

Baycrest

Enriching Care
Enhancing Knowledge
Enlightening Minds

Ethics At Baycrest

A Guide to
Ethical Values and Commitments of
Baycrest
Toronto, Ontario

Third Edition
July, 2006

*Dedicated to the Memory of former
Ethics Committee Member, Frankie Rosenfield.
Her sensitivity, generosity, compassion
and humility helped light our way.*

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Foreword

The Clinical Ethics Committee of Baycrest has attempted to bring together statements of values and practice relating to key ethical issues faced by clients, families and health care professionals of Baycrest. By expressing the philosophy and principles underlying current practice, it is hoped that this document will be a useful resource when making ethical decisions about important issues.

This guide begins with the foundation--the statements of ethics of care, life at Baycrest, and principles of ethical decision-making--and proceeds to discuss issues concerning living wills, cardiopulmonary resuscitation, and instructions about treatment. The following topics--transfer, nutrition, safety, medication and research--will be of interest to all and may involve ethical dilemmas should the need for decisions in these areas arise. The last section contains a brief outline of the role of the Clinical Ethics Committee as a resource on ethics. Included in their totality as appendices are six important documents: An ethical perspective regarding provision of health care to Holocaust Survivors; Clients' Rights and Responsibilities; Priority Setting; Ethical Principles for Nutrition and Hydration; and a list of companion documents referred to in this guide which have been published by Baycrest.

A word about language. The term *client* is used to refer to individuals receiving Baycrest services, whether they live in any of our residential settings or in their own homes. *Clients residing in Baycrest* includes continuing care patients in Baycrest Hospital. A *substitute decision maker* is the person who has the responsibility to give consent or make decisions for another person who is not capable of doing so, either temporarily or permanently. The substitute decision maker may obtain this power formally through a Power of Attorney for Personal Care, or informally (see the discussion in the section on living wills). In either case, the substitute decision maker must act, whenever possible, according to the client's known wishes.

Questions about the issues discussed in this guide or any other ethical dilemmas related to care provided at Baycrest should be addressed to members of the health care team or to:

The Chair of the Clinical Ethics Committee
Baycrest Centre for Geriatric Care
3560 Bathurst Street
North York, Ontario
M6A 2E1

Ethics of Care: Baycrest's Mission*

The mission of Baycrest is to enrich the quality of life of the elderly, guided always by the principles of Judaism

In addition to providing a comprehensive range of specialized services for the elderly, we also support and educate families, conduct research into aging, teach students and professional trainees, and help educate those who care for the elderly.

Baycrest plays a lead role in promoting the interests of the elderly, advocating for health and social service policy that values the elderly and recognizes their needs.

Baycrest's concept of care embraces the health, wellbeing and dignity of the individual, and serves physical, emotional, social and spiritual needs. All care is designed to meet the unique requirements of the individual and the family, and is guided by the values and principles of Judaism.

Baycrest supports staff in their effort to provide better care by providing an environment that encourages learning, innovation and personal development.

Fundamental to Baycrest is a partnership between the community, staff, volunteers and the individuals and families we serve within the Greater Toronto area.

Values and Operating Principles

As individuals and as an organization, we are committed to the following values as they reflect the Baycrest Mission and Philosophy. They guide all our endeavors, decisions and the way we relate with clients, families, staff, volunteers, donors, colleagues, and the community. We use them to set priorities and allocate our resources:

- Compassion and caring
- Social responsibility
- Respect for the uniqueness, dignity, and worth of human beings
- Ethics and competence
- Volunteerism
- Innovation and learning
- Community
- Excellence
- Advocacy for the needs of the elderly

* Abridged from Baycrest , "Statement of Values and Operating Principles"

Life at Baycrest

Personalized care, the dignity of the individual and the spirit of Jewish life are what make Baycrest.

Older adults who require assistance to help them live in the community or who can no longer live independently will find a warm, caring environment where the approach to care is focused on the whole person. Nurses, social workers, physicians, therapeutic recreationists, rehabilitation staff, other health care professionals, volunteers and support staff work as a team, providing health care and cultural, religious and social programs that improve our clients' quality of life. Care plans are designed to maximize the individual strengths of each client and family and encourage autonomy.

Clients are encouraged to participate in a wide variety of recreational, social and educational programs geared to their physical and cognitive abilities and interests. Client Councils guided by a formal Bill of Rights (Appendix II) allow clients to become involved in decisions affecting their life at Baycrest.

Families are encouraged to participate actively in the clients' life. Family Advisory Councils and family groups meet regularly to discuss concerns and contribute ideas regarding programming and care.

The client is the primary decision maker, whenever possible. Families need to understand that the client's wishes will always be considered paramount in any decision-making. When clients are impaired for physical or psychological reasons, the substitute decision maker, either in the form of the family or the client's legal representative will be responsible for decisions.

Jewish Values and Traditions at Baycrest

Everything Baycrest does is predicated on the Jewish principle of respect for elders and for one's parents. That is why Baycrest has set standards that guide behaviour and day-to-day decision-making while ensuring this important principle is upheld. A Task Force comprised of staff from a variety of disciplines throughout the organization took on the challenge of proposing new, shared values that will provide a unified guide for our decisions and actions. In developing these it was agreed that the new Values should be reflective of all aspects of the organization and readily embraced by all stakeholders; that the Values should be easily remembered; and that the Values must 'stretch' the organization. By embracing these Values, Baycrest has agreed to integrate them into the fabric of the organization.

At Baycrest we believe...

Compassion comes from caring relationships that are promoted and nurtured through sensitivity, understanding, trust, and integrity.

Advocacy is essential in promoting change and socially responsible choices that are needs of the elderly, and is best achieved through a strong collective voice of clients, volunteers, and community partners.

Respect comes with the understanding that each person is unique, with intrinsic dignity.

Excellence is achieved when we reach beyond what was ever thought possible through discovery, and life long learning.

Principles to Guide Decision-making

Clients of Baycrest and their families or substitute decision-makers may be called upon to make decisions, which have major consequences for themselves or others. Regardless of their magnitude, whether they involve day-to-day behaviour or life and death situations, these decisions will have implications for the client's quality of life and perhaps for the lives of those around them. When challenged with difficult decisions, people find it helpful to have a framework to guide the decision-making process.

Care at Baycrest, as at any health care organization, is provided in the context of a shared system of ethics and values that have been formulated by society as a whole, various legal and professional bodies, as well as our religious and cultural beliefs. A brief overview of the sources and specifics of the principles that guide clinical practice at Baycrest will provide a framework and context for the discussion of ethical issues that follows in this document.

The following are commonly accepted ethical principles that incorporate the shared values of our society and community and apply to the provision of care at Baycrest:

Sanctity of life - As part of Jewish religious principles and tradition, appreciation for the sanctity of life will always influence decision-making at Baycrest.

Respect for persons - Each person is unique with the right to have his or her unique needs addressed to the extent possible. The philosophy of client-centred care, the guiding principle of practice at Baycrest, expresses respect for persons.

Autonomy - Each person has a right to make personal choices and to have his or her choices respected within the bounds of the law, institutional values and policies and the sensibilities of staff and other clients. Clients' wishes will be solicited whenever possible, and will be an essential component when planning care or following instructions in an advanced directive.

Beneficence - Each staff member is obliged to do "good", to promote others' welfare and well-being, in accordance with their professional code of ethics.

Nonmaleficence - Each staff member is obliged whenever possible to prevent or do no harm. Nonmaleficence is linked to beneficence when staff are (1) not doing evil nor causing harm, (2) preventing evil or harm, or (3) removing evil or sources of harm and thereby promoting good.

Justice - Each person has a right to be treated fairly, in the process of making decisions (procedural justice) or in the way limited resources are allocated (distributive justice). Procedural justice is reflected when all interested parties

have an opportunity to be heard and all options are explored when making decisions. Distributive justice considers access to health care and social service resources based on the various components of need.

Veracity - Each person is entitled to be told the truth, to the extent he or she wishes to know it. Caregivers expect truthful and accurate information from clients and their families. A relationship based on truth and sharing information in an objective, accurate and comprehensive manner fosters trust between clients, families and health care professionals. This mutual trust is the essential element in relationships formed to meet the common goal of enriching the quality of life of the client and providing the highest quality of care.

Advance Care Planning

It is possible that at some point in the future you will become unable to make decisions for yourself. In the case of a condition like Alzheimer's Disease, your ability to make your own decisions may decrease slowly over time. Alternatively, you may experience a sudden change in your decision-making ability due to situations such as a serious accident or stroke, or other medical condition that compromises intellectual function.

What is advance care planning?

You may choose to prepare for such a possibility by doing advance care planning. **Advance care planning** includes making decisions about the type of personal care, including health care, living arrangements, food, clothing, hygiene, and safety, that you want to receive in the future. This can be done by preparing a Power of Attorney for Personal Care in which you name a substitute decision-maker.

A **substitute decision-maker** is a person or persons who will make decisions on your behalf if you become incapable. Persons who are incapable are not able to understand the nature of treatment choices or appreciate the consequences of their decisions.

Why is advance care planning important?

Reasons for doing advance care planning include:

- Ensuring that you receive the type of personal care you desire
- Promoting communication between you and your substitute decision-maker(s), care providers, family, and friends
- Providing information that will help your substitute decision-maker(s) and healthcare providers make decisions about your personal care
- Reducing the burden of decision-making for your substitute decision-maker(s) and care providers

It should be understood that the preparation of a Power of Attorney for Personal Care is not required by Baycrest Centre for Geriatric Care. Under all circumstances, Baycrest will provide the highest quality care possible to those it serves.

What is a Power of Attorney for Personal Care?

In a **Power of Attorney for Personal Care** document you name a person or more than one person to be responsible for making personal decisions on your behalf should you become incapable. The person you name on the document is known as your Attorney for Personal Care. You can also provide written instructions about the type of personal care you do or do not want to receive should you become incapable at some point of time in the future. Decisions about life-sustaining treatments such as ventilators, intensive care, intravenous, and tube feeding may be included.

The Attorney(s) for Personal Care whom you name should be someone you trust, who knows you well, and is capable of making personal decisions on your behalf. It is important that you discuss your wishes with your Attorney for Personal Care.

A Power of Attorney for Personal Care is a legal document and must be prepared according to legislative guidelines outlined in the *Substitute Decisions Act* (1992). This includes being signed and witnessed. This document can be revised or revoked at any time. The Power of Attorney for Personal Care only takes effect when you become incapable and hence are unable to make an informed decision.

Who will make decisions for me if I become incapable and have not prepared a Power of Attorney for Personal Care?

According to the *Health Care Consent Act* (1996), if you become incapable and do not have someone appointed to make decisions for you such as a guardian, Attorney for Personal Care, or a representative appointed by the Capacity and Consent Board, the authority for making personal decisions will be given to the following individuals, in the order presented:

1. Your spouse or partner
2. A child or parent
3. A brother or sister
4. Another relative
5. A suitable other unrelated person willing to act in this capacity

If there is more than one child, parent or sibling, unless specifically named, all have equal status in substitute decision-making.

If no one on this list is available, capable, or willing, the Public Guardian and Trustee becomes the substitute decision-maker of last resort.

If I wish to do advance care planning, how should I proceed?

There are a number of people and resources available to assist you in this process. It is important that you discuss your health situation with your doctor and

other members of the healthcare team. You may also wish to consult with a lawyer and/or a religious or spiritual leader. This will ensure that you are well informed and can make decisions that reflect your specific situation. It is also important to talk about advance care planning with your substitute decision-maker(s), family, and friends.

If you wish to make a Power of Attorney for Personal Care, social work staff at Baycrest can direct you how to start. A Guide to Advance Care Planning is also available at no charge on-line at www.gov.on.ca/mczcr/seniors or by calling 1-888-910-1999.

What should I do if I already have a Power of Attorney for Personal Care?

If you have already prepared a Power of Attorney for Personal Care, it is important that your substitute decision-maker(s) is aware of the document and familiar with its contents. You should also inform your doctor or another member of the healthcare team, so that they know who to talk to when treatment decisions need to be made if you should become incapable. You should also provide a copy of the document to Baycrest so that it can be placed in your health record.

Cardiopulmonary Resuscitation

The CPR/DNR Policy

Cardiopulmonary Resuscitation (CPR) is a heroic form of medical treatment used when a person has suffered a cardiac and respiratory arrest. As this treatment is only potentially successful under very limited and clearly defined circumstances, Baycrest has developed a protocol and medical practice guidelines for responding to cardiac arrest for clients residing in Baycrest. Known as the CPR/DNR policy, (short form for Cardiopulmonary Resuscitation/Do Not Resuscitate), the goal of the protocol and guidelines is:

- to ensure that clients for whom CPR might be appropriate have the opportunity to make an informed decision regarding CPR or DNR, and
- to eliminate unnecessary and unwarranted CPR for clients who have died from a major medical condition or disease process and have not experienced a *true* cardiac or respiratory arrest, and for whom CPR would not be potentially successful.

The CPR/DNR protocol and guidelines have as their foundation the following principles:

- All clients residing in Baycrest will be approached to discuss CPR/DNR as it relates to their health condition, unless they have indicated a desire not to have such a discussion. The content of any advance directives or living wills will be reviewed. When clients are not capable of participating in such discussions, inquiries will be made about wishes expressed when the client was capable.
- For clients in the Palliative Care Program, DNR status will be assumed except under exceptional circumstances in which a CPR attempt might be deemed appropriate.
- If a DNR order is not in place, CPR will be administered only if the client meets the medical indicators and guidelines for cardiac arrest. (see section below: What is A DNR Order?)
- DNR orders will be reviewed yearly at the annual care conference or at any other time at the request of the client or substitute decision- maker.

CPR/DNR: A Guide for Clients and Family Members

Most peoples' understanding of Cardiopulmonary Resuscitation or CPR is based on what they have seen on television or at the movies. A person collapses from a heart attack and a crash cart, led by doctors and nurses, comes rushing down the hall to bring the victim back to life.

This popular image has led many people to believe that CPR is used to save someone from dying, or to bring a person who has died back to life. This is not a completely accurate picture of CPR.

What is CPR?

CPR is an emergency method of life saving under certain limited circumstances, usually an event which causes the heart to stop beating in a person who otherwise has normally working organs such as the heart, kidneys, liver and brain. If these organs are significantly damaged, the body cannot sustain itself and the heart stoppage is usually a result of the deterioration of the body in general.

CPR involves artificial respiration (breathing into the person's mouth or the use of a respirator bag) and external heart massage, usually after a sudden event such as a cardiac arrest, drowning or high voltage electric shock in a body that is otherwise reasonably healthy. If the heart is stopped for too long, permanent brain damage or death will occur, regardless of the cause of the heart stopping.

How effective is CPR?

CPR's effectiveness depends on the previous health of the person, the cause of the heart stoppage and the speed with which CPR can be administered. CPR is most effective if begun within a few minutes after a cardiac arrest, and if there is follow-up care in a hospital intensive care unit. It is most successful when the victim is a reasonably healthy person who has had a sudden loss of normal heart function. In these situations, attempting CPR may be very worthwhile, with a survival rate ranging from 10 to 40 percent.

What is the role of CPR in a long-term care setting such as Baycrest?

People who become patients and residents in long term care settings such as nursing homes, homes for aged and chronic care hospitals usually have many chronic health problems affecting many organs of the body including the heart, kidneys, liver and brain. Research and experience have shown that CPR is unlikely to have a positive outcome for most of these individuals, especially when they are also very elderly. When someone with many chronic health problems has a cardiac arrest, it is usually not an isolated event nor is it likely to be reversible. The cardiac arrest is usually part of a complex process. Many parts of the body are already affected by disease and a cardiac arrest is often the final step in a progressive and complex process of deterioration leading to death.

What are the chances of surviving cardiac arrest?

The odds of Baycrest residents and in-patients surviving a cardiac arrest are similar to those, which exist in other long-term care settings. Even under the best circumstances with the least compromised individuals, only 2 to 3 percent of people whose hearts stop unexpectedly, survive after receiving CPR. Based on studies of outcomes in Baycrest and other similar populations and, because of pre-existing medical conditions, for the vast majority of clients residing in Baycrest the likelihood of surviving CPR is closer to zero.

Why not try CPR anyway?

If CPR were a simple, painless and dignified procedure that was readily available, there would be no reason to recommend against using it in the long-term care setting. However, CPR requires intense treatment by doctors, nurses and other staff members, and the procedure itself may cause painful damage to the chest wall, ribs and internal organs.

CPR involves placing the person on a hard surface, either on a board if in bed or directly on the floor, pumping the chest vigorously and forcefully and, at the same time, breathing for the person. A breathing tube may be inserted into the windpipe and oxygen delivered to assist in breathing. In many cases, an intravenous line must be quickly inserted to deliver medications, and it is often necessary to apply a number of electrical shocks to the heart through paddles placed on the chest.

Some people residing in a long term care setting respond at first to the CPR treatment. It is then usually necessary to transfer them to an intensive care unit at an acute care hospital to be maintained on a respirator. However, the vast majority of people who survive at first in these circumstances die within a few hours or days.

Why is this information important?

When clients are admitted to residence in Baycrest, we want to do everything humanly possible to make them comfortable and maximize their ability to take part in activities and enjoy life. However, we feel it is our duty to make sure that clients and families are made aware of the facts about the CPR procedure and its outcome in this population, before discussions are held about the possibility of a DNR (Do Not Resuscitate) order.

What is a DNR order?

A DNR order will protect the person from unnecessary attempts at CPR, which will offer virtually no medical benefit. When a person has agreed to a DNR order, this order is written into the health care record (the chart) by the physician. It tells the medical and nursing staff that, in the event of disorder affecting the heart such as a heart attack or other cause of cardiac arrest, certain resuscitative procedures are not to be started. If there is no DNR order, CPR will only be tried if the person has had a cardiac arrest in circumstances in which it is medically indicated: the event is witnessed (observed) by a health care provider and the person is not suffering from an illness which has been shown to negate any of the potential benefits of CPR. The vast majority of our clientele at Baycrest suffer from such illnesses. Even in the absence of a DNR, the staff is not obliged to undertake CPR unless the event is witnessed and the person is not suffering from a condition (such as an acute infection, heart failure, impaired kidney function, a recent stroke) that would make the exercise futile in terms of possible success.

A DNR order applies only to the process of CPR and not to any other medical treatments. All other treatments can be considered and decisions about them will be made as usual, based on the person's needs and interests and potential benefits. All Baycrest clients, regardless of a DNR order, will receive the treatment and care necessary to ensure their maximum functioning and comfort.

To Transfer and/or to Treat

As in any multi-level care system, not all forms of acute medical treatment and symptom management are available in all locations within Baycrest. In situations in which the Baycrest client's condition could be improved by treatments available elsewhere, Baycrest will recommend transfer to its on-site Concentrated Care Unit (Acute Care of the Elderly Unit) or to an acute care hospital, as appropriate.

In non-emergency situations, the decision to transfer and the alternative courses of treatment and expected outcomes will be discussed with the client or substitute decision-maker in advance. In emergency situations, the decision to transfer and/or to treat will be based on the known wishes of the client or substitute decision maker and the attending physician's assessment of the situation.

A decision not to treat or not to transfer within Baycrest or to an acute care facility may be appropriate in some cases, especially when a client is terminally ill. In such situations, Baycrest will endeavor to cooperate with the client's or substitute decision maker's choice and provide appropriate treatment and care in place, or transfer the person to the Palliative Care Unit of Baycrest Hospital.

However, Baycrest cannot accept unqualified Do Not Treat/Do not Transfer requests. If the client's treatment decision, or that of the substitute decision-maker, appears to be inconsistent with Baycrest's policies, the legislation of the Province of Ontario or basic principles of ethical practice, Baycrest will take reasonable steps to assist the client or substitute decision-maker to make appropriate decisions or to transfer the client to a facility in which such a decision can be carried out.

Nutrition and Hydration

Baycrest provides an extensive program of eating assistance strategies developed under the umbrella of the **EATing Program**. The purpose of this program is to maintain clients' abilities to eat for as long as possible. The program aims to prevent the development of excess disability in eating and to enable clients to feed themselves to the extent possible. Clients with eating difficulties are assessed in a variety of ways including observing eating habits, exploring preferences and physical limitations, conducting swallowing studies and measuring nutritional intake. Based on the assessment, appropriate foods and food textures are offered and an individualized care plan is developed. This plan details a program for maximizing independence in eating while providing the required assistance through appropriate utensils, visual and other sensory cues, and feeding when necessary.

However, in situations where a thorough evaluation shows that a client cannot swallow or eat in a manner adequate to maintain sufficient nutrition, or that feeding by mouth constitutes a danger, other appropriate feeding methods may be proposed to provide liquid food on a continuous basis. Options include a tube inserted through a vein (intravenous), below the skin for the purpose of hydration (hypodermoclysis), through the nose (nasogastric), or directly into the stomach (gastrostomy). Baycrest recognizes the right of clients with the capacity to make decisions, or substitute decision makers of those clients who are not capable who have knowledge of the person's wishes, to refuse the insertion of feeding or intravenous devices. Such clients residing in Baycrest will continue to be offered food and liquids by mouth. Baycrest prefers an approach to care that provides nutrition and hydration in keeping with the individual client's right to choose.

Decisions about inserting feeding, intravenous or subcutaneous devices are made on an individual basis in the context of the individual's condition and prognosis. Clients and substitute decision makers are encouraged to consult with their care team, Rabbi or other spiritual leader, family members or other significant persons before making a decision. The advantages of tube feeding, including maintaining nutrition and hydration and prolonging life, must be weighed against the disadvantages which may include physical discomfort during placement and complications while the tube is in place. When the client is not competent to make the decision, all efforts will be made to learn what the client would have wanted, given the client's condition and prognosis, and the benefits and burdens of the treatment.

When the views of the client residing in Baycrest cannot be determined and the substitute decision maker agrees, consideration will be given to a trial of tube feeding. Such a trial may be seen as a step that would give the substitute decision makers and the clinical team more time to reflect and to observe the client's response, both clinically and behaviourally. At the conclusion of the pre-specified period of time (e.g. one month), the team, in consultation with the

family or significant others, may re-evaluate and decide whether or not tube feeding should be extended or terminated, based on whether the goals of the process were or were not achieved. As in all situations in which clients resist feeding, the causes of any resistance to tube feeding will be thoroughly explored.

The ethical principles used in nutrition/hydration decisions can be found in Appendix V.

Client Safety and the Policy of Least Restraint

Baycrest Centre for Geriatric Care believes it is essential for clients to maintain their dignity and independence by being permitted to take "the risks of normal everyday life." In recognizing our responsibility to provide a safe environment for our clients, every effort is made to identify and manage the risk factors that exist. For example, environments are modified, wanderers receive appropriate supervision by staff and are protected by electronic perimeter alarms, and those at risk of falling are assessed and prescribed interventions to decrease the level of risk. The philosophy of least restraint underlies all these approaches. The operating principle at Baycrest is that restraints of any kind should only be used after all other interventions have been tried and have proven unsuccessful. Restraints used to remove the risks of normal living may undermine the dignity of clients and greatly reduce their quality of life. They may also present physical and psychological risks in themselves.

Baycrest believes that physical restraints constitute an extraordinary measure. If the use of a restraint is deemed necessary for a resident or in-patient, the goal will be to use the least restrictive type of restraint for the shortest period of time possible.

The use of restraints will be considered in situations where the benefits outweigh the risks according to the following protocol:

- A restraint will be applied when other measures have failed to maintain safety and/or facilitate treatment.
- In non-emergency situations, the decision to restrain will follow a systematic multi-disciplinary assessment and appropriate consultation with the client and the substitute decision maker.
- A physician's order will be written stating the type of restraint to be used and the period of time of its use.
- Written consent for the use of a restraint will be signed by the client, if capable, or by the substitute decision maker.
- Careful and continual evaluation of the restraint will be undertaken during its use. It will be discontinued as soon as possible.

In an emergency situation, the Registered Nurse may make the decision to apply a restraint and will notify the physician as soon as possible. At such times, the physician's order will be sufficient until the client or the substitute decision maker is available to give informed consent.

To minimize the need for the use of restraints, clients will be individually assessed regarding the need for appropriate safety measures. They will be periodically reassessed as their needs change throughout their stay.

The Use of Psychoactive Medications

There are times when treatment with psychoactive medications is recommended following assessment of the client's condition and weighing the risks and benefits of the treatment. Psychoactive medications are drugs prescribed to modify mood, mental status or behaviour. Treatment with these drugs has four goals: to minimize suffering, to improve behaviour that is dangerous to the client or others, to decrease interpersonal difficulties and to provide the client with the opportunity to participate in the activities of the Centre.

Psychoactive medications have positive therapeutic effects when used appropriately. These medications have been found to be especially effective when specific symptoms have been identified, when no other intervention is available or adequate (such as following brain injury) and when the expected benefits to the improvement of quality of life outweigh the risks.

As part of the consent process, clients and substitute decision makers will be given an explanation of the expected benefits and risks, as well as the right to refuse such treatment. Every client receiving psychoactive medications will be continually monitored by a physician and periodically reassessed to determine the appropriate course of treatment.

Research

Baycrest is an academic centre affiliated with the University of Toronto. It is committed to participating in research, which will contribute to knowledge in the field of aging. At the same time, Baycrest is sensitive to the concerns and rights of clients and families with respect to taking part in research. To ensure that research projects undertaken at Baycrest protect the safety, rights and privacy of its clients, Baycrest adheres to a strict approval system for all its research proposals. In addition, informed consent must be obtained before clients participate in research.

The Approval Process for Research Projects

The goals of the approval process for research projects are:

- To provide a mechanism to ensure that all research carried out at Baycrest Centre for Geriatric Care is acceptable in terms of scientific merit, human research ethics, and resource requirements;
- To facilitate research by ensuring that approvals can be obtained within a reasonable time frame; and,
- To ensure that all research being carried out at Baycrest is reviewed and approved.

Formal research approval is required for studies, which involve (a) access to research subjects at Baycrest (patients, residents, members, or families) or (b) any departure from normal clinical practice for purposes of the research.

The project approval protocol is as follows:

- 1) The researcher prepares and signs a finalized proposal.
- 2) The researcher obtains the signature of his/her Department Head, then submits the finalized proposal to the Vice-President, Research or designate.
- 3) The Vice-President Research or designate forwards the proposal to the Research Ethics and Scientific Review Committee for scientific, ethics and resource review and approval.
- 4) The Research Ethics and Scientific Review Committee reviews the project.
- 5) The Research Advisory Committee of the Board of Directors receives regular reports on all projects, which have been approved.

A Resource on Ethics: The Clinical Ethics Committee

The Clinical Ethics Committee of Baycrest was formally convened in June 1991 to help clients, families, staff and volunteers with difficult decisions regarding care.

The purpose of the Clinical Ethics Committee is to serve as a resource on ethical issues related to the care of clients through providing consultation on specific cases, conducting case reviews of situations involving ethical issues, providing education on ethical analysis and developing policy for managing ethical dilemmas.

The Clinical Ethics Committee is comprised of a multidisciplinary team of highly respected representatives from various disciplines across the Centre including Medicine, Social Services, Nursing Services, other Professional Services, Administration, and Pastoral Care. Other individuals represent the Research Community, the Legal Community, the Ethics Community, the general Community, and the Baycrest Client/Family Community.

The main responsibilities of the Clinical Ethics Committee are:

- To foster the development of standards of ethical practice in all areas of clinical practice at Baycrest;
- To establish and review the ethical aspects of clinical practice at the Baycrest;
- To initiate and review ethical guidelines for practice;
- To serve as consultants to the Baycrest community on specific complex cases.

The Case Consultation Process at Baycrest

The goal of a case consultation is to assist the care team to respond to ethical dilemmas in client care by helping to identify the ethical principles involved, and to facilitate a process of ethical deliberation in order that morally sound decision options can be reviewed. The consultants do not make the decision. The decision rests with the care team.

An ethical dilemma may result in a request for a case consultation at any point during a client's stay at Baycrest. For example, a need may arise during ongoing care related to pain management, or at a critical time when there is pressure to make a decision about a change in treatment, such as inserting or removing a feeding tube.

The consultation process has the following steps:

- 1) A request to consult on a particular clinical situation is sent to the Committee or staff Ethicist.
- 2) The Baycrest Ethicist and/or other Committee members respond in a timely fashion. Effort is made to identify a consult team representing a cross-section of backgrounds and clinical expertise.
- 3) The consultation meeting is held.
- 4) A written summary from the consult team is sent to the requesting parties.
- 5) The case is reviewed by the Clinical Ethics Committee for educational purposes and to consider the need for policy review.
- 6) The Committee is available to interested parties for support and/or additional consultation, if desired.

The Clinical Ethics Committee can be reached through:

The Chair of the Clinical Ethics Committee
Baycrest Centre for Geriatric Care
3560 Bathurst Street
North York, Ontario
M6A 2E1

Appendix I: Provision of Health Care to Holocaust Survivors – An Ethical Perspective*

Comment [IT1]:

Comment [IT2]:

As health care workers we have ethical responsibilities that underlie the services we provide, and influence the quality of relationships we form. We are responsible for conducting ourselves according to accepted concepts of right and wrong, and what constitutes sound ethical practice. We are constantly making ethical decisions and are held accountable to their justification. We are governed by ethical principles that guide our behaviour towards each other and with our clients and their families

Ethical Principles

In general, the principles most health care providers are guided by include a responsibility to respect the client:

- To treat him/her with dignity,
- To encourage independence and autonomous decision-making,
- To do good in the name of serving the patient's best interests,
- To do no harm, and
- To apply some measure of fairness in allocating resources.

Survivors' Perceptions of Health Care Providers

Each Holocaust Survivor has his/her own unique story of hardship and survival. While there is no one model of care that fits all clients, ethical care requires all caregivers to be sensitive to certain facts about all clients' stories. Each Holocaust Survivor has his/her own unique story of hardship and survival and professionals have a duty to understand past experiences and their influences on the person today.

It is equally important to understand the historical facts about the role of medical personnel in the horrific crimes and torturous experiments that were committed under the Nazi regime of World War II. One must be open to learning what beliefs Holocaust Survivors have about how they might be cared for, or possibly abused by caregivers, given their own knowledge and personal experience of power abuse during the Holocaust. Any fears they harbour about possible mistreatment by medical staff due to other medical staff's role in Nazi medical experimentation and death selection must be respected and understood. Ethical care also includes sensitivity to how the person's stories are elicited and an honouring of those wishing to keep some part or all of their stories private.

Questions to Ponder in Providing Treatment

Ethical principles to be considered in providing healthcare to patients were described above. One might consider: What meaning do they each have to each unique Holocaust Survivor? What do they mean for the health care provider working with a Holocaust Survivor? How does or should one understand their ethical obligations and duties in relation to their care of Holocaust Survivors? The Holocaust is a story at a minimum about horrific power abuse. What meaning does this have for the elderly Holocaust Survivors confronted with health care workers? And what is the caregiver's obligation to pay particular attention to how issues of power differential will be perceived by the client?

* Refer to Holocaust Manual

Appendix II:

Baycrest Clients' Rights and Responsibilities

CLIENTS' RIGHTS

1. Every client has the right to be treated with courtesy and respect and in a way that fully recognizes the client's dignity and individuality and to be free from mental and physical abuse.
2. Every client has the right to be properly sheltered, fed, clothed, groomed and cared for in a manner consistent with his or her needs.
3. Every client has the right to be told who is responsible for and who is providing the client's direct care.
4. Every client has the right to be afforded privacy in treatment and in caring for his or her personal needs.
5. Every client residing in Baycrest has the right to keep in his or her room and display personal possessions, pictures and furnishings in keeping with safety requirements and other clients' rights.
6. Every client has the right
 - I. To be informed of his or her medical condition, treatment and proposed course of treatment,
 - ii. To give or refuse consent to treatment, including medication, in accordance with the law and to be informed of the consequences of giving or refusing consent,
 - iii. To have the opportunity to participate fully in making any decision and obtaining an independent medical opinion concerning any aspect of his or her care, including any decision concerning his or her admission, discharge or transfer to, from or within Baycrest, and
 - iv. To have his or her medical records kept confidential in accordance with the law.
7. Every client has the right to receive reactivation and assistance towards independence consistent with his or her requirements.
8. Every client residing in Baycrest who is being considered for restraints has the right to be fully informed about the procedures and the consequences of receiving or refusing them.
9. Every client has the right to communicate in confidence, and if residing in Baycrest to receive visitors of his or her choice and to consult in private with any person without interference

10. Every client residing in Baycrest whose death is likely to be imminent has the right to have members of the client's family present twenty-four hours per day.
11. Every client residing in Baycrest has the right to designate a person to receive information concerning any transfer or emergency hospitalization of the client, and where a person is so designated, to have that person so informed forthwith.
12. Every client has the right to exercise the rights of a citizen and to raise concerns or recommend changes in policies and services on behalf of himself or herself or others to the clients' council, Baycrest staff, government officials or any other person inside or outside Baycrest, without fear of restraint, interference, coercion, discrimination or reprisal.
13. Every client has the right to form friendships, to enjoy relationships and to participate in the clients' council.
14. Every client residing in Baycrest has the right to meet privately with the person of his or her choice in a room that assures privacy; and when spouses reside in the same facility, they have a right to share a room according to their wishes, if an appropriate room is available.
15. Every client residing in Baycrest has a right to pursue social, cultural, religious and other interests, to develop his or her potential and to be given reasonable provisions by Baycrest to accommodate these pursuits.
16. Every client has the right to be informed in writing of any law, rule or policy affecting the operation of Baycrest and of the procedures for initiating complaints.
17. Every client residing in Baycrest has the right to manage his or her own financial affairs where the client is able to do so, and where the client's financial affairs are managed by Baycrest, to receive a quarterly accounting of any transactions undertaken on his or her behalf and to be assured that the client's property is managed solely on the client's behalf.
18. Every client residing in Baycrest has the right to live in a safe and clean environment.
19. Every client residing in Baycrest has the right to be given access to protected areas outside Baycrest in order to enjoy outdoor activity, unless the physical setting makes this impossible.

Clients also have the right:

To expect all staff to be advised of the above rights and to assume that all staff will respect the above rights;

To expect all staff, upon being hired, and thereafter through in-service training, will have up-to-date knowledge of gerontology and geriatrics as these affect their careers and the client's life at Baycrest.

CLIENTS' RESPONSIBILITIES

As in all human societies, individuals have not only rights but also obligations and responsibilities to one's fellow clients and to the management of the facility in which one is receiving care.

1. Every client has the responsibility to observe the rules and regulations of Baycrest in effect at the time of admission to any program and as altered from time to time.
2. Every client has the responsibility to treat one's fellow clients and staff with courtesy and consideration, and to bear in mind their rights at all times.

3. Every client has the responsibility to observe at all times the no smoking regulations for one's own protection and that of other clients and staff.
4. Every client has the responsibility to participate always, and with promptness, in fire and disaster drills.
5. Every client has the responsibility to use with care all supplies, linens and furnishings, just as if they were one's own.
6. Every client has the responsibility to provide truthful information to the appropriate Baycrest staff and administration concerning all aspects of his or her mental, physical and financial status, and to keep them informed of any relevant change in these.
7. Every client has the responsibility to consider that other clients may require more assistance, and more urgently, than oneself. One cannot always be served first.
8. Every client has the responsibility to report promptly anything he or she feels needs attention, i.e., safety hazards, security, or anything one feels is not right.
9. Every client has the responsibility to give the head nurse, department head or any of the administrative staff an opportunity to correct a complaint or grievance by speaking to him/her directly. If satisfaction is not obtained within a reasonable time period, the client should write to or go to an elected officer of the Clients' Council, or contact the Client Representative to seek assistance with resolution of the concern.
10. Every client residing in Baycrest has the responsibility to leave word, in accordance with Baycrest policy, when leaving the unit. This is for one's own benefit and safety.

Clients and staff also have the right:

To expect all clients to be advised of the above responsibilities and to assume that all clients will fulfil the above responsibilities.

**Appendix III:
Baycrest Centre for Geriatric Care
Responsibilities And Expectations Of Families**

This Section is Currently Under Review

Appendix IV: Priority Setting in Health Care

Baycrest Centre for Geriatric Care is committed to providing its clients with the best care possible. Along with other health care institutions in Ontario, Baycrest receives its funding from the Ontario government. Baycrest uses this money from the government to fund the various resources that are needed to make the Centre function as best as possible. Because the funding is limited, Baycrest must make decisions about how to spread the funds among all the resources needed. For example, Baycrest must decide how many beds it can afford to offer to the public, how much money should be invested in certain technologies or areas of health care, and how many physicians, nurses, and other staff members to hire. The process of deciding how much funding to put into various resources is known as “priority setting.”

These decisions raise difficult ethical questions. There are many different ways of setting priorities in health care. Some believe that clients who are most in need should be given priority, while others contend that clients who will get the most benefit from the resources should be given priority. Still others claim that resources should be divided equally among all those in need. There is no one right way to make these difficult decisions. Baycrest will do its best to ensure that priority setting is done as fairly as possible and will always strive to maintain its commitment to act in the best interests of its clients.

Baycrest adheres to a fair process model for priority setting entitled “Accountability for Reasonableness” (See Daniels, N. and Sabin, J. 2002, *“Setting Limits fairly: Can we learn to share scarce resources?”* Oxford: Oxford University Press), and aims to satisfy the ensuing four conditions:

- Relevance Condition: decisions made on basis of reasons
- Public Condition: decisions and rationales should be transparent
- Revision and Appeal Condition: processes in place for fair appeals
- Enforcement Condition: to ensure other three conditions are met

Appendix V: Ethical Principles for Nutrition/Hydration Decisions

Often, decisions regarding tube feeding are highly emotional and may involve resolving conflicting beliefs and values. The ethical principles of Respect for Persons, Autonomy and Beneficence are some principles that might be considered during the deliberation. Even these principles may be in conflict with each other. In such cases a thoughtful ethical discussion involving the team and the patient/family/ Substitute Decision-Maker (SDM) should take place to attempt to resolve dilemmas. The Baycrest Ethicist or members of the Clinical Ethics Committee are other potential resources and may also be included in the discussions.

Some of the issues to be considered during the discussion are:

Respect for Individuals:

- Valuing the unique quality of each patient's needs
- Treating the client in a dignified manner
- Respecting family, cultural and religious beliefs, and the meanings associated with eating
- Encouraging options that are in patient's best interest

Autonomy:

- Respecting the client's right to make informed choices about treatment options. For example, a patient might choose to have a feeding tube inserted and may later change his/her mind and wish it to be removed. The client or SDM's decision must be respected.
- When the patient is deemed incompetent to make this decision, the SDM will decide among treatment options according to the patient's previously stated competent wishes; when that knowledge is absent, currently made decisions are to be in accordance with the best interests of the patient (A fact sheet for SDM's is included in the resource: Fact Sheet for Eating and Swallowing Problems contained within the Clinical Practice Guidelines for Feeding Tube Insertion Document)
- Even when the client is deemed incompetent, the family and team members must consider the client's behavioural and emotional responses to the treatment offered when assessing the benefits and burdens of continuing it.

Beneficence:

- Promoting client's welfare/best interest
- Maximizing safety (for example, by avoiding aspiration)
- Maximizing pleasure (for example, joy related to tasting of food, or being fed by a loved one)
- Maximizing comfort
- Increasing quality of life
- Prolonging life

Appendix VI:**Baycrest****List of Companion Documents**

Baycrest Living Will - available from Social Services Department

Jewish Life at Baycrest - available from Education Department

Clinical Practice Guidelines for Feeding Tube Insertion – Baycrest Internet (pending)

Caring for Your Loved One – available from Education Department

Parenting Your Parent – available from Education Department

Memory Loss and Dementia – available from Education Department

Visiting with Elders – available from Education Department

Preparing for Approaching Death – available from Palliative Care Unit