Ethics Centre in collaboration with:

Department of Quality and Patient Safety
Social Work
Palliative Care Consult Team

Special appreciation is extended to:
The Dialysis Program
Amy Canter, Dr. Daniel Schwartz and Julie Burnett for sharing their work in advance care planning with dialysis patients and their families

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Planning for Future Care: Why is this important?

As a patient or as a family member of someone who is ill or injured, you want to know that the best possible care is being provided when it matters most. This brochure was developed as a way to assist patients and their families in considering the kind of care the patient would want if living with advanced life-limiting illness, an unexpected incapacitating illness and/or at the end stage of his/her life.

Experts agree that advance care planning is not about "legislation, lawyers and doctors but rather about relationships, communication and families" (Singer 1995). When patients are recovering from a serious health problem or are struggling with a chronic illness, conversations about the end stage of life and decisions that may need to be made can be very difficult but also very important.

❶ What is an Advance Care Plan (ACP)?

An ACP is a set of instructions you provide others regarding your future medical treatment and personal care if decisions need to be made at a time when you are unable to understand health information or direct your own care choices. An ACP allows you to specify unwanted medical treatments as well as outline your care preferences. These instructions will help your family and/or your Substitute Decision Maker (SDM) make decisions on your behalf.

Research indicates that people complete an ACP because they want to:

- inform others about which medical treatments they do not wish to receive
- inform others about the kind of care they would prefer to receive at the end of their life
- continue to direct their care as much as possible
- identify desired alternative levels of care (e.g., home care, nursing home or palliative care unit)
- preserve family relationships by preventing conflict over end-of-life care decisions

Godkin (2008) found that many people who complete an ACP do so in order to preserve and promote positive relationships within their family during the final phase of their life. It is not uncommon for disagreements to surface between loved ones who hold a different opinion about what would be the best plan of care for the patient. Many people who engage in advance care planning believe that by holding these discussions with loved ones and writing down their wishes, their loved ones will be informed and disagreements less likely to occur.

At Sunnybrook we believe that having advanced knowledge of a patient's care wishes are key to determining how best to provide quality care at a time when the patient anticipates no longer being able to make those decisions.

Possible Scenario

Harriet suffered from cardiovascular disease for 15 years. During an urgent admission to hospital for congestive heart failure, she spoke with her social worker about writing down her wishes for future care. Harriet had been single all her life and wanted her niece Joanna to look after her and her affairs if she became too ill. The social worker explained to Harriet that she could complete a Power of Attorney for Personal Care document. In this document, Harriet could identify how she expected to be cared for if she became too ill to speak for herself and could name her niece Joanna as her SDM. Harriet didn't want to die in hospital and wanted to state this along with her other wishes. The social worker advised Harriet that this could all be part of her Power of Attorney for Personal Care document. Harriet decided to talk with her physician and her niece Joanna before completing this document.

❷ Why discuss advance care plans?

Every year, serious health circumstances arise for many Canadians and they become unable to make their own decisions about personal care and medical treatments. This can happen slowly over time (as with Alzheimer's disease) or it can happen suddenly, without warning (as with stroke or a heart attack). Intensive or aggressive medical therapies such as life support may be offered when determined to be medically appropriate, but do not always improve the quality of a person's life. It is important to think about what quality of life means to you and the medical treatments you would want to receive and under what circumstances. Overall, ACPs tell others how you would like to be cared for at the end stage of your life if there is no reasonable hope of recovery.

People are encouraged to review their ACP to ensure that the wishes and preferences stated are relevant to their changing health and life circumstances. It is not uncommon for people to change their ACP over time.

❸ Quality of life

Quality of life is a very personal consideration and can change over time, according to age and health status. Quality of life involves "living the best way a person knows how until death occurs" (Godkin, 2008).

Thinking about and discussing advance care plans often helps an individual identify what has always been important in his/her life.

The following are sample questions you may wish to consider when determining what is important to you. These might also serve to direct conversations with a loved one:

- What defines a good quality of life for you?
- What gives you fulfillment on a daily basis?
- What aspects of life are essential to your sense of satisfaction?
- Is independence important to you?
- Is the ability to communicate with loved ones important to you?
- Is it important for you to enjoy your surroundings?
- Were it not possible to live at home, under what circumstances would you agree to live in an institutional care setting?

Possible Scenario

Paul was 84 years old and living independently when he was diagnosed with colorectal cancer. During a visit with his oncologist, he told his physician how important his gardening was to him. He asked his doctor how long he could expect to have the physical strength to work in his garden. This led to a discussion about what was important to him in his life and how this ought to inform decisions regarding aggressive life support measures should his heart or other vital organs become affected by his illness. For Paul, being outdoors, being able to care for his property, etc., were vital to his happiness. If these activities were not possible anymore, he did not wish to be aggressively treated if his heart, lungs or kidneys failed.

❹ Who can be my Substitute Decision Maker (SDM)?

Many people complete a Power of Attorney for Personal Care document in which they name the person they wish to have as their SDM. The person they name may be a relative or a close friend and must be at least 16 years of age. It is very important to consult with the person you have chosen to name in your Power of Attorney for Personal Care document as this person must also be willing and available to assume this responsibility.

For those patients who have not completed such a document identifying an SDM, health care providers will refer to a rank-ordered list of people found in the Health Care Consent Act (1996).

For more information about the role and responsibilities of the SDM, please refer to the Sunnybrook Health Science Centre brochure *Making Care Decisions When a Patient is Incapable: The Role and Responsibilities of a Substitute Decision-Maker* as well as the Ontario Health Care Consent Act:
http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm

❺ What is the role of the SDM?

An SDM is a person with the legal authority to make decisions about treatment options on behalf of someone who has been found incapable of making decisions about his/her own treatment. Key to such decisions are the previously stated capable wishes of the patient as understood by the SDM. If wishes are not known, or if it is not possible to comply with these wishes, then the SDM has a responsibility to consider the patient's values and beliefs to determine which options would serve in the best interests of the patient in their current circumstances.

For further guidance on what constitutes best interests and the responsibilities of the SDM, please see Sunnybrook Health Science Centre brochure *The Role and Responsibilities of a Substitute Decision-Maker* as well as the Ontario Health Care Consent Act:
http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm

Possible Scenario

Carolina had been a devoutly religious woman all her life. Although Carolina had four children, it was her daughter Marlene whom she selected as her SDM in her Power of Attorney for Personal Care document. When Carolina was too ill to speak for herself, Marlene informed her mother's care team that discussions held about end of life care should include Carolina's priest. This request was based on a conversation Marlene had with her mother several weeks earlier in which Carolina directed Marlene to ensure that her spiritual advisor was included in such discussions when the time came.

❻ Having the conversations: Finding an ally

Many people do not want to burden their immediate family members with discussions about dying, death or burial wishes. In these instances, it can be helpful to identify a good friend, family member, religious adviser or care provider with whom you enjoy a good relationship. These people can help you identify what has been important to you in life, what you want for your loved ones, the treatments you may not wish to receive, and the way you would want your care to be provided in your final days of life.

This friend or ally may not be the one who will make care decisions when you are no longer capable of doing so. However, this person can help you to prepare your advance care wishes so that it is easier for you to inform your SDM.

Possible Scenario

Alex had always been close to his brother Gordon and asked him to help write his advance care plan. After their discussion, Alex was able to complete his advance care plan. In this conversation with his brother, Gordon identified his own wishes which he subsequently shared with his family. This conversation helped his family years later when Gordon became ill. It particularly helped his wife, who was his substitute decision maker, to determine a plan of care that was consistent with Gordon's wishes.

❼ What issues should I discuss in advance with my family, friends and SDM?

Would you wish to have Cardiopulmonary Resuscitation (CPR) attempted?

CPR refers to a set of procedures provided to a person if the heart stops beating and the person is close to death or has died as a result. It can include chest compressions, electric shock, drugs and artificial breathing.

Would you want to be admitted into an Intensive Care Unit (ICU)?

The ICU is the part of a hospital where many life supporting measures can be offered if they are medically indicated. These treatments can include life supporting medications, central lines and/or artificial breathing/mechanical ventilation. Artificial breathing/mechanical ventilation is required when a person cannot breath on his or her own. A machine pushes oxygen into a person's lungs through a tube placed in the windpipe (trachea). This is provided only in an Intensive Care Unit (ICU).

How would you feel about receiving life sustaining treatment?

Life sustaining treatments can include dialysis when a person's kidneys are no longer working or may involve intravenous lines that provide fluids and tubes that provide nutrition. Many people choose to have some type of life sustaining treatment provided in the event of a serious illness or injury, particularly if there is a reasonable chance of recovery.

An important element of an ACP is guidance as to the withholding or withdrawing of life sustaining treatments. These treatments can be identified as unwanted by a person in his/her ACP when achieving an adequate quality of life is unlikely or when the burden of illness, or burden of the treatment, becomes unbearable.

Patients on life sustaining treatments who are still capable of directing their care can consult with their family and medical team to identify the conditions under which withdrawal from these treatments would be desirable to them. These conversations can also include the care options that would be consistent with the patient's wishes. A person can include in his/her ACP the conditions under which such treatments should be withdrawn in order to reduce their burden or suffering at the end of life.

Alternative care options include a shift in the goals of care that focus primarily on maintaining comfort. At this time, support is provided to the patient and family throughout the period of intervention withdrawal and the dying process.

Have you considered alternative levels of care?

Alternative levels of care involve the different settings in which you can receive quality end of life care. Many people include in their ACP preferences about where they would most like to be cared for at end of life. For example, some people prefer to be cared for at home while others may prefer to be cared for in an institutional palliative care setting. These preferences should also be discussed in advance so that you can direct your SDM on how and where you would like care delivered at end of life.

Possible Scenario

Betty's Community Care and Access Case Manager asked Betty whether she had considered her future needs for alternative levels of care. Betty had been diagnosed with dementia and although living well at home with the assistance of her husband and son and his family, she was likely to need more care in the future. Betty's cultural and religious background emphasized the importance of family ties and keeping elderly loved ones in their homes cared for by family and friends. Betty was certain that she wanted to remain at home until the end. She felt it was the duty of her family to provide this support to her. Betty's Case Manager asked to meet with Betty and her family to discuss advance care planning.

❽ Having the Conversations: Knowing What is important

The following are questions you can ask yourself or ask a loved one to consider as part of the conversations about advance care planning:

- Under what circumstances would I agree to being fed by a tube?
- When would I agree to have my breathing supported by a machine?
- How long would I agree to be supported on such a breathing machine?
- Would I agree to receive cardiopulmonary resuscitation if I would survive only to remain unconscious?
- Would I agree to have cardiopulmonary resuscitation attempted if I were dying from a terminal disease?
- If I were unable to care for myself and if my family could not provide the care I needed at home, would I agree to moving to an appropriate institutional setting based on my care needs?
- I don't know what the nature of my dying process will be. However, if I am dying and incapable of directing my care, I want my SDM to consider the following when making decisions about life sustaining treatment: (The following points are offered as suggestions only)
    - *I never wanted to be connected to a breathing machine or to receive nourishment through feeding tubes.*
    - *The importance of my religious beliefs and thoughts about quality of life should be considered.*

The following space is provided for you to include your own thoughts:

References:

1. "Making Care Decisions When a Patient is Incapable: The Role and Responsibilities of a Substitute Decision-Maker", Sunnybrook Health Sciences Centre

2. Dialysis Program Advance Care Planning Brochure, Sunnybrook Health Sciences Centre

3. Ontario Health Care Consent Act (1996):
   http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm

4. National Kidney Foundation (1999)
   Advance Directives: A Guide for Patients and their Families
   New York: National Kidney Foundation Inc.

5. Government of Ontario (2007)
   A Guide to Advance Care Planning: The guide is free of charge and can be obtained by calling 1.888.910.1999 or visiting **www.citizenship.gov.on.ca/seniors.**

6. Godkin, D. (2008) Living Will: Living Well. Edmonton: University of Alberta Press.

7. Singer, P. (1995) Advance Directive Fallacies. Health Law in Canada 16 (1), 5-9.

For further assistance please contact:

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(2010/05/17)