PRC Quick Tips

Société Alzheimer Society

BRANT, HALDIMAND NORFOLK, HAMILTON HALTON

Understanding Dementia
When Emotional Decisions Need to be Made

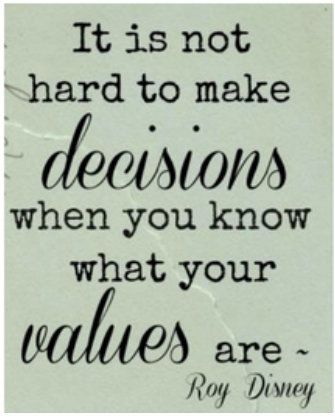
I cannot stress how important it is for family members to verbalize to one another how we feel about certain life and death situations before we are face to face with a dilemma. We go from day-to- day believing we are invincible, but one never knows how quickly tragedy can strike and we are faced with situations and decisions that will knock us to our centre. It is so important for individuals to appoint someone to make decisions for you should you become incapable of making these decisions for yourself.

This appointment of a substitute decision maker is important at any age, and not just as we reach our older years. If you are old enough to be reading this article, you should have had the 'discussion' of your wishes and ensured you have appointed the appropriate individual to carry out your wishes.

Be specific with your wishes

Although many times we tell our loved ones we do not want 'heroic measures to keep us alive' we must be more specific.
-would you want to have a feeding tube?
-would you want to be kept alive on a ventilator?
-would you want Cardiopulmonary Resuscitation (CPR)?

We want our appointed decision maker to make 'informed decisions' about these situations. It is so important to understand what these procedures are and what they mean to you under the circumstances of your physical condition.



Substitute Decision Maker Hierarchy

In Ontario, there is a hierarchy that is used if you have not appointed a substitute decision maker through a Power of Attorney for Personal Care.

1. Your spouse or partner is first in this hierarchy, and if they are not available or in existence.
2. Next is your children or parents.

The important thing is that these individuals will be the ones to speak on your behalf if you are not able to. They should be making the decision based upon your wishes. They cannot do this if they do not know what you would want. What ends up happening many times (unfortunately) is they make decisions under stress and these decisions may be made filled with emotion and fear of losing you. Ensure you look at this hierarchy and decide if this is the person you want to make the decision for you if you are no longer able. If not, it is important to have someone appointed to make this decision. In this case it is advised to use a lawyer to appoint this individual. This individual does not have to be a family member. It could be a close friend. This individual needs to know you have chosen them as they may refuse to take on this responsibility. You must also realize that in an emergency in which there is not time to contact your substitute decision maker, and the physician does not know your wishes, they do not need consent in order to treat.

When do SDMs make health care decisions?

SDMs only make health care decisions for a patient if the patient is deemed mentally incapable by the health care professional offering the treatment.

Requirements to be an SDM

The person(s) highest in the hierarchy can act as an SDM only if he/she is:

a. Mentally capable with respect to treatment proposed,

b. 16 years of age unless he/she is the parent of the incapable person,

c. Not prohibited by court order or separation agreement from having access to the incapable person or giving or refusing consent on his/her behalf,

d. Available, and

e. Willing to assume the responsibility of giving and refusing consent

Resources that may be helpful:
"A Guide to Advance Care Planning" at: www.ontario.ca/seniors or by calling 1-888-910-1999

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Would you want CPR?

CPR is a wonderful thing and has saved many lives but, there are some things one must understand about this procedure. Most people's understanding of CPR comes from what we see on television. A person collapses from a heart attack and a crash cart, led by doctors and nurses, comes rushing down the hall to save this person from impending death. This popular image has led many to believe CPR is used to bring dying people back to life or a person who has died back to life. This image of CPR is not completely accurate. CPR is an emergency method of life saving under certain limited circumstances, usually an event which causes the heart to stop beating in a person who otherwise has normally working organs such as the heart, kidneys, liver, and brain. If these organs are significantly damaged, the body cannot sustain itself, and the heart stoppage is usually a result of the deterioration of the body in general.

CPR involves artificial respiration (breathing into the person's mouth or the use of a respirator bag) and external heart massage, usually after a sudden event such as a cardiac arrest, drowning, or high-voltage electric shock in which a body that is otherwise reasonably healthy. If the heart is stopped for too long, permanent brain damage or death will occur, regardless of the cause of the heart stopping (taken from the book "Moments that Matter; cases in ethical eldercare" by Michael Gordon M.D., MSc, FRCPC).

What is the role of CPR in long term care homes or chronic care hospitals?

People in these settings usually have many chronic health problems affecting many organs of the body including the heart, kidneys, liver and brain. Research and experience have shown that CPR is unlikely to have a positive outcome for most of these individuals, especially when they are also very elderly. The cardiac arrest is usually part of a complex process. Many parts of the body are already affected by disease, and a cardiac arrest is often the final step in a progressive and complex process of deterioration leading to death. (Moments that Matter: cases in ethical eldercare; Michael Gordon M.D., MSc, FRCPC).

I once heard a specialist say, "The 'R' in CPR does not stand for 'resurrection'!"

Would you want a feeding tube?

The issues of a feeding tube cause a lot of anguish for decision makers. The social powers of food and drink reflect the basic human need and desire to nourish those we love, from birth to death. The availability of artificial nutrition and hydration (AHN) has made end-of-life care decisions even more difficult for all concerned in the decision-making process. Individuals that can no longer ingest or digest adequate amounts of food and/or fluid can now be offered feeding tubes and intravenous infusions to sustain them in both short-term and long-term medical situations. Unfortunately, because we associate eating and drinking with nurturing, love and compassion individuals feel obligated to artificially supply nutrition to the sick and the dying. Artificial nutrition should only be offered if it is to sustain an individual until they stabilize and recover from an illness. If your relative has been diagnosed with a progressive disease that will get worse over time, the inability to take food in is part of the dying process. It is hard enough to make the decision for someone to have a feeding tube; it is even harder to make the decision to have it removed if it continuously causes pain and discomfort related to infection. While everyone's case is unique, it is important to know the pros and cons of having a feeding tube inserted. You want to make an 'informed decision' based on the proper medical information available. This is why it is important to have these discussions while someone is still capable to tell you their wishes, so you are not making poor decisions while emotions are high. Artificial hydration and nutrition (AHN) is a medical treatment and the ethical principle of autonomy requires that informed decisions made by competent patients, or their substitute decision makers, be respected. This ethical principle is supported legally by Health Care Consent Acts in most common-law (English-speaking countries) jurisdictions (Moments that Matter: cases in ethical eldercare).

For more information, please contact us:

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