END OF LIFE ISSUES - DYING WELL

BIOTECHNOLOGY REFERENCE GROUP
Canadian Council of Churches

Introduction

With the growth in medical technology, such as the use of drugs, respirators, resuscitation equipment, tube feeding, there has been an expansion of our capability to extend life. At the same time there are growing cries for legal sanctions to end life when requested, often arising from the experience of people who are terminally ill or severely disabled, or from their caregivers. Decisions to prolong or end life are surrounded by complex webs of personal relationships and professional responsibilities as well as questions of personal autonomy.

There are rarely clear solutions in the midst of these decisions. They take careful thought and reflection on the multi-faceted situation. Discussion with family, friends and church members is helpful in the process. The following information and considerations are offered to assist in reflection on end-of-life situations from a Christian perspective. At the end of each section are several scenarios as concrete examples for reflection and discussion in a family or community setting.

End-of-Life: How is it defined? A Medical Perspective

This period is usually loosely defined as that time when health is declining such that a person is within a few days or weeks of death and no medical intervention is likely to alter that course. Traditions vary; some define this time more precisely than others and according to their concept of medical futility. In some Jewish traditions, for example, a patient is on the brink of death (the state of *goses*) when it is predicted that the patient cannot survive more than 72 hours even by artificial support. Before this time, everything must be done to keep the person alive. End-of-life issues manifest differently according to the projected time to the end of life and the rate of deterioration toward death. For example, a person may have an illness whose course cannot be altered by medical intervention but the person may be expected to live for several weeks or even months rather than days. This may lead to a decision to not institute resuscitation when the heart and/or lung stop functioning during the time remaining. However, the degree to which other interventions such as intravenous nutrition and the treatment of infections such as pneumonia are instituted may need to be discussed and decided upon.

The following questions could be part of that discussion:

1. Is intensive care including ventilator support appropriate?
    i. When is it appropriate?
    ii. When initiated, what criteria should be established to end such support?
    iii. Who should be involved in these decisions?

2. What advanced directives have been initiated or expressed?
    i. Durable power of attorney for health care
    ii. Living will

iii. Previously verbally expressed wishes

3. What support is available to help the patient and/or surrogate decision-maker decide issues as they arise?
    i. Family
    ii. Church/faith community
    iii. Trusted friends

4. What can be done to best ensure that a person with a terminal illness will receive care that maximizes functioning and minimizes symptoms that impede functioning.
    i. How often are needs being assessed?
    ii. In what environment is the patient living (e.g., home, hospice, hospital)?
    iii. Who are the primary caregivers and what relationships need to be established with what individuals?
    iv. What treatment plan has been agreed upon, how often is it being reassess and with whom?

As Christians face these situations and decisions we keep in mind how we understand life and death as God's people. With the *Beginning Guidelines* (Biotechnology Reference Group) as a framework, the following considerations would also be appropriate:

1. Consider decisions of life and death in light of the need to affirm and protect human dignity.
    - What constitutes human dignity?
    - What is the relationship between human dignity and our designation as bearers of the image of God? (Gen 1:27)
    - In what way(s) does our creation in God's image affect our relationship with our neighbour?
    - What are the implications of our creation in God's image for end of life decision making?

For Discussion:

You have been notified by phone that your 48 year old husband who has been well until now was in a serious car accident. His injuries are considered life-threatening and the medical personnel acted quickly at the hospital to save his life. Before you arrived at the hospital he was placed on a ventilator when it became clear that he could not breath on his own.

After 48 hours it has become clear that the injuries to the brain were so severe that there will be little or no recovery. The physician in charge of his care recommends that the respirator be removed. You are told that he may continue to breath on his own and may live for a few hours or even days or more but that he would much more likely stop breathing and die within a few minutes. Since no decision had been made previously concerning who would make decisions for him in this situation, as his next-of-kin you are given the details of their opinion and are asked whether or not you approve of this decision

2. Consider issues of life and death in light of God's providential care and the inherent dignity of human life.

- ❖ Life is a gift from God. Is death the enemy against which we must fight until the end or the door through which we pass to be with the Lord? If the latter is true, how should Christians prepare for that event?
- ❖ What determines an appropriate limit to life?
- ❖ Is sustaining life with extraordinary measures appropriate in all situations?

For Discussion:

Your 84-year old widowed father lives in a retirement home. He is in fairly good health but is becoming forgetful and uses a walker because of arthritis. He contracts pneumonia and is transferred to the hospital. While considered previously capable of making his own decisions, his family now deems that he is incapable of making decisions about his own care. Also observing that this appears to be the case, the admitting physician asks you whether you or someone else has been designated as your father's substitute (or surrogate) decision-maker. The physician also states that he would like to discuss whether or not a 'Do not resuscitate' (DNR) order should be written. To your knowledge he has never made up a 'Living Will' and you have never discussed this with your father. Furthermore, you do not recall him ever stating previously whether or not he would wish to be resuscitated if his heart stopped or he stopped breathing in this kind of situation. Your sister is flying in to visit and arrives tomorrow. The hospital is anxious to have a decision made. You call your sister and by phone it is decided that you should be the substitute decision-maker. Your sister feels that a DNR order should be written but you are concerned that he should be given every opportunity to recover even if his heart stops or he stops breathing.

3. Consider decisions of life and death in light of our life in community. A decision to stop supporting remaining life due to perceived futility of treatment involves a community of those directly and indirectly affected by the decision – family, friends, caregivers, professionals. This requires sufficient, in-depth reflection by all parties.
   - ❖ How is the community invited to share in the decision?
   - ❖ Who needs to be involved in the discussion?
   - ❖ How will differences in perspective be heard and considered?
   - ❖ How will opposing perspectives and needs be balanced? What values will inform the balance?
   - ❖ How is expert medical opinion combined with prayerful reflection and meditation in seeking the guidance of the Holy Spirit?
   - ❖ In making end of life decisions, how do we understand 'God's will' for the situation?

For Discussion:

Your 37-year old sister has terminal breast cancer. She has been cared for at home by her husband who has taken off work and by the visiting nurse who comes in twice per day. She also has 2 small children. Until now, she has been kept comfortable and relatively pain free. However, she has become incontinent of urine and the suggestion is made by the visiting nurse that she should be admitted to hospital for terminal care. Her husband is distraught with his grief and the challenges of parenting the children in the midst of it. He is also aware of her previously stated wish to stay home until the end. At this point he feels guilty that he cannot fulfill this wish. He asks the visiting nurse if there is any other way to care for her outside of the hospital. He has heard of hospice care but knows nothing about it. He is also disappointed that his church community have not been more supportive in helping him care for her at home and in providing help in dealing with his grief.

4. Consider decisions of life and death in light of implications for the whole community (family and wider society) and of the need to protect our physical, biological and ethical integrity through legislation.
    - ❖ Do our laws appropriately support and/or protect end of life decisions?
    - ❖ Is there sufficient protection for all involved (patient, medical personnel, caregivers)?
      Eg. If physician-assisted suicide (see below) or euthanasia were permissible what implications (if any) are raised for those who are: terminally ill; mentally ill; severely disabled?
    - ❖ In end of life decisions there are often competing needs and concerns. What does it mean to act justly in the midst of these? (For example: the costs of technology to prolong life reduce resources available for other needs.)

For Discussion

- ❖ Your 65 year old grandfather has had Parkinson's disease for 5 years. He has been deteriorating gradually but with medication he has been functioning well at home. He develops pneumonia which quickly deteriorates so that he will likely soon be unable to breath adequately on his own. He is admitted to hospital and the physician contacts the physician in the intensive care unit (ICU) anticipating that your grandfather will need respiratory support soon. Although there are plans to expand the unit, it is currently full. On further review of the existing cases in the unit, it is decided that a patient can be transferred to a regular hospital bed, leaving that bed available for the next patient requiring ICU services. However, the intensive care physician has just been notified that a patient with severe trauma needs to be admitted to an intensive care unit urgently. The physician talks to you and to the physician in charge of your grandfather on the hospital ward as to whether he should be considered a candidate for respiratory support given the severity of his Parkinson's disease. He asks about his quality of life and whether he has a living will or had previously stated preferences as to what he would want done in this situation.

<u>Additional Information regarding Physician-Assisted Suicide:</u>

Studies raise concern that those who invoke PAS (physician-assisted suicide) or euthanasia may have pain and/or underlying depression that could be better treated and thus avoid a desire for PAS or euthanasia. Since PAS was legalized in the Netherlands in the 1990's, most of the studies reflecting the most experience with this problem are from that country.

- ❖ In the Netherlands, van der Lee et al. showed that depressed terminally ill cancer patients were four times more likely to request euthanasia than those who were not depressed. 44% of depressed patients requested euthanasia while of those who requested euthanasia, half were depressed. Depression appears to be more involved in requests for euthanasia while pain has been over-emphasized as a reason for such requests (van der Lee et al. Euthanasia and Depression. Journal of Clinical Oncology 23: 6607, 2005).
- ❖ Another study from the Netherlands showed that sedation is a common practice in the terminally ill and that over 60% of the time terminal sedation is done with the partial or explicit intent of hastening death. Consent could not be obtained in 41% of patients and in those who could not consent, substitute decision-makers were sometimes not approached about giving consent.

While pain was the most common reason for considering terminal sedation in this study, ethically preferable alternatives such as consultation of palliative care specialists were seldom obtained. (Rietjens, et al, Physician Reports of Terminal Sedation with out Hydration or Nutrition for Patients nearing death in the Netherlands. Annal of Internal Medicine 2004; 141: 178).

- Summary of a position paper of the American College of Physicians on PAS: "…the American College of Physicians-American Society of Internal Medicine does not support the legalization of physician-assisted suicide. Its practice would raise serious ethical and other concerns, as outlined above. Physicians cannot give to individuals the control over the manner and timing of death that some seek. But, throughout patients' lives, including as patients face death, medicine must strive to give patients the care, compassion, and comfort they need and deserve." (Physician-Assisted Suicide – Position Paper. Annal of Internal Medicine 2001; 135: 209).\
- In a study of patients with acute myotrophic lateral sclerosis (ALS) (a progressive neurological disease leading to death), patients to whom religion was important were less likely to choose to end their lives by euthanasia or PAS. Data reported from ALS treatment centres in the US suggest that many therapeutic strategies to improver quality of life for these patients are underused (Verdink et al. Euthanasia and Physician-Assisted Suicide among Patients with Amyotrophic Lateral Sclerosis in the Netherlands. New England Journal of Medicine 2002; 346: 1638; Gandzini and Block. Physician-Assisted Death – A Last Resort? New England Journal of Medicine 2002; 346: 1663.)

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