Compassion & Respect toward the End of Life

Steps and Tools to Redefine Healing & Hope in Nursing Homes

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The Coalition for Compassionate Care of California is a statewide partnership of more than 95 regional and statewide organizations dedicated to the advancement of palliative medicine and end-of-life care in California.

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.
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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 of the kind of elder we all hope to embody. 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.
Compassion and Respect toward the End of Life

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 as well. 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.

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
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.

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

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.

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 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.
Compassion and Respect toward the End of Life

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.

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 interventions 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 interventions 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.
Compassion and Respect toward the End of Life

**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 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.

**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 decisions, including those related to life-sustaining treatments, pain management, and comfort measures.
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 form 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 interventions 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 interventions 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 decisionmaker before signing it.

**HELPFUL TOOLS IN THE 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

**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.

**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.
Advance Care Planning \(\text{(cont.)}\)

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.

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.

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.

**INCLUDING FAMILY MEMBERS IN DISCUSSIONS**

In addition to this formal role in medical decisionmaking, 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.

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 interventions 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.  

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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.
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, M.D.

When does dying begin? For the majority of persons 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.

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 well-being...
USE OF THE TERMS PALLIATIVE CARE AND COMFORT CARE

Palliate means to relieve or lessen without curing.

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.

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.
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.

HELPFUL TOOLS IN THE CARE TOOLKIT:

- The INTERACT Daily Assessment Pocket Card and the INTERACT Early Warning Report help direct caregivers communicate their observations to licensed staff so there is time to respond appropriately

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

- **Short period of evident decline**
  - Mostly frailty and dementia
- **Prolonged dwindling**
  - Mostly heart and lung failure
- **Long-term limitations with intermittent serious episodes**
  - Monthly cancer


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.

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.
Resident-directed care means residents have a right to refuse any aspect of care. This includes not just medical interventions, 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 thought. 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.

**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. 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.

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.

Helpful Tools in the CARE Toolkit:


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

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.
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

**Helpful Tools in the CARE Toolkit:**

- **S-B-A-R Report to the Physician** provides a checklist for clear communication
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

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.
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 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.

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?

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.
• 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.

HELPFUL TOOLS IN THE 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 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.\textsuperscript{2}

**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, flameless 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

\textsuperscript{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.
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.

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:

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

- 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

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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.

Many family members wish to be present when a loved one dies. Recently issued 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.

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.

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.
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.

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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.
The tools and resources included 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.

Tools included with the CARE Recommendations and available at www.CoalitionCCC.org are:

**STEP ONE: ADVANCE CARE PLANNING**
- Advance Healthcare Directive
- Advance Healthcare Directive Fact Sheet
- POLST Form
- POLST Frequently Asked Questions

**STEP TWO: RESIDENT-DIRECTED CARE CONSIDERATIONS TOWARD THE END OF LIFE**
- INTERACT Early Warning Daily Assessment Pocket Card
- INTERACT Early Warning Report
- Tube Feeding: A guide for decision making
- CPR: A guide for decision making
- S-B-A-R

**STEP THREE: DYING WELL**
- Hospice in Nursing Homes
- FICA Spiritual Assessment

Additional tools available through the Coalition for Compassionate Care of California, www.CoalitionCCC.org include:

- POLST case studies, role plays and cue cards
- Sample Comfort Care Policy
- Sample Comfort Care Plan
- Common Pain Misconceptions
- Leveraging Patient Cues at the End of Life
- Consistent Assignment: The Key to Individualized Care
- Learning Circles
- They’re Playing Your Song

And much more . . .
Advance Health Care Directive Form Instructions

You have the right to give instructions about your own health care.

You also have the right to name someone else to make health care decisions for you.

The Advance Health Care Directive form lets you do one or both of these things. It also lets you write down your wishes about donation of organs and the selection of your primary physician. If you use the form, you may complete or change any part of it or all of it. You are free to use a different form.

INSTRUCTIONS

Part 1: Power of Attorney

Part 1 lets you:

• name another person as agent to make health care decisions for you if you are unable to make your own decisions. You can also have your agent make decisions for you right away, even if you are still able to make your own decisions.

• also name an alternate agent to act for you if your first choice is not willing, able or reasonably available to make decisions for you.

Your agent may not be:

• an operator or employee of a community care facility or a residential care facility where you are receiving care.

• your supervising health care provider (the doctor managing your care)

• an employee of the health care institution where you are receiving care, unless your agent is related to you or is a coworker.

Your agent may make all health care decisions for you, unless you limit the authority of your agent. You do not need to limit the authority of your agent.

If you want to limit the authority of your agent the form includes a place where you can limit the authority of your agent.

If you choose not to limit the authority of your agent, your agent will have the right to:

• Consent or refuse consent to any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a physical or mental condition.

• Choose or discharge health care providers (i.e. choose a doctor for you) and institutions.

• Agree or disagree to diagnostic tests, surgical procedures, and medication plans.

• Agree or disagree with providing, withholding, or withdrawal of artificial feeding and fluids and all other forms of health care, including cardio-pulmonary resuscitation (CPR).

• After your death make anatomical gifts (donate organs/tissues), authorize an autopsy, and make decisions about what will be done with your body.

Part 2: Instructions for Health Care

You can give specific instructions about any aspect of your health care, whether or not you appoint an agent.

There are choices provided on the form to help you write down your wishes regarding providing, withholding or withdrawal of treatment to keep you alive.

You can also add to the choices you have made or write out any additional wishes.

You do not need to fill out part 2 of this form if you want to allow your agent to make any decisions about your health care that he/she believes best for you without adding your specific instructions.
Part 3: Donation of Organs

You can write down your wishes about donating your bodily organs and tissues following your death.

Part 4: Primary Physician

You can select a physician to have primary or main responsibility for your health care.

Part 5: Signature and Witnesses

After completing the form, sign and date it in the section provided.

The form must be signed by two qualified witnesses (see the statements of the witnesses included in the form) or acknowledged before a notary public. A notary is not required if the form is signed by two witnesses. The witnesses must sign the form on the same date it is signed by the person making the Advance Directive.

See part 6 of the form if you are a patient in a skilled nursing facility.

Part 6: Special Witness Requirement

A Patient Advocate or Ombudsman must witness the form if you are a patient in a skilled nursing facility (a health care facility that provides skilled nursing care and supportive care to patients). See Part 6 of the form.

You have the right to change or revoke your Advance Health Care Directive at any time

If you have questions about completing the Advance Directive in the hospital, please ask to speak to a Chaplain or Social Worker.

We ask that you complete this form in English so your caregivers can understand your directions.
You have the right to give instructions about your own health care. You also have the right to name someone else to make health care decisions for you. This form also lets you write down your wishes regarding donation of organs and the designation of your primary physician. If you use this form, you may complete or change all or any part of it. You are free to use a different form.

You have the right to change or revoke this advance health care directive at any time.

Part 1 — Power of Attorney for Health Care

(1.1) DESIGNATION OF AGENT: I designate the following individual as my agent to make health care decisions for me:

Name of individual you choose as agent: _________________________________________________

Relationship: _________________________________________________

Address:  __________________________________________________________________________
                                                      ______________________________________________________________________________

Telephone numbers: (Indicate home, work, cell) ________________________________

ALTERNATE AGENT (Optional): If I revoke my agent’s authority or if my agent is not willing, able, or reasonably available to make a health care decision for me, I designate as my first alternate agent:

Name of individual you choose as alternate agent: __________________________________________

Relationship: _________________________________________________

Address:  __________________________________________________________________________
                                                      ______________________________________________________________________________

Telephone numbers: (Indicate home, work, cell) ________________________________

SECOND ALTERNATE AGENT (optional): If I revoke the authority of my agent and first alternate agent or if neither is willing, able, or reasonably available to make a health care decision for me, I designate as my second alternate agent:

Name of individual you choose as second alternate agent: ________________________________

Address:  __________________________________________________________________________
                                                      ______________________________________________________________________________

Telephone numbers: (Indicate home, work, cell) ________________________________
(1.2) AGENT’S AUTHORITY: My agent is authorized to 1) make all health care decisions for me, including decisions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care to keep me alive, 2) choose a particular physician or health care facility, and 3) receive or consent to the release of medical information and records, except as I state here:

_________________________________________________________________________________________
_________________________________________________________________________________________
(Add additional sheets if needed.)

(1.3) WHEN AGENT’S AUTHORITY BECOMES EFFECTIVE: My agent’s authority becomes effective when my primary physician determines that I am unable to make my own health care decisions unless I initial the following line.

If I initial this line, I want my agent to make health care decisions for me immediately even though I am still able to make them for myself. _____

(1.4) AGENT’S OBLIGATION: My agent shall make health care decisions for me in accordance with this power of attorney for health care, any instructions I give in Part 2 of this form, and my other wishes to the extent known to my agent. To the extent my wishes are unknown, my agent shall make health care decisions for me in accordance with what my agent determines to be my best interest. In determining my best interest, my agent shall consider my personal values to the extent known to my agent.

(1.5) AGENT’S POST DEATH AUTHORITY: My agent is authorized to make anatomical gifts, authorize an autopsy, and direct disposition of my remains, except as I state here or in Part 3 of this form:

_________________________________________________________________________________________
_________________________________________________________________________________________
(Add additional sheets if needed.)

(1.6) NOMINATION OF CONSERVATOR: If a conservator of my person needs to be appointed for me by a court, I nominate the agent designated in this form. If that agent is not willing, able, or reasonably available to act as conservator, I nominate the alternate agents whom I have named. _____ (initial here)

Part 2 — Instructions for Health Care

If you fill out this part of the form, you may strike out any wording you do not want.

(2.1) END-OF-LIFE DECISIONS: I direct my health care providers and others involved in my care to provide, withhold, or withdraw treatment in accordance with the choice I have marked below:

☐ a) Choice Not To Prolong
   I do not want my life to be prolonged if the likely risks and burdens of treatment would outweigh the expected benefits, or if I become unconscious and, to a realistic degree of medical certainty, I will not regain consciousness, or if I have an incurable and irreversible condition that will result in my death in a relatively short time.
   Or

☐ b) Choice To Prolong
   I want my life to be prolonged as long as possible within the limits of generally accepted medical treatment standards.
(2.2) OTHER WISHES: If you have different or more specific instructions other than those marked above, such as: what you consider a reasonable quality of life, treatments you would consider burdensome or unacceptable, write them here.

___________________________________________________________________________________________________________
___________________________________________________________________________________________________________
___________________________________________________________________________________________________________
___________________________________________________________________________________________________________
___________________________________________________________________________________________________________

(Add additional sheets if needed.)

Part 3 — Donation of Organs at Death (Optional)

(3.1) Upon my death (mark applicable box):

☐ I give any needed organs, tissues, or parts

☐ I give the following organs, tissues or parts only: __________________________________________________________

☐ I do not wish to donate organs, tissues or parts.

My gift is for the following purposes (strike out any of the following you do not want):

Transplant Therapy Research Education

Part 4 — Primary Physician (Optional)

(4.1) I designate the following physician as my primary physician:

Name of Physician: __________________________________________________________

Address: ___________________________________________________________________

____________________________________________________________

Telephone: __________________________________________________________________

Part 5 — Signature

(5.1) EFFECT OF A COPY: A copy of this form has the same effect as the original.

(5.2) SIGNATURE: Sign name: _______________________________________ Date: ______________

(5.3) STATEMENT OF WITNESSES: I declare under penalty of perjury under the laws of California (1) that the individual who signed or acknowledged this advance health care directive is personally known to me, or that the individual's identity was proven to me by convincing evidence, (2) that the individual signed or acknowledged this advance directive in my presence, (3) that the individual appears to be of sound mind and under no duress, fraud, or undue influence, (4) that I am not a person appointed as agent by this advance directive, and (5) that I am not the individual's health care provider, an employee of the individual's health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a community care facility for the elderly nor an employee of an operator of a residential care facility for the elderly.
FIRST WITNESS
Print Name: ____________________________________________________________
Address: __________________________________________________________________
Signature of Witness: ___________________________________ Date: ______________________
SECOND WITNESS
Print Name: ____________________________________________________________
Address: __________________________________________________________________
Signature of Witness: ___________________________________ Date: ______________________

(5.4) ADDITIONAL STATEMENT OF WITNESSES: At least one of the above witnesses must also sign the following declaration:
I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance directive by blood, marriage, or adoption, and to the best of my knowledge, I am not entitled to any part of the individual’s estate on his or her death under a will now existing or by operation of law.

Signature of Witness: ____________________________________________________________
Signature of Witness: ____________________________________________________________

Part 6 — Special Witness Requirement if in a Skilled Nursing Facility
(6.1) The patient advocate or ombudsman must sign the following statement:

STATEMENT OF PATIENT ADVOCATE OR OMBUDSMAN
I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by section 4675 of the Probate Code:

Print Name: ___________________________________ Signature: __________________________
Address: __________________________________________________________________________ Date: ______________________

Certificate of Acknowledgement of Notary Public (Not required if signed by two witnesses)
State of California, County of ________________________________
On this ____________________ (date) before me ________________________________, Notary Public, personally appeared ________________________________, (name(s) of signer(s), who proved to me on the basis of satisfactory evidence to be the person(s) whose name(s) is/are subscribed to the within instrument and acknowledged to me that he/she/they executed the same in his/her/their authorized capacity(ies), and that by his/her/their signature(s) on the instrument the person(s), or the entity upon behalf of which the person(s) acted, executed the instrument.
I certify under PENALTY OF PERJURY under the laws of the state of California that the foregoing paragraph is true and correct.
WITNESS my hand and official seal. Seal

Signature of Notary ________________________________
What is an Advance Health Care Directive (AHCD)?
An AHCD is a way to make your health care wishes known if you are unable to speak for yourself or prefer someone else to speak for you. An AHCD can serve one or both of these functions:

- Power of Attorney for Health Care (to appoint an agent)
- Instructions for Health Care (to indicate your wishes).

Is the AHCD different from a Durable Power of Attorney for Health Care?
The AHCD was enacted by July 2000 legislation and replaced the DPAHC and the Natural Death Act Declaration. However, if you had already completed one of these forms that was valid before July 1, 2000, it is still valid now.

I’ve never completed an “advance health care directive” before. Why should I?
Persons of all ages may unexpectedly be in a position where they cannot speak for themselves, such as an accident or severe illness. In these situations, having an “advance health care directive” assures that your doctor knows your wishes about the kind of care you want and/or who the person is that you want to make decisions on your behalf.

Does this mean only one person can decide for me? What if I want others involved, too?
Often many family members are involved in decisionmaking. And most of the time, that works well. But occasionally, people will disagree about the best course of action, so it is usually best to name just one person as the agent (with a back up, if you want). And you can also indicate if there is someone who you do NOT want to make your decisions for you.

But I thought the doctors make all those life-and-death decisions anyway?
Actually, doctors tell you about your medical condition, the different treatment options that are available to you and what may happen with each type of treatment. Though doctors provide guidance, the decision to have a treatment, refuse a treatment or stop a treatment is yours.

What if something happens to me and no form has been completed?
If you are not able to speak for yourself, the doctor and health care team will turn to one or more family members or friends. The most appropriate decisionmaker is the one with a close, caring relationship with you, is aware of your values and beliefs and is willing and able to make the needed decisions.

My “values and beliefs?” But I haven’t talked with anyone about these!
That’s why it is a good idea to talk with family or close friends about the things that are important to you regarding quality of life and how you would want to spend your last days and weeks. Knowing the things that are most important to you will help your loved ones make the best decisions possible on your behalf. If your agent doesn’t know your wishes, then he or she will decide based on what is in your best interest.

What if I don’t want to appoint an agent? Or don’t have one to appoint?
You do not have to appoint an agent. You can still complete the Instructions for Health Care and this will provide your doctors with information to guide your care.
What kinds of things can I write in my Instructions for Health Care?
You can, if you wish, write your preferences about accepting or refusing life-sustaining treatment (like CPR, feeding tubes, breathing machines), receiving pain medication, making organ donations, indicating your main doctor for providing your care, or other things that express your wishes and values. If you have a chronic or serious illness, you also may want to talk with your doctor about specific treatments that you could face and ask him/her to help you document your decisions in a POLST form.

A POLST form – I've never heard of that!
POLST stands for Physician Orders for Life-Sustaining Treatment and was adopted in California in 2009. This is a voluntary form, which must be signed by you (or your agent) and your physician, and indicates the types of life-sustaining treatment you do or do not want if you become seriously ill. POLST asks for information about your preferences for CPR, use of antibiotics, feeding tubes, etc. POLST doesn’t replace your AHCD, but helps translate it into medical orders that must be followed in all healthcare settings (home, nursing home, hospital).

If I appoint an agent in my AHCD, what can that person do?
Your agent will make all decisions for you, just like you would if you could. Your agent can choose your doctor and where you will receive your care, speak with your health care team, review your medical record and authorize its release, accept or refuse all medical treatments and make arrangements for you when you die. You should instruct your agent on these matters so he/she knows how to decide for you. The more you tell them the better they will be able to make those decisions on your behalf.

When does my agent make decisions for me?
Usually the agent makes decisions only if you are unable to make them yourself – such as, if you’ve lost the ability to understand things or communicate clearly. However, if you want, your agent can speak on your behalf at any time, even when you are still capable of making your own decisions. You can also appoint a “temporary” agent – for example, if you suddenly become ill, you can tell your doctor if there is someone else you want to make decisions for you. This oral instruction is just as legal as a written one!

Are there other oral instructions that don’t involve a written form?
Yes. You can make an individual health care instruction orally to any person at any time and it is considered valid. All health care providers must document your wishes in your medical record. But it is often easier to follow your instructions if they are written down.

Can I make up my own form or use one from another state?
Yes. That’s why this law is so flexible. Any type of form is legal as long as it has at least 3 things: 1) your signature and date, 2) the signature of two qualified witnesses, and 3) if you reside in a skilled nursing facility, the signature of the patient advocate or ombudsman. These signatures, however, must include special wording.

Sounds difficult. Do I need an attorney to help with this?
No. Completing an advance health care directive isn’t difficult and an attorney is not necessary. But actually the most important part of this is talking to your loved ones. Without that conversation, the best form in the world may not be helpful!

OK, I’ll talk to them! But what should I do with the form after I complete it?
Make copies for all those who are close to you. Take one to your doctor to discuss and ask that it be included in your medical record. Photocopied forms are just as valid as the original. And be sure to keep a copy for yourself in a visible, easy-to-find location – not locked up in a drawer.
What if I change my mind?
You can revoke your form (or your oral instructions) at any time. Also, it’s a good idea to try and retrieve old forms and replace them with new ones.

Do doctors or hospitals require a patient to have an Advance Health Care Directive form?
No, they cannot require you to complete one. But doctors and hospitals should have information available to you and your family about the form and your right to make healthcare decisions.

RESOURCES

Check the California Coalition for Compassionate Care website at www.CoalitionCCC.org for updates on advance health care directive materials and community education programs.

Advance Health Care Directive Forms:
• Download forms in English, Spanish and Chinese from the Coalition website at www.CoalitionCCC.org.
• Forms are often available at no charge from your local hospital – call the Social Services or Patient Education department. Or ask your doctor.
• The California Medical Association has an Advance Health Care Directive Kit available in English or Spanish for $5 that includes a form, wallet card and answers to commonly asked questions about advance directives. To order single copies, call 1-800-882-1262 or visit www.cmanet.org.
• Five Wishes is a user-friendly advance directive that addresses the medical, personal, emotional and spiritual wishes of seriously ill persons. To order single copies in English or Spanish at $5 each, send a check or money order to Aging With Dignity, PO Box 1661, Tallahassee, FL 32302-1661. A companion 30-minute video is available for $19.95. For more information call 1-888-5-WISHES.
• Caring Connections has state-specific forms that can be downloaded at www.caringinfo.org.

Fact Sheets in Spanish and Chinese:

Booklets for consumers:
• Finding Your Way: A Guide for End-of-Life Medical Decisions. This 13-page, easy-to-read booklet helps those who are starting the advance care planning process or considering whether to initiate or withdraw life sustaining treatment when the end of life is near. Also available in Spanish.
• Mrs. Lee’s Story: Medical Decisions Near the End of Life. This 16-page booklet written in Chinese and English relates the story of 91-year old Mrs. Ming Lee to introduce health issues that concern Chinese elders and their families. It includes basic information on advance care planning and advance directives, pain management and hospice care.

For a single copy of either of the above booklets, send $1.50 check payable to “Center for Healthcare Decisions” to CHCD, 3400 Data Drive, Rancho Cordova, CA 95670 or visit www.chcd.org. Also available at volume rates.
HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact physician. This is a Physician Order Sheet based on the person’s current medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

<table>
<thead>
<tr>
<th>Last Name</th>
<th>First/Middle Name</th>
<th>Date of Birth</th>
<th>Date Form Prepared</th>
</tr>
</thead>
</table>

**A**
**CARDIOPULMONARY RESUSCITATION (CPR):**  *Person has no pulse and is not breathing.*

- [ ] Attempt Resuscitation/CPR
- [ ] Do Not Attempt Resuscitation/DNR  *(Allow Natural Death)*

*(Section B: Full Treatment required)*

When not in cardiopulmonary arrest, follow orders in **B** and **C**.

**B**
**MEDICAL INTERVENTIONS:**  *Person has pulse and/or is breathing.*

- [ ] Comfort Measures Only  *Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Antibiotics only to promote comfort. Transfer if comfort needs cannot be met in current location.*
- [ ] Limited Additional Interventions  *Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.*
- [ ] Do Not Transfer to hospital for medical interventions. Transfer if comfort needs cannot be met in current location.
- [ ] Full Treatment  *Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. Transfer to hospital if indicated. Includes intensive care.*

Additional Orders: ________________________________

**C**
**ARTIFICIALLY ADMINISTERED NUTRITION:**  *Offer food by mouth if feasible and desired.*

- [ ] No artificial nutrition by tube.
- [ ] Defined trial period of artificial nutrition by tube.
- [ ] Long-term artificial nutrition by tube.

Additional Orders: ________________________________

**D**
**SIGNATURES AND SUMMARY OF MEDICAL CONDITION:**

Discuss with:
- [ ] Patient
- [ ] Health Care Decisionmaker
- [ ] Parent of Minor
- [ ] Court Appointed Conservator
- [ ] Other:

**Signature of Physician**
My signature below indicates to the best of my knowledge that these orders are consistent with the person’s medical condition and preferences.

Print Physician Name  |  Physician Phone Number  |  Date
------------------------|--------------------------|-----------

Physician Signature (required)  |  Physician License #

**Signature of Patient, Decisionmaker, Parent of Minor or Conservator**
By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Signature (required)  |  Name (print)  |  Relationship (write self if patient)
----------------------|----------------|---------------------------

Summary of Medical Condition  |  Office Use Only

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED
Directions for Health Care Professional

Completing POLST

• Must be completed by health care professional based on patient preferences and medical indications.
• POLST must be signed by a physician and the patient/decisionmaker to be valid. Verbal orders are acceptable with follow-up signature by physician in accordance with facility/community policy.
• Certain medical conditions or medical treatments may prohibit a person from residing in a residential care facility for the elderly.
• Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid.

Using POLST

• Any incomplete section of POLST implies full treatment for that section.

Section A:

• No defibrillator (including automated external defibrillators) should be used on a person who has chosen “Do Not Attempt Resuscitation.”

Section B:

• When comfort cannot be achieved in the current setting, the person, including someone with “Comfort Measures Only,” should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
• IV medication to enhance comfort may be appropriate for a person who has chosen “Comfort Measures Only.”
• Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), bi-level positive airway pressure (BiPAP), and bag valve mask (BVM) assisted respirations.
• Treatment of dehydration prolongs life. A person who desires IV fluids should indicate “Limited Interventions” or “Full Treatment.”

Reviewing POLST

It is recommended that POLST be reviewed periodically. Review is recommended when:

• The person is transferred from one care setting or care level to another, or
• There is a substantial change in the person’s health status, or
• The person’s treatment preferences change.

Modifying and Voiding POLST

• A person with capacity can, at any time, void the POLST form or change his/her mind about his/her treatment preferences by executing a verbal or written advance directive or a new POLST form.
• To void POLST, draw a line through Sections A through D and write “VOID” in large letters. Sign and date this line.
• A health care decisionmaker may request to modify the orders based on the known desires of the individual or, if unknown, the individual’s best interests.

This form is approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST Task Force.

For more information or a copy of the form, visit www.capolst.org.

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED
Frequently Asked Questions for Consumers

What does ‘POLST’ stand for?
POLST stands for Physician Orders for Life-Sustaining Treatment.

What is the POLST form?
POLST is a physician order that helps give seriously ill patients more control over their end-of-life care. Produced on a distinctive bright pink form and signed by both the doctor and patient, POLST specifies the types of medical treatment that a patient wishes to receive towards the end of life. As a result, POLST can prevent unwanted or medically ineffective treatment, reduce patient and family suffering, and help ensure that patients’ wishes are honored.

What information is included on the POLST form?
The decisions documented on the POLST form include whether to:

- Attempt cardiopulmonary resuscitation,
- Administer antibiotics and IV fluids,
- Use a ventilator to help with breathing, and
- Provide artificial nutrition by tube.

Is POLST required by law?
Filling out a POLST form is entirely voluntary, but California law requires that the physician orders in a POLST be followed by health care providers.

Who should have a POLST form?
Doctors say that seriously ill patients and those who have a significant chance of dying in the next year should have a POLST.

Does the POLST form replace traditional Advance Directives?
The POLST form complements an Advance Directive and is not intended to replace that document. An Advance Directive is still necessary to appoint a legal health care decisionmaker, and is recommended for all adults, regardless of their health status.

If someone has a POLST form and an Advance Directive that conflict, which takes precedence?
If there is a conflict between the documents, the more recent document would be followed.

Who completes the POLST form?
A health care professional, usually a doctor, nurse, or social worker, completes the form after having a conversation with the patient to understand his/her wishes and goals of care. Both a doctor and the patient must sign the POLST form in order for it to be valid.

What if my loved one can no longer communicate her/his wishes for care?
A health care professional can complete the POLST form based on family members' understanding of their loved one’s wishes. The appointed decisionmaker can then sign the POLST form on behalf of their loved one.

What happens to my POLST form after it is completed and signed?
The original POLST form, on bright pink paper, stays with you at all times.
• In a hospital, nursing home, or assisted living facility, the form will be in your medical record or file.
• If at home, place your form in a visible location so it can be found easily by emergency medical personnel – usually on a table near your bed, or on the refrigerator.

Can I change my POLST form?
Yes, you can change your POLST form at any time should your preferences change. It is a good idea to review the decisions on your POLST form when any of the following occur:
• You are transferred from one setting to another, for example you go from your home to the hospital, or you are discharged from the hospital to a nursing home;
• There is a change in your overall health, or you are diagnosed with an illness;
• Your treatment preferences change for any reason.

What happens if I don’t have a POLST form?
Without a POLST form, emergency medical personnel, nurses and doctors would not know your treatment wishes. You will most likely receive all possible treatments, whether you want them or not. Talking about your treatment choices with your loved ones and doctor before a problem occurs can guide them and help ensure you get the care you want.

Are faxed copies and/or photocopies valid? Must pink paper be used?
Faxed copies and photocopies are valid. Pulsar Pink paper is preferred and used to distinguish the form from other forms in the patient’s medical record; however, the form will be honored on any color paper.

How can I get a POLST form?
Patients can request the form from their health care provider. It is important to discuss your goals of treatment with your health care provider so you can decide if POLST is right for you, and how to document your decisions appropriately on the form. The form can also be found at www.caPOLST.org, along with other helpful resources.

Where do they use POLST now?
POLST was originally developed in Oregon. There are a number of states which currently have POLST programs in place or that are developing POLST programs. For more information on the national POLST effort, visit www.POLST.org.

When was POLST authorized in California?
California State POLST Legislation (AB 3000 (Statutes 2008, Chapter 266)) went into effect on January 1, 2009.

What if I travel to another state – will my POLST form be valid?
The California POLST form is valid in California. If you are traveling to another state, it is a good idea to take both your Advance Directive and your POLST form with you. Both documents, even if not legally binding, will help health care providers know your wishes.

How can I find out more about POLST?
Talk to your doctor, or visit the California POLST website at www.caPOLST.org.
**S-B-A-R**

**Report to Physician**

**BEFORE CALLING THE PHYSICIAN:**
1. Assess the patient
2. Review the chart for the appropriate physician to call
3. Know the admitting diagnosis
4. Read the most recent **PROGRESS NOTE** and the assessment from the RN of the prior shift
5. Know the **CODE STATUS / POLST / INTENSITY OF CARE / PIC**
6. Keep your information **concise**
7. Have available when speaking with the physician:
   - Chart, Allergies, Meds, IV Fluids, Labs / Results

**SITUATION:** (State the situation, issue or circumstance of what is going on)
- State your name and hospital/unit/SNF/Hospice
- I am calling about (Patient Name, Attending Physician)
- The problem I am calling about is:_____________

**BACKGROUND:** (Give history, background and any other information pertinent to what has led up to the event that is going on now)
- State the admission diagnosis and date of admission
- State the pertinent medical history
- Give a brief synopsis of the pertinent treatment to date

**ASSESSMENT:** (Inform the MD of your assessment)

Most recent vital signs:
- BP___ Pulse____ Respirations____ Temperature____ Pain level____
- Patient is__ is not___ on oxygen. Amount of oxygen____ O2 Sats._____

Any changes from prior assessments, such as:
- Mental status
- Respiratory rate/quality
- Wound drainage
- Skin color
- Pulse rate/quality
- GI/GU (nausea/vomiting)
- Neuro checks
- Critical lab values
- Pain
- Musculoskeletal
- Oxygen Saturation
- I/O status

**RECOMMENDATION:** (Discuss what you think you need to resolve the problem)

I recommend you:
- Come to see the patient when possible
- Talk to the family about Code Status
- Ask for a consult
- Transfer to acute care
- Other suggestions_____________

Are there any tests needed?
- Xray, CBC, Metabolic Panel, other lab tests?
- Other_____________

If a change in treatment is ordered, then ask:
- How often do you want vital signs? ______
- Would you like to specify call parameters?
- If the patient doesn’t improve, when would you like us to call again? ______

READ BACK ALL VERBAL OR TELEPHONE ORDERS
Early Warning Daily Assessment to Identify Residents with Acute Changes

<table>
<thead>
<tr>
<th>Question</th>
<th>YES?</th>
<th>NO?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seems like himself/herself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talking the same</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall function the same</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participated in usual activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ate the same amount</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drank the same amount</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weak</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agitated or nervous</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tired or drowsy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confused</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help with dressing, toileting, and transfers</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you detect a change, fill out an Early Warning Report and discuss the change with the charge nurse.
Early Warning Report

If you have identified an acute change while caring for a resident today, please circle the change and discuss it with the charge nurse before the end of your shift.

Resident: ____________________________________________________________

S: Seems like himself/herself
T: Talking the same
O: Overall function the same
P: Participated in usual activities

A: Ate the same amount
N: AND
D: Drank the same amount

W: Weak
A: Agitated or nervous
T: Tired or drowsy
C: Confused
H: Help with dressing, toileting, transfers

Staff ________________________ Reported to _____________________________

Date ___________________ Time _______________________________________


This material was prepared by GMCF, the Medicare Quality Improvement Organization for Georgia, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. Publication No. 8SOW-GA-NHSS-07-06
Tube Feeding

“I’ve been asked to decide about a feeding tube…”

Making a decision about a long-term feeding tube for yourself or for someone you love may be challenging and emotional. Those who have faced a similar decision have told us that having honest answers to their questions was most helpful.

HOWEVER…..Every situation is different… what may help someone with a short term correctable eating problem may not be best for long-term use for a person who is in the final stages of a terminal illness.

What is a feeding tube?

A temporary feeding tube can be inserted through the nose into the stomach (N-G tube) for short term use. A feeding tube for long term use is called a Percutaneous Endoscopic Gastrostomy (PEG) tube. A small surgical opening is cut through the skin and stomach to place the tube that allows formula to be delivered directly to the stomach.

Who is helped most by having a feeding tube?

Those who function independently but are receiving chemotherapy or radiation for certain cancers and some stroke survivors in rehabilitation whose swallowing ability is expected to return may benefit from temporary feeding tubes. Persons with ALS (Lou Gehrig’s disease) may benefit because swallowing problems may occur before they reach the terminal phase of their disease.

When are feeding tubes less helpful?

When those in very late stages of dementia lose their ability to swallow, often this is not an isolated event but may represent progression of the disease to a terminal phase. In terminal stages of many diseases including advanced dementia, the gastrointestinal system shuts down and digestion becomes ineffective.

Will my loved one starve?

Some people fear that not providing a feeding tube at the end of life means they are letting their loved one “starve to death.”

This is not true. Starvation occurs when a hungry person whose body needs and can use the nutrients is deprived of food. When a dying person’s body begins to shut down, the body may be unable to adequately use nutrients that tube feeding would provide, and the chance for bloating and discomfort increases.
**What are some possible complications related to feeding tubes?**

Feeding tubes may cause no problems, but some complications have been identified such as: bleeding (1%), infection and skin irritation (1-4%), leakage around the tube (4%), vomiting or nausea (9-10%) and diarrhea or cramping (12%).

**What else should be considered when making a decision about a feeding tube?**

It is hard to separate our love and respect for a person from what might be the best decision for that person. Any decision about tube feeding must be made with consideration of general health status and overall goals of care. Prevention of suffering should be a major standard for evaluating individual risks and benefits. Asking the question, “Will the benefit of a tube be significant enough to outweigh any risks and discomfort?” can be helpful.

Clarification of personal, religious and cultural values in the context of overall prognosis and life expectancy may aid decision making.

**Will a feeding tube prevent pneumonia?**

Findings from several recent studies of individuals with late stage dementia or advanced terminal diseases show no evidence that pneumonia is prevented with a feeding tube. In some cases, pneumonia risk may be increased with feeding tubes.

**What choice do I have if I decide not to have a feeding tube?**

For those who still have some swallowing ability, careful hand feeding may be tried. For those who are in advanced, terminal stages of disease, maintaining excellent mouth care and providing ice chips or moist swabs will alleviate dry mouth and promote comfort.

**Where can I get more information about feeding tubes?**

A summary of studies, guidelines, and expert position statements are available at the Coalition for Compassionate Care of California web site: www.CaliforniaCare.org

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CPR/DNR

Being asked to make a decision about cardiopulmonary resuscitation (CPR) can be complicated. Few of us have ever seen CPR performed. Our understanding of CPR may come from what we see on TV …where it looks easy and seems to be very successful without any complications. Unfortunately, these TV images of CPR are not completely accurate.

This brochure provides answers to some common questions about what CPR involves and what else is important to think about when making a decision about CPR.

WHAT DOES CPR LOOK LIKE?

CPR is a longer process than most people realize. It is an attempt to re-start the heart when the heart has stopped beating. The person is placed on a hard board or on the ground and the center of the chest is pushed in about 2 inches (to provide 100 to 125 pounds of pressure). These chest compressions must be done 100 times each minute. Artificial respiration using a special mask and bag over the person’s mouth to pump air into the lungs may be started. When the emergency team arrives, a breathing tube may be inserted into the windpipe to provide oxygen, and a number of electrical shocks may be given with paddles that are placed on the chest. An intravenous line (IV) will be placed in a vein and medications will be given through the IV line.

If the heart continues to respond to these treatments, the person is taken to the emergency department. Those who survive will then be transferred to the intensive care unit at the hospital and attached to a ventilator (breathing machine) and a heart monitor. At this stage, most persons are still unconscious.

WHO IS LEAST LIKELY TO BENEFIT FROM CPR?

Risk factors that are more frequent among older persons may contribute to lower chances of CPR survival as age increases. Most older adults do not have the type of heart rhythm that responds to CPR. Having any chronic disease that affects the heart, lungs, brain and kidneys can lower chances for survival after cardiac arrest. If a person has multiple advanced chronic illnesses, CPR survival will be even lower.

Individuals in advanced stages of dementia have CPR survival rates three times lower than those without dementia. Several studies that looked at survival of frail nursing home residents in advanced stages of illness who were dependent on others for all of their care showed CPR survival rates of 0 – 5% even if they were transferred from the nursing home to the hospital before the cardiac arrest.

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Older adults in terminal stages of cancer had CPR survival rates 0 – 1%. Unlike younger persons whose healthy bodies may be able to withstand the shock of a cardiac arrest and respond to treatment, those at an advanced age with serious underlying health problems may be dying from progressive organ failure. Their bodies do not have enough reserve to tolerate the lack of oxygen that occurs with cardiac arrest, their hearts may not be able to pump effectively enough to respond to CPR attempts. Those with liver or kidney failure may not be able to use the emergency drugs that are given.

**WHO IS MOST LIKELY TO BENEFIT FROM CPR?**

The success of CPR depends on the reason the heart 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 all those who have CPR will survive. 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.

**ARE THERE ANY COMPLICATIONS FROM CPR?**

On TV CPR looks fast and uncomplicated. It is different in real life situations. Serious complications are likely. The most common complications are rib fractures that have been documented in up to 97% of CPR attempts, and breastbone fractures documented in up to 43% of cases. The risk of these fractures increases with age as does the chance for multiple fractures. This may be due to a decrease in muscle mass and an increased rate of osteoporosis with age. Approximately 59% of those who have CPR will have bruising of the chest, and about 30% may have burns from the defibrillator. Permanent brain damage may occur from lack of oxygen in up to 50% of those who have CPR attempted.

Other less frequent complications of CPR that have been identified include bleeding in the chest (0-18%), damage to the trachea or esophagus (0-20%), damage to abdominal organs (0-31%), lung damage (0-13%), and damage to lips and teeth (0-8%).

**WHAT HAPPENS IF I DECIDE NOT TO HAVE CPR?**

After careful consideration of all possible benefits and risks, many individuals decide that they do not want CPR attempted. However, some people are afraid that if they say they don’t want CPR they won’t get the kind of care they should. A decision not to have CPR applies only to the CPR process. Overall care and treatment will not be affected by choosing not to have CPR. If you do not want CPR done, an order will be written in the medical record so that CPR will not be attempted if the heart stops beating and breathing stops. The order is called a DNR (Do NOT Resuscitate) order and is used to protect a person from unnecessary attempts at CPR.
Spiritual Assessment Tool

An acronym that can be used to remember what is asked in a spiritual history is:

F: Faith or Beliefs
I: Importance or influence
C: Community
A: Address

Some specific questions you can use to discuss these issues are:

F: What is your faith or belief?
   Do you consider yourself spiritual or religious?
   What things do you believe in that give meaning to your life?

I: Is it important in your life?
   What influence does it have on how you take care of yourself?
   How have your beliefs influenced your behavior during this illness?
   What role do your beliefs play in regaining your health?

C: Are you part of a spiritual or religious community?
   Is this of support to you and how?
   Is there a person or group of people you really love or who are really important to you?

A: How would you like me, your healthcare provider, to address these issues in your healthcare?

General recommendations when taking a spiritual history:

1. Consider spirituality as a potentially important component of every patient's physical well being and mental health.
2. Address spirituality at each complete physical examination and continue addressing it at follow-up visits if appropriate. In patient care, spirituality is an ongoing issue.
3. Respect a patient's privacy regarding spiritual beliefs; don't impose your beliefs on others.
4. Make referrals to chaplains, spiritual directors, or community resources as appropriate.
5. Be aware that your own spiritual beliefs will help you personally and will overflow in your encounters with those for whom you care to make the doctor-patient encounter a more humanistic one.

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Hospice in Nursing Homes
Developed by the California Association for Health Facilities
and the
LightBridge Hospice & Palliative Care

There are ever increasing expectations on health care providers to deal with pain management and end of life issues effectively. Nursing homes need to take advantage of available resources to improve these services. Hospice is such a resource. Working with hospice offers an opportunity for collaboration of expert professionals on the statutory and regulatory requirements related to end of life care such as POLST and F309 – pain management. Nursing homes are encouraged to schedule a meeting with local hospice providers to educate each other about their unique role in the health care continuum and explore possibilities for working together to better meet the needs of the residents they serve.

Hospice brings additional expertise
- Experts in pain management and symptom control
- Experts in the “dying process”
- Experts in psychosocial and spiritual support needs of the dying person and their family

Hospice brings additional resources
- Home Health Aide Services to supplement facility services
- Many Hospices provide unique programs such as aroma therapy, massage
- Training for nursing home staff and families
- Extended relationship and follow up with families for one year after a resident’s death
- Offset of costs in end of life supplies, medications, equipment
- For facilities with 24 hr RN staffing, possible utilization of nursing home as hospital alternative

Opportunities for increased collaboration between hospice and nursing homes
- For private pay residents, education for families on potential impact to daily room and board charges.
- New federal Conditions of Participation set forth explicit requirements for improved communication and collaboration between hospices and nursing homes.