



Ian Anderson Continuing Education Program in End-of-Life Care

Module 4

END-OF-LIFE DECISION-MAKING



Authors:

Laura Hawryluck, MSc, MD, FRCPC
Physician Leader, Ian Anderson Program, University of Toronto
Assistant Professor, Critical Care Medicine, University Health Network

Appendix II – The Law in Ontario
Judith Wahl, Advocacy Centre for the Elderly

Case Scenario

Mrs. Linda Scott is a 70-year-old widowed woman with Alzheimer's Disease. She worked as a bookkeeper so when she started having problems balancing her checkbook 4 years ago she became concerned and came to visit you. You eventually diagnosed her with Alzheimer's disease. In the last year and a half, her health has continued to deteriorate and while she still lives at home, she requires 24-hour care to help her with her activities of daily living. This care is provided by her long time friend Martha, a 65-year-old woman. Linda's only family are two cousins who live in the United States who she has not seen for 7 years.

At the time of her diagnosis, Linda told you and Martha that she would "never want to go on a respirator" and, furthermore, did not want "any artificial feeding contraptions inserted" should she come to need them. You have not discussed these decisions with her since.

In the last few days, Martha noticed that Linda seems to be having more trouble with her speech and seems to choke when she swallows. When Martha brings her to the hospital, a CT scan is done which shows evidence of a new stroke. After a few days, it becomes evident that Linda's swallowing difficulties are not improving. Furthermore, since the stroke, Linda has not been able to communicate or to understand any information. Martha discusses Linda's previously expressed wishes with the medical team and they agree to make her DNR. In view of her difficulties swallowing, the medical team wants to insert a NG but Martha objects.

Feeling strongly that feeding is a necessary to live, the medical team asks for a bioethics consult. The bioethicist tells them that since Linda expressed these wishes regarding feeding 4 years ago, they may not reflect her current wishes. These, he feels, are not known since a lot can happen in 4 years. The bioethicist therefore recommends that her family in the United States be contacted and feeding discussed with them. The cousins say that while they have not seen or talked to Linda for 7 years, they do not think she "would want to starve to death".

Introduction

As individuals, we all have a sense of who we are; we all have our own goals and ambitions. In the course of our lives, each of us has discovered things we value and believe in and, which give us happiness. We are shaped by our families, our past experiences, our society and our culture. The choices we make and the way we live our lives are a reflection of who we are, our goals, values and beliefs. We bring our sense of self to all of our life experiences including that of illness and, in turn, our sense of self is influenced by our state of health.

For these reasons, when we are diagnosed with a serious or life-threatening illness, our reactions to the news, the decisions we make and, what influences our decisions are not based solely on medical facts, risks and benefits. While we take these facts into account, the ways we interpret them, the importance we place on different risks and benefits are deeply personal. For this reason, decisions are never purely based on medical facts. In truth, it may be difficult for our physicians, and for perhaps all but our most intimate loved ones, to predict what our decisions will be since they are based on our particular and distinct values and beliefs.

Once the shock of hearing the diagnosis and prognosis of serious illness is over, patients and their families must confront very difficult decisions. At the end of life, most patients want to know how treatment options would improve their quality of life and allow them the best opportunity to achieve their remaining goals. By exploring what patients expect and/or hope for, treatment options, their risks and benefits can be discussed in the context of these hopes and expectations and the likelihood of various treatments achieving the desired outcomes can be examined.

Physicians have a duty to truthfully inform patients of the expected course of illness, without conveying false hope, and to help patients decide which of the available treatment options are best for them. In these ways, physicians show respect for the intrinsic self-worth and dignity of the person and moreover, show that they see and care about the patient not solely as a patient but, more importantly, as a unique person.

Objectives:

- ❑ Construct a care plan that includes patient centred goals of care established with patients and families to enhance patients' sense of control at the end of life
- ❑ Be able to discuss the role of **Advanced Care Planning** with dying patient and their families – being sensitive to issues of religion and culture – and provide guidance in constructing advanced directives
- ❑ Be able to assess **capacity** in terms of end-of-life decision-making
- ❑ Be able to develop an approach to end-of-life decision-making with capable and incapable people
- ❑ Be able to demonstrate understanding of the ethical and legal role of **Substitute Decision-Makers** in end-of-life decision-making
- ❑ Be able to list the three elements of **Consent**, demonstrate understanding of their importance clinically with respect to consent to treatments at the end of life
- ❑ Discuss the use of specific treatments at the end of life including **life-sustaining treatments, DNR orders, antibiotics, artificial nutrition and hydration** at the end of life and how to avoid the inappropriate prolongation of dying
- ❑ Be able to discuss the **withholding and withdrawal** of therapies at the end of life
- ❑ Be able to discuss how their own personal experiences of death and dying and their previous experience in caring for dying patients have influenced their attitudes towards treatments at the end of life
- ❑ Be able to list the factors that lead to requests for euthanasia/assisted suicide and be able to address requests for euthanasia/ assisted suicide
- ❑ Be able to reflect on the importance of caregiver stress on his/her ability to care for dying patients

What is Quality End of Life Care?

- End-of-life care encompasses pain and symptom control, communication about diagnosis, prognosis and treatment options, advanced care planning and the emotional and psychological support of patient and families.
- All physicians have an obligation to provide quality end-of-life care.

The Patient's View: FIVE Components of Quality End of Life Care Identified by Patients:

1. Adequate pain and symptom management
2. Avoiding inappropriate prolongation of dying
3. Achieving a sense of control
4. Relieving burden
5. Strengthening relationships with loved ones

Singer P.A., Martin D.K., Kelner M., Quality End-of-Life Care: Patient's Perspectives, *JAMA* 1999 281(2) 163-168

- People want to obtain relief from pain and other distressing symptoms. Unfortunately, studies such as the large SUPPORT trial have shown that 50% of patients still die in pain and 33% of these people experienced severe pain in the last days of their lives. Other symptoms such as fatigue occur 58%, generalized weakness in 43%, confusion in 28-39%, anxiety in 21%, dyspnea in 20-40%, sleepiness 24-57% nausea in 12-71%.
- People want to enjoy their lives even if they don't have long to live. To achieve their remaining goals and to respect what is important to them and what gives them happiness, people need to feel in control of decisions related to their care. If a dying person is no longer capable of making health care decisions, good advance care planning would mean that their substitute decision-maker or their written advance directive would be able to guide decisions in view of their previously expressed wishes, values and beliefs.

- The involvement of loved ones in their lives is very important to dying people. Fears of burdening loved ones with their care and with the stress of acting as substitute decision-makers and, ultimately witnessing their death – as well as fears of isolation – leads most people to welcome their loved ones' involvement in meetings about end-of-life decision-making and, to welcome their involvement in discussions about dying. Such involvement strengthens relationships with their loved ones.
- Bioethics has placed a lot of emphasis on the principles of autonomy and self-determination and their importance in decision-making. However, confronted with a serious illness or with the end of life, autonomy may be seen as less important by dying patients. More importance is placed on being a member of a community composed of loved ones and family members and on relationships with loved ones and family within this “community”

To ensure you, as a physician, are providing quality end-of-life care, ASK:

Am I adequately treating pain and other symptoms?

Am I helping patients and families to set goals?

Am I inappropriately prolonging dying?

Am I helping patients and families achieve a sense of control, relieving burdens on their families and strengthening their relationships with their loved ones?

Am I involving a multidisciplinary team and working with this team to provide best quality of end of life care?

Singer P.A., Martin D.K., Kelner M., Quality End-of-Life Care: Patient's Perspectives, *JAMA* 1999 281(2) 163-168

Advance Care Planning

- Advance care planning is a process whereby the patient, with the help of his/her health care providers, family members and loved ones, makes decisions about his/her future medical care.
- Advance Care Planning involves discussion of the diagnosis, prognosis, the expected course of the illness and the possible treatment alternatives, their risks and benefits and should be placed in the context of the patient's goals, expectations, fears, values and beliefs.

- From the perspective of people engaged in advance care planning – as explored by Martin et al in people with HIV/AIDS – such planning is seen as a way to confront death, achieve a sense of control and strengthen relationships with their family and loved ones.
- Physicians have an ethical obligation to work with patients and help them make decisions about their future treatments and care and to support the patient and his/her family through the course of their illness and the processes of consenting to and/or the withholding and withdrawing of various treatments.
- When a patient is capable, physicians should help them plan for the possibility of becoming incapable to make medical decisions by helping them appoint a substitute decision-maker(s). Physicians should then work with the dying person and his/her substitute decision-maker to explore the dying person's values and fears, what is important to him/her in regards to quality of life (values history). Advance care planning may (but does not always have to) include writing a "living will", a written advance directive to be invoked in the event a patient becomes incapable
- Planning for incapacity involves more than the appointment of a person to act on one's behalf. Physicians should encourage and help patients talk with their substitute decision-maker(s) about their values and beliefs, what is important to them in terms of their quality of life and what treatments (including life-sustaining ones) they would be prepared to undergo to maintain or attempt to restore that quality of life.
- If a patient is not capable from the start of the physician-patient relationship, their appointed substitute decision-maker should be contacted or arrangements for a substitute decision-maker need to be made if one had not been designated.
- As a first step in helping a person engaged in advance care planning, physicians and other health care providers must determine if the person is capable of making health care decisions

Capacity

- To be deemed capable of making health care decisions, a person must **understand** the nature of the decision and **appreciate** the reasonably foreseeable consequences of a decision or lack of decision
- **TO UNDERSTAND:** a person must be able to grasp and retain the relevant information to the decision at hand. If doubts about the person's ability to understand arise, the following questions must be explored:

1. Has the person been given the relevant information in language appropriate to their level of understanding and in their language of fluency?
 2. Has the person been educated about his/her illness and the treatment alternatives AND been given opportunities to ask any questions he/she may have?
 3. Does the person understand that he/she has a choice and what each alternative involves and its risks and benefits?
 4. Can the person remember the information long enough to reach a decision?
 5. Can he/she remember the choices he/she has previously made and be consistent in his/her decision-making over time?
- **TO APPRECIATE:** a person must be able to grasp how a given treatment will affect him/her personally. Moreover, he/she must be able to show that his/her reasoning is based in reality. If doubts as to the abilities of a person to appreciate the information he/she has been given arise, the following questions should be explored:
1. Does the person understand how the risks and benefits of a given treatment and the available alternatives will affect him/her personally in his/her current situation?
 2. How did he/she arrive at his/her decision? *

*The point is not whether the decision is reasonable or what the physician would have chosen but whether it was reasoned, based in reality and consistent with the person's previously expressed values and beliefs. If a person's reasoning seems strange, physicians may seek to explore it in context of appropriate religious and cultural background.

- Capacity is assessed in relation to particular decisions. A person may be incapable of making financial decisions but may still be able to make decisions regarding health care.
- Legally, people are presumed capable unless proven otherwise. Some provincial legislation has declared an age of majority below which a person is deemed incapable, while others do not have an age of majority (range is from no age restriction in Ontario to 18 years of age in PEI and Saskatchewan). Physicians should familiarize themselves with their provincial legislation.
- Respect for the intrinsic value and dignity of others means that incapable people must be protected from making decisions that may result in harm or choosing treatments that they would not have chosen if they were still capable. To be declared incapable is to have large restrictions placed on autonomy and self-determination; therefore, if a person seems to be incapable because he/she either doesn't understand or doesn't appreciate the treatment options and their risks and benefits, he/she will need a formal capacity assessment

- Capacity may be transient and change over time: delirium, drugs, lack of sleep, strong emotions (e.g. depression, shock, denial) and the underlying illness itself may render a person incapable; however, his/her incapacity may only be temporary. Reversible causes must be ruled out, treated and capacity must be reassessed.
- To help health care providers assess a person's capacity when facing a medical decision, three forms of capacity assessment are described in the medical literature:
 1. cognitive function testing: e.g. Mini-mental → do not assess judgment & reasoning
 2. general impressions: biased and not reliable
 3. specific capacity assessments
- If you, as the person's health care provider, have doubts about a person's capacity to make a medical decision after you have provided and explained the required information, a specific capacity assessment is needed to explore the person's ability to understand and appreciate the information relevant to decision and consequences of the choice
- One such tool to help health care providers perform a specific capacity is the Aid to Capacity Evaluation (ACE) developed by Dr. E. Etchells and available through the University of Toronto Joint Centre for Bioethics website (www.utoronto.ca/jcb/) and reproduced in the Appendix of this module
- In cases where you, as the person's physician, are uncertain of his/her capacity, these specific capacity assessments can be done by psychiatrists, psychologists, nurses, social workers, bioethics committees or by Consent and Capacity Review Boards.
- Unfortunately, capacity assessments have so far not been standardized from one province to another. Different provincial consent acts describe how capacity should be assessed and describe how a person can challenge determinations of incapacity and who may give consent when person a is deemed incapable
- If a person is not capable of making health care decisions, physicians must involve their appointed substitute decision-maker or the government office of Public Guardian and Trustee.

End-of-Life Decision-Making with Capable Patients

- Discussion of the expected course of illness and which decision points are likely to be encountered should not occur when the purpose of the meeting was to disclose the news of a serious and/or life-threatening illness. Studies have shown that patients and their families retain, at best, 50% of the information they are provided with. Moreover, the emotional responses to bad news will further decrease their ability to process information.
- Unless the person's illness is immediately life threatening and urgent decisions are required, end-of-life decision-making is best deferred to a separate meeting.
- Patients and their loved ones will need time to think about their goals and expectations and how these need to change based on the diagnosis and expected disease course. They will need time to reflect on the treatment options, their risks and benefits in relation to their notion of quality of life, their life circumstances, past experiences, values, beliefs and in the context of their relationships with their loved ones.
- Physicians should therefore not expect patients to make important, major decisions, which will affect their remaining life on the spur of the moment. In fact, physicians must be prepared to meet on more than one occasion in order to help a seriously ill or dying patient decide between various treatments. **End-of-life decision-making is a process not a one-time event.**
- If the patient is already in the hospital, it is very helpful to ask other members of the medical team (RN, social work, pastoral care and consulting services if relevant and appropriate) to participate in meetings regarding decision-making. Other members of the team can help convey the relevant information, discuss alternatives and offer emotional and psychological support.

12 STEPS TO END-Of-LIFE DECISION-MAKING:

1. Start the meeting*
2. Purpose*
3. What do they know and understand about their illness?*
4. What questions do they have?*
5. Describe expected and likely course of illness as much as possible – avoid FALSE hope**
6. What are patients and families hoping for?
What is most important to them?
7. What are they afraid of?
8. Listen and show empathy by responding to emotions*
9. Work with the patient and family as a team to develop realistic goals***
10. Make a plan and follow up – What do we need to decide now? What do we have time to reflect on? What may we need to decide in the future? Who do we need to consult and what will their role be?
11. Document what was discussed, what was decided, what issues are outstanding and why. Comment on when remaining issues will likely be discussed.
12. Review and revise (if and when needed)

} Values
History

* see [Communication with Patients and Families Module](#): Ask who the patient wants to be present and ensure that they are, ensure privacy and avoid interruptions. If the patient is at home, physicians should ask the patient if he/she would want the health care team in the community to be present and this team should be informed of the outcome of the discussions to ensure continuity and quality care.

** Physicians need to avoid giving false hope of cure or of greater benefit than likely or expected. On the other hand, physicians should avoid painting the situation worse than it is in order to get the patient to decide what the physician feels to be in his/her best interests. Goal is to hope for the best course of illness or for best quality of life for the longest possible time but we need to plan for the worst or the unexpected.

*** Physicians must therefore be aware of their own values, beliefs and attitudes towards life-sustaining treatments as well as death and dying. They must reflect on

how their own past experiences, both personal and professional, impact on their feelings regarding the treatment options available to a given patient. These values, beliefs and experiences can affect the way the information regarding alternatives is conveyed to the patient and ultimately may bias the decision-making process by imposing the physician's values on the patient.

- With any meeting with patients and families, it is important to decide on the purpose of the meeting. By stating you want to discuss their illness, its expected course and work with them to decide upon treatment options, you allow the patients opportunity to state if they are prepared to discuss these issues or if another time would be better. While such discussions can be deferred (and should be deferred if the patient has had a particularly bad day or is tired or emotionally depleted), it must be emphasized that these discussions are important and need to occur in the near future. A time at which these issues will be discussed should be arranged
- Physicians must not let their reluctance, or the reluctance of their patients, to discuss difficult (and sad) decisions delay these discussions. Such delays may preclude reflection and lead either to decisions being made in crisis situations or, to unwanted life-sustaining interventions.

Suggested Ways to Introduce the Purpose of End- of-Life Decision- Making Meetings:

“Now that you have had some time to adjust to the bad news of being told that we cannot cure your cancer, I wanted to meet today so that we could discuss what you expect and hope for, what goals you would like to fulfill in your remaining time. Then we can talk about what treatments are available, what the benefits and risks of these different treatments are, and how these treatment will allow you to achieve your expectations, hopes and goals”

“ I wanted to meet with you today to discuss what may happen now that you have been found to have this illness and to help you plan for the future. In the next few months you may be faced with some important and difficult decisions about different treatments including life support. I wanted to talk to you about these issues now when you are feeling relatively well so that we can think about which treatments you would want and what would be important to you in deciding about these treatments including going on life support if there comes a time that you need to”

AVOID:

“It doesn’t look good”*

“Do you want us to do everything?”**

“We will refrain from aggressive or extraordinary measures”

*Very vague: Tell them what you are seeing, what is happening. Can be less frightening to patients and families if they know what is happening and what to expect.

** This practice should be discarded since 1) gives no information on what is involved in “everything” and is not helpful in informing the patient and, 2) opposite to “everything” is nothing: implies physicians are abandoning and/or not trying to do what is best for the patient

- It is important to emphasize that it is impossible to predict with certainty the course of illness for a particular individual and that unexpected complications either of the illness itself or of its treatments may arise. (see Prognosis section in [Communication with Patients and Families Module](#))
- Health care providers need to avoid giving false hope of cure or of greater benefit than likely or expected. The temptation to alleviate distress by providing false hope either of cure or of greater benefit from a given treatment than is medically possible must be avoided. Excessive optimism may reassure but eventually leads to disappointment and loss of trust, as it should, since false hope robs patients of their dignity by failing to allow them to plan their future or to make health care decisions that would reflect their sense of self, values and beliefs.
- On the other hand, health care providers should avoid painting the situation worse than it is in order to get the patient to decide what the physician feels to be in his/her best interests. Goal is to hope for the best course of illness or for best quality of life for the longest possible time but we need to plan for the worst or the unexpected.
- Patients’ desire for control over decision- making process is variable and even those who seek information may not want to make the decision. Elderly patients and those who are acutely ill are predisposed to follow their physician’s recommendations.

After the meeting, if members of the team involved in caring for the patient were not able to be present, inform them of what occurred and document the meeting in the chart. This will help the team support the patient emotionally and psychologically as help them re-explain any medical options in cases of confusion or misunderstanding. Such a strategy also helps avoid any confusion within the medical team(s) regarding the goals of treatment and improves the quality of care provided to the patient and family.

After the meeting, document:

1. Who was present at the meeting
2. The patient's medical condition and what he/she was told regarding its likely course
3. The goals, expectations, hopes and fears of the patient and their family
4. Treatment options that were discussed and decisions reached
5. Plans for follow-up and ongoing treatment and care
6. Outstanding issues needing discussion and when such discussion will likely occur

- Review of the treatment plan should occur at the patient's request, when the patient's health changes, if he/she develops an unexpected acutely life threatening illness, with a change in the setting of care (e.g. hospitalization or nursing home).

Subsequent discussions as illness progresses should include*:

1. What the patient and family expect the final days will be like
2. What the final hours of living will be like and what to expect during the dying process
3. How pain and other symptoms will be treated
4. Where they would like to die: home, hospice or hospital

* See Module on [The Last Hours](#)

End-of-Life Decision-Making when the Patient is Incapable

- When a person is incapable, they risk losing their dignity and respect for their intrinsic value as persons since their beliefs, goals and culture may not be honored.
- Written advance directives and the appointment of substitute decision-makers are attempts to ensure that, when incapable, a person is still able to express their goals, choose treatments to reflect the things that matter to them.

Substitute Decision-Makers

- Most provinces have legislation that allows people to appoint substitute decision-makers in the event they become incapable. Since provincial law varies, physicians need to be familiar with the law in their own province
- Unless a substitute decision-maker is appointed in a Durable Power of Attorney for Health Care Decisions, most provincial legislation details who the physician may turn to as substitute decision-maker. In this legislation, the order of people who may act as substitute decision-maker is: 1) the patient's spouse or partner, 2) his/her child(ren), 3) his/her parent(s), 4) his/her sibling(s) or 5) other relatives. Once appointed, the substitute decision-maker or power of attorney for personal care or the guardian appointed by the Consent and Capacity Board has the authority over all other family members with respect to making decisions for the incapable person
- Substitute decision-makers are asked to decide not what treatments they personally would want in the patient's situation but **what the patient would have wanted if he/she was still able to tell the health care team**
- Some studies have shown, concerningly, that relatives and partners cannot accurately predict a patient's preferences for life-sustaining treatments. When a patient appoints a substitute decision-maker, he/she should therefore be encouraged to discuss what is important for him/her in terms of quality of life and what he/she would be willing to undergo to maintain this quality of life.
- Substitute decision-makers should be welcomed in meetings discussing decision-making at the end of life and discussing specific interventions
- If the patient's wishes are not known or cannot be predicted, decisions can be made according to what substitute decision-makers and the health care team feel to be in the patient's best interests.

- The appointment of a substitute decision-maker has to have more meaning than filling out a legal document. The legal document should be used as a starting point of or, as an end to, these discussions.

Families and Loved Ones as Substitute Decision-Makers

- When the family acts as substitute decision-maker, they experience the same emotions as families do when the patient is competent (see [Communication with Patients and Families Module](#)). However, as surrogates, they are under additional pressure to understand the severity of illness, the treatment options and to make the “best decision”.
- As substitute decision-makers, families may experience more anxiety since they fear making the “wrong” decision. If the decision involves withholding or withdrawing life-sustaining treatments, they may feel guilty that they abandoned or even that they killed their loved one.
- Families may also feel guilty that they did not talk with their loved one about what treatments they would want to undergo, what likelihood of benefit would justify the burdens

DO NOT SAY:

“What do you want us to do?”

“Do you think we should pull the plug/ stop aggressive treatment/ stop everything?”

“Its time to withdraw care”*

* Implies you stop caring about the patient. We never withdraw care, we withdraw treatment.

Ways to Focus Substitute Decision-Makers on their Role

“We need you to help us decide what the best treatment course will be by sharing with us your knowledge of the kind of person your father is”

“What is important to your husband? What does he value, believe? What does he like to do?”

“If your father was able to sit with us today and participate in this discussion, knowing the available treatment options, what their risks/benefits are at this point in time, what do you think he would say or be thinking?”

“Sometimes it is hard for families to separate what is best for them from what is best for loved one. Do you ever find that difficult?”

“What has he said about his friends who have been ill and the treatments they received?”

- ❑ It is important for the entire health care team to show caring, respect and support for the family acting as substitute decision- maker in order to emphasize that they are working with them as a team.
- ❑ To show the family/substitute decision-maker that you truly see their role as being part of the team, show you also care about their well being during this difficult time. Ask the family where they are staying, if they are eating and sleeping. Ask them how they are coping and offer the help and support of other team members such as social workers and chaplains. Ask them if there is anyone you could call for them and if there is anyone else they wish you to discuss the patient’s illness with. If there are children ask them if they would like you (or if you do not feel skilled, another team member) to explain what is happening to the children.

End-of-Life Decision-Making with Substitute Decision-Makers:

1. Start the meeting
2. Purpose
3. Explore what patient's previously expressed wishes and values
4. Acknowledge the difficulty of the substitute's situation *
5. Normalize the experience**
6. Empathize
7. Place decision in a teamwork context***
8. What are the physicians recommendations in view of seriously of illness, and in context of patient's expressed values, goals and beliefs

* They are after all being asked to play an important role in decision-making when least able to do so. Even if they had discussed end-of-life issues with their loved one, it is hard to imagine all the possible scenarios that could arise and will take time to sort through their knowledge of their loved ones goals and values and how these would have affected their decision. This may result in them needing even greater time to reflect on a given decision than the patient would have needed if capable. Surrogates need to know how urgent a particular decision is: need to tell them realistically how much time you anticipate they have to arrive at a decision.

**Normalize experience: "When we talk about withdrawing life support, many people feel they are "pulling the plug" or giving up on a loved one, do you?"

***Substitute and health care providers form a team whose goal is to respect patient's wishes, values, goals and culture. Such a strategy removes the onus and burden of decision-making from the surrogate and may lessen stress and guilt that may occur if they feel they are solely responsible for a decision to withhold or withdraw life support leading to death: "We will work together to do what your father would have wanted – to respect your father's wishes – to try to give him a quality of life he would have thought worth living."

Intra-Family Conflict*

- Emotional and psychological stress as well as the physical fatigue of seeing and caring for a seriously ill loved one may re-open old conflicts within the family and it may seem that these conflicts occurred only yesterday

Helpful phrases in event of conflicts between family members:

“It sounds like you have had a number of disagreements in the past. We can’t resolve these today and we are not here to do so. We need to concentrate on how we can best respect your mother’s wishes, goals or values.... or what treatments would be in your mother’s best interests.”

“Can you share with me how you decided or what makes you think, this would be best course of treatment for your mother?”

“Who is closest? Who knew her the best – who would have best insight into her values, goals, beliefs?”

Lo B., Caring for Patients with Life-Threatening or Terminal Illness, The Medical Interview, Lipkin MJ, Putnam SM, Lazare A. Ed, Springer 1995 p.303-315

- Other team members such as nursing staff, social workers, bioethicists, pastoral care representatives or mediators may also be helpful in addressing conflicts with the family
- If a person is estranged from his/her family, he/she may choose to appoint a friend or partner. If no one is available or if no one has been appointed, the office of the Public Guardian and Trustee (PGT) may assume the role of decision-maker on the patient’s behalf. However the office of PGT will often try to seek out family members and perhaps even friends before assuming this role

*See [Conflict Resolution Module](#) for more details

Health Care Providers and Conflict with Substitute Decision-Makers*

- If doubt arises that the substitute is acting according to the patient’s expressed wishes or values or in the patient’s best interests, physicians should explore whether the surrogate understands the patient’s current situation, the expected course of illness and the risks and benefits of the treatment options. While the surrogate may have been given this information, he/she may not have clearly understood it or appreciated its implications.

- ❑ If communication is not the problem, physicians can consult with their colleagues and obtain a second opinion regarding their perception of the situation and appropriate treatment course.
- ❑ If concerns over the surrogate's decision-making persists, the hospital bioethics committee or a mediator can be consulted. If the dispute is not resolvable legal counsel may be sought as a last resort.

*See [Conflict Resolution Module](#) for more detailed discussion

Written Advance Directives/ Living Wills

- ❑ Some patients may not appoint a substitute decision-maker; instead, they may only have a written advance directive that describes what kind of treatments they would want in the event of an acute or life-threatening illness.
- ❑ Currently, provincial legislation varies as to scope of advance directives, the requirements for witnessing and the process needed to activate an advance directive
- ❑ Studies have shown that 62% of medical outpatients want to discuss their preferences in end-of-life care however only 10% of Canadians have completed an advance directive form
- ❑ Written advance directives are most useful if the person discusses his/her goals and values that would affect his/her decision-making in the context of current or future illness with his/her physician and/or family and loved ones.
- ❑ **Problems with written advance directives:**
 1. Some people change their minds (or act in such a way that loved ones wonder if they have changed their mind) but do not have time to change their written advance directives.
 2. Others want to undergo life-sustaining treatments; however, when they actually do need these life-sustaining treatments, the likelihood of benefit in view of their values and goals are very small. Families and physicians may then wonder if the patient would have truly wanted to undergo such interventions.
 3. Written advance directives may only vaguely define which medical interventions should be undertaken based on anticipated prognosis which at time of an acute deterioration in health status may not be quite clear. Such imprecise language and the difficulties in predicting the outcome of an acute

illness leads to very subjective interpretations and perhaps to unwanted interventions

4. The actual situation or illness that occurs may not have been anticipated and written advance directives alone may not provide any guidance.

- Family members may refuse to bring in advance directives if they disagree with the contents or out of fear of losing their loved one when clear that this event is imminent. Gentle acknowledgement of their emotions, education that following an advance directive, as hard as it is, shows the love they feel for their loved one by respecting his/her well thought out wishes, values and beliefs is needed
- Help for people wanting to prepare a written advance directive may be obtained from the *“Let me Decide”* and *“Living Will Booklet”* from the Joint Centre for Bioethics at the University of Toronto

Consent

- Patients have the right to make decisions about their medical treatments and care even at the end of life
- If a person is capable consent to treatments should be obtained from him/her. If a person is incapable, consent must be obtained from the substitute decision-maker
- When a person is nearing the end of his/her life, it is important that physicians place all discussions and consent for treatments in context of how these treatments will affect the patient’s remaining quality of life, whether they will prolong life and whether the benefits of such treatments outweigh their burdens and discomfort.
- Obtaining consent for treatments or procedures should not be used to avoid discussing and confronting the larger issues of death and dying and the remaining hopes and goals of patients. Treatments should always be considered based on their ability to increase the likelihood of achieving goals that the patient deems worthwhile.

Involving the multidisciplinary team in discussions about different treatment options including life support, withholding or withdrawing treatment is important:

1. to avoid confusion among team members regarding goals of treatment
2. to avoid confusion between the patient and family and team regarding the goals and risks/benefits of different treatment (“mixed messages”)
3. to allow the team to provide psychological and emotional support and
4. to improve the quality of care

- ❑ A signed consent form is not a replacement for the process of obtaining consent. Such a form may satisfy legal requirements but not the ethical obligations of the physician. Under the law there are no fixed rules as to when a form is required. Treatment against a patient’s consent is considered battery under common law. Inadequately informed consent is negligence.

Three elements are necessary for consent:

1. Disclosure
2. Capacity*
3. Voluntariness

* Capacity has just been discussed in detail in the sections above. The following discussion will therefore concentrate on disclosure and voluntariness

Disclosure:

- ❑ Disclosure is defined as a process during which physicians provide information relevant to the decision in question and ensure the patient understands this information.
- ❑ Disclosure is key to informed participation in health care and to develop and maintain trust in the physician-patient relationship.
- ❑ In Canada, **the reasonable person standard is seen as the ethical and legal standard of disclosure.** According to this standard of disclosure, physicians must reveal any facts material to the decision of a reasonable person in the patient’s situation i.e. what would a reasonable person want to know in light of his/her life, goals, values and beliefs, fears and circumstances?

- If such information is not already known to them, physicians must discover it.
- Most people's desire for information correlates with this reasonable personal standard.

Information that physicians should disclose includes:

1. Prognosis and consequences if the patient remains untreated or there is a delay in treatment
2. Reasonably accessible treatment alternatives, their benefits and risks* and likelihood of achieving the desired goal
3. Side effects, both reversible and irreversible and expected discomforts of treatment alternatives and the chance of these side effects occurring whether treatment is successful or not.
4. Limits of medical knowledge in areas of uncertainty and of ongoing research
5. Information that the patient specifically asks about
6. Physician's opinion regarding which treatments should be undertaken in view of relevant patient's goals, values and expectations

Dickens B. M., *The Doctrine of "Informed Consent": Informed Choice in Medical Care, Justice Beyond Orwell* Abella R.S. & Rothman M.L. eds. 1985 p. 243-263

*Differences in the way information is disclosed and to whom it is disclosed may exist in certain cultural groups (see modules on [Culture](#) and [Communications with Patients and Families](#))

- If a given treatment is not effective for a given problem or if it would not fulfill the patient's goals, such treatments do not have to be discussed with the patient or family e.g. surgery for multiple liver metastases. However, physicians may have different beliefs regarding what is a risk or chance worth taking than their patients. For example a physician may feel the possibility of a 5% chance of success is so low that the benefits of treatment do not outweigh the burdens and so treatment should not be administered. His/her patient may disagree and feel that 5% is worth the side effects and risks of the treatment in question. As long as open honest discussion of risks, benefits and alternatives occurs, the patient understands and appreciates the imparted information and such discussion occurs in the context of his/her goals values and beliefs, it is not for the physician to decide that a 5% chance precludes administering the treatment.

Voluntariness

- ❑ People have the legal and ethical right to make decisions free of undue influence
- ❑ Undue influence can arise from both external and internal sources
- ❑ **External sources** can include:
 1. Force: is employed when physical restraints or sedation are used to enforce a particular treatment
 2. Coercion: a decision is coerced when implicit or explicit threats are used to make a patient decide upon a certain treatment course
 3. Manipulation: a decision is manipulated when information is deliberately distorted or omitted to make a patient decide upon a certain treatment course
- ❑ Physicians are expected to recommend certain treatments above others based on their professional expertise and their knowledge of the patient's goals, values and expectations. While physicians can try to persuade patients and their families to follow their recommended therapies, any attempts to force, coerce or manipulate a decision is unethical and not to be condoned. Physicians must recognize and respect the differences between their own values and beliefs and those of their patients
- ❑ Family members and loved ones may also attempt to influence the patient's decision. If physicians suspect that the family is using undue influence, they should discuss the decision with the patient without family members being present and explore the reasons the patient arrived at his/her decision.
- ❑ **Internal sources** include:
 1. Limited alternative treatments resulting in little choice,
 2. Pain and other symptoms which may destroy concentration and understanding or which may be so distressing that he/she would do anything to alleviate it
 3. Emotional and psychological factors
- ❑ Poorly controlled pain and other distressing symptoms should be treated and emotional and psychological distress alleviated and decision-making deferred until the patient is capable.

Specific Treatments and Their Role at the End of Life

Life Support

- When a patient is in the last stages of his/her illness and is nearing the end of his/her life, life-sustaining interventions are usually not undertaken since they would only serve to prolong the dying process.
- However, a patient who has a short life expectancy is not automatically excluded from the Intensive Care Unit (ICU). If an ICU admission would allow the patient to achieve a specific goal (i.e. time to say goodbye to family members, a chance of being present at a wedding) or, if the patient's religious or cultural beliefs makes him/her feel obliged to try all possible interventions to prolong his/her life, life-sustaining treatments, their anticipated benefits, risks and discomfort should be explained.
- Most people have no idea what ICU implies in terms of the severity of illness or, for that matter, what life support involves. Physicians cannot just ask patients whether they would want to go on life support without explaining severity of illness that requires ICU care, what the ICU can offer, what is involved in "life support" and what its limitations are.
- Many people have serious misconceptions of the power of ICU to restore health especially in view of current TV shows which detail resuscitation attempts nothing short of miraculous.

Suggested way to explain ICU:

“Many people have heard of life support through the news or TV shows but don’t really feel they have a clear idea of what life support is, when you would need it or what it can and cannot do. Can you tell me what you understand about life support?”

“The ICU is a place in the hospital where we use machines and powerful drugs to treat seriously ill people who would not survive without these drugs and machines and may not survive even with them.”

“When we talk about life support, we are talking about two broad categories of treatment: 1. the ventilator, the ‘breathing machine’
2. drugs to support your blood pressure and heart”

“Not everyone who is in the ICU needs all of these types of life support but they are on at least one or they would not be in the ICU.”

“Life support can prolong your life and potentially restore you to the same quality of life you enjoyed before you became so sick that you could not live without the help of machines. However, life support will not cure you of your underlying illness or give you a better quality of life than you had before. It may only restore you to a weaker state of health.”

Suggested way to explain ventilatory support:

“When you are put on a ventilator, you are given drugs to make you drowsy and a tube is put down through your mouth into your windpipe. This tube is then hooked up to a machine that helps you breathe. You cannot talk while this tube is in your mouth but you can write or mouth words to communicate with us. You cannot eat while this tube is in and we will need to put another smaller tube, either through your nose or mouth into your stomach to feed you. Both of these tubes are taped to your face to hold them in place. While we can give you some drugs like morphine and valium to make you more comfortable while you have the breathing tube in, it still will feel strange and will give you a sore throat.

We would also likely need to place a monitoring device, like an intravenous into an artery in your wrist or your leg so that we can follow your oxygen levels and your blood pressure.

While it is difficult to predict how long you will need life support, most people will need to be on the ventilator at least a week. But it could be shorter than this or a lot longer depending on why you need it.”

Suggested way to explain inotropic support:

“Sometimes a very bad infection or a heart attack can make your blood pressure fall so low that it would not be able to supply your brain and your body with enough oxygen to keep you alive. In the ICU we can use drugs to support your blood pressure until antibiotics have a chance to fight the infection (or until we can see if there is anything we can do to treat your blocked arteries). In other words, these drugs will support your blood pressure but won't fix the problem that caused your blood pressure to fall

Because these drugs can damage the smaller veins in your arm, we need to start what is called a central line. This is a special intravenous that is placed in the larger veins either in your neck, under your collarbone or in your leg. We can give you some drugs to make you drowsy while we put these in and we freeze the skin to minimize any discomfort. As with any procedure, there is a risk, albeit small, of infection. There is also a risk of bleeding, usually just some bruising at the site but sometimes more. If the intravenous is placed in the neck or under the collarbone there is also a risk that the needle may hit the lung causing air to leak out of the lung and the lung to collapse. If this happens another tube will have to be put into the chest to drain the air until the lung heals – usually about a week.

We would also need to place a monitoring device, like an intravenous, into an artery in your wrist or your leg so that we can follow your oxygen levels and your blood pressure.”

- If uncertainty among the medical team exists regarding the role of life support in view of the patient's goals, beliefs and medical condition, consultation with colleagues (including an intensivist) and discussion with the team may be helpful.
- If the patient wants or needs more information about life-sustaining treatments than his/her physician and/or medical team is able to provide or in situations in which the benefit is not certain, an intensivist can be consulted.
- Patients may even request a visit to the ICU to help them decide if they wish to be placed on life-sustaining treatment and such a visit should be arranged if it would help with decision-making. The goal of such a visit is not to scare the patient but to make it easier for him/her to decide if he/she would want to go on life support. Patients and families must be prepared for what they will see upon entering the ICU.

Time-Limited Trials of Life-Sustaining Treatments

- May be offered if patients and families understand and appreciate the potential benefits of ICU care and wish to see if they will benefit from life-sustaining treatments but fear:
 1. the discomfort involved,
 2. having to live their remaining life dependent on a machine and /or
 3. living in a persistent vegetative state
- Physicians should discuss with patients that life-sustaining treatment can be withdrawn, while keeping the patient comfortable:
 1. at the patient's request
 2. if the anticipated benefits do not materialize
 3. If the burdens > benefits
 4. after a predetermined time has passed whether or not the patient will be able to live without life support
- Physicians should reassure patients that if ventilator is withdrawn, they would be kept comfortable with drugs like morphine and valium to take away any pain, shortness of breath and discomfort, however they will likely die.
- The **advantage** of time-limited trials is that they may allow a patient to achieve a specific goal or allow the patient and family to feel that they have tried "everything" even in face of slim odds.
- The **disadvantage** is that it may be harder to stop life-sustaining treatments than to start them. While, ethically and legally, withholding and withdrawing treatments are considered equivalent, in practice withholding and withdrawing feel very different; at the time life support is being withdrawn, everyone is aware that there

are no further treatments to try and recognize that death is expected and imminent.

Religious/Cultural Beliefs and Life-Sustaining Treatments

- Some people believe that all attempts must be made to continue living since life, any life, is precious.
- While physicians may strongly feel that the burdens outweigh the benefits of life support in these situations, physicians are not the ones who should judge which beliefs should be supported or what quality of life is worth living. While physicians can recommend the patient not undergo life-sustaining treatments, whether the patient's beliefs and values should be supported is not a decision to be made by individual physicians whose personal biases will lead to widespread inconsistency.

Is there a role for life support at the end of life? – Things to ask and discuss

1. In what context does the physician anticipate the patient may need life support?
2. What does the patient know and understand about the ICU and life support?
3. Clarify any misconceptions: explain ventilator and inotropic support
4. What can life support do in context of patient's goals, expectations?
5. What won't life support accomplish?
6. Explain the role of a trial of life-sustaining treatments
7. If a trial of life support is undertaken, what would make patient and physicians decide to withdraw such life-sustaining treatments?
8. What would the physician recommend in view of the patients' goals, hopes, expectations and fears?

DNR Orders

- ❑ After the physician and patient have discussed the situations in which life support may be needed and what is involved, the discussion should turn to cardiopulmonary resuscitation in event of cardiac or respiratory arrest.
- ❑ As with life support, many people have misconceptions about what is involved in CPR and its likelihood of success.
- ❑ The CMA, CHA, CNA, CHAC, in cooperation with the Canadian Bar Association, developed a **Joint Statement on Resuscitative Interventions** last updated in 1995 and distinguish 4 general categories of CPR as a treatment option:
 1. People who are likely to benefit
 2. People for whom benefit is uncertain
 3. People for whom benefit is unlikely
 4. People who will almost certainly not benefit – patient will either not recover due to underlying illness or will never be able to experience any benefit
- ❑ Physicians must give patients a realistic, accurate picture of what's involved in resuscitation, discuss the likelihood of success, risks of neurological damage, the need for life support afterwards and fact that CPR may not only fail to achieve goals but worsen the patient's overall health.
- ❑ Physicians perpetuate the myth that CPR is easy and usually successful by asking "If your heart stops would you want us to restart it with CPR or using the paddles and giving you electric shocks?"
- ❑ Instead, we need to put CPR in context of seriousness of the situation: "If your heart was to stop you would die within 10 minutes. We can attempt to resuscitate you by doing CPR and using electric shocks to restart your heart. To increase our chances of success we would also put a tube through your mouth into your windpipe to breathe for you since you would not be breathing. This is not an easy, or even a very successful, endeavor for the most part. We may break some of your ribs and bruise some of your internal organs. If we can't restart the heart quickly, brain damage will occur. This brain damage can be significant and can range from loss of memory to being chronically dependent on others to help with your day-to-day activities such as getting dressed, eating and going to the bathroom. If we are successful at restarting your heart you will need to be on life support afterwards.

Only 1-4% of patients with chronic illnesses survive to leave the hospital and almost no one with cancer survives. Many of the people who do survive are sicker and they may have brain damage that could be severe. Half of the people who live need others to help them in their day-to-day lives".

- Physicians should help patients and families make choices that do not increase likelihood of harm and that make “medical” sense: e.g. it does not make sense to undergo CPR without intubation, since poor oxygenation will decrease the chances of a successful resuscitation and increase chances of neurological injury. However, wanting intubation without CPR does make sense in context of a respiratory arrest.
- Patients do not need to decide about CPR/ resuscitation right away. They should be encouraged to think about it and discuss with their loved ones. However they need to be informed that our current policy is to attempt to resuscitate unless asked not to.
- In situations in which chances of successful resuscitation are non-existent (severe left ventricular dysfunction, advanced liver failure, metastatic cancer), physicians are not obliged to offer CPR. However, in these situations, patients should be told that CPR would not be offered because it would not be successful. Such a disclosure not only keeps the patient informed and shows respect for them as persons but also gives them the opportunity to answer questions and seek a second opinion
- DNR orders have a very narrow scope: in the event of a cardiopulmonary arrest, do not resuscitate. These orders by themselves say nothing about admission to ICU and life support, hence the need to discuss ICU admission separately.
- Unfortunately health care providers often translate DNR to mean the patient wants limited treatment for his/her underlying illness or for any acute exacerbations or complications of this illness. Such assumptions may not accurately reflect the patient’s wishes, expectations or values. Before assuming other treatments will not be undertaken, discussions must occur with the individual patient.
- Attitudes that DNR implies that a patient does not need the same attention should not be condoned. Education of team members is crucial as to meaning and scope of DNR orders. Patients who refuse ICU admission and CPR deserve perhaps more attention since:
 1. One of the fundamental goals of Medicine is to alleviate a person’s discomfort no matter what his/her code status is and,
 2. No ICU interventions will be available to reverse any iatrogenic or otherwise avoidable causes of deterioration in health.
- Another common assumption is that DNR means the patient has given up and so should the medical team. A code status of DNR does not mean the patient has given up hope of quality of life or even, depending on the situation, of cure. It may simply mean the patient recognizes the severity of illness and the gravity of the situation in which CPR would be needed and understands chances of

successful resuscitation are uncertain or low AND does not wish to undergo CPR.

- ❑ In effect, when the team makes assumptions about the implications of a DNR order, the team may be trying to develop their own treatment plan for the patient. When DNR is interpreted as implying other limitations should be imposed on treatment options, the team is displaying behavior that at best can be characterized as paternalistic and should not be condoned.
- ❑ Documentation of the goals of treatment, as described above, should ensure other team members are aware of the plan and avoid misinterpretations of DNR orders.

Slow Codes

- ❑ If a patient wishes to undergo CPR against the recommendations of his/her physician, the concept of a “slow code”, in which resuscitation is attempted at a slower pace for a shorter time, may arise.
- ❑ **Slow codes are always inappropriate** since, if successful, the longer time to return to spontaneous circulation usually will have resulted in severe CNS damage and thus caused harm to the patient.
- ❑ If resuscitation is unlikely to be successful, it will be unsuccessful no matter what the pace of the attempt. Slow codes represent a paternalistic expression of physicians’ beliefs when the patient is without a voice and needs to trust them the most.

Artificial Nutrition

- ❑ When we are born, we depend on others to feed us. This is one of the first ways we show caring for others. When illness makes us unable to eat or drink on our own, we return to this state of dependency. Therefore, it is not surprising that our loved ones want to help us eat and drink. They may be shocked at the thought of not doing so; after all, we all know the discomfort that accompanies hunger and thirst.
- ❑ If a person is unable to swallow or unable to meet his/her caloric needs, artificial nutrition may be seen as a way of improving his/her nutrition, hydration and energy. When a person is nearing the end of his/her life however, artificial nutrition may not achieve these goals

- ❑ Patients and families need to be taught what to expect in the dying process: decreased appetite and dehydration is a normal part of dying. The dying person may not feel the thirst and hunger that would be expected from not eating or drinking. Natural endorphins prevent the dying person from feeling hunger and artificial hydration with IV fluids may not remove thirst.
- ❑ Families can be taught good mouth care which will be more effective in alleviating any sensation of dry mouth and allow them to show caring.
- ❑ As with other treatments, physicians need to discuss with patients and families what is involved in artificial nutrition including the insertion of nasogastric tubes (NG), G (gastric) or J (jejunal) tubes.
- ❑ There is a risk that IV hydration may worsen peripheral edema, ascites, pulmonary edema, and dyspnea especially if patient is already hypoalbuminemic.
- ❑ Patients and families also need to know that NG tubes, G/J tubes may limit the places that are able to care for them in their remaining life. Such tubes may add to the difficulties in caring for them at home and may limit the nursing homes and hospices that will be able to accept them.
- ❑ Some people believe that to withhold or withdraw artificial hydration is euthanasia or assisted suicide since we are dependent on nutrition and hydration to live. However, artificial nutrition and hydration is a medical treatment just like any other and carry burdens just like any other. Withholding and withdrawing such interventions is not done to hasten death but is done in the realization that the burdens may outweigh the benefits.

Withholding/Withdrawing Treatments

- ❑ When a patient is nearing end of life, the burdens of some treatments may outweigh their benefits or treatments may not achieve the desired, anticipated benefits. These treatments can include, among others, antibiotics, artificial nutrition, hydration and life support. Patients and their physicians may decide therefore to either withhold or withdraw these therapies.
- ❑ The intent when treatment is withheld or withdrawn is not to cause or hasten death: these practices are different from euthanasia and assisted suicide.
- ❑ The practices of withholding and withdrawing treatments are deemed to be ethically equivalent and are ethically and legally permissible.
- ❑ A decision to withhold or withdraw certain therapies can occur at any time at the person's request, with changes in his/her goals and priorities (see section on

Quality End-of-Life Care), with deteriorations in his/her health due to either progression of the underlying illness or to unexpected acute illnesses or when health care setting changes from hospital to home, nursing home or hospice.

- As when consenting to treatment, physicians must ensure the patient is capable when deciding to withhold or withdraw treatments. When patients are nearing the end of their lives, they need to understand and appreciate the consequences of withholding and withdrawing the therapies in question, namely that while they may not die, they *are* likely (expected) to die.
- Physicians should make sure the patient is not being coerced or manipulated into withdrawing treatments out of fears of being a burden (financial or otherwise) and that he/she is not acting out of depression (see [Psychological Symptoms Module](#)).

Withholding and Withdrawing Treatments – Things should explain to and discuss with the patient and family:

1. How the treatment(s) will be withdrawn
2. What to expect as treatment(s) are withdrawn
3. What likely course of illness will be *
4. How pain and distress will be treated
5. Where they would like to die: hospital, home or hospice? ***
6. What religious or cultural rituals are important for them to observe/participate in?

* This should include the caution that although death is expected it may not be certain (e.g. a few people survive contrary to all predictions when life support is withdrawn). People also need to know that the timing of death is out of our power as health care providers to control. However, physicians should reassure the patient and family that they will not be abandoned in that they will be kept comfortable for as long as it takes for death to occur.

** This provides an opportunity to discuss 1) level of sedation i.e. is being as awake as possible so important that discomfort can be tolerated? Do religious beliefs mean it is important to be as conscious as possible until death? 2) potential side effects such as drowsiness, nausea and how they will be treated. Many people fear being alone, being abandoned, pain and distress more than death (see [The Last Hours](#), [Pain Management](#) and [Symptom Management](#) modules).

*** Encourage the family to spend as much time with the patient as desired no matter what the setting is. Explore and discuss whether the resources exist to fulfill the desire to die at home or in a hospice and maintain comfort. This is where teamwork

within the medical team and community is crucial. Fulfilling a desire to die at home may take some creative planning and the medical team may need to educate and involve family in administering drugs. However, the inconvenience or the time needed to plan and arrange needed resources are not excuses for failing to attempt to fulfill a dying patient's wish to die at home.

To improve quality of end-of-life care when Rx is withdrawn, document:

1. Patient's medical condition and reasons leading to the withdrawal of treatment in question
2. Goals of ongoing treatment and care
3. The way in which treatment(s) will be withdrawn
4. The way in which pain, symptoms and suffering will be evaluated
5. The ways in which pain and distress will be alleviated: pharmacological and non-pharmacological means, in anticipation of pain and distress or in response to it.
6. The ways any drugs used to alleviate pain and distress will be increased and reasons for increasing doses

Euthanasia/ Assisted Suicide

- ❑ **Euthanasia** is defined as “the deliberate act undertaken by one person with the intention of ending the life of another person in order to relieve that person's suffering where that act is the cause of death” (30)
- ❑ May be:
 1. voluntary: in accordance with the expressed wishes of a capable patient
 2. non-voluntary: when patient's wishes are not known
 3. involuntary: against the wishes of a capable patient
- ❑ Illegal in all its forms under the Canadian Criminal Code which considers such acts murder carrying a minimum sentence of life imprisonment
- ❑ **Assisted suicide:** is “the act of killing oneself with the assistance of another who provides the means, the knowledge or both” (36)
- ❑ Under the Canadian Criminal Code s. 241: everyone who a) counsels a person to commit suicide or b) aids or abets a person to commit suicide, whether suicide ensues or not, is guilty of an indictable offense and liable to imprisonment for a term not exceeding fourteen years
- ❑ **Arguments in favour of legalization:** 1) right to die, 2) mercy and compassion, 3) consistency (those who are healthy enough to commit suicide can without

committing offense, those who are unable to do so without assistance in greater need cannot), 4) gain in trust in the patient-physician relationship (know will provide a way out of unbearable suffering)

- ❑ **Arguments against:** 1) sanctity of life, 2) value of suffering (opportunity for personal growth), 3) violation of the Hippocratic Oath, 4) loss of trust in the patient-physician relationship, 4) abuse of power, 5) cessation of research in palliative care, 5) slippery slope
- ❑ Special Senate Committee 1995 report “*Of Life and Death*” recommended against legalization mainly in response to the slippery slope/abuse argument. However, the Committee also recommended that the different motive (of compassion) should be reflected in the criminal code and these crimes should be prosecuted as 3rd degree murder or compassionate homicide carrying a lesser sentence than life in prison. Criminal code has not yet been revised.
- ❑ Research has shown that people with HIV begin to think about assisted suicide when they experience a sense of loss or disintegration of self. This loss of self is due to a combination of a loss of physical health, and the loss of community (caused by them being seen as “other” because they have HIV and AIDS AND are dying) and ultimately leads them to view assisted death as an option worthy of consideration.
- ❑ Other studies have shown that requests for assisted suicide/euthanasia are driven by fears of being a burden, loss of independence/control, poor pain and symptom control, fears of prolonged dying and fears of technological death



Really a Call to Improve Quality of End-of-Life Care

Ways to respond to requests for assisted suicide/euthanasia in practice

“I understand that you would like me to help you die. Can you tell me why you want me to help you die now? Maybe we can discuss the reasons, issues and concerns that may be leading to this request and discuss other ways of dealing with them.”

“Unfortunately I can’t help you die. I would like to understand what led to this request and discuss if there is anything I can do to make life seem more bearable and worth living.”

“I can see that you are worried and upset. I cannot help you commit suicide or euthanize you but I would like to discuss why you want me to help you die and I would like to discuss other ways we can deal with these issues together.”

References

Quality End-of-Life Care

1. Singer P.A., Martin D.K., Kelner M., Quality End-of-Life Care: Patient's Perspectives, JAMA 1999 281(2): 163-168
2. Singer P.A., MacDonald N., Bioethics for Clinicians 15. Quality End-of-life Care, CMAJ 1998 159:159-162
3. Desbiens N.A., Wu A. W., Broste S. K., Wenger N.S., Connors A.F. Jr., Lynn J., et al.,. The SUPPORT Investigators, Pain and Satisfaction with Pain Control in Seriously Ill Hospitalized Adults: Findings from the SUPPORT Investigators, Crit. Care Med. 1996 vol. 24(12): 1953-1961
3. Coyle N., Adelhart J., Foley K.M., Portenoy P.K.. Character of Terminal Illness in the Advanced Cancer Patient: Pain and Other Symptoms During the Last Four Weeks of Life, J. Pain Sympt Management 1990 vol. 5: 83-93
4. Fainsinger R., Miller MJ, Bruera E., Hanson J., Maceachern T., Symptom Control During the Last Week of Life on a Palliative Care Unit, J. Pall Care 1990.6:3-4

Advance Care Planning

5. Singer P.A., Robertson G., Roy D.J., Bioethics for Clinicians 6. Advance Care Planning, CMAJ 155(2): 1689-1692
6. Singer P.A., Martin D.K., Lavery H. V., Thiel E. C., Kelner M., Mendelsohn D.C., Reconceptualizing Advance Care Planning from the Patient's Perspective, Arch Int Med 1998 158: 879-884
7. Martin D.K., Thiel E.C., Singer P.A., A New Model of Advance Care Planning—Observations from People with HIV, Arch Int. Med 1999 159:86-92
8. Tsevat J., Cook E. F., Green M.L., Matchar D. B., Dawson N.V., Broste S.K. et al. For the SUPPORT Investigators, Health Values of the Seriously Ill, Ann Int Med 1994 122:514-520

Capacity

9. Etchells E., Sharpe G., Elliot C., Singer P. A., Bioethics for Clinicians: 3. Capacity, CMAJ 1996 155: 657-661
10. Appelbaum P.S., Grisso T., Assessing Patients' Capacities to Consent to Treatment, NEJM 1988 319(25): 1635-1638
11. Office of the Public Guardian and Trustee/ Ontario Ministry of the Attorney General, Guidelines for Conducting Assessments of Capacity, Queen's Printer for Ontario, June 1996

Consent and End-of-Life Decision-Making – Capable Patients

12. EPEC Project, Module 1: Advance Care Planning, 1999 Robert Wood Johnson Foundation/ AMA
13. EPEC Project, Module 7: Goals of Care, 1999 Robert Wood Johnson Foundation/ AMA

14. Doukas D.J., McCullough L.B., The Values History: The Evaluation of the Patient's Values and Advance Directives, *J Fam Practice* 1991 32(2):145-153
15. Etchells E., Sharpe G., Walsh P., Williams J.R. Singer P.A.: Bioethics for Clinicians 1. Consent, *CMAJ* 1996 155(2) 177-180
16. Etchells E., Sharpe G., Burgess M.M., Bioethics for Clinicians: 2. Disclosure, *CMAJ* 1996 155(4): 387-391
17. Dickens B. M., The Doctrine of "Informed Consent": Informed Choice in Medical Care, Justice Beyond Orwell Abella R.S. & Rothman M.L. eds. 1985 p. 243-263
18. Etchells E., Sharpe G., Dykeman M.J., Meslin E.M., Singer P.A., Bioethics for Clinicians: 4. Voluntariness, *CMAJ* 1996 155(8): 1083-1086

End-of-Life Decision-Making – Incapable Patients

19. Lazar N.M., Greiner G.G., Robertson G., Singer P.A., Bioethics for Clinicians: 5. Substitute Decision-Making, *CMAJ* 1996 155(10): 1435-1437
20. Drane J.F., Coulehan J.L., The Best Interest Standard: Surrogate Decision Making and Quality of Life, *J. Clin Ethics* 1995 6(1):20-29
21. Lo B., Caring for Patients with Life-Threatening or Terminal Illness, The Medical Interview, Lipkin MJ, Putnam SM, Lazare A. Ed, Springer 1995 p.303- 315
22. Lynn J., Why I Don't Have A Living Will, *Law Medicine & Health Care* 19 (1-2): 101-104
23. Bowman K W, Communication, Negotiation and Mediation—Dealing with Conflict in End-of-Life Decisions, *J Pall Care* Oct. 2000
24. A Guide to End-of-Life Care for Seniors, Fischer R., Ross M.M., MacLean M. Eds, University of Toronto & University of Ottawa 2000

Specific Treatments at the End-of-Life

Life Support and DNR Orders

25. EPEC Project, Module 8: Sudden Illness, 1999 Robert Wood Johnson Foundation/ AMA
26. CMA Policy Summary, Joint Statement on Resuscitative Interventions (Update 1995), *CMAJ* 1995 153(11) 1652A-C
27. Gazelle G., The Slow Code---Should Anyone Rush to Its Defense, *NEJM* 1998 338(7): 467-469

Withholding and Withdrawing Treatments

28. EPEC Project, Module 11: Withholding and Withdrawing Treatment, 1999 Robert Wood Johnson Foundation/ AMA
29. Hawryluck L.A., Consensus Guidelines on the Use of Analgesics and Sedatives in Dying Intensive Care Unit Patients, MSc. Thesis University of Toronto 1999
30. Annas GJ, Do Feeding Tubes have More Rights than patients, *Hastings Centre Repts*, Feb. 1986 26-32
31. Gillick MR, Rethinking the Role of Tube Feeding in Patients with Advanced Dementia, *NEJM* Jan 2000 342(3): 206-210

32. Finucane TE, Christmas C, Travis K, Tube Feeding in Patients with Advanced Dementia, a Review of the Evidence, JAMA 1999 282: 1365-70
33. OBrien LA, Siegert EA, Grisso JA et al., Tube Feeding Preferences among Nursing Home Residents J Gen Int Med 1997 12: 364-371
34. Sullivan RJ jr Accepting Death without Artificial Nutrition or Hydration, J Gen Int Med 1993 8: 220-224

Euthanasia/Assisted Suicide

35. EPEC Project, Module 5: Physician Assisted Suicide, 1999 Robert Wood Johnson Foundation/ AMA
36. Special Senate Committee on Euthanasia and Assisted Suicide, Of Life and Death, Senate of Canada Press, June 1995
37. Lavery J, Losing Yourself to AIDS, The meaning of Euthanasia and Assisted Suicide, PhD Thesis, University of Toronto 1999

Websites Resources

www.utoronto.ca/jcb

www.cme.utoronto.ca/endoflife

www.lastacts.org

<http://rcpsc.medical.org/english/public/bioethics/medicine.htm>

Detailed Case Scenario

Mrs. Linda Scott is a 70-year-old widowed woman with Alzheimer's disease. She worked as a bookkeeper so when she started having problems balancing her checkbook 4 years ago she became concerned and came to visit you. You eventually diagnosed her with Alzheimer's disease. In the last year and a half, her health has continued to deteriorate and while she still lives at home, she requires 24-hour care to help her with activities of daily living. This care is provided by her long-time friend Martha, a 65-year-old woman.

You have been Linda's doctor for the last 10 years. In this time you have come to know her as an extremely independent, intelligent woman. Widowed for 7 years she overcame the grief of her husband's death and eventually developed an extensive circle of friends with whom she would travel across the country. She became very close to one of these friends, Martha Watling, who eventually moved in with her 5 years ago. Linda is extremely well read and you always have lively discussions on topics as wide ranging as philosophy to the latest murder mystery. She has no children. Both of her brothers are dead. Her only family is two cousins who live in the United States who she has not seen for 7 years.

At the time of her diagnosis, Linda told you and Martha that she would "never want to go on a respirator" and, furthermore, did not want "any artificial feeding contraptions inserted" should she come to need them. You have not discussed these decisions with her since.

In the last few days Martha noticed that Linda seems to be having more trouble with her speech and seems to choke when she swallows. When Martha brings her to the hospital, a CT scan is done which shows evidence of a new stroke. After a few days, it becomes evident that Linda's swallowing difficulties are not improving. Furthermore, since the stroke, Linda has not been able to communicate or to understand any information. Martha discusses Linda's previously expressed wishes with the medical team and they agree to make her DNR. The medical team wants to insert a NG but Martha objects.

Martha did have Power of Attorney for Health Care at the time of diagnosis however, she did not feel comfortable fulfilling this role – said that she did not think she "would be strong enough to tell the doctors not to treat Linda". After discussing it with Linda her power of attorney was revoked a year ago and Linda had not found someone to assume this role since then. As her family doctor, you have not had any further discussions with Linda regarding feeding tubes since the time of her diagnosis. Knowing Linda, you do not think she would have changed her mind and you convey your opinion to the team.

Feeling strongly that feeding is a necessary to live, the medical team asks for a bioethics consult. The bioethicist tells them that since Linda expressed these wishes regarding feeding 4 years ago, they may not reflect her current wishes. These, he

feels, are not known since a lot can happen in 4 years. The bioethicist therefore recommends that her family in the United States be contacted and feeding discussed with them. The cousins say that while they have not seen or talked to Linda for 7 years, they do not think she “would want to starve to death.”

Teaching Instructions for Opinion Leaders

Directions for Opinion Leaders:

1. Distribute the case scenario. Allow participants a couple of minutes to read the information or have one of the participants read the scenario
2. Ask participants what issues in end-of-life decision-making are raised in this case scenario and what learning issues they would identify. Write these down on a flip chart, overhead or blackboard
3. The participants should identify a number of issues including:
 - ❑ The importance of discussing expected course of Alzheimer’s
 - ❑ The role and importance of advance care planning
 - ❑ Importance of patient’s goals, values and beliefs, perception of quality of life
 - ❑ What counts as an advance directive (legal standing of expressed wishes as advance directives)
 - ❑ Role of substitute decision-maker and who can act as substitute decision-maker
 - ❑ The use of artificial nutrition and other life-sustaining treatment near the end of life
 - ❑ Role and meaning of DNR orders
 - ❑ The importance of informed consent
 - ❑ The effect of physician’s personal values and beliefs on decision-making
 - ❑ Role of a bioethics consult
 - ❑ What to do if there is conflict between health care providers, health care providers and bioethicist, health care providers and substitute decision-makers
4. Participants should move on to request more background information about her advance care planning and expressed wishes and discuss role of advance care planning, what counts as an advance directive, who can act as substitute decision-maker

TIP: Again it may be useful to ask participants to reflect on their past experiences with substitute decision-makers and advance directives. What did they find helpful? What problems did they encounter: How did they resolve these problems?

5. Ask participants to reflect on the medical team's acceptance of Martha's request that Linda be made DNR and their failure to accept her in role of substitute decision-maker when it came to providing artificial nutrition.

TIP: Ask participants to reflect on the opposite scenario: have they ever had a patient who wanted either to be resuscitated, or to go on life support or to be given any treatment when they, as physicians, thought the benefits of such treatments were very questionable? What happened in these situations?

6. Ask them to comment on the role of bioethics consult and the recommendations of the bioethicist. Was this good advice?
7. Move on to ask how participants would respond to the cousin's comment "Linda would not want to starve to death".
8. Ask participants what they would do now as Linda's doctor. What would they say to Martha? To the team? To the bioethicist?

TIP: Ask participants to reflect on situations in which they have doubts whether the substitute decision-maker was truly expressing the values of the patient. What did they do in these situations?

9. Review the learning issues that have not been dealt with and assign tasks.

APPENDIX I

Aid to Capacity Evaluation (ACE)

1. Disclaimer
2. General Information
3. Instructions for Administration
4. Training Session
5. Form

13 pages attached

<http://www.utoronto.ca/jcb/disclaimers/ace.htm>

Included with the permission of Dr. E. Etchells

Appendix II

Health Care Consent, Substitute Decisions and Advance Care Planning – The Law in Ontario

The law is the framework in which physicians and patients and their substitutes address end-of-life care. The law is not “separate” from the process that takes place. The End-of-Life Decision-Making module describes what needs to be considered in providing good end-of-life care. Much of what is described in this module is “the law” although not so identified as such (i.e., the need to get consent from a patient or a substitute if the patient is not capable, the determination of capacity, the role of advance planning). This section more specifically describes the law that applies to health care consent, substitute decisions, and advance care planning in Ontario. It follows the order of the module and uses the same section headings to assist in relating the law to the appropriate section in the module.

Applicable Legislation:

The legislation that applies to these issues in Ontario is:

- the *Substitute Decisions Act* (“SDA”)
- the *Health Care Consent Act* 9 (“HCCA”)

Both acts are important and together establish a comprehensive scheme for health care consent, substitute decision-making, and advance care planning.

End-of-Life Care and Advance Care Planning

The law confirms that a patient has the right to consent or refuse consent to treatment, as long as he or she is mentally capable in respect to treatment (HCCA S.10). A patient may refuse treatment, even if the treatment would be to his or her benefit, in the opinion of the physician. A patient has no right to insist on treatments that are not medically indicated. A physician has the obligation to offer treatments that would be appropriate for a patient in end-of-life care, using good medical judgment, taking care not to impose the physician’s own values in determining what treatment is offered or not offered to the patient (also see section on Disclosure for consent).

A patient may want help and support from loved ones, family and friends, or the physician and the health team in making a decision about consent to treatment however, the capable patient is the decision-maker (HCCA s.10). The law requires that the capable patient must consent or refuse consent to treatment. If the patient is not capable and the physician must get consent to treatment from a substitute decision-maker, the consent must come from the proper substitute, although the substitute may also seek support or help from other family and friends, or from the physician and/or the health team. (HCCA s.10)

Written advance directives of the patient or wishes about future health treatment, **however expressed** by the patient (orally, by signals, through alternative communication means such as Bliss Boards etc. – HCCA s.5) may guide decision-making by substitutes (long-term or in an emergency- HCCA s.21) or by physicians (in an emergency only – HCCA s.10 and 26).

In Ontario, physicians must get consent to treatment from the capable patient or from his or her proper substitute if the patient is not capable in a non-emergency situation, even if the patient prepared a written advance directive or expressed wishes about treatment by some other means. The wishes and documents “speak” to the substitute, not the physician, except in an emergency. The substitute interprets the advance directive and what the patient meant by such terms as “no extraordinary measures, etc.” or other wording used in the advance directive. In an emergency, the physician that is aware of the wishes or advance directive may follow those wishes/advance directives in determining the emergency treatment to be delivered.

Substitutes can only **consent** or **refuse consent** to treatments. They cannot give an Advance Directive. (See section on Written Advance Directives below.)

The law confirms the importance of physicians having good communication with patients and their possible substitute decision-maker(s) on the patient’s values and beliefs, fears, and on what is important for quality of life to determine the patient’s wishes in respect to treatment. This communication will enable the physician to respect the wishes in an emergency situation as well as in situations where there is time to obtain consent.

Discussions with the patient will also help the physician determine who is the proper substitute decision-maker in the event that the patient becomes incapable in respect to treatment. The *Health Care Consent Act* contains a list of substitute decision-makers in order of priority – HCCA s.20 (see section on Substitutes below) that must be followed if the patient becomes incapable.

Capacity

The *Health Care Consent Act* confirms that the health practitioner offering the treatment is the person that must determine whether the patient is capable in respect to treatment (HCCA s.10). A patient is capable of making treatment decisions if the patient is able to understand the nature of the decision and can appreciate the reasonably foreseeable consequences of the decision or lack of decision. No specific test to assess capacity as defined in this legal definition is prescribed in the legislation. Note that the MMSE does not assess judgment or reasoning which are elements of the legal definition of capacity therefore a low score on the MMSE alone is not sufficient to assess capacity in this context.

If you, as the patient's health practitioner are uncertain about the patient's capacity, you can get assistance in this determination from other health practitioners and other people; however, the legislation requires that you come to an opinion of the patient's capacity to consent or refuse consent to treatment. You can adopt the opinion of others; however, the health practitioner that offers the treatment is responsible for the opinion about capacity determination. (s.10 HCCA).

If you find that a patient is not mentally capable to consent to treatment, you must follow the guidelines of the College of Physicians and Surgeons of Ontario in informing the patient of this finding of incapacity and the consequences of the finding. This would include the patient's right to challenge the finding of incapacity before the Consent and Capacity Board (HCCA s. 17)

If you find that the patient is not capable of consenting to treatment, you must turn to the patient's proper substitute decision-maker, as defined by the *Health Care Consent Act* (HCCA s.10 and 20).

If you find the person incapable, you cannot begin treatment, even with the substitute's consent, if you are informed that the patient intends or has applied to the Consent and Capacity Board for a review of the incapacity finding. Also you cannot begin treatment if you are informed that the patient or someone else intends or has applied to the Consent and Capacity Board (CCB) for an appointment of a "representative" for the patient. A "representative" is a type of substitute decision-maker in the list in section 20 of the HCCA.

In these circumstances, you can begin treatment if:

- a. 48 hours have elapsed since you were first informed that the intended application to the CCB was to be made and was not filed
- b. The application to the CCB has been withdrawn
- c. The CCB has rendered a decision and no one has informed you that they intend to appeal the decision of the CCB
- d. If someone has informed you that they intend to appeal the decision of the CCB and then 48 hours have passed since you were informed of the intent to appeal and no appeal has been started or the appeal of the Board's decision has been finally disposed of

Note that the requirement to delay treatment in the above circumstances does not apply if there is an emergency and need for treatment.

End-of-Life Decision-Making with Capable Patients

The law does not require that end-of-life decisions or any wishes expressed about end-of-life care need to be written into an advance directive form that is signed by the patient. The wishes and decisions may be documented in any appropriate way in the chart, in other formats, etc. The patient does not have to sign a written advance directive or consent – oral expression of wishes and oral consent is sufficient. Even

if wishes about treatment are documented in a form that the patient signs, the patient can change his or her wishes by communication in any form – orally, in writing, by alternative forms of communication (Bliss Boards) etc. The change does not have to be written in a new advance directive or consent.

Consent

A signed consent form is not required in law and, alone, does not satisfy the requirement in law to get an informed consent before giving treatment. A written consent that does not meet the other criteria necessary to a proper consent – capable, voluntary, informed, obtained without fraud or misrepresentation – will not be a valid consent. A consent may be oral and still meet the legal requirements.

Note that an advance directive is **not** a consent. It is only an expression of wishes for future treatment. This is one of the reasons that the “wishes” speak to the substitute and not the physician as the physician must still get proper consent from a capable patient or from his or her substitute decision-maker if incapable even if an advance directive exists.

A patient (or substitute where appropriate) may consent to a **plan** of Treatment that does contain wishes for withholding or withdrawal of treatment **but** the plan, and the wishes so expressed about withdrawal and withholding of treatment, must relate to the health problems that the person has or is likely to have in the future given the person’s **current** health condition (HCCA s.1). Note that the consent for the plan for present and future treatment must relate to the person’s current health condition and cannot be broadly expressed.

An advance directive, in contrast, may be broadly expressed and may include wishes about treatments, or withholding or withdrawing treatment that would ordinarily not be necessarily related to a patient’s present health condition.

Note that only the patient can prepare an advance directive. A substitute cannot. Advance directives are wishes and only patients can express wishes for themselves. Substitutes only provide **consents** or refusals of consents and may consent to a plan of care that includes consent to some future treatments (and withdrawal and withholding of treatments) only if those treatments relate to the patient’s present health condition.

DNR Orders

As DNR orders are considered in law as an “advance directive”, substitutes, including the Public Guardian and Trustee, cannot “consent” to such an order, only the patient can express this wish. However, it is still important to discuss this matter with substitutes if the patient is not capable so that they are aware of what this means and will not misinterpret what is being done.

End-of-Life Decision-Making When the Patient is Incapable/Substitute Decision-Makers

Families and Loved Ones as Substitute Decision-Makers

In Ontario, a person aged 16 or older may prepare a Power of Attorney for Personal Care (equivalent to a Durable Power of Attorney for Health Decisions referred to in the module). In that document, the person may appoint an “attorney”, who will act as his or her substitute decision-maker for not only health care, but all other personal care decisions (decisions about shelter, hygiene, safety, nutrition, and clothing). If the patient has prepared such a document, and it is valid and has not been revoked, the person named as attorney is usually the person’s health care decision-maker if the patient becomes incapable for this purpose. One major exception to this is if the patient has a **guardian** with authority to make treatment decisions. This is a person that is appointed as substitute for the patient by the court.

In Ontario, if the patient is not capable for treatment, the physician must obtain substitute consent or refusal of consent from the person in the patient’s life that is highest in priority in the following list, as long as they meet the requirements to be a substitute:

- a. The Guardian of the Person with authority for health treatment decision-making (this person will be appointed through a Court Order)
- b. The attorney for **personal care**. Note that there may be more than one person appointed as attorney in the same power of attorney for personal care. If the person’s are appointed **jointly**, then they must give or refuse consent together. If they are appointed **jointly and severally**, then they can act together or one of them alone may give or refuse consent. Note as well that in Ontario there are two kinds of Power of attorney, this type and the Continuing Power of Attorney for Property. The attorney appointed in a Continuing Power of Attorney for Property has no authority as an attorney for treatment decisions.
- c. The patient’s representative – this is a person appointed by an order of the Consent and Capacity Board to be a substitute for the patient. Either the patient can ask the board to appoint a representative for him or her or someone can apply to become the patient’s representative.
- d. The patient’s spouse or partner. A spouse is a person of opposite sex to the patient to whom he or she is married or who have been living together in a conjugal relationship outside marriage for at least one year or are together the parents of a child or have entered into a cohabitation agreement. A person is not a spouse if the patient and the “spouse” are living separate and apart within the meaning of the Divorce Act. A partner is a person with whom the patient has lived together for at least one year and their relationship is close and personal and of primary importance in both persons’ lives. This can include a same sex partner as well as two friends that have formed a platonic important bond and that reside in the same premises.

- e. A child or parent of the incapable person or the Children's Aid Society or other person lawfully entitled to give or refuse consent in place of the parent. This does not include a parent who only has right of access.
- f. A parent who only has right of access.
- g. A brother or sister
- h. Any other relative
- i. The Public Guardian and Trustee (HCCA s. 20)

A person in the above list may give or refuse consent as substitute for the patient only if he or she meets the following requirements:

- a. The substitute is capable
- b. The substitute is at least 16 years old unless he or she is the patient's parent
- c. The substitute is not prohibited by court order or separation agreement from giving or refusing consent for the patient
- d. The substitute is available. This means that he or she may be contacted in a reasonable time, considering the needs of the patient.
- e. The substitute is willing to assume the responsibility as acting as substitute for the patient. A possible substitute may decline to act and the physician then may proceed to obtain consent or refusal of consent from the next person in priority.

If there is more than one person at the same priority ranking that meet the requirements to be a substitute, such as more than one child (son and daughter), all persons at that same ranking have the same right to be the patient's substitute. They must decide amongst themselves if one of them will act as substitute or they must concur on whether to give or refuse consent. The physician cannot choose amongst them. They must do this. If there is conflict and they refuse to select one person and they all want to act and/or they do not concur in the decision, the physician may turn to the Public Guardian and Trustee for the decision. The physician does not go to the next person down in the ranking.

When making decisions for the patient the substitute must give or refuse consent in accordance with any wishes expressed by the patient when still capable that are applicable to the particular decision to be made. If the substitute does not know of any wishes that apply, then the substitute must make decisions that are in the best interest of the patient. The *Health Care Consent Act* contains a detailed explanation of what the "best interests" means in section 21(2).

The health team may and should advise the substitute what is considered to be in the patient's best interests, but it is the substitute that ultimately has the responsibility of making this decision. The health team should work as much as possible as a team with the substitute, although the law does put the final responsibility on the substitute for the decision-making.

Intra-Family Conflict

If a person is estranged from his/her family, under Ontario law, he or she, while capable, can appoint a friend as his/her attorney for personal care in a Power of Attorney for Personal Care. Also, if the patient should become incapable before preparing a Power of Attorney for Personal Care, then the friend can apply to the Consent and Capacity Board to be appointed as the patient's representative. A representative ranks higher than the patient's family members as a substitute decision-maker. It is also possible for the patient, although incapable, to ask the board to appoint his or her friend as his/her representative. The Public Guardian and Trustee in Ontario will not assume the role of treatment decision-maker for the patient unless there is no person in the patient's life ranking higher than the OPGT on the list in the *Health Care Consent Act* that is available and willing to act as the patient's substitute decision-maker. The patient's family, although higher ranking in the list, may choose to not act as substitute and the Public Guardian and Trustee can then act as treatment decision-maker.

Written Advance Directives/Living Wills

In Ontario, a person may prepare a Power of Attorney for Personal Care in which he/she names an attorney, a person to act as a substitute decision-maker for health and other personal care decisions. In that document, the person may include any wishes about treatment. This section on wishes is sometimes called the "advance directive" portion of the document. As well, a person may express their wishes about treatment in any other way – in writing, orally, through alternative communication means (i.e. Bliss Boards, etc). If expressed in writing, this document is often called an advance directive or living will. That document need not name a substitute.

There is no reference to the term "advance directive" or "living will" in the Ontario legislation however as the *Health Care Consent Act* states that a person may express wishes in any form, this type of document is a valid expression of wishes.

For a written document to give authority to appoint a substitute decision-maker as recognized in the hierarchy in the *Health Care Consent Act*, the document **must** be a Power of Attorney for Personal Care and not just an "advance directive". It does not need to be called a Power of Attorney for Personal Care on its face but it must meet the technical requirements to be a Power of Attorney for Personal Care (see below).

Just because a document is not called a Power of Attorney for Personal Care, that does not change the status of the document to something other than a Power of Attorney for Personal Care if it meets the technical requirements to be one. Likewise, if it does not meet the technical requirements for a Power of Attorney for Personal Care, the document called the advance directive will not be successful in giving authority to the person named in it to be the substitute decision-maker for the patient.

What is a Power of Attorney for Personal Care?

A Power of Attorney for Personal Care

- ❑ names a substitute decision-maker (an attorney)
- ❑ may contain directions and wishes about future health care/treatment/anything else related to “personal care”
- ❑ must be witnessed by 2 witnesses
- ❑ **must be in writing**

The grantor (the person who gives it) must

- ❑ be capable at the time of signature to make a Power of Attorney for Personal Care (see *Substitute Decisions Act* for specific definition of capacity to give a power of attorney for personal care)
- ❑ be capable for any particular matter on which he or she has included directions or wishes in the Power of Attorney for Personal Care
- ❑ be age 16 or over

Who can create a Power of Attorney for Personal Care? **Only** an individual may create a Power of Attorney for Personal Care for him or herself. A family member or a substitute decision-maker **cannot** prepare a power of attorney for personal care on behalf of another person, whether that person is capable or incapable.

Who can create an advance directive? **Only** an individual may create an advance directive for him or herself. A family member or a substitute decision-maker **cannot** prepare an advance directive on behalf of another person, whether that person is capable or incapable. Substitutes can consent to **treatment or care** plans that relate to the patient's current medical condition only, not a written advance directive.

Who can be named as the attorney for personal care? A patient cannot name a health care practitioner or the health team or anyone else that provides him or her with health care (or residential, social, training, or support services) as his or her SDM in a Power of Attorney for Personal Care unless that person is the patient's spouse, partner, or relative (SDA s. 46(3)). Likewise, unless a particular health practitioner is one of the persons in the patient's life listed in the hierarchy of substitute decision-makers in the *Health Care Consent Act*, the health practitioner cannot act as the patient's substitute.

Who interprets the wishes in the patient's Power of Attorney for Personal Care or advance directive? The patient's substitute interprets the POAPC/advance directive/oral wishes and how it applies to the treatment for which the physician is seeking consent or refusal of consent **not** the health practitioner except in an emergency. In an emergency, the health practitioner may follow the last capable wishes of the patient expressed in any form that he or she is aware of. If he or she knows of **oral** wishes that are different than what is in the written advance directive, then he or she must honour the last capable oral wishes.

A patient may revoke a POAPC by execution of a revocation (a document in writing that must be witnessed by two witnesses and meet the same technical requirements as a Power of Attorney for Personal Care). Also, if the patient executes a new Power of Attorney for Personal Care, and that second Power of Attorney for Personal Care does not specify that the patient wishes to have multiple Powers of Attorney for Personal Care, the first Power of Attorney for Personal Care is revoked on execution of the second POAPC.

However, if the patient has expressed wishes about personal care (including health care) in the Power of Attorney for Personal Care, the patient does not need to execute a formal revocation to change those wishes. As the *Health Care Consent Act* states that the patient can express wishes about health care in writing, orally, or by alternative means, the patient **may simply change the wishes orally** without changing the written document. Last capable wishes override previous wishes however expressed. Of course, the patient may want to change the written document if he or she is able to in order to avoid any confusion, however no formal process is necessary for the later wishes not written into the document to be honoured

Preparation of a Power of Attorney for Personal Care or an advance directive cannot be required as a condition of admission to any hospital or long-term care facility or other health facility in Ontario. Although hospitals and health facilities may create policies about written advance directives, unless the policy is in accordance with the law the policy is not legal and does not need to be followed by patients.

Policies of facilities cannot require that patients execute a particular form of advance directive or communicate their wishes about future health care in writing only. It must be recognized that some people do not want to create an advance directive. It may not be culturally appropriate or fit into their personal system of beliefs. That is one of the reasons that the Ontario legislation was drafted to ensure that everyone in the province had a substitute decision-maker. A substitute decision-making system ensures that physicians and other health care practitioners always have someone to turn to get a consent or refusal of consent to treatment in the event that the patient is unable to communicate his or her wishes or is not mentally capable to give or refuse consent to treatment.

There are many kits and booklets on advance directives available in Ontario. Many contain misinformation about the Ontario law and may be more confusing than helpful. The *Living Will Booklet* from the Joint Centre for Bioethics at the University of Toronto accurately describes the law and complies with Ontario legislation. Many lawyers will also assist patients in preparing Powers of Attorney for Personal Care and advance directives.

The Ontario law supports the importance of good communication between the physician and the patient and his/her substitute about end-of-life care and decisions. This is one of the reasons that advance directives/living wills were not given

particular status in the legislation and are treated as just one way that patients may express wishes. It is the “wishes” of patients for health care that are key – and these wishes may be expressed in any way through any form of communication.