AMDA TOOL KIT

Starting & Maintaining a Long Term Care Ethics Committee

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The Society
For Post-Acute And
Long-Term
Care Medicine™

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AMDA – Dedicated to Long Term Care Medicine (formerly the American Medical Directors Association), the professional association of medical directors, attending physicians, and others practicing in the long term care continuum, is dedicated to excellence in patient care and provides education, advocacy, information, and professional development to promote the delivery of quality long term care medicine. The AMDA Ethics Committee identifies issues concerning the ethical conduct of the association and its members as well as issues regarding the bioethics of health care decision making and develops policy statements to submit to the Board of Directors for action.

Section 1 >> Mission

Every functioning ethics committee should have a statement of purpose or mission. These are the basic philosophies and overall goals of the committee. Each committee should create an individualized mission, because each facility and each committee differs. At the core, however, the mission should include some of these basic principles:

- Increasing awareness of ethical issues and dilemmas in long-term care (LTC);
- Contributing to proper management of ethical issues;
- Developing mechanisms to enhance autonomy of residents;
- Respect for individual residents and staff (stakeholders);
- Facilitating teamwork;
- Ethics education of staff and residents, committee, families, and administration (everyone);
- Transparency of dealing with ethical issues; and
- Upholding of values—compassion, confidentiality, anonymity, and facilitation.

The statement of purpose should be compatible with the organization’s mission statement.

AMDA’s position statement on ethics committees (Resolution E98) further states,

> “Ethical issues are part of everyday life in long term care settings. They include respecting individual rights and privacy in an institutional setting, issues of autonomy in states of dependency, informed consent, resource allocation, conflict resolution and many others. In addition, addressing issues surrounding end of life care including advance directives, withholding and withdrawing life sustaining treatments, do-not-resuscitate orders, determination of decision making capacity, and use of surrogate decision makers, requires skill and knowledge of basic ethical principles. Medical Directors should take leadership in assuring that their facilities have appropriate mechanisms in place for addressing these issues.”

Ethics committees are an acknowledged means of fulfilling these specific roles in the institution:

- They are used to ensure the development, promotion, and protection of values.
- They provide an opportunity for multidisciplinary dialogue that clarifies ethical and legal concerns, considers aspects of fiscal responsibility, and guides decision making for complex dilemmas.

Ethics committees can fulfill these roles by providing the following functions for issues of an ethical nature:

- Policy development and review;
- Quality assurance activities;
- Education;
- Resource for staff, clinicians, administration, patients, families, and community;
- Monitoring judicial decisions and legislative action;
- Consultation and review of case-specific dilemmas;
- Serving as the mandated appeals process under the Patient Self-Determination Act (PSDA) and many state regulations.

The audience for this tool kit is intended to be primarily the medical director with regard to establishing the committee. However, this tool kit can be used with the active support of the medical director by other facility staff interested in establishing an effective ethics committee.

Section 2 >> Composition

The membership of the committee should be well balanced, reflecting the diversity of the community in which the facility is located. Although size may depend on the situation, a group of 7 to 10 persons is suggested. The committee provides a platform for all involved to engage in an open discussion and review of the ethical principles.

It is important that the governing board approves the ethics committee; this ensures broad-based organizational support.

It is essential that group members be able to discuss sensitive issues in a confidential manner. If a conflict of interest does arise, a member should excuse himself or herself from the deliberations. A stable core membership is necessary to allow for committee self-education and familiarity with the processes. Suggestions for membership include

- **Medical Director -** The medical director, by the nature of his or her training, has used ethical principles in the management of complex medical cases. The most common questions are related to end-of-life care and to the determination of when treatment is futile. The committee may depend on the medical director to help interpret medical aspects of events in a manner understandable to nonmedical colleagues.
- **Administrator -** The administrator has a vested interest in the performance of the facility. She or he will understand the goals for utilizing the resources of the facility (nursing, time, dollars) to provide the best practicable care for all the residents. It is in the best interest of the administrator to see the evolution of medical decision making. However, it is important to ensure that administrative concerns are not influencing the application of ethical principles. The administrator's presence should not hinder the ability of all other members to freely express their opinions. In a survey of AMDA members, all respondents indicated that the administrator was a member of the committee and that his or her presence was beneficial. However, one respondent indicated that the presence of nursing home management was detrimental for ethics committee deliberations that focused on conflict resolution.
- **Director of Nursing or Staff Nurse -** This person should represent the pulse of her or his medical community and the concerns of the nursing staff toward any conflicts that have arisen. Because this person often deals with problem solving, she or he may be the main person to recognize the evolving issues or may be the individual who brings up the "case."   It is likely that the viewpoints of the staff will be provided by this individual if other staff members are unable to attend. This person's observations of resident comfort or discomfort associated with various procedures may be extremely useful in the determination of burdens and benefits. Also, the involvement of this person helps to confirm the validity of the process to the care team, who may be left to carry out the recommendations of the committee.
- **Social Worker -** This person is often the face of the facility to the families. The social worker has experience in helping families and friends—and the resident—adapt to the new environment of the facility. This professional can help to identify potential conflicts early and provide insight as to

why the situation has reached a critical point. The social worker's knowledge of the family and of the family dynamics involved may be a useful bridge to understanding for all involved.

- **Chaplain, Clergy, or Hospice Director** - If the LTC facility has a spiritual adviser, it would be useful to include this person in the core team of the committee. Members of this profession are respected for always considering the individual’s best interest. Chaplains or clergy in similar positions often have counseling backgrounds and have dealt with grief and loss on many levels. The ethical conflicts that arise are often a byproduct of loss of independence. If the facility does not have a spiritual adviser on staff, the committee should consider adding a local religious leader to its membership. If a seminary, college, or university is nearby, a teacher of religious studies, a theologian, or an ethicist from that institution may also be considered. Persons with formal training in clinical pastoral education should be knowledgeable in the values, traditions, and beliefs of residents who come from different faith backgrounds than their own.

- **Independent Individual From the Community** - In selecting this individual, the committee needs to consider the strengths and weaknesses of the group. This person should not have any position or interest in the facility. A representative from one of the community’s service organizations that is active in providing services to the geriatric population could be considered.

- **An Attorney Knowledgeable in Health Care Law** - This person could be a standing committee member or an invited participant.

In addition to the core ethics committee group, the following individuals may be invited if a specific problem warrants it:

- Resident or residents involved in the dilemma. This is not always possible, but one must always remember that the resident does not necessarily need to be legally competent to have input that may assist in reaching the best possible decision.

- Representatives from the family or friends (responsible person or person with power of attorney) of the resident. They often have wrestled with the marked and often sudden changes in the life situation of the resident. They have been forced to make decisions that are complicated and that involve issues with which they are not familiar or comfortable.

- The attending physician may have a long history with the family and resident and may be able describe best to the committee the history of the resident’s current medical condition and how medical decisions have been made to date.

Nursing or certified nursing assistants who have taken care of the resident. These individuals often invest themselves in the resident’s well-being and are aware of many aspects of their life situation.

Medical specialist for difficult clinical situations (e.g., dietitian or speech language pathologist for cases involving feeding issues, respiration therapist for a resident on a ventilator).

Section 3 >> Education and Core Competencies

Education of committee members is crucial to establishing and maintaining a successful ethics committee. There are several dimensions to this phase of committee development (modified from an article by Winn and Cook, Annals of Long-Term Care 2000;8:35-42). It is important to encourage open discussion, to establish respectful interpersonal relationships, and to promote trust. Components of the education process are as follows:

- Explain and discuss the goals and objectives of the committee.
- Set a realistic agenda.
- Review and discuss ethical principles in health care.
- Review and discuss models of ethical decision making.
- Determine the format of education, such as
    - Article review,
    - Case illustrations,
    - Retrospective case review, and
    - Invited speakers.
- Identify resources, personnel, literature, costs, and budget.

Initially, one or two people should be designated to convene the appointed committee members and to facilitate the first two or three meetings. Thereafter, the membership should decide whether this format should be continued throughout the education phase. Eventually, a chairperson should be selected, preferably through the consensus of the committee members rather than by appointment by the facility management or administration.

First and foremost, the facilitators should discuss the rationale that has brought about the decision to establish an ethics committee in the LTC facility. The steps leading up to the convening of the first committee meeting should be carefully reviewed, while encouraging interactive discussion when needed to clarify questions, issues, or concerns.

Second, a copy of the proposed guidelines for the ethics committee should be distributed and discussed. The committee members should be given the opportunity and the authority to decide minor changes in the guidelines that reflect the culture and perspective of the committee members, as long as the proposed changes do not contribute to liability. Legal counsel input may be needed but often can be given quickly if the counsel is a member of the committee. Both establishing a process of discussion and encouraging self-direction of the committee are very important to promoting trust between the committee and the facility management, which is key to the continued functioning of an effective committee.

Third, the time commitment of members must be discussed. During the initial education phase of the committee, meetings generally should be held monthly or every other month, with each meeting lasting 1 to 2 hours. Any member who is not able to fulfill such a time commitment should be allowed to resign so that another member can be appointed.

Fourth, confidentiality of committee discussions should be reviewed. The committee must decide whether to keep minutes. If minutes are to be kept, then a secretary should be designated and appropriate precautions taken to ensure confidentiality of the minutes.

After the completion of these steps, the committee should be ready to proceed with its self-education. The committee facilitators (and consultant, if one is available) will need to set a realistic schedule and determine when the basic education of the membership should be completed. Once completed, the committee may decide to meet less regularly; quarterly meetings are usually sufficient.

Several educational formats may be used to encourage member interest, interaction, and continued participation. These formats include article review, case illustrations from texts or practice, and invited speakers. For committees that have been functioning for more than 6 months to 1 year, case consultation and retrospective case review are other educational opportunities.

As new members join the committee, their education to the new role and to the committee should be as comprehensive as when the committee was first formed.

Core Competencies

Ethics committees in LTC nursing facilities will face issues that generate requests for consultation from a variety of domains. These may include, but may not be limited to, the following:

- Ethical dilemmas arising from caring for older adults in the face of declining functional capacity;
- Ethical dilemmas arising from transitions of care and placement of older adults;
- Ethical dilemmas arising from care near the end of life;
- Decision making processes and assessment of capacity for informed consent in residents with various levels of impaired cognition;
- Shared decision making processes with the patient, family, or legally authorized representative when the resident’s decisional capacity is declining;
- Maintaining resident privacy and confidentiality in the facility;
- Professionalism of medical practice in the nursing facility;
- Ethical issues of resource allocation in the facility;
- Ethical issues in business and management in the facility;

- Ethical issues for staff in the workplace, including moral distress;
- Ethical issues involving research in the facility (however, the ethics committee is not an institutional review board [IRB]);
- Ethical issues regarding the validity or interpretation of advance directives executed before admission to the facility.

To provide a setting in which consultations involving issues from these various domains may be effectively performed, a nursing facility ethics committee should manifest each of several core competencies, either collectively or within at least one member of the committee.

A nursing facility ethics committee must have, within its members, certain assessment and analysis skills, including the ability to

- Identify the nature of the value uncertainty or conflict that underlies the need for consultation;
- Access relevant ethics literature, policies, guidelines, and standards.

A nursing facility ethics committee must have, within its members, certain process skills, including the ability to

- Establish expectations for consultation and determine whom to involve;
- Utilize institutional structures and resources to facilitate the implementation of a chosen option;
- Communicate and collaborate with other responsible individuals, departments, or divisions within the institution;
- Facilitate formal meetings;
- Document and communicate consultative activities;
- Identify systems issues and delegate follow-up;
- Evaluate the consultation process and provide quality improvement;
- Effectively run a consultation service in the facility.

A nursing facility ethics committee must have, within its members, certain interpersonal skills, including the ability to

- Listen well and communicate interest, respect, support, and empathy to residents, family members, staff, and other involved parties;
- Educate residents, family members, staff, and other involved parties regarding the ethical dimensions of the issue generating the consultation;
- Elicit the moral views of the resident, family members, staff, and other involved parties;
- Represent the moral views of residents, family members, staff, and other involved parties to others;
- Enable all involved parties to communicate effectively and be heard by other parties;
- Recognize and attend to various relational barriers to communication.
- A nursing facility ethics committee must have, within its members, certain knowledge competencies, including knowledge of
- Moral reasoning and ethical theory as it relates to health care ethics consultation;
- Bioethical issues and concepts that typically emerge in health care ethics consultation in the nursing facility;
- Health care systems as they relate to ethics consultation in the nursing facility;
- Clinical context as it relates to ethics consultation in the nursing facility, particularly geriatric issues and syndromes, as well as patterns of the trajectory of functional decline in older adults;
- The particular health care institution in which the committee is working, as it relates to ethics consultation;
- Local health care institutional policies relevant to ethics consultation;
- Religious, cultural, and moral beliefs and perspectives of the resident and staff;
- Relevant codes of ethics, professional conduct, and guidelines of accrediting organizations as they relate to ethics consultation;
- Health law relevant to ethics consultation.

This section was adapted and modified from: *Core Competencies for Healthcare Ethics Consultation*, 2nd ed. 2011. Glenview, IL: American Society for Bioethics and Humanities. Modifications were made by members of the AMDA Ethics Committee to tailor the competencies to the specific task of a Long-Term Care Ethics Committee.

The steps in starting and maintaining an ethics committee are as follows:

Clarify the Purpose	• The purpose(s) of any ethics committee (EC) should be included in its mission statement.
	• ECs can serve many purposes. Many assume the responsibility to do most, if not all, of the following:
	  ◦ Educate consumers and staff in general and in case-specific circumstances
	  ◦ Support interdisciplinary team* in applying ethical reasoning
	  ◦ Assist in resolution of ethical dilemmas among the interdisciplinary team
	  ◦ Policy review and policy development
	  ◦ Support the activities of the institutional review board (IRB)
	* Interdisciplinary team includes each professional discipline involved in patient care and includes the patient and/or the patient surrogate; it may also include lay people from the community.

Authority & Type	• What authority will the EC have within the organization? Generally, ECs have the authority to hear certain complaints (consultation requests) and to advise, facilitate, and mediate; rarely do ECs dictate or arbitrate. • Where does the EC sit within the organizational structure? (Clarify this within the organizational bylaws, including purpose, structure, status, and reporting mechanisms.) • If the EC is a shared venture among facilities (for example, by a group of skilled nursing facilities), how will the participating facilities be invited or for that matter, selected or excluded? • Will there be a budget? What will the funding source be? Ask the executive director.

Committee Structure	• How will the EC be organized? At a minimum, a chair and a secretary are needed; a vice-chair helps in transition over time. • Will the EC have officers or "just" a chairperson? In most places, the chair will be chosen because of training, experience, competence, and interest. This person does not have to be a physician. • Are there qualifications for the chair or officers? What? • Discipline-specific (for example, a physician, an ethicist)? • Education in ethical reasoning? • Demonstrated competence in ethical reasoning? • Length or type of clinical experience? • Demonstrated leadership skills? • How long will the terms of office be? May the chair or officer serve more than one consecutive term? • How will the chair or officers be selected? • Appointed? If so, by whom or what other group? • Elected? If so, by whom? EC members or by key persons within the organization? • How will the activities of the EC be planned? Usually the chair keeps plans and records. • How will the activities of the EC be recorded? • Minutes should be kept recording (1) topic, (2) discussion, and (3) planned actions, including identification of individual(s) responsible and target dates. • How will activities occurring between meetings be documented?
EC Resources	• Determine what resources will be available to the EC. Most facilities keep a binder or an intranet web page with local policies and procedures (P&Ps); most facilities no longer keep a lot of

other material in print.

  - Library containing resources
  - Library with access to medical or other literature
  - ECs from nearby institutions that may provide support or guidance
- Determine the learning needs of the EC (see below)
- Are there experts within the organization or network or within the region that are available to provide expertise and support to the new EC? Under what terms? If no one has belonged to an EC before, a committee member should visit other nearby ECs.

Educational Needs Specific to this EC

- On the basis of the types of situations that presumably prompted consideration of forming an EC, determine what some of the educational needs of the EC members will be:
  - What is an ethical dilemma? It is a conflict between two or more ethical principles, but the question usually starts with someone feeling that something is being done that shouldn't be done.
  - What is the distinction between an ethical dilemma and a legal concern? Clinical judgment tells you what you can do, ethics tells you what you should do, and the law tells you what you must do.
  - What is the distinction between an EC and an IRB? People should understand that the ethics committee may be called upon to act as an IRB for the facility, preferably for research that's already been IRB approved somewhere else, if they want to permit research. Also, people need to understand the distinction between research and performance improvement (PI) (including collaborative PI).
  - What is ethical reasoning? How to reason ethically? What are the goals and purposes of this EC? To resolve ethical problems arising within the facility, and—more importantly—to work within the system to prevent ethical

problems from arising in the future.

- How does this EC function?
- What are some of the issues likely to be addressed by this EC? Someone said bioethics is a series of footnotes on the doctrine of informed consent. Most clinical ethical concerns in LTC relate to decision making capacity and goals of therapy as they relate to consent and end-of-life care, as outlined below.

Policy Review & Development

- What policies are needed?
  - Will need a policy to determine how cases will be reviewed by the EC. This policy must address the following:
    - How will cases be brought to the EC? Unlike other consultations, requests can ordinarily be initiated by anyone. Sometimes patient or family requests are done differently than provider requests.
    - Will the EC be able to accept or decline cases for review? Ordinarily, the chairman decides whether an ethical issue is present and (in turn) whether a task team should be convened for consultation or some other intervention done with a request for review at the next EC meeting.
    - By what process will the cases be reviewed? Requests for consultation should be reviewed by the whole committee at its next meeting if there is no time pressure. If the recommendation is needed ASAP, a subcommittee could meet and provide a recommendation and that recommendation be reviewed at the next full EC meeting.
    - Who will be involved in which steps of the process? Anyone on the EC who receives a request for consultation should start a workup to establish their opinion about the case in point.

  - How will the EC reach a conclusion upon case review? Consensus? Vote? Who will present the decision of the EC to the clinicians, patient, and family involved? The results of a consultation should be shared with everyone involved.
  - Will the EC be the final arbiter? Are the decisions recommendations only or are they binding? Generally, ECs provide facilitation or mediation; rarely does this issue require an authoritative or arbitrative decision (and then it's usually not so much an ethical issue as an administrative or legal issue that must be implemented).
  - Will the EC's decision or recommendation become part of the medical record?

- How are policies written? Draft policies should be reviewed by the committee as a whole, generally after they are written by the best policy writer or taken from draft competencies.
- How often are policies reviewed? Policies and procedures should have a date of expiration; 2 years generally works. One problem is that there are often ethical issues with the P&Ps and it is difficult to get to all of them.
- What organizational policies must the EC review? When? How often? The EC should be selective in reviewing the most important or needed P&Ps.

Sharing the EC With the Community

- How will people learn about the EC? Clinicians? Patients? Families? Consumers? Third-party payers? Will it be enough to e-mail everyone highlights of the committee's work quarterly? Will it be enough to post notices and brochures of how to access the committee?
- How will the organization or network be kept aware of the EC's work?
- How will the work of the EC be evaluated? Where is the EC accountable in the organizational chart?

Consider & Anticipate Barriers to the EC's Success	• Is there interest among the staff in having or working with an EC? Is there an opposition to an EC? • What ethical problems do the staff identify now, if any? What are the gaps that need to be closed? • Who has training, experience, and competence now? Who needs to be trained? • How much turnover is there among the staff? Among key positions? • What is the culture within the organization? Will frank discussions be possible among colleagues and across disciplines? Will peoples' schedules tolerate one more meeting, because the committee will need to meet often enough to keep momentum up? • Will there be compensation for additional responsibilities with EC membership (financial, recognition, education)? How will allowances be made for the additional time this is going to take? How much extra money is available for outside continuing education? • Does the administration value the goals proposed by the EC? Does the outside management (board, owners) value this?

Section 5 >> Procedures

Whatever the form the venue for ethics takes in your institution, a clear set of policies and procedures must be in place to address the variety of issues that may arise. The form these procedures take may be influenced by a number of factors, including not only the nature of the various issues that may confront the institution, but also state and federal laws and regulations governing commonly occurring ethical issues.

As an example, New York's Family Health Care Decision Act requires health care facilities, such as hospitals and LTC facilities, to establish an "Ethics Review Committee" and spells out many of its functions and parameters. Thus, the policies and procedures designed must conform to those state laws. In some cases, it may be necessary to solicit help from the institution's counsel to be certain that procedures do conform to the law.

Note that neither the term ethics nor the phrase ethics committee appears in the federal regulations governing skilled nursing facilities. Moreover, neither term appears in "Appendix PP—Guidance to Surveyors of Long Term Care Facilities" in the Medicare State Operations Manual. Nonetheless, the regulations and associated surveyor guidance strongly emphasize residents' rights and self-determination. In that ethical dilemmas may arise when resident rights conflict with established ethical principles, surveyors may request ethics committee policies and procedures as well as documents generated by the ethics committee to determine whether the facility is in compliance with the rights spelled out in federal regulations.

Policies and procedures should be sufficiently specific to address the most common issues facing ethics committees, but not so detailed or extensive that compliance becomes challenging. For instance, an ethics committee with a large membership may find it difficult to convene a quorum for urgent cases that arise unexpectedly. In such cases, it may be practical to provide alternative mechanisms other than having the entire committee convene.

Creating the Forum

The first step in creating a venue for consideration of ethical issues and dilemmas is to determine the structure and members of the team. Depending on the size of the organization, the structure of the organization, and the availability of participants, the group may vary. These are just a few examples and are not meant to be complete:

1. **Institutional Ethics Committee—**this is the most common and familiar forum, composed of members from a single institution.
2. **Multilevel Organization Ethics Committee—**for larger organizations comprising multiple levels of care, it may be practical to create a single ethics committee that manages the ethical considerations throughout the organization.
3. **Regional Ethics Committee—**some skilled nursing facilities may be too small to support their own ethics committees. Instead, they may contribute one or more members to a regional ethics committee that comprises members from several geographically clustered institutions.
4. **Ethics Consultation Service—**for skilled nursing facilities that are unable to assemble an ethics committee, it may be more practical to acquire the services of an ethicist or to identify an individual within the organization with ethics expertise to provide consultative guidance when requested or required.

Meeting Structure

Meeting structure will, to a large extent, be dictated by the composition and structure of the ethics committee. However, the following recommendations are intended to encourage an evolving and capable group:

1. **Establish regular meeting times—**Although not everyone may be able to make every meeting, having a regular meeting time will help to create a sense of purpose and permanence. The initial meetings may be more frequent and may be preoccupied with developing policies, procedures, and a curriculum for training. Thereafter, meetings may be less frequent.
2. **Consider having an established ethics expert provide initial ethics training—**Before the group can consider real cases, it will be important for the membership to gain some proficiency in the principles and methodologies of ethical deliberation. Having a recognized expert, particularly one with some experience setting up or running ethics committees, will give the team a good head start. The following table may be useful in outlining ethical principles and dilemmas that should be addressed during training:

Medical Indications

1. The Principles of Beneficence and Nonmaleficence
2. What is the patient's medical problem? History? Diagnosis? Prognosis?
3. Is the problem acute? Chronic? Critical? Emergent? Reversible?
4. What are the goals of treatment?
5. What are the probabilities of success?
6. What are the plans in case of therapeutic failure?
7. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?

Patient References

1. The Principle of Respect for Autonomy
2. Is the patient mentally capable and legally competent? Is there evidence of incapacity?
3. If competent, what is the patient stating about preferences for treatment?
4. Has the patient been informed of benefits and risks, understood this information, and given consent?
5. If incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards for decision making?
6. Has the patient expressed prior preferences, e.g., Advance Directives?
7. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?
   In sum, is the patient's right to choose being respected to the extent possible in ethics and law?

The Principles of Beneficence and Nonmaleficence and Respect for Autonomy

1. What are the prospects, with or without treatment, for a return to normal life?
2. What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?
3. Are there biases that might prejudice the provider's evaluation of the patient's quality of life?
4. Is the patient's present or future condition such that his or her continued life might be judged undesirable?
5. Is there any plan and rationale to forgo treatment?
6. Are there plans for comfort and palliative care?

The Principles of Loyalty and Fairness

1. Are there family issues that might influence treatment decisions?
2. Are there provider (physicians and nurses) issues that might influence treatment decisions?
3. Are there financial and economic factors?
4. Are there religious or cultural factors?
5. Are there limits on confidentiality?
6. Are there problems of allocation of resources?
7. How does the law affect treatment decisions?
8. Is clinical research or teaching involved?
9. Is there any conflict of interest on the part of the providers or the institution?

Adapted from: Jonsen AR, Siegler M, Winslade WJ. Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine. 2002. New York, NY: McGraw Hill.

3. **Establish an agenda—**It will take time for the committee to develop a basic mastery of the principles and practice of ethics. The first few meetings may be entirely filled with training and with sample cases. Thereafter, as the committee is asked to deliberate on real ethical dilemmas, continuing to provide articles and other materials will assist in the continuing educational development of the committee. Also, should there not be a case to consider at a scheduled meeting, the team may opt to discuss a particular ethics article or develop a new policy and procedure dealing with ethical matters.

4. **Select a chairperson—**The chairperson should be a good moderator and one who is committed to open discussion when either real or sample cases are presented. The chairperson should be flexible enough to be able to change the agenda if a particular case does not materialize or if an interesting article or current event dealing with relevant ethical issues arises.

Policies and Procedures

Once the membership and meeting structure have been settled, it will fall upon the committee to develop policies and procedures for the committee to move forward. Before developing formal policies and procedures, it may be helpful to start by developing an Ethics Committee Charter that describes the composition, mission, structure, and functions of the committee. (Generally, a charter will not require administrative approval, whereas a formal policy and procedure will.) This can become the basis for a more formal policy and procedure.

The policy should begin by stating the purpose and mission of the ethics committee (see Section 1: Mission). Note that the mission or statement of purpose of an ethics committee may differ from committee to committee.

The policy should then address the following general issues:

- The goals of ethics consultation and the ethics committee.
- Who may request ethics consultation.
- Who may perform ethics consultations.
- What requests are appropriate for the ethics committee.
- How participants’ confidentiality and, when appropriate, anonymity, will be protected.

Among the functions and purposes of the ethics committee, the following may be included:

- Increasing awareness of ethical issues and dilemmas in LTC.
- Contributing to proper management of ethical issues and dilemmas.

- Developing mechanisms to enhance the autonomy of residents and patients.
- Respecting individual residents and staff (the stakeholders).
- Facilitating teamwork.
- Educating staff, residents, families, administration, and the committee itself in ethics principles and methodologies.
- Dealing with ethical issues transparently.

Clearly, the facility's own values should color the list of functions and purposes.

The major thrust of the procedures will, of course, spell out how the committee will identify and initiate ethics consults. As noted before, certain areas may need to be spelled out in state legislation, such as authorizing DNR (allow natural death) orders when no one is available to function as an agent for a patient or resident who lacks decision making capacity. Otherwise, the procedure should spell out fairly clearly the means by which the committee will become involved in ethical dilemmas and conflicts. A sample policy is included in the forms section (see Section 7: Sample Policy and Forms).

The issues that should be covered may include:

1. Who may contact the ethics committee.
2. How the ethics committee is to be contacted, both during working hours and at night or on weekends and holidays.
3. How the ethics committee will perform initial fact-finding to determine the appropriate manner in which the conflict is to be handled.
4. What is the method for case analysis.
5. How the ethics committee will report its findings and recommendations.

1. Who may contact the ethics committee

Generally speaking, it is advisable to cast as wide a net as possible when identifying who may contact the ethics committee. Obviously, the patient or resident is primary, but family members, staff, and other employees should have access as well. It will be up to the ethics committee to then determine the appropriate route to take. The committee may serve as a resource for attending physicians facing troubling choices or conflicting care demands.

2. How the ethics committee is to be contacted, both during working hours and at night or on weekends and holidays

It may be most convenient to set up a dedicated phone line with voice mail to allow easy contact with the ethics committee. In addition, it would be advisable to distribute a flyer or pamphlet describing the purpose and function of the ethics committee, including not only the ethics “hotline,” but the names of key members who can also be contacted. A mechanism would need to be instituted to ensure that the “hotline” is checked regularly.

3. How the ethics committee will perform initial fact-finding to determine the appropriate manner in which the conflict is to be handled

It is impractical to immediately involve the entire committee once a request for ethics consultation has been received. The committee will need to decide how the initial assessment of the case will be made. One option is to have an individual evaluate the case and determine whether a full committee meeting is necessary. Another option is to designate rotating teams of two or three members to evaluate and triage the case. Some requests may turn out to have relatively straightforward solutions and will not require the full committee to be convened. For instance, in the case that a patient has clearly stated a decision, but had a family member disagree, the committee member or subgroup might quickly determine that autonomy is the operative principle and that no real ethical conflict exists (naturally, how to handle this so as to educate the patient, family, and the health care team is something that needs to be handled sensitively and thoroughly).

4. What is the method for case analysis

Whereas it is not necessary to indicate the specific methodological analysis that will be used for deliberating ethics cases (e.g., The “four quadrant” method of Jonsen, Siegler, and Winslade as illustrated in the table on pages 22-23), it is advisable that one or more structured formats be adopted by the committee.

There will also be cases in which the full committee will need to meet with the patient, resident, family, or health care team. The policy and procedure need not specify when this is appropriate, but should allow for the attendance of key involved individuals when appropriate.

5. How the ethics committee will report its findings and recommendations

One of the most controversial and contentious issues facing ethics committees is whether the findings and recommendations of the committee should be recorded in the medical record. A variety of viewpoints exist, but it is probably a good idea to document the deliberation and recommendations of the ethics committee in the medical record. This should, of course, be done by a member of the committee with the necessary writing skills to express fairly complex principles succinctly and nonjudgmentally.

It is also a good idea to maintain clear minutes. The committee will need to confer with facility counsel to determine how these are best maintained and the impact on discoverability. In some cases, it may be preferable to refer to cases by only numbers or initials so as to maintain confidentiality should the minutes be subject to discovery, survey, or other audits. Keeping good minutes will also allow the committee to revisit past cases to learn the impact of their input.

Advance Directives for Residents Who Lack Decision Making Capacity

A common problem facing ethics committee is the lack of advance directives in residents who lack decision-making capacity. This issue was discussed in detail by Volicer et al (J Am Geriatric Soc 2002;50:761). After careful review of the ethical, legal, and clinical perspectives, the authors concluded that advance care planning for residents of LTC facilities who lack decision making capacity is ethically sound. The process encourages clinicians and proxies to discuss and plan for end-of-life scenarios before the onset of crises by considering the patient's expressed or inferred wishes. Advance proxy planning also helps to build trust and shared understanding and reduces undue burdens on the patient, family, and health care team.

The authors recommended the following as the minimum criteria for a process of advance care planning for residents of LTC who lack capacity:

1. The process of proxy planning should include at least one meeting (face-to-face if possible) between the patient's proxy and members of the interdisciplinary team. This meeting should be held soon after admission but after the staff has completed a full assessment of the resident.
2. During the meeting, the proxy and others who know the patient should carefully consider and articulate the patient's previously expressed goals, values, and preferences to the extent that they are known.
3. If the patient had executed a formal advance directive while competent, the directive should be examined and used to help to establish the patient's wishes. The proxy plan should be consistent with any specific instructions expressed in an advance directive document. In the absence of specific instructions, plans should be based on the patient's goals and values and on the best interests of the patient as determined by the proxy with the help of the health care team.
4. The attending physician should document the proxy plan in an explanatory progress note and on a standardized proxy planning form. An example of one such form ("Long Term Care Advance Proxy Planning") is reproduced in the forms section (see Section 7: Sample Policy and Forms). An appropriate physician order should be entered on the basis of decisions contained in the proxy plan. Ethical planning should be a part of the overall care planning process. Periodic mandatory care planning meetings may be an efficient and appropriate venue for the resident, family, and care team to revisit and reconfirm prior decisions regarding goals of care and to update advance directives.
5. Proxy planning forms are intended to help guide discussion, clarify decisions, and document plans. They are not to be used as a substitute for ongoing discussions between the proxy and

members of the health care team. Even after a proxy planning form is completed, clinicians need to be in regular communication with the proxy to provide information about changes in the patient's status, to seek guidance, and to obtain informed consent as appropriate.

6. Proxy planning documents should be prominently and consistently filed in the patient's medical record. The documents should accompany patients when they are transferred to other settings.
7. The patient's proxy should sign the proxy planning document and receive a copy.
8. The proxy may choose to change or revoke the plan at any time. In addition, the form should be reviewed with the proxy and updated on an annual basis or sooner when any of the following occurs: patient transfer to another setting, significant change in the patient's health, or availability of new treatments. Any changes to the proxy plan need to be documented in the patient's chart and on the proxy planning form itself.
9. If an existing proxy dies, loses decision making capacity, or becomes unavailable, a new proxy plan should be instituted with a substitute proxy. The new proxy should take into consideration decisions made by the previous proxy.
10. Conflicts between the proxy, other family members, and the clinical staff concerning the type or level of treatment that cannot be resolved at a meeting of family members with interdisciplinary staff should be referred to a local ethics advisory committee for consultation.
11. To ensure quality, the proxy planning process should be regularly evaluated from the perspective of its various participants. Interviews with family members after the patient's death should be conducted with appropriate sensitivity to their loss.

A modified POLST (Physician Orders for Life-Sustaining Treatment Paradigm) form (“Long Term Care Advance Proxy Planning”), recommended by this article for use in LTC facilities is included in the forms section (see Section 7: Sample Policy and Forms) for states that did not adopt the POLST form already. State-specific POLST forms are available at http://www.ohsu.edu/polst/programs/sample-forms.htm.

Section 6 >> Cases

These cases are combined from elements of actual ethical problems and issues that commonly occur in LTC and were edited to highlight significant issues. They are intended as potential material for discussion and self-education by an ethics committee as it prepares for more formal case consultations or as its composition changes. Sample questions have been added to help focus the discussion, although many additional questions might arise as well. These additional questions may at times be as or more useful than those suggested. Depending on learning styles, many health care workers find ethical principles easier to discuss in the context of actual cases rather than as abstract principles. This is a commonly used format in legal education as well.

CASE 1

A 90-year-old woman has been admitted to the LTC facility owing to progressive immobility from prior osteoporotic fractures and end-stage arthritis. On initial evaluation, she is found to have a blood pressure of 220/116 on multiple determinations in varying positions. She is cognitively intact, but refuses to take any medication to lower her blood pressure despite careful explanations of her high risk of stroke or other cardiovascular events. She states, “I’m too old for pills and if the Good Lord wants me, I am ready.” Her physician asks that the facility require her to take her medicine, asserting that failure to do so would be “assisted suicide.”

What ethical principles are in conflict in this case? Does one of these principles “trump” the other?

Does this case meet the criteria for assisted suicide?

CASE 2

An elderly woman is admitted to the LTC facility for rehabilitation after surgical repair of a femoral fracture. The social worker discovers that the patient has had a long history of reclusive behavior before her accident. After admission, the resident refuses to bathe or shower and gradually develops a remarkable odor that is increased by her frequent urinary incontinence. She is otherwise cheerful, participates actively in her therapy (although the therapists ask not to be assigned to her), sleeps well, and eats enthusiastically. Cognitive screening tests reveal no evidence of a dementing illness. The families of several other residents approach the unit manager to insist that the patient be either cleaned up or kicked out.

What ethical principles are in conflict in this case?

What rights does a facility have to limit the independence of individual residents?

CASE 3

A 60-year-old male is admitted to the facility after a coronary artery bypass graft complicated by a small stroke. He is a lifelong smoker with a history of diabetes mellitus and elevated cholesterol levels. He also has a history of a first schizophrenic break at age 20 with several psychiatric hospitalizations since then. Although the transfer orders state that he is supposed to be on an anti-psychotic medication, he refuses it. He states that he had stopped taking it at home and had refused it in the hospital (a review of hospital records confirms this) because of the literature associating these medications with cardiovascular risk factors and sudden cardiac death. He also states that they make him feel as though his “mind was half asleep.” His attending physician refuses to discontinue the order for the anti-psychotic because “crazy people don’t get to decide not to take psych meds.”

> *What ethical principles are in question here?*
>
> *Does a history of psychiatric illness automatically mean that a resident loses autonomy? If not, how would we determine whether this resident has decision-making capacity in this case?*
>
> *The day nurse proposes that she could put the medicine in his morning coffee without his knowledge. Would that be an ethical solution for this conflict? If not, why not?*

CASE 4

An 80-year-old widower has been a resident of the LTC facility for several years with rapidly progressing dementia. He is estranged from his only son, who lives across the country but also has not visited or called his father since admission. On the other hand, his best friend, Frank, comes to visit regularly, bringing him his favorite donuts from the local shop and taking him out to the garden for some fresh air. Recently, an enlarging mass has been noted on the resident’s chest x-ray and a decision needs to be made regarding possible biopsy and treatment. The resident clearly lacks capacity to make medical decisions for himself.

> *Who should make the decision? Why?*
>
> *Would this decision be different if the resident said “just ask Frank?”*

CASE 5

Peter is a 72-year-old man with known Alzheimer’s disease who has been a resident of the LTC facility for nearly a year. Before his admission, he was known to have an elevated prostate-specific antigen (PSA) level and his urologist had recommended follow-up in 6 months to a year. The value is now significantly higher. His daughter, who is also his designated representative, asks to meet with the urologist to discuss further workup and management. But the nurses on the unit are concerned, saying that Peter knows perfectly well what is going on and should be allowed to make his own decision. They describe the daughter as “bossy and controlling.”

> *Does the diagnosis of dementia automatically imply an inability to make medical decisions? How is capacity determined and by whom? What happens when some members of the interdisciplinary team disagree with others? Should the facility have a policy or should decisions regarding capacity be made on a case by case basis?*

CASE 6

Mr. S. has just returned from the hospital after sustaining a second and much more massive stroke. He has been losing significant weight and clearly experiences great difficulty chewing and swallowing. The speech and language pathologist evaluated him and recommended a feeding gastrostomy. His wife is refusing, but his daughter wants the procedure done. The social worker, after a long discussion with the wife, believes that her decision is being made because the wife is tired of visiting him and is unhappy with the financial burden of paying for his care. She is ready to “move on” and wants him to get out of the way. She has been seen frequently around town in the company of another man and rumors have started.

> *Who should decide about the feeding tube? Is there such a thing as a disinterested surrogate? What should be done when a facility suspects/knows that a surrogate is not acting in the resident’s best interest?*

CASE 7

Mrs. C is a 90-year-old woman with longstanding chronic obstructive pulmonary disease (COPD) and a recently diagnosed lung cancer metastatic to bone. She has been lethargic, moaning, and grimacing. Her obvious pain has not responded to non-narcotic analgesics or low doses of narcotics. The hospice team recommends morphine but the nursing staff is reluctant to administer it because of concern that it will suppress her respiration and hasten her death. They believe it would violate the religious principles on which the facility was founded as well as their own, deeply held, religious and ethical beliefs.

> *Would the principle of double effect (see Section 8: Bioethics Glossary) apply here?*
>
> *Does the facility actually have specific ethical or religious concerns that might overrule the clinical decisions of the interdisciplinary team or of residents and their families?*
>
> *If so, how are these expressed or explained?*
>
> *Should individual staff members be allowed to refuse to carry out medical orders on the basis of their own ethical beliefs? Are there limits to this or mechanisms to minimize the effects of a*

> *refusal on the rights of a resident? Does it matter if the expressed belief of a staff member is not actually the valid doctrine of their religious affiliation?*

CASE 8

Mrs. B. is a 70-year-old woman with end-stage renal disease who has been on hemodialysis for more than 10 years. When she started dialysis, she gave consent herself and made her own arrangements to get to the center. Now she has declined significantly, requiring a wheelchair for mobility and has been placed in a LTC facility. At her care planning conference, she informs the team that she has decided to forgo hemodialysis even though she is aware that she is unlikely to live more than 2 weeks without treatment. She requests a hospice referral, stating that the discomfort of dialysis is becoming excessive and she is tired and "wants to go to the Lord." Several members of the team are concerned that withdrawing a treatment that has clearly been effective amounts to euthanasia. They propose administering antidepressants and continuing dialysis.

> *Is there an ethical difference between withholding a treatment initially and withdrawing it later?*
>
> *Is this patient a valid candidate for hospice/terminal care because she could definitely live for several more years if she simply continued her treatments?*

CASE 9

Mrs. S is a 90-year-old widow with six of her eight children still alive. Many years ago she signed a Living Will stating that if she were "permanently and irreversibly terminally ill" she wanted her physicians to forgo any "extraordinary measures" and simply provide pain relief. Two years ago she had a large stroke and is unable to speak, although she appears to recognize her children. She now has a large breast mass and the surgeon is proposing a simple mastectomy. Four of the six children wish to proceed, but two are opposed, stating that surgery in a 90-year-old woman with advanced vascular disease and cancer should be considered extraordinary and a violation of her expressed wishes.

> *Is this a decision where majority rules? If not, how should a decision be made? Who interprets a Living Will?*
>
> *What constitutes an "extraordinary measure?" Could a measure be ordinary for one person and extraordinary for another?*

CASE 10

Mr. P is completely deaf in the right ear but only mildly hearing impaired in the left ear. He uses a hearing aid at times, which is kept at the nursing station during the night. Although he has moderate stage dementia, he is normally interactive and cooperative when he understands what is happening. However, on two occasions he has struck nursing assistants on the night shift when they came to assist him to the bathroom or to help him get dressed in the morning. In both cases, the nursing assistants claim to have introduced themselves and to have informed him of their plans, but he states that he had no idea who they were and he thought they were trying to hurt him. The nursing supervisor on nights proposed that a large sign be placed above his bed warning the staff that the resident is hearing-impaired and that they should speak loudly but slowly into his left ear.

> *Would this be a violation of Mr. P's privacy rights?*
>
> *Does the staff have rights to personal safety as well?*
>
> *Could Mr. P waive his rights in this case?*

RESIDENT RIGHTS AND ORGANIZATIONAL ETHICS	**POLICY # RI 100-A**
TITLE: ETHICS REVIEW COMMITTEE	**EFFECTIVE DATE: 11/10**
(FORMERLY ETHICS ADVISORY COMMITTEE)	**SUPERSEDES: 7/10**

POLICY

Nursing Center shall have an Ethics Review Committee to assist patients/residents, staff and families in making decisions when moral conflicts arise or at end of life. The Ethics Review Committee will serve a mainly advisory function

PURPOSE

1. To consider and respond to any health care matter or request for assistance in resolving a moral dispute presented by a Person Connected with the Case, including, but not limited to:
    a. Initiation of Palliative Care
    b. Review of existing advance directives
    c. Disagreements among family members/caregivers
    d. Questions about a patient/resident's best interest
    e. Resolving disputes when the Health Care agent's wishes are contrary to the patient/resident's advance directives

2. To consider and respond to any health care matter or request for assistance in resolving a dispute presented by a Person Connected with the Case, including, but not limited to:
    a. The determination of incapacity for a patient/resident
    b. The choice of a surrogate
    c. A decision by a surrogate

    d. A recommendation or concurring opinion for treatment for a patient/resident, who lacks a surrogate

    e. A clinical determination for decisions to withdraw or withhold life-sustaining treatment

3. To provide education, policy development or case consultation when requested or required

DEFINITIONS

Attending Physician means a physician, selected by or assigned to the patient, who has primary responsibility for the patient's care and treatment. Where more than one physician shares this responsibility, or where a physician is acting on the attending physician's behalf, any such physician can act as the attending to carry out responsibilities under this Policy.

Decision-making capacity means the ability to understand and appreciate the nature and consequences of proposed health care, including the benefits and risks of, and alternatives to proposed health care, and to reach an informed decision.

Ethics Review Committee means the interdisciplinary committee established to carry out the responsibilities of this Policy.

Health care provider means an individual or facility licensed, certified, or otherwise authorized or permitted by law to provide health care in the ordinary course of business or professional practice.

Health or social service practitioner means a registered professional nurse, nurse practitioner, physician, physician assistant, psychologist or licensed clinical social worker, licensed or certified under the Education Law acting within his or her scope of practice.

Person Connected with the Case means the patient, any person on the surrogate list, the parent or guardian of a minor patient, the facility's administrator, an attending physician, any other health or social services practitioner who is or has been directly involved in the patient's care, and any duly authorized state agency, including the facility director or regional director for a patient transferred from a mental hygiene facility and the facility director for a patient transferred from a correctional facility.

RESIDENT RIGHTS AND ORGANIZATIONAL ETHICS POLICY # RI 100-A

TITLE: ETHICS REVIEW COMMITTEE EFFECTIVE DATE: 11/10

(FORMERLY ETHICS ADVISORY COMMITTEE) SUPERSEDES: 7/10

Life-sustaining treatment means any medical treatment or procedure without which the patient will die within a relatively short time, as determined by the attending physician to a reasonable degree of medical certainty. Life-sustaining treatment includes CPR.

COMPOSITION OF THE ETHICS REVIEW COMMITTEE

1. The membership of the Ethics Review Committee shall be interdisciplinary, and will include at least five members who have demonstrated an interest in or commitment to patient/resident's rights. Members must include the following:
    a. Physician
    b. Social worker
    c. Registered nurse
    d. A person without any governance, employment or contractual relationship with VCRN
2. Nursing Center shall offer the Residents' Council the opportunity to appoint up to two persons to the Committee, none of whom may be a resident of or a family member of a resident of Nursing Center and both of whom shall have expertise in or a demonstrated commitment to patient/resident rights or to the care and treatment of the elderly or facility's patients/residents through professional or community activities, other than activities performed as a health care provider.
3. A Person Connected with the Case may not participate as an Ethics Review Committee member in considering that case.

RESIDENT RIGHTS AND ORGANIZATIONAL ETHICS POLICY # RI 100-A

TITLE: ETHICS REVIEW COMMITTEE EFFECTIVE DATE: 11/10

(FORMERLY ETHICS ADVISORY COMMITTEE) SUPERSEDES: 7/10

FUNCTION AND AUTHORITY

1. The Ethics Review Committee shall carry out the following responsibilities:
    a. Consider and respond to any health care matter or request for assistance in resolving a dispute presented by a Person Connected with the Case, including, but not limited to: the determination of incapacity for a patient, the choice of a surrogate, a decision by a surrogate, a recommendation or concurring opinion for treatment for a patient/resident who lacks a surrogate, or a clinical determination required for decisions to withdraw or withhold life-sustaining treatment; and
    b. In cases where the surrogate has decided to consent to withdraw or withhold life-sustaining treatment for a patient/resident who is not terminally ill or permanently unconscious, the Ethics Review Committee shall review the decision and determine whether the decision meets the standards set forth in this Policy for such decisions.
2. The facility may assign other duties to the Ethics Review Committee, such as education, policy development or case consultation, or may designate another committee in the facility to carry out such functions.
3. When the Ethics Review Committee carries out the functions in 1(b) above, it has the authority to determine whether a surrogate’s decision meets the standards of the applicable policies for such decisions.
4. The Ethics Review Committee’s response to any other matter presented by a Person Connected with the Case or any dispute shall be advisory and nonbinding, and may include:
    a. Providing advice about the ethical aspects of proposed health care;
    b. Making a recommendation about proposed health care; or
    c. Providing assistance in resolving disputes about proposed health care or other matters, such as the determination of incapacity or the choice of surrogate.

RESIDENT RIGHTS AND ORGANIZATIONAL ETHICS	**POLICY # RI 100-A**
TITLE: ETHICS REVIEW COMMITTEE	**EFFECTIVE DATE: 11/10**
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PROCEDURE

1. The Ethics Review Committee will meet at least quarterly and whenever requested to review a case or to make a determination as required by the Family Health Care Decisions Act.
2. If there is no outstanding case at the time of the meeting, the Ethics Review Committee has the option of engaging in education or training.
3. The Ethics Review Committee shall respond promptly, as required by the circumstances, to: (a) any request for assistance in resolving a dispute by a Person Connected with the Case, or (b) to a request for consideration by a Person Connected with the Case of a case requiring a determination by the Committee regarding a surrogate decision to withdraw or withhold life-sustaining treatment.
4. The Committee shall promptly give the patient/resident, if there is any indication of the patient/resident's ability to comprehend the information, the surrogate, other persons on the surrogate list directly involved in the decision or dispute regarding the patient/resident's care, the attending physician, a designated representative of the facility's administration, and any other person the Committee deems appropriate the following:
    a. Notice of any pending case consideration concerning the patient/resident, and for patients/residents on the surrogate list, information about the Ethics Review Committee's procedures, composition and function; and
    b. The Committee's response to the case, including a written statement of the reasons for approving or disapproving a surrogate's decision to withdraw or withhold life-sustaining treatment for a patient who is not terminally ill or permanently unconscious.
5. The Ethics Review Committee shall permit Persons Connected with the Case to present their views to the Committee and to have the option of being accompanied by an advisor when participating in a Committee meeting.
6. The Committee's response to each case covered above shall be included in the patient/resident's medical record.

7. Following the Ethics Review Committee's consideration of a case concerning the withdrawal or withholding of life-sustaining treatment, treatment shall not be withdrawn or withheld until the persons listed above in section #4 have been informed of the Committee's decision.

Nursing Center may establish policies or procedures to seek to resolve any disputes that arise by less formal means before referring the matter to the Ethics Review Committee, including, but not limited to an ethics, social work or other consultation, or a committee composed of a subset of the Ethics Review Committee.

CONFIDENTIALITY

1. Committee members and consultants shall have access to medical information and records necessary to perform their functions in accord with this Policy. Any such information disclosed to Committee members, consultants or others shall be kept confidential, except to the extent necessary to accomplish the purposes of this policy, or as set forth below, or as otherwise provided by law. Notwithstanding any other provision of law, the proceedings and records of the Ethics Review Committee shall be kept confidential and shall not be released by Committee members, consultants, or other person privy to such proceedings and records.
2. The proceedings and record of an Ethics Review Committee shall not be subject to disclosure or inspection in any manner, including under Article 6 of the Public Officers Law or Article 31 of the Civil Practice Law and Rules.
3. No person shall testify regarding the proceedings and records of an Ethics Review committee, nor shall such proceedings and record otherwise be admissible as evidence in any action, or proceeding of any kind in any court or before any other tribunal, board, agency or person.
4. In cases where the Committee makes a decision to approve or disapprove a surrogate's decision to withdraw or withhold life-sustaining treatment for a patient who is not terminally ill or permanently unconscious, Ethics Review Committee Records and proceedings may be obtained by and released to the New York State Department of Health.

RESIDENT RIGHTS AND ORGANIZATIONAL ETHICS	**POLICY # RI 100-A**
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5. Nothing in this Policy shall prohibit the patient, the surrogate or other persons on the surrogate list, from voluntarily disclosing, releasing or testifying about Ethics Review Committee proceedings and records.
6. Nothing in this Policy shall prohibit the State Commission on Quality of Care and Advocacy for Persons with Disabilities, or any person or agency with or under contract with the Commission which provides protections and advocacy services, from requiring any information, report or record from a nursing home in accord with the provisions of Mental Hygiene Law Section 45.09.

RESPONSIBILITIES

Administration shall monitor compliance to this policy and procedure.

REVIEWED/APPROVED

DATE: _______________ **BY:** _______________________________ **TITLE:** ______________________

DATE: _______________ **BY:** _______________________________ **TITLE:** ______________________

DATE: _______________ **BY:** _______________________________ **TITLE:** ______________________

ETHICS COMMITTEE CONSULTATION REQUEST

Date of request: ____________ Consult requested by: ______________________________

Patient's Name: _____________________________________ Room: __________

Age: _______ Race: __________ Gender: M F Religion: _____________

Physician aware of request?
Y N

Attending Physician: _________________________________

Check one or more of the following categories, then briefly state reason for consult request:

☐ Concern over ability to meet clinical or emotional needs of the patient

☐ Concern that surrogate decision maker is not acting in the patient's best interest

☐ Conflict between regulations and family's wishes for specific interventions

☐ Conflict with physician, family, or facility over direction of care

☐ Conflict within family over direction of care

☐ Conflict over rights, privacy, &/or safety concerns

☐ Conflict over withholding/withdrawing life-prolonging interventions (specify intervention: ______________________________________)

☐ Conflict over advance directives

☐ Concerns about patient's behavior (e.g., aggressiveness, inappropriateness, etc.; specify: ______________________________________)

☐ Request for participation in research project

Question to be answered:

____

____

____

Patient History (attach relevant medical records, if necessary):

____

____

____

____

____

Patient's decision making capacity: _______________________________________

____

Patient's wishes: ☐ unknown ☐ known: ______________________________

____

Advance Directive Status:

Living Will? Y N Guardian / medical power of attorney appointed? Y N

Do not resuscitate? Y N Name: ________________________________

Do not intubate? Y N Relationship: ____________________________

Do not hospitalize? Y N Phone: ________________________________

Other directives: ____

ETHICS COMMITTEE WORKSHEET

Date of Ethics Committee Meeting: ___________

Patient's Name: ________________________________ Room: _________

Age: ______ Race: _________ Gender: M F Religion: ____________

Attending Physician: _____________________________

Stated Reason for Consultation Request:

☐ Concern over ability to meet clinical or emotional needs of the patient

☐ Concern that surrogate decision maker is not acting in the patient's best interest

☐ Conflict between regulations and family's wishes for specific interventions

☐ Conflict with physician, family, or facility over direction of care

☐ Conflict within family over direction of care

☐ Conflict over rights, privacy, &/or safety concerns

☐ Conflict over withholding/withdrawing life-prolonging interventions (specify intervention: ____________________________________)

☐ Conflict over advance directives

☐ Concerns about patient's behavior (e.g., aggressiveness, inappropriateness, etc.; specify: ____________________________________)

☐ Request for participation in research project

Ethics committee restatement of consult (question to be answered)**:**

____

____

____

____

Informants for Ethics Committee

☐ Patient ☐ Family ☐ Friend ☐ Attending Physician ☐ Other Physician

☐ Nurses ☐ Social Workers ☐ Chaplain ☐ Attorney

☐ Medical Records ☐ Other ____________________________

Patient’s decision making capacity: ____

____

Patient’s wishes: ☐ unknown ☐ known: ___________________________________

____

Advance Directive Status:

Living Will? Y N Guardian / medical power of attorney appointed? Y N

Do not resuscitate? Y N Name: ______________________________________

Do not intubate? Y N Relationship: _________________________________

Do not hospitalize? Y N Phone: ______________________________________

Other directives: ____

Committee Members Present:

1. ________________________________
2. ________________________________
3. ________________________________
4. ________________________________
5. ________________________________
6. ___________________________________
7. ___________________________________
8. ___________________________________
9. ___________________________________
10. __________________________________

ETHICS COMMITTEE WORKSHEET

Relevant Ethical Issues Comments:

☐ Autonomy ______________________________

☐ Beneficence ______________________________

☐ Non-maleficence ______________________________

☐ Paternalism ______________________________

☐ Truth telling ______________________________

☐ Confidentiality ______________________________

☐ Double Effect ______________________________

☐ Justice ______________________________

☐ Stewardship ______________________________

☐ ______________________________

☐ ______________________________

☐ ______________________________

☐ ______________________________

☐ ______________________________

☐ ______________________________

☐ ______________________________

☐ ______________________________

Who will be affected by this decision?

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________

Possible Recommendations: Comments / Issues / Discussion

1. ____________________

2. ____________________

3. ____________________________ ____

4. ____________________________ ____

Other Comments: ____

Recommendation:

☐ Defer recommendation pending further data collection: ________________________

____

☐ Defer recommendation (reason: ____)

☐ Other: ____

☐ Recommendation written and submitted: (date: __________________)

ETHICS COMMITTEE RECOMMENDATIONS

Date of consult: ___________

Patient's Name: ___________________________________ Room: _________

Age: ______ Race: _________ Gender: M F Religion: ____________

Attending Physician: _______________________________

Ethics committee restatement of consult (question addressed)**:**

____

____

____

Relevant Ethical Issues	Comments:
☐ Autonomy	____
☐ Beneficence	____
☐ Non-maleficence	____
☐ Paternalism	____
☐ Truth telling	____
☐ Confidentiality	____
☐ Double Effect	____
☐ Justice	____
☐ Stewardship	____
☐	____
☐	____

Recommendations:

1. ____

2. ____

LONG TERM CARE ADVANCE PROXY PLANNING

This template is not an official VA form, but is provided as an example to assist local facilities in developing their own form, which must be reviewed and approved by the local medical records committee. VA Form 10-0137, "VA Advance Directive" should still be used for advance care planning by patients who have the ability to make their own health care decisions (see VHA Handbook 1004.2). Forms like this one may be used to facilitate advance care planning on behalf of patients who lack decision-making capacity. The form is intended to promote: a) in-depth discussion between health care teams and proxies of patients who lack decision-making capacity; and b) documentation of treatment preferences and goals of care. The "proxy" is the patient's legal guardian or health care proxy, if available, or the person designated by the patient and/or family to make health care decisions on the patient's behalf. The involved parties should discuss the patient's personal values, treatment preferences, and best interests. The overall goals for care, including providing or not providing life-sustaining treatments, should be clarified. In addition, health care teams should explain to proxies how available levels of care vary across different health care settings. This form should not be used as a checklist in the absence of discussion. After completion, the original of the approved form should be placed in the patient's medical record, and a copy given to the proxy.

PATIENT/RESIDENT INFORMATION:

______________________	______________________	______________________
(Last Name First Name Middle Initial)	(Social Security Number)	(Date of Birth)
______________________	______________________	______________________
(Attending Physician)	(Service of Specialty)	(Office Phone or Pager)
______________________	______________________	______________________
(Proxy)	(Daytime Phone)	(Evening/Weekend Phone)
______________________	______________________	______________________
(Alternate if proxy listed above is not available)	(Daytime Phone)	(Evening/Weekend Phone)

Advance Directive on File? _______Yes _______ No

MEDICAL INTERVENTIONS (check one option from each pair):

Attempt Resuscitation	☐	or	☐	**Do Not Attempt Resuscitation**
Transfer to Acute Care Facility	☐	or	☐	**No Transfer to Acute Care Unless Required for Comfort** (This will restrict certain interventions)
Advanced Interventions (Consider oral/nasal airway, bag-mask/demand valve, monitor cardiac rhythm, IV medication and fluids)	☐	or	☐	**Comfort Measures Only** (Oral and body hygiene, food and fluids orally, oral medications, positioning, wound care, warmth, appropriate lighting, other measures to relieve pain and suffering and assure privacy and respect for the dignity of the patient/resident)
Administer Antibiotics	☐	or	☐	**No Antibiotics Except if Needed for Comfort**
Initiate Artificial Nutrition/Hydration	☐	or	☐	**No Feeding Tube/IV fluids** (Provide other measures to assure comfort)

Other Instructions: ____

____

CARE PLANNING CONFERENCE ATTENDEES (check all who are present):

Health Care Team

☐ Attending Physician

☐ Chaplain Service

☐ Dietary Service

☐ Nursing Service

☐ Physical Rehabilitation

☐ Respiratory Therapy

☐ Social Work Service

☐ Other ____________(specify)

Patient/Proxy

☐ Patient (it may be appropriate for the patient who lacks decision-making capacity to attend this conference, especially if he or she retains some ability to communicate)

☐ Proxy (specify name and relationship to patient) ___________________________

☐ Other family members or friends of patient (specify names and relationships to patient)

____

____

____

____

SIGNATURES:

_____________________________________ Attending Physician Signature

_____________________________________ Proxy Signature

DOCUMENT REVIEW: (This care plan must be **discussed with the proxy** and updated whenever there is significant change in the patient or resident's status or condition, or in case of transfer or readmission. Otherwise the plan must be discussed and updated every year.)

☐ Scheduled Review ☐ Change in Condition or Status ☐ Transfer/Readmission

I, ________________________, discussed this plan with ______________________ on ___/___/____.
Name of Attending Physician Name of Proxy Date

____
Attending Physician Signature

Notes (***update information on preceding page if necessary***): ___________________________________

____

☐ Scheduled Review ☐ Change in Condition or Status ☐ Transfer/Readmission

I, ________________________, discussed this plan with ______________________ on ___/___/____.
Name of Attending Physician Name of Proxy Date

____
Attending Physician Signature

Notes (***update information on preceding page if necessary***): ___________________________________

____

☐ Scheduled Review ☐ Change in Condition or Status ☐ Transfer/Readmission

I, ________________________, discussed this plan with ______________________ on ___/___/____.
Name of Attending Physician Name of Proxy Date

____
Attending Physician Signature

Notes (***update information on preceding page if necessary***): ___________________________________

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Section 8 >> Bioethics Glossary

1. Philosophical Context of Ethics

Bioethics: that branch of ethics dealing with issues arising from what it means to be human in the face of physical limitation, medical therapy, illness, and death; the tension between the value placed upon life, in particular human life, and the frailty of life at the margins, the beginning and the end, particularly where life is technologically created or maintained; the proper ends of medicine in the era of an expanding realm of biotechnology; and the ethics of human relationships embedded within these situations.

Epistemology: the branch of philosophy concerned with the question, "What is truth?" Epistemology deals with questions concerning the existence and nature of truth claims, proper warrant or proof for claims to knowledge, and various types of knowledge claims.

Ethics: the branch of philosophy concerned with the question, "What is good?" Ethics deals with questions concerning what is right, obligatory, virtuous, or moral. The study of ethics includes ethical theory and applied (practical) ethics.

Metaphysics: the branch of philosophy concerned with the question, "What is reality?" Metaphysics deals with questions concerning the nature of reality; the existence or nature of God; the nature, meaning, and purpose of humanity, including the relationship of mind and body and the question of defining human personhood; and the nature of causality, human freedom, and determinism.

Modernism: a worldview perspective that sees reality through the interpretive lens of modern scientific discoveries; historically, Modernism traces back to the explosion of learning beginning with the Renaissance and Enlightenment and continuing to the present day.

Postmodernism: a literary and philosophical movement that has questioned the possibility of any truth claims or metaphysical knowledge; the movement represents a spectrum from modest claims as to the relativity of much or all of what can be known, to a radical rejection of the possibility of any metaphysical, epistemological, or ethical claims.

Worldview: a comprehensive set of underlying metaphysical and epistemological assumptions that frames a way of looking at and interpreting reality and that forms the basis for an ethical theory, ethical principles, and ethical postulates. Any religious, secular, or philosophical perspective that forms the basis for ethical judgments is in this sense a worldview or may serve as the basis for a worldview.

2. Ethical Theory

Absolutism: the belief that some moral principle or principles are true for all people in all places at all times.

Casuistry: moral decisions are best made through an analysis of analogous cases to the one at hand; less emphasis on ethical principles or universal rules and more focus on the details of the case and how it compares to case paradigms in the past.

Consequentialist ethics: the rightness or good of an action is defined by the goodness of its consequences.

Deontological ethics: the rightness or the good of an action is defined in relation to a duty or obligation that is independent of the goodness of the consequences of the act.

Descriptive ethics: the study of the various beliefs and practices of how people approach decisions of a moral nature; what are prevailing attitudes, beliefs, and behaviors in regard to ethical questions; and what are prevailing public and institutional policies in regard to ethical issues.

Divine Command Ethics: the source of ethical standards is found in the commands of God, usually as expressed in sacred writings of a particular religious tradition.

Emotivism: morality is a matter of human emotions rather than objective reason.

Ethical Egoism: ethics is derived from considerations of one's own self-interest.

Intuitionism: the rightness of an action is a determination of individual intuition, rather than a product of ethical reasoning.

Meta-ethics: the study of methods of moral reasoning and the meaning of moral terms such as *good*, *right*, *virtue*, and *obligation*.

Mid-level Principilism: an approach to ethics that seeks to derive principles from common morality; these serve as an abstract and comprehensive framework for ethical deliberation. These principles are not absolute, but serve as prima facie ethical obligations.

Normative ethics: the approach to ethical issues that attempts to provide answers to specific questions concerning acceptable moral standards of behavior.

Relativism: the belief that the rightness of all moral principles or actions varies with the particular historical or sociocultural setting.

Rights vs. Duties: a right is a claim of one person upon another for an action or nonaction; a duty is an obligation one person owes to another for an action or nonaction.

Utilitarianism: a form of consequentialism. The good is defined by the principle of utility; the balance of positively and negatively valued outcomes determines if an act is good.

Virtue Ethics: emphasizes character virtues rather than the rightness of an action.

3. Some Terms Relevant to Applied Ethics in Long-Term Care

Abuse and Neglect: Elder abuse may be defined as an act or series of acts causing harm or distress to an older person, within a relationship in which there is an expectation of trust. Abuse may be physical, emotional, financial, or sexual. Abusers may be family members, caregivers, staff responsible for caring for the person, or others. Neglect is the failure to provide for the physical, emotional, or social needs of an older adult within a relationship in which such provisions are expected. Self-neglect is a problem for some older adults.

Active Dying: In hospice care, *active dying* refers to the final stage of life in which changing physical signs indicate the high likelihood of death within hours to days. Although such predictions are inherently imprecise, recognition of such changes can help prepare family and staff for the impending death of the patient.

Advance Directives: Advance directives are statements made by a person with decisional capacity about future treatment choices in the event of loss of decisional capacity. Advance directives include the Living Will and the Power of Attorney for Health Care (Health Care Proxy).

Affordable Care Act of 2010: also called the Patient Protection and Affordable Care Act, this legislation includes many provisions to be implemented over several years. The aim is to increase the number of insured Americans and to reform the health care system. Elements include an individual mandate to purchase insurance, employer mandates, state-based exchanges and subsidies, expansion of Medicaid, and reduction in Medicare spending.

Ageism: discrimination or negative attitudes against older adults that is based solely on their age.

Agent: a person acting on behalf of another; in the case of medical care choices, one who acts for another whose decisional capacity is diminished.

Alternative Therapies: a term used for treatment practices that are not part of standard care as practiced by medical and osteopathic physicians and allied health professionals.

Anonymity: concealing the identity of a patient in a case report. Maintaining anonymity is important in ethics case discussions to protect the privacy of the patient.

Assisted Living: a residential model providing general protective oversight or assistance with activities necessary for independent living to mentally or physically limited persons.

Autonomy: "self-law"; a principle in contemporary bioethics focused on the right of individual patient choice, unencumbered by avoidable limitations such as inadequate disclosure of information.

Beneficence: literally, "doing good"; a principle of bioethics focused on seeking the best interest of, or best outcome for, the patient.

Best Interests: a basis for decision making by a surrogate agent for a patient whose wishes or choices in a specific medical care situation are not known or clearly specified; the basis then becomes what a reasonable person might decide is ultimately in the "best interest" of the patient in that set of circumstances. See *Substituted Judgment*.

Capacity: Decisional capacity is determined by medical professionals. It is the ability of a patient to comprehend relevant information, evaluate available treatment options, and express a choice among those options. Capacity may be partial or intermittent.

Caregiver: one who provides individualized care to another; may be paid or unpaid and may be a family member, friend, staff, or outside personnel. Caregiver burden may be quite variable; caregivers of older adults may experience significant stress.

Competence: the ability to perform a task; used to refer to the legal determination as to whether an individual is able to make a decision of a particular type.

Compliance: adherence to a prescribed plan of care and treatment.

Confidentiality: a key element of the patient-physician relationship, maintaining secrecy of health information to protect the privacy of the patient. Legal obligations may represent exceptions to this principle, such as required reporting of abuse, certain communicable diseases, or suspicion of a crime. Breaching confidentiality may be justifiable when there is a high probability of harm to a particular person, when it is likely that the harm can be prevented, or when other measures have failed to reduce the likelihood of harm. Confidentiality is also a key guideline for case discussion within an ethics committee.

Conflict of Interest: the existence of competing priorities or values for a person in a particular situation. For example, financial conflicts of interest may exist for a caregiver or decision making agent for an impaired patient. A conflict of interest may exist for an ethics committee member if he or she has a personal relationship with the patient who is being discussed. In the latter case, the decision of whether to recuse oneself from the discussion should be entertained. Although conflicts of interest do not always disqualify one from the performance of one's duties, an ethics committee should seek to identify and understand such conflicts in analyzing a particular case.

Consent: the voluntary granting of permission from one person allowing another to perform an action. See *Informed Consent*.

DNH: a Do Not Hospitalize directive.

DNI: Do Not Intubate; a directive to not place an endotracheal tube to maintain an airway by which assisted ventilation is administered.

DNR: Do Not Resuscitate; a directive to not begin resuscitative efforts in the event of cardiac arrest.

Double Effect: a doctrine or principle with its roots traceable to the philosophy of Thomas Aquinas and the Catholic moral tradition, but with various formulations in contemporary moral reasoning, which is sometimes invoked in ethical dilemmas when an act may have both good and bad effects. The general contours of this principle are that, when an act has a desired effect, such as relief of pain and suffering, and also an effect considered harmful, such as sedation or respiratory depression, the act may be permissible under the following conditions: the action is good or neutral; the agent intended only the good effect, even if the bad effect could be foreseen; the bad effect is not the means to achieving the good effect; and the benefit of the good effect outweighs the undesired outcome of the bad effect.

Euthanasia: literally, “good death.” A distinction once was made between passive and active euthanasia, the former referring to withdrawal of life-supporting care leading to death, and the latter referring to an intentional act causing immediate death through lethal administration of medication. *Euthanasia* is now primarily used to refer to active euthanasia, with the physician as the agent causing the death. See *Physician-Assisted Suicide*.

Extraordinary vs. Ordinary Treatment: a distinction often cited in clinical ethics dilemmas about which treatments ought to be continued or discontinued when the benefits and burdens of the treatment are in dispute. Typical examples would include the provision or continuation of technologically supplied feeding or hydration. Because there is no consensus on the definitions of “ordinary” and “extraordinary” care, invoking this distinction in ethical deliberation usually reveals a deeper level of fundamental disagreement over values and beliefs about human life and the ends of medicine.

Family Concerns: In ethical dilemmas of late life, families face many competing emotional, social, psychological, financial, clinical, and practical issues surrounding the care of the patient. Ethical approaches to these care dilemmas often require taking these diverse issues into consideration, while attempting to sort out personal agendas or loyalties that may be clouding the fundamental ethical issue.

Fragmentation of Care: an obstacle to the integrated care of older adults caused by transitions across the spectrum of “silos” of care (home, assisted living, acute hospital, subacute care, long-term care), with multiple medical care providers and unconnected medical information systems. The advent of hospitalists and the diminishing role of primary care attending physicians in hospitals and nursing facilities may have exacerbated this phenomenon. The promise of electronic health records to offer integrative solutions to this problem has yet to be realized and likely will not be sufficient alone.

Functional Decline: the decline of ability to perform activities essential to independent daily living. Trajectories of decline vary in their pattern, duration, and permanence, depending on the underlying etiologies of decline. Understanding the trajectory of functional decline of a given older adult may be important in the approach to a particular ethical dilemma.

Futility, Medical: the concept of medical futility developed in part in response to the phenomenon of patient or family requests for continued aggressive care in cases in which the opinion of the medical team was that achieving the desired result was highly improbable and would serve no meaningful purpose. There are a variety of definitions of futility. More objective definitions focus on futility in terms of interventions that cannot be performed because of the physiological state of the patient or the inability of the treatment to have a physiologic effect. More subjective definitions of futility focus on burdens and benefits of treatment. Because of this variety in definitions, *futility* lacks precision and usefulness as a clinical term. Its use often indicates ethical divergence concerning the goals and expectations of care of an older adult among members of the care team, family, or significant others.

HIPAA: Health Insurance Portability and Accountability Act of 1996; federal legislation protecting privacy, security, and portability of insurance.

Hippocratic Oath: an ancient medical oath from the school of Hippocrates, dating probably to the fourth to fifth century BC, that enumerates a physician's duties toward teachers and patients, including prohibitions on abortion, euthanasia, and sexual relations with patients.

Hospice: a model of interdisciplinary care for those nearing the end of life, emphasizing aggressive symptom treatment rather than disease treatment; the goals are relief of suffering while allowing for the maximal achievable quality of life.

Iatrogenesis: the occurrence of side effects as a result of medical diagnostics or treatment; because of the increased frailty and greater amount of medical treatment of older adults, iatrogenic complications are more often seen. Examples include drug reactions and interactions, infections with resistant organisms, bleeding from anticoagulant-related coagulopathy, and deconditioning and pressure sores from prolonged hospitalization.

Informed Consent: voluntary permission granted by a patient for a particular treatment that includes the following elements: 1) adequate and understandable information is given to the patient concerning the diagnosis, prognosis, and the likely benefits and burdens of the recommended treatment and alternative treatments, including no treatment; 2) the presence of decisional capacity of the patient; 3) demonstrated understanding by the patient of the information; 4) freedom from coercion. See *Consent*.

Justice: No one definition is universally accepted. A basic definition is that which conforms to what is right. Some define justice as giving one what is one's due. Others define it as fairness, still others as speaking for those who cannot speak for themselves. Some religious notions of justice measure it by conformity to the character of God as one relates to God and fellow humans. Justice invariably includes a social dimension, thus the debate over societal resource allocation. Libertarian theories of justice focus on rights of property and liberty. Egalitarian theories focus on justice as fairness, emphasizing equitable distribution or redistribution of resources, including health care. In a pluralistic society, reaching a consensus on the definition of justice inevitably confronts the problem of fundamental disagreement over the underlying worldviews.

Living Will: an advance directive that expresses a patient's desire for withholding or withdrawing of life-prolonging treatments in the event of a terminal or incurable illness from which, in the opinion of the attending physician, there is little hope of recovery.

Moral Distress: a concept in the nursing literature that refers generally to the distress experienced by nursing personnel when internal or external factors prevent one from following the course of action one believes is right in the care of patients.

Nonmaleficence: the intentional avoidance of causing harm to a patient. This foundational principle of bioethics has also been expressed by the term primum non nocere, or "first, do no harm." See *Iatrogenesis*.

Palliative Care: Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Parentalism (Paternalism): the belief that because a physician has a more informed perspective, he or she may choose the course of treatment in the patient's best interest without obtaining fully informed consent from the patient.

Patient Self-Determination Act (PSDA): On December 1, 1991, the federal PSDA took effect, requiring health care institutions to ask all adults admitted as inpatients whether they have an advance directive and to inform them of their right to execute advance directives. The purpose of the law was to educate patients about state laws regarding withholding and withdrawal of care, to encourage wider use of advance directives, and to reduce the cost of unnecessary care at the end of life.

Patient-Physician Relationship: at the heart of medical practice is the relationship between the patient and the physician and the obligations entailed therein. Duties that define that relationship include truthfulness, respect, fidelity, privacy, confidentiality, and disclosure of potential conflicts of interest such as might occur in a dual role as attending physician and researcher. Various models of the relationship have been proposed, ranging from procedural or contractual to a more covenantal model.

Persistent Vegetative State (PVS): complete loss of cerebral cortex function, with preserved brain stem function. PVS results in sleep-wake cycles without awareness being present.

Personhood: perhaps the central issue in bioethics, the definition of personhood is as controversial as defining what is good or just. Intrinsic definitions grant personhood status on the basis of membership in the human race, at whatever stage of development or decline. These definitions are often grounded in a religious concept such as bearing the image of God. Functional definitions grant personhood status on the basis of particular levels of cerebral development or rational capacities such as self-reflection. Such views may not acknowledge personhood until several years of age. Fundamental disagreement over these definitions makes some bioethical dilemmas intractable.

Physician-Assisted Suicide: deliberate or intentional provision of a lethal prescription by a physician to a patient, who then is the agent for his or her suicide.

Power of Attorney for Health Care: an agent who has been designated by another person to make health care decisions and provide consent for treatment in their place.

Prima Facie Duty: an obligation that applies unless there is an overriding consideration of an equal or greater obligation.

Proxy Consent: the granting of consent by an agent for another.

Quality of Life: a subjective concept often introduced into ethical discussion, broadly referring to the burden of diminished function caused by medical conditions, in light of which considerations of proportionally appropriate care are entertained.

Rationing of Care: allocation of treatment decisions, whether justified on the basis of limited resources, societal policy, or ability to pay.

Research: medical research includes the study of human subjects to determine if proposed treatments are safe and effective. Ethical guidelines are intended to ensure a reasonable balance of risks to research participants and possible benefits to participants and future patients. Informed consent principles must be practiced. Proper study design and data analysis must be free of bias. Institutional Review Boards (IRBs) are tasked with reviewing and monitoring research projects to ensure ethical standards.

Resource Allocation: see *Rationing of Care*.

"Slippery Slope" Argument: the "slippery slope" argument is a form of ethical reasoning that moral compromise on a debatable issue will lead to further moral compromise of a greater degree in the same direction. For example, if a society legalizes voluntary euthanasia, the "slippery slope" argument raises the concern that non-voluntary euthanasia will be practiced as well as voluntary euthanasia. See *Spectrum of End of Life Decisions*.

Spectrum of End of Life Decisions: whereas the order of the following list is subject to variation, individuals, institutions, and society will find that somewhere along this spectrum, a line will be drawn representing a point beyond which it is ethically impermissible to go. That line will describe a major parameter of ethical controversy.

- Usual care - aggressively treating asymptomatic physiologic abnormalities and diagnoses regardless of their likelihood to either prolong life or relieve symptoms

- Time-limited trials of treatments to determine their potential to relieve symptoms or prolong life.

- Withholding of certain treatments (by autonomous or proxy decision)

- Withdrawal of certain treatments (by autonomous or proxy decision)

- Provision of only “comfort care” and pleasure feeding

- Aggressive pain and symptom treatment even if decreased intake and shortening of life occurs as an unintended result (“double effect”)

- Voluntarily stopping eating and drinking

- Aggressive pain and symptom treatment to the point of intended therapeutic sedation to relieve suffering, expecting the likelihood that life will be shortened (sometimes referred to as terminal sedation)

- Physician-assisted suicide

- Voluntary euthanasia

- Non-voluntary euthanasia (euthanasia without knowing patient wishes)

- Involuntary euthanasia (euthanasia against patient wishes)

Stewardship: an ethic that embodies responsible planning and management of resources. The concept of stewardship has been applied in diverse realms, including with respect to environment, economics, health, property, information, and religion, and is linked to the concept of sustainability.

Substituted Judgment: a theoretical model for decision making for a person lacking decisional capacity that emphasizes the agent making a decision as close to conformity with the person’s wishes and preferences as may be determined. See *Best Interests*.

Supererogatory: actions that go beyond the obligations or duties defined as ethical are referred to as supererogatory. Heroic or altruistic actions may be included in this category.

Surrogate Decision Making: the term “surrogacy” is used by some states (e.g., Illinois) to define a process whereby an individual patient who has not executed a Power of Attorney for Health Care (Health Care Proxy) and is now decisionally incapable may be represented by a surrogate decision maker. Procedures are defined, including a rank ordering of those who are eligible to serve as a surrogate decision maker.

Therapeutic ("terminal") Sedation: a treatment plan intended to relieve intractable pain and suffering by means of intentional sedation when other palliative measures have failed.

Transitions of Care: in geriatric medicine, transitions from one level of care to another are recognized as points of discontinuity and risk for patients. Transitions may become necessary as functional decline and clinical change occur. Transfer of information concerning diagnoses, medical care, medical orders, advance directives, code status, and other vital data is often problematic. Transitions often occur as patient autonomy is diminishing. Ethical practice of medicine will focus on reducing the effects of fragmented care and seeking proper decision making processes for the patient.

Triage: resource allocation decisions in the face of limited resources.

Truth-telling: Truthfulness between physician and patient is at least a prima facie obligation. It is foundational to respect for persons and for autonomous decision making. It may be bounded by other considerations where capacity is diminished or lost. It may conflict with the right to privacy in cases of serious communicable disease.

Unilateral Determination of Futility: some have advocated for the right of physicians to declare a particular medical treatment futile unfettered by the opinion of the patient or family. Given the diversity of definitions of futility, this position is difficult to defend without a more objective definition of futility.

VSED - Voluntarily Stopping Eating and Drinking: a deliberate choice by a person to stop oral intake of food and water in order to hasten death.

Withdrawal of Treatment: a choice to discontinue a treatment currently being provided. Ethical dilemmas may arise over decisions involving the withdrawal of life-sustaining treatments such as ventilator support, tube feeding, or dialysis.

Withholding of Treatment: a choice to not begin a particular treatment. There is no ethical distinction between withdrawal and withholding of a treatment as a consent to a procedure or treatment on one day does not necessarily imply a consent that that treatment be continued.

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