



# Improving End-of-Life Care in California's Nursing Homes

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## Introduction

The California HealthCare Foundation (CHCF) focuses considerable attention on the nature and quality of end-of-life care in California nursing homes. This attention has revealed substantial anecdotal evidence that too few nursing home residents receive effective palliative care at the end of life. One element of CHCF's focus on the issue has been to sponsor a project by The HSM Group Ltd. (HSM) to study barriers to appropriate end-of-life palliative care in nursing homes, and potential approaches to reducing those barriers. This study explored a number of specific, related questions:

- Why do so few nursing home residents have effective advance health care directives?
- Why are nursing home residents often transferred to hospitals during the end-of-life period, and how many of these transfers are necessary?
- What aspects of the nursing home context constrain the delivery of palliative care at the end of residents' lives?

The study followed up on these questions by examining how the problems they highlight might be addressed, and by whom. This report summarizes the study's findings.

## Nature of the Study

The HSM study, conducted during October and November 2007, had three major components: provider and family focus groups; a survey regarding facility policies and practices; and interviews with experts in the nursing home field.

HSM organized four focus groups to discuss the nature of end-of-life care in California nursing facilities. Two focus groups, of ten participants each, were comprised of nursing home administrators; another group (nine participants) was of nursing home directors of nursing (DONs). The nursing homes represented by these administrators and DONs were a mix of facility size and for-profit/nonprofit status; all were skilled nursing facilities (SNFs). The final focus group consisted of eight relatives of nursing home residents who had died within the previous 12 months; many of these family members had been their relative's appointed health care surrogate.

Another project component was a written survey of the three professional focus group members (representing 39 facilities), which sought information about each facility's end-of-life care policies and practices. HSM also conducted interviews with a dozen experts in the nursing home field, including educators, providers, and executives with various long term care associations.

## Low Percentage of Formal Advance Directives

One of the major factors in the low numbers of California nursing home residents who receive appropriate palliative care at the end of life is how few of them have properly executed advance directives. For California nursing homes residents, data available in the first three months of 2008 suggest how low the rates of completion are: Only 1.1 percent of residents have a properly completed "living will" (according to the Minimum Data Set, a federal data base with information about

individual nursing home residents), while 18 percent have a durable power of attorney for health care decisions. These low figures are particularly troubling given that many nursing homes residents do, in fact, express preferences for intensity of care: 42 percent do not wish to be resuscitated, and 7 percent do not wish to be transported to the hospital. Cultural differences also play a role in the use of advance directives: Providers noted that Latino, African American, and Asian American residents at their facilities have been somewhat more reluctant than others to embrace the advance directive.

The study also revealed inconsistency and confusion among nursing home administrators and staff about what constitutes a legally binding advance care document. Most facilities (86 percent) in this study have new residents complete the facility's own version of a Preferred Intensity of Care (PIC) or Preferred Intensity of Treatment (PIT) document. But these documents are neither legally binding advance directives nor medical orders that staff and attending physicians are compelled to follow, and they may conflict with an existing advance directive.

Also, it is often an admissions clerk, rather than a professional staff member, who handles the PIC or PIT process. This process rarely involves in-depth discussion with resident and family, since it is usually well beyond the clerk's work capacity or competence to conduct a value-based end-of-life care discussion. Moreover, while admission may seem an obvious time to discuss an advance directive, the circumstances in that moment are often very stressful for both the resident and family members. For this reason, admission may in fact not be a good moment to encourage and discuss, let alone actually prepare, an advance directive.

The intake process is at least a good opportunity to identify who does and does not have a directive. In some facilities, if a resident indicates that he or she does not have an advance directive, this fact is noted in the resident's chart, and the topic might be raised again

during care conferences. However, facilities report that they do not maintain statistics on the number of residents with completed formal advance directives.

In sum, the nursing home admission process does not now effectively address the problem of the low number of Californians with advance health care directives. As a result, most residents who might want and benefit from palliative care are without the documentation that most effectively increases the odds that they will receive such care.

### **Unnecessary Hospital Transfers**

Study participants were unanimous in believing that many residents are precipitously transferred to hospitals for treatment during changes in condition near the end of life—sometimes in a round robin of transfers and returns—instead of remaining in the nursing home and receiving appropriate palliative care there. The study found several aspects to this phenomenon: confusion and inadequacies regarding advance health care directives; staffing insufficiencies; fear of litigation and regulatory citation; financial disincentives; and a climate within nursing homes that seeks to avoid the stigma of death in the facility.

#### **Poor Follow-Up on Hospital Transfers**

Nursing home administrators in this study all reported that a high percentage of nursing home resident hospital transfers are unnecessary. Yet a survey of these administrators, other nursing home officials, and DONs showed that only 61 percent of their facilities performed routine quality reviews to assess the appropriateness of transfers. And upon the death of a resident, only 45 percent of the facilities regularly reviewed the quality of care that had been provided at the end of life.

## Lack of Clarity Regarding Resident End-of-Life Preferences

The high number of end-of-life hospital transfers is traceable in large measure to confusion in nursing homes regarding residents' end-of-life care choices. This problem becomes particularly disruptive when an attending physician or other staff member is faced with a resident's suddenly worsening condition. When the physician or other staff member has doubts about the proper course of action, the default position is usually to send the resident to the hospital.

In the first instance, confusion about what to do arises from the low number of completed advance directives (as discussed in the previous section). Moreover, even if staff members know of an advance care directive expressing the resident's wishes, a surrogate named in the document may override what appear to be the document's clear directions. Both administrators and DONs interviewed for this study reported that frequently an emotionally wrought family member who is also the advance directive surrogate ignores the resident's specific preferences. This problem may be exacerbated when the resident completed a PIC or PIT form that contradicts the terms of the advance directive.

Also, because there is widespread discomfort talking about death, discussion with family too often fails to make clear when a resident is in the process of dying. Family members' lack of understanding about the transition to

### Public Guardians

A problem raised in two focus groups was the case of residents—many with dementia or Alzheimer's—who have a public guardian. Regardless of the resident's condition, providers in this study asserted that public guardians usually choose not to make decisions that limit treatment, either upon admission or during a change in the resident's condition. This leaves the facility without directions, resulting in hospital transfers, as well as resuscitations, tube feedings and other interventions.

dying frequently leads them to consider the resident's change in condition as an episodic problem to be aggressively treated, including transfer of the resident to the hospital emergency room.

## Staff Inadequacy

Both administrators and DONs in this study emphasized that hospital transfers are in large part the result of staff inadequacy. This deficiency has two components: staffing levels; and poor staff education and training in palliative care and end-of-life care decision-making.

### Staffing Levels

When asked what would have improved the dying experience for their loved ones, the single factor most often mentioned by family members in this study was increasing the number of staff. Nowhere is the staffing shortfall more starkly illustrated than in the decision to transfer residents to the hospital emergency room.

Many attending physicians visit nursing home residents infrequently—once a month, or less. This means that they are unlikely to know, from clinical observation, when change in a resident's condition is underway or imminent, and so will not have considered the question of hospital transfer for that resident. Infrequent visits also mean that physicians are less likely to discuss treatment preferences with the resident and family members.

When a transfer decision needs to be made, the attending physician probably will not be at the facility, and may not even be available for consultation. A high percentage of transfers occur in the evenings and on weekends, when neither a DON nor a physician is usually in the facility. When the attending physician is unavailable, the call goes to a covering physician who probably is unfamiliar with the resident and family, is unlikely to come to the facility to assess the situation, and tends to choose the simplest course of action—transfer to the hospital. Even when the attending physician is available by phone, limited clinical information about the resident's present condition, plus

an unwillingness or inability to come to the facility, usually leads to a recommendation of hospital transfer.

When a resident has a sudden condition change and no physician or DON is available, immediate responsibility falls to staff—usually Licensed Vocational Nurses (LVNs)—not trained to handle such crises. LVNs focus on care delivery rather than clinical problem solving, and many lack advanced clinical skills required to assess and interpret a change in condition, which would also be beyond their scope of practice. Also, LVNs may fear repercussions if a patient dies while under their care, so they tend to resolve doubts about care in favor of hospital transfer.

Administrators in this study felt that greater presence of social workers or geriatric nurse practitioners in facilities could lead to better coordination of end-of-life care, including reduction of hospital transfers. But because of cost, most facilities are unwilling or unable to employ nurse practitioners or professionally trained social service personnel.

### Staff Training and Education

Most physicians, nurses, and nursing home administrators receive little formal training regarding death and dying, or palliative care. Pain management and end-of-life training is provided to staff in some nursing homes by a hospice service that works with the facility, but this training is neither extensive nor systematic. The lack of training not only limits physicians' and nurses' ability to conduct difficult conversations with residents and families about end-of-life preferences but also dissuades them from pursuing such conversations at all.

Admissions personnel are usually charged with asking new residents about their end-of-life preferences and advance directives, but these clerical staff members are not often provided with professional training in this regard.

Efforts by the nursing homes in this study to compensate for the lack of formal end-of-life education of physicians and nurses present a mixed picture (from a small survey sample of 39 facilities). Almost all the facilities provide staff in-service education on pain management (96 percent), hydration and nutrition (93 percent), and the role of hospice in nursing homes (93 percent). But only 58 percent of these nursing homes provide training in facilitating end-of-life care decisions. And these nursing homes are significantly deficient in setting expectations for staff on providing quality end-of-life care: Only 14 percent of surveyed facilities define quality end-of-life care as part of job descriptions, and only 7 percent include the subject in performance evaluations.

### Fear of Litigation and Regulatory Citation

Providers in this study reported that among physicians, nursing home staff, and facility administrators alike, there is substantial fear of litigation if treatment is withheld from a resident who appears to be near death, especially if this is contrary to some family member's wishes. [See "Is There a Doctor in the House? Physician Liability Fears and Quality of Care in Nursing Homes," California Healthcare Foundation, August 2008, [www.chcf.org](http://www.chcf.org).] This makes the simplest course of action—to phone for an ambulance and send the resident to the hospital—also the "safest" course of action. The irony that this anxiety does not arise from concerns about the resident is not lost on nursing home staff: "The dead person isn't suing us," as one administrator put it, "[it's] the family."

Another concern for nursing home staff is the potential for regulatory disciplinary action when treatment is withheld, even when following a resident's preferences. Withholding certain care such as nutrition and hydration increases the likelihood of scrutiny by surveyors and the need for documentation by staff. Participants in this study believe that many facilities are so fearful of such citations that they continue active treatment—forcing a dying resident to keep doing physical therapy was one example cited—to the resident's detriment. Families reported

that they were uncomfortably aware of this litigation/regulation anxiety, believing that staff concerns about strict adherence to regulations tended to interfere with appropriate personalized care of the resident: “Especially when you have Medicaid and Medicare involved and you ask them something and they start coming back with all their rules to the point where you just want to go in there, grab your mother and run and go, ‘We’re out of here.’”

### **Mixed Message from Regulators About Hospice**

Hospice is one way to deliver appropriate palliative end-of-life care to a nursing home resident. But in addition to financial factors complicating the use of hospice in nursing homes (see “Financial Considerations,” below), providers report that facilities using hospice have recently come under scrutiny by surveyors for duplication of services and thus technically “double dipping” of funds. Providers recount surveyors asking to see the charts of residents on hospice more often than those of other residents and questioning why a resident is receiving hospice when the nursing home could provide the same care.

As a result of this heightened scrutiny, administrators and DONs feel extra pressure to justify the involvement of hospice. This can have a double-edged effect: On one hand, administrators may be more reluctant to suggest hospice for residents; on the other, if hospice is used, the facility may restrict or withhold its own delivery of some end-of-life care.

### **Financial Considerations**

Providers and experts in this study pointed to financial factors that may inhibit facilities and attending physicians from providing comprehensive palliative care. The study participants were uncertain, however, about the extent to which these matters were determinative of, as opposed to merely contributing to, care decisions.

One of these factors is that Medicare and Medi-Cal (Medicaid) reimbursement structures may provide financial benefits to a facility when a resident is

transferred to a hospital and then returned to the facility. If the resident is covered by Medi-Cal, the facility is paid for three days to hold the bed—without providing services—while the resident is in the hospital. When the resident returns, the SNF can be reimbursed, for a time, at the higher Medicare rate. On the other end of the equation, providers note that it takes more time, staff, and stress to provide good palliative care, yet there is no additional Medi-Cal or other reimbursement for doing so.

Another financial aspect inhibiting palliative care involves physicians. Thorough communication with residents and family is often key to choosing palliative end-of-life care, as opposed to treatment interventions. But doctors are not reimbursed for talking (especially extensively) to patients and families about end-of-life care, while they are compensated for performing procedures. And physicians receive higher reimbursement for services rendered in a hospital than in a nursing facility.

### **Avoiding Attention and Stigma from a Death in the Facility**

Providers admitted that a factor in hospital transfers is the extra attention paid, and stigma attached, to the facility and to on-duty staff because of a resident death. A death at the facility can mean added scrutiny from state and/or local agencies, including, at times, even a police visit. And a record of deaths in a facility may lead to a negative perception within the nursing home industry. As a result, when staff members recognize that a resident is actively dying, they may tend to send that person to the hospital to avoid the death occurring in the facility.

### **Nursing Home Self-Perception as a Barrier to Palliative Care**

Many of those interviewed in this study noted a connection between the poor public image of nursing homes and the lack of comprehensive end-of-life care. For years, the nursing home industry has been trying to change public perception of their facilities from places to die to, instead, places to get better. As part of this

### Ambivalence Toward Hospice

Providers in the study expressed considerable ambivalence about hospice in nursing homes, stemming from a combination of logistical, financial, and interpersonal issues.

Financially, hospice can work either to a facility's benefit or detriment. Hospice nurses and aides relieve facility staff of some care duties, and hospice can cover the cost of some equipment. Also, Medicare may designate some residents as hospice inpatients, paying the facility at a higher rate. However, if a resident is referred to hospice before all his or her Medicare SNF days are exhausted, the facility would receive a rate lower than the SNF rate.

Relations between facility and hospice staff members can also be complicated. Some facility staff appreciate hospice nurses' expertise and welcome the hospice staff's taking on of certain duties. Also, some nursing facility DONs and LVNs are glad to receive palliative care and other end-of-life care training from hospice nurses. However, some nursing home staff members chafe at the interventions of hospice providers, complaining of poor communication with hospice staff, loss of control over resident care, and the failure of hospice to provide expected care. There can also be logistical problems because facility and hospice nurses cannot give or take orders to or from each other. Hospice management of a resident's care plan can also cause friction. And some nursing home providers contend that hospice was designed for the cancer patient, and believe that the model does not work as well for other facility residents (e.g., those with congestive heart failure, dementia, COPD).

approach, administrators promote—to residents, families, and staff—the prolonging of life. Within this paradigm, however, there is little space for difficult discussions about end-of-life matters, and resistance to the very concepts of end-of-life care and the dying process. Perhaps tellingly in this regard, fewer than half of this study's facilities review residents' deaths to assess quality of care at the end of life.

Also, many nursing facility leaders believe that the routine care they provide is already “palliative.” As a result, they see no need to enhance end-of-life care services or to

establish a specific palliative care framework within the institution. Notably, not one of the nursing facilities represented in this study has a formal palliative care program.

### Opportunities for Improvement in Nursing Home End-of-Life Care

The participants in this study contributed a number of ideas for improving end-of-life care in California nursing homes. Some suggestions focused on developing programs to expand awareness of end-of-life choices and to facilitate the preparation of easily comprehensible, effective advance directives. Others focused on improving training for facilitating end-of-life decisions as an integral part of staff responsibilities. There were also recommendations to help ensure that decisions about hospital transfer are the same no matter when a change occurs in a resident's medical condition.

#### 1. Improve End-of-Life Care Skills

Palliative care skill-building should be incorporated into required continuing education for nursing home medical directors, administrators, nurses and physicians, and could perhaps even be mandated—similar to dementia care education for certified nursing assistants (CNAs). There already exist a number of programs designed to improve nursing home staff awareness of and competence in end-of-life care, including:

- **The End of Life Nursing Education Consortium (ELNEC) project**, a program of the American Association of Colleges of Nursing and the City of Hope Hospital in Duarte CA, provides nursing faculty, staff development educators, and nurses with training in end-of-life care so they can train nursing students and practicing nurses. One course (ELNEC-Geriatric) in this “train the trainer” program is developed specifically for nursing home staff.
- **Respecting Choices**, developed in Wisconsin, is a comprehensive approach to advance care planning. It focuses on professional training and organizational

change that would take place throughout a health organization or community. One aspect of the Respecting Choices curriculum addresses nursing home communication specifically related to Physician's Orders for Life Sustaining Treatment (POLST).

- **Palliative Care Educational Resource Team (PERT)** is an educational program for licensed nursing staff and CNAs. The program developers (led by Mary Ersek, Ph.D., R.N., of Swedish Medical Center in Seattle) have tested a Train-the-Trainer format in which the curriculum is taught to educators, who then conduct in-service training in their own facilities.
- A program for CNAs under development by the Coalition for Compassionate Care (CCC) focuses on normalizing death in nursing homes.

## 2. Address Provider Concerns About Regulatory Issues

In 1997, an interorganizational statewide task force was formed to improve end-of-life care in California skilled nursing facilities. Known as the ECHO (Extreme Care, Humane Options) Long-Term Care Task Force, its members included the California Department of Health Care Services, the California Association of Health Facilities, Aging Services of California (then known as the California Association of Homes and Services for the Aging), the California Board of Registered Nursing, and other healthcare professionals, long term care representatives, and consumer advocates. The task force produced a set of recommendations to improve end-of-life care in nursing homes that were consistent with patient-centered care and also complied with regulations governing nursing home care. The California Coalition for Compassionate Care field-tested the recommendations in 1999 and used them extensively in statewide training programs in 2000. The ECHO recommendations are available for use, along with educational materials, at [www.finalchoices.com](http://www.finalchoices.com).

### The POLST Paradigm

The Physician Orders for Life-Sustaining Treatment (POLST) is a bright pink form that translates the wishes of an individual about life-sustaining medical treatment into a set of physician's orders, signed by both physician and patient. Completing a POLST is much more significant than simply filling in a form: It requires physicians and other health care providers to engage patients with serious, life-limiting illness in a discussion about their preferences for end-of-life medical interventions and intensity of care. The form transfers with the patient, and must be honored across all settings of care.

Oregon initially developed the POLST system in the early 1990s to address a common challenge: Nursing home residents were being transferred to emergency rooms without any information to guide the staff there about patient preferences for intensity of interventions. The POLST paradigm has been adopted by West Virginia and Washington, as well as by parts of 12 other states. National groups have developed excellent resources that could be useful in the adoption of POLST in California, especially the Respecting Choices curriculum for training health care providers on how to introduce the POLST form and elicit patients' wishes.

Since August 2007, eight community coalitions in California have been working to implement POLST: in Humboldt, Mendocino, Riverside, Alameda, Ventura, Yolo, Sacramento and Santa Clara counties. Leadership for the spread of POLST in California is provided by the California Coalition for Compassionate Care, based in Sacramento, CA.

Since 2000, there have been sporadic organized efforts to address end-of-life care in nursing homes, but nothing on the scale of the ECHO Task Force. Given the high degree of turnover in nursing homes, consistent focus on this issue is needed, and reanimating the task force could be very helpful in this arena. The active engagement of the Licensing and Certification Program of the California Department of Health Care Services in the task force would help allay provider fears about developing programs that do not fit into the regulatory framework.

### 3. Expand the Use of Advance Directives

The task of increasing the use of advance directives must target the public, nursing homes, and—since directives must be signed while the person is competent—those in the health care system who see patients before they become nursing home residents: physicians, home health care staff, residential care facility staff, senior services professionals, and hospital personnel.

With regard to nursing homes themselves, the nursing home membership organizations—California Association of Health Facilities (CAHF) and Aging Services of California—could create a target number (perhaps 75 percent, initially) of residents who have an advance directive. Trade associations could be important coordinating bodies for pilot educational and training programs. If the rate of advance directives became a reported quality measure for nursing homes, the rate would likely improve. Similarly, inclusion of advance directive percentages in pay-for-performance analysis would likely increase their use.

While the day of admission may be too stressful a time to focus on advance directives, facilities should be encouraged to initiate the conversation with a resident and family within the resident's first two weeks at the facility. Because of the costs involved, simply calling for added staff to address this systemic problem is not likely to produce widespread results. Instead, existing staff might be better deployed to engage residents and family in end-of-life care planning, including the preparation of advance directives, and to ensure that end-of-life care preferences are followed when a resident is actively dying.

**End-of-life care specialist.** With additional preparation and support, the charge nurse on duty should be able to communicate not only a resident's condition but also end-of-life care preferences to the responsible physician, and to carry out treatment orders. To increase the likelihood that such preferences will be fully understood and implemented, facilities could create an end-of-life

care specialist: charge nurses specially trained, and present on each shift. With proper documentation in the chart when a resident's condition changes, the end-of-life care specialist could call the attending or on-call physician and convey the resident's condition in the specific context of the resident's end-of-life care preferences, reducing the tendency to transfer residents to the hospital as a fallback position.

**Nursing home social worker.** Initiating end-of-life conversations with new residents might be handled well by a nursing home social worker. However, individuals in that role in California do not necessarily have a social work degree, and may have had little experience dealing with death and dying. Focused end-of-life care training could both allow the social worker to take on this job and at the same time raise the status of the social worker position in the facility.

### 4. Adopt “Physician Orders for Life-Sustaining Treatment”

Over the next few years, there will be increasing opportunities for nursing homes in California to engage in community coalitions and other efforts to promote the use of POLST. Interested facilities can find out more about POLST online at: [www.finalchoices.org](http://www.finalchoices.org).

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## Conclusion

There are a number of barriers to providing appropriate end-of-life care to nursing home residents. California's overall poor record regarding completion of advance directives among the general population is not remedied among people in nursing homes—those most in need of clarity about end-of-life wishes. Even when some treatment preference documents are prepared, they are too frequently incomplete, ignored, or overridden. This poor preparation of residents and families for end-of-life care, plus lack of end-of-life care training among nursing home staff, and systemic pressures against delivery of comprehensive palliative care in the nursing home, results in unwanted treatment, unnecessary hospital transfers, and end-of-life scenarios that run counter to the best interests of many residents.

In response to this situation, providers in the field are identifying ways to increase appropriate palliative care at the end of life for nursing home residents, without necessarily requiring large amounts of money or significant changes in care. These include public and professional education programs, projects to improve and increase the use of advance directives in nursing homes, adjustments in staff roles to clarify end-of-life choices and to ensure that they are honored, and implementation of new programs such as POLST.

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## ABOUT THE AUTHOR

The HSM Group, Ltd., based in Scottsdale, Arizona, is a health care consulting business. It provides market research, training, economic models, consulting, and strategic planning to many areas of the health care industry, including managed care organizations, health systems and hospitals, pharmaceutical manufacturers, medical products manufacturers, and health care trade organizations. More information on HSM is available at [www.hsmgroup.com](http://www.hsmgroup.com).

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## ABOUT THE FOUNDATION

The California HealthCare Foundation is an independent philanthropy committed to improving the way health care is delivered and financed in California. By promoting innovations in care and broader access to information, our goal is to ensure that all Californians can get the care they need, when they need it, at a price they can afford. For more information on CHCF, visit us online at [www.chcf.org](http://www.chcf.org).