



CARE RECOMMENDATIONS

Compassion And Respect toward the End of life
Steps and Tools to Implement Palliative Care in Nursing Homes

February 2010 | Revised July 2015





The Coalition for Compassionate Care of California is a statewide partnership of regional and statewide organizations dedicated to the advancement of palliative medicine and end-of-life care in California.
CoalitionCCC.org



The California Culture Change Coalition is a collaborative of providers, resident-advocates, state and federal regulators and direct care workers dedicated to fostering culture change on a broader scale than can be achieved through the individual efforts of one organization.
CalCultureChange.org



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Purpose and use of this document

This document is designed to be used by staff serving residents in nursing homes to:

1. Facilitate conversations with residents and family members to clarify goals of care in light of the individual resident's specific preferences.
2. Provide care that addresses residents' physical needs, while also honoring their emotional, psycho-social, and spiritual needs.
3. Establish processes and rituals that acknowledge the sacredness of the human spirit in residents, staff and family members.
4. Create a culture in which resident's individual needs and preferences are known and honored.

This document will benefit all residents in nursing homes. It is not limited to residents who are in the last days or hours of life. Rather, all residents will benefit from the holistic, compassionate, person-centered care outlined in this document.

THIS DOCUMENT IS DEDICATED TO

NEWELL ERWIN

October 19, 1926—October 18, 2009

Newell was a role model for the kind of elder we all hope to be. She inspired us with her strength, presence and constant good will. We are richer for having known her.

Newell was a founding board member of the California Culture Change Coalition.

JULY 2015

CARE (Compassion And Respect toward the End of life) Recommendations: Steps and Tools to Implement Palliative Care in Nursing Homes, are a combination of palliative care principles and culture change practices that provide practical concepts, tools and resources to guide skilled nursing facilities in providing quality, person-centered care that is consistent with residents' wishes.

The *CARE Recommendations* were created through a collaborative process that brought together nursing home leaders, providers, consumers and regulators, including representatives of the California Association of Health Facilities (CAHF), Leading Age of California, California Long-Term Care Ombudsman, California Department of Public Health (CDPH), and Centers for Medicare and Medicaid Services (CMS). Since their initial release in 2010, the *CARE Recommendations* have been recognized by CMS as a valuable tool to assist nursing homes in meeting survey requirements. CMS' revised Interpretive Guidelines on F-309 issued in 2012 cites the *CARE Recommendations* as a useful resource.

Interest in palliative care and resident-directed considerations toward the end of life has grown tremendously in the last few years. National programs, such as Advancing Excellence in America's Nursing Homes and the CMS Quality Assurance and Performance Improvement (QAPI) have incorporated patient-centered care as a key element of quality improvement programs.

With so many opportunities for positive change, it can be hard to know where to focus your staff's time and talents. The *CARE Recommendations* are designed not just to inspire you, but more importantly, this document is designed to provide easy-to-use guidance, tools and online resources that will allow you to make tangible changes in the way your staff care for seriously ill or aging residents.

Since the initial publication of the *CARE Recommendations* we've witnessed changes in our national conversation about advance care planning and the end of life. Media is having a positive influence—physicians are talking about the kind of care *they* wish to receive, and documentaries are highlighting the importance of decision-making and palliative care in the face of serious illness.

The nation has come a long way in the last five years. If we stay the course we're hopeful one day soon all nursing home residents will receive the compassion and respect deserved at the end of life.



Judy Thomas, JD
Chief Executive Officer
Coalition for Compassionate Care of California



Darren Trisel, MSA, NHA, RCFE, MT
President, Board of Directors
California Culture Change Coalition

Letters of Support



DEPARTMENT OF HEALTH & HUMAN SERVICES
CENTERS FOR MEDICARE & MEDICAID SERVICES
Consortium For Quality Improvement and Survey & Certification Operations
Western Consortium – Division of Survey & Certification

April 9, 2010

CARE Task Force Committee
Judy Citko, JD
Executive Director
Coalition for Compassionate Care
1215 K Street, Suite 1917
Sacramento, CA 95814

On behalf of the San Francisco Regional Office, I would like to thank you for your hard work in production of your CARE (Compassion and Respect toward the End of Life) Recommendations “Steps and Tools to Redefine Healing and Hope in Nursing Homes.” CMS continues to be a firm supporter of the Culture Change movement and the re-define of quality of care and quality of life for nursing home residents.

This document and accompanying toolkit further enhance efforts to recognize and implement creative methods to provide high quality care and services in homelike settings. Additionally, these recommendations work to assure that end of life experiences are dignified and consider the resident and their entire support network. Inclusion of resident’s holistic needs and preferences in conjunction with coordination of care and services is essential in the provision of true person-centered, person-directed care.

Sincerely,

Steven D. Chickering
Associate Regional Administrator
Western Consortium Survey and Certification Officer

Denver Regional Office 1600 Broadway, Suite 700 Denver, CO 80202	San Francisco Regional Office 90 7 th Street, Suite 5-300 (SW) San Francisco, CA 94103-6707	Seattle Regional Office 2201 Sixth Avenue Seattle, WA 98121
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“CMS continues to be a firm supporter of the Culture Change movement and the re-define of quality care and quality of life for nursing home residents.”

—Steven D. Chickering
Associate Regional Administrator
Western Consortium Survey and Certification Officer
Centers for Medicare & Medicaid Services



State of California—Health and Human Services Agency
California Department of Public Health



ARNOLD SCHWARZENEGGER
Governor

May 28, 2010

Judy Citko, JD Executive Director
Coalition for Compassionate Care
CARE Task Force Committee
1215 K Street, Suite 1917
Sacramento, CA 95814

Dear Ms. Citko:

On behalf of the California Department of Public Health (CDPH), please accept our appreciation for your work in the development of the Compassion and Respect toward the End of Life (CARE) Recommendations. Your dedication in creating the “Steps and Tools to Redefine Healing and Hope in Nursing Homes,” exemplifies a strong commitment to improving the quality of care, dignity and support for individuals who are at the end of life.

CDPH supports our mutual efforts to improve health care through the coordination of care and services that meet individual preferences and the right to choose at the end of life. We look forward to working with you as facilities increasingly implement more focused, person-centered, person-directed care.

Sincerely,

Kathleen Billingsley, R.N.
Deputy Director
Center for Health Care Quality
California Department of Public Health

“Your dedication... exemplifies a strong commitment to improving the quality of care, dignity and support for individuals who are at the end of life.”

—Kathleen Billingsley, RN
Deputy Director, Center for Health Quality
California Department of Public Health

Overview: What is a good death?

I know that how you remember and take care of my neighbors is how you will remember and take care of me.

—Helen Keller, age 93

We can do better

Death may be a natural part of life, but talking about it in our culture isn't—and this is clearly true for those of us who work in nursing homes. Although nursing home residents do die, few nursing homes have established customs and practices to provide guidance in caring for residents and talking with families about the final phase of a resident's life.

The result is often care that is more burdensome than beneficial, including transferring residents to the emergency room without considering their goals of care, continuing to provide interventions that are no longer useful, and ignoring or minimizing the experience of death. When decisions are made on the spur of the moment, without advance care planning on the part of residents, family members and the care team, our residents suffer, our families often are distressed and staff members are cut off from constructive ways of handling the grief and sadness that comes with the loss of a resident they cared for.

There is room for improvement. This document explores ways to honor resident choice at the end of life, support and educate family members so they are prepared for their loved one's death, and replace interventions that prolong suffering with ones that provide comfort and honor the human spirit. We offer ways in which to bridge the gap between the reality that our residents will die and the belief that good care dictates that we must do everything in our power to prolong the life of a resident, without considering what it is that the resident really needs and desires.

Good end-of-life care is grounded in person-directed care

Good end-of-life care is inherently person-centered and resident-directed. Person-centered care "puts the person before the task" and includes resident choice and empowering all caregivers, including direct caregivers, to honor resident choice. Resident-directed care promotes resident choice in every aspect of daily life.

Overview: What is a good death? (cont.)

Resident-directed and person-centered care is at the heart of the culture change movement that is becoming an accepted norm in nursing homes. Endorsed by the Centers for Medicare and Medicaid Services (CMS), the overall goal of culture change is to shift from institutional to individualized care in every aspect of nursing home care. The more specific goals are to:

- Provide care and activities designed to respond to resident choices
- Provide a living environment that is designed to be home-like rather than institutional
- Facilitate close relationships between residents, family members, staff and the community
- Support and empower all staff to respond to resident needs and desires

Good end-of-life care is in philosophical alignment with person-directed care. Good end-of-life care requires paying close attention to the individual resident. It involves knowing the resident's values, goals, and preferences and then aligning the care the resident receives with the resident's wishes. It requires observing the resident closely for signs of suffering or decline. It involves caring for the whole person—physically, emotionally, mentally, socially, and spiritually—as well as those who are close to the resident. Just like person-directed care, good end-of-life care starts on the day of admission.

Nursing homes that embrace person-directed practices have the foundation for providing good end-of-life care. And, nursing homes that provide good end-of-life care will be utilizing person-directed practices.

Confronting challenges

Most of us would prefer to die surrounded by people who know us and care about us. But all too many nursing home residents, including those for whom the nursing home has become their home, face a different reality. Often, they will be transferred to a hospital where they are surrounded by strangers who may attend to their physical needs but who have no history that guides care with respect to the resident's psychological, emotional, and spiritual needs. Residents are often alone, frightened, and disoriented when they are transferred by ambulance and admitted to the emergency room. Being hooked up to the array of technological devices that hospitals offer can be traumatic and the care provided may not reflect the wishes of the resident or provide enough benefit to justify the burden on the resident.

Good end-of-life care starts on the day of admission.

Determining whether a transfer to the hospital is in the resident's best interests requires physicians and nurses to work as a team utilizing their best clinical and communication skills. Physicians and nurses should be sensitive to the stress that a hospital transfer can cause to a resident. At the same time, nursing homes need to recognize the limitations of the care they can provide. Distinguishing between changes in

What is a good death?

condition that would benefit from care in a hospital and those changes where the resident's decline would be exacerbated by the transfer require critical thinking. Transfers should happen only after thoughtful consideration and communication.

Nursing homes that are committed to reducing unnecessary suffering that can accompany a hospital transfer are committed to staff competency in:

- Clarifying the goals of care for each resident
- Focusing on the resident as a whole person, not just the resident's clinical issues
- Reducing suffering and providing comfort measures
- Recognizing the active dying process
- Clarifying what can be done to address residents' comfort needs
- Communicating with residents and family members in a way that reduces anxiety and fear

Embracing end-of-life care can be challenging for nursing homes which have been plagued by a public perception of inadequate care. Some people believe that promoting nursing homes as a place to die is equated with passive neglect or, worse yet, active abuse. In reality, good end-of-life care involves active, intensive caring. In fact, when a nursing home attends to the emotional and spiritual needs of residents toward the end of life, the nursing home often enjoys greater family satisfaction and staff retention.

Recognizing opportunities for healing and hope

It is possible for residents to experience healing, though there is no cure for their underlying condition, and to feel hopeful, though they are near life's end. A good death:

- Is consistent with resident and/or family beliefs, wishes, and values
- Is free of fear, pain, and suffering
- Provides an opportunity for meaning and completion
- Acknowledges the emotional connections that family and staff members have with the residents

Care toward the end of life is holistic care. Consequently this document addresses more than clinical decisionmaking and interventions; we also address the backdrop against which decisions are made – the culture of the nursing home. Quality of care is broader than performing specific tasks correctly. Quality considers the human needs—the psychological, social, emotional, and spiritual needs—of the residents, family members, and staff.

Caring for staff empowers them to care for residents

Death is difficult for everyone. When staff members believe they have done what they can to make the resident comfortable, alleviate the family member's anxiety, and honor and respect the resident's wishes, it is easier to handle the loss. When the culture of the nursing home supports and encourages caregivers, they are empowered to take care of residents in the best possible way. Having specific, thoughtful processes that address the end of life empowers staff to meet the resident's death with closure and without the feeling of regret.

Step One: Advance care planning

With the proper training and preparation, a peaceful and positive death is possible for each and every one of us.

—Sangye Khadro, Tibetan Buddhist nun

Providing good care toward the end of life requires knowing each resident as a unique individual—what they hope for, what they fear, and what makes life worth living. Sometimes we avoid these conversations out of fear—not knowing what to say, being unsure about how to respond to what the resident might bring up, or simply being uncomfortable with facing our own mortality. If we fail to give our residents the opportunity to talk about what they want and what they fear most, we miss the opportunity to help them regain a sense of control, to provide reassurance that we will be able to manage pain, and to reinforce that we will do our best to meet their needs.

Our residents may have thought about what they want at the end of their lives. Many of them may be more prepared than we are to have a conversation about what they want or don't want. Without such conversations, residents and family members often feel robbed of control over their lives.

Most people have thoughts on what constitutes quality of life for them based on their own beliefs about family, independence, spirituality, mobility and mental capacity. What residents and family members often don't know is how their goals and preferences will play out given their particular circumstances and medical condition. Residents and family members are better able to alleviate their fears and make thoughtful decisions when they are informed about the course of the resident's disease, as well as the potential implications of the treatment options that are available.

Online CARE Toolkit



The Advance Healthcare Directive is a way for residents to make their healthcare wishes known if they are unable to speak for themselves.

The Advance Healthcare Directive Fact Sheet answers common questions about advance healthcare directives.

[COALITIONCCC.ORG/CAREtoolkit](https://coalitionccc.org/CAREtoolkit)

Advance care planning begins on admission

Only a small percentage of residents have put their wishes in writing before entering a nursing home. Yet, our residents frequently communicate their wishes to us—although sometimes in a vague way. Residents say things like “I don’t want to be a burden to anyone” or “I’ve lived my life, I’m ready for God to take me.” These unstructured moments are an opportunity to find out more and to provide reassurance. Many residents and family members feel very relieved when physicians and nurses are willing to talk about death—because they are ready to talk about it. When a resident expresses such sentiments, there is an opportunity for caregivers to expand the conversation by asking open-ended questions such as “tell me more about why you feel that way...”

Communicating in advance eases the distress of everyone involved—and provides direction for a physician or nurse who is not familiar with the resident, but who must nevertheless make decisions in a very short period of time. Advance care planning is the process that ensures that residents and family members fully grasp the implications of their decisions. Physicians, nurses, and others learn what the resident wants. In other words, both sides have critical information that they need to impart to each other. Consequently, end-of-life decisions should be discussed with residents by healthcare professionals.

Residents will be more candid about their end-of-life wishes when they trust that caregivers truly care

about them as human beings. Nursing homes can create an environment that fosters trust by expressing interest in and curiosity about a resident’s life. What is the resident’s story? What does the resident hope for? Questions such as these express to residents that it is our privilege as caregivers to share this journey of life together.

The first step in providing healing and hope in nursing homes is to establish a structured process for advance care planning that includes the following components:

1. Residents and family members are fully informed about the resident’s medical condition and about common medical treatments toward the end of life.
2. Residents have the opportunity to express their wishes clearly.
3. The facility has policies, procedures, and processes in place for documenting, communicating, and honoring those wishes to provide care and medical treatments consistent with the resident’s wishes.

Advance care planning is a person-directed process, based in conversation, which enables us to know our residents’ values, goals, and treatment preferences. Facilities that invest staff time and resources upfront in making sure that the conversation is done well, save time and energy avoiding situations where decisions have to be made during a crisis. Both the advance directive and POLST (Physician Orders for Life Sustaining Treatment) form provide important mechanisms for documenting resident wishes.

Step One: Advance care planning (cont.)

The role of the advance directive

An advance directive is a way for a resident to make his/her wishes for future healthcare treatment known. There are many different versions of the advance directive, however, all of them can be used by a resident to do one or both of the following:

- Appoint an agent to speak for the resident when the resident is unable to do speak for him/herself (sometimes referred to as a “Durable Power of Attorney”), and/or
- Indicate the resident’s values, goals, and preferences for treatment (sometimes referred to as a “Living Will”).

Nursing homes benefit tremendously when a resident has an advance directive that names a surrogate decisionmaker. Having clarity about who has authority to speak for a resident facilitates smooth communication when a critical healthcare decision has to be made.

Federal Law

The **PATIENT SELF DETERMINATION ACT** requires that, during the admission process, nursing homes ask residents if they have an advance healthcare directive and provide information about advance healthcare directives. For residents that have an advance healthcare directive, the nursing home should obtain a copy and put it in a prominent place in the medical chart. This enables staff to honor the resident’s wishes. Residents with capacity who don’t have an advance directive should be encouraged to complete one. When an advance healthcare directive is completed in a California nursing home, an ombudsman must witness the signing.

POLST: Translating resident wishes into a physician order

California has adopted the use of the POLST (Physician Orders for Life-Sustaining Treatment) form to complement the advance directive and increase the likelihood that a person's wishes regarding clinical interventions toward the end of life are honored. POLST translates a patient's values and preferences for end-of-life care into a physician's order that follows the patient across healthcare settings. POLST addresses a range of treatment options and enables our residents to clearly express treatment preferences regarding life-sustaining measures such as resuscitation, nutrition, and intensity of care. POLST is recognized and honored across all treatment settings, regardless of whether the individual is at home, in a long-term care facility, or in the hospital.

The POLST is a voluntary form which complements the advance directive and is not intended to replace it. In fact, if a resident has an advance directive, it should be reviewed when completing a POLST form to make sure the two forms are consistent. POLST is also a physician order. While other members of the nursing home team may assist with initiating the conversation, the physician is responsible for making sure that the treatment choices reflect informed decisions.

This form provides a framework for discussing some of the common end-of-life medical treatments and providing residents and family members with information they need to make informed choices. Specifically covered on the POLST form are decisions about:

1. Cardiopulmonary Resuscitation (CPR)
2. Medical treatments and transfer to hospital
3. Artificially administered nutrition

It is safe to assume that most residents will have a limited understanding of the consequences of their choices. For example, most people know CPR from what we see on television where the process looks easy and the outcome is successful. Few understand that CPR may result in broken ribs, punctured lungs or brain damage caused by lack of air. And, it is often not successful.

Many people believe that in the absence of a feeding tube their loved one will face a painful death by starvation. In reality, as the body approaches death, it begins to shut down and its ability to process and receive nutrition from food decreases. Studies have shown that in persons with end-stage Alzheimer's disease, feeding tubes may not prolong life, and can increase the risk of complication.

We owe it to residents and family members to provide information that helps them understand the implications of these interventions in light of the resident's medical condition. The POLST form provides a structure for these conversations, which should be grounded in information about the resident's medical condition. For this reason, it is critical that staff assisting with completion of POLST be well qualified and trained in how to have these conversations. And, the physician should review the form—and the treatment options in light of the resident's specific medical condition—with the resident or the resident's decision-maker before signing it.

Step One: Advance care planning (cont.)

Advance care planning is an on-going process

Advance care planning does not end once a resident has completed an advance directive or a POLST form. Rather, these documents should be reviewed on a regular basis to make sure they continue to accurately reflect the resident's wishes. For example, when a resident has a significant change in condition, it may affect the intensity of care the resident wants to receive. Or, a resident may make a comment to a staff member that provides additional insight into the resident's treatment wishes. Care conferences provide a good opportunity for regular review of residents' advance care planning wishes and documents.

Advance care planning is more than the single act of filling out an advance directive or the POLST form.

Online CARE Toolkit



The *Physician Order for Life-Sustaining Treatment (POLST)* form states what treatment residents want toward the end of their lives.

POLST Frequently Asked Questions answers common POLST questions.

Decision Guides is an educational series that explains the complex topics of life-sustaining treatments, using consumer-friendly language with evidence-based information.

Incorporating advance care planning into the care conference

One of the most transformative activities nursing homes can undertake to move their culture from institutional to resident-directed is to re-examine how care conferences are conducted. The purpose of a care conference is to set individualized goals for the resident's care based on what the resident and family members want and what is realistic for the resident.

Perhaps we should borrow a slogan from the disability rights movement: "Nothing about me without me." The care conference should include input from the resident, resident's family or legal decisionmaker, attending physician, nursing staff and direct caregivers. Care conferences conducted in this way provide the ideal forum for completing, reviewing, and updating the advance directive and POLST form.

Direct care staff is critically important in care conferences because residents often express concerns about the end of life during the daily processes of providing care. Direct caregivers and other staff who frequently interact with residents often have information about the resident's concerns that would not otherwise surface in the more formal setting of a care conference.

[COALITIONCCC.ORG/CAREtoolkit](https://coalitionccc.org/CAREtoolkit)

Advance care planning

Nursing homes can encourage residents and family members to participate in care conferences by:

- Notifying them in advance of the time and place of the care conference and inviting them to attend, and
- Scheduling care conferences at a time of day that is convenient for residents and family members. Ideally family members would attend in person, but allowing them to participate by conference call is preferable to not having them attend.

Resident-directed care and capacity

Advance care planning and medical decision making should be resident-centered at all times. By law, treatment decisions must be based on and consistent with the resident's known wishes and personal values. If the resident has not expressed his/her wishes, then decisions are to be made in the resident's best interest.

Tag F280: Resident Participation in Care-Planning

A comprehensive care plan must be ... prepared by an interdisciplinary team ... and to the extent practicable, [with] the participation of the resident, the resident's family or the resident's legal representative.

When residents have capacity, they retain the right to make their own treatment decisions. For residents' whose capacity comes and goes, paying close attention to the resident and timing discussions so that the resident can participate as much as possible avoids the stress of having to guess about the resident's wishes.

Family plays an important role in advance care planning and medical decision making. However, their authority to make decisions for the resident goes into effect only if and when the resident lacks capacity or delegates such authority to them. If the resident has specifically named who he/she wants to speak for him/her, then that is the person who has authority to speak for the resident, not other family members.

Tag F241: Dignity

The facility must provide care for residents in a manner and in an environment that maintains or enhances the resident's dignity and respect in full recognition of his or her individuality.

Step One: Advance care planning (cont.)

Including family members in discussions

In addition to this formal role in medical decision-making, family members are a tremendous resource in caring for residents and can provide insight and perspective. This is especially true when caring for residents from differing cultures. Conversations with family members can provide invaluable information about cultural values and practices toward the end of life that are important to the resident and to the family. It is hard to know a resident without knowing how they fit into the family and what their family members also hope for them.

Conversations with family members provide invaluable information about cultural values and practices at the end of life that are important to the resident.

Family members will have differing levels of familiarity with medical conditions, differing types of attachment, and differing ideas about what their roles should be. Sometimes family members are not ready to step in as surrogate decisionmakers even though the resident can no longer make decisions. Sometimes family members need time to get used to the idea that their loved one's health is deteriorating and that death may be approaching.

We may think it's time to let go but the family member is not ready. Some family members operate from a premise that if the resident could live longer, the resident should live longer. They believe that medical treatments with even the slightest chance of prolonging life should be tried.

Finally, some family members believe it is completely inappropriate to have any part in decisions related to the end of life. They feel "it's not my place" or "it's up to the Lord." In these instances, it is important to provide answers to questions and keep the family member informed, but not to attempt to persuade the family member to think differently. In this way, you keep the door open for continuing dialogue and increased understanding on both sides.¹

¹ *Calling the Question of 'Possible Dying' Among Nursing Home Residents: Triggers, Barriers, and Facilitators* by Mercedes Bern-Klug appeared in the *Journal of Social Work in the End-of-Life and Palliative Care*, Volume 2(3) 2006.

Step Two: Resident-directed care considerations toward the end-of-life

What chills my bones is indignity. It is the loss of influence on what happens to me. It is the image of myself in a hospital gown, homogenized, anonymous, powerless, no longer myself.

What scares me is to be made helpless before my time, to be made ignorant when I want to know, to be made to sit when I wish to stand, to be alone when I need my wife's hand, to eat what I do not wish to eat, to be named what I do not wish to be named, and to be told when I wish to be asked, and to be awoken when I wish to sleep.

—Donald Berwick, MD, Former Administrator, Centers for Medicare and Medicaid Services

When does dying begin? For the majority of people admitted to nursing homes, including those admitted for rehabilitation, advanced age and serious chronic illness, death is no longer theoretical. At what point should they be considered dying? It is difficult for anyone to gauge the seriousness of any particular episode. Most of us have witnessed residents who have temporary setbacks only to recover. Sometimes a resident dies unexpectedly. Despite our best efforts, we do not always get it right.

When a person takes a turn for the worse, usually the nursing staff decides to wait and see or to transfer residents to the hospital for further diagnosis of the condition and possible intervention. In most nursing homes, it is common that orders for comfort care or for the provision of hospice services are not written until the week of death, sometimes only hours before death.

We believe that every resident would benefit from the simultaneous provision of palliative care, even if the primary goal of their care is rehabilitation and discharge. For many residents there may come a point, however, when the facility needs to recognize that the resident is in active decline and transitioning to active dying. Given that death is unpredictable, it is recommended that all residents are afforded the opportunity to express their wishes on admission and at regularly scheduled care planning intervals. In addition, all residents deserve to have their pain and symptoms managed and to be made as comfortable as possible.

Tag F 279:

Comprehensive Care Planning

The care plan must describe the following: (i) The services that are to be furnished to attain or maintain the resident's highest practicable physical, mental and psychosocial wellbeing...

Step Two: Resident-directed care considerations toward the end-of-life (cont.)

Use of the terms *palliative care* and *comfort care*

In ordinary language, the terms *palliative care* and *comfort care* are often used interchangeably. They are not quite the same.

Palliative care is both a philosophy of care and a process for delivering care. The term “palliate” means to relieve or lessen without curing. Palliative care focuses on relieving the stress and symptoms of serious illness such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, and difficulty sleeping. Palliative care means focusing resources on

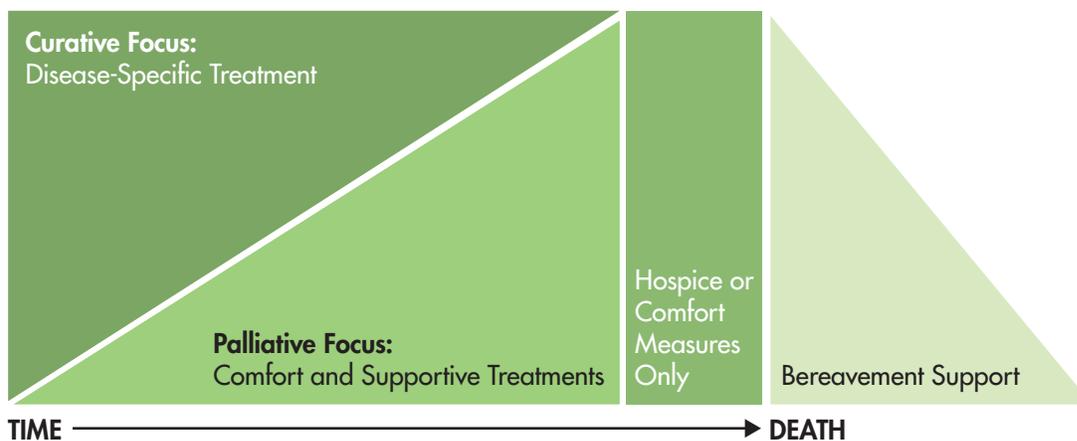
intensive symptom management and quality of life; it does not involve the lessening of curative or rehabilitative measures. It is also interdisciplinary in nature so the resident has access to the entire team, including physicians, nurses, and social services.

While all nursing homes should be able to provide basic palliative care, sometimes residents’ palliative needs are so great that it may require more intensive or specialized resources than are available in the nursing home.

In long-term care, federal regulations state that we have to maintain or attain the highest practicable level of well-being for our residents. How do you maintain someone’s highest level of well-being when he or she is dying? In the past, the practice has been to treat with aggressive and invasive procedures up to the end of a resident’s life. For many residents who are dying, however, this regulation is better met by developing and carrying out an interdisciplinary palliative care plan.

“Palliate” means to relieve or lessen without curing.

PALLIATIVE CARE DIAGRAM



Palliative care is one form of healthcare that can assist those diagnosed with a terminal illness as well as those who have a chronic disease. Palliative care can be provided at the same time as treatment that is meant to cure.

Resident-directed care considerations toward the end-of-life

Change of condition

Certain events cause the healthcare team to ask the question “is this person dying?” Sometimes these trigger events are dramatic but often they are quite subtle. We usually recognize dramatic events such as a heart attack, stroke, and hip or spine fracture. However, there are often signs of medical, functional, and psychosocial decline that are less obvious, such as:

- Weight loss
- Increase in falls
- Repeated incidences of infection, including urinary tract and pneumonia
- Pressure ulcers that heal very slowly or not at all
- Pain
- Extreme fatigue
- Increased dependency on oxygen

Other indicators are behavioral in nature, including:

- Refusing to eat
- Refusing medications
- Wanting to stay in bed
- Not wanting to participate in activities or rehabilitation

Often the decline is noticed by direct caregivers first—but the change can be subtle. Nursing homes that assign the same caregivers to the same residents—consistent assignment—stand a better chance of picking up the subtle signs of a final decline.

Although prognoses are always uncertain, the primary care provider, facility staff, resident, and/or family need to be aware of the course that most likely lies ahead.

Online CARE Toolkit

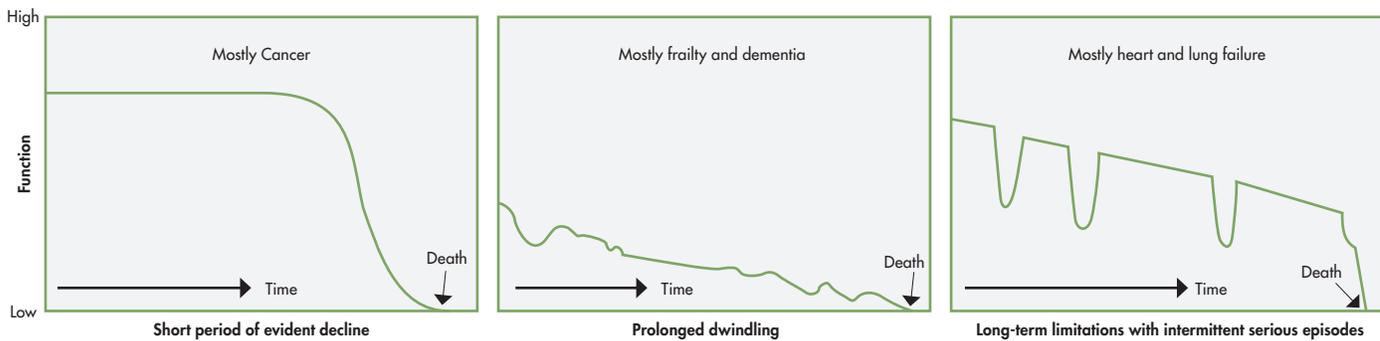


The *INTERACT Stop and Watch Early Warning Tool* helps direct caregivers communicate their observations to licensed staff so there is time to respond appropriately.

[COALITIONCCC.ORG/CAREtoolkit](https://coalitionccc.org/CAREtoolkit)

Step Two: Resident-directed care considerations toward the end-of-life (cont.)

The following graphs depict the typical course for many of our residents:



Source: Joanne Lynn and David M. Adamson, *Living Well at the End of Life: Adapting Healthcare to Serious Chronic Illness in Old Age*, Rand Health, 2003.

The last phase of life may be a period of days, weeks or years, and it can begin unexpectedly. This fact, and the attention on rehabilitation in order to meet perceived regulatory requirements, combines to create confusion around what should be done toward the end of life. There is not necessarily a clear boundary between when treatment aimed at prolonging life ceases and end-of-life care begins. When evidence of a decline is identified by the nursing home's clinical team, regulatory sanction can be avoided by asking two key questions:

1. Is this decline reversible or irreversible?
2. Does the resident and the family desire a curative or comfort care-only approach?

If the decline is irreversible or the nursing home has documentation of the resident's wishes not to continue curative treatment, then rehabilitative or restorative measures can be discontinued. This includes such interventions as weighing residents and attempting to force them to eat. Regulatory sanction is usually the result of failure to notice early warning signs of decline, to plan accordingly, to communicate clearly with other members of care team, including the physician, as well as family members, and to adequately document the changes on the care plan.

Regulatory sanction is usually the result of failure to notice early warning signs of decline, to plan accordingly, to communicate clearly with other members of care team, including the physician, as well as family members, and to adequately document the changes on the care plan.

Resident-directed care considerations toward the end-of-life

Resident-directed care means residents have a right to refuse any aspect of care. This includes not just medical treatments, such as those outlined on the POLST form, but also the ordinary aspects of care such as eating and taking medications.

Evidence-based care practices

We are learning that many interventions such as tube feeding and CPR, which were thought to be life-sustaining and commonly used in nursing homes, are not always as beneficial as we once believed. Decisions about any form of treatment must be made on a case-by-case basis and in the context of the resident's overall goals of care. Prevention of suffering should be a standard for evaluating the risks and benefits of any intervention. Most family members are unaware that these interventions have serious medical risk that accompanies the benefit. It is up to us to make them aware of the implications.

Residents are often alone and frightened when they are transferred by ambulance.

Tube feeding

Many people fear that not providing a feeding tube at the end of life means letting the resident starve to death. In the terminal stages of many diseases including advanced dementia, the gastrointestinal system shuts down and digestion becomes ineffective. This is not to be confused with starvation, which occurs when a hungry person, whose body can benefit from food and nutrients, is deprived of them.

For someone who is terminal, the body may not be able to use the nutrients that the tube feeding provides and bloating and discomfort may increase. There is little evidence that tube feeding prevents pneumonia, or prevents pressure ulcers or causes them to heal. Each situation, however, must be evaluated individually. Tube feeding may help someone with a temporary eating or swallowing problem, for example following cancer treatment or stroke, but may not be best for someone in the final stages of a terminal illness.

Cardiopulmonary resuscitation

The success of CPR depends on the reason the heart has stopped, how healthy the person was before the heart stopped, and how long the heart has been stopped before CPR is started. It is hard to know in advance how effective CPR will be for a specific person, but many studies have shown who is most likely to benefit from CPR and who is not. In general, about 15% of those who have CPR will survive.

Step Two: Resident-directed care considerations toward the end-of-life (cont.)

For nursing homes residents, the survival rate is less than 2%. This number may increase for those who have no major health problems, have a sudden, unexpected collapse, have CPR started within a few minutes of when the heart stops, and have the type of heart rhythm that responds to electrical shocks. Of those 15%, many will not return to the same level of functioning they had prior to their heart stopping.

For older people, especially, the serious complications often outweigh the benefits. The most common complications are rib fractures that have been documented in 97% of CPR attempts, and breastbone fractures documented in up to 43% of cases. Approximately 59% of those who have CPR will have bruising of the chest and about 30% may have burns from the defibrillator.

Online CARE Toolkit



Decision Guides explains the complex topics of life-sustaining treatments in easy-to-read language, and is intended to supplement conversations between patients and healthcare providers. Topic covered include: *Artificial Hydration, CPR, Tube Feeding, and Ventilation.*

[COALITIONCCC.ORG/CAREtoolkit](https://coalitionccc.org/CAREtoolkit)

Stop and think before you transfer

Most people express the desire to die in their own home. When a resident has lived in a nursing home for a period of time, it is their home. Yet, many nursing home residents spend their last days and hours in a hospital.

There are many reasons why transfer to the hospital is so frequent, including lack of confidence in our ability to provide the appropriate care, fear of legal liability, fear of regulatory sanction, family pressure due to unrealistic expectations or feelings of guilt, and failure to recognize and manage escalating symptoms.

We need to think carefully about transferring residents to the hospital at the end of their lives. Residents are often alone, and frightened when they are transferred to the hospital by ambulance. They may endure long and uncomfortable waits in the emergency room before being admitted to the hospital. And being hooked up to the technological devices that hospitals provide can be traumatic and recovery after hospitalization may be extensive and prolonged. The care provided may not be of enough benefit to justify the burden to the resident.

Resident-directed care considerations toward the end-of-life

While transfer decisions must be made on a case-by-case basis, it is safe to say that many residents do not derive significant benefit from a hospital transfer toward the end of life. Most of the decisions to transfer are made when nurses consult with the physician after a resident's condition changes; these decisions often occur during the evenings or on weekends, when the on-call physician is engaged in making the decision and does not know the resident. Often these decisions are made without consideration of the resident's previously expressed goals and preferences.

Frequently, family members are not contacted regarding the decision to send the resident to the hospital, and when they are, families often think it's their job to second guess the resident's wishes. Many families, however, are looking to the physician and nursing home for guidance in these moments. In these instances, simple statements communicated confidently can be effective and comforting to family members, such as "We can make your loved one comfortable and aggressively manage pain." If a POLST form has been filled out in advance, nurses can remind families and physicians of the resident's previously expressed wishes.

The way in which nurses communicate to physicians and family members can ensure that when a resident is transferred to the acute care hospital, it is consistent with the resident's goals and values. S-B-A-R provides a standardized way of communicating with other healthcare providers. **The acronym stands for Situation, Background, Assessment and Recommendation.** Staff and physicians can use S-B-A-R to share critical information about a resident's condition and make a sound clinical decision about whether a transfer is in the resident's best interest. It improves efficiency by providing a standardized format of communication that helps caregivers speak about a resident's condition in a concise and complete way.

This simple, yet highly effective communication technique can be used when:

- Nurses are calling physicians
- Nurses are handing off residents to one another
- Nurses are transferring residents to other facilities or to other levels of care

Online CARE Toolkit



S-B-A-R Communication Form & Process Note provides a checklist for clear communication.

COALITIONCCC.ORG/CAREtoolkit

Step Two: Resident-directed care considerations toward the end-of-life (cont.)

Managing pain and reducing suffering

Eliminating pain and suffering is central to the provision of comfort care. Symptoms that need to be assessed and addressed include breathlessness, nausea, anorexia, weakness, insomnia and constipation.

Pain is a personal, individualized feeling of hurt. Pain is whatever the person experiencing pain says it is and exists whenever the person says it does. Many patients experience pain but do not report it. This can be due to a variety of factors such as the misconception that pain is a normal part of the aging process, the belief that some pain and suffering is necessary, fear that pain may be a new disease, and concerns about not being a good patient. In addition, it can also be due to dementia. Consequently, nursing homes should adopt protocols for pain management that require routine pain assessment and establish standards for addressing pain, including for patients who can't verbalize pain.

Although we have made progress in managing pain, nurses often have concerns about the use of pain medication, particularly narcotics. Staff barriers to effectively manage pain include the misconception that pain is a normal part of aging, worries about the regulation of controlled substances, concerns about managing the side effects of pain medication, and concerns about developing tolerance to the drugs or overdose. However, when nurses are able to ensure the resident's comfort, they are more comfortable with providing comfort care.

Helping families understand

While our primary allegiance is to our residents, it is hardly possible to care for a resident without caring for the family members as well. Nursing homes often find themselves dealing with family members who are struggling emotionally. Providing information to families about the signs and symptoms of dying will help them better understand what their loved ones are experiencing. Common signs and symptoms at the end of life may include:

- Decreased need for food and drink because the body functions are shutting down
- Dryness of mouth and difficulty swallowing
- Increased sleeping and difficulty waking up
- Increased restlessness
- Decreased urine output as kidneys shut down
- Breathing may sound labored because of relaxed vocal cords and a small amount of oral secretions collecting at the back of the throat
- Change in breathing patterns – ten to thirty second periods with no breathing
- Moaning sounds which do not necessarily signify pain
- Arms and legs may become cool to the touch and bluish in color
- The underside of the body may become darker and the hands and feet may be mottled due to decreased circulation
- Fever

Resident-directed care considerations toward the end-of-life

These symptoms are often frightening to family members who feel helpless and want to reduce their loved ones' suffering. Family members can derive satisfaction knowing that they can help with the care and comfort of their loved one. Staff may suggest to family members that they:

- Regularly moisten the residents mouth
- Massage the resident's hands and feet
- Play music the resident enjoys
- Sing or read aloud to the resident
- Observe the resident's religious, cultural, or personal customs and rituals

Maintaining care that is resident-directed

Most people fear the loss of dignity and control that comes with advancing age and admission to a nursing home. Most of us want a say in the care that is provided to us. For many staff, the idea of shifting control to residents and family members is both unfamiliar and uncomfortable.

Many of us believe that we know what is right for residents and believe that professionals with a greater degree of technical knowledge should make decisions on behalf of our residents.

Many of us, however, are increasingly recognizing that residents deserve to retain their right to make large and small decisions as they near the end of life for as long as possible. Knowing that we are honoring the dignity of each and every resident and being able to provide comfort are the reasons we chose to work in healthcare in the first place.

Step Three: Dying well

*I came in through the front door;
I shouldn't have to leave through
the loading dock.*

—resident, Fairport Baptist Homes,
Fairport, New York

A person-centered philosophy of caring

It sounds paradoxical, but when we include death as part of life we embrace the fullness and meaning of our own lives. No one wants to feel as if their life is of little consequence to the communities in which we live and work. Each of us wants to matter to others and to be remembered for the contribution we have made.

In the traditional model of institutional nursing home care, we have tried to eliminate the experience of

Person-centered care encourages staff to establish close and loving relationships and recognizes that caregivers feel genuine grief and pain when a resident dies.

death. This perception leads nursing homes to delay the provision of end-of-life care, and to transfer residents to a hospital without thinking about what is in the patient's best interests. It is common practice when a resident dies to remove the body as quickly as possible to avoid upsetting the other residents. Few nursing homes have developed bereavement practices other than adhering to legal requirements.

A new philosophy of person-centered care is emerging that challenges many of the values and practices of the past. Nursing homes that are on their culture change journey intentionally examine every aspect of daily routine in order to create policies and practices that emphasize that quality of life is as important as quality of care. Homes with a focus on person-centered care build on the intrinsic motivation of staff to care holistically for residents, for their totality as human beings and not just their clinical needs. Nowhere is this new philosophy more evident than in the practices being created and adopted to care for residents in the final days of life.

In the institutional model of care, the emphasis has been on curing or rehabilitation, on maintaining professional distance, and on not upsetting the resident with the realities of death. Many of us trained in this model of care were cautioned "don't get too close to the residents" or "you need to maintain your objectivity." Yet, caring for residents is the primary reason most of us wanted to work in nursing homes in the first place. Person-centered care encourages staff to establish close and loving relationships and recognizes that caregivers feel genuine grief and pain when a resident dies. To deny the sacredness of death is to deny the sanctity of life. Nursing homes that embrace culture change are devising practices that nurture staff, residents, and their loved ones.

Regardless of background, as we approach death, everyone has the same human needs. First and foremost, we all want to be seen for our spirit that lives in us despite a deteriorating body. When we as caregivers can see beyond a resident's outward appearances and struggles and connect with the resident's spirit, we honor the resident and ourselves.

As human beings, we have deep unconscious instincts to cling to life and this can show up at the end of life in the form of physical agitation, restlessness, or pain. It is often said that "people die the way they lived," which means that someone who has been irritable and resistant will likely struggle more than someone who has gone through life with grace and ease. Dying doesn't change that. In supporting the resident's spirit, however, we create an environment of respect, dignity, comfort, and reassurance. Being a gentle, caring presence helps to alleviate the struggle that residents may experience as their physical body winds down.

The care plan needs to reflect the things that are important to the resident at the end of life, including wishes for the presence of family members, and religious and cultural practices.

A person-centered model of caring

While the advance directive and POLST form make resident choices about medical decisionmaking explicit, there are many other aspects about care toward the end of life that can be equally as important to residents and family members. Even people with dementia can participate in conversations about what matters to them. Certified nursing assistants (CNAs) play a particularly important role in care conferences because they often have unprompted conversations with residents about what is important to them. The care plan needs to reflect the things that are important to the resident toward the end of life, including wishes for the presence of family members, and religious and cultural practices.

As a nursing home begins to examine its practices many questions often emerge:

- What messages are our current practices sending to our residents and family members about the value of a resident's life?
- If we were residents, what would we want if we died in our nursing home?
- Can we do more for our dying residents? What matters to them toward the end of life?
- Why are we so uncomfortable talking about a death with residents when they are often aware that a death has occurred?
- How can we better include family members so they have a sense of peace when a loved one passes?

Answers to these questions often lead nursing homes to make changes in their practices toward the end of life.

Step Three: Dying well (cont.)

Online CARE Toolkit



Hospice in Nursing Homes outlines how nursing homes and hospices can partner to meet individual resident needs.

Cultural and spiritual considerations

Many cultures and religions have specific practices around the end of life and death. What may seem respectful in one culture may seem cold and distant to someone from another culture. And belonging to a particular culture does not necessarily mean the resident will welcome the practices of that culture at the end of their life.

While we cannot expect that all nursing home staff will become experts on the practices of other cultures, we can expect that the nursing home staff will make the effort to find out what matters to individual residents and their family members. The term “cultural humility” is beginning to be used to describe the attitude of being aware of one’s own culture, being interested in learning more, and being committed to honoring the traditions and values specific to each individual resident.

Spirituality refers to the way individual residents seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred. While we are used to asking residents about their medical history, we are not used to asking them comparable questions about their spiritual history. Yet, this kind of information can benefit us tremendously in providing care that nurtures the resident emotionally and spiritually. Taking a spiritual history does not require specialized training, but rather sensitivity and compassion. For residents who would benefit from a more formal spiritual assessment and support, providing them with access to a chaplain can be very beneficial.²

Online CARE Toolkit



The *FICA Spiritual Assessment* helps identify a resident’s spiritual needs.

COALITIONCCC.ORG/CAREtoolkit

² *Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference* by C. Puchalski, B. Ferrell, et. al. appeared in the *Journal of Palliative Medicine*, Vol. 12, No. 10, 2009.

The comfort of ritual and sacred space as death nears

It is important for nursing homes to honor the customs and rituals of their residents. At the same time, many homes are creating meaningful rituals of their own that are inclusive of the entire community. Ritual does not have to be associated with a particular religion or cultural custom. It can be anything the nursing home determines serves the residents and the community of people who live, work and visit the home – as long as the practice is what the resident wants or would have wanted. This step explores some of the practices that honor the lives of residents and bring peace and comfort to family members and staff.

Some nursing homes have created Sacred Journey Kits that include things such as CD players with a variety of appropriate music, aroma therapy including scented oil diffusers, quilts, flame-less candles, note cards, and reading material that is religiously or culturally appropriate. These materials are on hand and are individualized by the caregivers who know the resident's preferences.

As death nears, many nursing homes have found the following guidelines to be helpful:

1. Clear the space of clutter, especially unnecessary medical equipment
2. Diffuse outside noise and distractions as much as possible
3. Provide privacy
4. Soften lighting
5. Provide the presence of something beautiful or meaningful to the resident

Step Three: Dying well (cont.)

No one has to die alone

Comforting a resident toward the end of life is more than performing clinical tasks. Bringing comfort to a resident means attending to all the human needs—the emotional, psychosocial and spiritual. It includes notifying family members as soon as it is recognized that death is near so they have adequate time to be at the bedside if that is their desire. Some homes have adopted a practice of putting a door hanging, with a resident's permission, of a rose, butterfly, or something similar to alert staff and visitors that the resident is at the end of life. This provides adequate time for other residents and staff to pay their respects and spend a quiet moment saying goodbye.

When direct caregivers are consistently assigned, trust develops between the caregiver and the resident.

Just like everyone else, residents want to know that their life mattered and that they touched other people's lives. As residents face life's end, statements such as "please forgive me," "I forgive you," "thank you," and "I love you" can help residents say their final good-byes.³

Not all staff members are equally comfortable with the process of dying. Fears include being alone with a dying person, not knowing what to do or say, not understanding the symptoms of death, and not knowing how to deal with pain. Peer-to-peer coaching by a staff member with more experience is often helpful. Some guiding principles that may be useful are:

- Take a quiet moment before entering the room.
- Focus on the dying person. If he or she wants to talk, be available. If not, be silent.
- Share memories and acknowledge what the person has meant to you.
- Be present, be patient.
- Provide reassurance with gentle touch to the feet, hands, and forehead of the resident.
- Speak gently. Hearing is the last sense that is lost. An unresponsive resident can likely still hear what is being said.

Consistent assignment of staff helps ensure that residents' preferences are known and honored—especially cultural or religious practices that are important to the resident. When direct caregivers are consistently assigned, trust develops between the caregiver and the resident. This gives caregivers the opportunity to learn the resident's preferences and draw upon that knowledge in the final days of a resident's life to create a peaceful physical environment. Examples of this knowledge might include reading poetry or sacred texts that are meaningful to the resident, providing music that the resident enjoys, looking at photographs of family, or soothing touch to ease pain.

³Byock, Ira. *The Four Things that Matter Most*. New York: Free Press, 2004.

Many family members wish to be present when a loved one dies. Federal Interpretive Guidelines require nursing homes to allow visitation, with the resident's permission, whenever it is convenient for family members.

Our actions and attitudes can communicate to family members that they are in the way, or that they are part of the community caring for the resident at this time. Asking family members to participate in simple tasks, such as washing a resident's face and hands, swabbing his/her mouth, or reading to the resident are ways of including family in meaningful, caring activities. Most family members welcome the opportunity to be useful. Some nursing homes demonstrate their care and concern for family members by providing a place to gather and talk, a few simple snacks, a basket of toiletries to use for freshening up, and a place to sleep when necessary.

Although our goal is to ensure that no one has to die alone, many people who work in end-of-life care have observed that some residents die when staff and family have left the room, even for a brief period of time. It appears to be a conscious decision on the part of the dying person. Staff can help to assure family members that this is not a failure on their part.

Caring for the deceased

Many current nursing home practices reveal our discomfort with death and send an unfortunate message to other residents in the home. Moving a resident immediately following the death is one such practice. When we don't announce the death of a resident, other residents wonder if they too will leave the nursing home as if their stay was of no consequence to anyone else.

Some nursing homes now wash the body and cover it with a beautiful shroud or a special quilt. An American flag might also be appropriate. Family members often want to help with the practice of washing the body and placing the shroud. Some nursing homes use a chime to notify that a death has occurred and then allow a period of time before the mortuary arrives to ensure that residents and staff have the opportunity to pay their final respects.

This is also a time when simple prayers and religious or secular readings can be offered. Some nursing homes have adopted the practice of putting a resident's belongings in an attractive box to return to family members. Finally, some nursing home caregivers have adopted the practice of serving as pallbearers side by side with family members as they escort the body to the waiting hearse.

Step Three: Dying well (cont.)

Caring for the living

It is not possible to work in a nursing home without experiencing the emotions of grief and loss. Even when we are pleased to see a resident discharged to home. Even when we know that we might not have them in our lives in the same way we did for a few short weeks. Working in a nursing home means saying goodbye. It is not for everyone. The death of a resident, especially one that the staff has come to know and love, is not easy. It honors all of us as human beings when we create ways to pay tribute in memory of a resident and to acknowledge our own sadness.

Providing compassionate care at the end of life brings healing and hope for our residents, their family and perhaps most importantly, for ourselves.

There are many ways to memorialize the life of a resident. Some homes have created formal services, either secular or religious, to remember those who have left our presence. Some nursing homes use journals or cards so that staff members can write their memories of the person who has died. Then they review it together and give it to the family as a remembrance. Even something as simple as gathering together to share memories with family members honors the work we have done, the loss the family members feel, and the life of the resident. We gather strength to continue our work when we acknowledge our loss. Caring for residents at the end of life is perhaps the most challenging aspect of care giving. Our values are in practice in everything we do at this time—whether explicitly stated or implicit in our activities.

We are each unique individuals and as human beings we are body, soul, and spirit. The body needs food, warmth, hygiene, and movement. The soul needs caring relationships, art, music, and meaningful activities. The spirit needs recognition and respect, religious ritual and support, prayer and inspiration. Person-centered care is about providing care the way we would want it provided if we were in a nursing home.

Providing compassionate care at the end of life brings healing and hope for our residents, their family and perhaps most importantly, for ourselves.

CARE Task Force

The *CARE Recommendations* are the result of a consensus process that brought together the thoughts and contributions of many individuals and organizations. Thank you to all the healthcare professionals who gave their support, experience, and comments to these recommendations. Their commitment to a collaborative process is a model for improving end-of-life care in California.

**Mary Cadogan, DrPH, RN,
GNP-BC**

Professor, Adjunct Series
University of California, Los Angeles
School of Nursing

Jack Christy

Director of Public Policy
Aging Services of California

Judy Thomas, JD

CEO
Coalition for Compassionate Care
of California

Bonnie Darwin

Executive Director
California Culture Change Coalition

Tim Gieseke, MD, CMD

Education Chairperson
California Association of
Long-Term Care Medicine

Michael GuntherMaher, MD, FACP

Medical Director, Hospice
Kaiser Permanente, Sacramento/Roseville

Deborah Kania, RN

Administrative Director
Sutter Oaks Midtown

Kathe Kelly, RN, BSN, OCN

Southern California Cancer Pain Initiative
ELNEC Geriatric Program
City of Hope

Terri Mack

California Department of Public Health

Lynne Mantz

2008-2009 President
Hospital Services for Continuum Care
Board of Directors
California Hospital Association

Jill Mendlen

President and CEO
Lightbridge Hospice and Palliative Care

Jocelyn Montgomery, RN, PHN

Director of Clinical Affairs
California Association of Health Facilities

Kate O'Malley, RN, MS, GNP

Senior Program Officer
California HealthCare Foundation

Darren Orgel

Long Term Care Surveyor
Centers for Medicare and
Medicaid Services

Nancy Jewel Poer

Author and Consumer Advocate

Kelley Queale

Director of Communications
California Association of Health Facilities

Joseph Rodrigues

State Long-Term Care Ombudsman
California Department of Aging

CDR Victoria Vachon, MBA, MSN, RN

*Centers for Medicare and
Medicaid Services*

Sanford Weinstein, MD

California Department of Public Health

The **CARE Task Force** would like to acknowledge the importance and significance of the **ECHO (Extreme Care, Humane Options) Nursing Facility Recommendations** in creating this document. The ECHO Recommendations, published in January, 2000, were the first guidelines in the nation on end-of-life care in nursing homes. As such, the ECHO Recommendations were groundbreaking in bringing together the key concepts of advance care planning and palliative care and applying them to the nursing home setting.

In the ten years since the ECHO Recommendations were published, many things have changed in nursing homes, yet many of the same challenges continue. The CARE Recommendations build off of the ECHO Recommendations putting the key concepts into the context of current nursing home public policy and practices, including culture change philosophy.

Online CARE Toolkit



The tools and resources mentioned in the CARE Recommendations are intended to assist nursing home staff facilitate end-of-life conversations with residents and their families.

Nursing homes that are equipped with the necessary attitudes, knowledge and skills provide the best possible end-of-life care for residents. These tools are intended to be a starting point.

Resources

STEP ONE: Advance care planning

- Advance Healthcare Directives
- Advance Healthcare Directive Fact Sheet
- POLST Form
- POLST Frequently Asked Questions
- POLST Consumer Brochure
- Decision Guides for life-sustaining treatment

STEP TWO: Resident-directed care considerations toward the end of life

- INTERACT Stop and Watch Early Warning Tool
- Artificial Hydration
- CPR
- Ventilation
- Tube Feeding
- S-B-A-R: Communication Form & Process Note

STEP THREE: Dying well

- Hospice in Nursing Homes
- FICA Spiritual Assessment

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Notes



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CARE

RECOMMENDATIONS

CARE Recommendations offers guidelines and tools for providing quality end-of-life care that is consistent with residents wishes. It explores ways to honor residents' choices at the end of life, support and educate family members to prepare for their loved one's death, and replace interventions that prolong suffering with ones that provide comfort and honor the human spirit.

CARE Recommendations assists nursing homes to:

- Facilitate conversations with residents and family members to clarify residents' goals of care and specify their care preferences
- Provide care that addresses resident's physical needs, while also honoring their emotional, psycho-social, and spiritual needs
- Establish processes and rituals that acknowledge the sacredness of the human spirit in residents, family members and staff
- Create a culture in which a resident's individual needs and preferences are known and honored



1331 Garden Highway, Suite 100
Sacramento, CA 95833

(916) 489-2222
info@CoalitionCCC.org



10011 Folsom Boulevard #300
Sacramento, CA 95827

info@CalCultureChange.org
calculturechange.org