

**POST-ACUTE AND LONG TERM CARE MEDICAL ASSOCIATION  
WHITE PAPER  
RESOLUTION C08**

**SUBJECT: THE ROLE OF A FACILITY ETHICS COMMITTEE IN  
DECISION-MAKING AT THE END OF LIFE**

**INTRODUCED BY: ETHICS COMMITTEE**

**INTRODUCED IN: MARCH 2008**

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## **1. BACKGROUND**

### *Trends in End-of-Life Care in Nursing Homes*

Increasing numbers of Americans spend their last days in long term care, with a rise expected from 25% in 1998 to 40% by 2020.<sup>1</sup> For those with dementia, 70% die in a nursing home.<sup>2</sup> In addition to the sheer numbers of older Americans dying in nursing homes, the clinical complexity of their care is increasing. As hospital stays have become shorter, the burden of completing a course of acute care has shifted to the nursing home. A Post-Acute and Long-Term Care Medical Association (PALTmed) survey as well as CMS data has confirmed these trends recognized by practicing long-term care physicians.<sup>3</sup>

The shift toward greater acuity in nursing home care occurs in a population already characterized by multiple comorbidities, reduced function, and frailty. This creates a milieu in which increased pace of decline is a likely occurrence, despite the best of care. When clinical decline occurs in such a setting, ethical concerns may arise as to whether care goals should be modified in the face of possible impending death.

Research on end-of-life care in nursing homes is limited. A review of available studies suggests that the care is often inadequate, with poorly controlled pain, low rate of referral to hospice care, excessive hospitalization near the end of life, inadequate use of advance care planning, and family dissatisfaction.<sup>1</sup>

One obstacle to adequate end-of-life care in nursing homes may be the culture created by excessive regulatory scrutiny. Weight loss and functional decline are approached as definite indicators of poor quality of care rather than possible harbingers of an inevitable and imminent dying process. In a pay-for-performance reimbursement system linked to these measures, the recognition and proper management of imminent dying may be delayed or overlooked altogether. Another obstacle to adequate care near the end of life may be the tendency to hospitalize some dying patients out of fear of blame or litigation.

These and other underlying assumptions of nursing home practice must be examined and modified to enhance the possibilities for improved end-of-life care in nursing homes.<sup>4</sup>

### ***Ethics Committees in the Nursing Home***

A facility ethics committee offers a venue in which end-of-life care and its dilemmas can be discussed. However, the development of ethics committees in long-term care facilities has lagged behind that of hospitals. Between 1983 and 1985, the prevalence of hospital ethics committees rose from 26% to 60%.<sup>5</sup> In contrast, a national survey of nursing homes in 1988 found that only 2% of the sample of 1278 responding facilities had ethics committees.<sup>6</sup> Those facilities with committees tended to have more beds and a religious affiliation. A report from the year before found 10% of Minnesota facilities had ethics committees, most commonly in religiously affiliated homes in urban areas with higher percentages of skilled beds.<sup>7</sup> In 2004, a survey of one metropolitan county in the southwestern US found 29% of nursing homes had ethics committees.<sup>8</sup>

Attitudinal barriers to forming an ethics committee were explored in the 1988 survey. These included widespread belief that ethical issues could be resolved without a committee. Many perceived a committee as undesirable bureaucracy not sufficiently close to the clinical situation.

Conversely, in the 2004 survey, 67% of the facilities without a committee expressed reasons for interest in developing a committee. These included the need for expert guidance in ethical dilemmas, the need for resolving clinical problems in which issues with the family had developed, and a need to determine best practices in the facility.

Smaller facilities may not have the personnel or the volume of cases to maintain an ethics committee. In New Jersey, a statewide initiative was launched to provide a network of regional long-term care ethics committees, offering education and consultation to facilities. Only 27% of the participating facilities had their own in-house committees.<sup>9</sup> Other options for smaller facilities may include collaboration with other nursing homes or local hospital ethics committees.

The purpose of this paper is to explore the rationale for developing a facility ethics committee within the context of previously stated PALTmed positions and resolutions, the purposes of such a committee, and recommendations for committee structure and function, as it relates to the process of end-of-life decision making within the facility.

## **2. PREVIOUS PALTmed POSITION PAPERS AND RESOLUTIONS**

PALTmed has produced a number of stated positions related to end-of-life care and ethics in the nursing home. These are summarized as follows:

- Resolution D97: PALTmed recommends that each facility should have an ethics “mechanism” to assist in managing decisions such as do-not-resuscitate and other end-of-life issues.
- Position P97: PALTmed supports the Patient Self Determination Act and the attention of physicians to advance directives upon admission to the nursing home. PALTmed acknowledges that withholding or withdrawing any medical intervention with informed consent may be appropriate in a particular patient’s care. PALTmed supports the aggressive treatment of symptoms associated with dying. PALTmed opposes physician involvement in assisted suicide or active euthanasia. PALTmed supports education, policies, and research that enhance end-of-life care.
- Resolution E98: PALTmed recognizes the significance and helpfulness of ethics committees in the nursing home and strongly encourages their development. PALTmed sees ethics committees as an acknowledged means fulfilling the roles of developing and protecting values in the facility, and providing a setting for multidisciplinary dialogue to clarify ethical and legal concerns, aspects of fiscal responsibility, and to guide decision making in complex dilemmas. This resolution lists the roles for ethics committees as policy development and review; quality assurance activities; education; resource for staff, clinicians, administration, patients, families, and community; monitoring judicial decisions and legislative action; and consultation and review of case-specific dilemmas. Training should be provided to committee members to ensure reliable ethical analysis, and the committee composition should reflect the community which the facility serves.
- Resolution I99: PALTmed recognizes the significance of end-of-life care planning. All nursing home residents should have access to such care planning. The expected outcomes are respect for advance directives, safe and comfortable dying, and effective grieving. Medical directors should be provided with sufficient training, education and institutional involvement to assess and improve end-of-life care in the facility.
- Resolution G00: PALTmed opposes the assisted suicide or active euthanasia of any person regardless of age.
- White Paper on Hospice in Long Term Care (2000) endorses access to quality hospice care in the nursing home.
- White Paper J03: Surrogate Decision-Making and Advance Care Planning in Long-Term Care. In this detailed overview of the dilemmas surrounding care when a patient has lost decisional capacity, the PALTmed Ethics Committee defines the key concepts of competence, decision-making capacity, and assessment of decision-making capacity, surrogate decision-making, advance directives, guardianship, autonomy, substituted judgment, and best interest. A hierarchy of medical decision-making when there is no advance directive is described. Guidelines for guardians, surrogates, and health care providers in their respective roles in the decision-making care are given. Comments are made on clinical and ethical dilemmas related to CPR, tube feeding, hospitalization, and antibiotic therapy. The reader is strongly encouraged to examine this valuable

guide in ethical dilemmas involving decisionally incapacitated patients.

- White Paper on Long Term Care and Hospice (2007) reaffirms the obligation to provide high-quality palliative and end-of-life care in the nursing home. Hospice services in long term care should be of sufficient quality to meet the unique needs of patients with terminal dementia and other chronic degenerative diseases. The barriers to hospice utilization in skilled nursing facilities inherent in existing payment systems should be reevaluated.

### **3. THE RATIONALE FOR A FACILITY ETHICS COMMITTEE**

#### ***Facing End-of-Life Dilemmas in Settings of Diversity***

End-of-life dilemmas arise in settings of diversity. There is clinical diversity in the increasingly complex care of older patients with more frailty and comorbidities. There is sociocultural and religious diversity with variable expectations for end-of-life care from one particular tradition to another. There is interpersonal diversity from patient to patient in expectations, preferences, and level of involvement in care decisions. There is diversity from family to family in levels of expectations, preferences, and involvement in care decisions. And there is often diversity of opinion among members of the health care team caring for a long term resident as to what would constitute the best plan of care.

The challenge of approaching end-of-life decision-making is further complicated by the ethical diversity of this age. Because contemporary clinical bioethics is situated in postmodernity, it is inherently an exercise in diversity, what one bioethicist has termed a “cacophonous plurality of bioethics.”<sup>10</sup> Without a single universally accepted ethical theory, the appeal to several competing mid-level ethical principles characterizes much of the discourse in clinical ethics.<sup>11</sup> Those less optimistic about the feasibility of such an approach claim that all we can hope for is a purely procedural ethic in which the permission of the patient is the primary guide to action.<sup>10</sup>

In practical terms, this diversity of perspective makes it desirable to create a forum in which the ethical issues surrounding end-of-life care decisions can be discussed safely and confidentially by those involved who seek to explore such issues. A facility ethics committee is one model for offering such a forum. Its contribution will be greatest in offering a venue to approach end-of-life decisions by clarifying the relevant clinical and personal facts, identifying the relevant ethical principles, assessing options, and framing the questions which are pertinent to the next steps in a particular case.

#### ***Ethical Principles in End-of-Life Care Decision Making***

The following principles are commonly referred to in discussions of end-of-life care. This is meant to be a representative, not an exhaustive, list. What is significant about these principles is the diversity of perspectives on the meaning and relative importance of each principle. Such tensions are further evidence of the need for a forum to discuss the ethical issues surrounding end-of-life care.

## *Autonomy*

Autonomy (“self-rule”) emphasizes the right of an individual to exercise free, uncoerced choice in the medical care she receives or refuses. While not all cultures accord autonomy the same level of priority, in the United States it is well-protected by law. The doctrine of informed consent illustrates the important value placed on autonomous choice. Acknowledged requirements of informed consent include competence of the patient, disclosure of information concerning proposed medical treatment, including possible risks and benefits, demonstration of understanding of the information by the patient, freedom from coercion in making a decision, and the granting of consent.

In end-of-life decision-making, several challenges to autonomous choice may be present. First, end-of-life care situations may often, though certainly not always, involve impaired decision-making capacity. It should be noted that decision-making capacity is a different concept from competence, which is a legal category. Medical decision-making capacity may still be present when financial competence has been deemed no longer present, for example. (See PALTmed White Paper J03, “Surrogate Decision-Making and Advance Care Planning in Long-Term Care.”) It is essential that attending physicians in long-term care assess the decision-making capacity of patients in an ongoing fashion to facilitate patient involvement to the fullest extent possible in end-of-life decisions.<sup>12</sup>

Second, in cases of genuine loss of decision-making capacity, advance care planning offers a possible mechanism for some degree of autonomy in end-of-life decisions. The Patient Self Determination Act of 1991 requires health care facilities to determine if a patient has advance directives on admission and offer information and assistance to them regarding advance care planning. Yet even if advance directives exist, the actual degree of autonomy provided may be limited. Advance directives tend to be either very general, such as the living will documents now available in all states, or very procedure-specific, such as directives to not use a feeding tube under any circumstances. Thus they do not always speak to the specific clinical choices faced at specific stages of decline. Advance directive preferences may also change over time, yet may not be reflected in the extant documents if no updating of the written document occurred. Documents may be unavailable when they would be most relevant, especially at times of transfer between health care settings. It is essential that long-term care facilities offer advance care planning to all residents and maintain and transfer advance care planning documents diligently to optimize patient autonomy.

A third challenge to the decision-making autonomy of patients near the end of life is the force of subtle coercion which can come from many directions. Older adults are often fearful of being a burden, financially or emotional. They may feel compelled to choose a course of action they believe will be less burdensome to other family members. Some may wish to please their family or physician and accept care recommendations which they might otherwise refuse. It is important that attending physicians and others communicate openly and honestly with patients, listening for what their most important goals of their care at all times, especially near the end of life.

A fourth category of challenges to maintaining autonomy in end-of-life care is the proxy or surrogacy process. When an individual has lost the capacity for his own medical decisions, legal provisions for substituted decision exist. If a durable power of attorney for health care (or health care proxy) has been appointed, that individual is empowered to make decisions regarding medical care for the patient. If no such advance directive appointment was made, many states have a surrogacy process by which a decision-maker may be appointed. It is advisable that a proxy or surrogate attempt to represent what the patient would have wanted for their care (“substituted judgment”). In reality, it is often not possible to know what a patient would have wanted in the particular situation at hand. In such a case, appeal is made to a “best interests” standard, and the actual choice is reflective of the surrogate preferences rather than the patient choice.

In the face of these challenges to preserving the right of autonomous choice of medical care near the end of life, it is essential that long-term care facilities provide mechanisms to guard the diminishing autonomy of each person under their care. An ethics committee can contribute to a climate in which the highest possible degree of autonomy is maintained for each resident.

### *Beneficence*

Beneficence is simply “the doing of good.” The simplicity of the definition begs the obvious question of defining the “good.” As discussed above, ethical diversity creates a conundrum for beneficence. Some see the highest good in medical care as the prolongation of life. Others see the highest good as relief of suffering. Some see the good as entailing transparent truthfulness between patient and physician. Others may believe that a parentalistic approach is better in some situations, such as withholding the news of a terminal cancer from a moderately demented patient who has manifested inability to retain new medical information on previous occasions.

The very notion of a “best interests standard” in cases where a decisionally incapacitated person has no pertinent advance directive reflects a moral sense, a desire to do well by the patient. In end-of-life decisions, there will frequently be more than one idea of what beneficence entails (e.g., it means going to the hospital for more tests, or, it means enrolling in hospice, and so forth). A facility ethics committee offers a forum to articulate and consider the various views in a given case.

### *Non-maleficence*

Nonmaleficence is the avoidance of doing harm to a patient – *primum non nocere*, “first, do no harm.” The avoidance of iatrogenesis is an increasingly compelling priority in medical care as the end of life is approaching. Older adults in long-term care are frailer, are on a greater number of medications with greater potential for adverse drug reactions, and are more susceptible to complications of invasive procedures and surgery, as well as infections with multi-drug resistant organisms as a consequence of hospitalization and

impaired skin integrity. The hazards of hospitalization must be taken into account in the medical care decisions near the end of life.

An ethics committee can provide an opportunity for discussions of such risks and increase the awareness of committee members when considering end-of-life care options in particular cases.

### *Justice*

As with beneficence, justice may take on a number of definitions, depending on the ethical perspective from which one is speaking. To some, the demands of social justice entail special protection of the most vulnerable and those who cannot speak for themselves. For others, justice is defined in terms of equitable distribution of societal resources.

While discussions regarding the justice of allocating scarce resources are an important societal issue, such macroeconomic concerns should not determine specific end-of-life care decisions for an individual patient in long-term care. A facility ethics committee can discuss the justice surrounding societal decisions concerning the distribution of resources in end-of-life care while insuring that “bedside rationing” of care is avoided.

### *Respect for Persons*

This principle is regarded by some as having been neglected in the preeminence given to respect for autonomy.<sup>13</sup> It broadens respect beyond the right of informed consent to a notion of valuing the person. Respecting a person near the end of life entails more than respect for autonomous choice.<sup>14</sup> While the definitions of what that respect entails will be diverse, it is evident broader definitions should be entertained. A facility ethics committee can offer a venue to discuss how staff can show respect to an individual patient near the end of life even after autonomy has been lost.

The foregoing principles of bioethics are the grist for ethical analysis of particular cases. A facility ethics committee will encounter these and other principles, and conflict between the priorities of principles, as it considers issues surrounding decision-making in end-of-life care.

## **4. THE PURPOSE AND FUNCTIONS OF A FACILITY ETHICS COMMITTEE**

The purpose of a facility ethics committee is to provide support to patients, staff, and family members in addressing ethical issues encountered in long-term care. The three primary functions commonly cited for an ethics committee are education, policy development and review, and case analysis.<sup>15,16,17</sup> Each of these functions are important in the contribution of an ethics committee to end-of-life decision-making.

### *Education*

- **Self-education:** The ethics committee should educate itself by readings, discussions and presentations concerning end-of-life issues. Resources may be from internal expertise or from outside consultation from those with bioethics expertise. Topics can include, but not be limited to, the state legal statutes and mechanisms available for advance care planning and DNR decisions; surrogacy mechanisms; classic end-of-life cases (e.g., Quinlan, Cruzan, Wanglie, and Schiavo); principles of bioethics and models of ethical reasoning; and any existing institutional policies regarding end-of-life care and decision-making. In addition, the concept of trajectories of decline of frail, older adults can be presented to educate non-clinical as well as clinical members of the committee about patterns of decline which can be seen near the end of life and which may affect clinical decision-making.<sup>18</sup> The role of palliative and hospice care in long-term care should be part of the educational material. An orientation manual including the above topics may be developed which will be helpful to new members of the committee. It may be helpful to review the orientation manual periodically to discuss areas of interest.
- **Education of other staff and residents:** The ethics committee can develop in-service programs to educate other staff on ethical issues such as advance directives and hospice care. Talks given to residents can be an opportunity to increase completion of advance directives and enhance understanding of available choices for care planning, palliative care, and hospice.
- **Education of family members:** In formal presentations to residents, or individual encounters in patient care, or in consultative case analysis, the involvement of family members provides an opportunity to educate them about end-of-life care options.

### ***Policy Review and Development***

- The facility ethics committee should assist in the development of end-of-life care policies to ensure the maximal degree of autonomy possible, and the highest degree of respect for individual patients.
- Facility policies regarding advance care planning should comply with the Patient Self-Determination Act which requires that health care facilities inform patients upon admission of their right to express advance wishes for their medical care.
- The facility ethics committee should be familiar with facility policies regarding end-of-life care. This may be especially relevant in faith-based institutions. Facility policies regarding end-of-life care may be discussed as deemed appropriate or necessary by the committee.
- When the facility ethics committee assesses any facility policy regarding end-of-life care, it should do so with the priority of respect for the personhood and autonomy of the individual patient.

### ***Case Review***

- The facility ethics committee should be available for case consultation upon request from any staff member, patient, or family member, concerning ethical aspects of care. End-of-life decision-making issues will be a primary focus of most long-term care facility ethics committees.
- Selection of cases for consultation should be optional. Recommendations coming from an ethics committee in a nursing facility should also be considered optional. The role of a facility ethics committee is advisory rather than prescriptive.
- All case discussions must strictly guard confidentiality and maintain anonymity.
- When possible, cases should be presented by the individual who raised the ethical concern. A nonmember may present a case as a guest. Cases should be reviewed in advance by the chairperson or convener of the committee for appropriateness and for clarification of the pertinent ethical questions.
- Case presentations should describe the facts of the case. This is best done in narrative form. Case facts include a) biographical facts – tell the narrative of the patient’s life story briefly to set the context of the current situation; b) clinical facts – describe patient’s condition, the clinical trajectory, the pertinent medical diagnoses, symptoms, prognosis, and current and proposed treatment plans; c) psychosocial facts – what is the patient’s decision-making status? What advance care planning is in place? What are the patient’s expressed wishes, if known? If decision-making capacity is impaired, who is the authorized proxy for medical care decisions? What do we know about the proxy’s wishes for the patient’s care? Who are other key stakeholders in the decision process?
- Case presentations should describe the values of the patient and others involved in the case which are pertinent to the issue at hand.
- Case presentations should seek to identify the loyalties or possible conflicting agendas of any of the key stakeholders in the situation.
- A central ethical question should be formulated to guide the discussion.
- Discussion should clarify the pertinent ethical questions, identify the relevant ethical principles and tension among ethical principles, explore the range of options for care in the face of the approach to the end of life, and offer constructive suggestions to the case presenter for next steps. The committee does not “make the decision”; rather, it seeks to clarify the questions and identify additional considerations for thought, leading to reasonable options for care.

The American Society for Bioethics and Humanities has identified core competencies for health care case consultations. Committee members should collectively have skills and abilities in defining and analyzing the nature of ethical conflict in a particular case, facilitation of meetings, building moral consensus, respectful and empathetic listening and communication with and among all persons involved in a case, eliciting and representing moral views, and addressing relational barriers to communication<sup>21</sup> (cited in Powers<sup>17</sup>, 186-87).

## **5. THE COMPOSITION OF A FACILITY ETHICS COMMITTEE**

Medical directors should play a key role in a facility ethics committee. Their medical training and experience in caring for older adults, especially in end-of-life settings, brings a unique perspective to each facility they attend. If a facility has an ethics committee, it would be preferable if the medical director is a permanent member and key facilitator of the development of the committee.

Term-limited appointments to the committee may be assigned to allow for rotation of as many staff as possible over time. Unit nurses, attending physicians, social workers, and other staff members may rotate onto the committee. As those who provide the most direct patient care, nursing assistants offer a unique perspective and should be invited to sit on the committee. Members of the board of directors and outside community residents are also potential members of a facility ethics committee.

It is important that the key leadership in administration and nursing be supportive of the purpose and role of the facility ethics committee. Without such support it will be difficult for the ethics committee to establish an effective identity and mission within the institution. The executive director, administrator, and director of nursing are all key leaders whose presence on an ethics committee provides important lines of communication regarding ethical concerns raised by staff and residents. These key leaders may themselves also face ethical issues which they may wish to bring to the committee.

However, the presence of upper level institutional leadership on the committee must not become a hindrance to the participation of lower level staff members. Each committee member must have an equal voice in committee discussions. There must be a climate conducive to open, safe discussion of issues. Employees must be free from fear of reprisal for their participation in ethics committee discussions. All members of the committee must embody respect for others sufficient for the task of ethical deliberation.

Faith-based facilities or those facilities with a chaplain should consider having the chaplain sit as a permanent member of the committee. Chaplain representatives may provide supportive leadership on the committee, perhaps as chairpersons or co-conveners of the committee along with the medical director.

Resident and/or family involvement as committee members can strengthen the overall perspective of the committee and should be encouraged when possible. The facility ethics committee may wish to discuss ways to appropriately recruit and develop resident or family representation on the committee.

A facility ethics committee may wish to invite an outside ethicist, if available, from a local college, seminary, or hospital to provide teaching in ethical principles and practical strategies for case review.

## **6. COMMON ETHICAL ISSUES FACED BY A FACILITY ETHICS COMMITTEE IN END-OF-LIFE CARE**

### ***Is it time to withhold, withdraw, or otherwise limit aggressive medical care?***

Establishing the prognosis for an individual patient who is experiencing decline in long-term care is laden with uncertainty. While exact length of life remaining cannot be accurately quantified, the clinical course to the present moment can be an indicator of further future decline in cases of multiple, chronic, incurable comorbidities.

Joanne Lynn identifies three predominant patterns of trajectory of decline toward dying.<sup>18</sup> These are, with estimates of frequency:

- 1) extended maintenance of good function despite known fatal illness, typically a cancer, with an abrupt, rapid decline to death over weeks or months (20% of Americans)
- 2) slow decline in physical capacities punctuated by serious exacerbations, with death often coming suddenly; recovery from a particular episode may be to previous level of function, but eventually rescue attempts fail; this is the paradigm for CHF, COPD; (25% of Americans)
- 3) long-term dwindling of function, with years of requiring personal care assistance; half of these may have cognitive impairment as well; dying often occurs after what would have in earlier stage of life been an easily overcome illness, such as pneumonia, urinary sepsis, or fracture (40% of Americans).

A facility ethics committee can assist physicians, patients, staff and family members as they contemplate the clinical trajectory on which a particular patient is journeying. The goal for many persons facing a potential end-of-life situation is to ensure a “soft landing” at the end of the trajectory of decline. The process of arriving at a soft landing, a dying and death that is least traumatic, will involve first of all a recognition of a particular patient’s trajectory when it is accelerating toward dying. The most optimal end-of-life care begins well before the moment of death with an acknowledgment by all involved that the time is approaching to define the goals of care.

The role of the attending physician is essential in this process of assessment. Many Living Will documents identify the judgment of the attending physician as the adjudicator of the optimal time to withhold, withdraw, or otherwise limit care. Physicians’ professional expertise is sought in helping to evaluate the prognosis of the patient. Their involvement in such determinations is vital. The interdisciplinary, collaborative, and deliberative nature of a facility ethics committee provides a setting where physicians can engage with other professionals and involved persons to best make an assessment of the trajectory of decline. Interdisciplinary evaluation including nursing, social work, chaplaincy, and other disciplines may be helpful in identifying the potential for amelioration, reversibility, or inevitability of the trajectory of decline.

### ***Who should decide questions of end-of-life care for the patient?***

Facility ethics committees should be fully aware of the state statutes for proxy or surrogate decision-making. The committee should be aware of and committed to protecting the overriding right of the patient to make decisions concerning her own health care. The priority list for decision-making starts with the patient's present expressed wish; if not available, the patient's previously executed advance directive, if applicable; then those of either a court-appointed guardian or health care proxy. If no guardian or proxy exists, a surrogate may be identified in concert with relevant state surrogacy acts. Some states have a defined order of priority for appointing a surrogate. This is generally first a spouse, then adult children, siblings, and finally other family members. A facility ethics committee should educate itself, the facility staff, facility residents and family members of the surrogate decision-making process.

There are unique legal and ethical issues surrounding the care of children living in long-term care settings. Assent, a term used in the clinical research arena, refers to the willingness of a child to agree to go along with a plan of care. While this paper has been written from the perspective of adult long-term care, physicians and nurses caring for children in long-term care should be aware of these issues.

### ***How should end-of-life decisions be made?***

When a patient has sufficient decision-making capacity, end-of-life decisions such as do-not-resuscitate or the decision to forego a feeding tube may take place solely between patient and physician. Other family members may be involved as appropriate, but the decision rests with the patient in the end. Ethics committees should be aware that some patients with unfettered decision-making capacity may elect to give their decision-making role to a child or spouse. Even when a patient has full decision-making capacity, however, the input of the physician is significant and may greatly influence the decision. There is thus an aspect of the decision-making process which is shared.

Ethics committees often become involved when either the decision of an apparently capable patient is questioned, when the patient is clearly incapable of deciding, or when members of the health care team question the prescribed course of care. When the wishes of a patient regarding a particular intervention or care plan are not accessible, the actual process of coming to a decision becomes a joint venture between, at a minimum, the attending physician as the source of medical expertise and advice, and the duly authorized decision-maker, whether a court-appointed guardian, a patient-selected proxy, or a procedurally-identified surrogate, as the final agent of choice.

The complementary roles of physician and surrogate decision-maker define a shared process of decision-making. From the family perspective, important aspects of the physician role in end-of-life care in nursing homes are time spent face-to-face with family caregivers, and timely communication about changes in health status, especially when the patient is actively dying.<sup>19</sup> From the physician perspective, it is challenging but necessary to build a working relationship with the surrogate decision-maker when caring for an older adult on a trajectory of decline toward the end of life.<sup>20</sup>

A facility ethics committee can assist in the building of a therapeutic alliance between physician and surrogate by providing the physician with interdisciplinary insights gained from other members of the facility staff as they interact with the patient and surrogate in end-of-life care. These insights may help the physician understand more fully the perspective of the patient or surrogate. The involvement of the attending physician when his patient is discussed will enhance the potential role of the committee in strengthening the alliance between physician and surrogate.

## **7. CONCLUSION**

Nursing facility ethics committees will be an increasingly important resource to augment the quality of end-of-life care for older adults in the years ahead. They can provide support to patients, physicians, family members and facility staff in facing the ethical challenges presented by patients on trajectories of active decline. Ethical principles to keep in focus include respect for the patient as a person as well as respect for the patient's autonomy.

Ethics committees fulfill the primary roles of education, policy review, and case consultation. Educational initiatives should focus on advance care planning and palliative and hospice care. Policy review should focus on insuring patient autonomy and access to end-of-life care options such as hospice. Case consultation should be elective and advisory, not mandatory or prescriptive. Confidentiality and anonymity must be maintained. The committee composition should reflect the diverse disciplines providing care at the facility as well as the community which the facility serves. Administrative support of the existence, purpose, and function of the facility ethics committee is essential. Working relationships within the committee must be guarded to prevent unhealthy hierarchical dynamics which might stifle candid discussion of important ethical issues embedded within the institutional life of the facility.

The leadership of the facility medical director is crucial in building and maintaining a functioning facility ethics committee. Medical director bring clinical expertise and clinical judgment to the table. In addition, medical directors can attempt to educate administrators as to the value of an ethics committee in helping staff provide better care to patients and their families near the end of life.

## **8. RECOMMENDATIONS**

1. PALTmed strongly recommends the development of facility ethics committees or similar ethical mechanisms. Facilities may wish to form collaborative relationships with local hospital ethics committees, hospices, or other nursing facilities to provide a forum for discussion of ethical issues in end-of-life care. Such ethical mechanisms can assist all involved in assuring the availability of high-quality end-of-life care to the residents of nursing facilities.

2. The PALTmed Ethics Committee recommends the development of a tool kit on the development of facility ethics committees.

3. PALTmed may wish to consider additional position statements on the approach to ethical issues surrounding the care of children living in long-term care setting.

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