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# Improving Care for Seriously Ill and Dying Residents of Long-Term Care Facilities

by Don Reynolds

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*Midwest Bioethics Center recently concluded a three-year initiative to improve care for seriously ill and dying citizens of Kansas City. The initiative, called PATHWAYS, addressed five recurring issues in end-of-life care: advance care planning, resuscitation status, the orientation of care, spiritual support, and pain and symptom management. One PATHWAYS strategy addressed these issues from the perspectives of seriously ill and dying residents of long-term care facilities, their families, the professionals who care for them, and the facilities where they reside.*

**T**he PATHWAYS long-term care strategy had three components: a pilot project to improve end-of-life care in four Kansas nursing homes; guidelines for providing care to seriously ill and dying long-term care residents; and a mediation service to help people work through issues relating to the care of seriously ill and dying long-term care patients. The pilot project was described in a prior *Bioethics Forum* (Kenner 1999). The guidelines document and our mediation service are the subjects of this article.

## Guidelines for Care

*Long-Term Care Guidelines: Improving Care for Seriously Ill and Dying Residents of Long-Term Care Facilities* reflects the work of more than one hundred individuals who helped write, review, and finalize this project. The Kansas City Regional Long-Term Care Ethics Consortium sponsored the document.

When it is used in a long-term care setting, the term palliative care means seeking to increase a resident's ability to function by relieving or alleviating symptoms (i.e., pain or seizures) without attempting to cure. Palliative care includes nursing and personal care to make residents comfortable, especially by relieving pain and other causes of suffering, controlling symptoms, reducing anxiety, and providing comprehensive support. Sometimes, increasing a resident's overall

comfort and ability to function may involve diagnostic, therapeutic, mechanical, medical, and surgical interventions and treatments. It may also include withdrawing or withholding a life-prolonging measure. The foundation of *Long-Term Care Guidelines: Improving Care for Seriously Ill and Dying Residents of Long-Term Care Facilities* is the proposition that palliative care is the primary goal of nursing home care.

The claim that palliative care is the primary goal of long-term care reflects a fundamental, but frequently overlooked, distinction between the hospital and nursing home models of care. While hospital care consists of discrete health care procedures, basic nursing home care is a bundle of caring activities.

We call the discrete health care procedures that characterize hospital care, health care. Health care is about identifying and providing fitting responses to a patient's health situation. The methodology for identifying fitting responses to health situations is a process in which a patient (or someone acting on the patient's behalf) and a physician work together to make a decision. In other words, while it may have an important relational aspect, health care is fundamentally transactional.

Though nursing home care is frequently described as a list of services, this description is misleading. Basic nursing home care is essentially a purchased relationship. The services that comprise nursing home care are best understood as a structured, continuous effort to meet each resident's physiological, psychological, social, and spiritual needs. Of course when residents need health care, they ought to receive it. However, we need to understand that in nursing homes health care is supplemental, and usually intended to further the larger goal of palliative care. Our failure

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to understand that nursing home care is essentially a purchased relationship in which some health care may be provided is problematic for seriously ill and dying nursing home residents. How problematic? In a presentation to a palliative care symposium at the Kansas University Medical Center, Sarah Forbes (1998) summarized her research on dying in a long-term care facility this way, "The usual dying experience in a nursing home is cold, lonely and painful."

If palliative care is a sensible framework for nursing home care, it ought to challenge the basic assumptions and practices that have allowed institutional long-term care to become the "cold, lonely and painful" place that Forbes documented. The section on resuscitation status in the *Long-Term Care Guidelines* illustrates how the palliative care framework challenges these long-held assumptions.

Without first obtaining consent, hospitals routinely attempt to resuscitate patients whose hearts have stopped beating or who have stopped breathing. The argument for attempting resuscitation without consent is that consent can be fairly inferred from the circumstances in which resuscitation is attempted — a hospital emergency.

The circumstances of most resuscitation attempts that occur in nursing homes are different in at least three ways. The majority of long-term nursing home residents prefer that resuscitation not be attempted (Murphy et al. 1994). Attempted resuscitation of nursing home residents rarely succeeds (Potter 1998). Most nursing homes do not have equipment or personnel trained to provide advanced resuscitation techniques. The fair inference of consent for attempted resuscitation that hospitals make becomes an unfair inference when it is applied to nursing home residents who consider cardiopulmonary arrest to be an anticipated, not unwelcome event. *Long-Term Care Guidelines: Improving Care for Seriously Ill and Dying Residents of Long-Term Care Facilities* is not the first document to argue against attempting to resuscitate long-term care residents without consent (Zweig 1998). However, it may be the first to suggest that unconsented attempts to resuscitate residents are inconsistent with the facility's primary goal.

*Long-Term Care Guidelines: Improving Care for Seriously Ill and Dying Residents of Long-Term Care Facilities* is filled with practical insights, observations, and suggestions for nursing homes that want to provide outstanding care for their seriously ill and dying residents. The following samples are drawn from the five topical issues included in the PATHWAYS initiative.

### *Advance Care Planning*

No effort to improve the care of seriously-ill and dying long-term care residents is sufficient that does not improve communication among people who are interested in the care: residents (and their surrogates), families, nursing home staff, physicians, hospice organizations, and regulators. Of course we ought to use existing communication tools well, but we also need to devise new communication tools.

In our community, most long-term care residents make advance directives. In some facilities, nearly all residents have identified the persons they want to make their health care decisions when they cannot act for themselves. A smaller percentage of residents have said how they want to be cared for

when they are very sick; however, this smaller percentage approaches 50 percent in many facilities. Notwithstanding their substantial use and widespread legal support, advance directives are not a substitute for the process of caring communication.

Advanced aging and dying are related. Because the majority of long-term care residents are of advanced age, no group is more likely to benefit from advance directives. However, the relationship between advanced age and dying also uniquely complicates all efforts to acquire, present, and honor an advance directive. To coordinate end-of-life care, long-term care providers need to know and understand their residents' health care preferences. The Patient Self-Determination Act (Source Date) requires that information about advance directives be provided in connection with admission to the facility. However, admission to a nursing home is not the best moment to address end-of-life health care preferences. Admission is an emotionally charged time for new residents and their families. Other tough issues are often in play: frailty, disability, declining mental status, personal and family finances, the family home, personal possessions, unresolved guilt, grief, loss, fear, and anger. These issues complicate, if they do not overwhelm, any pointed consideration of end-of-life health care preferences.

Dementia among the elderly is particularly troublesome for long-term care providers, primarily because it makes advance directive information difficult, if not impossible, to attain. The dementia may be so severe that the individual can no longer make health care decisions. If questions about one's preferences were not addressed earlier, when the resident had decisional capacity, the wishes cannot be fully ascertained.

The families of long-term care residents often operate on a false assumption, namely, that the spouse, siblings, or adult children of the older adult automatically have authority to make decisions for their older adult. Long-term care facilities are guided by regulations that require residents to make their own placement decisions and

participate in their health care decisions. If the resident cannot make or communicate informed decisions because of mental or physical impairment, then the facility must look to an appropriate surrogate for all decisions. A designated surrogate is a durable power of attorney for health care or a guardian assigned by the court.

Many family members also assume that they can execute a health care treatment directive or a living will for the nursing home resident lacking decisional capacity. They must be informed that the intent of the document is to allow the individual

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to communicate his or her own health care wishes; family members cannot presume to speak for them. Long-term care facilities can perform a valuable service by encouraging persons to make advance directives before they enter a long-term care facility and to discuss them with family members, health care providers, and others they think may become involved in their health care decisions.

At the time of admission and thereafter, every effort should be made to help residents and their families understand the individual's right to accept or refuse treatment and to make advance directives. The staff person designated to address these issues should be well informed and able to discuss advanced directives and end-of-life issues. Meaningful discussion will help residents understand the difficulties that might occur without advance directives, such as receiving more aggressive care than they prefer.

Although some residents in a long-term care setting are admitted for a short time only for rehabilitation, respite, or care at the end of life, the majority live in the facility for months or years.

Thus, tracking advance directives, maintaining current documents, and monitoring the residents' continued decisional capacity becomes an additional responsibility of the long-term care provider. Although the emphasis in the Patient Self-Determination Act is in terms of adequate documentation during the admission process, other staff — either social workers, chaplains, or nursing administrators — must include this in their job responsibility. Continued resident and family/surrogate education on the issue and continued discussion are a standard.

### ***Resuscitation Status***

A policy to reverse the automatic application of CPR to dying residents is proposed. Our intent is to provide accurate information, promote informed consent, and ensure care for people near death.

Due to the low likelihood of successful resuscitation for most nursing home residents, "No CPR" shall be the default policy. Residents and surrogate decision makers shall be informed of this policy prior to admission, accompanied by information about CPR risks and benefits as described in the literature, and the outcomes of attempted CPR in this nursing home. Residents shall also be informed whether advanced life support services are available in this nursing home and what additional care can be provided by EMS services and at the nearest hospital. Patients with complex, multi-system problems such as end-stage dementia, metastatic cancer, sepsis, severe metabolic abnormalities or persistent vegetative state shall not be offered attempted CPR.

For those residents who request CPR after receiving this information, an order to attempt CPR shall be written. The following principles should guide the use of CPR for those who request it:

For pulseless residents who experience a witnessed arrest, basic CPR will be initiated by nursing home personnel. Emergency medical services will be summoned.

Unless they were observed to be functioning normally in the previous minutes, basic CPR will not be initiated nor will emergency medical services be summoned for pulseless residents who experienced an unwitnessed arrest.

Advanced life support will be discontinued if the patient's initial cardiac rhythm is unfavorable, if resuscitation has not occurred within fifteen minutes or if the resident arrives in the hospital emergency department without a pulse or blood pressure.

Residents and family members will be assured that palliative care and other forms of medical therapy will be available to nursing home residents as they approach death (Zweig 1998).

### ***Treatment Orientation***

The advent of technological medicine has benefited many persons. Intensive and prolonged treatments can ameliorate acute and chronic conditions. If a serious illness is met with an aggressive health care intervention, a life may be maintained and an acceptable quality of life may be restored. The majority of persons who report an intensive care experience say they would undergo the care again. However, other people live for weeks, months, or years with a condition that diminishes the quality of their life and eventually causes their death. For these persons intensive and prolonged treatment offers no benefit, and prolonged dying may trap them in an unacceptable quality of life and expose them to more suffering. Palliative care, which is the primary goal of long-term care, avoids the pitfall of unwanted care at the end of life. Palliative care responds to the sense that for seriously ill and dying residents it is good to provide caring that primarily

- enhances functioning,
- enables control,
- encourages relationships,
- supports family,
- lessens pain and suffering,

- nurtures spiritual growth, and
- supports both a meaningful life and a dying process as free from pain and suffering as possible.

Since the quality and the orientation of care at the end of life are directly related, clarity about the orientation of care is extremely important. If palliative care is the primary goal of long-term care, then the default orientation for care in a long-term care facility is always palliative care. Since health care is transactional, maintaining clarity about the orientation of care ought not be a conceptual challenge. Long-term care is always palliative except when a resident and a physician agree to reorient care by adopting a discrete plan of medical care. If they make such a plan, once it has been completed or abandoned, the orientation of care reverts to palliation.

Not only is maintaining clarity about the orientation of long-term care conceptually manageable, if a long-term care facility's organizational culture is supportive, it is practicable as well. A supportive organizational culture includes the following features:

- An institutional attitude that encourages watchfulness for clues that it's time to revisit the resident's care plan.
- A motivated care team that is open to timely and appropriate treatment reorientation.
- A care team that is trained to recognize and report clues that trigger the plan development process.
- A resident-centered process for reorienting care that promotes communication with the resident and family.
- A mechanism for resolving conflict in difficult cases.

### *Spiritual Support*

Until we recognize the multidimensional aspects of aging persons we cannot support them in their dying process. Typically residents of long-term care

facilities lack the support they need to meet the spiritual aspects of the inevitable end of life.

Despite its relevance to medicine's fundamental goal of healing, modern medicine gives insufficient attention to the spiritual dimension of the human experience. This dimension can and should be integrated into health care models and practice, most especially into the care of seriously ill and dying residents of long-term care facilities. Providing spiritual support demonstrates concern for the whole person.

To discover the true nature of a person is to know the values which that person holds. But one cannot reflect on a person's values unless one knows the relationships which that person calls valuable. Unlike hospitals, long-term care facilities are positioned to know more of an individual's values and beliefs.

The American philosopher, William James (1892, p. 151), had this to say about relationships:

Between what a man calls "me" and what he simply calls "mine," the line is difficult to draw. We feel and act about certain things that are ours very much as we feel and act about ourselves. Our fame, our children, the work of our hands, may be as dear to us as our bodies are, and arouse the same feelings and the same acts of reprisal if attacked. And our bodies themselves, are they simply ours, or are they us?

Such relationships must be plumbed if we are to serve chronically ill and dying long-term care residents.

In *Devotions Upon Emergent Occasions*, John Donne wrote, "No man is an Island, intire of it selfe . . . every man is a piece of the Continent, a part of the main. . . ." To know another, specifically to know one's meaning for (or experience of) suffering, life, dying and death, one must understand the person's network of relationships with other individuals, with human groups, with the sacred, and with the environment. Such a network of relationships constitutes the spiritual dimension of a human subject.

Spirituality refers to the nonmaterial and transcendent dimensions of human experience, to a person's ability to find purpose, meaning, and serenity in his or her life. Religion refers to the specific beliefs and practices of organized religious groups and institutions. The relationship between spirituality and religion is a complex one. The spirituality and religion of many older adults are fused in ways that cannot be generally and reliably teased apart.

While every aspect of human life potentially contributes to spirituality; values, ideas, beliefs, religion, experience, morality, culture, and ethnicity often play particularly powerful roles. Rituals and practices often support spirituality. The diversity of human spirituality deserves respect, and should be particularly honored by people who care for seriously ill and dying residents of long-term care facilities.

Though a methodology may be in place, many long-term care providers do not use it to recognize and support the spiritual values of residents. In every assessment, physicians, nurses, social workers, chaplains, and nurse assistants should express themselves in language that the resident can understand, and should include the resident's story in his or her own words.

The objective of these guidelines is to improve our understanding of the spiritual dimension of seriously ill and dying persons. The guidelines also contain strategies designed to help families, long-term care facility staff, and others provide more complete and care-full caring for those who are seriously ill or dying.

### ***Pain and Symptom Management***

Palliative care is an active, total care that embraces the notion that it is good to alleviate and ease symptoms in lieu of continued attempts to cure residents with end-stage diseases. It requires aggressive symptom management and spiritual support to maintain the best quality of life for the resident and family/surrogate. This type of care requires a willingness by both the resident and care providers to share the development of

treatment plans and presents challenges that are contrary to more traditional, curative plans.

These guidelines are intended to recognize common assumptions and barriers in providing this type of care and to outline strategies that will assist organizations in promoting an environment conducive to palliative care intervention. The workgroup who prepared the guidelines believed that using these guidelines, health care providers and caregivers in long-term care facilities can begin to manage symptoms for the terminally ill so that dying can become a meaningful time for individuals and families.

### ***Toward a New Consensus***

The technological momentum of medicine paired with current cultural expectations have made present health care for the chronic/seriously ill and dying problematic. Most deaths in the United States occur in institutions that seek to prolong life and prevent death. It is safe to say that there is no pervasive consensus on when to initiate palliative or comfort care as an alternative to the more

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aggressive, curative plan of care. The training of physicians and other health care professionals focuses on efforts to reverse the disease process, and death is often viewed as a failure. Communication skills necessary to meet the responsibilities of caring for the dying are often lacking as is the knowledge base required for management. As documented in the SUPPORT study, residents' symptoms, such as pain, are not adequately relieved, their emotional needs are not met, and they lack opportunities to discuss their

goals and preferences with physicians. There is hesitation to initiate a less curative plan of care until shortly before death. *Long-Term Care Guidelines: Improving Care for Seriously Ill and Dying Residents of Long-Term Care Facilities* is a strategy that is seeking to change this experience for patients who are living in long-term care facilities.

### Consultation/Mediation

The third PATHWAYS long-term care strategy is Long-Term Care Ethics Case Consultation. In 1994, Missouri's Long-Term Care Ombudsman began referring end-of-life ethics cases to Midwest Bioethics Center for telephone consultation. A case that the Ombudsman referred in the spring of 1995 demonstrated the limitations of telephone consultation and led to the establishment of the mediation service that we call Long-Term Care Ethics Case Consultation. In that case, the wife of an incapacitated long-term care resident who had been designated as the agent in her husband's durable power of attorney for health care decisions could not overcome a nursing home's refusal to honor her husband's advance directive. The case ended in a classic long-term care confrontation — the facility's Saturday morning ultimatum for the wife to back-off the advance directive, move her dying husband out of the facility, or pick him up in the parking lot that evening. Afterward, the Kansas City Regional Long-Term Care Ethics Consortium advised Midwest Bioethics Center that while the case was disappointing, it was far from singular.

If long-term care professionals aren't surprised when an articulate health care proxy, acting pursuant to an impeccably prepared advance directive document cannot make ordinary end-of-life decisions for a nursing home resident, it's problematic. When they're not surprised that the combined support (albeit at a distance) of Midwest Bioethics Center and Missouri's Long-Term Care Ombudsman proves ineffectual, it's time to revisit the way we do ethics in long-term care settings.

Because we thought face-to-face mediation might have met the challenge presented in the preceding case, we established the Long-Term Care Ethics Case Consultation in spring 1996, assisted by a

grant from the American Bar Association's Commission on Legal Problems of the Elderly.

Other long-term care mediation programs across the country have struggled to develop a caseload. However, supported by Missouri's Long-Term Care Ombudsman Program, the Kansas City Regional Long-Term Care Ethics Consortium, and the reputation of Midwest Bioethics Center, Long-Term Care Ethics Case Consultation has established a growing flow of cases — more than 100 in four years.

### Case Profiles and Outcomes

After four years, a profile of the usual case has emerged. It is factually complex and involves multiple participants — one case had nineteen participants. Almost every case involves the long-term care of someone who is seriously ill and dying. Though some cases require extensive preparation, once prepared, they tend to resolve themselves easily. A significant number of cases reflect the tensions that accompany the provision of hospice care to nursing home residents. Recently we've begun to receive requests to resolve issues that reflect problematic aspects of the Medicare and Medicaid reimbursement systems.

The four-year track record of Long-Term Care Ethics Case Consultation is a success rate of about 95 percent. I think there are three reasons why the process has been so successful.

- First, though they may be unhappy with each other, participants in a Long-Term Care Ethics Case Consultation are rarely unhappy with the seriously ill and dying person who is at the center of the case. The core principal of all mediation is the idea that when people negotiate in good faith they find mutually satisfying solutions to the issues that divide them. When these issues are emotionally intense, factually complex, and involve numerous participants, it is very helpful that the beneficiary of a successful negotiation (the seriously ill and dying person) is sympathetic to everyone.
- Second, few people want exclusive responsibility for hard end-of-life decisions.

Since they bring a bias in favor of shared decision making to these situations, the participants tend to embrace Long-Term Care Ethics Case Consultation more effortlessly than participants in other types of mediation do.

- Third, framing Long-Term Care Ethics Case Consultation as an ethics activity is extraordinarily helpful. Ethics in the context of health care operates on the assumption that for every health care situation there is a fitting response, a response that best reflects the patient's interests. While we may strongly disagree as to whether the fitting response to a particular case is medical, surgical, or palliative, the calculus of health care ethics does not admit the existence of plausible situations for which there are no fitting responses. As a result, participants come to Long-Term Care Ethics Case Consultation with a healthy optimism that their work will result in progress.

Long-Term Care Ethics Case Consultation has received financial support from the American Bar Association, Missouri's Long-Term Care

Ombudsman Program, The Homer McWilliams Trust Fund Grant at Baptist Medical Center, and the Members of Midwest Bioethics Center. All indications are that Long-Term Care Ethics Case Consultation, unlike other PATHWAYS strategies, will survive the conclusion of the PATHWAYS project and become one of Midwest Bioethics Center's ongoing programs.

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