



COMMON ETHICAL PRINCIPLES:

- ◆ **Respect for autonomy:** This principle entails accepting the resident's right to make decisions for the conduct of life and also acting on that respect. It also means treating the resident with respect and dignity.
- ◆ **Non-maleficence:** With a resident who is dying, this principle to not inflict harm intentionally might require that painful medical tests not be carried out, since there may be no chance of benefit for the resident.
- ◆ **Beneficence:** Treatment must have some potential to help the resident, and health care providers are morally obligated to provide such care.
- ◆ **Justice:** Health care professionals must treat residents equitably and fairly.

It is not acceptable to decide who receives a scarce resource on the basis of characteristics such as gender, etc.

Although these principles are useful when making treatment and other decisions, invoking them often does not solve complex ethical dilemmas. Sometimes the principles may conflict and sometimes it is not clear which principle is the most important in a situation. If these concerns arise then the best approach to deal with ethical dilemmas a case-based approach is favoured.

This suggests that ethical analysis must make sense in the real world rather than being based solely on abstract concepts.

- ◆ The context of a situation and the relationships of the various parties involved must be adequately considered for a proper decision to be made.
- ◆ Individuals are seen as unique, while at the same time belonging to a community of people.
- ◆ Equal rights and opportunities for women as well as men must be available within society.

INFORMATION DISCLOSURE – TELLING THE TRUTH

It is difficult decision to know what to tell a resident who has a terminal illness – how to communicate “bad news”? Until recently, health care providers often felt that their duty of non-maleficence meant that they should not give a resident very bad news. However, this viewpoint has changed.

Knowledge allows residents to participate in autonomous choices about care-related options. This knowledge may help the resident to think about how to spend the latter part of life. Residents have a right to:

- ◆ Accurate information concerning diagnosis, prognosis, treatment
- ◆ Treatment alternatives, risks and benefits and help to understand the implications of that information
- ◆ Information provided in a timely, compassionate manner
- ◆ Information even if they have not directly asked for it (Not disclosing certain information may be considered ethically as no different from lying)

There are some potential qualifications to the statements noted above:

- ◆ If the resident indicates that he/she does not want to know, this should be respected. However, it is not enough to assume the resident does not want to know.
- ◆ If the health care providers reasonably believe that disclosing it would cause substantial harm to the resident.

FAMILY REQUESTS FOR NONDISCLOSURE OF INFORMATION

Sometimes a family member requests that the resident not be told certain information, often because of an honest belief that the loved one will be harmed by the knowledge. It is necessary then to explore the basis for the request:

- ◆ Does the family know how the resident dealt with bad news in the past?
- ◆ Is the family having difficulty facing the prospect of their loved one’s death?
- ◆ Are they afraid that the resident will become worse or ‘give up’ if the truth is revealed?

Understanding the motivations can help the health care providers work with the family and the resident. However, the family’s request does not change the health care provider’s obligation to be truthful with the resident unless, for example, the resident has clearly indicated that he/she wants information to be communicated only to the family.

PROMOTING INFORMED CONSENT

Informed consent requires that the resident has sufficient information to understand what is involved in the decision, understands that information, and makes a decision freely, based on personal values and wishes. The obligation to obtain informed consent for health care is important and is a legal requirement for many types of health care interventions in Canada.

SUBSTITUTE DECISION-MAKING

There are times when a resident will not be capable of making a decision about health care. At this point, it will be necessary to call upon a substitute to make such decisions. A substitute decision-maker:

- ◆ Needs the same elements of informed consent as the resident
- ◆ Has the same right to information and understanding as the resident
- ◆ May be chosen through the hierarchy of decision-maker according to Provincial Legislation

There are some guidelines for substitute decision-makers to use when making health care decisions:

- ◆ Carry out the resident's wishes if these are known. The individual may have expressed the wishes in a variety of ways, which could include discussions with the substitute or written advance directive.
- ◆ When the resident has not clearly expressed preferred wishes that are applicable to the clinical situation, the substitute can rely on the values held by the individual, and on opinions on the topic that he/she may have previously expressed.
- ◆ In the absence of knowing what the resident would want in the situation, the substitute should act in his/her 'best interest' by:
 - taking all of the factors about the resident's condition and treatment alternatives into account along with the known or assumed values and attitudes of the resident
 - accepting that they are not being asked to make decisions on their personal values but, rather, what appears to be the preference or appropriate choice for the resident.

CAPACITY AND ASSESSMENT

The cornerstone of respect for autonomy is translated into honouring the resident's right to make personal health care decisions, and supporting the decision whether or not we agree with those decisions. The determination as to when to remove decision-making authority is an ethical as well as legal task. Health care providers are often faced with such decisions when they are caring our residents.

In order to be capable of making health care decisions, a person must be able to "understand information relevant to a treatment decision and appreciate the reasonably foreseeable consequences of a decision or lack of decision".

GLOBAL VERSUS SPECIFIC ACCOUNTS OF CAPACITY

The traditional understanding of incapacity, of 'global incapacity', was that once a person was declared incompetent, decision-making authority was removed forever, or until such time as the condition causing it was reversed. Today there is a new understanding of what it means to be incapable (incompetent). This is the concept of "specific" incapacity, which means that decision-making authority is removed from a person only for those situations in which the capacity is compromised.

- ◆ A resident may not be able to make a decision concerning a treatment that requires a complex risk-benefit explanation, but may be capable of making a decision about a simpler type of treatment, especially one which has occurred previously.
- ◆ A resident may not be able to make a decision about a specific treatment, but may be capable of designating the surrogate who should make the decision.

PRESUMPTION OF CAPACITY

Given this contemporary understanding of capacity, the first principle of determining a resident's ability to make a decision is the presumption of capacity.

- ◆ It is not enough to base the assumption of incapacity on a diagnosis classification of Alzheimer Disease.
- ◆ The resident must be able to communicate in some fashion his/her preferences that would be expected to be reasonably stable over time.

ASSESSMENTS OF CAPACITY

The assessment of capacity must relate to the specific decision that needs to be made. While standard tests of cognitive ability are useful in a comprehensive assessment of a resident, they may not be sufficient to determine whether the older person is capable of making a given decision. The assessment should determine whether the resident:

- ◆ Understands the nature of the decision to be made and the information relevant to it
- ◆ Appreciates the consequences of the choices he/she makes

It is the responsibility of the assessor with the help of those caring for the resident to be sure that the assessment is as fair as possible. In order to provide conditions that will give the resident the best chance of succeeding, one should:

- ◆ Provided a test that is meaningful to the decision, individualized and realistic
- ◆ Choose a time(s), location, and an assessor the resident is comfortable with
- ◆ Use communication techniques that enhances the ability of the resident to understand the assessment

FLUCTUATION IN CAPACITY

A resident capacity to make decisions may fluctuate over time or as medical conditions changes.

- ◆ A resident whose competency fluctuates is not necessarily unable to make decisions.
- ◆ If during lucid moments, the resident is able to communicate stable preferences, this may be taken as a valid expression of a capable preference or decision.

CAPACITY AND ADVANCE CARE PLANNING

Although a resident must be capable when an advance directive or power of attorney is executed, this does not mean that the resident's current wishes or attitudes do need to be considered. An advance directive or durable power of attorney for personal care does not come into effect until the resident is incapable of making the type of decisions covered in the document.

CONFIDENTIALITY: PROTECTING HEALTH RECORDS OF RESIDENTS

In the process of receiving health care, residents are asked to reveal information about themselves that they might not share with anyone else. Confidentiality:

- ◆ Is expected by the health care providers who have a duty to treat this information with respect and is stipulated by virtually all health care providers' Codes of Ethics
- ◆ Means sharing the resident's information only with those who are involved in the care of the individual and who have a need to know

Keeping information confidential is a way of respecting a resident's autonomy; the individual retains control over what happens to the information. It also promotes mutual trust and communication between health care providers and residents.

An ethical dilemma occurs when a resident asks a health care provider to promise not to reveal something discussed to other health care providers that may be necessary for proper care. This can often be dealt with by discussing ahead of time the limits of confidentiality.

Methods to protect confidentiality included:

- ◆ Providing private areas for residents to discuss with health care providers
- ◆ Keeping health records in a secure area such as the nursing station or supervisors office
- ◆ Refrain from discussing resident information in public areas such as the hall or the diningroom
- ◆ Keeping bulletin boards containing resident information out of public view
- ◆ Consulting with others, including the resident, when there is a question about the appropriateness of sharing information
- ◆ All staff and volunteers are to complete and review a confidentiality agreement on commencement of employment and at performance appraisal

There are times when it is permissible, even obligatory, to breach confidentiality. These situations usually occur when there is an unacceptable risk of harm to the resident or someone else, and include:

- ◆ Certain communicable diseases that must be reported by law to the authorities
- ◆ A medical condition such as a mental illness that may result in personal harm or harm to others; such information may be revealed to police if necessary for proper care, safety and public protection
- ◆ A reasonable suspicion of elder abuse; such cases must be reported to police and the Ministry of Health

Respecting Privacy

It can be difficult to keep information from the resident's family, but unless the resident gives permission (**Release of Information Form**) it is not acceptable to discuss the individual's condition with family members. It cannot be assumed that because someone is older, family members are the primary avenue of communication about the resident's condition. The relationship and lines of communication should be established early in the relationship between the health care provider and the resident.

Access to Records

The Supreme Court of Canada has enshrined the rights of residents to have access to their health records. The information is the resident's even if the actual document belongs to the Nursing Home. This confirms the concept that the provision of information is part of the trusting relationship between health care provider and resident.

ETHICAL ISSUES IN PAIN CONTROL

Health care providers may disagree about the amount of analgesic medication that should be given, leaving them feeling that they are not able to meet the palliative goal of maintaining comfort, or in contrast that they are hastening the resident's death.

- ◆ It is important to realize that it is ethically acceptable or even obligatory to provide, at the resident's request, pain relief that may also, as a consequence of the medication's other effects, shorten the resident's life.
- ◆ It is also important to realize that some residents could choose to have a certain level of pain in order to avoid sedation

Substitute decision-Makers

When a substitute decision-maker is making decisions about pain relief, there may be conflict between that person and the health care team about appropriate scheduling or amounts of medication. A process to follow this situation would include:

- ◆ Exploring the reasoning for the substitute decision-maker's decisions and explaining the health care provider's concerns
- ◆ Following up on the substitute decision-maker's reasoning or concerns. Is the substitute having difficulty dealing with the impending death of the resident? What would the resident want?
- ◆ Determining whether the health care provider believes that the substitute decision-maker is neither acting on the request of the resident nor in the resident's best interests. If so, outside help (e.g., legal intervention) may be considered.

ADDRESSING ETHICAL CONFLICTS

Participants in Conflict

Many issues may result in conflict in the provision of care. While it is not necessary for everyone to agree on all points in order to work together, it is important to respect others' points of view and to take them into account when treatment goals and a plan of care is decided upon.

Disputes between Resident/Family and Health Care Providers

There may be several reasons for differences between what residents or family members and health care providers see as appropriate treatment or goals of care. Open communication is the key to resolution. While it may be tempting for health care providers to use the authority they possess to convince the resident or family of the provider's point of view, being aware of one's own inherent authority in the situation can be the first step to avoiding its abuse.

Disputes within Health Care Teams

It is in the nature of teamwork that differences of opinion about the "right" course of action will occur. There can also be significant disputes between members, which require resolution. In these instances, the issue becomes how these differences are addressed:

- ◆ Are minority views listened to and considered?
- ◆ What support is there for a team member who cannot in conscience take part in a decision that has been made?
- ◆ For the individual, is the decision one that can be accepted even though it does not coincide with personal beliefs? If not, what is the next course of action?

This could include meeting again with the team, consulting outside experts being reassigned or resigning in an extreme case. If the team member believes that a resident is being harmed by the decision, this may mean a whole other set of actions from notifying the administrator to taking legal action.

When there are differences within the health care team, the members must decide how this will be presented to the resident and/or family. The differences among team members should be presented in a way that is understandable to the resident. Acknowledging disagreement in the team can often leave the resident or family feeling better able to express their own conflicts and sources of concern.

Professional Advisory Committee

This committee is available to provide help in situations where the resolution of a dilemma has not been achieved. This committee is made up of a number of disciplines for consultation purposes. Their role may include:

- ◆ Assisting in the definition and clarification of the issues
- ◆ Identifying options
- ◆ Making recommendations or suggestions as to how a dilemma might be resolved

After consultation with the Professional Advisory Committee, the Health Care Team will abide by the wishes of the resident/family. This is the route to ensure resident and family is making an informed decision. We will respect the resident and/or family's wishes.

Every health care provider caring for residents face ethical issues daily. The issues often revolve around the tension between respecting the autonomy of residents and acting beneficently toward them, i.e., in a way that we consider to be in their best interest. By understanding our own values, and those of the people around us, we can recognize and deal with the ethical dimension that is inherent in the practice of health care.

Seniors are important, integral and vital participants of Canadian society. Health care providers need to assure seniors that their enormous value is uppermost when their care is undertaken. The legacy of strength, experience and wisdom that resides in this population is important and the ethical issues that surround the care of our residents must always be taken into consideration, especially when dealing with the difficult issues.



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Ethical Decision-Making Worksheet

The decision-making worksheet is a step-by-step tool to guide staff through the process of resolving an ethical issues. The worksheet takes into account the facts, emotions, ethical principles, various alternatives and their potential consequences, and the evaluation of the outcomes:

1. Identify the facts
2. Determine the ethical principles in conflict
3. Explore the options
4. Act on the decision and evaluate

Step :1 Identify the Facts

Gather information/facts on the case

Re-state the details of the case. What are the main issues or areas of concerns/tension? Who are the individuals involved/who else needs to be involved? How does the resident's history/prognosis affect this case? Are there other factors to consider, including organizational policies, directives and regulations?

Reflect on the different emotions

Reflect on the emotions of 1) the resident, 2) family/others and 3) you. Examine the emotional factors influencing each individual, such as existing feelings, values, biases and prior experiences. **Ask yourself:** How do I feel about this particular resident/family? How are my life experiences influencing my reaction? What are the family/cultural/societal traditions and customs that are influencing my reaction?

Step 2: Determine the Ethical Principles in Conflict

Identify ethical issues (i.e. what ethical principles are in conflict?)

Principle	Explain the Issue

Step 3: Explore Options

Explore options and consider their strengths and weaknesses

Brainstorm and discuss options either alone or with peer at Professional Advisory Meetings. Be creative and use your imagination. Consider a compromise. Predict the outcomes for each alternative. Does the alternative fit with the resident/family values? Question whether the alternative meets the organizational policies, directives and Regulations.

Option	Strengths	Weaknesses

Step 4: Act on Your Decision and Evaluate

Develop an action Plan (Note: the actual plan should be documented in the chart)
Given all the information that you have, choose the best option available. Develop an action plan. Present your suggested alternative and action plan to the resident and those involved in such a way that it allows them to accept the plan. Re-examine the alternatives of other factors come to light, if the situation changes, or if an agreement cannot be reached. Determine when to evaluate the plan. Document and communicate the plan

Step 4: Continued

Evaluate the plan

What was the outcome of the plan? Are changes necessary? Document the evaluation

Self-evaluate you decision

How do you feel about the decision and the outcome? What would you do differently next time? What would you do the same? What have you learned about yourself? What have you learned about this decision-making process?