

Guidelines for End-of-Life Care in Long-Term Care Facilities



**With Emphasis on Developing
Palliative Care Goals**

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Emphasis on Developing Palliative Care Goals

**Developed by
Missouri End of Life Coalition's
End of Life in the Nursing Home Task Force**

**Missouri Department of
Health and Senior Services
Division of Senior Services and Regulation**

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**Missouri Department of Health and Senior Services
Division of Senior Services and Regulation
Missouri End of Life Coalition's End of Life in the Nursing Home Task Force
Post Office Box 570, Jefferson City, MO 65102-0570**

About Us

The Missouri Department of Health and Senior Services enhances quality of life for all Missourians by protecting and promoting the community's health and well being of citizens of all ages.

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The Missouri End of Life Coalition **Mission Statement**

The Missouri End-of-Life Coalition is committed to fostering cooperation, education, and research to promote high quality care for the dying.

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Disclaimer

The guidelines in this manual are not a guarantee of compliance with the regulations for Medicare/Medicaid certified facilities and Missouri licensure. Before implementing these guidelines, each facility must develop written policies and procedures, specific to each facility, and instruct their staff regarding the appropriate use of these tools. We also recommend that the facility's legal counsel review its policies and procedures prior to implementing them.

Acknowledgments

The Missouri Coalition's End of Life Task Force gratefully acknowledges the Nursing Facility Quality of Care Fund and Incarnate Word Foundation whose generous gift enables us to provide a copy of this manual to each intermediate care and skilled nursing facility in Missouri.

Emphasis on Developing Palliative Care Goals

Recognizing a continuing need to discuss critical issues related to developing and revising plans of care for patients residing in nursing facilities at the end of life, the Missouri End of Life Coalition established an End of Life in the Nursing Home Task Force to provide guidance on appropriate palliative care objectives for residents in long-term care facilities.

The task force and the Missouri Department of Health and Senior Services, Division of Senior Services and Regulation have produced this consensus document. Between 2001 and 2003, the group met with key healthcare agencies and organizations throughout Missouri to ensure that expertise in long-term care, pain and symptom management, nutrition, spiritual and psychosocial care, administration, and public health were fully represented.

The goals of the task force were to

- identify barriers to proper end-of-life care;
- increase the clarity of the value and role of end-of-life care goals for LTC facility residents and their families;
- develop clinical tools to assist in the identification of appropriate residents for end-of-life care goals and educate care givers about these goals provide for their implementation and appropriate use;
- identify common language and culture difference and provide education to develop clearer communication;
- investigate barriers to providing effective hospice services in nursing facilities by profiling existing facilities where hospice care is provided effectively and efficiently;
- review the conditions of participation related to hospice in facility settings;
- develop a process by which LTC facilities are encouraged to utilize hospice to provide the benefit from hospice care for dying patients and their families;
- provide education for hospices, long- term care facilities, hospice regulators, and long- term care regulators on nursing facilities requirements regarding hospice and end-of-life care for LTC facilities residents.

The resulting guidelines are a source of information for facility staff.

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GUIDELINES FOR END OF LIFE CARE IN LONG-TERM CARE FACILITIES

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INTRODUCTION

Purpose

The Missouri End-of-Life Coalition was formed in the spring of 1998. The Coalition is comprised of professionals, practitioners, policymakers, regulators, affiliated professional associations and end-of-life care providers. The mission of the Coalition is to foster cooperation, education and research to promote high quality care for the dying. The Coalition identified access to adequate end-of-life care (including hospice care) in nursing homes as a problem, and formed a task force of nursing home and hospice associations, providers, and state survey agencies to deal with this problem.

The initial goal was to identify state regulatory and reimbursement concerns and other barriers that impede utilization and access. In its initial attempt to explore the problem in 1999, the task force gathered two focus groups of providers to discuss the issue. The focus groups perceived regulatory issues as barriers; however, they did not find any regulations preventing the adequate provision of appropriate end-of-life care in Missouri nursing homes. The access barriers they did find include the existence of myths and a lack of education and coordination among nursing homes, nursing home surveyors, and hospice agencies.

Many regulatory concerns have been expressed about the care provided for residents dying in long-term care (hereafter, LTC). The committee felt it was important for state survey agencies to give direction to LTC facilities and hospice providers to correct or diminish misinformation. This manual is designed to help LTC staff understand their role and responsibility to provide palliative care. Palliative care is an important and necessary goal for nursing home residents, 30 percent of whom will die from chronic or acute illness within the first year of their admission into a nursing facility. The goal of this manual is to show LTC staff when and how to set appropriate palliative care goals. It will also serve as a reference tool and guide to additional resources.

Dying in Nursing Homes

Death in America is changing. Many years ago death occurred in homes; then it moved into hospitals, and recent trends indicate that death is moving into nursing home settings. Currently, 28 percent of deaths in Missouri occur in nursing homes, compared to a national average of 24 percent (Abbasi and Rudman, 1994). Some sources estimate that by 2020, 40 percent of deaths in this country will occur in nursing homes (Christopher, 2000).

Death is already a frequent occurrence in the long-term care setting as approximately one-third of nursing home residents die within one year of admission. Research has shown that the quality of end-of-life care throughout the healthcare system is in need of improvement. Nursing homes, like all other healthcare institutions, face major challenges in meeting family expectations at the end of life (Hanson, Danis, and Garrett, 1997). Pain and symptom control, and spiritual and emotional supports are necessary and require a specialized focus at the end of life (Keay, 1999).

Recently, much attention has been given to the discrepancy between the way individuals desire to die and the way they are dying. Dying in our country is not always a peaceful process. In a national survey in 1999, half of the respondents said the healthcare system does not always keep dying patients pain-free (Fackelmann, 1999). In 1997, the American Health Decisions Project conducted thirty-six focus groups throughout the country and found that people fear reaching the end of their lives dependent on machines. Participants expressed a preference for a natural death in familiar surroundings and in the presence of loved ones. Participants said they did not believe the current healthcare system is consistent with their views on death and dying, and that current planning options do not support patient management of the death and dying experience (Stanley, 1997).

Further research tends to substantiate the public's fears. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), published in 1995, discovered that 38 percent of seriously ill patients who died during the study spent at least ten days in an intensive care unit of a hospital. It also found that of patients who were conscious when they died (about 50 percent of the study group who died in the hospital), family members reported moderate to severe pain in these patients at least half the time. Data show that Missouri is no different. A recent study by Brown Medical School (2001) found that 47 percent of terminally ill patients in Missouri nursing homes experience persistent pain.

Numerous studies have tried to determine the causes of our inability to provide better care for the dying. Barriers to proper care for the dying include inadequate reimbursement, cultural attitudes on death and dying, discomfort with communicating

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bad news and prognoses, and healthcare providers' lack of education on caring for the dying. In a survey conducted by the American Medical Association (AMA) in 1997-1998, only four medical schools required coursework on care for the dying. In response to its survey, the AMA developed a curriculum to help practicing physicians improve their end-of-life practice (Emmanuel, VonGuten, Ferris, and Portnoy, 1999).

As a result of the attention being brought to these limitations in the healthcare system's focus on dying in America, a new specialization is gaining attention and support. This medical specialization involves the practice of palliative medicine.

Defining Palliative Care

Many groups have defined palliative medicine. Each definition has a common focus on relieving suffering and improving quality of life. Palliative medicine has traditionally been tied to the provision of hospice care; however, there are numerous obstacles to the use of hospice care. Therefore, the “palliative care movement” has broadened beyond hospice and now recognizes that hospice care is only one model of palliative medicine. It is not necessary for a resident to be in a hospice program to receive palliative care. Residents can benefit significantly from a palliative approach in which attention to the patient’s physical, spiritual, and psychosocial problems becomes the guiding philosophy.

Regardless of the exact program or model, the World Health Organization (WHO) defines palliative care as

the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment (1990).

WHO expanded the definition to include six additional points regarding palliative care. Palliative care:

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of care, fostering opportunities to grow;
- offers an interdisciplinary team to help residents live as actively as possible until death; and
- offers support systems for the family during the resident’s illness and their own bereavement (1990).

Principles of Palliative Care

“Principles for Care of Patients at the End of Life,” authored by renowned palliative physicians Christine Cassell and Kathleen Foley, is a declaration of basic principles for all healthcare professionals. It has been endorsed by a growing number of physician organizations. The American Medical Association, American Association of Hospice and Palliative Medicine, American Geriatric Society, American College of Physicians, American Association of Family Practice, American Medical Directors Association, American College of Surgeons, American Academy of Pediatricians, and the American Pain Society, among others, have accepted these principles.

These principles are quite applicable to the LTC facility and should guide efforts at providing humane, palliative care:

- Respect the dignity of both patient [resident] and care givers.
- Be sensitive and respectful of the patient’s [resident’s] and family’s wishes.
- Use the most appropriate measures that are consistent with patient [resident] choices.
- Encompass alleviation of pain and other physical symptoms.
- Assess and manage psychological, social and spiritual/religious problems.
- Offer continuity (the patient should be able to continue to be cared for if so desired by his primary care and specialist providers).
- Provide access to any therapy that may be expected to improve the patient’s [resident’s] quality of life including alternative or nontraditional treatments.
- Provide access to palliative care and hospice care.
- Respect the right to refuse treatment.
- Respect the physician’s professional responsibility to discontinue some treatments when appropriate with consideration of both patient [resident] and family preferences.¹
- Promote clinical and evidence-based research on providing care at the end of life.

¹ While these principles may provide overall guidance for end-of-life care, the work group urges long-term care facilities to consult with their legal counsel with regard to surrogate decision-making issues.

Identifying Residents for Palliative Care

Deciding if a resident is appropriate for palliative care is not an easy task. Physicians, residents, families and staff are challenged to determine when a resident is coming to the end of his or her life. Since most people are somewhat familiar with the hospice model of palliative care, we will use hospice criteria to help LTC staff identify residents eligible for palliative care. The following general criteria are used by hospice agencies to determine eligibility. The eligible patient:

- has been diagnosed with a terminal or life ending illness;
- has a life expectancy of six months or less, as determined by the attending physician and the hospice interdisciplinary team;
- is seeking palliative care (pain and symptom relief) rather than curative treatment.
- understands, as do the family and his or her physicians that artificial, life prolonging procedures are not consistent with hospice care; and
- has been approved for admission to hospice services by the attending physician and the hospice medical director.

The most difficult part of determining a patient's eligibility for hospice benefits is the physician's certification that the patient has a prognosis of six months or less. To help physicians and hospices identify patients who may be hospice appropriate, the Centers for Medicare and Medicaid Services (CMS) have issued a Local Medical Review Policy (LMRP) that defines (by disease) prognostic criteria that should be examined to determine the patient's eligibility.

These guidelines examine documentable evidence that "if the disease follows its normal course: the prognosis would be six months or less." Currently, twelve guidelines have been identified including lung disease, heart disease, kidney failure, HIV, stroke and coma, dementia, liver failure, ALS, lung cancer, prostate cancer, breast cancer and decline in health status. The LMRPs for Dementia and Decline in Health Status are included in the appendix section of this manual. Other LMRP guidelines can be viewed on the web at www.iamedicare.com/provider/policies.

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GOALS OF CARE

Purpose and Objectives

This chapter identifies four types of resident goals in long-term care: rehabilitation, prevention, maintenance and palliation. Goals for care need to reflect the resident's change of condition. These goals result from purposeful conversations with the resident/responsible party, family, facility staff, and physician.

Objectives

- Understand the diversity of residents in long-term care facilities, and thus the need for individualized plans of care.
- Appreciate the need for, and know how to develop and change the plan of care based on the resident's or responsible party's wishes.
- Apply regulatory guidance for end-of-life care in long-term care.

Individualized Care — Purposeful Observation and Conversations

Long-Term Care facilities care for a wide variety of residents. Caregivers may have a difficult time meeting all the needs of this diverse population. A LTC facility may have residents with any combination of the following characteristics:

- physical impairment
- cognitive impairment
- behavioral symptoms
- mental illness
- mental retardation
- young residents
- very old residents
- cultural diversity
- lifestyle diversity
- residents in the last stages of life

As a result of diverse needs in this population, it is important that the care plan be based on the individual resident's strengths, needs and problems. These individualized care plans are developed using interdisciplinary experts including the resident, physician, family, social worker, activities director, dietitian, charge nurses involved in the resident's care, and nurse aides directly responsible for the resident's care. This individualized care planning process forms the basis of the Resident Assessment Instrument (RAI) which is required in every Medicare/Medicaid certified facility. An RAI coordinator should also be a member of the planning team. Individual care planning is the standard of practice for any care delivery system.

Residents living in the end stages of life have great needs, and their care plans should be revised frequently. The "art and science" of nursing is portrayed at its best in palliative caregiving.

Purposeful Observation and Conversations

Individualized care requires that facility services "fit the resident," rather than expect the resident's goals and needs to "fit the facility." This approach celebrates the uniqueness of each resident. Generic care does not consider the uniqueness of each resident, but treats all residents alike. If a facility develops expertise in providing individualized care to a variety of residents, then individualized care will automatically continue across the continuum of care as the resident's condition declines.

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Recognizing subtle changes in each resident can be difficult and requires that purposeful attention be given to each one, including participation in purposeful conversations with the resident or the responsible party. These purposeful observations and conversations are important; as the resident's condition changes; so, too, will the goals of treatment and symptom management.

Advance Care Planning

Resident-centered, end-of-life care planning requires an understanding of the resident's cultural and religious beliefs, values, preferences, and fears. Caregivers must also know about the things that give joy and quality to the resident's life. The more knowledge the interdisciplinary care planning team has about the resident's value system, the more likely it is to establish a care plan that meets the resident's needs and allows for appropriate interventions as symptoms change.

Defining Quality of Life

An individual develops preferences based on religion, culture, life experiences, family relationships, and one's particular view of living and dying. The Interdisciplinary Team (IDT) should engage in purposeful conversations with residents to ensure that their values and preferences are understood. The team can help residents articulate their unique concepts of quality of life by asking questions. For example,

- As you look into your future, what do you want?
- Have you thought about what you would like the last phase of your life to be like?
- What will be most important for you during that time?

An individual's views may change over time as life circumstances change. Therefore, ongoing discussions are needed to ensure that the IDT adequately understands the resident's current view of life. The team's openness and acceptance will facilitate its understanding of what quality of life means to the resident. End-of-life care discussions may include cardiopulmonary resuscitation (CPR), artificial nutrition and hydration, hospital transfer, withholding diagnostic tests, and treatment of an existing diagnosis, such as congested heart failure or osteoporosis.

Residents without Decision-Making Ability

Residents without decision-making ability comprise a large portion of the long-term care population. Court appointment of a legal guardian may be necessary if a resident has not executed a living will or advance health care directives, or designated a surrogate decision-maker through a durable power of attorney for health care. Guardianship may also be necessary if these documents do not provide appropriate authority or guidance with respect to a particular situation. If there is no legal decision maker and no living will or advance directives addressing the situation, the facility is urged to consult its attorney for advice. Ethical issues relating to surrogate decision-making are addressed in a Midwest Bioethics Center document entitled, *Considerations Regarding Life-Prolonging Treatment for Residents of Long-term Care Facilities*. This guidelines document suggests that "Surrogates recognized by providers/facilities and not appointed by [the resident] or court order should share in the decision making process with the physician, family, and

representatives of the facility.”¹ The IDT must have ongoing discussions with the family or the surrogate decision maker as conditions and symptoms change. Using an Ethics Case Consultation may be appropriate if conflicts arise between the goals of the family or surrogates and those the facility deems appropriate. Documenting these decisions is necessary to demonstrate the individualized nature of the decision and the coordination of care resulting from the process.

Shaping Care and Setting Goals

The purpose of advance care planning is to allow the resident to help shape the care he or she receives during the last stages of life. Physical or cognitive declines cannot be predicted with certainty. The IDT will make better decisions if it has relevant information about

- the resident’s clinical condition and prognosis, and
- personal beliefs and social views.

With this information, the team can respond appropriately and proactively when decisions are needed. Consistent with state law, the decision of the resident or the resident’s surrogate should direct the goals of care. With the appearance of each symptom, the IDT team should determine the goal of treatment for that symptom and begin care to reach that goal.

Ethics Case Consultation

Situations of conflict may arise within the IDT. The conflict can be between family members or between professional staff and family members regarding the goals of care. Ethics case consultation is a mediation service in which participants use a neutral third party to help work through issues that arise in connection with the development and adoption of a resident’s care plan or other care-related matters. The candid give and take encouraged by the mediation process includes articulating interests, gathering facts, venting feelings, thinking creatively, clarifying value conflicts, and finalizing agreements.

LTC facilities can develop an ethics committee within their facility. Another option is available in Missouri. The Missouri Long-Term Care Ombudsman Program in conjunction with Midwest Bioethics Center has developed a program called “Long-Term Care Ethics Case Consultation” to serve facilities confronted by these situations. A member of the Midwest Bioethics Center provides the mediation service for these special situations. Since the inception of this program in the 1990s, the Center has provided numerous case consultations.

¹ While these principles may provide overall guidance for end of life care, the work group urges long-term care facilities to consult with their legal counsel with regard to surrogate decision-making issues.

Regulatory Compliance for Advance Directives

The federal requirement at F156 says:

“The facility must comply with the requirements specified in subpart I of part 489 of this chapter relating to maintaining written policies and procedures regarding advance directives. These requirements include provisions to inform and provide written information to all adult residents concerning the right to accept or refuse medical or surgical treatment and, at the individual's option, formulate an advance directive. This includes a written description of the facility's policies to implement advance directives and applicable State law.”

The guidance to surveyors at 42 CFR 483.10(b)(8) provides further information. 42 CFR 489.102 specifies that upon admission of an adult resident, the facility must:

- provide written information concerning his/her rights under State law (whether or not statutory or recognized by the courts of the State) to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment, and the right to formulate advance directives;
- document in the resident's medical record whether or not the individual has executed an advance directive;
- not condition the provision of care or discriminate against an individual based on whether or not the individual has executed an advance directive;
- ensure compliance with requirements of State law regarding advance directives;
- provide for educating staff regarding the facility's policies and procedures on advance directives; and
- provide for community education regarding the right under State law (whether or not recognized by the courts of the State) to formulate an advance directive and the facility's written policies and procedures regarding the implementation of these rights, including any limitations the facility may have with respect to implementing this right on the basis of conscience.

The facility is not required to provide care that conflicts with an advance directive. In addition, the facility is not required to implement an advance directive if, as a matter of conscience, the provider cannot implement an advance directive and state law allows the provider to conscientiously object.

The state requirement at 19 CSR 30-88.010 (9) says:

“Prior to or upon admission and at least annually after that, each resident or guardian shall be informed of facility policies regarding provision of emergency and life-sustaining care, of an individual's right to make treatment decisions for him/herself and of state laws related to advance directives for health-care decision making. The annual discussion may be handled either on a group or on an individual basis. Family members

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or other concerned individuals shall also be informed, upon request, regarding state laws related to advance directives for health-care decision making as well as the facility's policies regarding the provision of emergency or life-sustaining medical care or treatment. If a resident has a written advance health-care directive, a copy shall be placed in the resident's medical record and reviewed annually with the resident unless, in the interval, he or she has been determined incapacitated, in accordance with Section 475.075 or 404.825, RSMo. Residents' guardians or health care attorneys-in-fact shall be contacted annually to assure their accessibility and understanding of the facility policies regarding emergency and life-sustaining care.”

Describing the Goals of Care

A review of the literature related to LTC identifies several goal-setting categories. While some resources name only two categories, curative and palliative; other resources describe three categories: restorative, maintenance, and palliative. Four treatment goals are identified in the Resident Assessment Instrument User's Manual Version 2.0. These goals include rehabilitation, maintenance, prevention, and palliative care. Consistent with state law, the IDT should determine the overall goal of care with the resident/legal surrogate.

Likewise, as the resident's condition changes, ongoing communication between facility staff and the resident/surrogate or family is essential so that goals and interventions can change to address the resident's changing needs. The following examples describe goals of care:

- A resident with a recent stroke expresses the desire to recover speech and hand functions. He wants **rehabilitation** goals in these areas. After he reaches these goals, the IDT will set **maintenance** goals to maintain this level of functioning
- A resident with a diagnosis of dementia fell while walking unassisted. The fall fractured her hip. Prior to the fall, the resident's family had requested goals to **maintain** her level of functioning and **prevent** injury.
- A resident in the end stages of life wants to remain free of pain and enjoy his family daily. This resident needs **palliative** care goals to achieve the highest practicable level of pain control and psychosocial well-being within the family circle. Residents with palliative care goals may also have goals involving interventions for rehabilitation, maintenance, and prevention for some aspects of their care. They may need rehabilitation for an acute injury or measures to prevent complications such as pressure ulcers.

Ongoing Assessment and Care Plan Revision within the Palliative Care Goal

Palliative care can be the overall goal for the resident during the end stages of life, but specific interventions will be needed to maintain the resident and prevent suffering. The following are examples of these specific interventions:

- **Assessment during the early end-of-life period** — for example, a resident may choose not to eat in the dining room because of fatigue and discomfort. The facility will provide the necessary care and services to address her nutrition needs and help her attain an appropriate level of functioning.
- **Assessment throughout all stages** — a resident displays pain and symptoms of depression. The facility will adequately monitor this behavior and communicate with the physician to ensure that appropriate treatments are provided to manage these symptoms and help the resident maintain the highest quality of life.

- **Assessment of the resident in the imminent death stage** — in this stage, a resident’s respirations may become shallow and his or her mental status may deteriorate. The resident’s surrogate and the IDT or other professional staff, recognizing the risks and benefits of providing nutrition and hydration, may decide to withhold food and nutrition. In this case, the facility will provide all necessary care and services to keep the resident comfortable and manage the symptoms that arise from lack of nutrition and hydration.

Recognizing the Need to Revise Goals

Long-term care facilities serve a variety of residents. Some residents will spend a brief time in the facility before returning home; others will spend a relatively short time in the facility prior to dying. Still others may live in the facility as their home for a number of years before they die. Setting goals of care for the shorter staying residents, whether for rehabilitation or palliative care, may be more obvious than setting goals for residents who will live at the facility for many years. The IDT for the resident who is slowly declining from a chronic disease must recognize the resident’s clinical condition and prognosis and discuss any significant changes in the condition assessment. On the basis of this assessment, the IDT can have purposeful conversations with the resident or responsible party and set realistic goals for the resident’s care.

A health event (a fall, an infection, a hospitalization) or the appearance of a symptom or a change in the severity of a symptom requires a review of the care plan goals and interventions. Examples of such changes can be found in the sample care plans which are included in an appendix to this document. The Minimum Data Set (MDS) is also a useful tool in recognizing the need for changing goals.

The MDS and Goal Setting

The MDS is a federally required assessment form for documenting the resident’s strengths, needs and problems. Several MDS items can help staff recognize the need for decisions about goals. Section J5c. says, “end-stage disease, 6 months to live.” This item is the most significant to consider when making goal-changing decisions. The RAI manual gives the following coding directions:

“that in one’s best clinical judgment, the resident with any end-stage disease has only six or fewer months to live. This judgment should be substantiated by a well documented disease diagnosis and deteriorating clinical course. A doctor’s certification that the resident has six months or less to live must be present in the record before coding the resident as terminal on the MDS.”

This assessment can be the beginning of advance care planning (if that has not already begun) and revision of the resident's care goals. It can also be a good marker to remind the IDT to renew its purposeful conversations with the resident and his or her family, so that good end-of-life care can be planned and provided.

Other noteworthy MDS items that can help the facility staff recognize the need to change the goals of care include the following:

- Section A10. Advance Directives
- Multiple MDS items require an evaluation of a change in condition in various sections. The following items ask for the assessor to indicate a change compared to the status of the resident 90 days ago or since the last assessment. These items include:
 - Section B6. Change in Cognitive Status
 - Section C7. Change in Communication/hearing
 - Section E3 and E5. Change in Mood and Change in Behavioral symptoms
 - Section G9. Change in ADL Function
 - Section H4. Change in Urinary Continence
 - Section Q2. Overall Change in Care Needs
 - Section J1, J2, and J5. Problem Conditions, Pain Symptoms and Stability of Condition
 - Section K3. Weight Change
 - Section M1. Pressure Ulcers
 - Section P1, P5, and P6. Special Treatments and Procedures, Hospital Stay(s), and ER Visits

CMS Clarification of Significant Change in Status Assessment (SCSA)

The Centers For Medicare a& Medicaid Services Revised Long-Term Care Resident Assessment Instrument User's Manual Version 2.0 issued December 2002 gives the following guidance:

The key in determining if an SCSA is required for individuals with a terminal condition is whether or not the change in condition is an expected well-defined part of the disease course and is consequently being addressed as part of the overall plan of care for the individual. If a terminally ill resident experiences a new onset of symptoms or a condition that is not part of the expected course of deterioration, an SCSA is required. Similarly, if the resident enrolls in hospice (Medicare Hospice program or other structured hospice program), but remains a resident at the facility, an SCSA should be performed if the terminally ill resident experiences a new onset of symptoms or a condition that is not part of the expected course of deterioration. The facility is responsible for providing necessary care and services to assist the resident in achieving his/her highest practicable well-being at whatever stage of the disease process the resident is experiencing.

If a resident elects Medicare Hospice program, it is important that the two separate entities (nursing facility and hospice program staff) coordinate their responsibilities and develop a care plan reflecting the interventions required by both entities. The need to complete an SCSA will depend upon the resident's status at the time of election of hospice care, and whether or not the resident's condition requires a new assessment. Because a Medicare-certified hospice must also conduct an assessment at the initiation of its services, this is an appropriate time for the nursing facility to evaluate the MDS information to determine if it reflects the current condition of the resident.

- Complete an SCSA for a newly diagnosed resident with end-stage disease when:
 - a change is reflected in more than one area of decline; and
 - the resident's status will not normally resolve itself; and
 - the resident's status requires interdisciplinary review and/or revision of the care plan
- Complete subsequent SCSA's based upon the degree of decline and the impact upon the comprehensive care plan Consider the following criteria:
 - completion date of the last MDS;
 - clinical relevancy and accuracy of the MDS to the resident's current status; and
 - the need to change the resident's care plan to reflect the current status.

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Regulatory Compliance for Goals of Care

State Regulations

The regulations for intermediate care and skilled nursing facilities address the plan of care requirements of the facility. Thus, 19 CSR 30-88.010(11) begins,

“Each resident shall be afforded the opportunity to participate in the planning of his/her total care and medical treatment, to refuse treatment. . . .”

Federal Regulations — Achieving the Highest Practicable Level of Well-Being

The principal regulatory directive in LTC is that each resident receives individualized care. The resident’s views, values, and desires guide the goal setting and subsequent care plan interventions. The fundamental regulatory goal in long-term care is “for the resident to receive the necessary care and services to attain or maintain the highest practicable physical, mental and psychosocial well-being in accordance with the comprehensive assessment and plan of care.” Key words that are to be emphasized in this requirement are, “in accordance with the comprehensive assessment and plan of care.” This goal requires that a resident’s health condition and prognosis be assessed on an ongoing basis and a plan of care developed based on this assessment. It does not mean that regardless of the resident's condition, the facility must continue to provide rehabilitation or restorative goals. Issues of medical appropriateness and futility may need to be addressed.

The dependency needs of end-of-life residents can be compared to the dependency and vulnerability of an infant. The role of the caregiver focuses more on soft music, touching (or massage), feeding, and changing. Instead of providing heavy meals or rich supplements, the caregiver may offer bits of comfort food that provide pleasure such as ice cream or pudding. Instead of assisting with toileting, the use of briefs may provide greater comfort. Providing personal care to one in this stage of life demands that the caregiver be as vigilant and attentive as he or she would be in caring for a newborn.

Factors That May Lead to Abuse and Neglect

The Centers for Medicare and Medicaid Services (CMS) developed a training program designed to detect and prevent abuse and neglect in a variety of settings, including long-term care facilities.

CMS identified “isolation” as a consistent predictor of abuse and neglect. The resident who is in the final stages of life frequently becomes very dependent on caregivers. This dependency puts the resident at increased risk for isolation and avoidance by staff who feel inadequate or uncomfortable dealing with the resident and/or family. Staff may fail to recognize the increased needs of the resident during this time and the resident may require one-on-one interactions for activities and social services to remain psychologically and socially involved in living.

The resident’s physical ability to perform self-care functions such as feeding may diminish and require a greater amount of staff time to meet nutrition and hydration needs. As a result of cognition and communication incapacity, the resident may become more dependent on facility staff for accurate ongoing assessment and needs fulfillment. The resident may become isolated not only because of cognitive and physical dependency, but also because staff may feel somewhat inadequate in dealing with a dying resident. The resident’s dependency and the staff’s feelings of inadequacy combine to create many challenges to providing high quality palliative care in LTC.

Avoidable Versus Unavoidable Outcomes

Pressure sores, weight loss, and other physical symptoms are often seen in end-of-life residents, but they may also be avoidable. The State Operations Manual (SOM) consistently directs the surveyor to obtain information to determine if a negative resident outcome is avoidable or unavoidable. The surveyor will investigate whether the facility accurately assessed the resident’s needs, developed a care plan to address the needs, consistently implemented the care plan and had ongoing evaluation and revision of the care plan as needed to meet the needs of the resident.

Throughout the regulatory investigative process and informal dispute resolution conference, the state agency must determine avoidable versus unavoidable outcomes. Many times the facility’s defense during the investigation or on appeal is to describe the terminal condition of the resident. This terminal condition is only one piece of information to consider in making compliance decisions. The ongoing assessment, care plan development, and its implementation and revision are the additional elements that determine whether a negative outcome is avoidable or unavoidable.

The care plan is sometimes inaccurately viewed simply as the care plan that is included in the resident's chart. In reality, the entire “plan of care” describes the care the resident is expected to receive from all disciplines.

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Documentation

Purposeful observations and conversations should be documented in the resident's record. All members of the IDT should contribute information to help translate the resident's values and beliefs into care goals and interventions. Their purposeful observations and conversations need to be ongoing, fully documented and the documentation revised as needed to reflect ongoing information.

The IDT should amend its instruction as often as necessary to inform direct care givers about changed interventions. All caregivers should know where these instructions are located and how to check for care changes. Symptoms should be assessed, interventions initiated, and an evaluation of the intervention's success should be documented.

CASE STUDY
Mrs. Smith

Scenario I

Mrs. Smith has a diagnosis of metastatic cancer. She is currently receiving radiation therapy for treatment of a brain tumor. Her current functional status is ambulation with a walker to the dining room for meals and to activities of her choice. She tires easily and becomes short of breath, and requires the direct care staff to provide limited assistance with activities of daily living (ADLs). She fell several times in the past. Her walking, standing and sitting balance is good unless she rises too quickly. She denies pain during routine assessments. She has had several conversations with her physician about her prognosis and treatment options. Mrs. Smith's daughter lives across the country and is unable to visit frequently because of her own health problems. Mrs. Smith talked with her daughter about her prognosis and treatment options and the daughter supports her decisions. Mrs. Smith's physician is admitting her to the skilled nursing facility for care.

Upon admission to the skilled facility, the Social Service Designee (SSD) asked Mrs. Smith about advance directives for healthcare. Mrs. Smith provided her with a copy of her healthcare directions. The SSD also discussed surrogate decision-making options permitted under state law with Mrs. Smith.

The resident opted to make her daughter her attorney-in-fact through a durable power of attorney and a durable power of attorney for healthcare decisions. The facility filed the durable power of attorney documents in the resident's medical record.

The RAI coordinator prepared for the initial care plan meeting. She talked with Mrs. Smith to determine the resident's personal goals for treatment in the nursing home. The RAI coordinator asked, "what are you hoping will happen?" The resident's response was that she wanted to get through the radiation therapy and "be strong enough

Admitted to LTC for assistance with ADLs and symptom management following radiation therapy.

Admission requirement to determine Advance Directive for Health Care. Identify surrogate legal decision making authority.

What is the resident's goal for care? IDT meets and set goals.

Overall Goal: Mrs. Smith will return to her apartment after radiation therapy

Scenario I, continued

to go back to her apartment.” The RAI coordinator talked with Mrs. Smith’s physician to understand the goals for the nursing home stay.

The IDT, consisting of Mrs. Smith, the RAI Coordinator, SSD, physical therapist, charge nurse on the unit where Mrs. Smith lives, and the nurse aide who cares for her on the day shift, met to discuss the care the resident wants to receive and her goals for treatment. Since Mrs. Smith’s goal was to be able to go back to her apartment and live independently after the radiation therapy, the RAI Coordinator developed a care plan for the resident with three goals. The first goal was to **maintain** her present abilities while trying to increase her conditioning; the second was to provide **rehabilitation** services to restore her to an independent lifestyle and the third goal was the **prevention** of any further falls. The SSD asked Mrs. Smith about her psychosocial and spiritual needs. Mrs. Smith relied heavily on her faith for support. The resident wanted continued contact with her minister and members of her church.

During the radiation therapy Mrs. Smith was weak and fatigued most of the time. Therapy was scheduled three times a week for strength building activities. The nurse aides assist her with her ADLs when she needs assistance but the nurse aides understand her rehabilitation goal; they will not do the activities for her unless she asks, even though she is slow. To attain the goal of preventing falls, the nurse aide will monitor her for balance and safety when she is performing ADLs.

After radiation therapy Mrs. Smith was discharged back to her apartment. Three weeks later she was readmitted to the skilled facility with weakness, falls, delirium, weight loss, and dehydration.

The RAI coordinator talked with Mrs. Smith to determine “what she hoped would happen” with this admission. She

Specific Goals:

- **Maintain** nutrition and ADL functioning
- **Rehabilitation** to strengthen her condition
- **Prevention** of falls

Discharged and readmitted

Scenario I, continued

was incoherent much of the time and was unable to express her wishes. Consistent with state law and her advance directive, the physician and nursing staff talked with her daughter and determined the goals of treatment to be for palliative care at this time.

Over the next two weeks Mrs. Smith had intermittent confusion and periods of extreme agitation. The nursing staff identified the periods of agitation and relieved them with pain medication. A pain medication was ordered on a regular basis with other pain meds for breakthrough pain as evidenced by increased agitation. A mild sedative was also ordered for increased agitation. The RAI Coordinator had conversations with Mrs. Smith and phone conversations with her daughter frequently during these weeks.

Within a few weeks, Mrs. Smith began sleeping more and refused to eat. She began having longer periods of delirium. The RAI Coordinator and the SSD had frequent phone conversations with her daughter to inform her of her mother's condition and obtain direction about treatment decisions. The IDT met to discuss the decreased need and desire for food as a part of the dying process. Staff members were instructed to offer foods and fluids, but not to force, or give anything orally to Mrs Smith if she was not alert. The care plan was updated frequently due to her rapidly declining condition.

The SSD provided emotional support and guided the direct care staff in meeting Mrs. Smith's emotional needs. The SSD talked with the resident's minister and someone from the congregation visited daily. She discussed funeral arrangements with the daughter.

Mrs. Smith's level of consciousness continued to change until she was unable to communicate verbally. Her breathing patterns changed and oxygen was ordered per nasal canula. Fluids were withheld and attention to mouth care was provided. The RAI Coordinator talked with Mrs. Smith's daughter about her deteriorating condition and

Goal of care:

Palliative care

- Alleviate pain
- Provide hydration
- Address ancillary needs
- Reassess often

Nonverbal communication of pain exhibited by restlessness and agitation — to be treated by pain meds.

Frequent communication with family regarding treatment decisions

Emotional and spiritual support provided

Scenario I, continued	
<p>offered as much support over the phone as possible since she was not able to travel to be with her mother. Mrs. Smith seemed comfortable and died peacefully.</p> <p>Bereavement follow-up arrangements were provided for the residents and staff of the LTC facility; and the funeral services were held at the facility.</p>	<p>Peaceful death with bereavement services at the facility</p>

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PAIN MANAGEMENT

Purpose and Objectives

Purpose

The purpose of this chapter is to describe basic pain management principles. The reader will learn the different types of pain, how to recognize pain, and how to use pharmacological and nonpharmacological pain treatments.

Objectives

- Understand how the management of pain affects the quality of life of the LTC resident.
- Develop an awareness of misconceptions and consequences of untreated pain.
- Recognize different types of pain and identify appropriate analgesics for each type.
- Utilize pain assessment tools as needed for facility residents.
- Understand how to determine correct doses of analgesics, as a resident needs change.
- Understand that all team members have a role in assessment and treatment of pain.

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Introduction — Responsibility for Effective Pain Relief

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage. However, a more clinically applicable definition is that of McCaffery and Beebe (1989), who state that pain is what the patient says it is. It should always be regarded as totally subjective (i.e., defined by the person experiencing it). In the LTC setting, residents do not always verbalize their pain but will express it in other ways.

Residents in LTC facilities often suffer acute and chronic painful diseases, have multiple diseases, and take many medications. They may have more than one source of pain and an increased risk for interactions between drugs and interactions between the drugs they take and other diseases. Pain is common at the end of life as a result of arthritis, circulatory disorders, immobility, neuropathy, cancer, and other age-related conditions. Everyone experiences pain differently. Pain cannot be measured like blood pressure or temperature; we must rely on the resident's description of pain.

Pain assessment may present unique problems in elderly residents. Older residents often report pain very differently from younger residents because there are physiologic, psychological, and cultural changes associated with aging. The institutionalized elderly are often stoic about pain.

LTC facilities have the additional challenge of determining signs and symptoms of pain for residents who cannot communicate verbally — perhaps because of dementia or other conditions. One person's report of severe pain may feel like almost nothing to another. The caregiver's challenge is to assess all potential factors relevant to the resident's pain status without imposing personal biases.

According to pain experts, the resident's self-report or feeling of pain is the single most reliable indicator of pain. Pain should not be accepted as something the resident "just has to live with." All LTC staff and the resident's family share in the role of evaluating and managing the resident's pain. The direct caregivers, activities director, social workers, and housekeeping and dietary staff frequently spend the greatest amount of time with the resident. Doctors and charge nurses usually control the dose and frequency of pain medication, but they don't see the resident as often as their colleagues do. A resident may appear pain free when lying still, but caregivers see the resident's pain when he or she is moving or during ADLs. The caregiver must report this information to the charge nurse. It is important for everyone caring for the resident to understand the importance of recognizing and reporting pain.

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The process of pain management in the facility begins with an affirmation that residents should have access to the best level of pain relief that may safely be provided. In any LTC facility, the quality of pain control will be influenced by the availability of a pain management program and the training, expertise, and experience of its members.

Common Misconceptions about Pain

One of the most common misconceptions about pain has already been mentioned — the best judge of pain is not the person caring for the resident. The resident — the person in pain — knows pain the best. Other misconceptions and realities about pain management include the following:

- **Misconception:** The caregiver is the best judge of pain.
- **Reality:** The resident knows best about pain he or she is feeling. Pain is whatever the resident says it is.

- **Misconception:** A person with pain will always have obvious signs such as moaning, abnormal vital signs, or not eating
- **Reality:** Persons adapt to chronic pain, and do not always show outward signs. A resident may watch television as a distraction from pain, or go to sleep to escape pain. Vital sign abnormalities are not always an indicator of pain.

- **Misconception:** Pain is a normal part of aging.
- **Reality:** Elderly residents may not report their pain because they believe that pain is a natural part of aging. Pain is common in many chronic diseases, but it is not inevitable with aging. Analgesic medications can be used appropriately and effectively even in the very elderly to relieve suffering and enhance quality of life.

- **Misconception:** Addiction is common when opioid medications are prescribed.
- **Reality:** Addiction is very rare in patients who take opioid medications for pain; in fact, it occurs less than one time in 1,000 cases.

- **Misconceptions:** Morphine and other strong pain relievers should be reserved for the late stages of dying.
- **Reality:** Severe pain at any stage of life may require strong pain medications to give relief. Morphine and other medications do not have to be “saved for when the resident really needs it.” Most residents’ pain can be easily controlled with oral medications over time, and tolerance is not usually a problem. If the resident’s need for pain medications increases, the increase is usually an indication that the disease is progressing, not a sign that the resident is developing a tolerance for drugs. There is no ceiling or maximal daily dose for morphine and other opioids.

- **Misconception:** Morphine and other opioids can easily cause lethal respiratory depression.
- **Reality:** Opioids should be started at low doses and titrated upward to control a resident's pain. If the pain is intense or the resident has a tolerance for these medications, the necessary doses may be quite high. A resident who has been taking opioids can tolerate significant dose increases if the pain remains severe.

- **Misconception:** Pain medications should be given only after the resident develops pain.
- **Reality:** A steady state of pain control is the desired goal. Pain control is much easier and more consistent if medications are given before the resident experiences pain. A resident should not have to "earn" his or her pain medication by experiencing pain.

- **Misconception:** Anxiety always makes pain worse.
- **Truth:** Anxiety and pain often go together, but it is not known if anxiety can cause pain. We do know, however, that pain often causes anxiety.

Consequences of Untreated Pain — What Happens If Pain Isn't Properly Treated

A person with untreated pain may experience other symptoms besides pain:

- poor appetite and weight loss
- disturbed sleep
- withdrawal from talking or social activities
- sadness, anxiety or depression
- physical and verbal aggression, wandering, acting-out behaviors, resist care
- difficulty walking or transferring; may become bedbound
- skin ulcers
- incontinence
- increased risk for use of chemical and physical restraints
- decreased ability to perform ADL's
- impaired immune function

The caregiver should remember these signs and symptoms when caring for residents who are unable to tell the nurse about their pain. Many of the experiences linked to untreated pain can affect facility quality indicators and survey findings.

Descriptions of Pain

Caregivers responsible for residents should understand the sources of pain and help the IDT with pain management. The information in the following two tables will help staff understand pain by its duration and type.

Table 1.—Categories of Pain by Duration			
	Acute Pain	Chronic Cancer Pain	Chronic Non-Malignant Pain
Duration	Brief, goes away with healing (Usually 6 months or less)	Pain is expected to have an end, with cure or with death	No predictable ending
Key Reminders	<ul style="list-style-type: none"> • Acute pain is not necessarily more severe than chronic pain • Acute pain may be slow in onset. • Examples are broken bones, strep throat, and pain after surgery 	<ul style="list-style-type: none"> • Aggressive treatment recommended • Addiction not a concern 	<ul style="list-style-type: none"> • Difficult to find specific cause • Often can't be cured • Frequently undertreated

When a resident becomes a hospice patient, the hospice team may take a different approach to treating chronic, nonmalignant pain. This pain now has a predictable ending, the patient's death. Pain control is always important, but especially important when residents are trying to maintain quality of life as they face the end of their lives.

Table 2.—Categories of Pain by Type

	Somatic	Visceral	Bone	Neuropathic
Source	Skin, muscle, and connective tissue	Internal organs	Sensitive nerve fibers on the outer surface of bone	Nerves
Examples	Sprains, headaches, cuts, and arthritis	Tumor growth, appendicitis, gastritis, chest pain	Cancer spread to the bone, fractures, and severe osteoporosis	Diabetic neuropathy, phantom limb pain, cancer spread to nerve plexus
Description	Usually localized, sharp to dull, tends to worsen with movement or touch	Not localized and can refer to other sites, more constant and dull, less affected with movement	Tends to be constant, more intense, and worse with movement	Burning, stabbing, pins and needles, shock-like or shooting
Pain Medication	Most pain medications will help — if pain severe, need stronger medication	Stronger pain medications	Stronger pain medications, opiates work well with NSAIDS as adjuvant	Opiates + tricyclic antidepressants or other adjuvant

Pain Assessment

Healthcare providers have developed several standard pain assessment tools. Sample tools are provided in the appendixes to this document. Of course, asking about pain is an important part of any assessment. In the past, asking about pain was not done routinely. Some caregivers feared that asking about pain would put the idea of pain in the resident's mind. Others were unsure about what they would do if their questions elicited a pain report. It is, however, the responsibility of everyone caring for the resident to report pain.

The charge nurse is then responsible to further assess the reports of pain from all sources, including the family, direct caregivers, clergy, or other facility staff, and obtain treatment orders. Assessments to identify and treat pain must be ongoing. Elderly residents require frequent monitoring. Monitoring may have major implications for quality assurance, quality of care, and quality of life among this population of residents.

Assessing Pain in Residents with Dementia or Communication Difficulties

The resident's report of pain is the best method for assessing pain but sometimes the resident is unable to report pain. Residents with dementia or other cognitive disabilities will have difficulty communicating their pain symptoms.

Facility staff should consider the following guidelines when assessing residents with dementia or communication problems:

- **Ask the resident if he or she is having pain.** You might be surprised at the resident's level of understanding and response. Residents with significant cognitive impairment can often understand a simple question about pain and respond to the caregiver. You might want to use a term other than the word "pain." Try using hurt, discomfort, uncomfortable, aching, or soreness. The assessor should ask concrete questions rather than abstract questions. For example, an abstract question is "are you having pain?" A concrete question might be, "does your arm hurt?" Or, "does your back ache?" Residents with cognitive impairment will need to be assessed in the present moment. They will not remember past pain. It must be frequently assessed on an ongoing basis.
- **Consider the disease condition and procedures that may be causing pain.** A skin tear on the leg from the wheelchair's rough edge, a fractured hip, a fall that results in a bruise on the elbow, physical therapy goals for ambulation daily following a hip fracture are among likely reasons for pain treatment. It may help caregivers to think, "if I were that resident, would I want something for pain?"

- **Use proxy pain reporting.** Families often report to the nurse that their loved one is in pain. Housekeepers, the maintenance person, social workers, activity aides, and dietary staff are often extended family who observe and interact with the resident frequently throughout the day. They should be encouraged to report the resident's pain.
- **Be alert for behaviors that may indicate pain.** Actions speak louder than words when residents are in pain. Pay particular attention to physical aggression, verbal aggression, facial expressions, restlessness, and resistance to caregivers. When implementing a facility behavior intervention program, start with considering the pain assessment of each resident. The following list of actions may represent pain.
 - **Facial expressions:** frown, grimace, fearful, sad, teeth clenched, eyes wide open or shut tight
 - **Physical movements:** restless, fidgeting, absence of movement, slow or cautious movements, guarding, rocking, rigidity, rubbing, holding parts of body, wandering
 - **Vocalizations:** groaning, moaning, repeated phrases, yelling out, noisy breathing
 - **Social:** sleepless or sleeping most of the time, irritability, agitated, combative, crying, trying to get attention, refusal to go to activities, loss of appetite, withdrawn, resist care
 - **Aggression:** physical or verbal

Treatment of Pain

Rules of Thumb

These common sense rules can help guide LTC staff in decision-making for effective pain management:

- Use the lowest effective dose by the simplest (e.g., oral) route
- Start with the simplest single agent, and maximize its potential before adding other drugs. If combination therapy is necessary, use adjuvant (i.e., additional) medication to increase effectiveness.
- Use scheduled, long-acting pain medications for constant or frequent pain, with prn, short-acting medication available for breakthrough pain.
- Treat breakthrough pain with one-third the 12 hour scheduled dose.
- If three or more prn doses are used in a day, increase the scheduled dose. Increase the dose by one-fourth to one-half of the prior dosage. Remember to consider increasing the prn dose when you increase the scheduled dose.
- Be vigilant at assessing the side effects of medications. Treat or prevent side effects, such as constipation and nausea. Change medication as necessary.
- Use the World Health Organization's (WHO's) step-wise approach, which is also called the WHO Analgesic Ladder.
- Reevaluate and adjust medications at regular intervals and as necessary.
- Do not stop pain medications in terminal patients. Change the route if needed.

The World Health Organization (WHO) Analgesic Ladder

Severity of Pain	Drugs	Reminders	Adjuvant Therapy
Mild	<u>Acetaminophen</u> — e.g., <i>Tylenol</i> . Good relief of simple pain, easily available, few side effects	Elderly patients should have no more than 2.5 – 4 grams per day. Can be toxic to the liver	Adjuvant means in addition to. The use of adjuvant medications or therapies can be used with any severity of pain, and their use is determined by the type of pain.
	<u>NSAIDs or Non-Steroidal Anti-Inflammatory Drugs</u> — e.g., <u>aspirin</u> , <u>Ibuprofen</u> (<i>Advil</i> , <i>Motrin</i>), <u>Naproxen</u> (<i>Aleve</i>). Help with a wide variety of pain, anti-inflammatory, esp. good for bone and joint pain.	Look for GI upset, use with caution in patients with bleeding disorders. May exacerbate congestive heart failure or renal failure.	<i>Medications:</i> Bone pain — NSAIDs. Nerve or neuropathic pain — Tricyclic Antidepressants (<i>Pamelor</i>) and anticonvulsants (<i>Tegretol</i> and <i>Neurontin</i>). Pain associated with edema — corticosteroids (<i>Prednisone</i> , <i>Dexamethasone</i>). Pain associated with anxiety and or nausea — Lorazepam (<i>Ativan</i>) or alprazolam (<i>Xanax</i>) Therapies: Nerve blocks, radiation therapy, heat, ice, local balms, massage, comfortable atmosphere, Metastron (used for bone pain-given by radiation oncologist)
Moderate	<u>Combination Analgesics</u> . Preferred choices are mixtures of hydrocodone and acetaminophen (<i>Lortab</i> , <i>vicodin</i>) or oxycodone and acetaminophen (<i>Percocet</i>). Other combination drugs with Propoxyphene (<i>Darvocet</i> , <i>Darvon</i>) and Codeine (<i>Tylenol #3</i>) are not recommended because they produce more side effects with less pain relief.	Most combination drugs have acetaminophen. Remember to keep the 24 hour dose of acetaminophen less than 4 grams per day.	
Severe	<u>Opioids</u> . Morphine: Flexible dosing, short and long acting doses, inexpensive. Quick acting concentrated liquid morphine, e.g., <i>Roxanol</i> can be given to patients having difficulty swallowing, and may also be helpful for breathing discomfort. Oxycodone: Short and long acting doses can be given to residents who had confusion with morphine. This drug is very expensive. <u>Fentanyl</u> (<i>Duragesic</i>): Convenient when given as a 72 hour patch, but expensive, absorption varies depending on body fat, and you can't change doses quickly due to slow peak effect.	Slow breathing and sedation usually go away in 1 or 2 days after beginning medications or increasing dose. Patients should be on laxatives with any opioid. Increase laxative doses when pain doses are increased. Do not crush long acting opioids (<i>MS Contin</i> , <i>Oxycontin</i>) Less than 1% of people taking opioids become addicted, but most do develop a tolerance so doses may need to be increased.	

Pain Management in the Elderly

Elderly residents present several pain management problems. First, relatively little attention has been paid to the topic of geriatric pain control in medical or nursing texts. This inattention is ironic because elderly people often suffer acute and chronic painful diseases, have multiple diseases, and take many medications. They may have more than one source of pain and an increased risk for drug-drug as well as drug-disease interactions. It has been estimated from population studies that the prevalence of pain is two-fold higher in those over age 60. More than 80 percent of elderly people suffer various forms of arthritis, and most will have acute pain at some time.

Second, pain assessment may present unique problems in elderly residents. They often report pain very differently from younger residents because of physiologic, psychological, and cultural changes associated with aging. Institutionalized elderly are often stoic about pain.

Cognitive impairment, delirium, and dementia represent serious barriers to pain assessment. Preliminary reports from ongoing work among the nursing home population suggest that many residents with moderate to severe cognitive impairment are able to report acute pain reliably at the moment or when prompted, although their pain recall and integration of pain experience over time may be less reliable.

Opioid Use in the Elderly

Educating staff is essential for good pain management. Opioid analgesics are effective for relieving moderate to severe pain. Studies indicate that opioids of equal potency produce higher plasma concentrations in older persons. The evidence shows a greater sensitivity to opioids in older persons, especially opioid-naïve residents, in both analgesic properties and side effects. Smaller starting doses of opioids are required to avoid increased side effects and toxic reactions.

When selecting opioids for older residents, consider the duration of action, formulation availability, side-effect profile, and resident preference. When prescribing opioids for a resident with no history of narcotic use, review the resident's drug regimen for possible drug interactions. Older persons may have fluctuating pain levels requiring rapid titration or frequent use of breakthrough medication. Long-acting opioids are generally suitable for residents once steady pain levels are achieved; occasionally a resident in severe pain can be started on low-dose sustained release opioids. Once achieved, controlled-release formulations of morphine, oxycodone, dihydromorphone, or fentanyl can be used. Fentanyl patches should *not* be placed on areas of the resident's body that may receive

excessive heat (such as on the back of a bedfast resident) as that can affect the absorption of the patches. In addition, these patches may be contraindicated for residents with exceptionally low body fat.

Pain Management Risk for LTC Residents

Frail and elderly residents are at particular risk for both under- and over-treatment of pain. Age-related changes in the resident can contribute to a variety of adverse drug effects that have been reported. Non-opioid analgesic drugs, including NSAIDs and acetaminophen, are effective and appropriate for a variety of pain complaints. However, it is recognized that the risk for gastric and renal toxicity from NSAIDs is increased among elderly residents, and unusual drug reactions including cognitive impairment, constipation, and headaches are also more common in the elderly population.

Facility staff should be aware of drug side effects. All members of the IDT should be aware of all possible side effects and monitor the resident for their occurrences. The pharmacist is a key member of the team for recognizing and communicating the side effects to facility staff. The facility needs an ongoing method for communicating the drug side effects to all staff. The care plan could be one communication method for staff to know the adverse drug reactions.

What Everyone Can Do to Manage Pain

It is the role of the doctors, nurse, therapist, and family to determine the medical treatment for pain. Treatment may include medication, whirlpools, braces, ultrasound, or massages. But there are important things that everyone can do:

- Show that you care. A kind reassuring word and a soft touch go a long way.
- Let the resident know what you are going to do, even if he or she doesn't understand. Talk to, not around, the resident. Remember hearing is the last sense to go.
- Make the room pleasant. A comfortable temperature, soft lighting, soft music, and noise control can all increase pain tolerance.
- Take care of the basics. Repositioning, glasses and hearing aides, dry clothes, a comfortable bed or chair, toileting, food and fluids are often more important to the resident than any pill.
- Communicate with your team. Let others know what works best for the resident.
- Always report pain to the charge nurse or team. Pain is not a normal part of aging and all residents should have their pain managed.
- Understand the care plan for pain. Not all pain can be cured, but it can be treated in a thoughtful, effective fashion. A care plan for any resident with problem pain should involve a team approach.

- Relaxation methods can include a variety of techniques to help decrease anxiety and muscle tension; for example, imagery, distraction, and progressive muscle relaxation.
- Tactile strategies, for example, stroking and massage, can provide comfort through the sense of touch.
- Music and art therapy, meditation, and other relaxation techniques can be very helpful.
- Don't forget the team. Physical therapy can help with mobility and safety issues. Occupational therapy can help with difficult positioning and splints.

MDS and Regulatory Requirements

The following MDS items could be primary or secondary triggers for recognizing a resident's pain. The assessor should consider these items when developing care plan goals and interventions.

Section E.1. Mood and Behavior Patterns

- Repetitive verbalizations — for example, calling out for help
- Persistent anger with self or others — for example, easily annoyed, anger at placement in nursing home, anger at care received
- Repetitive health complaints — for example, persistently seeks medical attention, obsessive concern with body functions
- Sad, pained, worried facial expressions — for example, furrowed brows
- Crying, tearfulness
- Repetitive physical movements — for example, pacing, hand wringing, restlessness, fidgeting, picking
- Reduced social interaction

Section E.4. Mood and Behavior Patterns

- Wandering
- Verbally abusive behavioral symptoms
- Physically Abusive Behavioral Symptoms
- Socially inappropriate/disruptive behavioral
- Resists care

Section F. 2. Psychosocial Well-Being

- Covert/open conflict with or repeated criticism of staff
- Unhappy with roommate
- Unhappy with residents other than roommate

Section I.1. Disease Diagnosis

- Deep vein thrombosis
- Arthritis
- Hip fracture
- Missing limb
- Osteoporosis
- Pathological bone fracture
- Cancer

Section I.2. Infections

- Wound infection

Section J.2. Pain Symptoms

- Frequency
- Intensity

3. Pain Site

- A through J.

Section K. Oral/Nutritional Status

- Mouth Pain

Section L. Oral/Dental Status

- Inflamed gums (gingival); swollen or bleeding gums; oral abscesses; ulcers or rashes

Section M. Skin Condition

Ulcers

- Stage 1
- Stage 2
- Stage 3
- Stage 4

Other Skin Problems or Lesions Present

- Abrasions, bruises
- Burns
- Open lesions other than ulcers, rashes, cuts
- Rashes e.g. intertrigo, eczema, drug rash, heat rash, herpes zoster
- Skin tears or cuts
- Surgical wounds

Skin Treatments

- Ulcer care
- Surgical wound care
- Application of dressings

Foot Problems and Care

- Infection of the foot e.g. cellulitis, purulent drainage
- Open lesions on the foot

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State Licensure Requirement

Regulation 19 CSR 30-85.042 (67) requires the facility to address the residents' pain needs:

“Each resident shall receive personal attention and nursing care in accordance with his/her condition and consistent with current acceptable nursing practice.”

Federal Certification Requirements

Regulation 42 CFR Section 483.20(b), F272 requires facility staff to make a comprehensive assessment of the resident, including the resident's pain needs:

“A facility must make a comprehensive assessment of the resident's needs, using the RAI specified by the state.”

Regulation 42 CFR Section 483.20(k), F279 requires facility staff to develop a comprehensive care plan to address the pain needs of the resident:

“The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet a resident's medical, nursing, mental and psychosocial needs that are identified in the comprehensive assessment.”

Regulation 42 CSR Section 483.25, F309 requires the facility staff to meet the pain needs of the resident:

“Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.”

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NUTRITION AND HYDRATION

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NUTRITION AND HYDRATION

Purpose

This chapter discusses the resident's needs and comfort or distress related to nutrition and hydration during the final stages of life, and reviews regulatory guidance on the use of parenteral and enteral feeding.

Objectives

- Understand that nutrition and hydration goals are based on the needs and wishes of each resident/surrogate.
- Recognize the IDT's responsibilities to help the resident meet all nutrition and hydration needs.
- Know that although food and hydration usually provide comfort and nourishment, in the end stages of life they may cause distress.
- Maintain regulatory compliance with nutrition, hydration, and artificial feedings.
- Provide families with information and support regarding nutrition and hydration at the end-of-life.

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In Accordance with the Comprehensive Assessment and Plan of Care

Caring for the nutritional needs of residents during their elder years and also when they enter the final stages of life can be as different as night and day. The World Health Organization defines Palliative Care as the “active total care of patients whose disease is not responsive to curative treatment. . . .” For WHO, the goal of palliative care is to achieve “the best quality of life for patients and their families.” The Medicare Hospice benefit encourages defining the end-of-life by a timeframe of six months or less to live. What guidelines do we have for meeting nutrition and hydration goals within that timeframe?

The regulatory requirement for the resident to achieve the highest level of well-being *in accordance with the comprehensive assessment and plan of care* applies to any resident at any time during his or her stay at the long-term care facility. The assessment and plan of care depends on what the resident/surrogate wishes to achieve for each change in a symptom complex. As the resident’s strength and communication skills decline, his or her dependency on facility staff will likely increase. Providing individualized care will often require increased staff or family time to meet the resident’s nutrition and hydration needs. For example, the room-bound resident may require more one-on-one help with feeding. Engaging the resident’s family and friends can be important in meeting the resident’s nutrition and hydration needs. The facility should always consider current standards of medical practice in providing comfort to the resident.

Appropriate Nutrition and Hydration Goals

The primary goal of nutrition and hydration in terminal illness is resident comfort: improving quality of life by giving the resident maximum enjoyment from eating. Another goal is to maintain the resident’s nutritional status or optimize the resident’s intake. These goals can be difficult to balance in the long-term care facility. A facility can help achieve this balance by identifying foods the resident tolerates and desires. LTC staff should provide these foods as often as possible whenever the resident requests them. These foods provide nutrition, hydration, and comfort to the resident. The facility that can respond to the resident’s requests is providing the highest practicable level of nutrition and hydration for the resident’s well-being in accordance with the comprehensive assessment and plan of care.

A resident’s nutritional needs change as his or her illness advances. Allowing the resident/legal surrogate as much control as possible is the best way to maximize the resident’s intake while minimizing discomfort. The IDT can assist this effort. For

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example, one of the primary functions of the team is to communicate with the family. The team should designate a staff person to communicate with and support the family and thereby help the facility understand and implement the resident's wishes. Comfort and diminished distress from symptoms should be the goals of any intervention. As the illness advances, food and hydration can cause distress.

The appropriate time for the IDT to contribute its expertise to the resident's care in this matter is during assessment of significant change that points to a revision of care plan goals. Team members will include the following:

- **Registered Dietician (RD).** The dietician should work closely with the resident and family regarding the resident's likes, dislikes, cravings for, and intolerance of certain foods. This information will assist the RD in making menu changes or recommending the best supplements to maximize the resident's nutritional intake. Menu changes can include offering high protein, high caloric foods, such as eggs, milkshakes, custard, and peanut butter. If the resident doesn't tolerate meat, eggs, cheese or beans for protein, the RD may recommend adding powdered nutritional supplement to other foods to increase nutritional value. Alcoholic drinks, if medically allowed, can be enjoyable for the resident while stimulating the appetite. The team should encourage the family to bring the resident's favorite foods from home. A variety of options should be tried to maximize the resident's enjoyment of food and nutritional intake.
- **Dietary Manager.** This IDT member is an important link between the nursing department and the dietary department. The dietary manager should establish a system for receiving the physician's orders and dietary recommendations, and for ensuring that the dietary department prepares and delivers the food to the nursing department. Often the dietary manager is responsible for making the RD's recommendations available to the physician for consideration.
- **Occupational Therapist (OT).** This member can assess the resident's needs for assistive devices, including the use of a straw, sippy cup, noney cup, built up utensils, plate guards, or other implements.
- **Physical Therapist (PT).** PTs can recommend positioning for optimum comfort and safe intake of food and liquid. Proper positioning can make the difference between safe swallowing and choking or aspiration. It may also make the difference between optimal intake and poor intake resulting from weakness, fatigue, or pain.
- **Charge Nurse.** Nurses should observe the resident at frequent intervals or assist the resident frequently to evaluate the amount of assistance the resident needs at the current time. The resident may need supervision, cueing, limited assistance, extensive assistance or total assistance. The charge nurse should direct the caregiver in the amount of assistance needed at each meal. The charge nurse should evaluate the resident's chewing and swallowing safety at each meal. Assessing the resident's use of dentures is important to prevent the dentures from

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becoming a hindrance to the resident's ability to eat. Providing good and frequent oral care to the resident can also increase the resident's appetite. Communicating changes in the resident's condition and the RD's and OT's recommendations is often the charge nurse's responsibility.

- **Nurse Assistant (NA).** The nursing assistant should help the resident get into the correct position for eating and drinking, acquire the appropriate adaptive utensils, including vision glasses and dentures, and provide the appropriate amount of assistance needed. Cleansing the mouth and teeth frequently can increase the resident's appetite. NAs should help make the atmosphere and food presentation pleasant and remove excess food as soon as the resident has eaten all that he or she desires. The staff should provide food whenever the resident is hungry, not just at mealtime.
- **RAI/MDS Coordinator.** These coordinators should direct the completion of an accurate assessment, help develop the care plan with other team members, and ensure that the plan is communicated to all staff on all shifts involved in the resident's care. The resident's condition will change frequently at the end stages. These changes should be reflected on an on-going basis in the resident's plan of care. Daily and hourly changes should be addressed in the interdisciplinary notes and communicated to all staff.
- **Pharmacist.** The pharmacist should work closely with the facility staff regarding review of the resident's drug regimen when the goals of care are palliative. The pharmacist needs to remain informed of the care goals so that he or she can make appropriate recommendations. Recommendations should be made to the physician regarding the adverse effects of the resident's medications. The pharmacist should review the medications to ensure the medications are not adversely affecting the resident's appetite. Decisions to discontinue medications should be made by the physician after discussion with the IDT.
- **Physicians.** The doctor should review the current plan of care and modify existing physician orders that conflict with the palliative care goal. Dietary restrictions should be lessened unless doing so would cause immediate harm or discomfort. The physician, pharmacist, and nurse should review the drug regimen to ensure it does not affect the appetite and is not causing discomfort.

Inappropriate Nutrition and Hydration Goals

Traditional goals of a balanced diet and achieving an ideal weight are not realistic or appropriate in end stages of life. Traditional diets that restrict salt, cholesterol, or sugar may no longer be appropriate unless the resident prefers the restrictions. Side effects rarely occur because amounts of sodium, sugar, and calories are self-restricted. The goal is to provide foods the resident wants and will eat. Educating family about the resident's changing nutritional needs is part of the staff's responsibility.

Comfort versus Distress

The primary nutrition and hydration goal for residents in the end stages of life is comfort. The facility should evaluate interventions with that goal in mind as the resident's condition changes over time. Interventions for residents in end of life will be highly individualized. Standardized care plans or a "one size fits all" approach is not going to work. The "end-of-life stage" is such a broad category, and the resident's needs are so different that most authors refer to the last days or week of life as "imminent death." A nutrition and hydration intervention that brings comfort at an early stage of end-of-life can cause distress at a late stage of end-of-life. Therefore, the resident's care must be based on the comprehensive assessment and wishes of the resident. LTC staff must also attend to the manner in which food is provided. The resident may like the comfort and enjoyment of food but not like being fed in a hurried manner or in amounts that he or she can't handle safely. The professional staff must be aware of all aspects of the delivery of care and instruct, direct, and redirect caregivers who assist dependent residents with their nutritional needs.

Food and Hydration as Comfort

The nutrition and hydration goal is to optimize intake, provide pleasure, and promote comfort measures. The resident who is seriously ill usually cannot eat very much without feeling full or satisfied. The caregiver should offer frequent, smaller feedings to optimize intake and keep the resident more comfortable.

Food and Hydration as Distress

Often in the late stages, bodily systems fail, and the resident is unable to metabolize food normally. The disease process decreases the resident's energy levels and changes eating from a pleasant experience to a distressing one. Food cravings can change from one moment to the next, with the resident requesting food, then rejecting it after eating only a bite or two. The process of shutting down normal bodily functions is natural; it is not starvation. It is normal to have no thirst or hunger and to refuse all intake when death is imminent. The dying resident should never be made to feel guilty for not trying to eat. Even if the resident wants to eat, he or she may be unable to do so. Forcing one to accept food and fluid can increase rather than alleviate distress. The dying process may be prolonged by a few days with food and fluids, but such intake does not improve the quality of remaining life.

Lack of Food and Hydration as Comfort

Gradual dehydration appears to be the body's way of preventing distressing symptoms, such as lung congestion, shortness of breath, rattling secretions (death rattle), vomiting, and edema. Decreased output means less need for a bedpan, urinal, commode, or catheter. Dehydration is not a painful process and has even been described as causing a euphoric effect. The production of natural analgesics (endorphins) helps the body perceive that suffering has decreased.

Lack of Food and Hydration as Distress

Lack of food and hydration will cause the skin and mucous membranes to dry out which, if not cared for, will cause distress. However, this effect can be managed. A dry mouth and lips can lead to painful cracking, swelling, and oral infections. Assessment and interventions to minimize distressing complications of the dying process must be an active continuous process.

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Nutrition and Hydration Regulatory End-of-Life Guidelines

The Centers for Medicaid and Medicare Service directs surveyors for long-term care facilities to review unintended weight loss and hydration. The following guidance is from the State Operations Manual, Appendix P, investigative protocol:

“If a resident is at an end of life stage and has an advance directive, according to State law, (or decision has been made by the resident’s surrogate or representative, in accordance with State law) or the resident has reached an end of life stage in which minimal amounts of nutrients [fluids] are being consumed or intake has ceased, and all appropriate efforts have been made to encourage and provide intake, then weight loss [dehydration] may be an expected outcome and does not constitute non-compliance with the requirement for nutritional [hydration] parameters. Conduct observations to verify that palliative interventions, as described in the plan of care, are being implemented and revised as necessary, to meet the needs/choices of the resident in order to maintain the resident’s comfort and quality of life. If the facility has failed to provide the palliative care, cite non-compliance with 42 CFR 483.25, F309, Quality of Care.”

Medications

Medications can decrease and stimulate the appetite. Caregivers should consult the resident's physician and pharmacist to assess what medications should be part of the resident's drug regimen and whether any medications may be hindering oral intake. First, all medications should be reviewed to ensure that they are necessary given the resident's changing condition. Then medications that might improve appetite can be considered. If a medication is used to stimulate the appetite, the resident's response to the drug should be monitored and its effectiveness evaluated on an on-going basis. Staff should know how to recognize side effects and interdisciplinary reviews of all care including medications should be a regular part of the resident's care.

Below are some commonly used medications available to improve appetite.

- **Steroids.** These drugs have been used to reduce inflammation and pain, reduce nausea, and stimulate intake. They are most commonly used in cancer patients, but can be tried cautiously in other residents. The side effects from these drugs may negate the drug benefit for some patients.
- **Megace (*megestrol*).** Megace has been used with some success to stimulate appetite. The therapeutic response isn't immediate. If confusion is provoked by drug by-product retention, a trial of parenteral hydration may be appropriate to relieve confusion.
- **Periactin (*cyproheptadine*).** This medication has been used to improve appetite, but the evidence is anecdotal; it has not been well studied in terminal illnesses. Side effects can include sedation and confusion.
- **Remeron (*mirtazapine*).** Remeron is a unique antidepressant, which at lower doses can stimulate appetite and help control neuropathic pain. This drug may be sedating. Other antidepressants can be tried if anorexia is based primarily on depression and not other physiologic causes.
- **Marinol (*dronabinol*).** Marinol is approved for use in AIDS patients and has been used by some physicians to treat elderly residents. Its use is controversial because it can lead to multiple Central Nervous System effects.
- **Pain control medications.** Pain control medications that affect the residents' comfort level may also help them take in more nourishment.

Parenteral and Enteral Feedings

The resident/legal surrogate has the option of choosing parenteral or enteral feedings. Hospice nurses report the difficulty many families have in making decisions about artificial nutrition or hydration (whether it is implementing this intervention or withholding existing nutrition). The physician and/or facility staff needs to spend time talking with the family about the benefits and burdens of parenteral and enteral feedings.

Residents receiving tube feedings need special considerations to optimize the benefits and minimize complications. Tube feedings may play a specialized role in head and neck or esophageal cancers. With these diseases the resident loses the ability to swallow safely relatively early in the dying process. Other considerations also relate to the negative effects of tube feedings. These interventions are associated with a high incidence of aspiration, self-removal, restraints, and symptoms such as nausea, rattling pulmonary secretions, and diarrhea. These problems may result from the failure of the kidneys or gastrointestinal systems. At the end of life, the gastrointestinal system fails to absorb food. This can result in the resident's continued weight loss, abnormal lab values and pressure sore development or failure to heal.

Potential fluid overload and discomfort become highly likely with multi-system organ failure at the end of life. Artificially given fluids may hasten and aggravate the dying process, and not comfort the resident.

In case of doubt about the role of dehydration in a particular resident, a short trial of rehydration may be appropriate, allowing an assessment of its clinical impact and benefit. Sometimes mental confusion is provoked from drug by-product retention and a trial of parental hydration may be appropriate.

Regulatory Compliance in the Use of Feeding Tubes

Decisions revolving around the placement of feeding tubes are frequently difficult for facility staff who struggle with regulatory compliance. The federal regulation 42 CFR 483.25(g), (F321) for nasogastric tubes gives the following direction:

“Based on the comprehensive assessment of a resident, the facility must ensure that a resident who has been able to eat enough alone or with assistance is not fed by naso-gastric tube unless the resident's clinical condition demonstrates that use of a naso-gastric tube was unavoidable.”

The Guidance to Surveyors Section states: the intent of this regulation is that a naso-gastric tube feeding is utilized only after adequate assessment, and the resident's clinical condition makes this treatment necessary.” This requirement is “intended to prevent the

use of tube feeding when ordered over the objections of the resident. Decisions about the appropriateness of tube feeding for a resident are developed with the resident or his/her family, surrogate or representative as part of determining the care plan.”

The Resident Assessment Protocol: Feeding Tubes states the following in its statement of the problem:

“Where residents have difficulty eating and staff have limited time to assist them, insertion of feeding tubes for the convenience of nursing staff is an unacceptable rationale for use.” The RAP gives further directions by saying, “Assure informed consent and right to refuse treatment. Informed consent is essential before inserting a nasogastric or nasointestinal tube. Potential advantages, disadvantages, and potential complications need to be discussed. Resident preference is normally given the greatest weight in decisions regarding tube feeding. State laws and judicial decisions must also be taken into account. In any case, when illness is terminal and/or irreversible, technical means of providing fluids and nutrition can represent extraordinary rather than ordinary means of prolonging life.”¹

¹ While these principles may provide overall guidance for end of life care, the work group urges long-term care facilities to consult with their legal counsel with regard to surrogate decision-making issues.

Family Attitudes

In our society, eating and drinking together or giving food and drink is a symbolic gesture of giving love. The sharing of food is almost always associated with social events and celebrations. When a relative enters the dying stage of life, the family should be encouraged to understand that refusing food is not a rejection of their love. This concept of food as a symbol of love can make it difficult for caregivers and family to accept the resident's decrease in food consumption during the dying process. The resident in the imminent death phase often accepts, even welcomes, not being pressured to eat. But family and caregivers may have difficulty accepting the resident's refusal of food and fluid. Staff should explain the decreasing desire for food and fluid during the end of life and the comfort and distress associated with it. It is important to help the family refocus its energy into nourishing the loved one's emotional relationships. Encourage the family to replace their desires to provide nourishment and nurturing for the body by providing nourishment and nurturing for the mind and spirit.

During the end of life, the resident is not the only person who may need help. The family must also cope with the emotional and psychological aspects of their loved one's condition. The facility staff needs to expand their assessment to include the needs of family members. Often families don't know how to act when the resident can no longer carry on a conversation.

For example, a wife who visited her husband after he had suffered a stroke, had no rehab goals, and was unresponsive, said to the nurse: "I don't know what to do in there." After all the usual responses in such situations, the nurse asked her what her husband had enjoyed doing before he had the stroke. The woman said that he had loved sports and always read every word in the sports section of the paper. The nurse suggested she read some of the paper to him. This suggestion gave the wife a sense of direction, and she was delighted. Bringing the paper to her husband gave purpose to her visits.

Often the family is at a loss for something to do when they can no longer offer food or fluids. The facility staff can suggest activities that family members can do during their time at the bedside, including, for example,

- applying lotion to hands and feet,
- giving a back massage,
- applying moisturizer to the lips,
- remembering earlier times and happenings that bring back good memories,
- playing audiotapes with nature sounds and appropriate music.

- talking about past life memories and experiences
- sitting in silence and sharing the time

Facility Staff Becomes Like Family

The facility's professional staff should be aware of one another's emotional attachment to these residents. This emotional attachment is the caring quality that allows us to show love and concern for one another. Often the facility staff becomes a surrogate family to the resident. This caring quality needs to be nurtured, and staff, too, should go through a healthy grieving process when the residents they care for enter the last stages of life. Such a process will help them express these same caring emotions time after time as residents die at the facility.

In one facility, for example, a resident lived for many years with no family or friends to visit him. His diagnosis was Huntington's Chorea, which made it considerably difficult for him to eat or for staff to feed him. One nurse aide had developed an emotional attachment to him and was his most successful caregiver. She could always get him to eat with the least amount of difficulty and the most enjoyment for both the resident and the nurse aide. When he died, the Director of Nurses recognized the aide's grief. The DON talked with the administrator about it, and the facility held a memorial service for the resident. Staff purchased a willow sapling (the resident's favorite tree), and everyone helped the nurse aide plant the tree in memory of the resident.

LTC facilities can develop a network of resources within their community who can provide grief counseling for their staff and families. The administrative staff should monitor the needs of staff and families so that all aspects of the death and grieving process are addressed in a healthy manner. During this time, everyone needs good memories and support as they deal with the difficult situations of living and helping others during their time of dying.

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SPIRITUAL AND PSYCHOSOCIAL CARE

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SPIRITUAL AND PSYCHOSOCIAL CARE

Purpose and Objectives

This chapter presents the resident as a whole person with physical, psychosocial, and spiritual care needs. Nursing home staff members are not professional clergy or psychologists, but they can recognize these needs and provide appropriate interventions. The interventions can be divided into two kinds: staff can *listen* to a person's life review; and they can seek professional assistance for the resident through *referrals* for more intensive psychosocial and spiritual care. Under state and federal regulations, nursing homes are legally responsible for meeting the residents' psychosocial needs.

Objectives

- Understand the importance of psychosocial and spiritual care.
- Know how to provide psychosocial and spiritual care interventions for a resident during the later stages of life.
- Understand the regulatory requirements for meeting the needs of residents as whole persons.

Spiritual Care — Religion and Spirituality

The approach of death often inspires a search for peace and inner healing. Such peace or inner healing can replace fear and despair with hope and serenity. Hope for a physical healing may persist in those with incurable illnesses, but hope for other kinds of healing can also be strongly desired in the face of death. One can hope for comfort, personal growth, love, reconciliation, courage, self-forgiveness, renewed happiness for one's family, or that one's beliefs will be fulfilled.

A basic tenet of dealing with persons is to view the individual as a whole being — as a physical, psychological, social, and spiritual being. It is almost impossible to work effectively with only part of a person or with only one of these dimensions. Recognizing and treating the whole person is the basis for treating the person with dignity. Spiritual and psychosocial caregiving requires, like other kinds of caregiving, a team approach. When a facility cares for the physical needs of a resident's pressure sore, for example, a direct caregiver is needed to turn and reposition the resident at intervals, a treatment nurse is needed to change the dressing and track the progress of the sore, and a skilled health professional is needed for debriding the sore. Likewise a spiritual or psychosocial wound requires a team approach. All team members can listen to the resident and family but a professional caregiver — a chaplain, priest, psychologist, or social worker is needed for more intensive spiritual and psychosocial interventions.

The resident's need for hope continues throughout end of life and imminent death. The best support for the resident and family depends on knowing what the resident or family is hoping to achieve at the current time. The resident may be hoping to avoid severe pain. Assuring the resident that his or her pain will be aggressively treated can provide a great deal of support. Residents may hope that they will see certain people before their death. Letting a resident know that these persons are on their way to the facility often gives the resident the support needed to live a little longer. Similarly, a family member may hope that the resident will not die alone. Frequent communication and assuring them that they will be called when the resident's condition changes can help them remain hopeful. Many times a resident manages to live to reach a certain goal — an anniversary, a family visit, the birth of a child. Listening to what the resident or family hopes for and validating the resident's feelings often provides the groundwork for meaningful support.

Spiritual Care

Residents are diverse in their spiritual needs. Facilities and caregivers are diverse in their ability to meet these needs. Some facilities are faith-based and have a significant faith culture associated with their care delivery system. These facilities may also have resources readily available, such as a chaplain or religious leader, and regularly scheduled

religious services. However, many residents may not share the facility's religious affiliation or may not belong to any formal faith affiliation. Facilities that do not have a religious affiliation may have more limited access to spiritual and psychosocial care resources. Caregivers are also diverse in their ability to meet the resident's spiritual and psychosocial needs. Some may not be comfortable in meeting these needs or feel very inadequate in this role.

Spiritual care of dying persons is a recognized aspect of living and dying. The World Health Organization's definition includes the need to provide spiritual care:

“Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and psychological, social and spiritual problems is paramount.”

Over the centuries, religious institutions have cared for the dying. Dr. Cicely Saunder, founder of the hospice movement, focused on the importance of spiritual care. Spiritual care is recognized as an essential part of a quality palliative care program and a requirement of the Joint Commission on Accreditation of Health Care Organizations, and hospice agencies. It may also be a consideration in fulfilling the long-term care regulatory requirements to meet the psychological and social needs of the resident.

Spiritual care should be resident centered and based on the resident's own beliefs. Staff should never seek to impose their own religious or spiritual beliefs on the resident.

Religion and Spirituality

Religion and spirituality are different. Webster's Dictionary defines religion as a “belief in a divine or superhuman power or powers to be obeyed and worshiped as the creator(s) and ruler(s) of the universe, any specific system of belief, worship, conduct etc., often involving a code of ethics and philosophy.” Thus, the concept of religion may deal more with the dogma, practices, and rituals of worship of a specific organized group. Spirituality is more abstract. Webster defines the spiritual as being “of the spirit or soul as distinguished from the body or material matters.” Spirituality explores the person's inner meaning of life now and after death. It helps the person “relate to the world within, the world around and the world beyond.”

Psychosocial Care

The psychosocial dimension of end-of-life care, which encompasses both cognitive function and emotional health, calls for openness and sensitivity to the feelings and emotional needs of the resident and his or her family. Caregiving typically combines clinical and nonclinical interventions. The following symptoms can be associated with emotional and spiritual suffering:

- Anxiety
- Depression
- Helplessness
- Aloneness
- Financial distress
- Meaninglessness
- Need for forgiveness
- Fear of the unknown
- Loss of important roles
- Conflicted relationships
- Hopelessness
- Inability to enjoy/celebrate
- Need to forgive

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Subsection 5.4 Assessing Psychosocial and Spiritual Suffering	Issued 09/01/2003

Assessing Psychosocial and Spiritual Suffering

Psychosocial and spiritual suffering is real, but can be difficult to recognize and treat. Many times residents experience spiritual or psychosocial pain but translate the pain into physical complaints. Physical pain is easier to talk about than psychosocial or spiritual pain. A variety of assessment tools are available for assessing belief systems and unresolved issues in a nonthreatening way. One of the best assessment tools is listening to the resident or family member. Listen to what the person is saying. Does the person talk about hope or fear, joy or sadness, “good old stories,” or regret missed opportunities during their lifetime? The Interdisciplinary Team is essential in this area of the resident's care. The facility staff listens to the resident's needs and reports these signs and symptoms to the appropriate healthcare professional for further intervention.

A long-term care facility may or may not have access to a professional spiritual caregiver. Faith-based facilities frequently have better access to a chaplain, minister, priest or rabbi of the facility's faith, but they may have limited access to spiritual professional caregivers of different faiths. Facilities should develop access to community professional spiritual caregivers of all faiths. Facilities should encourage and arrange visitations by the resident's local spiritual leaders on an on-going basis. Local ministerial alliance organizations can provide facilities with ministers for a variety of religious affiliations.

A facility may be able to provide psychosocial support through its qualified social worker. If there are barriers to psychosocial services within the facility, and the resident cannot leave the facility, facility staff may consider accessing the services of a hospice agency.

Psychosocial and Spiritual Care Interventions

Psychosocial and spiritual care interventions can be categorized in two ways: basic caregiving involves listening, and professional caregiving involves listening and seeking further explanation of “life stories involving fear, anger, and other affective states,” frequently with referrals to other professionals. The following interventions can be helpful.

- Put aside your schedule and tasks. Offer your presence as a comfort and an opportunity for communication. Encourage the family or significant others to sit with the resident, even if nothing is said.
- Arrange for the clergy, rabbi, or other spiritual leader to visit the resident if the resident or family members so desire.
- Listen to stories or life reviews. Doing so is an excellent way to acknowledge the person’s value to self and others.
- Allow expressions of anger, guilt, hurt, and fear without minimizing or explaining them away. Encourage the resident to acknowledge these feelings, and then let them go.
- Avoid clichés such as “It is God’s will,” “Time heals all wounds,” “God wants him in heaven,” and so forth. Such messages may not match the resident’s beliefs. Never say, “Everything is going to be all right” or “You shouldn’t feel that way.”
- Read scriptures or other materials if the resident or family wishes to hear them.
- Encourage appropriate joy and humor. Laughter brings a lift to the spirit, celebrates life, and keeps things in perspective.
- Share prayers, meditation, or music if the resident and family desire them.
- Use massage and relaxation to help the resident relax and deal with disturbing psychosocial or spiritual matters. These techniques also help relieve pain and other distressing symptoms.
- Encourage completion of funeral arrangements.
- Encourage the resident to accept gratitude from others.
- Identify what constitutes a “good death” to the resident.
- Identify specific rituals or ceremonies important to the resident and family.
- Identify cultural issues that affect the resident and family.
- Encourage the family to give the resident permission to let go, when appropriate.
- Explain that it is all right to cry; tears are normal, and show caring.
- Encourage expressions of affection.
- Be present with the resident and family if they want support.
- Listen to the last wishes and regrets of the resident.

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- Communicate to the resident that what is happening is natural and that he or she is not alone.
- Assist the resident in reframing goals that are attainable and meaningful; for example, explore the strengths, priorities and past experiences that helped the resident cope with life in earlier stages.
- Help the resident identify relationships that need closure.

Regulatory Requirements

The fundamental federal regulatory requirement for psychosocial care in certified facilities is 42 CFR Section 483.25 (a):

“Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being in accordance with the comprehensive assessment and plan of care.”

The following MDS information can help the facility identify residents who find strength in faith or exhibit spiritual or psychosocial needs. Some state and federal requirements are listed in this section.

MDS Sections

Section AC. Customary Routine:

- Usually attends church, temple, synagogue (etc.)
- Finds strength in faith

Section F. Psychosocial well-being:

1. Sense of initiative/involvement
 - Establishes own goals
 - Pursues involvement in life of facility (e.g., makes/keeps friends; involved in group activities; responds positively to new activities; assists at religious services)
2. Unsettled relationships
 - Openly expresses conflict/anger with family/friends
 - Absence of personal contact with family/friends
3. Past roles
 - Strong identification with past roles and life status
 - Expresses sadness/anger/empty feelings over lost roles/status
 - Resident perceives that daily routine (customary routine, activities is very different from prior pattern in the community)

Section N. Activity Pursuit Patterns:

4. General Activity Preferences
 - Spiritual/religious activities

The Right to Participate in Groups, State Licensure Requirements

19 CSR 30-88.010 (30) states:

“ Each resident shall be permitted to participate, as well as not participate, in activities of social, religious or community groups at his/her discretion, both within the facility, as well as outside the facility, unless contraindicated for reasons documented by physician in the resident’s medical record.”

The Right to Participate in Groups, Federal Requirements

42 CFR Section 483.15(d), F245 states:

“A resident has the right to participate in social, religious, and community activities that do not interfere with the rights of other resident in the facility.” The Interpretive Guidelines to the Surveyors says, “The facility, to the extent possible, should accommodate an individual’s needs and choices for how he/she spends time, both inside and outside the facility.”

Social Services, Federal Requirements

42 CFR Section 483.15(g), F 250 states:

“The facility must provide medically related social services to attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident.” The interpretive guidelines to the surveyors says, “Medically related social services means services provided by the facility’s staff to assist residents in maintaining or improving their ability to manage their everyday physical, mental and psychosocial needs.” The guideline examples include:

- Maintaining contact with family (with resident’s permission) to report on changes in health, current goals, discharge planning, and encouragement to participate in care planning;
- Assisting staff to inform residents and those they designate about the resident's health status and health care choices and their ramifications;
- Assisting resident with financial and legal matters (e.g., referrals to funeral homes for preplanning arrangements;
- Providing or arranging provisions of needed counseling services; through the assessment and care planning process, identifying and seeking ways to support resident’s individual needs and preferences, customary routines, concerns and choices;
- Building relationships between residents and staff and teaching staff how to understand and support residents’ individual needs; promoting actions by staff that maintain or enhance each resident’s dignity in full recognition of each resident’s individuality;
- Assisting residents to determine how they would like to make decisions about their health care and whether or not they would like anyone else to be involved in those decisions;
- Finding options that most meet the physical and emotional needs of each resident;
- Providing alternatives to drug therapy or restraints by understanding and communication to staff why residents act as they do, what they are attempting to communicate, and what needs the staff must meet;
- Meeting the needs of residents who are grieving; and
- Finding options, which most meet their physical and emotional needs.

SPIRITUAL AND PSYCHOSOCIAL CARE

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HOSPICE CARE IN THE NURSING HOME

Purpose and Objectives

This section on hospice care in the nursing home provides LTC facilities an overview and guidelines for partnering with Medicare-certified hospices to benefit terminally ill patients and their families. It reviews the responsibilities of the facility and the hospice, and the sharing of responsibilities that facilitate the provision of palliative care.

Objectives

- Define hospice and identify the scope of care.
- State the general criteria in determination of hospice eligibility.
- Differentiate between the responsibilities of the LTC facility and those of the hospice team when collaborating in caring for the terminally ill.
- Know how to formulate a coordinated plan of care to be used by the skilled nursing facility and hospice.

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Definition of Hospice Care

Missouri and federal statutes entitle residents in LTC facilities to receive hospice services in the final stages of their life. Regulations establish that the nursing facility is the patient's home and the hospice interdisciplinary team offers the patient, the caregiver system, and the family a program of care defined in the Medicare/Medicaid hospice benefit.

By federal and state definition, “*Hospice care* is intended to meet the physical, emotional and spiritual needs of patients and their families facing life ending illnesses. The goal of hospice care is to provide comfort to the patient by assisting with pain and symptom management and to enhance the quality of life for both the patient and family.”

Residents electing hospice are not “giving up”; nor are they receiving less care. In fact, nursing home patients receive the benefit of LTC staff and the added benefit provided by a team of medical professionals focused on palliation and comfort. The challenge in providing this care is that each provider must cooperate with, communicate with, establish, and agree upon coordinated services that will not only reflect the hospice philosophy, but also be responsive to the unique needs of the resident and his or her desires. To be successful in meeting these needs, both the LTC provider and the hospice provider must be knowledgeable and attentive to the Medicare conditions of participation and state licensure regulations of each entity.

Hospice Services

The hospice scope of care includes

- Skilled Nursing
- Medical Social Services
- Personal Care
- Spiritual Support
- Volunteer Support
- Bereavement Support
- Physician Services

Resident's benefit from hospice care in several ways. By electing hospice, the resident has clearly asked that his or her care be focused on palliation. There are significant benefits to this choice, especially the added attention of nurses to help manage the pain and symptoms relating to the life-ending illness, and the one-to-one emotional support for the resident and the family. However, because the hospice is financially responsible (in Medicare/Medicaid cases) for all medications, medical supplies, and equipment related to the terminal diagnosis, patient and families may have received an additional benefit of fiscal relief. Moreover, hospice volunteers visit residents on an as needed basis and often provide valuable interaction with the resident or family.

Determination of Hospice Eligibility

General Criteria

Patients must meet the following criteria before they are eligible to elect the hospice benefit. The patient must be

- diagnosed with a terminal or life ending illness;
- have a life expectancy of six months or less, as determined by the attending physician and the hospice interdisciplinary team;
- seeking palliative (pain and symptom relief) rather than curative treatment.

In addition, the patient, family, and physician must understand that artificial, life-prolonging procedures are not consistent with hospice care; and that admission to hospice services is approved by the attending physician and the hospice medical director.

The most difficult part of determining a patient's eligibility for hospice benefits is the physician's certification that the patient has a prognosis of six months or less. To help physicians and hospices identify patients who may be hospice appropriate, the Centers for Medicare and Medicaid Services (CMS) has issued a Local Medical Review Policy (LMRP) that defines prognostic criteria (by disease). This LMRP should be examined to determine whether the patient is eligible. The guidelines examine documentable evidences that "if the disease follows its normal course" the prognosis is for six months or less. The current guidelines include lung disease, heart disease, kidney failure, HIV, stroke and coma, dementia, liver failure, ALS, lung cancer, prostate cancer, breast cancer and decline in health status. Two of the 12 current LMRP guidelines are provided in the appendix: the LMRPs for Dementia and for Decline in Health Status. The other guidelines can be viewed on the Internet at:

<http://www.iamedicare.com/Provider/policy/policyhome.htm>

In a healthcare environment marked by constant change, the task before us is to bring together two providers, a LTC facility and a hospice, each with its distinct culture, and use their respective strengths to provide compassionate skilled care of the highest quality to individuals who are in the final weeks and months of life.

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Subsection 6.5 Core Services	Issued 09/01/2003

Core Services

Hospice core services, which can best be described as people services, include physician services, nursing services, medical social services, spiritual counseling, bereavement counseling, dietary counseling, and volunteer services. Hospice Medicare Conditions of Participation (42 CFR 418.80) state that these services must be provided by hospice employees. The Medical Director and dietary counselor may be contracted services of the hospice agency. Many of these services are shared with the LTC facility through an integrated plan of care. Collaboration is essential for both providers.

Hospice provides core services through a 24-hour, 7 days a week, on-call system. In the partnership of the hospice and the LTC facility, the interdisciplinary hospice team and its resources are available not only to the patient and family but also to facility staff.

Responsibilities of Providers

Service	LTC Facility	Hospice	Collaborative relationship
Nursing Services	RNs, LPNs, CMTs and CNAs in the role of daily caregiver. Continue provision of care as with all patients.	RN coordinates and reviews care plan. Makes intermittent visits, based on patient need. Educates staff and families. Reviews record. Assigns and supervises hospice aide as needed.	Maintain communication to fulfill plan of care and inform each other of changes in care plan.
Physician Services	Attending physician and the LTC medical director will continue to follow state and federal regulations for visitation schedule.	The hospice medical director complements the attending physician's care as a resource on palliation. Provides for unmet medical needs related to the terminal diagnosis. The hospice medical director acts as a resource to help hospice staff manage pain and symptoms of discomfort.	Each provider shall identify lines of communication for medical care.
Medical Social Services, Spiritual Counseling, Dietary Counseling, Bereavement Counseling and other Counseling	Performs these services as agreed on in the plan of care in accordance with LTC state and federal regulation.	Provides spiritual emotional, nutritional counseling for resident and family as indicated in the interdisciplinary plan of care.	Maintains open communication between the hospice and facility for services performed and for changes in the patient's status that affect the plan of care.

**Responsibilities Related to the Eligibility/Admission Process
of LTC Residents Electing Hospice Services**

Hospice inquiries may be made by anyone directly involved with the patient. The LTC staff will be most sensitive to the time that a patient/legal surrogate may be ready to access hospice care. It is the patient's/surrogate's right to access hospice services if the resident qualifies for that benefit.

LTC Staff	Hospice Staff	Collaborative
Identify potential hospice patients.	Provide hospice information for facility to give patients and families.	Hospice and nursing facility must have a mutually agreed on contract before services can be provided.
Review legal paperwork (i.e., Advanced Directive, Living Will, DPOA). Identify legal representative who can make decisions on resident's behalf. Obtain a physician's order for hospice evaluation and potential admission.		
Educate resident/legal surrogate re: condition and treatment alternatives in understandable terms. Provide patient/surrogate with listing of hospice providers and offer brochures and literature.		
Contact hospice provider selected by patient/legal surrogate, and schedule an appointment for education /sign on. Assure that patient has signed release of confidential information. Provide hospice with documentation necessary to determine eligibility.	Respond to request to assess patient using guidelines to confirm eligibility. Report findings to attending physician, hospice, LTC facility and patient/legal surrogate. Verify hospice order for admission.	Review LMRP guidelines in the appendix or on the web at: www.iamedicare.com/Provider/policy/policyhome.htm
Provide hospice copy of I-M 62, if applicable, and notify LTC business office of change, evaluate the need for MDS reassessment to reflect hospice election and determine if a significant change in condition assessment is required. Notify hospice of care plan meetings.	Explain hospice services, conduct the intake process, and obtain a signed election statement. Verify patient financial status and educate patient and family about financial responsibilities. Notify LTC of hospice election.	Modify the Plan of Care to ensure it reflects the change in needs/service.

Integrated Plan of Care

The purpose of the care plan is to provide a structure for the delivery of individualized care and treatment through the use of measurable objectives and timelines. The actual written plan of care may vary from facility to facility; however, the content incorporates the identification of problems, goals, and interventions, and designates the role of each team member. While long-term care plans generally focus on functional status, rehabilitation/restorative nursing, health maintenance and daily care needs, hospice plans to a greater extent address pain and symptom management, preparation for death and bereavement, and end-of-life tasks. The challenge for both the hospice and the LTC facility is collaboration to enhance the quality of services for the patient. The care plan is a communications tool between caregivers and promotes continuity by establishing resident/patient goals and objectives. Care planning sets the stage for implementing and evaluating care provided to the patient.

The hospice service retains overall professional management of the plan of care related to the terminal illness.

LTC Staff	Hospice Staff	Collaborative
Provides relevant physician orders, comprehensive assessment (MDS), and care planning through the RAI process, medication list, Durable Medical Equipment (DME) list, and social service notes needed to initiate palliative plan of care.	Provides initial hospice nurse assessment, completed guidelines for hospice appropriateness, medication list indicating payor source, physician orders certifying 6-month prognosis, and hospice plan of care.	Establish date/time to meet and formulate initial plan of care. Initial plan of care meeting should be 24 to 48 hours from admission to hospice services. Collect data and encourage patient and family participation.
Modifies the LTC plan of care to reflect the patient's palliative care wishes.	Develop hospice plan of care. Provide a copy for SNF records. Secure needed DME and hospice-related medications and supplies. Update as condition and needs change.	Determine patient's DME, medication, and treatment needs. Designate discipline responsible for delivery of patient care and identifies payor source of items and treatments needed.

LTC Staff	Hospice Staff	Collaborative
LTC facility continues providing daily care and communicates to hospice any change in condition or need.	Hospice assumes case management of patient's terminal condition. Documents the provision of care and service, which reflects the hospice philosophy, including the management of pain and other uncomfortable symptoms.	Develop and implement an integrated plan of care. Create and maintain a mutually acceptable communication system that maximizes the flow of information for enhanced care delivery.
Informs patient/legal surrogate and hospice of scheduled patient care plan meetings	Participates in patient care plan meeting and assists facility in establishing palliative care goals.	Hospice staff, LTC staff, the patient/family, and physician work together to set clear palliative care goals and communicate them to all parties.

Physicians Orders

Policy and protocol development regarding communications between the nursing home staff and hospice staff are valuable quality assurance tools to address medical orders. The attending physician shall participate in the development of the plan of care with the hospice interdisciplinary team, the patient/surrogate, and the LTC facility. The attending physician shall comply with all LTC standards related to the review of physician orders. A hospice patient may elect a different physician to assist in managing the pain and symptoms related to the terminal diagnosis. In this circumstance the hospice is responsible to all parties for coordinating, communicating, and ensuring the proper documentation of orders related to the terminal diagnosis.

LTC Staff	Hospice Staff	Collaborative
<p>The LTC staff shall secure and document orders with the primary physician and consulting physician in compliance with LTC state and federal regulations.</p> <p>Notify primary physician of consulting physician order changes.</p>	<p>The hospice will secure and document orders with the primary and consulting physician in compliance with hospice state and federal regulations.</p> <p>The hospice will identify and communicate with the SNF and the pharmacy regarding the payor source of medications, treatments, and supplies ordered by physicians.</p>	<p>The Hospice IDT and the LTC nursing staff will jointly determine the relationship of all physician orders/ treatments to the resident's terminal diagnosis and make recommendations to physicians related to the palliative care plan.</p>
<p>The LTC staff will communicate changes in physician orders with hospice in a timely manner.</p>	<p>The hospice will communicate changes in orders with the SNF in a timely manner</p>	<p>The LTC facility and hospice will have a predetermined plan for communication with physicians as reflected in the integrated plan of care.</p> <p>LTC and hospice staff will establish and abide by policy and protocols to supply and maintain supplies, medications, and DME.</p>

Medical Records Management

In accordance with accepted standards of practice, the hospice and the LTC facility must establish and maintain a clinical record for every individual receiving care services. Clinical records must be retained as required by state and federal law documenting all services furnished directly or by arrangement. The LTC facility and the hospice should decide what portions of the clinical record should be copied and which agency should retain the original forms.

The confidentiality of patient records must be maintained at all times. Information sharing may only occur after written authorization is secured from the resident/surrogate.

LTC	Hospice	Collaborative
LTC will establish and maintain a clinical record of the resident in accord with long-term care regulations	Hospice will maintain a clinical record of the resident receiving hospice services in accord with hospice regulation.	Decide where hospice documentation should be located in the chart. Determine best method to communicate to all disciplines that the resident has elected palliative services. Establish a method to clearly identify hospice contact information.
The LTC medical record will be available to Hospice	Hospice will provide appropriate documentation and consents to support all interventions.	Devise method to thin charts to ensure that all relevant information is easily accessible to all parties.
<i>*Missouri Medicaid</i> LTC will bill hospice for per diem room and board rate minus the surplus.	<i>*Missouri Medicaid</i> Hospice will file the appropriate paperwork to ensure timely Missouri Medicaid billing.	The nursing home and hospice will establish a mutually acceptable procedure for timely billing and reimbursement of Missouri Medicaid room and board.

Utilization of Therapy Services

Ancillary therapies, including infusion therapies; tube feedings; IV therapies; physical, occupational, and speech therapies may be part of the plan of care for a hospice patient. The hospice IDT is responsible for determining if these services are consistent with the resident's palliative care needs. The hospice IDT and the attending physician must make prior authorization for therapy services.

LTC Staff	Hospice	Collaborative
LTC staff may recommend therapies to the hospice team.	Hospice will obtain the orders and make arrangements for therapy services and nutritional counseling if consistent with the resident's plan of care.	The scope and frequency of therapy services will be documented and agreed upon by the hospice and LTC facility.
	Therapy services, goals, duration, and interventions will be included in the integrated plan of care and in the hospice progress notes.	Both staffs will monitor the efficacy of any therapy included in the plan of care and communicate recommendations.
Ancillary services may be purchased through the LTC facility (i.e., PT, OT, ST). If the LTC is using outside resources a contract must be in place.	Hospice will maintain appropriate personnel records on all therapists contracted through the facility. Hospice will provide required orientation and ongoing inservicing for LTC contract therapist.	The hospice/LTC facility must have a mutually agreed upon method to provide ancillary services. If the LTC therapy services are utilized, a contract is necessary before services can be provided.

Loss and Grief Services

Bereavement and grief support services are available to the family and significant others from admission to hospice through one year following the death of the patient.

	LTC staff	Hospice staff	Collaborative
Family/Significant other	Identifies and shares information related to patient/surrogate and family's coping, support, and grief needs.	Does ongoing risk assessment starting at admission. Explains and offers grief support, for example, counseling, printed information, and support groups. Identifies other community support resources. Provides individualized care for family and significant others in home setting.	The LTC facility and hospice formulate a joint care plan addressing bereavement needs. Assesses the need for hospice to provide grief support.
LTC Staff/ other residents	Provides grief support and services.	Provides grief education and support and identifies community resources as needed.	Assesses need for hospice to provide grief support.

Responsibilities at Time of Death

It is essential that the nursing home and hospice determine in advance who is responsible for notifying the physician, pharmacy, mortuary, and coroner (per county procedures). Collaboration is critical during this time.

LTC Staff	Hospice	Collaborative
<p>Calls hospice to inform them of imminent death. Provides support for patient, family, facility staff, and residents as needed.</p> <p>Determines who will contact family to report imminent death.</p>	<p>Makes visit to dying resident as needed. Provides counseling, spiritual, and volunteer support as needed for family and significant others.</p>	<p>Determine care/support needs. Ensure that needs are met and addressed.</p>
<p>At time of death, the LTC facility will return or destroy medications as per facility protocol.</p>	<p>Offers visit at time of death and assists with arrangements (e.g., calls to physician, mortuary, and coroner, as predetermined).</p>	
<p>Follows post death protocol for LTC facility</p>	<p>Manages extreme psychosocial response of family by involving hospice counselors and chaplains.</p>	<p>Support family members and follow predetermined protocols for dealing with difficult behaviors.</p>
<p>Notifies LTC facility staff and residents of death and funeral arrangements.</p>	<p>Notifies hospice IDT of death and funeral arrangements.</p>	<p>Attend visitation/funeral as desired.</p> <p>Provides ongoing support to LTC staff and residents.</p>

Hospitalization and Emergency Care

Emergency care should be consistent with the patient’s stated wishes in advance directives and physician orders. LTC staff should call the hospice in a timely manner for any change in condition to facilitate reassessment and revision of the plan of care. Nursing home staff should obtain approval of the hospice prior to transferring the patient to another care setting when the transfer is related to the terminal condition. When the transfer is unrelated to the terminal condition, communication with the hospice should occur as soon as possible. All emergency care related to the terminal illness (i.e., pain and symptom management) requires approval and coordination by the hospice.

LTC Staff	Hospice Staff	Collaborative
Determines a need for emergent care. Contacts the hospice for determination of relationship to terminal illness and appropriateness of transfer. Contacts family/legal surrogate and physician about change in condition.	Responds to LTC facility to assess patient’s needs and determine necessary actions. Provide emotional support for resident and family.	Develops protocols in advance concerning emergent care situations. Both staffs will communicate with each other in transferring the resident to the ER or other acute care setting.
Makes arrangement for transportation if unrelated to the terminal diagnosis.	If a hospice-related transfer to another care setting is imminent, the hospice will assist in arranging for ambulance transport (unless otherwise agreed upon).	The LTC and hospice will know the resident’s resuscitation status and abide by the patient’s advance care wishes.
Prepare transfer form to accompany patient to hospital. Make sure hospice status is identified and resident’s advance directive wishes are included in the package.	The hospice will send hospice plan of care, advance directives, and a current list of medications/ treatments. Hospice staff will continue to manage treatment of terminal illness while patient is hospitalized.	The LTC and the hospice will predetermine which entity will be responsible for receiving updates and reports on the resident’s status.

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LTC Staff	Hospice Staff	Collaborative
Will receive discharge orders from hospital.	Will communicate with the hospital to assist in discharge plans. Will work to ensure that patient returns to facility as soon as acute symptoms are controlled.	The LTC and the hospice will change the plan of care to reflect changes in condition, new orders, and any change in level of care.

Revocation/Decertification/Transfer

Since hospice services are elected by the resident/surrogate, it is the resident’s right to discontinue or transfer hospice services at any time. If a resident decides to pursue curative measures, or no longer wants hospice care, the resident/legal surrogate may *revoke* the hospice benefit. If, on the other hand, the patient no longer meets the criteria for appropriateness, the hospice may need to discontinue hospice services or *decertify* the patient. If a resident moves to another location or prefers to use another hospice, the resident may *transfer* his or her care.

	LTC Staff	Hospice Staff	Collaborative
Revocation of hospice benefits — The patient or surrogate elects curative treatment or no longer wants hospice. Only the resident/surrogate can revoke the hospice benefit.	Notifies patient or family of any new financial responsibility including DME, medications, and supplies Assesses and evaluates need for revised plan of care Notifies LTC billing staff of change in status.	Obtains a signed revocation form from the patient/surrogate and physician. Notifies, in writing, the LTC Business Office of revocation. Provides resident/family with information on community resources.	Discuss revocation and implications for care. Write discharge plan and summary.
Decertification — Patient no longer meets hospice criteria or hospice demonstrates other grounds for discharge and decertifies a resident from the hospice program.	Notifies patient and family of new financial responsibilities. Assesses and evaluates need for revised plan of care.	Consults with physician regarding disqualification due to improved status. Notifies LTC Business Office of change in status Notifies family of reason and provides patient/family with list of community resources.	Discuss discharge and care implications Write discharge plan and summary. Monitors condition changes that may indicate re-admission

	LTC Staff	Hospice Staff	Collaborative
Transfer — Resident moves out of service area, or desires another hospice provider, or moves to another care setting.	Arranges and prepares for transfer/discharge, per LTC regulations.	Facilitates transfer to new hospice or care setting, per protocol.	Discuss discharge and care implication. Write discharge plan and summary Arrange transport if needed.

Respite and Acute Patient Care in the Nursing Home

The majority of hospice patients residing in a LTC facility will receive hospice under the routine level of care. However, Medicare/Medicaid benefits provide for two other levels of care in which a hospice patient may be admitted to the skilled nursing facility for a short period of time. A contract must be in place, which determines payment for services including room and board. Hospice may then bill Medicare/Medicaid and pay for all services related to the terminal diagnosis. These levels of care are the following:

- **Respite Care** — Patient may be admitted to a facility to relieve family members or other caregivers for up to five consecutive days.
- **General In-patient** — Patient requires admission to SNF for pain or acute/chronic symptom management, which cannot be handled in the home setting

LTC	Hospice	Collaborative
Prepare room and staff for patient admission. LTC must have 24-hour on-site RN coverage in a Medicare/Medicaid certified facility.	Arrange transportation and schedule admission to SNF. Provide or arrange for delivery of sufficient medication, supplies, and DME.	Hospice and facility must have a mutually agreed upon contract for Respite or General Inpatient Care before services can be provided.
Call Hospice to collaborate on any standard admission procedures that may be deferred such as admission physical, or blood work.	Provide copy of all Hospice paperwork for SNF chart. Immediately communicate physician orders and plan of care to facility staff.	Develop an integrated plan of care.
RNs, LPNs, and CNAs provide the role of daily caregiver, as with all patients.	Assume case management of patient.	Maintain communication to fulfill plan of care and inform each other of changes in care plan or patient/family status.

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LTC	Hospice	Collaborative
Assist with discharge plans to home as per facility protocol Or Continue current care if patient chooses to remain in SNF under Routine Care.	Provide transportation to home and arrange for provision of DME, supplies, and medications at home. Notify facility bookkeeper of patient discharge. Or Assist patient/family with plans to remain in SNF under Routine Hospice Care	Assist each other with discharge plans Or Provide emotional support if patient chooses to stay in the SNF

Hospice Reimbursement

Medicare Hospice — The Medicare Hospice Benefit is used to reimburse hospices for providing and managing all care related to the hospice terminal diagnosis including intermittent visits by all hospice team members, supplies, medical equipment, and medications. Hospice is required to pay only for services that have been preapproved by the hospice program. Traditional Medicare or other reimbursement arrangements pay the cost of medical care for problems unrelated to the hospice diagnosis.

Medicaid Hospice — The Medicaid Hospice Benefit mirrors the Medicare benefit for Hospice services.

Medicaid Room and Board — Hospice bills Medicaid for room and board, then reimburses the Long-Term Care Facility.

Private Insurance — Most private or commercial insurance plans offer hospice benefits but the plans vary in coverage. The hospice and SNF must collaborate regarding reimbursement issues.

Reimbursement Source	LTC Staff	Hospice Staff	Collaborative
Medicare / Medicaid Routine Care	LTC Staff will notify Hospice of any change in patient condition or new physician orders to be approved for payment by Hospice.	Identifies medications, supplies, DME, and therapies related to the terminal diagnosis and paid by Hospice.	Determine a protocol for provision and maintenance of supplies, meds, DME, and therapies.
Missouri Medicaid Room & Board	LTC bills Hospice for per diem room and board rate minus the surplus.	Hospice files appropriate paperwork, and then bills Medicaid for nursing-home room and board. Hospice reimburses LTC for Medicaid room and board.	The nursing home and hospice establish a mutually acceptable procedure for timely billing and reimbursement of Missouri Medicaid room and board.

Reimbursement Source	LTC Staff	Hospice Staff	Collaborative
Medicare /Medicaid General In Patient or Respite Care	Facility bills Hospice for contracted per diem rate.	Hospice bills Medicare/Medicaid for general in patient or respite care. Hospice pays facility contracted rate.	A contract must be in place for acute in patient or respite care to be provided in the SNF.
Private Insurance	Staff will communicate with Hospice regarding arrangement of Hospice payment for services, DME, meds, supplies, and room and board.	Hospice will notify LTC staff of contract agreement and identify all services, supplies, DME, meds, and room and board, if applicable, to be paid by Hospice.	Establish a communication system and procedure for dealing with reimbursement issues for private insurance patients.

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Long-Term Care Regulatory Requirements and Expectations of Hospice Services

Regulatory Requirements

The State Operations Manual (SOM) for the skilled nursing facility directs the surveyor in reviewing a hospice resident's care (pp. 53-54):

When a resident has elected the Medicare hospice benefit, the hospice and the nursing facility must communicate, establish, and agree upon a coordinated plan of care which reflects the hospice philosophy, and is based on an assessment of the individual's needs and unique living situation in the facility. The plan of care must include directives for managing pain and other uncomfortable symptoms and be revised and updated as necessary to reflect the individual's current status.

The hospice must designate a registered nurse from the hospice to coordinate the implementation of the plan of care.

This coordinated plan of care must identify the care and services which the Skilled Nursing Facility/Nursing Facility (SNF/NF) and hospice will provide in order to be responsive to the unique needs of the resident and his/her expressed desire for hospice care.

The SNF/NF and the hospice are responsible for performing each of their respective functions that have been agreed upon and included in the plan of care. The hospice retains overall professional management responsibility for directing the implementation of the plan of care related to the terminal illness.

For residents receiving Hospice benefit care, the surveyor should evaluate the following to determine compliance:

- The plan of care reflects the participation of the hospice, the facility, and the resident to the extent possible;
- The plan of care includes directives for managing pain and other uncomfortable symptoms and is revised and updated as needed to reflect the individual's current status;
- Drugs and medical supplies are provided as needed for the needed palliation and management of the terminal illness and related conditions;
- The hospice and the facility communicate with each other when any changes are indicated to the plan of care;

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- The hospice and the facility are aware of the other's responsibilities in implementing the plan of care;
- The facility's services are consistent with the plan of care developed in coordination with the hospice, (the hospice patient/resident in a SNF/NF should not experience any lack of SNF/NF services or personal care because of his/her
- Status as a hospice patient); and
- The SNF/NF offers the same services to its residents who have elected the hospice benefit as it furnishes to its residents who have not elected the hospice benefit. The patient/resident has the right to refuse any services.

NOTE: If you have concerns about the resident in relation to care provided by the hospice agency, refer the issue to the State Agency (SA) responsible for surveying hospices.

CMS's Identification of Problem Areas

In June 2000, the Department of Health and Human Services CMS Region VII issued the Survey and Certification Regional Letter Number 00-07. This letter was in response to questions submitted to CMS by the Hospice Association of America. It identifies four major areas of concern with the implementation of hospice in LTC facilities:

- The provision of care and services does not reflect the hospice philosophy.
- Problems with the coordination, delivery and review of the plan of care between the hospice and the LTC facility.
- Ineffective systems in place to monitor/assure that the plan of care meets the resident's needs in the area of pain management and symptom control.
- Poor communication between the hospice and nursing home staff:
 - Nursing home staff are often not aware of the hospice philosophy;
 - The plan of care does not reflect the hospice philosophy or adequately address pain management and symptom control; and
 - Hospice and LTC staff do not communicate problems encountered with the pain management assessments and make needed revisions to the plan of care in an effective and timely manner.

SLTC's Interpretation of Major Concern Areas

The care and services do not reflect the hospice philosophy when the corporate, administrative or clinical leadership does not adopt the hospice philosophy. Each facility should evaluate its program to see if the program is committed to the hospice philosophy.

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Determine if the following are in place:

- Policies and procedures for providing end-of-life care.
- Palliative care protocols for pain management.
- Palliative care protocols for treatment of distressing symptoms.
- Care directives to maintain the residents' dignity.
- Care directives to assist the family/significant other in the loss.

Identified problems with the coordination, delivery and review of the plan of care between the hospice and the LTC facility. Problems arise when there isn't adequate coordination of care between the two providers. Surveyors report finding two separate care plans for residents receiving hospice benefits — the LTC care plan and the hospice care plan. Frequently, the hospice care plan is located in a different section of the chart or even a different section of the nurse's station. This fragmentation of the care planning can hamper the staff's ability to effectively care for the resident. Facilities must review their policy to assure integration of the hospice and LTC plan of care.

The hospice nurse's expertise in the management of pain and other distressing symptoms can contribute significantly to end-of-life goal setting and care plan development. The hospice nurse is an essential team member. The direct caregiver is another valuable team member in the assessment and care plan development process who frequently spends the most time with the resident. Good care requires ongoing communication skills to keep all staff persons informed of changing care needs.

Occasionally, the elder abuse hot line receives an allegation of neglect or starvation of a resident who is in the end stages of life. The state survey agency must respond to this allegation but the investigation can add a burden to the staff and family who are dealing with the end stages of a dying resident. Good communication and clear concise care planning regarding palliative care will reduce the likelihood of misinformed staff making allegations to the hotline. Documentation should support the goals of the interdisciplinary team and is a key component in dealing with this type of situation.

Ineffective systems to monitor and/or assure the plan of care is meeting the resident's needs in the area of pain management and symptom control. This issue, again, shows the need for the facility's leadership structure to adopt the hospice philosophy in assuring that pain management and symptom control is adequately addressed. Without this leadership, the coordination for quality end-of-life care will be haphazard and fragmented at best. Pain and symptom management in-service training are an integral part of caring for hospice residents. Due to LTC facilities high incidence of staff turnover, in-service training should be provided on an ongoing basis. A one-time in-service training by the hospice will not assure adequate pain management by the caregiver responsible for

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assessing and treating the resident's pain. The IDT should identify inadequate pain control or symptom relief, and will need to work together to determine the *cause* of the problem. Is inadequate pain control related to:

- staff's lack of knowledge in pain assessment,
- staff's attitude regarding narcotic administration,
- availability of the medication,
- inadequate physician orders for the treatment of the pain,
- resident's right to refuse treatment, or
- other causes, such as psychosocial, emotional or spiritual concerns?

If the facility staff identifies inadequate pain control or the pain escalates between hospice visits, the LTC staff should understand the process for changing pain medication orders. Sometimes, just knowing that the resident is on hospice and that the hospice provider should be consulted for pain management is an important communication obstacle that needs to be overcome.

Poor communication between the hospice and nursing home staff is probably the underlying cause of most of the problems discussed in regard to hospice in LTC facilities. Communication, leadership and accountability are the key factors in program development and implementation. When any of these factors are missing in either of the two providers, the results can be poor resident outcomes.

In summary, the LTC provider should have a clear philosophy and program designed to address the needs of the hospice residents. The hospice provider, resident/legal surrogate and the facility must work together to develop and implement an individualized plan of care for the resident. The means for accomplishing this objective is to communicate, communicate, and communicate.

Hospice Care in the Nursing Home Case Study

Mrs. Smith, Scenario II

Mrs. Smith has a diagnosis of metastatic cancer. She is currently receiving radiation therapy for treatment of a brain tumor. Her current functional status is ambulatory with a walker to the dining room for meals and to activities of her choice. She tires easily and becomes short of breath with ADLs requiring the direct care staff to provide limited assistance. She has fallen several times in the past. Her walking, standing, and sitting balance is good unless she rises too quickly. She denies pain during routine assessments. She has had several conversations about the prognosis and treatment options with her physician. Mrs. Smith's daughter lives across the country and is unable to visit frequently because of her own health problems. Mrs. Smith talked with her daughter about her prognosis and treatment options and the daughter supports her decisions. Mrs. Smith knows that her diagnosis is terminal but would like to have some time to return to her apartment to live independently. Mrs. Smith's physician is admitting her to the skilled nursing facility for care.

Upon admission to the skilled facility, the Social Service Designee (SSD) asked Mrs. Smith about advance directives for healthcare. Mrs. Smith provided her with a copy of her healthcare directives.

The RAI coordinator prepared for the initial care plan meeting. She talked with Mrs. Smith to determine her personal goals for treatment in the nursing home. The RAI coordinator asked Mrs. Smith: "what are you hoping will happen?" Her response was that she wanted to get through the radiation therapy **strong enough to return to her apartment**. The RAI coordinator talked with Mrs. Smith's physician to understand the goals for the nursing home stay. The Interdisciplinary Team, consisting of

Admitted to LTC for assistance with ADLs and symptom management due to radiation therapy.

Admission requirement to determine Advance Directive for Healthcare.

What is the resident's goal for care?

IDT meets and sets goals.

Mrs. Smith, Scenario II, continued

Mrs. Smith, the RAI Coordinator, the SSD, the physical therapist, the charge nurse on the unit where Mrs. Smith lives, and the nurse aide who cares for Mrs. Smith on the day shift, met to discuss the care she wants to receive and her goals for treatment. Since Mrs. Smith's goal was to be able to go back to her apartment and live independently after the radiation therapy, the RAI Coordinator developed a care plan using three types of goals in her care plan.

The first goal is to **maintain** her present abilities while increasing her conditioning; the second is to provide **rehabilitation** services to restore Mrs. Smith to an independent life style; and the third goal is the **prevention** of any further falls.

During the radiation therapy she was weak and fatigued most of the time. Therapists were scheduled to work with her three times a week for strength building activities. The nurse aides will assist her with her ADLs as needed but with the understanding that they will not do the activities for her unless she asks, even though she is slow, since rehabilitation is a goal. Finally, to accomplish the goal of preventing additional falls, the nurse aide will monitor her for balance and safety during all ADLs. The RAI coordinator has also asked for a hospice consult so that Mrs. Smith will understand the hospice benefit and feel comfortable electing it when her goals change from rehabilitation to palliative care. A hospice nurse explained the hospice benefit and answered Mrs. Smith's questions about payment. She also explained how hospice works with her doctor and Long Term Care Facility (LTC) team, and how hospice addresses comfort issues.

After radiation therapy Mrs. Smith was discharged back to her apartment. She was still able to ambulate and transfer independently with her walker. The hospice nurse came to her apartment and admitted her to hospice care. Mrs. Smith was still not having pain except for occasional evening headaches, relieved by one percocet. Mrs. Smith agreed to have the hospice SW visit her; she did not have a 24-hour caregiver and she knew that she would need to be placed back at the facility when she was no longer

Specific Goals:

- ❖ **Maintain** nutrition and ADL functioning
- ❖ **Rehabilitation** to strengthen her condition
- ❖ **Prevention** of falls

Hospice Consultation

Discharged to home

Hospice Admission

PRN Pain management for intermittent pain

RN, SW, HHA visits initiated

Mrs. Smith, Scenario II, continued

independently mobile. She agreed to have the aide visit and help with ADLs. She refused the chaplain, because she had frequent visits from her minister; and the volunteer, because she was sure there were others who would benefit more from the volunteer's services.

Mrs. Smith declined rapidly over the next several weeks. The hospice RN and SW were in frequent communication with Mrs. Smith's daughter. Mrs. Smith began to fall more frequently and was having difficulty getting out of bed. She developed a wound on her coccyx from sitting in her chair all day and she was also incontinent. She agreed to move to the LTC facility. The hospice SW coordinated the admission with the ECF SW, and also called the daughter to inform her and to assure her that the hospice team would be following her there. The hospice RN provided the LTC facility with an up-to-date medication list, hospice Plan of Treatment, and nursing care plans. Hospice notified the physician of admission to the LTC facility.

Upon admission, Mrs. Smith had increasing periods of confusion. She was restless at night in bed, and restless during the day in the chair. Over the next two weeks she had intermittent confusion and periods of extreme agitation. The nursing staff observed that her periods of agitation were relieved with prn pain medication, but also that they were occurring more frequently. The hospice nurse and LTC nurse reviewed Mrs. Smith's use of the prn pain medication together and its effects. The hospice nurse called the physician and a pain medication was ordered on a regular basis with pain meds for breakthrough pain as evidenced by increased agitation. A mild sedative was also ordered for increased agitation, and a stool softener to prevent constipation. Mrs. Smith still had periods of agitation. The LTC nurse and hospice nurse noticed that she relaxed more when they told her they had spoken with her daughter. The hospice nurse felt it might be beneficial for Mrs. Smith to have more support from the Hospice team. She contacted the daughter and received permission to have the hospice

Frequent communication with family regarding treatment decisions

Readmitted to LTC facility with Hospice involvement

Goal: Palliative Care
 Pain and symptom management
 Nutrition and hydration as able
 Emotional and spiritual support

SNF and Hospice Collaborate on Plan of Care

Nonverbal communication of pain exhibited by restlessness and agitation – treated by pain meds

Comfort meds added to Care Plan

Mrs. Smith, Scenario II, continued

Chaplain and a volunteer visit. The daughter agreed. During the chaplain's phone assessment with the daughter, she discovered that Mrs. Smith had also had an adult son who had died a few years ago. Mrs. Smith, her daughter explained, was never the same after his death, but she had found much comfort in reading the Psalms. Her daughter was also very surprised to discover that nobody had known about this son. She thought her mother would have shared that information. The hospice chaplain visited, read Psalms, and requested that the volunteer also read from this scripture. The chaplain also called Mrs. Smith's minister who began visiting more frequently.

Hospice Chaplain and Volunteer visits initiated for emotional and spiritual support

Within a few weeks Mrs. Smith slept more and began refusing to eat. The hospice nurse and social worker provided support and education to the staff that wanted to see Mrs. Smith eat more. The IDT team met to discuss the decreased need and desire for food as a part of the dying process. All staff were instructed to offer foods and fluids, but not to force, or give anything orally, to Mrs. Smith if she was not alert. The care plan was updated frequently because of Mrs. Smith's rapidly declining condition.

Hospice and SNF collaborate on nutrition issues

Care Plan continuously updated

The hospice social worker provided emotional support and guided the direct care staff in their efforts to meet Mrs. Smith's emotional needs. She discussed funeral arrangements with the daughter.

Funeral Arrangements made

Mrs. Smith's level of consciousness continued to change until she was unable to communicate verbally. Her breathing patterns changed and oxygen was ordered per nasal canula. Fluids were withheld and attention to mouth care was provided. The hospice social worker and nurse talked with Mrs. Smith's daughter about her deteriorating condition, supporting her by phone because of her inability to travel to be with her mother. The hospice nurse arranged for Mrs. Smith's daughter to talk to her mother the day

Continuous emotional support to patient and family

Mrs. Smith, Scenario II, continued	
<p>before she died. Her daughter was able to tell her that she loved her and say good-bye. Mrs. Smith seemed comfortable and died peacefully.</p>	<p>Peaceful death</p>
<p>The hospice bereavement coordinator called Mrs. Smith's daughter a few days after she died. She had been told by the hospice team to follow-up quickly since the daughter had been unable to be with her mother. The coordinator and Mrs. Smith's daughter developed a strong relationship over the phone, and this support continued with phone calls and mailings for 13 months after Mrs. Smith's death.</p>	<p>Bereavement follow-up for 13 months</p>

Integrated Plan of Care After Hospice Admission Mrs. Smith Scenario II					
Date	Problem/Need	Outcome/Goal	Intervention	Org.	Dis
6/14/01	Resident has terminal illness with prognosis of 6 months or less.	Resident will receive palliative care according to hospice philosophy.	Notify Hospice of any change in condition.	SNF	N
6/14/01		Resident/family will identify palliative care goals as relates to progression of disease.	Hospice IDT to provide services based upon the identified needs of the resident. Hospice on-call services available 24 hours, 7 days a week Hospice will be financially responsible for all medications related to the terminal condition. Hospice will furnish all supplies /equipment related to the terminal condition. SNF will provide room and board. Develop a coordinated care plan encourage resident/family participation.	H H H H SNF SNF/H SNF SNF/H	All All N N N All All All
6/14/01	Resident has right to execute advance directive.	Daughter will support resident's decision concerning End-of-Life care. Resident will communicate end-of-life care decisions to family and care providers.	Assess resident/daughter desires concerning end of life care. Encourage resident to review Power of Attorney for health care decisions with family and physician. Provide advance directives information and forms PRN	H-SNF H-SNF H	N/SW SW SW

*The regulation at F279 states, "The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables." A resident's condition often changes very frequently in the end states of life. The changing condition of the resident requires the facility to provide ongoing assessment. At times, the facility will be required to do weekly, daily, or hourly reassessments.

Section 6.0 Hospice Care in the Nursing Home

Subsection 6.20 Sample Integrated Plan of Care After Hospice Admission

Date	Problem/Need	Outcome/Goal	Intervention	Org.	Dis
	Resident has right to execute advance directive (cont.)		Ensure that physician/family/facility have copies of advance directives.	H	SW
6/14/01	Risk of falls, R/T, SOB, weakness	Will decrease the number of falls. *Timeframe: ongoing	Evaluate/provide DME Assist with transfers/ambulation based on the evaluated needs of the resident at the time Aide to assist with ADL Bath Review the Fall RAP Call bell within reach	H/SNF H/SNF H/SNF-2X per week. H/SNF	N All N All
6/14/01	Resident is experiencing loss of autonomy and control.	Maximize independence in the performance of self-care activities by allowing the resident to perform ADLs while staff monitor for SOB and fatigue. *Timeline: ongoing	Allow resident to perform personal care activities as tolerated. Encourage resident to participate in activities of choice. Provide opportunities for resident / daughter to communicate via telephone. Assess and address all spiritual and emotional needs.	SNF/H SNF/H SNF/H H	All N All SW / Chap
6/14/01	Potential for alteration in skin integrity R/T; immobility, disease process, poor nutritional intake.	Resident's skin will be maintained at optimal integrity Resident will report comfort. *Timeframe: ongoing	Assess skin condition for open areas, s/s infection weekly by licensed nurse. Turn Q 2 hrs by resident or staff. Assess skin condition each shift/visit by CNA and report. Document and monitor any change. Provide pressure-relieving devices for chair and bed as needed. Cleanse promptly after incontinence. Keep linens dry and wrinkle free.	H/SNF H/SNF H/SNF	N N N

Section 6.0 Hospice Care in the Nursing Home
 Subsection 6.20 Sample Integrated Plan of Care After Hospice Admission

Date	Problem/Need	Outcome/Goal	Intervention	Org.	Dis
9/10/01	Resident has stage II decubitus, ulcer on coccyx R/T immobility and disease process.	Stage II pressure sore will remain free of infection. *Timeframe: ongoing	RN to reevaluate appropriate pressure relieving device. Provide APP mattress Dressing changes q 4 days and PRN Cleanse wound with NS, pat dry, apply Duoderm, initial and date patch. Check to see if dressing is dry and intact daily.	H H <u>H-Mon.</u> <u>Wed Fri</u> <u>SNF-Sun.</u> <u>Tues. Sat.</u> <u>& prn</u> H-q visit SNF-daily	N N N N
6/14/01 6/30/01	Altered Emotional /Spiritual and Coping Skills	Resident/family and caregiver will experience effective coping skills.	Assess emotional and spiritual needs of patient/family and/or caregiver. Assess patient/family prior history of communication and coping skills. Encourage patient /family/care-giver communication and coping skills. Provide emotional support by being empathetic, listening, validating feelings and providing direction to help alleviate emotional stressors. Initiate chaplain and volunteer visits to read psalms and provide	SNF/H SNF/H SNF/H SNF/H H	SW/Chap SW/Chap All All Chap Vol

Section 6.0 Hospice Care in the Nursing Home
 Subsection 6.20 Sample Integrated Plan of Care After Hospice Admission

Date	Problem/Need	Outcome/Goal	Intervention	Org.	Dis
	Altered Emotional /Spiritual and Coping Skills (continued)		emotional and spiritual support. Communicate as needed with family minister per consent of patient.		
6/14/01	Alteration in nutrition related to disease process	Resident will be in control of what, how much, and when to eat. Family will verbalize understanding of anorexia and cachexia in terminally ill. Symptoms of anorexia/cachexia will be managed. *Timeframe: ongoing	Assess resident's food preferences and provide PRN. Instruct family and caregivers on role of decreased nutritional / fluid intake in dying residents. Monthly weights Mouth care q 4 hours and PRN Offer food and fluids PRN. Discontinue monthly weights.	SNF/H H SNF/H SNF/H SNF	Diet N N N Diet/N
9/6/01					
6/26/01	Resident in pain, R/T dx, of metastatic ca.	Resident will report that pain is reduced to her relief goals. Resident's family will verbalize understanding of resident's pain management plan. *Timeframe: ongoing	Instruct resident/family on causes of pain in terminally ill. Develop pain management plan inclusive of resident's goals and communicate to all disciplines. Perform ongoing pain assessment, utilizing pain rating scale with medication passes and prn. Document on the MAR. Administer medications and adjust per physician orders. Initiate bowel regimen and instruct resident/caregivers. Monitor pain medication and make recommendation for changes PRN	H SNF/H SNF/H SNF/H SNF/H SNF/H	N N N N N N

Section 6.0 Hospice Care in the Nursing Home
 Subsection 6.20 Sample Integrated Plan of Care After Hospice Admission

Date	Problem/Need	Outcome/Goal	Intervention	Org.	Dis
6/26/01	Resident has increased confusion and agitation.	Resident's agitation will be controlled within patient's/family's stated goal. *Timeframes: ongoing	Administer mild sedative per physician's order and monitor side effects. Monitor sedative use and make recommendations PRN	SNF/H SNF/H	N N
6/26/01	Impaired Bowel/Bladder Function	Resident will achieve and maintain optimal elimination function. *Timeframe: ongoing	Assess needs of resident re; urinary and bowel function. Assess need for foley catheter. Assess for signs and symptoms of urinary retention, constipation, and diarrhea. Obtain order and administer medications as needed for bowel/bladder dysfunction Monitor for s/s skin breakdown secondary to incontinence. Provide incontinent garments as needed.	SNF/H SNF/H SNF/H SNF/H SNF/H	N N N
/10/01	Potential for alteration in respiratory status related to progression of illness.	Resident dyspnea will be controlled within resident/daughter's stated palliative care goal. *Timeframe: ongoing	Assess respiratory status O 2- per nasal canula PRN HOB up to 45° to maximize respiratory capacity. Provide medication as ordered by physician. Family will be instructed on use of O2 for comfort and updated on changing needs.	SNF/H SNF/H SNF/H SNF/H H	N N N N N

END OF LIFE CARE FOR RESIDENTS IN NURSING FACILITIES

HOSPICE CARE IN THE NURSING HOME

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END OF LIFE CARE FOR RESIDENTS IN NURSING FACILITIES

ADR	adverse drug reaction
ADL	activity of daily living
AIDS	Acquired Immune Deficiency Syndrome
ALS	Amyotrophic Lateral Sclerosis (Lou Gehrig's disease)
AMA	American Medical Association
ATC	around the clock
CFR	Code of Federal Regulations
CMS	Centers for Medicare and Medicaid Services
CNA	certified nurse aide
CSR	Code of State Regulations
CPR	cardiopulmonary resuscitation
DME	durable medical equipment
DON	director of nurses
DPAHC	durable power of attorney for health care
DPOA	durable power of attorney
ECF	extended care facility
EOL	end of life
ER	emergency room
GI	gastrointestinal
HIV	Human Immunodeficiency Virus
HOB	head of bed
IDT	Interdisciplinary Team
LMRP	Local Medical Review Policy
LPN	licensed practical nurse
LTC	long-term care
MDS	Minimum Data Set
NA	nurse assistant/aide
NSAIDS	nonsteroidal anti-inflammatory drugs
OT	occupational therapy
POC	plan of care
PT	physical therapy
RAI	Resident Assessment Instrument
RAP	Resident Assessment Protocol
RD	registered dietician
RN	registered nurse
SLTC	Section for Long Term Care
SNF	skilled nursing facility
SOM	State Operations Manual
SSD	social service designee
ST	speech therapy
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments
WHO	World Health Organization

END OF LIFE CARE FOR RESIDENTS IN NURSING FACILITIES

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Activities of Daily Living: Basic personal activities, such as, bathing, eating, dressing, mobility, transferring from bed to chair, and using the toilet. ADLs are used to measure how dependent a person may be on requiring assistance in performing any or all of these activities.

Advance care planning: The process of identifying the resident's personal preferences and values, which, in conjunction with his or her current and anticipated medical status and goals, provide the basis for making decisions about end-or-life care.

Advance directive: This term may refer to any direction made before an individual loses decisional capacity regarding his or her healthcare treatment wishes. Written advance directives may include living wills, healthcare treatment directives, and durable powers of attorney for healthcare.

Assessment: Determination of a resident's care needs, based on a formal, structured evaluation of the resident's physical and psychological condition and ability to perform activities of daily living.

Care planning: The process used for each resident that includes measurable objectives, and timetables to meet a resident's medical, nursing, mental, and psychosocial needs identified in the comprehensive assessment. The care plan must describe the services that are to be furnished to attain or maintain the resident's highest practicable physical, mental and psychosocial well-being and any services that would otherwise be required but not provided because of the resident's exercise of rights to refuse treatment.

Chronic Disease: A disease that is permanent, or leaves residual disability, or is caused by nonreversible pathological alteration.

Centers for Medicare and Medicaid Services (CMS): The federal agency that runs the Medicare program. In addition, CMS works with the states to run the Medicaid program. CMS works to ensure that the beneficiaries in these programs get high quality healthcare.

Cognitive Impairment: A breakdown in a person's mental state that may affect a person's moods, fears, anxieties, and ability to think clearly. A diminished mental capacity, such as difficulty with short-term memory.

Deficiency: A finding that a nursing home has failed to meet one or more federal or state requirements.

Dehydration: A condition in which the body's loss of fluid is more than the body's intake of fluid.

Dementia: A progressive mental disorder that affects memory, judgment, and cognitive powers. One type of dementia is Alzheimer's disease.

Durable Medical Equipment: Equipment such as hospital beds, wheelchairs, and prosthetics used at home. DME may be covered by Medicaid and in part by Medicare or private insurance, and is also called home medical equipment.

Durable Power of Attorney for Health Care (DPAHC, sometimes DPOA): A legal document in which a competent person gives another person (called an attorney-in-fact) the power to make healthcare decisions, if he or she is unable to make those decisions. A DPAHC may include guidelines for the attorney-in-fact to follow in making decisions on behalf of the incompetent person.

Hospice Care: Services for the terminally ill that may be provided in the home, hospital, or long-term care facility. Hospice care includes home health services, volunteer support, grief counseling, and pain management.

Hydration: The level of fluid in the body. The loss of fluid, or dehydration, occurs when the body loses more water or fluid than it takes in. A body cannot maintain adequate blood pressure, get enough oxygen and nutrients to the cells, or rid itself of wastes if it has too little fluid.

Interdisciplinary team: A number of people working together, sharing information. Patient care IDTs are comprised of the resident, physician, social worker, nursing assistants, activities director, dietitians, and nurses. In hospice care, the team members are the nurse, aide, social worker, chaplain, and medical director.

Long-Term Care: A range of medical and social services designed to help people who have disabilities or chronic care needs. Services may be short- or long-term and may be provided in a person's home, in the community, or in residential facilities (e.g., nursing homes or residential care facilities).

Maintenance: Medical, nursing and support services aimed at helping a resident maintain his or her existing level of functioning, when rehabilitation interventions are no longer possible or desired. A maintenance goal of care requires regular assessment of the resident's medical status and personal preferences to ensure that the burdens of treatment do not outweigh the benefits.

Minimum Data Set (MDS): A core set of screening and assessment elements, including common definitions and coding categories, which forms the foundation for a comprehensive assessment of all patients of long-term care facilities certified to participate in Medicare and Medicaid. The items standardize communication about patient problems and conditions within facilities and between facilities and outside agencies.

Medicaid: Federal- and state-funded program of medical assistance to low-income individuals of all ages. Medicaid has income eligibility requirements.

Medicare: Federal health insurance program for persons age 65 and over (and certain disabled persons under age 65). Medicare consists of two parts: Part A (hospital insurance) and Part B (optional medical insurance which covers physicians' services and outpatient care in part, and which requires beneficiaries to pay a monthly premium).

Neglect: When caregivers do not give the person they care for all the goods or services they need to avoid harm or illness.

Nutrition: Eating enough of the right foods with vitamins and minerals to keep a body healthy. Malnutrition, or the lack of proper nutrition, can be a serious problem for older people.

Ombudsman: The Ombudsman Program is a public/government/community-supported program that advocates for the rights of all residents in twenty-four-hour long-term care facilities. Volunteers visit local facilities weekly, monitor conditions of care, and try to resolve problems involving meals, finances, medication, therapy, placements, and communication with the staff.

Palliative: Medical, nursing, and support services aimed at ensuring maximum comfort and dignity during the last stages of life. The emphasis is on controlling pain, relieving symptoms, and preserving support for the resident and family.

Prevention: Taking action to hinder the development of disease or injury.

Prognosis: The projected outcome of a disease; a person's life expectancy.

Provider: Professionals or agents of a facility who are authorized by law to provide healthcare.

Psychosocial care: Care that encompasses cognitive function and emotional health.

Quality of Care: A measure of the degree to which delivered health services meet established professional standards and judgments of consumer value.

Rehabilitation: The processes of treatment and education that help a disabled individual attain maximum functioning, a sense of well being, and a satisfying level of independence. The combined efforts of the resident, his or her family, friends and all medical, nursing, and allied health personnel and community resources are necessary to make rehabilitation possible.

Respite care: Service in which trained professionals or volunteers provide short-term care for an older person (in the home, from a few hours to a few days) so that a person's primary caregivers may have some time away from their caregiving role.

Restraint: Any manual method or physical or mechanical device, material, or equipment attached or adjacent to the resident's body, which the resident cannot easily remove, that restricts freedom of movement or normal access to one's body. Chemical restraint is defined as any drug that is used for discipline or convenience and not required to treat medical symptoms.

Skilled Nursing Facility: A facility certified by Medicare to provide twenty-four-hour nursing care and rehabilitation services in addition to other medical services. Missouri's licensure definition at RSMo198.006(17) states:

“a skilled nursing facility is any premises, other than a residential care facility I, a residential care facility II, or an intermediate care facility, which is utilized by its owner, operator or manager to provide for twenty-four hour accommodation, board and skilled nursing care and treatment services to at least three residents who are not related within the fourth degree of consanguinity or affinity to the owner, operator or manager of the facility. Skilled nursing care and treatment services are those services commonly performed by or under the supervision of a registered professional nurse for individuals requiring twenty four hours a day care by licensed nursing personnel including acts of observation, care and counsel of the aged, ill, injured or infirm, the administration of medications and treatments as prescribed by a licensed physician or dentist, and other nursing functions requiring substantial specialized judgment and skill.”

Surrogate: An agent who acts on behalf of a resident who lacks decisional capacity to participate in a particular decision; an appropriate surrogate may be

- designated by the resident (e.g., in a durable power of attorney for healthcare);
- the adult who is most involved with the resident and most knowledgeable about the resident's personal values and preferences; or one designated by a court (e.g., a guardian).

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WATCH FOR SIGNS	REPORT AND TAKE ACTION
Loss of Appetite	Loss of Appetite
<ul style="list-style-type: none"> • The resident turns away from food • The resident pushes food away • Making a face at the food • Loss of weight • Wasting away of muscle mass • Weakness • Watch for dental problems 	<ul style="list-style-type: none"> • Offer small frequent feedings • Feed meals high in calories and protein • Avoid fluid intake with meals to prevent feeling full • Involve the resident in menu planning • Have foods available whenever resident is hungry • Use smaller dinner plates for smaller helpings • Have the resident dress for meals and sit at the table • Avoid strong smells at mealtime • Record the intake of food and fluids • Ask the resident what would make mealtime more pleasant • Report to nurse • Use Aromatherapy (vanilla, cinnamon, homemade bread)

**GASTROINTESTINAL SYMPTOM MANAGEMENT/
CARE PLAN INTERVENTIONS**
for the Nurse Aide and Interdisciplinary Team

WATCH FOR SIGNS	REPORT AND TAKE ACTION
Dry Mouth	Dry Mouth
<ul style="list-style-type: none"> • Cracks in the side of the mouth • Tongue is dry and cracked with deep furrows • Occurs frequently with mouth breathing 	<ul style="list-style-type: none"> • Brush teeth, gums and tongue • Rinse the mouth with water or diluted mouthwash • Use a mouthwash <i>without</i> alcohol • Offer ice chips, sips of fluids, or popsicles every one-to-two hours, • Use a wet wash cloth to moisten the mouth • Apply Vaseline or lip balm to the lips several times daily • Use saliva substitutes • Serve moist foods with added gravies or sauces

WATCH FOR SIGNS	REPORT AND TAKE ACTION
Sore Throat and Mouth	Sore Throat and Mouth
<ul style="list-style-type: none"> • Verbal or facial expression of pain by the resident in his/her mouth or throat • Verbal or facial expression of pain when swallowing 	<ul style="list-style-type: none"> • Report the change in mouth and throat to charge nurse • Offer soft cool foods • Avoid spicy, acidic, hard or crunchy foods <p>Apply Vaseline or lip balm Use lots of liquids</p>

WATCH FOR SIGNS	REPORT AND TAKE ACTION
<p style="text-align: center;">Taste and Smell Changes</p>	<p style="text-align: center;">Taste and Smell Changes</p>
<ul style="list-style-type: none"> • Resident says “nothing tastes good” • Resident says odors bother him or her • Resident “makes a face” when food is served 	<ul style="list-style-type: none"> • Ask the resident if the food or liquid tastes O.K. • If odors bother the caregiver, assume that odors are also bothering the resident • Avoid foods with offensive odors (cabbage) • Remove any lid from the plate prior to serving food • Offer cold or room temperature foods • Provide good oral hygiene frequently throughout the day and night • Do not expose the resident to food odors during preparation • Remove the food tray when finished

WATCH FOR SIGNS	REPORT AND TAKE ACTION
<p style="text-align: center;">Bloating</p>	<p style="text-align: center;">Bloating</p>
<ul style="list-style-type: none"> • Complaints from the resident about feeling bloated 	<ul style="list-style-type: none"> • Report any complaint of bloating to the charge nurse • Monitor bowel movements • Provide small frequent feedings • Avoid carbonated beverages and gas-producing foods

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WATCH FOR SIGNS	REPORT AND TAKE ACTION
Nausea and Vomiting	Nausea and Vomiting
<ul style="list-style-type: none"> • Emesis • Dry heaves • Belching • Reports by the resident of being “sick at my stomach” 	<ul style="list-style-type: none"> • Report any nausea and vomiting to the charge nurse • Avoid physical activity after eating • Avoid foods likely to aggravate nausea such as fatty, greasy, and sweet foods, or foods with strong odors • Avoid eating or talking about food in front of the resident • Provide six small frequent feedings once nausea is controlled • Offer clear, cool beverages and carbonated drinks • Offer dry foods (toast, crackers) • Do not put the resident to bed immediately after he or she has eaten • Monitor constipation, which can increase nausea and vomiting • Apply cool wash cloth to forehead and back of neck to ease distress

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WATCH FOR SIGNS	REPORT AND TAKE ACTION
Diarrhea	Diarrhea
<ul style="list-style-type: none"> • Soft or liquid fecal material 	<ul style="list-style-type: none"> • Report the frequency and description of feces to the charge nurse as the resident's skin may breakdown quickly in the presence of diarrhea • Avoid foods that cause diarrhea • Check for incontinence and clean skin immediately after an incontinence episode • Check for fecal impaction with overflow incontinence • Use barrier creams as directed
WATCH FOR SIGNS	REPORT AND TAKE ACTION
Constipation	Constipation
<ul style="list-style-type: none"> • Formed or hard fecal material • Hard fecal material with liquid fecal material 	<ul style="list-style-type: none"> • Report to the charge nurse any hard formed stool or straining to pass fecal material • Chart the frequency of bowel movements • Increase dietary fiber as tolerated • Increase fluid intake to 2-to-3 liters a day, as tolerated • Increase physical activity

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WATCH FOR SIGNS	REPORT AND TAKE ACTION
Swallowing Problems	Swallowing Problems
<ul style="list-style-type: none"> • Drooling • Coughing after liquids • Holding food in mouth for long periods of time before swallowing • Pocketing food in the side of the mouth • Spitting food out • Pushing the hand of the caregiver away 	<ul style="list-style-type: none"> • Report swallowing problems and/or changes to the charge nurse • Increase supervision and cueing at meals • Provide frequent small feedings • Moisten food with sauces: avoid dry food • Cut food into small pieces • Avoid sticky foods, such as soft breads • Sit the resident upright to eat • “Chin tuck”: remind the resident to tuck his or her chin down toward the sternum or position the resident so the chin is down • Encourage the resident to chew carefully • Watch the resident swallow before offering another bite • Follow the speech therapist’s recommendations • Provide oversight and monitoring by licensed staff • Provide training for all staff involved in assisting residents with food and liquids

**GENERAL SYMPTOM
MANAGEMENT/CARE PLAN INTERVENTIONS
for Nurse Aide and Interdisciplinary Team**

WATCH FOR SIGNS	TAKE ACTION
Anxiety	Anxiety
<ul style="list-style-type: none"> • Sad, pained, worried facial expressions • Furrowed brows • Crying, tearfulness • Repetitive physical movements <ul style="list-style-type: none"> ◆ Pacing ◆ Hand wringing ◆ Restlessness ◆ Fidgeting ◆ Picking • Agitation • Short tempered 	<ul style="list-style-type: none"> • Report all symptoms of anxiety to the charge nurse • Determine whether fear, pain, or air hunger is present • Decrease stimulation and demands • Use music, relaxation tapes, or guided imagery • Talk with, listen to, and sit by the resident • Provide aromatherapy

WATCH FOR SIGNS	TAKE ACTION
Hiccups	Hiccups
<ul style="list-style-type: none"> • Hiccups 	<ul style="list-style-type: none"> • Report hiccups to the charge nurse • Have resident swallow two teaspoons of sugar • Provide ice water • Give the resident a swallow of crushed ice • Use a rebreathing bag or mask

**GENERAL SYMPTOM
MANAGEMENT/CARE PLAN INTERVENTIONS**
for Nurse Aide and Interdisciplinary Team

WATCH FOR SIGNS	TAKE ACTION
Cough	Cough
<ul style="list-style-type: none"> • Cough • Cough with sputum • Cough without sputum • Cough with shortness of breath • Cough without shortness of breath 	<ul style="list-style-type: none"> • Report all coughs to the charge nurse • Determine whether environmental factors may be causing the cough <ul style="list-style-type: none"> ◆ Dry air ◆ Cool drafts ◆ Cigarette smoke • Determine other possible causes of the cough <ul style="list-style-type: none"> ◆ Milk products ◆ Cold liquids • Provide Cough drops • Humidify the room air • Count respirations for one minute and report to charge nurse • Take and report the resident's vital signs: Blood Pressure, Pulse, and Temperature

Appendices GENERAL SYMPTOM MANAGEMENT/CARE PLAN INTERVENTIONS for Nurse Aide and Interdisciplinary Team	Page 3 of 5
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WATCH FOR SIGNS	TAKE ACTION
Depression	Depression
<ul style="list-style-type: none"> • Verbal expressions of distress • Resident makes negative statements <ul style="list-style-type: none"> ◆ Nothing matters. ◆ What’s the use? ◆ Where do I go? ◆ God help me. ◆ I am nothing. ◆ I am of no use to anyone. • Anger with self or others • Fear of being left alone • Agitation • Withdrawal • Weight loss • Not awake most of the day 	<ul style="list-style-type: none"> • Report distress to the charge nurse • Spend time with the resident • Answer questions honestly • Be sensitive and caring • Engage in meaningful activities • Allow the resident to cry

**GENERAL SYMPTOM
MANAGEMENT/CARE PLAN INTERVENTIONS**
for Nurse Aide and Interdisciplinary Team

WATCH FOR SIGNS	TAKE ACTION
Shortness of Breath	Shortness of Breath
<ul style="list-style-type: none"> • Rapid breathing • Gaspings breaths • Unable to lie flat in bed • Short of breath with minimal exertion • Abrupt change in behavior — agitation 	<ul style="list-style-type: none"> • Report breathing problems to the charge nurse • Take vital signs • Get an accurate respiratory rate (assess for one minute) • Assist resident with activities that cause shortness of breath • Alternate an activity with a rest • Position the resident for the most comfortable breathing • Sit the resident in an upright position • Support resident’s arms on pillows • Encourage relaxation • Use a gentle voice and gentle touching • Guide the resident in slow, deep breaths • Keep the room cool • Use a fan if resident desires • Sit with, and reassure the resident • Provide oxygen as ordered • Minimize exertion with all ADLs

Appendices GENERAL SYMPTOM MANAGEMENT/CARE PLAN INTERVENTIONS for Nurse Aide and Interdisciplinary Team	Page 5 of 5
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WATCH FOR SIGNS	TAKE ACTION
Odor	Odor
<ul style="list-style-type: none"> Recognize unpleasant odors 	<ul style="list-style-type: none"> Report odors to the charge nurse Determine the cause of the odors Use room deodorizer Provide sponge baths as often as needed to control the odor Change linens as often as needed Cleanse the resident and change linens immediately after incontinence Remove soiled linen from resident areas Report any efforts to control odors that are not effective

END OF LIFE CARE FOR RESIDENTS IN NURSING FACILITIES

IMMINENT DEATH/CARE PLAN INTERVENTIONS

If patient has hospice care and develops these signs, call hospice immediately!

WATCH FOR SIGNS	REPORT AND TAKE ACTION
<p style="text-align: center;">Respiratory Changes</p>	<p style="text-align: center;">Respiratory Changes</p>
<ul style="list-style-type: none"> • Labored breathing • Changes in breathing pattern (e.g., cheyne stoke, apnea) • Rapid respirations • Lung congestion • “Death Rattle,” or sounds of fluid accumulating • Low oxygen levels in the blood, which may cause confusion, irritability, sense of impending doom, fear, or anxiety 	<ul style="list-style-type: none"> • Provide oxygen 2 to 5L prn • Raise HOB as tolerated • Educate family/caregiver in changes expected, hydration issues, and dying process • Discuss benefits and consequences of decreasing/ discontinuing tube feeding • Obtain order for comfort • Provide reassuring, calm presence • Turn the resident’s head or position on side to drain secretions • Decrease feelings of shortness of breath with cool cloths, fan, or open window

IMMINENT DEATH/CARE PLAN INTERVENTIONS

If patient has hospice care and develops these signs, call hospice immediately!

WATCH FOR SIGNS	REPORT AND TAKE ACTION
<p align="center">Changes in Level of Consciousness</p>	<p align="center">Changes in Level of Consciousness</p>
<ul style="list-style-type: none"> • Loss of ability to swallow • Loss of ability to communicate • Terminal restlessness • Vision may become blurred • Eyes may become glassy, with a distant look • Hearing may become more acute • Levels of consciousness may vary widely • Fatigue and sleep may increase; coma may occur • The resident may <ul style="list-style-type: none"> ◆ Be confused about familiar people ◆ Say things that seem strange ◆ Pick at the air or bed covers ◆ Have muscle twitching in extremities ◆ See and talk with deceased people ◆ Ask for help 	<ul style="list-style-type: none"> • Obtain appropriate doctor’s orders especially regarding medications to keep patient as comfortable as possible • Discontinue diet • Discontinue oral meds • Oral care q___hr • Speak to patient as if she or he were aware • Speak directly to the dying person, even if he or she makes no response • Try to make a connection with the resident’s words • Touch the resident gently and remain present • Provide a calm atmosphere with minimal stimulation • Use artificial tears if the resident’s eyes are partially open • Support patient/family/caregiver by constantly reassuring and educating them in the dying process • Explain to the resident what is happening prior to any procedure

IMMINENT DEATH/CARE PLAN INTERVENTIONS

If patient has hospice care and develops these signs, call hospice immediately!

WATCH FOR SIGNS	REPORT AND TAKE ACTION
Circulation Changes	Circulation Changes
<ul style="list-style-type: none"> • Decreased Cardiac output • Hypotension • Increased pulse • Decreased pulse • Weaker and irregular pulse • Decreased urine • Lips, nailbeds, earlobes and fingers may look bluish • Extremities may become ashen, cool, and mottled 	<ul style="list-style-type: none"> • Complete bedrest • Educate family regarding normal expectations: signs and symptoms (S/S) of death may come and go • Keep the resident warm, but avoid electric or heavy blankets • Give cool sponge bath and/or acetaminophen if the resident is restless with fever
WATCH FOR SIGNS	REPORT AND TAKE ACTION
Family Support	Family Support
<ul style="list-style-type: none"> • Grieving emotions • Need to say good-bye • Need to know when loved one is likely to die • Unsure whether to stay or go 	<ul style="list-style-type: none"> • Educate and support family in their stages of grief • Reassure family/caregiver/ staff not to take displaced emotions personally • Help and support family to say good-bye to patient, and to reassure patient that those left behind will be okay • Educate family/caregiver regarding terminal S/S

IMMINENT DEATH/CARE PLAN INTERVENTIONS

If patient has hospice care and develops these signs, call hospice immediately!

WATCH FOR SIGNS	REPORT AND TAKE ACTION
<p style="text-align: center;">Psychosocial Changes</p> <ul style="list-style-type: none"> • Withdrawal • Wishes to complete unfinished business • Resists dying because of concern for a family member • Begins to see those, usually family members, who have died • Talks about seeing bright lights, peace, or God • Removes clothing • Seems fearful of unknown • Becomes sad at leaving loved ones behind • Requests confession or other rituals • Chooses time of death (e.g., after arrival of a grandbaby) 	<p style="text-align: center;">Psychosocial Changes</p> <ul style="list-style-type: none"> • Use gentle, soft voice and touch • Allow and encourage the resident and family to share experiences • Do not try to bring patient back to reality unless patient appears frightened or upset • Encourage the family to give the resident permission to let go • Encourage family members to talk to the resident even when there is no response • Explain to family members and the resident that tears are O.K. • Ask about important religious rites and arrange clergy as desired • Be willing to pray, read scripture, or play music if the resident desires • Do not impose your beliefs or interpretations on the resident or family

Appendices IMMINENT DEATH/CARE PLAN INTERVENTIONS for the Nurse Aide	Page 1 of 2
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WATCH FOR SIGNS	REPORT AND TAKE ACTION
<p style="text-align: center;">Respiratory Changes</p> <ul style="list-style-type: none"> • Labored breathing • Changes in breathing pattern (e.g., Cheyne Stoke, apnea) • Rapid respirations • Lung congestion 	<p style="text-align: center;">Respiratory Changes</p> <ul style="list-style-type: none"> • Raise HOB as tolerated <p>Report symptoms to charge nurse</p>
WATCH FOR SIGNS	REPORT AND TAKE ACTION
<p style="text-align: center;">Change in Level of Consciousness</p> <ul style="list-style-type: none"> • Loss of ability to swallow • Loss of ability to communicate • Terminal restlessness 	<p style="text-align: center;">Changes in Level of Consciousness</p> <ul style="list-style-type: none"> • Do not attempt to feed patient or give fluids if he or she is not alert enough to swallow • Oral care q _____ hr • Speak to patient as if he or she were aware • Support patient/family/caregiver by constantly reassuring and educating them in the dying process

WATCH FOR SIGNS	REPORT AND TAKE ACTION
Circulation Changes	Circulation Changes
<ul style="list-style-type: none"> • Decreased blood flow • Low blood pressure • Increased pulse • Decreased pulse • Mottling • Decreased urine • Bluish coloring of lips and extremities 	<ul style="list-style-type: none"> • Complete bedrest • Educate family regarding normal expectations: Signs and symptoms (S/S) of death may come and go.

WATCH FOR SIGNS	REPORT AND TAKE ACTION
Family Support	Family Support
<ul style="list-style-type: none"> • Grieving emotions • Need to say good-bye • Need to know when loved one is likely to die • Unsure whether to stay or go 	<ul style="list-style-type: none"> • Remember it is okay to show emotions in front of the resident and family and healing to reminisce about happier times • Reassure family/caregiver/staff not to take displaced emotions personally • Help and support family to say good-bye to patient and reassure patient that those left behind will be okay • Check with RN to see if religious rites have been requested

WATCH FOR SIGNS	REPORT AND TAKE ACTION
Pain/Discomfort	Look!
<ul style="list-style-type: none"> • Moans • Grimaces • Poor appetite • Withdrawal • Guarding, holding parts of the body • Refusing activity • Complaints of pain • Restlessness 	<ul style="list-style-type: none"> • Look for what triggers the pain, for example, moving, touching the painful area, meals, family visits, voiding or bowel movements • Look for external causes, for example, wet briefs, clothes too tight, wheelchair or brace not fitting correctly
	Report!
	<ul style="list-style-type: none"> • Report signs of pain to your charge nurse • Report unswallowed pills (the pills could be pain medicine, or a cause of discomfort) and report any dislodged analgesic patch
	Action!
	<ul style="list-style-type: none"> • Offer reassurance; explain that you will report the pain. Let the resident know you believe the pain and that you care • Reposition the resident to relieve the affected area • Communicate with your team about what works best for the resident • Make the resident comfortable in other ways, for example, provide dry clothes, fresh water, low noise, soft music

END OF LIFE CARE FOR RESIDENTS IN NURSING FACILITIES

Appendices PAIN ASSESSMENT Questions about Pain to be included in the Routine Nursing Admission Assessment	Page 1 of 1
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Questions About Pain to be included in the Routine Nursing Admission Assessment
Do you have any ongoing pain problems? Yes No
Do you have pain now? Yes No
If yes to either of the above: Location of pain: _____ (body figure drawing similar to the one in Forms 3.1 may be included in the assessment form to mark the location of pain)
Pain intensity on a scale of 0 to 10: Now: _____ _____
What, if any, medications do you take for pain relief? _____ _____
What, if any, other treatment do you receive for your pain? _____ _____
Is your pain satisfactorily controlled now? _____
Note: If a pain problem is identified and is not under satisfactory control, completion of a more comprehensive pain assessment tool, such as Forms 3.1 or 3.2 may be indicated.

This form may be duplicated for use in clinical practice. From M. McCaffery and C Pasero. 1999. *Pain: Clinical Manual*, Mosby, Inc., p. 59.

Initial Pain Assessment Tool

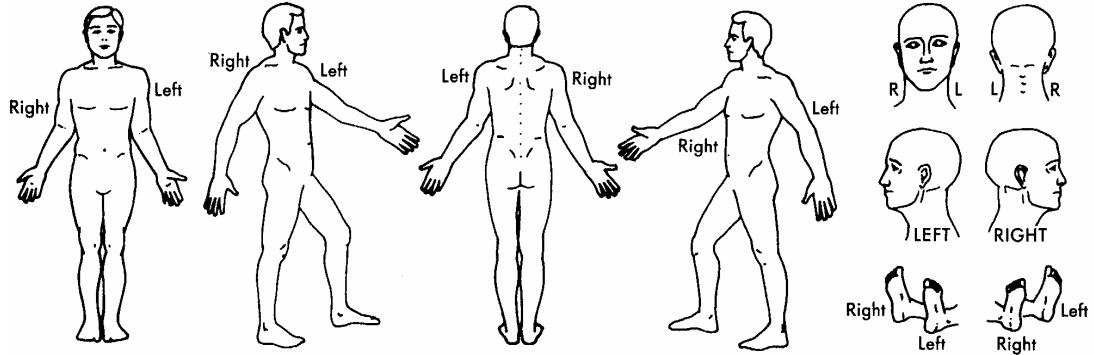
Date: _____

Patient's Name: _____ Age: _____ Room: _____

Diagnosis: _____ Physician: _____

Nurse: _____

1. LOCATION: patient or nurse mark drawing:



2. INTENSITY: Patient rates the pain. Scale used _____

Present: _____

Worst pain gets: _____

Best pain gets: _____

Acceptable level of pain: _____

3. QUALITY: (Use patient's own words, e.g., prick, ache, burn, throb, pull, sharp) _____

4. ONSET, DURATION, VARIATIONS, RYTHMS: _____

5. MANNER OF EXPRESSING PAIN: _____

6. WHAT RELIEVES THE PAIN? _____

7. WHAT CAUSES OR INCREASES THE PAIN? _____

8. EFFECTS OF PAIN: (Note decreased function, decreased quality of life)

Accompanying symptoms (e.g., nausea) _____

Sleep _____

Appetite _____

Physical Activity _____

Relationship with others (e.g., irritability) _____

Emotions (e.g., anger, suicidal, crying) _____

Concentration _____

Other _____

9. OTHER COMMENTS: _____

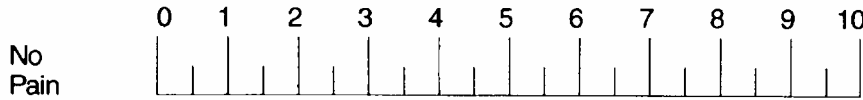
10. PLAN: _____

PAIN ASSESSMENT FORM

1. Intensity:

NURSE: _____
 PATIENT: _____
 DATE: _____

PAIN SCALE



Worst Pain Imaginable

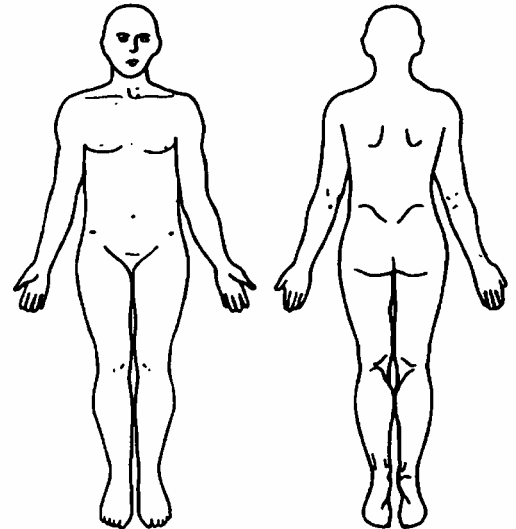
Pain Rating _____ mm

2. Where is your pain located? (I = Internal)
 Patient or Nurse mark drawing. (E = External)

3. How and when did your pain begin?
 Does something trigger your pain?

4. How long have you had the pain?
 Is it continuous or intermittent?
 Describe any patterns or changes.

5. Describe in your own words what your pain feels like: _____



6. What makes the pain better? _____

7. What makes the pain worse? _____

8. What has helped in the past? _____

9. What has not helped in the past? _____

10. What other symptoms accompany your pain? _____

11. How does your pain affect your: _____
 Sleep? _____
 Appetite? _____
 Physical activity? _____
 Concentration? _____
 Emotions? _____
 Social relationships? _____

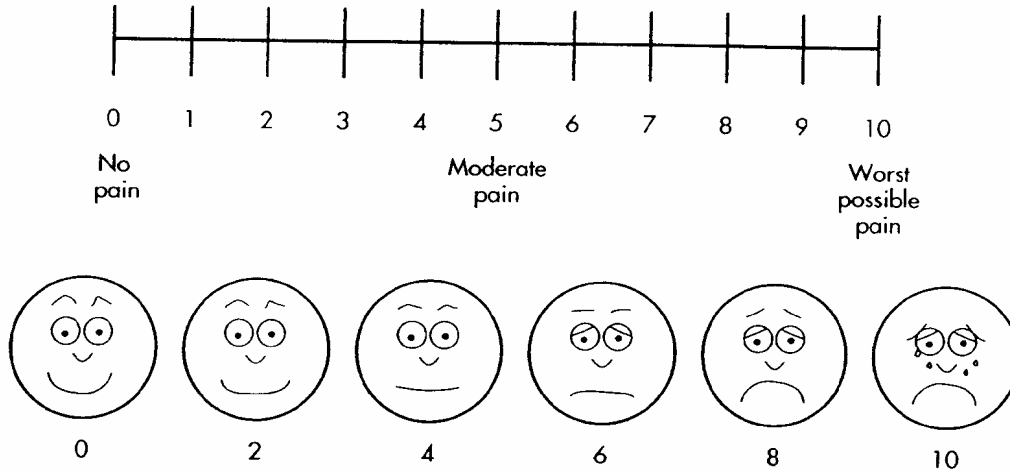
12. What do you think is causing your pain now? _____

13. Current Analgesic Regimen? _____

14. Plan/comments _____

PAIN ASSESSMENT
Pain Rating Scales

Pain Rating Scales



May be duplicated for use in clinical practice. As appears in McCaffery M, Pasero C: *Pain: Clinical manual*, p. 67, 1999, Mosby, Inc.

●●●●●
FIGURE 3.4 Example of how some clinical settings combine the horizontal numerical rating scale (NRS) with word anchors and the Wong-Baker faces scale. These are placed on one card or piece of paper so that the patient has a choice of pain rating scales. If the numerical scale with word descriptors is not easily understood, the faces scale is likely to be. The numbers beneath the faces have been changed from 0 to 5 to a 0 to 10 scale so that the recording of pain intensity is consistently on a 0 to 10 scale.
 Faces pain rating scale modified from Wong DL: *Whaley & Wong's essentials of pediatric nursing*, ed 5, pp. 1215-1216, St. Louis, 1997, Mosby.

Appendices My Bill of Last Rights	Page 1 of 1
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“My Bill of Last Rights¹”

The Right to Be in Control: Grant me the right to make as many decisions as possible regarding my care. Please do not take choices from me. Let me make my own decisions.

The Right to Have a Sense of Purpose: I have lost my job. I can no longer fulfill my role in my family. Please help me find some sense of purpose in my last days.

The Right to Reminisce: There has been pleasure in my life, moments of pride, moments of love. Please give me some time to recollect those moments. And please listen to my recollections.

The Right to Be Comfortable: The pain involved in dying is multifaceted. Although not all my pain can be taken away, please relieve whatever portion you can.

The Right to Touch and Be Touched: Sometimes I need distance. Yet sometimes I have a strong need to be close. When I want to reach out, please come to me and hold me as I hold you.

The Right to Laugh: People often – far too often – come to me wearing masks of seriousness. Although dying, I still need to laugh. Please laugh with me and help others to laugh as well.

The Right to Be Angry and Sad: It is difficult to leave behind all my attachments and all that I love. Please allow me the opportunity to be angry and sad.

The Right to Have a Respected Spirituality: Whether I am questioning or affirming, doubting or praising, I sometimes need your ear, a nonjudging ear. Please let my spirit travel its own journey, without judging its direction.

The Right to Hear the Truth: If you withhold the truth from me, you will treat me as if I am no longer living. I am still living, and I need to know the truth about my life. Please help me find that truth.

The Right to Be in Denial: If I hear the truth and choose not to accept it, that is my right. Please honor this right along with all these other rights. One day, you too will want the same rights.

¹ Facilitating a Meaningful Death Seminar, 9/19/01, handout materials taken from Douglas C. Smith, MS, MA, MDiv, *Caregiving: Hospice-Proven Techniques for Treating Body and Soul* (Macmillan Publishing, 1997), *Spiritual Healing* (Psycho-Spiritual Publications, 2000), and *Assessments and Care Plans: Being Patient-Centered and Following the CAAHO Standards* (Psycho-Spiritual Publications, 2001)

HO 1

RELIGIOUS PRACTICES FOR END OF LIFE CARE

Religion	Autopsy	Organ Donation	Beliefs and Practices
Orthodox Judaism	Only in special circumstances	With consultation of rabbi	Visits to the dying are a religious duty. To protect family and commit soul to God, a witness must be present when death occurs. Torah and psalms may be read and prayers recited. Conversation is kept to a minimum. Someone should be with the body after death until burial, usually within 24 hours. Body must not be touched 8 to 30 minutes after death. Medical personnel should not touch or wash unless death occurs on Jewish Sabbath, then nurse may give bath if wearing gloves. Water is removed from the room. Mirrors may be covered at family's request.
Hinduism	Permitted	Permitted	Priest ties thread around neck or wrist of deceased and pours water in the mouth. Only family and friends touch body.
Buddhism	Personal preference	Permitted	Buddhist priest is present at death. Last rites are chanted at bedside.
Islam (Muslim)	Only for medical or legal reasons	Not permitted	Before death, read Koran and pray. Resident confesses sins and asks forgiveness from family. Only family touches or washes body. After death, body is turned toward Mecca (east).
Roman Catholic	Permitted	Permitted	Sacrament of sick is administered to ill residents, to residents in imminent danger, or shortly after death.
Christian Scientist	Unlikely	Not permitted	No ritual is performed before or after death.
Church of Christ	Permitted	Permitted	No ritual is performed before or after death.

Hospice – Determining Terminal Status

*Cahaba Government Benefit Administrators Original Policy Effective: 07/31/2003
A CMS Contracted Regional Home Health Intermediary
400 E. Court Avenue
Des Moines, IA 50309-2017
Page 1 of 9*

Contractor's Policy Number

HOA03-002

Contractor Name

Cahaba Government Benefit Administrators

Contractor Number

00011

Contractor Type

Regional Home Health Intermediary

LMRP Title

Hospice – Determining Terminal Status

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CMS National Coverage Policy

• Social Security Act, Sections 1102, 1812 (a)(4) and (d); 1813 (a) (4); 1814 (a)(7) and (l); 1862 (a)(1), (6), and (9); 1861 (dd), 1871 • 42 CFR Part 418 • Medicare Hospice Manual, CMS Publication 21

Primary Geographic Jurisdiction

Colorado, Delaware, District of Columbia, Iowa, Kansas, Maryland, Missouri, Montana, Nebraska, North Dakota, Pennsylvania, South Dakota, Utah, Virginia, West Virginia, and Wyoming.

Secondary Geographic Jurisdiction

Those providers in Cahaba GBA Midwest's non-primary states who have selected Cahaba GBA Midwest as their alternate intermediary.

CMS Region

Region 7

CMS Consortium

Midwest

Original Policy Effective Date

07/31/2003

Original Policy Ending Date

N/A

Revision Effective Date

N/A

Revision Ending Date

N/A

LMRP Description

Medicare coverage of hospice depends on a physician's certification that an individual's prognosis is a life expectancy of six months or less if the terminal illness runs its normal course. This policy describes guidelines to be used by Regional Home Health Intermediaries in reviewing hospice claims and by hospice providers to determine eligibility of beneficiaries for hospice benefits. Although guidelines applicable to certain disease categories are included, this policy is applicable to all hospice patients. It is intended to be used to identify any Medicare beneficiary whose current clinical status and anticipated progression of disease is more likely than not to result in a life expectancy of six months or less. Clinical variables with general applicability without regard to diagnosis, as well as clinical variables applicable to a limited number of specific diagnoses, are provided. Patients who meet the guidelines established herein are expected to have a life expectancy of six months or less if the terminal illness runs its normal course. Some patients may not meet these guidelines, yet still have a life expectancy of 6 months or less. Coverage for these patients may be approved if documentation of clinical factors supporting a less than 6-month life expectancy not included in these guidelines is provided. If a patient improves or stabilizes sufficiently over time while in hospice such that he/she no longer has a prognosis of six months or less from the most recent recertification evaluation or definitive interim evaluation, that patient should be considered for discharge from the Medicare hospice benefit. Such patients can be re-enrolled for a new benefit period when a decline in their clinical status is such that their life expectancy is again six months or less. On the other hand, patients in the terminal stage of their illness who originally qualify for the Medicare hospice benefit but stabilize or improve while receiving hospice care, yet have a reasonable expectation of continued decline for a life expectancy of less than six months, remain eligible for hospice care.

Indications and Limitations of Coverage and/or Medical Necessity

A patient will be considered to have a life expectancy of six months or less if he/she meets the non-disease specific decline in clinical status guidelines described in Part I. Alternatively, the baseline non-disease specific guidelines described in Part II plus the applicable disease specific guidelines listed in the appendix will establish the necessary expectancy.

Part I. Decline in clinical status guidelines

Patients will be considered to have a life expectancy of six months or less if there is documented evidence of decline in clinical status based on the guidelines listed below. Since determination of decline presumes assessment of the patient's status over time, it is essential that both baseline and follow-up determinations be reported where appropriate. Baseline data may be established on admission to hospice or by using existing information from records. Other clinical variables not on this list may support a six-month or less life expectancy. These should be documented in the clinical record. These changes in clinical variables apply to patients whose decline is not considered to be reversible. They are listed in order of their likelihood to predict poor survival, the most predictive first and the least predictive last. No specific number of variables must be met, but fewer of those listed first (more predictive) and more of those listed last (least predictive) would be expected to predict longevity of six months or less.

1. Progression of disease as documented by worsening clinical status, symptoms, signs and laboratory results

A. Clinical Status

- 1) Recurrent or intractable infections such as pneumonia, sepsis or upper urinary tract.
- 2) Progressive inanition as documented by:
 - a) Weight loss not due to reversible causes such as depression or use of diuretics
 - b) Decreasing anthropomorphic measurements (mid-arm circumference, abdominal girth), not due to reversible causes such as depression or use of diuretics
 - c) Decreasing serum albumen or cholesterol
- 3) Dysphagia leading to recurrent aspiration and/or inadequate oral intake documented by decreasing food portion consumption.

B. Symptoms

- 1) Dyspnea with increasing respiratory rate
- 2) Cough, intractable
- 3) Nausea/vomiting poorly responsive to treatment
- 4) Diarrhea, intractable
- 5) Pain requiring increasing doses of major analgesics more than briefly.

C. Signs

- 1) Decline in systolic blood pressure to below 90 or progressive postural hypotension
- 2) Ascites
- 3) Venous, arterial or lymphatic obstruction due to local progression or metastatic disease
- 4) Edema

- 5) Pleural / pericardial effusion
 - 6) Weakness
 - 7) Change in level of consciousness
- D. Laboratory (When available. Lab testing is not required to establish hospice eligibility.)
- 1) Increasing pCO₂ or decreasing pO₂ or decreasing SaO₂
 - 2) Increasing calcium, creatinine or liver function studies
 - 3) Increasing tumor markers (e.g. CEA, PSA)
 - 4) Progressively decreasing or increasing serum sodium or increasing serum potassium
2. Decline in Karnofsky Performance Status (KPS) or Palliative Performance Score (PPS) from <70% due to progression of disease.
3. Increasing emergency room visits, hospitalizations, or physician's visits related to hospice primary diagnosis
4. Progressive decline in Functional Assessment Staging (FAST) for dementia (from ≥ 7A on the FAST)
5. Progression to dependence on assistance with additional activities of daily living
See Part II, Section 2.
6. Progressive stage 3-4 pressure ulcers in spite of optimal care

Part II. Non-disease specific baseline guidelines (both of these should be met)

1. Physiologic impairment of functional status as demonstrated by:
Karnofsky Performance Status (KPS) or Palliative Performance Score (PPS) ≤ 70. Note that two of the disease specific guidelines (HIV Disease, Stroke and Coma) establish a lower qualifying KPS or PPS.
2. Dependence on assistance for two or more activities of daily living (ADLs)
- a. Feeding
 - b. Ambulation
 - c. Continence
 - d. Transfer
 - e. Bathing
 - f. Dressing

See appendix for disease specific guidelines to be used with these (Part II) baseline guidelines. The baseline guidelines do not independently qualify a patient for hospice coverage.

Note: The word “should” in the disease specific guidelines means that on medical review the guideline so identified will be given great weight in making a coverage determination. It does not mean, however, that meeting the guideline is obligatory.

Part III. Co-morbidities – although not the primary hospice diagnosis, the presence of disease such as the following, the severity of which is likely to contribute to a life expectancy of six months or less, should be considered in determining hospice eligibility.

- A. Chronic obstructive pulmonary disease
- B. Congestive heart failure
- C. Ischemic heart disease
- D. Diabetes mellitus
- E. Neurologic disease (CVA, ALS, MS, Parkinson’s)
- F. Renal failure
- G. Liver Disease
- H. Neoplasia
- I. Acquired immune deficiency syndrome
- J. Dementia

CPT/HCPCS Section & Benefit Category

Medicare Part A Hospice Services

Type of Bill Code

81X Non-Hospital based hospice
82X Hospital based hospice

Revenue Codes

0651 Routine Home Care
0652 Continuous Home Care
0655 Inpatient Care
0656 General Inpatient Care
0657 Physician Services

CPT/HCPCS Codes

N/A

Not Otherwise Classified (NOC)

N/A

ICD-9 Codes that Support Medical Necessity

N/A – Hospice eligibility, i.e. terminal prognosis is not determined simply by diagnosis codes.

Reasons for Denial

Medical review of records of hospice patients that do not document that patients meet the guidelines set forth herein may result in denial of coverage unless other clinical circumstances reasonably predictive of a life expectancy of six months or less are provided. The condition of some patients receiving hospice care may stabilize or improve during or due to that care, with the expectation that the stabilization or improvement will not be brief and temporary. In such circumstances, if the patient's condition changes such that he or she no longer has a prognosis of life expectancy of six months or less, and that improvement can be expected to continue outside the hospice setting, then that patient should be discharged from hospice. On the other hand, patients in the terminal stage of their illness who originally qualify for the Medicare hospice benefit but stabilize or improve while receiving hospice care, yet have a reasonable expectation of continued decline for a life expectancy of less than six months, remain eligible for hospice care.

Non-covered ICD-9 Code(s)

N/A

Non-covered Diagnosis

N/A

Coding Guidelines

Claims are to include an ICD-9 code for the admitting diagnosis and the principal diagnosis if different from the admitting diagnosis. Codes that represent co-morbidities may be listed as secondary diagnoses. NOTE: The submission on a claim of codes reflecting co-morbidities does not make the Hospice agency financially liable for services and medications unless they are related to the terminal diagnosis. Such services otherwise eligible for Medicare coverage remain covered as non-hospice Part A and Part B benefits.

Documentation Requirements

General Guidelines:

Documentation certifying terminal status must contain enough information to support terminal status upon review. Documentation of the applicable criteria listed under the "Indications" section of this policy would meet this requirement. If other clinical indicators of decline not listed in this policy such as psychological and spiritual factors form the basis for certifying terminal status, they should be documented as well. Recertification for hospice care requires the same clinical standards be met as for initial certification, but they need not be reiterated. They may be incorporated by specific reference as part (or all) of the indication for recertification. Documentation should "paint a picture" for the reviewer to clearly see why the patient is appropriate for hospice care and the level of care provided, i.e., routine home, continuous home,

inpatient respite, or general inpatient. The records should include observations and data, not merely conclusions. However, documentation expectations should comport with normal clinical documentation practices. Unless elements in the record require explanation, such as a non-morbid diagnosis or indicators of likely greater than 6-month survival, as stated below, no extra or additional record entries should be needed to show hospice benefit eligibility. The amount and detail of documentation will differ in different situations. Thus a patient with metastatic small cell CA may be demonstrated to be hospice eligible with less documentation than a chronic lung disease patient. These situations are obvious. Patients with chronic lung disease, long term survival in hospice, or apparent stability can still be eligible for hospice benefits, but sufficient justification for a less than six month prognosis should appear in the record. If the documentation includes any findings inconsistent with or tending to disprove a less than 6-month prognosis, they should be answered or refuted by other entries, or specifically addressed and explained. Most facts and observations tending to suggest a greater than 6 month prognosis are predictable and apparent, such as a prolonged stay in hospice or a low immediate mortality diagnosis, as stated above. But specific entries can also call for an answer, such as an opinion by one team member or recovery of ADLS when they were part of the basis for the initial declaration of eligibility. Also the lack of certain documentation elements such as a tissue diagnosis for cancer will not create non-eligibility for the hospice benefit, but does necessitate other supportive documentation. Documentation submitted may include information from periods of time that fall outside the billing period currently under review. Include supporting events such as a change in the level of activities of daily living, recent hospitalizations, and the known date of death (if you are billing for a period of time prior to the billing period in which death occurred.) Documentation should support the level of care being provided to the patient during the time period under review, i.e. routine or continuous home or inpatient, respite, or general. The reviewer should be able to easily identify the dates and times of changes in levels of care and the reason for the change.

For Short-term General Inpatient Level of Care, supporting documentation might include:

- Pain requiring:
- Complicated technical delivery of medication requiring registered nurse to do calibration, tubing change, or site care
- Frequent evaluation by physician/nurse
- Aggressive treatment to control pain
- Frequent medication adjustment
- Transfusions for symptom relief
- Symptom changes:
- Sudden deterioration requiring intensive nursing intervention
- Uncontrolled nausea and vomiting

- Pathological fractures
- Respiratory distress which becomes unmanageable
- Open lesions needing frequent skilled care
- Traction and frequent repositioning requiring more than one staff member
- Complex wound care requiring complex dressing changes
- New or worsening delirium, agitation and/ or restlessness
- Psychological and social problems:
 - Acute anxiety, fear of dying and/or depression requiring intensive interventions
 - Collapse of family support requiring intensive skilled care in other than the home environment
- Patient/family teaching:
 - Complex medications, treatments, etc.
- Imminent death:
 - Requiring skilled nursing care for pain or symptom management due to a breakdown in the home support system.

Utilization Guidelines

N/A

Other Comments

Recognizing that determination of life expectancy during the course of a terminal illness is difficult, this intermediary has established medical guidelines for determining appropriateness for Medicare hospice services. These guidelines form a reasonable approach to the determination of life expectancy based on available research, and may be revised as more research is available. Coverage of hospice care for patients not meeting the guidelines in this policy may be denied. However, some patients may not meet the guidelines, yet still be appropriate for hospice care, because of co-morbidities or decline. Coverage for these patients may be approved on an individual consideration basis. This policy will be updated as medical research validates or invalidates the guidelines listed herein as predictive of terminal status.

Sources of Information and Basis for Decision

ICD-9-CM 2003, © 2002 Practice Management Information Corporation Medicare Contractor Medicare Directors Hospice Workgroup

B.Friedman, M. Harwood, M. Shields. Barriers and enablers to hospice referrals: an expert overview. J Palliative Medicine 2002; 5; 73-84

K.Ogle, B. Mavis, G. Wyatt. Physicians and hospice care: attitudes, knowledge, and referrals. J Palliative Medicine 2002; 5; 85-92.

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N. Christakis, E.Lamont. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *British Medical Journal* 2000; 320; 469-472.
E.Lamont, N. Christakis. Prognostic disclosure to patients with cancer near end of life. *Annals of Internal Medicine* 2001; 134; 1097-1143.
This policy consolidates, simplifies and supercedes the several current hospice local medical review policies on determining terminal status previously implemented by this contractor whose references are incorporated herewith.

Advisory Committee Notes

This policy does not reflect the sole opinion of the contractor or Contractor Medical Director. Although the final decision rests with the contractor, this policy was developed in cooperation with advisory groups, which includes representatives from relevant interested parties. Advisory Committee meeting date: Comments were received by regular and e-mail from the Intermediary Advisory Committee and reviewed prior to policy finalization.

Start Date of Comment Period

02/24/2003

Ending Date of Comment Period

04/10/2003

Start Date of Notice Period

06/17/2003

Revision History

N/A

Hospice – Determining Terminal Status Disease Specific Guidelines

Note: These guidelines are to be used in conjunction with the "Non-disease specific baseline guidelines" described in Part II of the basic policy.

Section I - Cancer Diagnoses

- A. Disease with distant metastases at presentation OR
- B. Progression from an earlier stage of disease to metastatic disease with either
 - 1. A continued decline in spite of therapy
 - 2. Patient declines further disease directed therapy

Note: Certain cancers with poor prognoses (e.g. small cell lung cancer, brain cancer and pancreatic cancer) may be hospice eligible without fulfilling the other criteria in this section.

Section II - Non-Cancer Diagnoses

A. Amyotrophic Lateral Sclerosis

General Considerations:

1. ALS tends to progress in a linear fashion over time. Thus the overall rate of decline in each patient is fairly constant and predictable, unlike many other non-cancer diseases.
2. However, no **single** variable deteriorates at a uniform rate in all patients. Therefore, multiple clinical parameters are required to judge the progression of ALS.
3. Although ALS usually presents in a localized anatomical area, the location of initial presentation does not correlate with survival time. By the time patients become end-stage, muscle denervation has become widespread, affecting all areas of the body, and initial predominance patterns do not persist.
4. Progression of disease differs markedly from patient to patient. Some patients decline rapidly and die quickly; others progress more slowly. For this reason, the history of the rate of progression in individual patients is important to obtain to predict prognosis.
5. In end-state ALS, two factors are critical in determining prognosis: ability to breathe, and to a lesser extent ability to swallow. The former can be managed by artificial ventilation, and the latter by gastrostomy or other artificial feeding, unless the patient has recurrent aspiration pneumonia. While not necessarily a contraindication to Hospice Care, the decision to institute either artificial ventilation or artificial feeding will significantly alter six-month prognosis.
6. Examination by a neurologist within three months of assessment for hospice is advised, both to confirm the diagnosis and to assist with prognosis.
7. Criteria:

Patients will be considered to be in the terminal stage of ALS (life expectancy of six months or less) if they meet the following criteria. (Should fulfill 1, 2, or 3).

1. Patient should demonstrate critically impaired breathing capacity.

- a. Critically impaired breathing capacity as demonstrated by all the following characteristics occurring within the 12 months preceding initial hospice certification:
 - i. Vital capacity (VC) less than 30% of normal (if available);
 - ii. Dyspnea at rest;
 - iii. Requiring supplemental oxygen at rest;
 - iv. Patient declines artificial ventilation; external ventilation used for comfort measures only.
2. Patient should demonstrate **both** rapid progression of ALS and critical nutritional impairment.
 - a. Rapid progression of ALS as demonstrated by all the following characteristics occurring within the 12 months preceding initial hospice certification:
 - i. Progression from independent ambulation to wheelchair to bed bound status;
 - ii. Progression from normal to barely intelligible or unintelligible speech;
 - iii. Progression from normal to pureed diet;
 - iv. Progression from independence in most or all activities of daily living (ADLs) to needing major assistance by caretaker in all ADLs.
 - b. Critical nutritional impairment as demonstrated by all the following characteristics occurring within the 12 months preceding initial hospice certification:
 - i. Oral intake of nutrients and fluids insufficient to sustain life;
 - ii. Continuing weight loss;
 - iii. Dehydration or hypovolemia;
 - iv. Absence of artificial feeding methods, sufficient to sustain life, but not for relieving hunger.
3. Patient should demonstrate both rapid progression of ALS and life-threatening complications.
 - a. Rapid progression of ALS, see 2.a above.
 - b. Life-threatening complications as demonstrated by one of the following characteristics occurring within the 12 months preceding initial hospice certification:
 - i. Recurrent aspiration pneumonia (with or without tube feedings);
 - ii. Upper urinary tract infection, e.g., pyelonephritis;
 - iii. Sepsis;
 - iv. Recurrent fever after antibiotic therapy;
 - v. Stage 3 or 4 decubitus ulcer(s)

B. Dementia due to Alzheimer's Disease and Related Disorders

Patients will be considered to be in the terminal stage of dementia (life expectancy of six months or less) if they meet the following criteria.

Patients with dementia should show all the following characteristics:

1. Stage seven or beyond according to the Functional Assessment Staging Scale;
2. Unable to ambulate without assistance;
3. Unable to dress without assistance;
4. Unable to bathe without assistance;
5. Urinary **and** fecal incontinence, intermittent or constant;
6. No consistently meaningful verbal communication: stereotypical phrases only or the ability to speak is limited to six or fewer intelligible words.

Patients should have had one of the following within the past 12 months:

1. Aspiration pneumonia;
2. Pyelonephritis or other upper urinary tract infection;3
3. Septicemia;
4. Decubitus ulcers, multiple, stage 3-4;
5. Fever, recurrent after antibiotics;
6. Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous six months **or** serum albumin <2.5 gm/dl.

Note: This section is specific for Alzheimer's Disease and related disorders, and is not appropriate for other types of dementia, such as multi infarct dementia.

C. Heart Disease

Patients will be considered to be in the terminal stage of heart disease (life expectancy of six months or less) if they meet the following criteria. (1 **and** 2 should be present. Factors from 3 will add supporting documentation.)

1. At the time of initial certification or recertification for hospice, the patient is or has been already optimally treated for heart disease or are patients who are either not candidates for surgical procedures or who decline those procedures. (Optimally treated means that patients who are not on vasodilators have a medical reason for refusing these drugs, e.g., hypotension or renal disease.)
2. The patient is classified as New York Heart Association (NYHA) Class IV and may have significant symptoms of heart failure or angina at rest. (Class IV patients with heart disease have an inability to carry on any physical activity without discomfort. Symptoms of heart failure or of the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.) Significant congestive heart failure may be documented by an ejection fraction of $\leq 20\%$, but is not required if not already available.
3. Documentation of the following factors will support but is not required to establish eligibility for hospice care:
 - a. Treatment resistant symptomatic supraventricular or ventricular arrhythmias;
 - b. History of cardiac arrest or resuscitation;
 - c. History of unexplained syncope;

- d. Brain embolism of cardiac origin;
- e. Concomitant HIV disease.

D. HIV Disease

Patients will be considered to be in the terminal stage of their illness (life expectancy of six months or less) if they meet the following criteria:

HIV Disease (1 and 2 should be present; factors from 3 will add supporting documentation)

1. CD4+ Count <25 cells/mcl or persistent (2 or more assays at least one month apart) viral load >100,000 copies/ml, plus one of the following:
 - o CNS lymphoma;
 - o Untreated, or persistent despite treatment, wasting (loss of at least 10% lean body mass);
 - o Mycobacterium avium complex (MAC) bacteremia, untreated, unresponsive to treatment, or treatment refused;
 - o Progressive multifocal leukoencephalopathy;
 - o Systemic lymphoma, with advanced HIV disease and partial response to chemotherapy;
 - o Visceral Kaposi's sarcoma unresponsive to therapy;
 - o Renal failure in the absence of dialysis;
 - o Cryptosporidium infection;
 - o Toxoplasmosis, unresponsive to therapy.
2. Decreased performance status, as measured by the Karnofsky Performance Status (KPS) scale, of ≤50%
3. Documentation of the following factors will support eligibility for hospice care:
 - o Chronic persistent diarrhea for one year;
 - o Persistent serum albumin <2.5;
 - o Concomitant, active substance abuse;
 - o Age >50 years;
 - o Absence of, or resistance to effective antiretroviral, chemotherapeutic and prophylactic drug therapy related specifically to HIV disease;
 - o Advanced AIDS dementia complex;
 - o Toxoplasmosis;
 - o Congestive heart failure, symptomatic at rest;
 - o Advanced liver disease.

E. Liver Disease

Patients will be considered to be in the terminal stage of liver disease (life expectancy of six months or less) if they meet the following criteria: (1 and 2 should be present, factors from 3 will lend supporting documentation.)

1. The patient should show **both** a and b:
 - a. Prothrombin time prolonged more than 5 seconds over control, or International Normalized Ratio (INR) >1.5;
 - b. Serum albumin <2.5 gm/dl.
2. End stage liver disease is present and the patient shows at least **one** of the following:
 - a. Ascites, refractory to treatment or patient non-compliant;
 - b. Spontaneous bacterial peritonitis;
 - c. Hepatorenal syndrome (elevated creatinine and BUN with oliguria (<400 ml/day) and urine sodium concentration <10 mEq/l;
 - d. Hepatic encephalopathy, refractory to treatment, or patient non-compliant;
 - e. Recurrent variceal bleeding, despite intensive therapy.
3. Documentation of the following factors will support eligibility for hospice care:
 - a. Progressive malnutrition;
 - b. Muscle wasting with reduced strength and endurance;
 - c. Continued active alcoholism (>80 gm ethanol/day);
 - d. Hepatocellular carcinoma;
 - e. HBsAg (Hepatitis B) positivity;
 - f. Hepatitis C refractory to interferon treatment.

Patients awaiting liver transplant who otherwise fit the above criteria may be certified for the Medicare hospice benefit, but if a donor organ is procured, the patient should be discharged from hospice.

F. Pulmonary Disease

Patients will be considered to be in the terminal stage of pulmonary disease (life expectancy of six months or less) if they meet the following criteria. The criteria refer to patients with various forms of advanced pulmonary disease who eventually follow a final common pathway for end stage pulmonary disease. (1 and 2 should be present. Documentation of 3, 4, and 5, will lend supporting documentation.):

1. Severe chronic lung disease as documented by both a and b:
 - a. Disabling dyspnea at rest, poorly or unresponsive to bronchodilators, resulting in decreased functional capacity, e.g., bed to chair existence, fatigue, and cough: (Documentation of Forced Expiratory Volume in One Second (FEV1), after bronchodilator, less than 30% of predicted is objective evidence for disabling dyspnea, but is not necessary to obtain.)
 - b. Progression of end stage pulmonary disease, as evidenced by increasing visits to the emergency department or hospitalizations for pulmonary infections and/or respiratory

failure or increasing physician home visits prior to initial certification. (Documentation of serial decrease of FEV1>40 ml/year is objective evidence for disease progression, but is not necessary to obtain.)

2. Hypoxemia at rest on room air, as evidenced by $pO_2 \leq 55$ mmHg; or oxygen saturation $\leq 88\%$ on supplemental oxygen determined either by arterial blood gases or oxygen saturation monitors; (These values may be obtained from recent hospital records.) OR Hypercapnia, as evidenced by $pCO_2 \geq 50$ mmHg. (This value may be obtained from recent [within 3 months] hospital records.)
3. Right heart failure (RHF) secondary to pulmonary disease (Cor pulmonale) (e.g., not secondary to left heart disease or valvulopathy).
4. Unintentional progressive weight loss of greater than 10% of body weight over the preceding six months.
5. Resting tachycardia >100 /min.

G. Renal Disease

Patients will be considered to be in the terminal stage of renal disease (life expectancy of six months or less) if they meet the following criteria:

Acute renal failure (1 and either 2 or 3 should be present. Factors from 4 will lend supporting documentation):

1. The patient is not seeking dialysis or renal transplant or is discontinuing dialysis;
2. Creatinine clearance <10 cc/min (<15 cc/min. for diabetics) based on measurement or calculation; or <15 cc/min (<20 cc/min for diabetics) with comorbidity of congestive heart failure;
3. Serum creatinine >8.0 mg/dl (>6.0 mg/dl for diabetics);
4. Comorbid conditions:
 - a. Mechanical ventilation;
 - b. Malignancy (other organ system);
 - c. Chronic lung disease;
 - d. Advanced cardiac disease;
 - e. Advanced liver disease;
 - f. Sepsis;
 - g. Immunosuppression/AIDS;
 - h. Albumin <3.5 gm/dl;
 - i. Cachexia;
 - j. Platelet count $<25,000$;
 - k. Disseminated intravascular coagulation;
 - l. Gastrointestinal bleeding.

Chronic renal failure: (1 and either 2 or 3 should be present. Factors from 4 will lend supporting documentation):

1. The patient is not seeking dialysis or renal transplant or is discontinuing dialysis;
2. Creatinine clearance <10 cc/min (<15 cc/min for diabetics) based on measurement or calculation; or < 15cc/min (<20cc/min for diabetics) with comorbidity of congestive heart failure;
3. Serum creatinine >8.0 mg/dl (>6.0 mg/dl for diabetics);
4. Signs and symptoms of renal failure:
 - a. Uremia;
 - b. Oliguria (<400 cc/24 hours);
 - c. Intractable hyperkalemia (>7.0) not responsive to treatment;
 - d. Uremic pericarditis;
 - e. Hepatorenal syndrome;
 - f. Intractable fluid overload, not responsive to treatment.

H. Stroke & Coma

Patients will be considered to be in the terminal stage of stroke or coma (life expectancy of six months or less) if they meet the following criteria.

Stroke

1. Karnofsky Performance Status (KPS) or Palliative Performance Scale (PPS) of 40% or less
2. Inability to maintain hydration and caloric intake with one of the following:
 - a. Weight loss >10% in the last 6 months or >7.5% in the last 3 months;
 - b. Serum albumin <2.5 gm/dl;
 - c. Current history of pulmonary aspiration not responsive to speech language pathology intervention;
 - d. Sequential calorie counts documenting inadequate caloric/fluid intake.
 - e. Dysphagia severe enough to prevent the patient from receiving good and fluids necessary to sustain life, in a patient who declines or does not receive artificial nutrition and hydration.

Coma (any etiology): Comatose patients with any 3 of the following on day three of coma:

- a. abnormal brain stem response;
- b. absent verbal response;
- c. absent withdrawal response to pain;
- d. serum creatinine > 1.5 mg/dl.

Documentation of the following factors will support eligibility for hospice care:

Documentation of medical complications, in the context of progressive clinical decline, within the previous 12 months, which support a terminal prognosis:

- a. Aspiration pneumonia;
- b. Upper urinary tract infection (pyelonephritis);
- c. Sepsis;
- d. Refractory stage 3-4 decubitus ulcers;
- e. Fever recurrent after antibiotics.

Documentation of diagnostic imaging factors which support poor prognosis after stroke include:

A. For non-traumatic hemorrhagic stroke:

1. Large-volume hemorrhage on CT:
 - a. Infratentorial: ≥ 20 ml.;
 - b. Supratentorial: ≥ 50 ml.
2. Ventricular extension of hemorrhage;
3. Surface area of involvement of hemorrhage $\geq 30\%$ of cerebrum;
4. Midline shift ≥ 1.5 cm.;
5. Obstructive hydrocephalus in patient who declines, or is not a candidate for, ventriculoperitoneal shunt.

B. For thrombotic/embolic stroke:

1. Large anterior infarcts with both cortical and subcortical involvement;
2. Large bihemispheric infarcts;
3. Basilar artery occlusion;
4. Bilateral vertebral artery occlusion.

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Midwest Bioethics Center’s
“Considerations Regarding Life-Prolonging Treatment
for Residents of Long-Term Care Facilities”

Members of the Missouri Long-Term Care Task Force convened by Midwest Bioethics Center developed the following policy guidelines out of growing concern about the issues surrounding life-prolonging treatment decisions for residents of long-term care facilities. Recent judicial and legislative actions (i.e., Cruzan, Patient Self-Determination Act) underscore the importance of policies that support resident-focused decision-making in long-term care facilities. However, both ethical and legal uncertainty surrounding residents’ rights to accept or to refuse life-prolonging treatments has led to confusion among long-term care facilities regarding policy development and appropriate action. Compounding providers’ confusion about residents’ legal and ethical rights is the uncertainty about regulatory sanctions. To address these problems, this document is intended to provide guidance to long-term care facilities for policy development in several key areas related to life-prolonging treatment decisions, including

- Residents’ rights;
- Advance directives;
- Surrogate decision making;
- Documentation of decisions;
- Conflict resolution;
- Care of residents who are dying;
- Hospice care.

These guidelines represent the views of this Task Force. They have been reviewed and discussed by the Missouri Division of Aging Ethics in Long-Term Care Task Force. There is general concurrence with the content of these guidelines.

1. Purpose/Rationale/Goals

- 1.1 Provide practical guidance to long-term care facilities developing policies and procedures about decisions regarding life-prolonging treatment and advance directives.
- 1.2 Provide guidance about decision making for persons who lack decisional capacity and have not made advance directives.

- 1.3 Offer guidelines for decision-making based on systematic, rational considerations that respect the dignity and autonomy of long-term care residents.
- 1.4 Establish a coherent philosophical/ethical foundation for decision-making about life-prolonging treatment and advance directives.
- 1.5 Provide support to individuals who are faced with making life-prolonging treatment decisions — especially decisions about withholding or withdrawing artificial nutrition and hydration.

2. Problems/Needs to be addressed

- 2.1 The traditional decision-making role of physicians and families/surrogates for persons without decisional capacity is unclear.
- 2.2 Because of legal concerns, providers and families/surrogates are reluctant to make healthcare decisions for persons without decisional capacity.
- 2.3 Policies and procedures regarding the use of life-prolonging treatment and advance directives are needed and should be developed by long-term care facilities.
- 2.4 People involved in the decisions of long-term care residents need education and guidance.

3. Definitions

- 3.1 Advance directives — this term may refer to any direction either written or oral that a person makes about his or her healthcare wishes prior to losing decisional capacity. Written advance directives may include living wills, healthcare treatment directives, and durable powers of attorney for healthcare. (For more explanation of oral directives, see section 9.)
- 3.2 Clinically appropriate — a treatment decision that is consistent with both prevailing medical standards of clinical practice and sound ethical decision-making criteria (see 8.4.b.i-iii).
- 3.3 Comfort care — a range of treatments intended to provide relief of pain and/or suffering, control symptoms, reduce anxiety, and provide comprehensive support to residents.
- 3.4 Decisional capacity — term used to reflect the ability of a resident to make a specific decision, for example, the ability to understand relevant information, to reflect on it, and to communicate (verbally or nonverbally) to providers.
- 3.5 Do not resuscitate (DNR) — a physician's order protecting a resident from cardio-pulmonary resuscitation where resuscitation has been determined either to be futile or to be inconsistent with the resident's values, wishes, and goals.
- 3.6 Durable power of attorney for healthcare decisions — a legal document that allows a person to name an agent to make health-care decisions.

- 3.7 Ethics committee — a multidisciplinary committee convened to integrate ethics into a healthcare providing institution/facility. Ethics committees serve three functions: education, policy review and development, and case consultation. They are an advisory resource; they do not make treatment decisions.
- 3.8 Family — a relative or intimate friend of the resident.
- 3.9 Futile — a treatment may be determined to be futile if the attending physician believes there is no reasonable expectation that the treatment will achieve its intended goal.
- 3.10 Hospice — a treatment approach for persons who are terminally ill involving the skilled and compassionate care of dying patients and their families. The goals of hospice include maximizing control by the resident, keeping the resident pain free, and comfortable during the final phases of life.
- 3.11 Informed consent — agreement by a resident with decisional capacity made voluntarily and without coercion upon a clear understanding of (1) the nature of the resident’s medical condition and prognosis, (2) the nature and purpose of the proposed treatment or procedure, and (3) the benefits and burdens of proposed treatment alternatives or nontreatment.
- 3.12 Life-prolonging treatment — interventions that are judged likely to be effective in prolonging the life of a resident or which are used simply to maintain bodily function.
- 3.13 Living will — a document stating a person’s wishes with regard to the use of life-sustaining (or death-prolonging) treatment in the event that the person has a terminal condition and is unable to communicate. Most states, including Missouri, have statutorily suggested forms. Use of the statutory form is not required. The term *living will* is also often used in a generic sense to refer to any document stating a person’s healthcare treatment wishes.
- 3.14 Provider — professionals and agents of the facility, authorized by law to provide healthcare.
- 3.15 Surrogate — an agent who acts on behalf of a resident who lacks decisional capacity to participate in a particular decision; an appropriate surrogate may be:
- a. designated by the resident (e.g., in a healthcare treatment directive, living will, or durable power of attorney);
 - b. the adult who is most involved with the resident and most knowledgeable about the resident’s personal values and preferences; or
 - c. designated by a court (e.g., a guardian).

No priority is intended in this listing.

- 3.16 Terminal condition — a condition or illness, usually thought of as irreversible, unrelenting, and without cure, which because of its nature can be expected to cause the resident to die.

4. Identification of Ethical Principles/Values

Healthcare has traditionally been based in large part on the assumption that human life is precious and that it should be preserved whenever possible. This principle is fundamental to the healthcare enterprise. However, taken as an absolute it negates other valuable ethical principles and does not provide a full understanding of the principles that should be considered when making decisions regarding withholding/withdrawing treatment.

The ethical imperative for healthcare providers is to care. Caring implies balancing all essential ethical principles.

4.1 The principle of autonomy.

Residents have the right to make decisions about the course of their lives; this is often called the right of self-determination.

4.2 The principle of beneficence.

Long-term care providers have an obligation to avoid harming and to promote the well being of their residents.

4.3 The principle of justice/equity.

All persons have a duty to respect the rights of others, to obey morally acceptable laws, and to distribute limited resources fairly.

5. Working Assumptions

5.1 When a resident has refused life-prolonging treatment or when it is clinically appropriate to withdraw such treatment, healthcare providers have an obligation to offer treatment and care that provides for a peaceful and dignified death with minimal suffering.

5.2 If doubt exists regarding the wishes of the resident/surrogate about possible benefits or burdens of a treatment when treatment wishes are not clear, providers should initiate time-limited trials for a reasonable period.

5.3 When a decision to forgo a particular life-prolonging treatment is made, both healthcare providers and the facility have a continuing obligation to provide a comprehensive range of comfort care and supportive treatment. The care of dying persons may be facilitated through a hospice approach.

5.4 Healthcare providers are obligated to respect reasonable requests of residents/surrogates to provide or to continue life-prolonging treatments.

5.5 DNR (Do Not Resuscitate) is a medical order that should be signed by the resident's primary physician. Orders not to resuscitate should be discussed with residents who have decisional capacity or with their surrogates if they do not have decisional capacity.

5.6 Healthcare providers should respect the request of residents/surrogates for consultation and opinions from additional experts.

6. A Summary of Relevant Law and Other Legal Tenets

6.1 Constitutional law: in the Cruzan case, the U.S. Supreme Court acknowledged a constitutional basis for a competent person's right to refuse medical treatment, including artificial feeding, defined as a right of "liberty" from unwanted medical treatment.

6.2 Federal Legislation: The Patient Self-Determination Act, passed by the U.S. Congress in 1991, requires nursing homes to inform their clients at the time of admission of their right to make healthcare treatment decisions with advance directives. Under this legislation nursing homes are required to

- a. maintain written policies and procedures concerning a person's rights under state law (whether statutory or recognized by the courts), to make decisions concerning their care including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives;
- b. ensure that this written information is provided to adult residents/surrogates at the time of admission;
- c. note in the resident's records whether an advance directive has been made by the resident;
- d. ensure compliance with advance directives consistent with state law;
- e. provide staff and community education on advance directives; and
- f. assure residents that they are not required to complete advance directives.

6.3 Missouri Statutes

- a. The Missouri Life Support Declarations Act (RSMo Chapter 459.010-459.055) grants competent individuals the right to sign an advance declaration ("statutory living will") for withholding or withdrawing "death prolonging procedures." However, a statutory living will may not direct the withholding/withdrawing of food or water. Use of the statutory form is not required. Living wills, which are not in the statutory form, are sometimes referred to as "common law living wills."
- b. A statutory living will becomes effective only when a declarant's medical condition is determined to be terminal and when he or she has lost decisional capacity. Terminal condition is defined in the statute as "an incurable or irreversible condition which, in the opinion of the attending physician, is such that death will occur within a short time regardless of the application of medical procedures."

- c. Missouri's Durable Power of Attorney for Healthcare Law (RSMo Chapter 404.800-.865; effective August 1991) allows competent individuals to designate a "surrogate" or "attorney-in fact" to make healthcare decisions for them in the event that they lack decisional capacity as determined by two physicians unless the durable power of attorney allows decisions as to incapacity to be made by one physician.

A surrogate must consider the individual's medical diagnosis, prognosis, and the benefit and burdens of proposed treatment as well as the individual's comfort care. The authority of a surrogate to withhold/withdraw artificial food or water must be specifically provided for in the document.

6.4 Missouri Case Law: The only clearly relevant Missouri case laws are *Cruzan v. Harmon* (760 SW2d 408 [Mo. 1998]) and the Warren case (*Murphy v. Wheeler*, 858 SW2d 263 [Mo.Ct. App. 1993]).

- a. Cruzan
 - a.i To be assured of legal protection, there must be clear and convincing evidence that the resident would request that artificial nutrition and hydration be withheld or withdrawn.
 - a.ii In addition to specific written advance directives, clear and convincing evidence may also be established by verbal statements that reflect what treatment choices a resident would make.
- b. Warren
 - b.i Guardians are authorized by statute to make healthcare treatment decisions (both to give and withhold consent) to further their wards' best interests without specific court authorization. Factors that may influence a determination of best interests include medical diagnosis and prognosis, benefits and burdens of treatment, preferences expressed by the ward, and the probability that a course of action will lead to recovery or relief of pain.
 - b.ii Court appointed guardians have statutory authority to make healthcare decisions in their wards' best interests without specific court authorization.
 - b.iii The clear and convincing evidence requirement in the Cruzan case should be limited to situations involving the withdrawal or withholding of artificial nutrition and hydration and should not control other life-sustaining care decisions.

The concurring opinion in Warren emphasizes that a court appointed guardian's authority to withhold consent to care pertains to treatment that is unnecessary or harmful, and that the power to consent to DNR orders without court approval is not unlimited. That is, the power is only to be exercised when a sufficient medical basis is established without regard to the patient's handicap, the social utility of the patient's life, or the value of that life to others.

6.5 Other Legal Tenets

- a. A resident's decision to forgo life-prolonging treatment does not constitute a decision to commit suicide.
- b. Requests by a resident for interventions intended to terminate his or her life should not be honored.
- c. Healthcare providers and/or facilities that have an objection to a decision to forgo treatment should inform the resident or surrogate of the objection and assist in the orderly transfer of care to another provider or facility.
- d. Any medical or surgical intervention may be withheld or withdrawn under appropriate circumstances.
- e. If a facility changes its policy or procedures regarding the use of life-prolonging treatment, the facility has an obligation to inform its residents/surrogates of those changes and has a duty to help the residents transfer to another facility if they desire.

7. A Summary of Missouri Division of Aging Regulations

7.1 A nursing facility is required to respect the rights of its residents. Those rights include

- a. The right to be informed by a physician of their medical condition and prognosis (19 CSR30-88.010[10]).
- b. The right to be afforded the opportunity to participate in the planning of their care and the right to refuse treatment (19 CSR30-88.010[11]).
- c. The right to be transferred or discharged only for medical reasons, or for their health or welfare or that of other residents or for nonpayment of stay (19 CSR30-88.010[14]).

7.2 The operator and administrator of a nursing facility have a responsibility to provide protective oversight to the residents of that facility and to assure that they receive appropriate nursing and medical care (19 CSR 30-85.042[3] & [67]).

7.3 A nursing facility is required to develop policies and procedures for dealing with medical emergency treatment procedures, admission and discharge procedures, and resident rights' issues. (19 CSR 30-85.042[13]). The facility's staff, all physicians with residents in the facility, and each resident must be informed of those policies and procedures. Facilities are required to relate information about advance directives to residents/surrogates on an annual basis (19 CSR 30-85.042[15] & [42] and also 19 CSR 30-88.010 [9]).

7.4 A nursing facility is required to meet the nutritional needs of a resident based on the individual's circumstances, medical condition, and goals of treatment as determined and justified by the physician (19 CSR 30-85.052 [1]).

8. General Guidelines for Decision Making

8.1 Model of Decision-Making Process

- a. Long-term care residents have the right to accept or refuse any health care treatment.
- b. Informed decisions must include participation by providers and residents/surrogates.
- c. Treatment decisions may be changed at any time if it is appropriate in view of a reassessment or change in the condition of the resident. The resident/surrogate should be involved in the decision.

8.2 Role of the Resident

- a. Residents with decisional capacity: Adults with decisional capacity have the right to accept or refuse any medical intervention. These rights are not restricted to residents who are terminally ill.

Residents who have been adjudicated incompetent or diagnosed as having a mental illness or mental retardation may have the ability to make some, if not all, healthcare treatment decisions.

- b. Residents who have advance directives: If a resident who has an advance directive stating his or her treatment preferences is currently without decisional capacity, his or her directive should be followed.
- c. Residents without decisional capacity and without advance directives: When possible, appropriate surrogates should be identified to act on the resident's behalf.

The legal authority of surrogates who have not been formally appointed by an advance directive or a court order may be open to challenge.

- c.i An appropriate surrogate is one who is appointed in the durable power of attorney, and has personal knowledge of the resident's goals and values. He or she must be willing to act on behalf of the resident.
- c.ii In many instances a family member will be an appropriate surrogate, but even when there is family, close friends or others may be better suited for this role.
- c.iii An adult who has lived with the resident prior to the resident being admitted to a long-term care facility may be given priority as a surrogate decision maker. For example, a person living with his or her spouse (or partner) may speak for his or her spouse (or partner).

c.iv Each facility should establish policies and procedures describing their internal process for recognizing an appropriate surrogate. Ethics committees may be helpful in this process.

c.v Requesting a court appointed guardian should be an option of last resort.

8.3 Role of Surrogate Decision Makers for Residents without Decisional Capacity

- a. Appropriate surrogates should participate in decision making for persons who lack decisional capacity.
- b. Surrogates named in durable powers of attorney for healthcare decisions:
 - b.i Generally, surrogates have the same authority as the resident would have if he or she had decisional capacity.
 - b.ii Missouri law requires that a surrogate's authority to withhold or withdraw artificially administered nutrition and hydration be expressly provided.
- c. Surrogates named in durable powers of attorney signed before August 1991:
 - c.i May or may not have legal authority to make healthcare decisions unless the durable power of attorney specifically contains that authority.
 - c.ii Prior to August 1991, many people who are now long-term care residents signed durable power of attorney documents which did not specifically mention healthcare decision making or decisions about withholding/withdrawing artificial nutrition and hydration.
 - c.iii The criteria provided in this document for selecting an "appropriate surrogate" should be applied to persons named in these durable powers of attorney.
- d. Surrogates named in nondurable powers of attorney:
 - d.i Do not have legal authority to make decisions of any kind for persons without decisional capacity.
 - d.ii Although not legally authorized by a nondurable power of attorney, surrogates named in nondurable powers of attorney may still be appropriate surrogates.
- e. Court Appointed Guardians
 - e.i The scope of authority of the guardian in Missouri is determined by the court order.
 - e.ii If a guardian has been appointed, facilities should request a copy of the court order and make it part of the resident's permanent record.
 - e.iii Guardians in Missouri must have "clear and convincing" evidence that they are acting in a manner consistent with the resident's wishes regarding withholding/withdrawing artificially administered nutrition and hydration.

- e.iv When a guardian has been appointed, before a provider/facility chooses to recognize the decision of a surrogate other than a court appointed guardian, the guardian must be notified of this decision (See section, 8.3.f.).
- f. Surrogates recognized by providers/facilities but not appointed by a resident's advance directive or court order should share in the decision-making process with the physician, family, and representatives of the facility.
- g. Ethics committees can assist in resolving conflicts that may arise between various recognizable surrogates and court appointed guardians.

8.4 Surrogate Decision-Making Criteria

- a. Substituted judgment decisions: If the providers and surrogate agree that the treatment decision is in accord with the resident's values and previously expressed preferences, that plan of care should be pursued.
- b. Best interest decisions: If the providers and surrogate don't know or cannot agree about what the resident would choose, then decisions should be based on what reasonable persons in the resident's position would choose. For example:
 - b.i In applying the best interest standard to residents who are terminally ill, major considerations are the burden of prolonging dying and whether the resident has the potential benefit of achieving some satisfaction from prolonged life.
 - b.ii In applying the best interest standard to residents who have a severe and irreversible illness or condition, the decision should be made by balancing the benefits and burdens to the resident in each case.
 - b.iii In applying the best interest standard to the resident with an irreversible loss of consciousness, consideration of the benefits and burdens to the caretakers and family are also appropriate.

8.5 Role of Healthcare Providers

- a. A provider's primary responsibility is to the resident.
- b. Decisions to forgo life-prolonging treatment must be resident focused.
- c. Providers' responsibilities include
 - c.i Fully informing the resident/surrogate regarding the resident's medical condition and prognosis to the extent information is available and involving the resident/surrogate in the decision-making process.
 - c.ii Recognizing and honoring residents' healthcare treatment preferences.
 - c.iii Ensuring that comprehensive and accurate evaluation of the resident's condition occurs on an ongoing basis.
 - c.iv Considering the entire range of reasonable treatment options.
 - c.v Considering and conducting therapeutic trials when appropriate.

- c.vi Respecting requests made by the resident/surrogate for additional consultation.
- c.vii Determining whether the loss of decisional capacity is due to temporary or reversible conditions, for example, depression caused by medication.
- c.viii Informing other providers of any decision to forgo or withdraw life-prolonging treatment.

8.6 Role of the Facility

The responsibilities of the facility include:

- a. Ensuring that appropriate care is provided to residents in accordance with the resident/surrogate's wishes.
- b. Informing residents/surrogates of their rights and promoting those rights.
- c. Making reasonable efforts to gather information about the resident's life, goals and values, medical history, and the existence of any advance directive.
- d. Supporting the resident's right to make autonomous decisions, including the resident's right to make, change, or revoke advance directives.
- e. Ensuring that residents/surrogates have all the available information regarding the resident's diagnosis, treatment options, risks and benefits associated with various treatment options, and the resident's prognosis.
- f. Verifying that loss of decisional capacity is not due to temporary or reversible conditions, for example, depression caused by medication.
- g. Verifying that residents are free from coercion so that they may make an informed and autonomous decision.
- h. Having appropriate policies and procedures in place to protect residents' rights to make treatment decisions.
- i. Facilitating consultation with the interdisciplinary care team or ethics committee when decisions are made to forgo life-prolonging treatment for residents without advance directives or appropriate surrogates.
- j. Providing a mechanism for conflict resolution.

8.7 Conflict Resolution

- a. Disagreements may arise between resident/surrogate and healthcare providers, among members of the interdisciplinary team, or between the primary decision makers and the facility itself. When such conflict occurs, it is imperative that the parties have access to the widest range of mechanisms to address and attempt to resolve such conflict. These mechanisms include
 - a.i additional medical consultation;
 - a.ii care management conferences;

- a.iii mental health counseling;
- a.iv pastoral counseling;
- a.v assistance from the ombudsman program; and/or
- a.vi review by an ethics committee.
- b. One of the ways a long-term care facility can discharge its responsibilities for supporting residents making these difficult decisions is through the creation and support of an institutional ethics committee.
 - b.i Ethics committees can assist facilities to address these issues proactively by promoting education about ethics and assisting with policy review and development.
 - b.ii A primary role of the ethics committee is that of providing a forum where questions and/or disagreements regarding decisions about life-sustaining treatment can be discussed and resolved.
 - b.iii Committee consultation and review may be undertaken in response to a formal request by a resident, family/surrogate, or provider directly involved in the care of the resident.
 - b.iv Consultation should be strongly considered in cases in which an appropriate surrogate cannot be identified for a resident without decisional capacity and in cases in which there is persistent disagreement among those responsible for making decisions.
- c. Smaller long-term care facilities may consider collaboration with other healthcare provider organizations in order to assemble appropriate resources for the development of an ethics committee.
- d. Resolution through litigation should only be an option of last resort.

9. Documentation

- 9.1 All discussions regarding decisions about withholding or withdrawing life-prolonging medical treatment must be documented in the resident's medical record.
 - a. Discussion with residents about their rights to choose or refuse treatment should be encouraged.
 - b. Staff should be educated to note all such conversations in the resident's chart; the notation should include what the resident said, when, and with whom the conversation was had.
 - c. Residents with decisional capacity who state specific treatment preferences should be encouraged to make written advance directives.
 - d. Procedures should be developed for storing this information so that it is easily retrievable.

- 9.2 Documentation regarding the process of selecting a surrogate not appointed by the resident is recommended.
- 9.3 Documentation of a resident's decisions to forgo life-prolonging treatment should include
- a. orders necessary to implement such decisions;
 - b. the basis for making the decision;
 - c. the process by which the decision was made, for example, "after consultation with the resident" or "after consultation with the family" or "in consultation with the ethics committee;" and
 - d. notice that all persons directly involved in the care of the resident have been informed about decisions to forgo life-prolonging treatment.
- 9.4 If a resident has an advance directive, it must be part of the resident's permanent medical record. Keep the directives in a designated location within the record to make them easily accessible.
- a. Federal legislation and state regulation requires that at the time of admission long-term care residents/surrogates must be informed of their rights to choose or refuse any medical or surgical intervention consistent with state law and of their right to make advance directives.
 - b. When admitting a resident from the care of another facility, institution, or organization, the long-term care facility should request a copy of any advance directive in the resident's records at the time of transfer.
 - b.i The resident/surrogate should be informed that a copy of the directive has been transferred to the facility.
 - b.ii The resident should be asked to confirm that the document appropriately represents his or her treatment preferences.
 - b.iii Conversely, when transferring residents to the hospital or to another facility, a copy of their advance directive should be transported with them.
 - c. It must be noted in the resident's record whether or not he or she has an advance directive, and if they are presented with a document, facilities must make the document part of the resident's permanent record. However, so long as a resident maintains decisional capacity, an advance directive has no effect.
 - d. If the resident is incapable of receiving information regarding advance directives, information about advance directives should be presented to the resident's surrogate. However, guardians or surrogates may not complete advance directives on behalf of the resident.
 - e. If a resident regains decisional capacity, information about advance directives should be given to the resident at that time.

- f. Facilities should discuss the right of self-determination (including the right to make advance directives) at least annually with all residents who have decisional capacity.
 - g. Facilities should provide assistance to residents who express interest in completing an advance directive.
 - h. Although having information provided in an advance directive (particularly the designation of a surrogate in a durable power of attorney for healthcare decisions) is extremely valuable to long-term care facilities, residents may not be required to complete an advance directive.
 - i. Long-term care facilities are required to develop a process whereby residents with decisional capacity are given an opportunity to review their directives at least annually (13 CSR 15-18.010 [9]).
 - j. Because of limitations on some older documents, for example, the terminal condition requirement in statutory living wills, facilities should offer to the resident more updated forms of advance directives such as a Healthcare Treatment Directive.
 - k. Residents/surrogates should be informed of new legislation (either state or federal) that may affect their rights to make healthcare treatment decisions.
- 9.5 Do Not Resuscitate Orders (e.g., DNR Orders, No Code Orders, No Code Blue Orders, Pre-Hospitalized Do Not Resuscitate Request Forms, Outside the Hospital Do Not Resuscitate Request Forms)
- a. DNR is a medical order for an individual resident that applies to cardio-pulmonary resuscitation (CPR) only.
 - a.i It requires a physician's signature after discussion with a resident with decisional capacity. (No other signature is required.)
 - a.ii The medical record should include the rationale for the decision.
 - a.iii Residents with decisional capacity should always be involved in DNR decisions.
 - a.iv DNR orders for persons without decisional capacity should be discussed with surrogates, and families should be informed of a decision to initiate a DNR order and of the rationale for making the order. However, their permission is not required.
 - a.v If there is no appropriate surrogate and CPR is deemed to be medically futile or clinically inappropriate, a decision to enter a DNR order can be made providing such a decision is within prevailing medical standards.
 - b. Advance directives and DNR orders are separate documents with separate purposes and one should not be confused for the other.
 - c. A determination to enter a DNR order may be based on

- c.i A resident's wishes after medical consultation, for example, a resident does not want CPR due to his/her perceived poor quality of life;
- c.ii Preferences stated in and consistent with an incapacitated resident's advance directive;
- c.iii Direction provided by a legally authorized agent after medical consultation, for example, durable power of attorney; and/or
- c.iv A determination by the physician that the treatment would be futile or clinically inappropriate for a resident without decisional capacity or an advance directive.

9.6 Transfer Orders

- a. A resident/surrogate may request transfer from a long-term care facility at any time and for any reason including a treatment decision that is inconsistent with a policy or the mission of a facility. The facility has an obligation to assist in the orderly transfer of that resident to another facility or location.
- b. Residents have a right to refuse hospitalization and residents'/surrogates' requests not to transfer should be honored.

10. General Guidelines for the Care of Dying Persons

- 10.1 Palliative care should be provided to dying persons.
- 10.2 Physical care should be directed by a plan of care that recognizes that the resident is dying.
- 10.3 Areas of special concern are pain medication, nutrition and hydration, and DNR orders.
- 10.4 Pain medications should support the goals of treatment.
 - a. Most often when caring for a resident who is terminally ill, the primary goal is to alleviate the pain and suffering of the resident as he or she describes it.
 - b. Some residents may choose to endure suffering in order to be more alert; other residents may choose to be sedated in order to experience less pain.
 - c. Addiction to narcotics is not a legitimate concern. Drug dependency is appropriate for a person experiencing persistent pain and is not the same as drug addiction.
- 10.5 The nutrition and hydration needs of each resident should be based on one's wishes, medical condition, and the goals of treatment as determined by the physician.
 - a. Food and water should continue to be offered as needed or desired (not just at meal times) to dying persons.

- b. Food and fluids should always be provided to any person who requests them. However, it is inappropriate to force feed a resident against his or her wishes. (Force feeding includes syringe feeding.)
 - c. It is inappropriate to threaten residents with tube feeding if they refuse to eat.
 - d. Appropriate mouth care is important for persons who are dehydrated.
- 10.6 Psychological, social, and spiritual needs of residents, families, and care providers are of primary importance and should be addressed in the plan of care.
- a. Needs and desires of the dying resident should be the primary concern rather than strict adherence to institutional rules.
 - b. Staff need to be supported in assisting residents to meet these needs as well as their physical needs.
 - c. Psychological, social, and spiritual services should reflect the resident/family's expressed wishes.
- 10.7 Bereavement support should be provided for survivors and caregivers.
- a. For the benefit of other residents, it is important to acknowledge death.
 - b. Staff should have an opportunity to discuss and affirm their feelings about a resident's death.
 - c. Residents should also have an opportunity to discuss and affirm their feelings about this experience.

Conclusion

The process that led to the development of these guidelines involved collaboration among many individuals with diverse backgrounds. The guidelines themselves provide relevant ethical, legal, medical, nursing, regulatory, psychological, social, and spiritual considerations to help long-term care facilities develop resident-focused policies concerning life-prolonging treatments. They reflect the importance of a common sense, resident-focused, interdisciplinary team approach to decision making in long-term care facilities. There are no simple solutions to these difficult decisions. The Task Force recommends that the decision-making process in long-term care facilities be expanded beyond legalistic and regulatory concerns to embrace the resident-focused considerations that are set forth in this document.

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