

End-of-Life Planning

Defining Generic Key Terms and Concepts

- **Euthanasia:**

Euthanasia, which can take different forms, is the act or practice of terminating the life of a person (Gifis, 1996). There is a difference, however, between terminating or rejecting medical treatment – sometimes called the right to die – and assisted suicide and mercy killing.
- **Advance Directives:**

An advance directive is made up of two main elements: a *durable power of attorney for health care* and a *living will*. A third element that may be necessary is called a *do not resuscitate (DNR) order* that alerts emergency medical staff that a patient does not wish to be resuscitated.
- **Living Will:**

A living will is distinct from an advance directive in that living wills are generally invoked when a person is considered *terminal*, while a health care directive is not limited to the terminal state. A living will outlines the type of care a patient would want or would reject in the terminal state. Generally, a living will works best when it uses specific terminology such as “do not resuscitate” or “do not intubate”. Generic phrases such as no heroic measures are simply too vague to provide guidance (Sabatino, 1999).
- **Palliative Care:**

Instead of a cure, medical treatment can be focuses on palliative care, sometimes called comfort care, to preserve the best quality of life by relieving pain, controlling symptoms and supporting the patient’s continuing involvement with life. At the same time, palliative care regards dying as a natural part of life and supports the patient and family in living through this process. The psychological, emotional, and spiritual work involved in the dying process requires energy that can be eroded by severe pain, persistent nausea, or unrelenting shortness of breath. Aggressive management of those symptoms offers patients the opportunity to deal with their anxieties about death, put affairs in order, and attend to the principal relationships that sustain them.
- **Hospice:**

The terms hospice care and palliative care are often used interchangeably, and though related, they are distinct from each other. Hospice care is a subset of palliative care that focuses on enhancing life during the final stages of a terminal illness.

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- **Do Not Resuscitate (DNR) Orders:**

If a senior's heart or breathing stops while in a health care facility, emergency staff is mandated to make every effort to resuscitate that person. However, there are patients for whom resuscitation is inappropriate, and there are patients whose living wills indicate they do not want to be resuscitated. Accredited hospitals and nursing homes are required to develop a DNR policy to deal with such cases. A DNR will not keep a person from getting other emergency medical treatment or pain relief. A person or their proxy may revoke a DNR at any time.

The Values of Hospice Palliative Care

All hospice palliative care activities recognize and support the following values:

- V1. The intrinsic value of each person as an autonomous and unique individual.
- V2. The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization.
- V3. The need to address patients' and families' suffering, expectations, needs, hopes and fears.
- V4. Care is only provided when the patient and/or family is prepared to accept it.
- V5. Care is guided by quality of life as defined by the individual.
- V6. Caregivers enter into a therapeutic relationship with patients and families based on dignity and integrity.
- V7. A unified response to suffering strengthens communities.

Source: *A Model to Guide Hospice Palliative Care*, Canadian Hospice Palliative Care Association

The Principles of Hospice Palliative Care

The following principles guide all aspects of hospice palliative care

- **GP1 - Patient/Family Focused**

As patients are typically part of a family, when care is provided the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patient's and family's personal, culture, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

- **GP2 - High Quality**

All hospice palliative care activities are guided by:

- the ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality
- standards of practice that are based on nationally-accepted principles and norms of practice, and standards of professional conduct for each discipline

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- policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines
 - data collection/documentation guidelines that are based on validated measurement tools
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- **GP3 - Safe and Effective**

All hospice palliative care activities are conducted in a manner that:

 - is collaborative
 - ensures confidentiality and privacy
 - is without coercion, discrimination, harassment or prejudice
 - ensures safety and security for all participants
 - ensures continuity and accountability
 - aims to minimize unnecessary duplication and repetition
 - complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organizations

 - **GP4 - Accessible**

All patients and families have equal access to hospice palliative care services:

 - wherever they live
 - at home, or within a reasonable distance from their home
 - in a timely manner

 - **GP5 - Adequately Resourced**

The financial, human, information, physical and community resources are sufficient to sustain the organization's activities, and its strategic and business plans. Sufficient resources are allocated to each of the organization's activities.

 - **GP6 - Collaborative**

Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.

 - **GP7 - Knowledge-Based**

Ongoing education of all patients, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

 - **GP8 - Advocacy-Based**

Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and develop, hospice palliative care activities and the resources that support them. All advocacy is based on the Canadian Hospice Palliative Care Association's model to guide hospice palliative care.

 - **GP9 - Research-Based**

The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the

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best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdictions.

Source: *A Model to Guide Hospice Palliative Care*, Canadian Hospice Palliative Care Association

Additional Thought-Provoking Questions:

- 1) Five Wishes—of interest perhaps to North American PROFESSIONALS as a method of promoting communication and stimulating dialogue. Review each of the five wishes and determine which points are important for you. Who would you share this discussion with?**

Five wishes is a living will document developed in America that talks about the persons' emotional and spiritual needs as well as medical wishes. It lets the person choose who he or she wants to make health care decisions for them when they can no longer make them for themselves. Five wishes lets a person say exactly how he or she wishes to be treated if they get seriously ill. It was written with the help of the American Bar Association's Commission on the Legal Problems of the Elderly and the nations' leading experts in end of life care.

PROFESSIONAL's can use the Five Wishes to engage in conversation with their clients about end of life planning issues. It can also be a useful guideline to discuss ones own end of life issues and those within ones own family.

The Five Wishes are:

Wish 1: The Person I want to make health care decisions for me when I can't make them for myself.

Note: encourage the person to choose someone who knows them very well, cares about them and who is able to make difficult decisions. Family members or a spouse may not be the best choice because they are too emotionally involved. Choose someone who is able to stand up for the wishes and who is preferably nearby so that he or she can help when needed. Whoever is chosen, make sure these wishes are discussed with him or her and that this person agrees to respect and follow these wishes.

Wish 2: My wish for the kind of medical treatment I want or don't want.

Note: this wish is prefaced by the following statement. "I believe that my life is precious and I deserve to be treated with dignity. When the time comes that I am very sick and am not able to speak for myself, I want the following wishes, and any other directions I have given to my health care agent, to be respected and followed". These matters may reflect wishes related to pain management, comfort issues and life support or extraordinary measures and in specific situations (i.e. close to death vs. in a coma or having permanent and severe brain injury with no expectation of recovery).

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Wish 3: My wish for how comfortable I wish to be.

Note: This wish may contain express requests for things like music to be played when possible until death, having poems or favourite passages read, being given additional medicine to relieve pain even if it makes one sleep a good part of the time or being kept fresh and clean at all times.

Wish 4: My wish for how I want people to treat me.

Note: This wish may contain express requests about who the person wants to be with them as they near death (i.e. family, friend, spiritual guide or minister), if they wish to have pictures of loved ones by their side, if they wish to have someone hold their hand near the end, or if they prefer to die in their own home, if that can be done.

Wish 5: My wish for what I want my loved ones to know.

Note: This wish may contain statements that the person wants family to know that the person loves them, may ask for forgiveness for times the person has hurt family, friends or others and also shows forgiveness for hurts the person has experienced from others. It is a wish that can evoke a need to make peace with themselves, their families and their communities or to remind love ones to celebrate the persons' life with memories of joy, not sorrow. Specific funeral/memorial service and burial requests may also be written in this

2) The Senate Sub-Committee Report, *Quality End of Life Care* –states:

“...die in relative comfort, as free as possible from physical, emotional, psychological, and spiritual distress. Each person is entitled to access skilled, compassionate, and respectful care at the end of life. This subcommittee sees care for the dying as an entitlement for all”.

