

A GUIDE TO BUILDING A HOSPITAL-BASED

Palliative Care Program

Center to
Advance
Palliative Care™

capc

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CAPC's MISSION is to increase the availability of quality palliative care services, in hospitals and other health settings, for people living with serious illness.

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INTRODUCTION

What is palliative care?

Palliative care, also known as palliative medicine, is the medical specialty focused providing relief from the symptoms and stress of serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, social workers and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Why hospital-based palliative care?

Fundamental shifts in the nature of today's population have forced hospitals to face new challenges. As medical advances allow people to live longer, chronic illness is transforming the demand for medical services. While acute care has historically been the prevailing focus of hospital care, today an increasing number of patients require long-term management of complex and multiple chronic illnesses.

Because they are rooted in a health care system structured to provide acute care, many institutions are hard-pressed to deliver well-managed, high-quality care for those with debilitating chronic and life-threatening illnesses. Hospitals are working to overcome the fragmentation of the health care system to better serve the needs of these patients and to balance services for episodic, acute illness with whole-patient care responsive to ongoing medical needs over time.

Hospital-based palliative care programs are enabling leading hospitals to provide patients with coordinated, effective, and efficient care. As a result, the number of academic, community, and faith-based hospitals instituting palliative care services continues to grow rapidly with strong and successful track records in:

- ▶ Improving patient outcomes through expert pain and symptom control
- ▶ Expediting communication and decision-making for patients, family members, and health care providers
- ▶ Increasing coordination among health care providers
- ▶ Easing patient transitions between care settings
- ▶ Boosting patient and family satisfaction and hospital loyalty
- ▶ Reducing the burden of time-intensive and complex cases to improve staff satisfaction and retention
- ▶ Applying a more systematic approach to outlier (long length of stay) patients
- ▶ Promoting beneficial care, resulting in more appropriate use of hospital resources, cost avoidance, and improved bed capacity
- ▶ Meeting The Joint Commission quality, training, and accreditation requirements.

A Guide to Building a Hospital-Based Palliative Care Program is intended to help hospitals, health systems, and health care partners establish and sustain hospital-based palliative care programs.

This *Guide* focuses on the provision of palliative care in the broadest sense, that is, availability of palliative care throughout the course of an illness and without regard to prognosis. However, program planners must also become familiar with the availability of hospice services within a hospital's inpatient setting and in the surrounding community to better identify palliative care resources and partners, and to understand the role of home-based and inpatient hospice in effective discharge planning and continuity of care. Appendix H provides a summary of Inpatient Hospice Care.

About CAPC

This *Guide* was developed by the Center to Advance Palliative Care, a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness. As the leading resource for palliative care development and growth, CAPC provides health care professionals with the training, tools and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings.

Funding for CAPC is provided through membership and the generous support of foundations and private philanthropy. Technical assistance is provided by the Icahn School of Medicine at Mount Sinai, in New York City. More information on CAPC's resources is available at www.capc.org.

About this Guide

A Guide to Building a Hospital-Based Palliative Care Program was developed by the Center to Advance Palliative Care (CAPC) to help hospitals establish high-quality, successful and sustainable palliative care teams.

Across the continuum, patient and family palliative care needs must be met by a genuine and collaborative partnership among all providers including hospitals, hospices, long term care facilities, and home health agencies. Close coordination between palliative care providers is critical to achieving continuity of care throughout the full course of an illness and across the continuum of care settings.

Successful hospital-based palliative care programs require strong leadership within the hospital. While *A Guide to Building a Hospital-Based Palliative Care Program* may be useful to any proponent seeking to establish palliative care services, the focus of this publication is on a hospital audience. References to the planning team, administrators, financial specialists, and the like will typically refer to professionals working within the hospital. Likewise, policies, procedures, and best practices will also be discussed in the context of the hospital.

Drawing on the experiences of a variety of thriving palliative care teams, the *Guide* describes seven stages to launching and running a quality program:

1. The Case for a Hospital-Based Palliative Care Program
2. Designing an Operational Plan
3. Presenting the Business Plan
4. Implementing Palliative Care Services
5. Measuring Program Quality and Impact
6. Marketing the Palliative Care Program
7. Sustaining and Growing the Program

The Appendices contain examples of tools and guidelines, as well as sample policies and procedures.

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BUILDING THE CASE FOR HOSPITAL PALLIATIVE CARE

Securing Support

Mission Alignment

The common denominator of all successful palliative care programs is an ability to demonstrate how the provided services contribute to the hospital's mission. Effective palliative care proponents understand the priorities of hospital leaders, and ensure that the program proposed, designed, budgeted, and implemented reflects and remains consistent with institutional goals. At each stage, proponents think and work from the perspective of hospital leaders, whose goals are often framed differently from those of palliative care proponents. While quality of care is a compelling concern for advocates and hospital leaders alike, administrators are also responsible for the institution's fiscal health and viability. As a result, proponents need to focus on the fiscal and operational impact of palliative care in addition to its clinical results. Aligning the palliative care program focus with the priorities of hospital leadership is sometimes called "mission alignment."

This section of the *Guide* will explain how to gain an understanding of hospital priorities and needs in order to constitute a compelling palliative care case and secure institutional support for a program.

This *Guide* will highlight the role of mission alignment in program design, budgeting, implementation, and sustainability. Mission alignment is a long-term process, not a one-time effort. Leaders of successful palliative care programs recognize the need to be responsive to the priorities of hospital leaders, not only at the outset, but also over the lifetime of the program.

Core Planning Team

Far beyond a one-person endeavor, building a palliative care program requires the establishment of a core planning team to take on the primary responsibility for program development. Completing the bulk of the work and investing both time and reputation to achieve success, the team will gather and analyze the information that will define the need for palliative care and the already available institutional strengths and resources. The team

will develop a compelling case demonstrating how palliative care services will contribute to hospital priorities and key initiatives.

The core team members and roles associated in making the case for a palliative care program¹ may include the following:

- ▶ **Medical staff leader**—A physician with known commitment to and experience in comprehensive care and expert symptom management. Prior knowledge of and experience with palliative care would be useful. The medical staff leader should have credibility and respect among peers. A leader will provide political influence, demonstrate the clinical need for a program, and generate program support among medical leaders and physicians at the hospital.
- ▶ **Nursing leader**—A clinically oriented nurse with advance practice skills. Prior knowledge of and experience with palliative care would be useful. The nurse should also be a staff leader with credibility and respect among peers. In partnership with the medical staff leader and administrators, the nurse representative will support the analysis demonstrating need for a hospital-based palliative care program.
- ▶ **Hospice representative**—Linkage to one or more hospice providers connects long established community palliative care expertise with the developing program and creates a crucial connection with existing community-based and inpatient hospice programs.
- ▶ **Administrative champion**—A high-level hospital administrator or board member who believes in the concept of hospital-based palliative care, recognizes both patient and hospital advantages, and is willing to bring the case forward. The administrative champion will also exert influence to help gain access to the hospital data necessary to make the case.

In choosing the planning team, select strong team members who work well together and are respected and recognized by hospital leaders and their colleagues. Of equal importance is the selection of a leader with the management and administrative skills necessary to collaborate not only with an interdisciplinary team, but also with associated programs, community institutions, leaders and stakeholders (see “Soliciting Colleagues Opinions and Support” on page 1.6). While the key players’ roles and involvement level will change over the program life span, ongoing support and commitment from the planning team will contribute to the long-term integration and sustainability of a hospital-based palliative care program.

¹ Information on core team members and roles is adapted from "A Guide to Palliative Care Programs and Services" Copyright 2002, HCA Management Services, LP, Nashville, TN and was developed with the assistance of Oncology Associates Inc., Victoria, VA, and used by permission.

Reconnaissance: Assessing Hospital Priorities

To forge the critical connection between the palliative care cause and the hospital leadership's mission, the planning team must perform quick reconnaissance to identify organizational priorities and assess concordance with palliative care benefits. The planning team can then make a case for a palliative care program that reflects the hospital's strategy, institutional and departmental priorities, and business concerns. Simple information-gathering techniques are outlined below:

- ▶ **Identify institutional priorities.** Begin by obtaining a copy of the hospital's mission statement or the most recent annual report, which should include the mission, vision, and goals of hospital leaders. Discussions with an executive at the vice-president level can also help to ascertain institutional priorities and initiatives for the year, as well as the fiscal calendar and best timing for new program requests. The goal is to identify a number of priorities that palliative care can help to address, such as reducing length of stay (LOS), improving nursing retention, or development of enhanced cancer care services.
- ▶ **Determine how management and administrative decision-making work in the institution.** The more the planning team knows about how decisions are made, the better the position of the palliative care program. Learn the answers to the following questions: Who reviews, approves, and funds programs? The chief operating officer? A department chairperson? How does that process work? What are the procedures and timing? Ask for a recent example of the process followed by a successfully-funded new program.
- ▶ **Determine ongoing initiatives related to palliative care and identify those in charge or their representatives.** What resources are already in place? Hospice contracts? Pain service? Case management? Who is working on length of stay initiatives, case management issues, discharge planning, The Joint Commission accreditation, quality improvement initiatives, and pain guidelines? What are manager perspectives on the clinical and financial impact of complex, long-stay patients? What are senior management's concerns about disciplines important to palliative care programs (medicine, nursing, social work, pharmacy, pastoral care, case management)? How are services integrated or coordinated between departments and/or disciplines?
- ▶ **Identify an administrative/financial champion to help the program thrive as part of the larger organization.** Who can be a supportive, knowledgeable ally with regard to ensuring that the palliative care program stays aligned with institutional priorities? The individual should be familiar with the budget cycle, information technology, accreditation schedule, and funding priorities.

- ▶ **Identify potential allies and possible sources of resistance.** Who has influence over new clinical programs and clinical decisions? The vice president for nursing? The head of social work? Department chairpersons? Who are recognized leaders within various medical specialties that treat the hospital's sickest patients (e.g., oncology, critical care, cardiology, and neurology)? What are their priorities? What is their level of interest in palliative care? Who would benefit from the implementation of a palliative care program? Who might feel threatened? What services related to palliative care are presently available, such as a pain service, case management, hospice partnerships, or support for caregivers? How might the palliative care team ally and collaborate with these initiatives?
- ▶ **Identify and gain an understanding of opinion leaders and stakeholders.** Every hospital has unique opinion leaders and stakeholders which may include the governing board; administrative leaders from various departments; physicians; patients and families; or community leaders, including those aligned with area hospice programs. The reconnaissance suggested here will help identify key stakeholders who will determine the palliative care program's success or failure. Working to gain the endorsement of opinion leaders and addressing the concerns of stakeholders will be worth the effort.

Opinion Leaders—Leaders and decision makers willing to lend support and use their influence within the hospital. While not taking primary responsibility for program development, these people can garner resources for the effort, mobilize allies, and lend their reputation and stature. Potential opinion leaders can be hospital administrators and board members, clinician leaders, or community advocates.

Stakeholders—Individuals who may have a vested interest in, or be affected by, the palliative care program. Since stakeholders have a significant influence, in that their actions can either facilitate or block program approval and development, understanding their views and interests will contribute to the palliative care initiative's success. Potential stakeholders include:

- **Senior Administrator**—*Senior managers have responsibility for tracking the hospital's patient population and the financial, clinical, and quality indicators (e.g., length of stay, ICU days, pain levels, patient satisfaction) that influence top decision-makers. Engagement of these individuals is critical to success.*
- **VP Nursing or Nurse Manager**—*Nursing leadership is especially important since nurses are the front line professional caregivers for hospitalized patients. Palliative care helps the nursing staff provide patients with high quality care and improves nurse retention.*

- **Social Workers**—Professionals work with patients and families within the hospital, and focus both on psychosocial needs and mobilizing community resources on behalf of patients and families.
- **Hospice Leadership**—Administrative and clinical leaders from community hospices are important resources and advocates for hospital-based palliative care programs. Hospice leaders will be interested in partnering to extend access to palliative care as well as ensuring continuity of care for those patients wishing to elect hospice services during the course of their illness.
- **Pain Management Specialist**—Pain management service providers may be interested in integrating any existing pain management programs/services with palliative care, in developing new pain management services, or in determining potential overlap and duplication with pain services.
- **Ethics Committee and Consultation Service**—Clinically active ethics programs are usually involved in the delivery of some core aspects of palliative care including support for complex decision-making and improving communications among patient, family, and health professionals.
- **Chaplain**—Spiritual care professionals offer supportive services and connections with community agencies and religious communities necessary to address the spiritual needs of patients who will be served by the palliative care program.
- **Clinical Pharmacist**—Pharmacists assist with more appropriate use of medications that result in better clinical care and significant savings for the institution.
- **Nutritionist**—Nutritionists assist in identifying alternative approaches to feeding and can contribute to hospital efficiency and/or decreasing length of stay.
- **Other Key Stakeholders**—A range of groups or individuals may have an interest or role in ultimate program success, including oncologists, intensivists, case managers, and discharge planners. In some organizations, the planning team includes a patient with a serious chronic disease or a family member with an ability to articulate what is needed and missing from the existing system of care. Such insight, or similar findings from patient/family interviews or focus groups, can be valuable during the project's planning phase to put a human face on the clinical need for palliative care.

Conducting a System Assessment and Needs Assessment

Once information has been gathered about hospital priorities, the planning team should conduct both a system assessment that focuses on existing strengths, and a needs assessment that identifies weaknesses, opportunities, and challenges. Conducting these assessments is essential to determining how a palliative care program can best leverage existing resources to address needs of both the patient and the hospital.

Soliciting Colleagues' Opinions and Support

Asking for input from colleagues is an essential first step in planning a new palliative care program. Interviewing colleagues not only allows the palliative care team to collect information helpful to making the case for palliative care, but also raises awareness within the hospital and builds support. Thinking of colleagues as palliative care program clients is key to generating support. While palliative care advocates tend to focus mainly on patient benefits, meetings with colleagues should be focused on how palliative care can help the colleague (talking points for clinicians are provided in Section 6: "Marketing the Palliative Care Program"), in addition to helping patients and families.

After collecting information on the institution, the planning team conducts the initial interviews that will continue throughout the process of securing support, implementing, evaluating, and sustaining the palliative care program.

The planning team has three goals while speaking to these groups:

- First, determine colleague perspectives. Identify key concerns so that the palliative care team can provide services responsive to colleague priorities.
- Second, gauge colleague interest in and opinions of palliative care. Find out who might support a program, what barriers exist, and what misperceptions about palliative care could impede establishing a program.
- Third, frame palliative care in a manner appealing to colleagues. Gain insight into these people's unique perspective to discuss the likelihood that a palliative care program could help meet both patient and institutional needs. A broad definition is important when discussing palliative care. Good palliative care is based on the needs of both patients and families, regardless of prognosis. Palliative care improves the quality of life for seriously ill patients, and builds professional pride and satisfaction for the institution.

In selecting interview subjects, look for people who have access to the information the planning team will need, as well as people who can help or hinder the case for palliative care. Potential interview subjects are:

- | | |
|----------------------------------|--|
| ■ Vice president of nursing | ■ Vice president of extended care services |
| ■ Hospital planners | ■ Hospitalists |
| ■ Case management leaders | ■ Intensivists |
| ■ Ethics committee leaders | ■ Oncologists |
| ■ Director of pain services | ■ Discharge planners |
| ■ Director of oncology | ■ Nursing home leaders |
| ■ Director of critical care | ■ Billing/information technology leaders |
| ■ Director of geriatrics | |
| ■ Hospice leaders | |
| ■ Director of home care agencies | |

System Assessment

The purpose of a system assessment is to identify existing strengths within the hospital system that could benefit a palliative care program through partnership, collaboration, and support. Examples of such resources include:

- MD and RN clinicians with interest and/or training in palliative care
- Relationships or contracts with hospice, including community-based and with hospital and/or system linkages
- Case management and discharge planning programs
- Hospital chaplaincy program
- Hospital focus on length of stay, ventilator days, and pharmacy/ancillary costs per day
- Palliative care interest based on personal or professional experience
- Pain services
- Computerized medical records
- Community interest in and support for palliative care
- Trustee or board or philanthropic interest in palliative care

A system assessment tool has been designed to help organizations focus on their existing infrastructure as they plan a palliative care program. The system assessment tool is provided in Appendix C.

Needs Assessment

Once a system assessment is performed, identify areas of need to highlight where palliative care programs make the greatest contribution. Major areas that have shown improvement as a result of palliative care include:

- Pain and symptom management
- Patient and family satisfaction
- Nurse retention and satisfaction
- Bed and ICU capacity
- Length of stay
- Pharmacy costs
- Establishment and strengthening of hospice partnerships
- Fragmented subspecialty care

Palliative Care Needs Assessment Checklist

- Does the hospital have a patient population that would benefit from a palliative care program?
- Does the hospital currently provide services that could benefit from collaboration with a palliative care program?
- Do pain and symptom distress scores for patients with life-threatening conditions show room for improvement?
- Do staff satisfaction surveys show staff stress related to perceived understaffing for the treatment of patients with life-threatening illness?
- How will the palliative care program save the hospital money?
- How will the palliative care program help the hospital increase bed capacity and revenues?
- How will the palliative care program help the hospital improve quality and meet The Joint Commission requirements?

- Time demands on physicians for complex communications and decision making
- Costs associated with outlier (long LOS) cases

A needs assessment will look at current care, the gaps in that care, and how the proposed palliative care program can leverage existing resources by facilitating “win-win” collaborative opportunities within the institution and with other providers in the community. A thorough needs assessment helps to ensure alignment with organizational priorities and resources, along with feasibility in the context of the practical constraints of the setting. By allowing the team to avoid preventable missteps and begin the process of building awareness and program support at the earliest stages, the needs assessment saves time in later stages of implementation. The above box lists a number of questions the planning team should address.

Using Hospital Data

An important aspect of making the case for palliative care is the collection and analysis of data from the hospital and affiliated partners. The purpose of analyzing these data is to illustrate the basic need for and expected benefits of a successful palliative care program. The types of data needed vary by institution, but cover three general areas: clinical outcomes; financial impact; and satisfaction among patients, families, and staff.

- ▶ **Clinical Outcomes.** The analysis will examine clinical outcomes for complex, long-stay hospital patients and offer predicted improvements in pain and symptom management, functional status, discharge plan, and quality of life.
- ▶ **Financial Impact.** Hospitals often review new clinical programs based on their potential for revenue generation. While palliative care programs do bring in income through clinical billing, their greatest impact is on **cost avoidance and increased capacity.** Management of complex cases through palliative care programs contributes to improvements in clinical care while leading to more effective resource utilization and earlier patient discharge to more appropriate community settings. By offering palliative care expertise to existing providers, the hospital is positioned to furnish the right care to the right patient at the right place and time. Since palliative care programs can reduce length of stay for complex cases, the hospital capacity increases for new admissions, thus directly contributing to revenue generation.
- ▶ **Patient and Staff Satisfaction.** Patient and staff satisfaction surveys generally show palliative care programs improve the satisfaction levels of patients, families, and staff. Increases in patient and family satisfaction have been linked to institutional loyalty and substantial philanthropic gifts. Higher staff satisfaction resulting from collaboration with palliative care programs results in better staff retention and greater physician loyalty, thus generating more referrals and an increase in market share.

Analysis of hospital data is not only important in the needs assessment and planning process, but is also critical to designing, operating, and on-going justification of a high-quality and effective program.

Finding Data in the Hospital

While the palliative care planning team might not be familiar with the information the hospital collects, hospital information technology (IT) staff will be and can serve as resources to help find and examine the necessary data. This effort simply helps leadership make a sound and pragmatic business decision. The analysis documents the hospital's clinical and financial need for palliative care services and the expected benefits to patients and hospital. Such institution-specific evidence is extremely powerful in shaping decisions about the program.

Page 1.11 lists hospital data required for palliative care needs assessment, along with other useful data. Data describing the patient population, associated costs, and revenues are usually available from the hospital information technology, billing, and medical records departments. A decision analyst from finance or case management should participate on the planning team to help obtain financial, demographic, and clinical data.

Quality or compliance staff will be good sources for data on clinical outcomes since The Joint Commission mandates regular assessment of symptom distress in hospitalized patients.

Likewise, since The Joint Commission requires that hospitals conduct post-discharge consumer satisfaction surveys, hospital quality or compliance staff are sources for data on untreated pain, delays in treatment, perceptions about an “impersonal” experience, poor communication, poor continuity of care, or other priorities for improvement.

Some specific areas in which palliative care addresses The Joint Commission requirements include standards for:

- Pain and symptom management
- Continuum of care
- Health care provider/patient/family communication
- Education and support of staff, patients, and families

Some human resource departments conduct employee surveys that provide employee satisfaction data and data on stress related to perceived understaffing for the care of patients with life-threatening illnesses.

Surveying Clinician and Staff Understanding

The planning team may want to conduct its own survey to assess clinician and staff understanding of and support for palliative care, and to document clinician priorities and concerns that could be addressed through a palliative care program. This exercise has additional benefits, as it:

- Serves as a tool to inform clinicians about palliative care
- Demonstrates interest in and respect for clinician opinions
- Yields data relevant to making the palliative care case to administrators

Sample clinician surveys and instructions for conducting this type of research may be found on CAPC’s web site, www.capc.org.

Applying Results

Specifically, the system and needs assessment analyses will help the team to:

- **Identify gaps in clinical care** such as inadequate pain management or prolonged LOS in specific patient subgroups. These are opportunities for clinical improvements.

Useful Data for Palliative Care Programs

Statistics Describing the Hospital

- Total number staffed acute inpatient beds in the hospital
- Overall hospital occupancy rate (e.g., average filled beds)
- ICU occupancy rate
- Average LOS for all admissions
- Average LOS for Medicare admissions
- Average LOS in ICU
- Number of admissions with a LOS of more than 20 days
- Number of admissions who die in the hospital
- List of top 20 Diagnostic Related Groups (DRGs) by case frequency for patients who die as inpatients
- Mean and median LOS for an admission within top 20 DRGs
- Mean and median LOS for top 20 DRG patients who died in the hospital vs. those in same DRG discharged alive
- Mean and median LOS for DRG 483 (tracheostomy with mechanical ventilation 96+ hours) for those who died in the hospital vs. those discharged alive
- Payer mix for patients who die in the hospital
 - *Percent of Medicare*
 - *Percent of Medicaid*
 - *Percent of private pay*
- Dedicated hospice unit (Yes/No)
- Number of hospice beds
- Hospice contract(s) (Yes/No)
- Number of hospice referrals per year

Description of Hospital Patient Population

- Annual number of admissions for patients under 21, 22-64, and over 65
- Total number of hospital admissions per year
- Total number of Medicare admissions per year
- Total number of Medicaid admissions per year
- Total number of private pay patients

Data on Clinical Outcomes

- Assessments of pain and symptoms
- The Joint Commission pain scores
- Advance care plans
- Documented goals of care
- Chart review of clinical assessments and interventions

Patient and Family Satisfaction Data

- Pain and symptom control
- Treatment quality
- Attitudes of providers
- Timeliness of provider response
- Provider communication
- Customer service

Measures of Staff Satisfaction

- Retention rate of staff
- Stress due to time pressures
- Perceptions of understaffing for care of patients with life-threatening conditions

- ▶ **Develop an implementation strategy** by determining which units or specialties have the highest concentration of patients in need of palliative care. For example, do the data suggest starting with oncology, surgery, cardiology, or critical care settings?
- ▶ **Estimate the financial opportunity** for avoiding unnecessary costs once clinical gaps are identified and addressed. By first determining what improvements are needed and the feasibility of closing the clinical quality gap, the resulting financial implications (such as reduced LOS or reduced cost per day) can be assessed.
- ▶ **Create program budgets** by identifying required resources including the number and types of palliative care staff necessary to care for the projected type and volume of palliative care patients.

Developing the Financial Case

Demonstrating contributions to hospital financial viability will help to secure administrator support for a new program. Palliative care programs make their major contribution to the bottom line through cost avoidance, through reduced LOS and reduced cost per day. Palliative care programs also enhance revenues by increasing hospital capacity. This is discussed later in this section (see “Sources of Revenue Credited to Palliative Care Programs”).

Unfortunately, hospital accounting practices may not track all costs by case, or may use cost allocation methods that inhibit clear identification of cost impact. Such a reality requires the team to conduct its own data collection and analysis in order to make the financial case for palliative care.

This section presents principles to guide financial analyses and suggestions for highlighting the important financial benefits achieved by hospitals with palliative care programs.

Estimating Financials for Palliative Care Programs

A first priority in demonstrating how palliative care programs can reduce unnecessary costs is to ascertain the volume of patients who will benefit from the palliative care program. The planning team can estimate program admissions using generally available hospital statistics on patient volume and type (e.g., total admissions in certain disease categories) and also derive estimates from more specific subsets of admissions (e.g., certain DRGs, admissions with LOS >10 days, etc.).

There is no “right” way to predict the volume of patient referrals or the impact that the palliative care program may have. Referral volume is a function of the need for and awareness of the palliative care program as well as a willingness to refer. Impact is a function of the opportunities for improvement, the comprehensiveness and consistency of the palliative care interventions, and the degree of compliance with recommendations. The following

sections demonstrate approaches to predicting potential patient volume using hospital data on total admissions and high potential DRGs. An approach to translating projected patient volume into potential savings based upon reasonable assumptions and outcomes from other programs follows.

The focus of palliative care is on patients suffering from debilitating serious and chronic illnesses. Assuming that patients who die in the hospital tend to be in great need of palliative care services, an analysis of the number of patients who die in the hospital helps predict the minimum potential volume of palliative care patients. There are two ways to estimate volume and other characteristics for a palliative care program. The first applies national mortality statistics to total admissions. The second uses DRGs with high inpatient death rates. These approaches are described below.

Estimating Financials through Total Admissions

National data indicate an average inpatient death rate of 2.5%.² Palliative care programs report that approximately 50% of palliative care inpatients die in the hospital. If this 50% represents the 2.5% of hospital admissions who die in the hospital, then the other 50% (those palliative care patients who are discharged) represents an additional 2.5% of hospital admissions who could benefit from palliative care. Thus, a conservative estimate of the potential volume for a palliative care program is 5% of all hospital admissions. If the inpatient death rate in the hospital is higher, then the estimated volume of potential palliative care admissions will also be higher.

A palliative care program will not receive referrals for all patients who could or should be referred, but referrals will increase over time as awareness increases. Thus, the planning team will need to set a number of referral rate targets for the first several years, e.g., what percent of appropriate palliative care patients will actually be referred. Projecting target goals for the initial years is discussed in “Estimating Staffing and Projecting Growth” in Section 2.

² Ratio of Deaths to Discharges 2.4% based on national statistics for 2000 from AHRQ Healthcare Cost and Utilization Project. Agency for Healthcare Research and Quality, Rockville, MD. www.ahrq.gov/data/hcup/hcupnet.htm

Ask hospital finance staff for the overall number of hospital admissions and average LOS for the latest 12 month period or calendar year:

1. Apply 5% estimate (discussed on page 1.13) to total admissions to approximate volume of patients who would benefit from palliative care services. In the example, 800 admissions could be referred to the program annually.
2. By assuming a 20% referral rate for Year 1 and applying it to the potential annual volume of 800 admissions who would be palliative care-appropriate, the team estimates a volume of 160 palliative care referrals in Year 1.
3. The planning team can also estimate the average LOS, total annual patient days, and average daily census. The team must know the hospital's average LOS; in this example it is 6 days. Since the majority of palliative care patients have more complex conditions, the team assumes average LOS in the palliative care program will be 2 days longer (i.e., 8 days).
4. Referrals to the palliative care program are unlikely to be made prior to the 3rd day of admission, so the team subtracts 3 days to estimate the average palliative care program LOS at 5 days.
5. By multiplying the estimated number of referrals to the program by the average program LOS, the team determines the total annual patient days in the program (which, when divided by 365 days, provides an estimate of the program's average daily census).
6. A census of 2.19 patients per day in year 1 has implications for estimating staffing needs. "Estimating Staffing and Projecting Growth" in Section 2 will demonstrate how daily census numbers help determine staffing needs.

Estimating Year 1 Referrals

Admissions/year	16,000
% Total Admissions Palliative Care Appropriate	x 5%
Potential Annual Volume Patients Who Could Benefit	800 patients
Referral Rate Year 1	x 20%
Estimated Year 1 Program Referrals	160 patients

Estimating Average Palliative Care Program LOS

Hospital's Average LOS	6 days
Assume LOS Increase	+2 days
Average LOS for Palliative Care Patients	8 days
Assume Day of Referral	- 3 days
Palliative Care Program Average LOS	5 days

Estimating Total Patient Days and Average Daily Census for Palliative Care Program

Estimated Year 1 Program Referrals	160 patients
Average Palliative Care Program LOS	x 5 days
Total Palliative Care Patient Days	800 patient days
	÷ 365
Average Palliative Care Daily Census	2.19 patients per day

Estimating Financials by Identifying High Potential DRGs

To understand the hospital patient population most likely to benefit from palliative care, examine hospital data by the Diagnostic Related Group (or DRG classification). For example, which DRGs represent patients most likely to have unmet palliative care needs? Which are associated with the most deaths in the hospital? Which have the greatest LOS? Which DRGs have the highest costs?

The following approach analyzes past admissions by DRG, identifies patients as likely palliative care candidates, and suggests admission subsets for analysis of the financial case. Data on these patient segments ensures that palliative care effects are visible to administrators.

To identify high potential DRGs, follow the steps below.

1. For the most recent 12 months or calendar year, request filtering of total admissions to include only those meeting the following criteria:
 - **The length of stay was longer than two days.** Typically, referrals to palliative care will not happen before the second or third day after admission. Patients with stays of two days or less are unlikely to be referred.
 - **Payers using a fixed rate of reimbursement (such as Medicare).** In this patient group, reduced LOS or more appropriate utilization of services is certain to represent fully realized savings to the hospital.
 - **The discharge status was “Mortality.”** Patients at the end of life clearly qualify for palliative care, yet data on their care is rarely analyzed.

Admissions can be filtered by other variables that can help to emphasize potential palliative care impact. For example, patients can be segmented by age or by admission to units other than medicine and surgery (e.g., neurology). For the filtered subset, identify the most frequent DRGs.

Exhibit 1 presents national data for the “Top 20 DRGs” associated with inpatient deaths. Such national data are helpful in identifying key DRGs and also provide benchmark data on LOS for comparison.

Exhibit 1. National Data on Top 20 DRGs for Inpatient Deaths

DRG	Description	# of Discharges	Mean LOS (days)	DRG as % of all Discharges	Deaths	% of DRG Discharges who Died	% of Total Inpatient Deaths	Ranked by Frequency
475	Respiratory system diagnosis with ventilator	190,058	11.3	0.5%	61,389	32.3%	7.1%	1
14	Specific cerebrovascular disorders except TIA	520,348	5.7	1.4%	54,637	10.5%	6.3%	2
123	Circulatory disorders w AMI, expired	54,491	4.4	0.1%	54,491	100.0%	6.3%	3
416	Septicemia age >17	293,080	7.3	0.8%	53,634	18.3%	6.2%	4
127	Heart failure & shock	1,019,065	5.1	2.7%	42,801	4.2%	5.0%	5
89	Simple pneumonia & pleurisy age >17 w CC	789,028	5.5	2.1%	40,240	5.1%	4.7%	6
79	Respiratory infections & inflammations age >17 w CC	240,909	8.5	0.6%	34,691	14.4%	4.0%	7
82	Respiratory neoplasms	131,369	6.5	0.4%	25,223	19.2%	2.9%	8
483	Tracheostomy except for face, mouth & neck diagnoses	90,210	40.4	0.2%	23,094	25.6%	2.7%	9
316	Renal Failure	198,530	6.3	0.5%	18,265	9.2%	2.1%	10
296	Nutritional & misc metabolic disorders age >17 w CC	399,916	4.8	1.1%	16,796	4.2%	2.0%	11
087	Pulmonary edema & respiratory failure	97,441	6.8	0.3%	16,273	16.7%	1.9%	12
148	Major small & large bowel procedures w CC	264,964	11.4	0.7%	15,368	5.8%	1.8%	13
385	Neonates, died or transferred to another acute care facility	84,071	5.8	0.2%	14,544	17.3%	1.7%	14
174	G.I. hemorrhage w CC	408,601	4.4	1.1%	13,075	3.2%	1.5%	15
203	Malignancy of hepatobiliary system or pancreas	64,833	6.4	0.2%	12,772	19.7%	1.5%	16
110	Major cardiovascular procedures w CC	99,828	8.9	0.3%	12,678	12.7%	1.5%	17
88	Chronic obstructive pulmonary disease	625,710	4.8	1.7%	11,888	1.9%	1.4%	18
172	Digestive malignancy w CC	64,509	7.0	0.2%	9,676	15.0%	1.1%	19
202	Cirrhosis & alcoholic hepatitis	92,907	6.1	0.2%	9,569	10.3%	1.1%	20
	Totals			14.8%	541,104		62.9%	

Total U.S. inpatient deaths: 860,934; Total U.S. discharges: 38,011,600

Statistics for U.S. hospital stays, Diagnosis Related Groups (DRGs), Healthcare Cost and Utilization Project (HCUP) Nationwide Inpatient Sample (NIS), 2001 (Data extracted, death statistics isolated, raw deaths calculated and ranked by Lynn Spragens Sept 23, 2003). Internet Citation: HCUPnet, Healthcare Cost and Utilization Project. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/data/hcup/hcupnet.htm>

2. Separate the admissions in the filtered subset by DRGs most frequently related to inpatient deaths, and request the following data for each DRG:

- **Number of admissions.**
- **Cost per admission or total annual cost per DRG.** Total annual cost will be helpful, since dividing the DRG's total annual cost by the DRG's total annual admissions will provide the cost per admission (substitute hospital charges only if costs are not available).
- **Average LOS per admission.** The total number of days per year for each DRG could be divided by the number of admissions in the DRG to calculate the average LOS for that DRG.

- Rank the DRGs in descending order by one or more measures (e.g., number of admissions, cost per admission, or average LOS per admission). Exhibit 2 shows hypothetical data ranked by cost per case. Choose approximately 20 of the highest ranked DRGs based on either frequency, costs, LOS, or need for palliative care from a clinical perspective. These admissions form a subset of data for more in-depth analysis (although the palliative care program will receive referrals far beyond these DRGs). This DRG analysis provides insight into the hospital's admission characteristics. In addition, the planning team now has important information on the costs for these admissions.

1.17

Exhibit 2: Hypothetical Example of Selected DRGs Ranked by Cost per Case

DRG	Description	# of Cases	LOS	Total "Cost"	LOS x #Cases= Total Days	Total Cost/ #Cases= Cost/Case	Total Cost/ Total Days= Cost/Day
483	Tracheostomy except for face	14	62.6	\$1,500,000	876	\$107,143	\$1,711.55
475	Respiratory system diagnosis with ventilator	39	11.1	\$650,000	433	\$16,667	\$1,501.50
82	Respiratory neoplasms	13	11.2	\$120,000	145	\$9,231	\$827.87
123	Circulatory disorders w AMI	35	6.3	\$292,000	219	\$8,343	\$1,332.72
127	Heart failure & shock	21	7.8	\$175,000	164	\$8,333	\$1,067.01
296	Nutritional & misc metabolic disorders age >17 w CC	11	9.0	\$85,000	99	\$7,727	\$858.59
79	Respiratory infections & inflammations age >17 w CC	26	8.5	\$187,000	222	\$7,192	\$842.19
416	Septicemia age >17	29	4.2	\$178,800	123	\$6,166	\$1,454.13
14	Specific cerebrovascular disorders except TIA	18	6.3	\$99,900	113	\$5,550	\$883.76
89	Simple pneumonia & pleurisy age >17 w CC	18	5.4	\$90,600	97	\$5,033	\$933.83

- For this subset of DRGs, ask the analyst to run a report for all admissions with a LOS greater than two days. This broadens the criteria to include all payers and people with any discharge status, not just those with a discharge status of mortality. Review this new listing to determine the DRGs that should be included in the program's initial focus. Are there clinical approaches that might better serve these patients? Where are they located in the hospital? Which specialists are involved? What unique resources might the palliative care program offer both clinicians and patients in these diagnostic categories?

5. Using this information, the team determines the top 20 DRGs and their average LOS. The team now defines a pool of patients who could benefit from palliative care as the total number of admissions in the top 20 DRGs. The average LOS for these patients can also be determined. Once the team assumes a referral goal for year 1 using the methods described on page 1.14, estimates of program referrals, average program LOS, and the program's average daily census can now be calculated. An example of this is shown below. If the total number of admissions in the top 20 DRGs equals 800 with an assumed referral rate of 20%, estimated program referrals equal 160 patients and average LOS for this patient pool equals eight days.

Estimating Year 1 Referrals		Program LOS		Estimating Total Patient Days and Average Daily Census for Palliative Care Program	
Potential Annual Volume Patients Who Could Benefit (based on total admissions for top 20 DRGs)	800 patients	Hospital's Average LOS	6 days	Estimated Year 1 Program Referrals	160 patients
Referral Rate Year 1	x 20%	Assume LOS increase	+2 days	Average Palliative Care Program LOS	x 5 days
Estimated Year 1 Program Referrals	160 patients	Average LOS for Palliative Care Patients	8 days	Total Palliative Care Patient Days	800 patient days
		Assume Day of Referral	- 3 days		÷ 365
		Palliative Care Program Average LOS	5 days	Average Palliative Care Daily Census	2.19 patients per day

Finding the Cost Savings

Up to this point, the team has taken steps to define a universe of relevant admissions (by focusing on DRGs, for example) and to highlight the clinical opportunities to serve that universe. Now the task is to estimate the potential savings that a palliative care program might generate.

Research demonstrates that by helping patients and their families decide on goals of care and selecting the treatments that meet such goals, palliative care can result in:

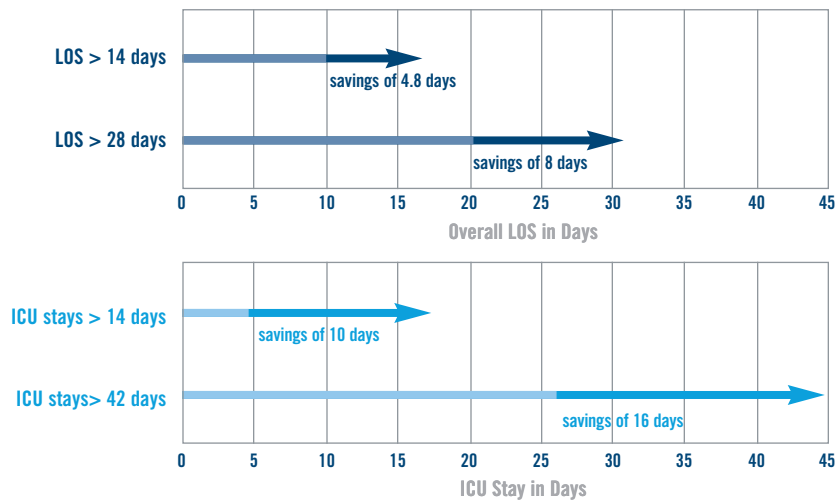
- Fewer trips to the ER
- Fewer unplanned admissions
- Reduced unnecessary ancillaries and pharmaceuticals
- Moving ICU days to lower intensity beds, and
- Reducing overall lengths of stay

In each case, the savings may come from shorter stays overall or a lower cost per day once the patient has been referred to palliative care. Savings might be realized by making

a significant impact on relatively few cases, or a smaller impact across a broad number of cases, or some mix of both.

In the case of patient LOS, the longer the LOS the greater the potential savings in bed days. The shaded areas in Exhibit 3 represent the savings in bed-days for patients who receive palliative care. Therefore, in documenting expected cost savings, long LOS patient groups should be examined to determine where the biggest initial opportunities might be.

Exhibit 3. Palliative care LOS savings as compared to non-palliative care, DRG-matched hospital deaths



Based on data from a presentation by: Sean Morrison, MD (Hertzberg Palliative Care Institute, Mt. Sinai Medical Center, NYC) at the CAPC seminar "Planning a Hospital-Based Palliative Care Program," New Orleans 10/11/2002.

One way to identify hospital savings is to compare the hospital's LOS data to national benchmarks as in Exhibit 4. Wherever the hospital's LOS data exceeds that of the national average there is an opportunity for clinical process improvement and cost savings. The box on page 1.20 offers sources for inpatient reference data to use in benchmarking hospital-specific data. Look for gaps to find opportunities for early program impact.

Once the team identifies potential areas for impact, a more in-depth investigation may be required to confirm the gap and determine what clinical process changes might improve the situation. Conducting interviews, chart reviews, and collecting anecdotal information may help explain why the hospital's data differ from national benchmarks.

Aggregate statistics are a necessary, but not sufficient, exercise to focus the clinical efforts of the palliative care team. A closer look at the detail behind an average LOS could reveal substantially different scenarios that generate the cost. For example, deviation from benchmarks could be due to processes affecting all patients, *or* most patients could be at or below benchmark, with a few outliers pulling up the averages. Closer analysis can also uncover other opportunities for intervention, as shown in Exhibits 5 and 6.

Exhibit 4: Hospital's LOS for Top DRGs Ending in Death Compared to National Benchmarks

Example: Top DRGs, Ranked by Case Frequency: LOS Compared to National Benchmarks

DRG	Description	# of Cases	LOS	Benchmark
475	Respiratory system diagnosis with ventilator	39	11.1	11.2
123	Circulatory disorders w AMI	35	6.3	4.4
416	Septicemia age >17	29	4.2	7.2
79	Respiratory infections & inflammations age >17 w CC	26	8.5	8.5
127	Heart failure & shock	21	7.8	5.1
89	Simple pneumonia & pleurisy age >17 w CC	18	5.4	5.9
14	Specific cerebrovascular disorders except TIA	18	6.3	5.9
483	Tracheostomy except for face, mouth & neck diagnoses	14	62.6	40.3
82	Respiratory neoplasms	13	11.2	6.9
296	Nutritional & misc metabolic disorders age >17 w CC	11	9.0	4.9

Based on actual results from a 300-bed hospital; used for illustration only

Benchmark LOS (data for year 2000) from the Agency for Healthcare Research and Quality (AHRQ):

<http://hcup.ahrq.gov/HCUPnet.asp>



Sources for Benchmark Hospital Data

Agency for Health Research and Quality (AHRQ)

Go to www.ahrq.gov and, under "Data & Surveys," select "HCUPnet."

Commercial Vendors

especially when data may be available through existing product or service relationships

Ask the utilization management or quality assurance staff in the hospital.

Exhibit 5. Hypothetical Distribution of Patient LOS

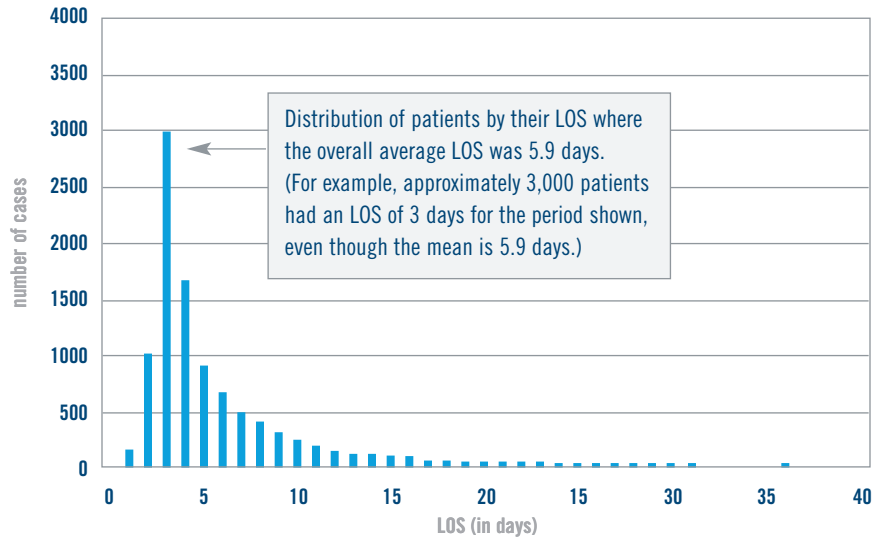
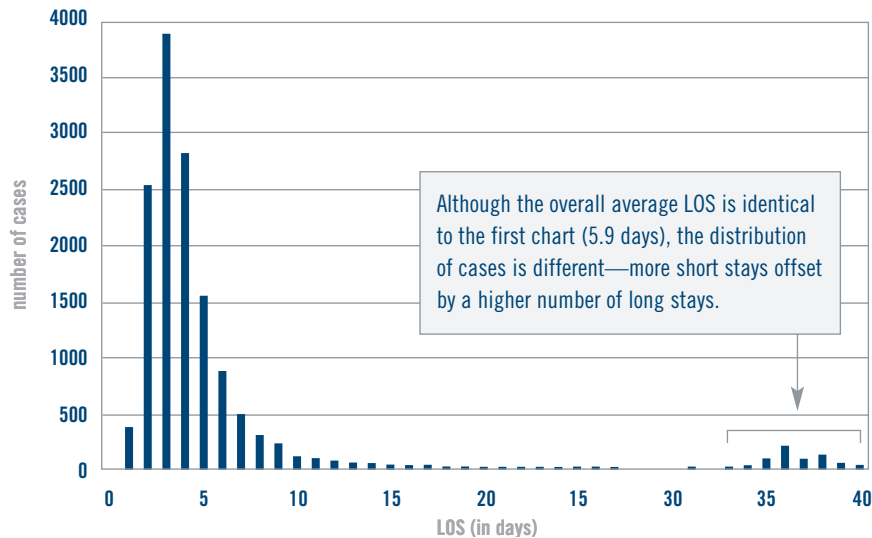


Exhibit 6. Contrasting Hypothetical Distribution of Patient LOS



Once the team’s analysis leads to identification of clinical opportunities, the next step is to outline a systematic process for translating these opportunities into referrals for palliative care. A number of programs have created “triggers” that automatically generate a referral. Examples of triggers include insertion of a feeding tube, tracheostomy placement, a six-day or greater LOS, or organ failure. Capturing and describing the situation before and after the palliative care referral through real patient stories is important in helping administrators visualize how care will be different, and in adding credibility to the team’s financial case.

Estimating Cost Avoidance

Many programs report that the most persuasive argument for hospital support is demonstrated hospital-specific cost savings resulting from formal palliative care services. The actual revenue derived from palliative care will be modest compared to the larger number of dollars saved. Net collections from professional billing are usually not proportional to the time commitment required. In addition, some interdisciplinary team services may not be reimbursable. For these reasons it is critical that palliative care programs: 1) pursue appropriate reimbursement rigorously, including billing for social work and advanced practice nurses if appropriate, and 2) develop credible approaches to demonstrating value through cost-avoidance tracking.

Palliative care programs that achieve budget neutrality through billing revenues consider themselves to be successful. Ways to maximize billing revenues are discussed in Section 4 under “Coding and Reimbursement for Services.”

Palliative care programs can create significant savings on a relatively small number of cases with extremely high costs. Savings can also come from a broad array of cases with more limited but systematic cost avoidance. Savings will come from either or both of two sources: *shorter* LOS or *lower costs* per day once the patient has been referred to palliative care. These savings have been attributed to better coordination of care, fitting the care setting to patient needs, less complex treatment approaches that produce equivalent or better clinical outcomes, and reduction in unnecessary drugs and procedures.

The team should now examine those high potential DRGs where clinical improvements could lead to cost savings. Exhibit 7 estimates savings from reduced LOS by examining those DRGs (identified in Exhibit 4) with a LOS over the national benchmark. By subtracting the national average from the hospital's LOS, the team can determine how many hospital days could be saved if clinical interventions brought the hospital to the national benchmark.

As shown in Exhibit 7, if the hospital's LOS for DRG 123 (Circ Disorder—AMI—Expired) could be reduced from its current 6.3 days to the national average of 4.4 days, the hospital would save 1.9 days per case. Since the current cost per day for DRG 123 is \$1,333, a reduction in LOS of 1.9 days would save the hospital \$2,532.70 per case (1.9 days x \$1,333). With 35 cases, the potential annual savings for this DRG alone would be \$88,645. Assuming that all six DRGs could be brought down to the national benchmarks and using the hospital information on cost per day, annual LOS savings from these DRGs would be \$768,656. Since the benchmarks are national averages, DRGs at or below the benchmark could also produce savings. An in-depth understanding of clinical drivers behind the LOS data will be necessary for determination of such savings.

Exhibit 7. Estimating Savings from DRGs with LOS over National Benchmark

DRG	Description	Current LOS	Benchmark	Days saved if @Benchmark	# of Cases	x	Current Cost/Day	=	"Potential" Savings
123	Circ disor - AMI - expired	6.3	4.4	1.9	x 35	x	\$1,333	=	\$88,645
127	Heart failure shock	7.8	5.1	2.7	x 21	x	\$1,067	=	\$60,499
483	Trach except face/mouth & neck	62.6	40.3	22.3	x 14	x	\$1,712	=	\$534,486
82	Respiratory neoplasms	11.2	6.9	4.3	x 13	x	\$828	=	\$46,285
296	Nutr/misc metab age > 17 w CC	9	4.9	4.1	x 11	x	\$859	=	\$38,741
Sample data from a 300-bed hospital								Potential Total:	\$768,656

DRG	Description	Current LOS	Benchmark	# of Cases	Current Cost/Day
475	Resp sys dx w/ventilator sup	11.1	11.2	39	\$1,602
416	Septicemia age > 17	4.2	7.2	22	\$1,454

Can you assume all cases will be referred to the program or just a portion?

Don't assume that for DRGs already at or below benchmark, no opportunity exists. In this case, these "benchmarks" are merely national averages.

Can you close the gap entirely? Half of it? Or perhaps can you do even better than the average? Talk to your organization about what goals are attainable.

Next, we'll look at savings on per-day costs...

Shorter palliative care patient LOS does not imply that these people are not living as long as non-palliative care patients. Several studies show that they may in fact be living longer, though typically in less resource-intensive circumstances (50-60% of palliative care patients are discharged to other settings such as home with hospice care, home care, or a nursing home).

Understanding the contributors to cost per day represents another opportunity for savings. Research has shown that the major contributing factors to reductions in cost per day are transfers out of the ICU and reduction in ancillary services and pharmacy costs.

ICU costs on average are two to three times the cost per day in other inpatient settings. As shown earlier in Exhibit 3, when palliative care patients were compared to DRG-matched non-palliative care patients, a reduction in ICU LOS for palliative care patients occurred. Palliative care patients in the ICU for more than 14 days before consultation had a 10-day reduction in ICU LOS. An even greater reduction of 16 ICU days was found for those who had been in the ICU longer than 42 days before consultation.

Variable costs due to ancillary services can also drop substantially after a palliative care referral. Exhibit 8 shows the results of a study comparing the two weeks before and after transfer to a high-volume, specialist palliative care unit in an acute care setting.³ The findings demonstrated an overall reduction in costs and charges of 66%. A study⁴ of ICU patients found reductions in ancillary costs ranging from 19% to 63%, as shown in Exhibit 9.

Exhibit 8. In-hospital Ancillary Costs Before and After Palliative Care Referral

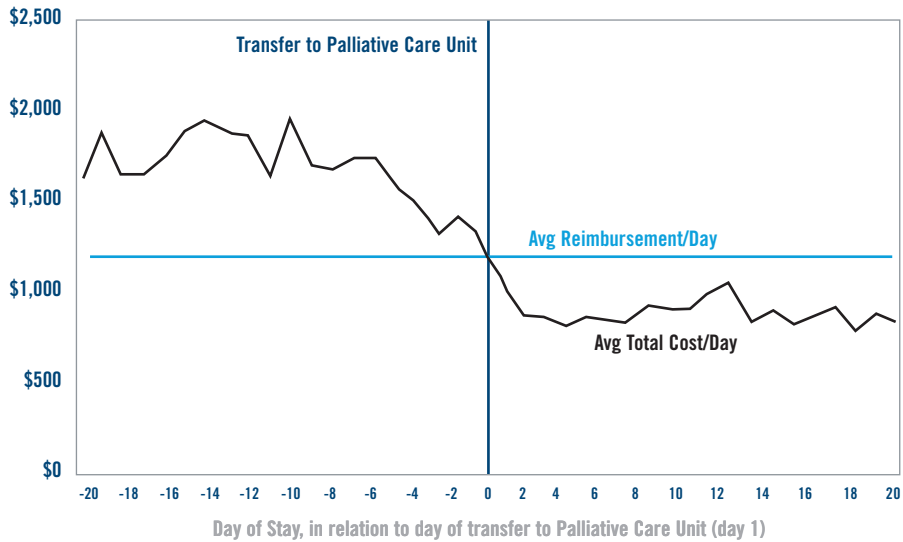
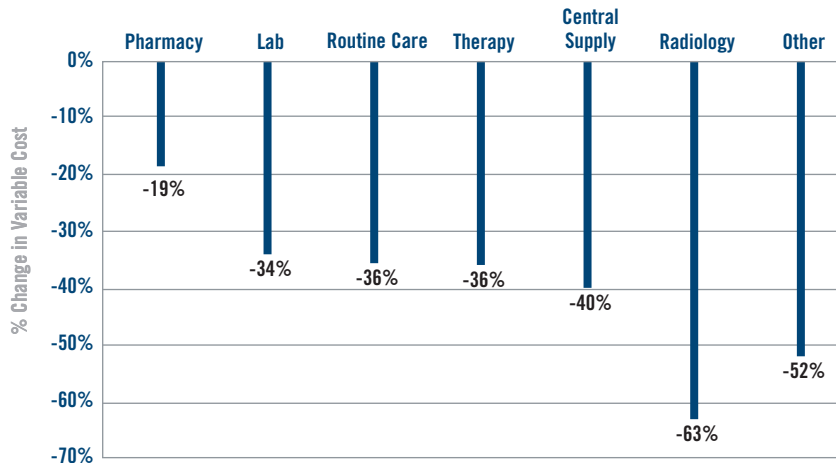


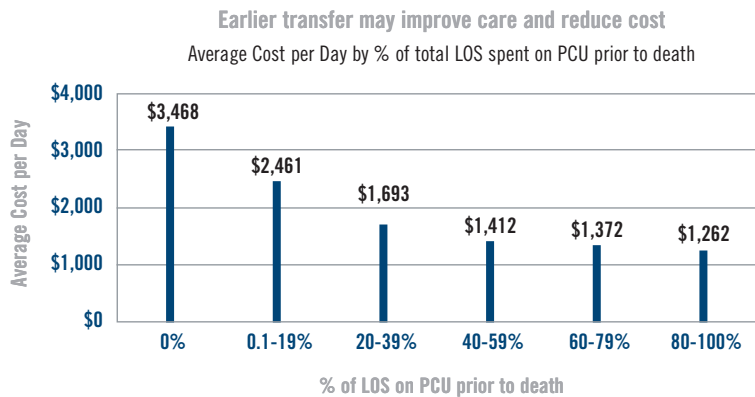
Exhibit 9. Impact of Palliative Care Consult on Ancillary Costs for ICU Patients

ICU Patients: Variable Cost Impact After Palliative Care Referral



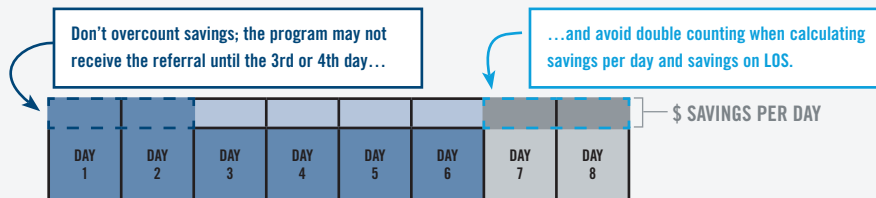
Earlier transfer of patients improves care and reduces costs. As shown in Exhibit 10,⁵ estimates of average cost per day savings increase as the proportion of the patient’s stay on the palliative care unit (PCU) increases. Such examples provide guidance when examining hospital-specific data, and emphasize the importance of understanding the services and clinical practices underlying the statistics.

Exhibit 10. Estimated Savings on Average Cost per Day by LOS in Palliative Care Unit



Avoid Double Counting Savings

One point of caution: When estimating savings from reductions in length of stay *and* cost per day, do not double count savings. That is, do not credit the program with cost per day savings for days after the patient has been discharged.



³ Smith TJ, Coyne P, Cassel B, Penberthy L, Hopson A, Hager MA. A high volume specialist palliative care unit and team may reduce in hospital end-of-life care costs. *J Palliat Med* 2003; 6(5): 699-705.

⁴ Chart from a June 23, 2003 presentation by: Kay Ross, RN, MSN, AOCN, Vice President, Oncology and Clinical Support, Central Baptist Hospital/Hospice of the Bluegrass. *Managing Financial Resources*.

⁵ Cited in presentation by Thomas J. Smith, MD, TPCU of Massey Cancer Center of Virginia Commonwealth University Medical Center. Sept. 2003

The value of working with the hospital's financial specialists cannot be overemphasized. Each hospital has a unique culture and financial accounting practices that the team should employ. Using existing accounting practices for estimating costs and savings will add credibility and build interest in the team's financial approach. The palliative care planning team contributes its understanding of the clinical practices that drive costs and how altering these practices achieves better clinical outcomes as well as more rational and efficient use of costly hospital resources. This clinical perspective is crucial to improving care processes and controlling costs, and is something financial experts cannot offer.

Sources of Revenue Credited to Palliative Care Programs

A substantial proportion of staff salaries and overhead can be recovered from clinical billing. Programs can expect to recover approximately 50-80% of staff salaries and overhead from reimbursement, depending on payer mix; a higher amount if primarily Medicare and commercial insurers, and a lower amount with high Medicaid or self-pay volume.

Palliative care programs can offer another important revenue opportunity for hospitals running at or near capacity, adding value by creating *incremental hospital revenue from the increased bed capacity* made available by reducing LOS. The palliative care program's ability to maintain high quality care while transferring patients out of heavily resourced units like the ICU offers greater revenue opportunities given the relatively higher costs and reimbursements. An important component of the financial case is explicitly stating that palliative care can contribute to revenue by increasing bed capacity. Exhibit 11 shows an example of such an analysis of revenue enhancement.

Exhibit 11. Revenue Enhancement

Example. If there were, say, 300 annual admissions *under fixed payment* where the average LOS of 6 days dropped to 5, it would mean

$$\begin{array}{r}
 300 \text{ cases} \times 6 \text{ days} = 1,800 \text{ days} \\
 -300 \text{ cases} \times 5 \text{ days} = 1,500 \text{ days} \\
 \hline
 300 \text{ bed-days}
 \end{array}$$

would now be available for other patients. If the average reimbursement per day were \$1,000, that would mean additional annual revenues of \$300,000.

As palliative care programs work to find the most appropriate care setting for patients, emphasizing continuity of care, there are additional advantages to health systems with affiliated or wholly-owned services such as hospice or home health services. Palliative care programs that partner effectively with these services have been shown to enhance continuity of care and improve case management while also increasing referral rates and LOS in these community hospice and home care programs.

Finally, the team must address expected billing revenue from palliative care services. These billing revenues will reduce palliative care staff costs while the service offers major contributions to the hospital in the form of cost savings and expanded capacity. Details on estimating palliative care service revenue and program costs are presented in Section 2 in “Estimating Program Costs and Revenues.”

Developing the Clinical Case

In the system and needs assessments, the team identified existing institutional strengths and clinical needs and determined how a palliative care program could benefit the hospital, health system, and/or health care partners and their respective patient populations.

It is also essential to present a clear picture of current care, gaps in that care, and how the proposed palliative care program will leverage existing strengths while addressing clinical needs, in order to win support.

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Palliative Care: A Case Example

MJ, an 85-year-old woman with multiple medical problems, including moderate dementia, coronary artery disease, renal insufficiency, and peripheral vascular disease, was admitted to the hospital with urosepsis. Her hospital course was complicated by the development of gangrene of her left foot resulting from her vascular disease, candidal sepsis, multiple pressure ulcers, and recurrent infections. She underwent five debridements under general anesthesia. When asked by the primary doctor, her family consistently said that they wanted “everything done.”

On day 63 of her hospitalization, a palliative care consult was initiated to help clarify the goals of care and to treat her evident pain and discomfort. She was persistently moaning in pain and resisting all efforts to reposition or transfer her or to change her dressings. The palliative care team met with her son (her health care proxy) and her two grandchildren. During a 90-minute discussion, the team explored with the family what they hoped to accomplish for the patient. The team reviewed the hospital course and clarified any confusion about her diagnoses and prognosis. Possible sources of discomfort and pain were identified. A treatment plan was initiated which included morphine sulfate to treat the pain associated with her necrotic foot, discontinuing her antibiotics, treating her fevers with acetaminophen, and transferring her to the palliative care unit. The patient was subsequently discharged two days later when a nursing home bed with a hospice contract became available. The family expressed tremendous satisfaction with the resolution of her hospitalization and continued to visit her daily in the nursing home, where two weeks after discharge, she was reported to be interactive and comfortable.

Measuring Quality of Care and Patient Satisfaction

As addressed in the needs assessment, the team can review The Joint Commission-mandated data collected on symptom distress to gain insight into variation in desired clinical outcomes. The Joint Commission requires that hospitals conduct post-discharge consumer satisfaction surveys, providing access to data on inadequate treatment of pain, delays in treatment, perceptions of an impersonal experience, poor communication, poor continuity of care, and other priorities for improvement.

Given the available data on quality of care and patient/family satisfaction, the team must present its case by showing exactly how the palliative care program will deliver improvements in quality and help meet The Joint Commission requirements through, for example:

- Pain and symptom management standards
- Standards for the continuum of care
- Standards for communication
- Advance care planning
- Advance directives
- Restraint reduction by treatment of delirium and agitation

Measuring Staff Need/Satisfaction

The hospital may periodically survey physician and nursing staff for satisfaction levels in areas that palliative care can address: staff frustration or fatigue with perceptions of understaffing for the care of complex patients, fragmentation in care delivery, and after hours calls. In particular, the team should try to demonstrate how employee dissatisfaction, stress, and turnover can be related to the strains of caring for patients with serious and complex illnesses and how staff, as well as patients, could benefit from the existence of a palliative care program.

More information on gathering and presenting data on quality of care is provided in Section 5, “Measuring Program Quality and Impact.”

Once the team has completed the analysis and identified opportunities, use this information to summarize the current situation at the hospital and how it would be different with palliative care. Presenting data on the current situation and offering true stories to put a face on the problem will help engage key decision makers. Describing how the palliative care program will actually alter the status quo at the bedside also lends credibility to the case. Each hospital scenario will be different, but the process remains the same, consistently uncovering variables to measure and monitor. As with the financial analysis involved in making the case, the clinical care analysis also serves as a baseline from which to measure improvements at later points in time.

Presenting the Case for Palliative Care

Pulling Together a Compelling Case

After developing the clinical case, the next step is to make a decision based on the planning team's findings. If a "go" decision is made, the team will synthesize the information into a compelling case for palliative care for presentation to the hospital CEO or other senior decision-maker(s).

The presentation should describe the current clinical and financial situation, opportunities for clinical intervention, and the potential outcomes of those interventions. Summarizing the situation before and after program implementation, and creating scenarios based on real patients, that describe how care will differ, will help administrators visualize the change and lend credibility to the team's projections.

To adequately present the case, the team may need to put together a business plan. In doing so, they must have a program design in mind. Depending on the timing, the palliative care planning team may benefit from going through the steps outlined in Section 4, "Implementing Palliative Care Services" and Section 5, "Measuring Program Quality and Impact" before presenting its case.

Presenting the Case

Keep in mind what decision-makers care about when presenting the case for palliative care. In order for the new program to be perceived as desirable, the presentation must demonstrate the following criteria:

- Organizational mission and goals are supported
- Expected impact justifies implementation effort and cost
- Financial projections exclude request for 'net' new funding
- Demonstrated committed and effective leadership
- Projections demonstrate program viability and low risk of failure
- Plans leverage existing resources and strengths in the hospital or system

The presentation should be simple and positive. Appeal to the key audiences and deliver the product as promised. The presentation must remain focused on providing support and respect for clinical colleagues and leaders, and not rest on criticism of the status quo. As a result, project leadership will be seen as credible and practical. The strength of the vision and the positive tone of the proposal will be powerful selling points. These intangibles may be the determining factors that set palliative care apart from the many other good ideas that compete for decision-makers' attention and resources.

Supporting Arguments for Palliative Care

A rapidly growing number of academic, community, and faith-based hospitals are offering palliative care services based on the following benefits for their institutions:

- ▶ **Palliative care addresses the needs of an aging population.** By 2030, the number of people in the United States over the age of 85 is expected to double to 8.5 million. To meet the needs of these patients, the hospital of the future must successfully deliver high-quality, financially viable care for these complex and often seriously ill patients.
- ▶ **Palliative care maximizes hospital efficiency.** A differently defined and organized approach to caring for hospital patients with complex illness, palliative care lowers costs for patients and payers while also increasing quality. Palliative care reduces fragmented care, prevents or promptly treats medical crises, and uses effective, efficient interventions. These benefits result in shorter hospital and ICU stays, thereby increasing capacity and lowering costs. Palliative care also improves staff retention and morale by supporting doctors and nurses in this difficult work.
- ▶ **Palliative care helps hospitals address new quality of care standards.** Palliative care programs help hospitals to meet pain and other quality standards required by The Joint Commission. *U.S. News & World Report* now includes the presence of palliative care services among its evaluation criteria for best hospitals.
- ▶ **Palliative care helps hospitals provide the services patients and their families are demanding.** Consumers now demand high standards of health care and an active role in treatment decisions. Numerous studies of people with serious illness show that patients and their families want the services provided by palliative care.
- ▶ **Palliative care enhances clinical outcomes and patient satisfaction.** Numerous studies show palliative care relieves pain and distressing symptoms in all stages of treatment, assists patients and their families with difficult decision making, helps patients complete life-prolonging or curative treatments, and increases patient and family satisfaction with the hospital and health care team. Palliative care also facilitates patient transitions between care settings.

The examples above illustrate how palliative care helps hospitals, health systems, and health care partners meet quality, clinical, and business imperatives. Since each institution is different, the proposal must also reflect local considerations. For a more complete set of arguments that make the case for palliative care, go to CAPC's web site, www.capc.org, and download *The Case for Hospital Palliative Care*.

Comparing Palliative Care to Related Services

How does palliative care differ from other related services such as geriatrics, hospice, case management, and pain management?

The key differentiator is that palliative care is broader, more comprehensive, and more coordinated in scope than any one of these approaches:

- ▶ Palliative care is for all patients facing debilitating serious illness, from the point of diagnosis and regardless of prognosis. It crosses all age groups and all diagnoses. Eligibility is based solely on patient and family need. It is delivered concurrently with all other appropriate curative or life-prolonging treatments.
- ▶ Palliative care systematically collaborates with, rather than duplicates, related services; working with geriatricians, pain experts, ethics teams, case managers, and hospice providers. For example, a palliative care program would assist case managers with placements and referrals of medically complex and seriously ill patients. Its focus on coordination of hospital resources delivers streamlined, high-quality care, thus reducing care delivery fragmentation and duplication.
- ▶ Palliative care addresses all facets of patient care including physical, emotional, and psychosocial services.

In making these points, the team must be careful not to give the impression that palliative care is so broad as to be amorphous or unachievable. Instead emphasize:

- ▶ Palliative care anticipates service demand and manages resource allocation by managing patient needs for pain and symptom control, emotional and decision support, and social services throughout illness.
- ▶ Costs are reduced by using hospital resources in a manner appropriate to the needs and goals of the patient and family.

“Palliative Care Contrasted to Related Hospital Services” on page 1.32 details these points and draws specific distinctions between palliative care and other services within the hospital.

Palliative Care Contrasted to Related Hospital Services

	PATIENTS SERVED	SERVICES PROVIDED	KEY DIFFERENCES
PALLIATIVE CARE	Patients of any age, at any stage of advanced and life-threatening illness	Throughout illness and simultaneous with other treatment, comprehensive, coordinated pain and symptom control; care of psychological and spiritual needs; family support; and assistance in making decisions and transitions between care settings.	Program open to all seriously ill patients, not limited to those with poor prognosis: <ul style="list-style-type: none"> ■ Patients do not have to forgo curative care ■ Palliative care team coordinates care from variety of health care providers, including specialists and primary care physicians to prevent service fragmentation
GERIATRICS	Elderly and frail patients	Provides high quality care for older adults that includes components of palliative care.	Provides a broad scope of services to a more limited patient age group.
HOSPICE CARE	Dying patients of any age	At the end of life and when curative treatment is not desired or not effective, comprehensive, coordinated pain and symptom control; care of psychological and spiritual needs; family support; and assistance in making transitions between care settings. Bereavement care for survivors.	Six-month prognosis required by Medicare and other funders. Coverage includes outpatient medications and supplies. Patients forego Medicare or other insurance coverage for curative or life-prolonging treatment.
CASE MANAGEMENT	All patients with complex care needs	Coordinates treatment plans guided by benchmarks, pathways, and standards.	Coordinates care and facilitates transitions between settings. Medical input not provided.
PAIN MANAGEMENT	All patients complaining of pain	Implementation of appropriate dosing and medication combinations as well as anesthetic and behavioral interventions to manage pain symptoms.	Focus is on effective management of pain symptoms of varying severity and chronicity to improve the quality of life. Limited in scope to pain only, usually for post operative or chronic pain not in context of advanced illness.

2 DESIGNING A PROGRAM

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2

SECTION TWO

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DESIGNING A PROGRAM

Characteristics to Consider in Program Design

The design of a successful palliative care program reflects the unique mission, needs, and constraints of the hospital it serves. The efforts described in Section 1 will enable the palliative care planning team to determine the mission, resources, and needs of the hospital. The goal of this section is to provide information that will guide the development of a program well matched to the hospital's circumstances. The program design will address the type and volume of patients to be served, how patients will be referred, and the type of service model and palliative care team that will care for them.

The completed program design will also allow budgeting and implementation planning. The design will require modification as the program grows and evolves.

Following are program characteristics to consider. The team should weigh the ideal characteristics of the program against hospital realities to determine the program's parameters. The purpose of this section is not to provide answers, but to raise questions to consider before working through the program design.

Interdisciplinary Resources

Because the needs of seriously ill patients and their families are multidimensional, a palliative care program requires an interdisciplinary team. The ideal team has a physician, nurse, and social worker with appropriate education and credentials in palliative care. Other team members may include clergy, rehabilitation professionals, pharmacists, psychologists, and psychiatrists. The team should have skills in pain and symptom assessment and management, care management and discharge planning, medical care across settings, and patient-health care provider communication.

The planning team will need to consider which resources the program will fund directly, and which will be accessed through collaboration with existing programs and departments in the hospital. For example, there may be hospices within the hospital's health system or in the community that could serve as a resource. The staffing model must fit the needs and resource constraints of the setting. For example, a 50-bed rural hospital may start out with a salaried half-time advance practice nurse (APN) with access to support as needed from

other hospital professionals. Conversely, a 1,000-bed tertiary teaching hospital will require a fully-staffed interdisciplinary team to provide appropriate quality of care.

In addition to the staffing suggestions above, consider the following in identifying the clinical expertise needed to support the program:

- ▶ **Team Members**—Team members, respected in their specialty and within the institution are key to generating confidence in and support for a program. Also, by representing a variety of specialties and backgrounds on a team (oncologists, internists, advance practice nurses, social workers, etc.), the palliative care program can attract referrals from the broadest group of colleagues.
- ▶ **Skills**—Skills required include complex medical evaluation, expert pain and symptom management, communication (professional to professional, to patient, and to family), an ability to address difficult decisions about the goals of care, sophisticated discharge planning, and an ability to deliver continuity of care and reliable access to services. Descriptions of core competencies for palliative care staff are provided in Appendix B.
- ▶ **Training Requirements**—The interdisciplinary team should have special training and/or work experience in palliative care, hospice, and/or nursing home settings, as well as a familiarity with the demands, culture, and standards of the acute hospital culture. Physicians and nurses should have or seek professional credentials in palliative care and other team members should be strongly encouraged to attend specialty training.

Once the clinical expertise needed to establish the program has been identified, the planning team must determine whether qualified staff already exist in-house, or will need to be trained or recruited from outside the hospital. Additionally, the team needs to decide whether these staff will serve the program full-time, part-time, or on an ad-hoc basis. The staffing structure will also depend upon the administrative home, the program model, hospital size, and estimated patient volume.

Visibility and Accessibility

The administrative structure and model chosen (e.g., consultative vs. inpatient service) will have a large impact on the visibility and reputation of the program, coordination with other departments, and service delivery to patients. Some considerations regarding visibility and accessibility are as follows:

- ▶ **Who are the team members?** Palliative care programs can serve patients from multiple clinical programs, including oncology, cardiology, pulmonary medicine, critical care,

neurology, and nephrology. Team members recognized in their specialty and respected within their institution are key to generating confidence in, and support for, a program. An institution's culture should be considered as well. A physician-led team may be more effective in a private practice or academic culture, while a nurse-led team may be ideal in a more institutional, capitated, or collaborative culture.

- ▶ **How does the team interact with colleagues?** The team's ability to work well and communicate effectively with each other and with other health professionals is an important consideration. Effective palliative care teams understand that the referring physician is the client; the goal is to support and supplement the care delivered by other providers to their most complex and seriously ill patients. While the team's work directly benefits the patient, a benefit must be shown to the clinicians treating that patient if support and referrals are to continue. Proper consultation etiquette ensures real help to the referring physician through educating clinicians about the benefits of palliative care, generating visibility and awareness of the program, and building support.
- ▶ **How does the team integrate with the hospital culture?** The ideal palliative care team consciously adjusts to the unique culture and practice patterns of their hospital. Team members often participate in hospital ethics committees and other groups to help integrate and build visibility for the vital role of palliative care. If the model chosen fits the culture and expectations of the hospital, the team's ability to improve patient care will be maximized.

Cost Control and Revenue Generation

While the palliative care program does not generate significant direct revenue, a high volume program can usually cover its own salaries and costs while contributing to significant cost avoidance and savings for the hospital. In addition, reductions in LOS generate hospital revenue from increased bed capacity and new admissions. In order to choose a realistic program size and structure, estimate how much revenue the program can generate given patient volume, payer mix, and the level of cost savings and capacity building that palliative care will bring to the hospital.

Integrating and Leveraging Existing Services

A palliative care program may leverage, supplement, or collaborate with a pain management program, case management, or hospice. It is important to identify related hospital services in order to be best positioned to fully partner and integrate with existing resources.

Palliative Care Program Structures and Models

Palliative care services may be provided through a variety of structures, such as consult services, inpatient units, and outpatient clinics. In addition, some programs combine an inpatient palliative care unit with a contract for inpatient hospice care.

There is no single correct palliative care program model. The right program structure is the one that best fits the needs, culture, and resources of each institution.

Selecting the appropriate delivery model may be a function of hospital size, patient load and bed capacity, physician practice patterns and culture, and availability of trained palliative care staff. For example, a consult service might best serve a hospital with limited bed capacity while an inpatient unit is possible for institutions with available beds. A large hospital may be the most appropriate site for an inpatient unit as approximately 10 beds and consistently high occupancy are needed to provide the necessary economies of scale for round-the-clock staffing.

Each model has its strengths and weaknesses. Here are some issues to consider:

- ▶ **Patient volume**—How many patients are expected to need palliative care?
Keep in mind that a geographic unit is most efficiently staffed with 10-12 or more beds. A consult service will have the greatest flexibility for responding to changes in patient volume and can reach the whole hospital, but it has less influence on clinical decisions and associated costs.
- ▶ **Risk level**—Consultative services entail lower start-up costs and tend to be acceptable to medical staff since consulting services are routine and familiar to physicians. A consultative service does not involve moving a patient from a familiar setting. Also, the consultative model is built on and uses existing programs and services whenever possible. An inpatient unit requires more staff and funding.
- ▶ **Degree of influence**—An inpatient unit may have greater influence over day-to-day patient care, visibility, and control of costs than that afforded by a consult service.³ The influence of an inpatient unit is based on its reputation for serving clinicians and patients in need. If patients are frequently discharged in good symptom control with an effective home care plan, the unit will draw referrals accordingly. If the program is there to assist physicians with difficult-to-manage, seriously ill patients and their families, those physicians will begin to rely upon the high-quality care they know they can access through referrals.
- ▶ **Staffing**—Will the program be physician or nurse-led? Will direct providers be house staff, attendings, nurse practitioners, or physician assistants? In some hospital cultures, a physician must be designated as the clinical leader in order to generate referrals. In other settings, advance practice nurses with the necessary skills serve as the front

³ See page 1.25.

line palliative care providers, with back-up from one or more physicians. The staffing structure and delivery of services will affect billing opportunities, staff costs, and revenue.

Deciding Where to House the Program

The decision on where to house a program depends on how and by whom the program was initiated. There is no 'right' administrative home. The typical program is placed within the clinical home or specialty of the leader. Successful programs have been administered by a range of professional specialties, including oncology, geriatrics, critical care, general medicine, neurology, hospitalists, nursing, hospices, and case management programs. In fact, many mature programs deliver care in various settings or coordinate with programs in other palliative care settings.

Each administrative home for a palliative care program has pros and cons. To anticipate any unintended consequences of an administrative home, ask, 'If I locate the palliative care program in Department X, how will people in Department Y perceive that?' The answers are specific to an institutional culture and unintended consequences will affect any administrative location. For example:

- If the program is aligned with a disease (such as cancer) or an age group (such as geriatrics), it may imply exclusion of other diseases (such as heart disease) or ages (such as middle-aged or young adults).
- If the palliative care unit is in a geographically or clinically isolated location, the distance may imply that the program is not part of mainstream medical care or it may be too inconvenient for physicians wanting to visit their own patients.
- If the palliative care service is attached to a hospice unit, palliative care may become confused with hospice and its associated requirements for a terminal prognosis, thereby creating the appearance of relevance only to the imminently dying.
- If the program is based in the hospital corporation, private practice clinicians may feel excluded.

Coordinating Patient Care Across Settings

The ideal palliative care program will contribute to an integrated delivery system on behalf of patients and families. Most seriously ill patients will receive care in multiple locations more than once over the course of a long illness. A typical patient will receive care at home (with

or without hospice or visiting nurses), in the emergency unit, in the hospital, and in a nursing home. Many patients will face these transfers with little or no communication between sites or providers. When possible, the palliative care program should attempt to provide:

- ▶ **Complex care management**—Programs should provide access seven days a week, 24 hours a day. Every patient and family should be able to contact a health care professional either acquainted with the case or having access to the patient’s medical information who can help with negotiating the health care system. Varying levels of complex care management are offered by Medicare managed care programs, Programs of All-Inclusive Care for the Elderly (PACE), hospices, and certified home health agencies, as well as an increasing number of hospitals. Leveraging existing complex care services or seeking grant support to fund new ones will contribute to building a high-quality and reliable safety net across settings.
- ▶ **Palliative care services outside the hospital**—Identify and affiliate with other qualified providers, including hospice partners and nursing homes with hospice contracts or palliative care expertise. Certified home health agencies with infusion capabilities and interest in developing palliative care services are also important potential providers of palliative care in the community.

Estimating Program Costs and Revenues

The operational plan requires a description of the resources required to run the program as well as an estimate of the revenues the program will generate. Even at early stages, the team should project the program’s expected growth over the next few years. One of the biggest mistakes described by established palliative care programs is a failure to plan for growth. Long-term program success is dependent upon the ability to handle growth.

Success for a palliative care program is defined by whether the patients who need the care actually receive the services. Thus, the team must design a program capable of responding whenever a colleague calls on behalf of a patient in need. A successful palliative care program never says no to a request for help.

Estimating Staffing and Projecting Growth

Staff salaries will represent the major cost for the palliative care program. Exhibit 12 shows an example of staffing ratios for a 500-bed hospital with growth projected over a seven-year period. In that timeframe, the program services expand from consultative only to a multiple site program with consultative, inpatient, and outpatient components.

Exhibit 12. Sample Staffing Projections for a 500-bed Hospital

	Year 1	Year 3	Year 5	Year 7
Model	Consultative	Consultative Inpatient Unit	Consultative Inpatient Unit Outpatient Services	Consultative Inpatient Unit Outpatient Services Multiple Sites
Patient Volume	220 new patients/year	600 new patients/year	900 new patients/year	1,600 new patients/year
Employees Needed	1 RN (APN) FTE .25 MD FTE	3 RN (APN) FTEs 2 MD FTEs 1 SW FTE	13 RN (APN) FTEs 4 MD FTEs 2 SW FTEs 1 Chaplain	30 FTEs
Characteristics	Stage of education and justification for palliative care	Increased patient type and volume	Stable, team expertise	Institutionalized palliative care services across settings

To estimate staffing needs for a consult service, the team must make some assumptions concerning staffing ratios. For example, 1.0 MD FTE may be needed for every 12 patients. By referring to the team's estimates of volume for a consult service, staffing needs can be determined. Exhibit 13 illustrates this process.

Exhibit 13. Estimating Service Volume in Order to Determine Staffing Needs

	Year 1	Year 2	Year 4
Assumed annual growth estimate		20%	30%
Number of cases [Annual growth = Prior year's number of cases x (1 + % growth)]	220	264	317
Avg hospital LOS for palliative care patient	8.0	8.0	8.0
Avg post-referral LOS in PC program (assumes referral to the PC program happens after day 3) [i.e., avg LOS minus the days before referral: 8.0 days - 3.0 days = 5.0 days]	5.0	5.0	5.0
Total palliative care inpatient days [Avg post-referral LOS x number of cases]	1,100	1,320	1,584
Average palliative care inpatient census/week [Total PC inpatient days / 52 weeks]	21.2	25.4	30.5
Average palliative care inpatient census/day [Total PC inpatient days / 365 days]	3.0	3.6	4.3

For illustration only, not based upon actual data

Take the assumed 1 MD FTE and multiply it by the average inpatient census per day (3.0). Then dividing by 12 (number of patients for 1 MD FTE), the team can determine what level of staff coverage will be required based on the organization's assumptions (.25 MD FTEs). This calculation does not include MD time for administration, teaching, or marketing a palliative care program.

1 MD FTE X 3.0 (avg daily census)/12 (patients per 1 MD) = 0.25 MD FTEs

Exhibit 14 presents an example of staffing ratios required for a 12-bed acute palliative care unit. The numbers are for illustration only and should not be assumed to be a model for staffing. Though staffing levels generally correlate directly to service volume, the program will find that certain minimum staff requirements are needed for an effective program (e.g., for education and outreach activities) even when early patient volumes may not appear to warrant it.

Exhibit 14. Sample Staffing Requirement Worksheet for 12-bed Acute Palliative Care Unit

Discipline	Ratio of Staff to Patients	Full Time Equivalent (FTE) Based on 12-patient census staffed 24/7
Physician	1:12	1
Registered Nurse	1:4	9
Social Worker	1:12	1
Nurse's Aide	1:4	9
Chaplain	1:12	1
Program Director	1:12	1
Ward Clerk	1:12	1

Budgeting for a Palliative Care Consult Service

To estimate the cost for a palliative care program, list each category of program staff—whether comprised of part-time, full-time, or both—in a worksheet as shown in Exhibit 15. Based upon projected daily census for the palliative care program, estimate how many FTEs are needed in each category. (For illustration only, these numbers should not be assumed to be a “model” for staffing.) For example, in this instance, assume a daily census of 12 palliative care patients will require at least a 1.0 MD FTE, plus coverage for vacations, call help, etc.

Exhibit 15. Staffing Worksheet—Budgeting for a 12 Patient Palliative Care Consult Service

Palliative Care Services BUDGET WORKSHEET for Staffing & Overhead								
	(A) Annual Salary	(B) Add-on for Benefits %	(B) Add-on for Benefits \$	(C) Salary + Benefits (A) + (B)	(D) Practice Overhead	(E) Total Cost of 1.0 FTE (C) x (C + D)	(F) FTE % for Pall Care Services	(G) Total Cost, Prorated @FTE % (E) x (F)
Physician Medical Dir. (clinical & educ. roles)	\$140,000	15%	\$21,000	\$161,000	40%	\$225,400	1.0	\$225,400
MD "replacement time" (vacations, etc.)	\$140,000	15%	\$21,000	\$161,000	40%	\$225,400	0.2	\$45,080
NP with clinical role and Program Coordinator	\$75,000	20%	\$15,000	\$90,000	40%	\$126,000	1.0	\$126,000
Social Worker (partnering w/ Dischrg Planning)	\$45,000	20%	\$9,000	\$54,000	20%	\$64,800	0.5	\$32,400
Ad hoc team members including chaplaincy and possibly a clinical pharmacist	\$40,000	20%	\$8,000	\$48,000	20%	\$57,600	0.5	\$28,800
Total Staff Costs	\$440,000			\$514,000		\$699,200	3.2	\$457,680

Ask human resources or the department administrator to provide average salary rates to use in budgeting (A), as well as benefits percentages (B). In general, the percentage of salary for benefits will decrease as salary increases. Salary plus benefits can now be determined (A+B=C).

2.10

Assign a placeholder for “practice overhead” (D) to provide rough estimates of program costs. The placeholder can be refined once more information is available regarding costs for space, office supplies, licenses, etc. and can be included in an overhead charge. The overhead charges for the physician will be influenced by whether the doctor is a private practice physician covering full clinic overhead, or a hospital-based physician (as well as by a budget methodology for “salary only” or other structure). The total cost for 1 FTE (E) can now be calculated by multiplying “Salary & Benefits” (C) by (1+D). So, $C \times (1+D) = 1 \text{ FTE cost}$. That is, if salary plus benefits equal \$140,000 and the overhead placeholder is 40%, then the staff expense of 1 FTE is equal to \$140,000 x 1.40. The staff expense (E) is then pro-rated by the actual number of FTEs (or fraction thereof) (F) to determine the total cost of each staff category (G). Summing the total cost for each staff category provides the total staff and overhead costs. Information on budgeted amounts for conference travel, brochures, PR expenses, etc. can be added if not already included in the overhead placeholder.

In this example, the estimated annual cost of staffing a 12 patient consult service is \$457,680. These costs must now be compared to estimated savings from reduced LOS and daily costs. For example, the analysis presented in Exhibit 7 showed an estimated cost savings of \$768,656 when LOS was reduced to the national average for 94 cases in five DRG categories.

Exhibit 16. Average Savings per Case vs. Volume of Cases per Year

Shaded blocks are greater than the estimated expenses in Sample Consult FTE Budget

		Average Savings per Case						
		\$500	\$750	\$1,000	\$1,250	\$1,500	\$1,750	\$2,000
Volume of Cases Per Year	220	\$110,000	\$165,000	\$220,000	\$275,000	\$330,000	\$385,000	\$440,000
	270	\$135,000	\$202,500	\$270,000	\$337,500	\$405,000	\$472,500	\$540,000
	320	\$160,000	\$240,000	\$320,000	\$400,000	\$480,000	\$560,000	\$640,000
	370	\$185,000	\$277,500	\$370,000	\$462,500	\$555,000	\$647,500	\$740,000
	420	\$210,000	\$315,000	\$420,000	\$525,000	\$630,000	\$735,000	\$840,000
	470	\$235,000	\$352,500	\$470,000	\$587,500	\$705,000	\$822,500	\$940,000
	570	\$285,000	\$427,500	\$570,000	\$712,500	\$855,000	\$997,500	\$1,140,000
	670	\$335,000	\$502,500	\$670,000	\$837,500	\$1,005,000	\$1,172,500	\$1,340,000
	770	\$385,000	\$577,500	\$770,000	\$962,500	\$1,155,000	\$1,347,500	\$1,540,000
	870	\$435,000	\$652,500	\$870,000	\$1,087,500	\$1,305,000	\$1,522,500	\$1,740,000

The hospital would also expect enhanced revenues from additional bed-days generated from decreased LOS. It will be important to estimate to what extent revenues from physician billing will help cover the costs of the consult service. Methods for estimating revenue are described at the end of this section.

Exhibit 16 on previous page indicates varying numbers of patients seen annually and average savings per case. The highlighted portion shows where the revenue exceeds the staffing expenses in the sample consult service budget.

Budgeting for a Palliative Care Inpatient Unit

Budgeting for a palliative care inpatient unit will depend upon the size of the unit. In most cases, a cost efficient inpatient unit needs to be of a certain size with six beds representing the minimal number. Ideally the unit should support more than 10 beds, since a minimum level of staffing will be required even during low referral volume, due to the need to staff for continuous direct clinical care (three shifts, 24/7). Achieving economic efficiencies with a small unit will be difficult unless staff can be shared with an adjacent unit.

Alternatively, it may be possible to maximize occupancy through sharing beds with other services (inpatient hospice or float overflow from other services). In any case, empty beds will translate into losses for the unit.

Some inpatient palliative care programs have found that about half of the patients referred to palliative care are best treated by consultation and are not transferred to a palliative care unit. Consequently, it is reasonable to assume that the volume for an inpatient unit is approximately 50% of the estimated total referral volume.

To determine the number of inpatient beds that can be supported by the program's estimated referral volume, use the following process:

1. Total estimated number of referrals X 50% = Total number of inpatient referrals
2. Assume what the minimum occupancy rate will be (e.g., 80%)
3. Number of Supported Beds =
$$\frac{\text{Number of inpatient referrals X Average LOS in PCU}}{365 \text{ days X } 80\% \text{ Occupancy Rate}}$$

Using a similar logic, Exhibit 17 shows the estimated number of inpatient referrals needed to support a dedicated inpatient unit with an assumed occupancy rate of 80% and varying average LOS on the unit.

Exhibit 17. Estimated Inpatient Referrals

Estimates of Referral Volume Needed for Dedicated Unit at 80% Occupancy

		Beds in Dedicated Unit					
		2	4	6	8	10	12
Avg LOS	5	117	234	350	467	584	701
	6	97	195	292	389	487	584
	7	83	167	250	334	417	501
	8	73	146	219	292	365	438
	9	65	130	195	260	324	389
	10	58	117	175	234	292	350

The formula used in calculating table cells is:

$$\# \text{ Referrals Needed} = \frac{\# \text{ Beds} \times 365 \text{ days} \times \text{Occupancy Rate}}{\text{Average LOS}}$$

The staffing budget example shown in Exhibit 18 follows the same basic format as the budget process used for estimating consult service cost. It assumes a 12-bed unit with staffing and occupancy similar to data reported by the Cleveland Clinic.⁶ Note that the unit beds are acute care beds, not hospice inpatient, rehab, or sub-acute intermediate care beds, and require continuous direct clinical care and comparable staffing ratios.

Exhibit 18. Staffing Worksheet—Budgeting for a 12-Bed In-Patient Palliative Care Unit

Palliative Care Services BUDGET WORKSHEET for Staffing & Overhead								
	(A) Annual Salary	(B) Add-on for Benefits %	(B) Add-on for Benefits \$	(C) Salary + Benefits (A) + (B)	(D) Practice Overhead	(E) Total Cost of 1.0 FTE (C) + (C X D)	(F) FTE % for Pall.Care Services	(G) Total Cost, Prorated @FTE % (E) x (F)
Physician/fellow @ full FTE cost	\$140,000	15%	\$21,000	\$161,000	40%	\$225,400	0.5	\$112,700
MD "replacement time" and call coverage @ full FTE cost	\$140,000	15%	\$21,000	\$161,000	40%	\$225,400	0.2	\$45,080
Physician Extenders	\$65,000	20%	\$13,000	\$78,000	40%	\$109,200	1.0	\$109,200
Unit Nurses (assumes 1:4 beds, 3 shifts)	\$50,000	20%	\$10,000	\$60,000	40%	\$84,000	9.0	\$756,000
PCNAs (patient care nursing assistants, 1:6 beds, 3 shifts)	\$30,000	20%	\$6,000	\$36,000	40%	\$50,400	6.0	\$302,400
Discharge Planner (Social Worker)	\$40,000	20%	\$8,000	\$48,000	40%	\$67,200	0.5	\$33,600
Administrative staff member at 0.5 FTE	\$30,000	20%	\$6,000	\$36,000	40%	\$50,400	0.5	\$25,200
Total Staff Costs							17.7	\$1,384,180

⁶ Davis MP, Walsh D, Nelson K, Konrad D, LeGrand S. The business of palliative medicine: Management metrics for an acute-care inpatient unit. Am J Hosp Palliat Care 2001;18(1): 26-9. Their program has 23 beds in a 1,000-bed hospital. This example roughly converted their statistics for a unit half that size (12 beds).

Work with the hospital's financial staff and follow their methods for these calculations. Hospital administration is more likely to believe the numbers from in-house financial experts. Some hospitals may prefer to evaluate the costs and benefits of a palliative care unit exactly like other units (in terms of nursing costs, patient costs, occupancy, DRG revenues, etc.). In that case, focus on the differential characteristics of a palliative care service, such as:

- ▶ Non-reimbursable costs of a consult team (e.g., nurses and social workers who cannot bill)
- ▶ Incremental costs in a palliative care unit atypical of most Med/Surgical units (e.g., bereavement coordinator)
- ▶ MD or provider time

Estimating Palliative Care Revenues

An analysis of expected revenues generated from the palliative care program is a required component of program design. The palliative care program can produce revenues from both hospital billing and physician services. Depending upon state regulations, reimbursement may exist for other professional (non-physician) services such as advance practice nurses. While the following sections examine hospital revenues, part B billing by hospice professionals is discussed in a report from the National Association of Home Care and Hospice (NACH) entitled "Hospice How-To: Becoming a Part B Supplier," in Appendix I.

▶ Hospital Revenues

On discharge, each Medicare case is assigned a DRG that best reflects the inpatient hospital care provided to the patient and, therefore, the reimbursement the hospital will receive for inpatient care. Determine the hospital's usual practice for allocating DRG revenues on patients transferred between the originating unit and the palliative care unit (e.g., pro-rated on the basis of charges, pro-rated based on days). This allows development of algorithms for estimating expected DRG revenue from inpatient palliative care units.

▶ Physician Revenues

Palliative care programs also generate revenue through physician reimbursement. Billing for physician revenues is discussed in more detail in Section 4, "Implementing Palliative Care Services." Demonstrate projected revenues from reimbursement for physician services as part of the program design.

Estimating physician revenue from palliative care services requires a set of assumptions about three variables:

1. Service mix (range of services provided and how they are coded)
2. Service volume (number of patients seen)
3. Payer mix (who provides the reimbursement)

Exhibit 19 illustrates how a program can estimate income projections from palliative care services. In the example, assume that all patients have Medicare coverage (and the billing physician participates in Medicare). The physician sees four new patients per day and follows-up on ten patients per day, along with one family meeting per day where the patient is present. The Medicare fee schedule in Exhibit 19, which varies by location, is based upon rates for San Diego. Given these assumptions, the estimated annual revenue from physician billings is \$485,567.

Exhibit 19. Palliative Care Service Annual Income Projections for Medicare Patients

Service	CPT Code	(A) Weekly Volume	(B) Medicare Fee	(C) Total income (A) x (B)
Initial Hospital Consultation: 80 minutes	99254	15	\$138.86	\$2082.90
Initial Hospital Consultation: 110 minutes	99255	5	\$191.06	\$955.30
Subsequent Attending Inpatient Care: 15 minutes	99231	25	\$33.01	\$825.25
Subsequent Attending Inpatient Care: 25 minutes	99232	30	\$54.54	\$1,636.20
Subsequent Attending Inpatient Care: 35 minutes	99233	45	\$77.47	\$3,486.15
Prolonged Hospital Service: an additional 30 minutes (after 35 minutes)	99356	2	\$87.82	\$175.64
Prolonged Hospital Service: each additional 30 minutes (after 65 minutes)	99357	2	\$88.20	\$176.40
Total for Week				\$9,337
80% paid by Medicare				\$388,454
20% collected from patients				\$97,114
Annual Total (52 Weeks)				\$485,567

Philanthropy and Palliative Care

Philanthropic dollars for a palliative care program may be necessary for a number of reasons:

- ▶ Clinical income is typically not enough to support core palliative care team salaries and operations
- ▶ Hospital and medical school support can be unreliable
- ▶ Grant dollars are usually earmarked for specific projects and uses
- ▶ Accepting support from pharmaceutical companies can create problems with perceived or real conflicts of interest

Philanthropy can help fill these gaps and provides a number of advantages:

- ▶ Philanthropic dollars can be applied to whatever aspect of the program needs support
- ▶ The community, corporation, and foundation linkages created are important on-going sources of advice, support, and visibility
- ▶ The dollars raised are usually free of the appearance of conflict of interest
- ▶ Philanthropy is available to both academic and non-academic institutions in most communities
- ▶ A diversified portfolio of sources of financial support for palliative care is provided, as required for program sustainability and stability

Individual donors, corporations, and foundations are all sources of philanthropy, with a considerable combined impact. Health organizations raised over \$19 billion in philanthropic dollars in the year 2000.

Palliative care presents a compelling cause for philanthropists. Advocates for palliative care are promoting a cause that improves the lives of others and the need to provide for these services is real and easy to justify. Most people, especially patients and their friends and families, can easily understand and be motivated to support the cause. For those who do not have first-hand knowledge of palliative care services, stories are powerful means of illustrating palliative care's impact on reducing human suffering.

What influences people to give? People influence people. Philanthropists, like most individuals, think in terms of people rather than causes and the leaders of palliative care programs are the most motivated and compelling advocates for palliative care. The personal relationships built by program leaders are the key reason that donors support a program.

As location is to real estate, so relationship is to philanthropy.

There are six basic steps that lead to major gifts. Throughout this process, strive to remain positive and personally committed. Individual persuasiveness is the most powerful selling point for palliative care.

- 1. Prospect identification**—Identify sources of prospective philanthropy, including patients and families, trustees, volunteers, colleagues, and databases.
- 2. Prospect research**—Learn about sources through colleagues, the library, the Internet, and subscriber services. If the institution has a development office, find out what resources and services are available.
- 3. Cultivation and education**—Build relationships and begin educating people about what palliative care is and why it is important.
- 4. Preparing the case**—Describe the program's needs. Explain the program beneficiaries and the cost. Describe the competency of the staff. Then underscore the importance of philanthropic gifts and how donors make a difference, including a range or menu of ways to give. Be prepared to make the case at all times. If a grateful family member asks how to help, make the case.
- 5. Solicitation**—If a potential donor indicates interest or offers to help, ask permission to make a follow up contact. Make the contact as scheduled and ask for money. Palliative care experts often forget this step. Be firm, positive, and self-confident. Asking for money is a difficult, but necessary, prerequisite to giving. The potential donor shares concerns about care of the seriously ill and giving to the palliative care program is a means of making a real difference in people's lives. Provide a menu of needs and giving opportunities with a range of costs.
- 6. Stewardship**—When someone has supported the program, it is critical to keep in regular touch by mail, phone, and in person. Try to engage donors as advocates: for example, some donors may be willing to join an advisory board, help plan for fiscal sustainability, or generate interest and support from other individuals.

It is extremely important to identify and follow institutional policies with respect to fundraising outreach. Established organizational offices of development can offer resources and guidance to support palliative care program philanthropic outreach.

There are a number of resources and guides for fundraising. CAPC's web site, www.capc.org, has information on soliciting philanthropic dollars. The hospital's development office may help with proposal writing, research on potential contributors, and ongoing stewardship.

2.16

3

PRESENTING THE BUSINESS PLAN

Overview of the Business Plan..... 3.1

3

SECTION THREE



Overview of the Business Plan	3.1
Importance of a Business Plan	3.1
Securing Approval for the Program	3.2

PRESENTING THE BUSINESS PLAN

Overview of the Business Plan

A business plan is a new program proposal with operational and budget information. Think of it as a story that tells the “who, what, why, when, where, and how” of a palliative care program. It explains how palliative care will improve the hospital’s performance and what is needed to achieve that end.

Importance of a Business Plan

Preparation of a business plan is a responsible approach to establishing a new program, including the benefits and risks entailed. A good business plan is a key step in winning support from hospital leaders, clinical departments, and other constituencies, and can also help in obtaining donor and grant support for a program. In addition, the business plan is a practical tool for testing the feasibility of the program and providing a roadmap for monitoring progress and reporting results.

The previous sections have explained how to assemble the content that will underpin a business plan. This section outlines how these pieces fit together.

The required components of a business plan are:

1. Executive summary, including a statement of program goals, milestones, and strategy
2. A financial/budget summary
3. An operational plan for implementation
4. Institutional and market analysis (a summary of the system and needs assessment)
5. Marketing plan
6. Appendix

An outline for a sample business plan is provided in the box on page 3.4. Keep in mind that the level of detail will vary by institution. Are decision makers are looking for a five-page or a 15-page business plan? Ensure that the finished product suits the expectations of

its institution. Many hospitals have sophisticated business planners on staff. Ask for their advice and help.

The team must summarize the financial implications of the program in a clear manner, since business decisions will hinge on financial feasibility. Exhibit 20 presents a sample financial summary that shows estimated revenue, costs, and the impact of cost avoidance. Information on how to estimate direct palliative care program revenue and cost is provided in Section 2 under “Estimating Program Costs and Revenues.” As emphasized in Section 1 under “Developing the Financial Case,” demonstrating hospital savings through cost avoidance and opportunities for revenue enhancement from increased bed capacity is also critical.

Opportunities for increased business to other units (e.g., Hospice) or parts of the health system (e.g., rehabilitation, home care) should also be highlighted. For example, hospital-based palliative care programs have been shown to increase hospice referrals by as much as 400%.

Securing Approval for the Program

The planning team will present the palliative care business plan to senior management for approval. The purpose of this face-to-face meeting is to:

- ▶ Clarify support for the palliative care program
- ▶ Solicit advice from decision makers on whether board or other levels of approval are needed
- ▶ Ascertain next steps for finalizing funding and moving the program forward

Following the meeting, securing the formal budget allocation for the program remains key. Sometimes a puzzling gap will exist between what appears to be a leader’s favorable decision and the program’s actual inclusion in budget line-items or authorized staff positions. Professional follow-up is often essential.

Exhibit 20. Financial Summary for a Palliative Care Program

Category	Year 1				
	Start-Up Expense	Outreach Activities	Patient Care	Systems Support	Total Year 1
Revenue					
Professional fees					
Inpatient Hospice revenue					
Donors & grants					
Contracted services (nursing homes, etc)					
Institutional support (hospital)					
Department support					
Total					
Expenses (should be organized to reflect direct and indirect classifications of institution)					
Program Director					
Physician time					
Staff / team time					
Supplies / software / computers					
Patient materials / education outreach					
Physician & caregiver education					
Billing & reporting service					
Space costs for beds, offices, etc					
Overhead charges (rent, util, insurance)					
Travel & conferences					
Total					
Contribution/deficit (before cost avoidance)					
Cost Avoidance Impact Targets:					
Cost avoidance (LOS)					
Cost avoidance (cost per day)					
Capacity management (ICU usage)					
Total Estimated Impact (Indirect \$)					

Sample Business Plan for Proposed Palliative Care Program

1. Executive Summary

The most important part of the business plan is the executive summary. This should be a simple, easy-to-present section that can be discussed with key audiences in ten minutes or less. This section synthesizes the contents of the overall plan into a concise, persuasive summary of:

- The context for the proposal
- The need or problem to be addressed
- How the proposed palliative care program will meet the need
- Key program features
- Funding requirements
- Expected impact and measures

2. Financial/Budget Summary

The financial summary is the program's budget. It identifies the program costs (both at the start-up stage and during program operations) and potential sources of revenue or cost avoidance that the planning team has identified in the preceding sections. Remember cost avoidance is especially important in making the financial case for the palliative care program, because palliative care is not a significant source of new revenue.

3. Operational Plan for Implementation

The operational summary outlines the program design as described in Section 3 of this Guide. It is a work plan that specifies:

- Organizational model and structure (e.g., consultation service based in oncology)
- Staffing requirements and roles
- Patient volume and program capacity projections
- Space needs

- Basic policies and procedures
- The degree of integration with other programs in the hospital and community

Briefly describe how the funds will be spent to implement project elements, hire staff, and care for patients and their families. Be sure to explain how the program will coordinate with related services, such as geriatrics, hospice, or pain management, and how it will differentiate itself. For example, how will the palliative care program coordinate with other departments to handle patient discharges and referral to outside resources?

4. Institutional and Market Analysis (a summary of the needs assessment)

Briefly describe how the palliative care program is an improvement over the process currently used to care for seriously ill patients, from clinical and financial perspectives. Also use this section to highlight identified patient and community needs. Openly acknowledge the program's potential downsides, including financial, political, or clinical disadvantages and explain how they will be addressed and tracked.

5. Marketing Plan

The marketing plan describes how the program will get the services to its audiences and position, promote, and communicate about them effectively over time. See Section 6: "Marketing the Palliative Care Program."

6. Appendix

The appendix will have any necessary detailed financial data, models for cost savings, revenue projections, and biographies.

4 IMPLEMENTING PALLIATIVE CARE SERVICES

Ensuring the Delivery of Palliative Care Services 4.1

Administrative Issues for Palliative Care Programs 4.7

4

SECTION FOUR

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IMPLEMENTING PALLIATIVE CARE SERVICES

Ensuring the Delivery of Palliative Care Services

This section describes how to put the program plan into action by demonstrating the scope and depth of daily operations, from referral to discharge. The infrastructure and processes for receiving, treating, and discharging palliative care patients will be described.^{7,8}

The team must exert clear leadership to ensure orderly and effective palliative care operations. Policies and procedures provide a shared understanding of roles and responsibilities and will be instituted within the larger context of the hospital. Along with implementation tools, policies and procedures are also essential in promoting institutionalized culture change and in delivering quality care at the bedside. Policies and procedures should be based on accepted standards of care and evidence-based guidelines that lead to good clinical outcomes. Appendix A provides the palliative care practice guidelines developed by the National Consensus Project.

Handling Referrals

As discussed throughout the *Guide*, positioning the program to generate, receive, and effectively handle referrals is crucial to success. Three of the best predictors of repeat referrals are:

- ▶ Responsiveness of the palliative care team to requests for consultations;
- ▶ Successful management of complex, difficult cases; and
- ▶ Remembering that the client of the palliative care team is the referring physician.

The palliative care team should develop policies for identifying patients likely to benefit from palliative care, as well as methods for prioritizing and responding to referrals in a timely

⁷ This section draws on work from the National Consensus Project for Quality Palliative Care (www.NationalConsensusProject.org).

⁸ This section draws on interviews with hospital-based palliative care professionals conducted by Sutton Group/LLC for the Center to Advance Palliative, and from the Palliative Care Toolbox developed by Hospital Corporation of America Cancer Care and Oncology Associates Inc.

manner. Criteria for appropriate referrals are often informal and somewhat experiential when palliative care programs are in the early stage of development. Policies that define the typical scope of palliative care and the types of patients typically served will help colleagues better understand when a palliative care referral may be beneficial.

Conversely, palliative care referral criteria should not be used to exclude a patient if a referring physician asks for help. (See Appendix D “Palliative Care Service Scope of Care”). The palliative care team should always respond to requests for consultations. These are opportunities to build relationships with referring physicians and educate staff on the scope and benefits of palliative care. If the consultant determines that a palliative care referral is not appropriate, the team should help resolve the current situation (e.g., address uncontrolled post-operative pain) and facilitate access to the appropriate care and services needed. Therefore, flexibility in application of referral criteria is recommended. Educating physicians, nurses, and staff on the scope and benefits of services—and most importantly, that palliative care can be offered simultaneously with curative or life-prolonging treatment—is key to generating referrals. A sample “Palliative Care Screening Tool” is provided in Appendix E-1.

A referral to the palliative care team can come from many sources: physicians, nurses, family members, patients, social workers, and case managers are among the more common sources. The primary physician must write the order for a palliative care consult/referral. If a physician does not initiate the referral (e.g., the referral comes from hospital staff or a family member), a member of the palliative care team will need to notify and request permission from the primary physician in order to provide a consultation.

If the primary physician does not write an order, negotiation may be required to discuss the role of the palliative care team and the patient’s specific palliative care needs. The role of the palliative care team can be one of providing advice (e.g., no orders are written), consulting with orders (e.g., provide pain management and symptom control), or taking total responsibility for the patient (e.g., where the palliative care physician becomes the primary attending on the request of a referring physician). Palliative care consultations cannot be billed without a request from the primary attending physician. Once a

Appropriate Palliative Care Referrals

- Team/patient/family needs help with complex decision-making and determination of goals of care
- Unacceptable level of pain or other symptom distress > 24 hours
- Uncontrolled psychosocial or spiritual issues
- Frequent visits to emergency department (eg, more than one time per month for the same diagnosis)
- More than one hospital admission for the same diagnosis in last 30 days
- Prolonged length of stay (>5 days) without evidence of progress
- Prolonged stay in ICU and/or transferred from ICU to ICU setting without evidence of progress
- In an ICU setting with documented poor prognosis

referral occurs, the primary physician introduces the appropriate members of the team to the patient.

Palliative care teams have implemented a variety of routine practices for generating and facilitating referrals. These include daily rounds with the ICU team, rotation of house staff through the palliative care service, or provision of outpatient palliative care services in high-risk patient care settings including oncology, AIDS, neurology, and geriatrics. In addition, many programs work with hospital administrators to develop clinical criteria that trigger automatic consultations to determine whether a referral is appropriate. Examples include ICU LOS of >7 days, hospital LOS>14 days, major organ failure, tracheostomy placement, or the insertion of a feeding tube.

Patient Assessments

The palliative care team will perform comprehensive formal assessments of the referred patient and family, documenting reasons for admission, and reviewing problems and symptoms as a basis for developing the plan of care. A physician or advance practice nurse performs the evaluation using an initial comprehensive assessment form. Once completed, the form is placed in the patient's chart. In some facilities these forms are computerized. See Appendix E-2 for an example of an initial assessment/consultation report and Appendix E-3 for an example of standardized progress notes for on-going care.

Palliative care specialists assess needs in the physical, psychological, social, cultural, and spiritual domains. These assessments and the accompanying documentation are coordinated to avoid unnecessary repetition and should be accessible to the entire team. The team will want to choose from among existing assessment tools for the assessment process. A sample form for capturing multidisciplinary evaluations is shown in Appendix E-4.

Data gathered from assessments are not only used to plan and direct care, but are also compiled for quality improvement and documentation of program impact. A sample tool used by palliative care team members to collect critical information such as patient date of referral, first contact, last visit, clinical outcomes, and demographic data is provided in Appendix E-5. Measuring quality of care is discussed in Section 5.

Care Planning

Subsequent to the initial assessment, a plan of care is developed together with the primary physician, other involved professionals, and the patient and family. It should address:

- Symptom and side effect management
- Family and patient understanding of disease status, preferences regarding treatment goals, and hopes for medical care outcome

- DNR status
- Advance directives
- Religious/cultural rituals preferred
- Wishes for care before and at the time of death
- Care setting (e.g., space for families, privacy, and attention to a home-like environment)
- Goals of medical care
- Decision-making needs and priorities
- Discharge options

Team and family conferences are the linchpin of the planning and decision-making process. Team conferences involve regular meetings of health professionals to discuss and develop the plan of care without the presence of the patient and/or family. Palliative care teams will need a format and process for team meetings to include documentation of recommendations resulting from the team meeting. Although the patient/family is not present at these meetings, the goals of care and issues to be addressed are discussed with the family and/or patient before and after the meetings.

The family care conference is a meeting among the patient (if possible), family, and health care team to facilitate communication and support decision-making about the plan of care, transition or discharge plan, and patient and family goals and resources. Most conferences are held to clarify the goals of care, support the decision-making process, and address communication issues. Once this conference has taken place, the care plan decisions are documented and placed in the patient chart. A sample patient/ family conferencing tool is provided in Appendix E-6.

Guidelines for care plans include, but are not limited to the following:

- Care plans are reviewed at regular intervals
- Care plans must be legible and identify support for continuity of care across settings
- Care plans are individualized and incorporate direct care from families when desired and feasible
- Care plans incorporate and respond to data from the physical, spiritual, cultural, psychological, and social assessments (see Appendix E-4)
- Care plans reflect realistic, measurable goals and objectives based on the integration of interdisciplinary findings

Treatment and Symptom Control

The palliative care team may opt to employ clinical protocol/pathway or treatment algorithms for each priority problem (e.g., pain management, dyspnea, nausea and vomiting, anorexia, dehydration, anxiety, depression). Some institutions have developed standing order forms for major protocols and pathways. However, as the Institute of Medicine⁹ has documented, many palliative care clinical practice guidelines are in early stages of development. Pain management guidelines are one example of well-defined evidence-based practices. Protocols and pathways for patient communications, and treatments for non-pain symptoms such as dyspnea, nausea, and vomiting are in development and testing phases.

Individual palliative care programs have developed guidelines, protocols, and policies for ventilator withdrawal and artificial feeding and nutrition (see Appendices F-1, F-2, and F-3). Additional samples of clinical guidelines from palliative care programs may be found at www.capc.org.

A standard progress note template is useful to document team visits, assessments, patient discussions, decisions, and symptom evaluations. These should be consistent with Medicare billing requirements for documentation of case complexity and consultation time. A sample progress note form is available in Appendix E-3 and at www.capc.org.

The daily activities performed by palliative care staff typically include:

- ▶ Routine assessment and documentation of disease status; pain and symptom management; side effects; patient/family understanding of disease and its treatment; psychosocial coping that addresses stress, anticipatory grief, social/cultural needs, and spiritual issues; decisions about goals of care; and discharge plans
- ▶ Responding to patient symptoms and patient/family distress
- ▶ Communicating with primary and consulting physicians and other professionals
- ▶ Communicating treatment alternatives to patients and their families
- ▶ Supporting patients and their families with decision-making regarding goals of care
- ▶ Educating family members on providing safe and appropriate comfort measures to the patient
- ▶ Recognizing the dying phase and offering appropriate patient and family support
- ▶ Addressing end of life concerns and expectations in the context of social and cultural customs

⁹ *Improving Palliative Care for Cancer*, Institute of Medicine, 2001.

- Writing progress notes and documenting for both clinical and billing purposes after each encounter with the patient and/or family
- Creating care settings that address safety, space for families, privacy, and attention to a home-like environment

Discharge Planning

Comprehensive discharge planning begins on admission. Social needs assessments can help identify family structure and relationships. Understanding the patient and family's work setting, finances, living arrangements, caregiver ability and availability, support, and any legal issues relevant to discharge planning can help determine needs and feasible discharge options. Access to transportation, prescription and over the counter medicines, and medical equipment will also affect discharge decisions.

The team needs to be familiar with community resources for patient discharge including:

- Hospice
- Outpatient pain management
- Outpatient palliative care
- Certified home health agencies
- Long-term care facilities
- Rehabilitation facilities
- Parish nursing support
- Other community resources such as Meals on Wheels, friendly visitor programs, and home medical care programs

The team should develop a list of local agencies and sources of support for patients and their families. A structured, active care plan that coordinates patient needs is essential upon discharge. Collaboration and prospective written and verbal communication with community agencies is key to formalizing the referral and follow-up processes.

The palliative care needs of patients and families across the continuum of healthcare settings may be best met by a genuine partnership between the hospital palliative care team and community hospice programs. Close coordination with hospice programs, which can provide palliative care services regardless of setting, is critical to assure the comprehensive and high-intensity palliative care required during the last months of an illness. Hospices are also prepared to provide bereavement support for the family.

While research shows that most patients would prefer to die at home, approximately 53% of all Americans and 50% of hospital-based palliative care patients will die in the hospital.¹⁰ Bereavement care requires attention to cultural and religious practices and preferences, the patient's possessions, and the family's wishes. The team, as a unit or in collaboration with partners such as hospice, must be capable of providing appropriate and sensitive care to the patient and family, as well as bereavement support for the family and hospital staff.

Staffing Issues

Physicians, nurses, patients, and families will require access to palliative care services 24 hours per day, seven days per week. Hence, a 24-hour on-call coverage schedule is necessary for team members. A range of common palliative care program position descriptions, standards for personnel performance evaluation, and a presentation on how to staff an interdisciplinary team are available at www.capc.org.

Patient Environment

If the palliative care service has an inpatient unit, a more home-like décor with rugs, curtains, and comfortable chairs or beds for family members choosing to stay should be sought. Religious articles may also be available as needed. In hospitals with a consultative palliative care model, home-like amenities and religious items may be stored for patient use as needed. Other environmental considerations to improve patient quality of life include pet therapy and access to the outdoors.

Administrative Issues for Palliative Care Programs

Financial Procedures for Billing and Tracking

A substantial proportion (50-80% in many programs) of staff salaries and overhead can be recovered from physician and/or nurse practitioner billing, therefore careful attention must be paid to accurate and comprehensive clinical billing and tracking processes.

Coding and Reimbursement for Services

Accepted billing procedures will vary across states and institutions. Therefore, an essential first step to developing policies and procedures for documenting, coding, and billing palliative care services is regular and close collaboration with hospital billing experts. Information to follow is consistent with guidance provided in the *AMA Medicare RBRVS: The Physicians Guide (2003)*.

¹⁰ National statistics for 2000 from AHRQ Healthcare Cost and Utilization Project. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/data/hcup/hcupnet.htm>

Coding for reimbursement almost always requires two parts:

- Procedure/service codes, which describe the *procedures performed* by the physician/nurse practitioner. These are referred to as CPT codes, which stand for Current Procedural Terminology (CPT™) codes. A complete listing of CPT codes is published by the American Medical Association.¹¹
- Diagnosis codes, which describe the *reasons* for the physician services. Diagnosis codes come from the International Classification of Disease-Clinical Modification codes (called ICD-9-CM codes) and are written by the National Center for Health Statistics. These diagnosis codes are published by several organizations, including the American Medical Association.¹² The ICD-9-CM book contains not only disease-specific codes, but also many symptom codes. These codes are revised and updated regularly and programs must ensure use of the most current (and billable) codes.

Using Evaluation and Management (E&M) Procedure/Service Codes

Physicians (and nurse practitioners in states that permit nurse practitioner billing) are reimbursed for direct patient care services related to palliative care. A number of criteria determine which CPT code to use, including:

- The nature of the procedure or service performed—Evaluation and Management (E&M) services are most common for palliative care
- Whether the physician is the primary attending/managing physician or a physician consultant
- The setting in which care was provided, that is, ambulatory outpatient, acute inpatient hospital, extended care institution, or patient home
- The intensity and complexity of patient care (e.g., extent of history and examination, complexity of medical decision-making in diagnosis and treatment)
- The amount of time spent delivering the service

Palliative care often involves patients with complex conditions requiring complicated decision-making. Palliative care also requires extensive amounts of time for information giving and/or counseling. Reimbursement for services allows the selection of *either complexity or time* as the most appropriate level of E&M CPT code. Whether using intensity or time, the medical record must reflect the major components needed to qualify a visit for a particular code. For billing purposes, if it is not documented, it did not happen.

¹¹ American Medical Association. Current Procedural Terminology 2004. Chicago, IL.

¹² American Medical Association. International Classification of Diseases 2004, 9th revision, clinical modification. Chicago, IL.

Selecting Current Procedural Terminology (CPT) Codes Based on Time

Each E&M code is associated with a level of intensity/complexity and an amount of time, as shown in Exhibit 21. Since palliative care services require a good deal of physician time, under certain conditions **time may be the best indicator for selecting the most appropriate code**. When more than 50% of face-to-face patient-physician (or nurse practitioner) interaction is dedicated to counseling and/or information giving, time can be used to determine the level of E&M code.^{13, 14} For example, a physician could have a prolonged interaction with a patient who does not have a complex history or physical condition. If based on intensity alone, the physician would select a lower level code; however, given the amount of time spent, a higher-level code would be more appropriate to describe the work associated with the encounter.

**Exhibit 21. Summary of Some CPT Evaluation and Management (E&M) Codes
Primary Attending/Managing Physician; Hospital Setting**

Initial Hospital Visit			Subsequent Hospital Visit		
CPT Code	Intensity/ Complexity	Time	CPT Code	Intensity/ Complexity	Time
99221	Low	30 min	99231	Low	15 min
99222	Medium	50 min	99232	Medium	25 min
99223	High	70 min	99233	High	35 min

The amount of physician/nurse practitioner time is calculated differently depending on the setting. **In the hospital, the total time that the physician is present on the hospital unit related to the case** determines which E&M code to choose. It includes time that the physician/nurse practitioner spent:

- Reviewing the patient's chart and results of tests and studies
- Interviewing and examining the patient
- Writing notes
- Communicating with other professionals to coordinate care
- Communicating with the patient's family

It **does not** include any time the physician/nurse practitioner spent conducting specific procedures or tests (specific procedures and tests are denoted by other CPT procedure codes and are billed separately).

¹³ Emanuel L, von Gunten CF, Ferris FD. Education for physicians in end of life care. Institute for Ethics, American Medical Association. The Robert Wood Johnson Foundation. www.epec.net, accessed 01.10.04.

¹⁴ von Gunten CF, Ferris FD, Kirschner C, Emanuel L. Coding and reimbursement mechanisms for physician services in hospice and palliative care. *J Palliat Medicine*. 2002; 3(2): 157-164.

In the non-hospital setting, when time is used to select the appropriate E&M code, **only the time the physician/nurse practitioner spends face-to-face with the patient** is used to determine which E&M code to choose. The time spent on activities related to the visit, but not face-to-face with the patient is not to be added into the calculation of time. This is because non-face-to-face time is already included in the total work connoted by the code.

In any setting, physicians/nurse practitioners who provide palliative care E&M services **may also report CPT codes for specific procedures or tests performed** (such as anesthetic injections, paracentesis, thoracentesis, etc.). For example, if a physician performed a paracentesis to relieve abdominal distension and discomfort during a home visit, the physician would report two CPT codes—both a CPT E&M code and a procedure code. The time required to conduct the procedure or tests should not be included when calculating the amount of time to determine the appropriate E&M code. Of course, since the time taken to conduct procedures and tests is not included in the E&M time calculation, the procedure time is also not relevant in the calculation to determine whether the 50% criterion is applicable.

While Exhibit 21 showed some of the E&M CPT codes for hospital visits by a primary attending/managing physician, Exhibit 22 provides CPT codes for reporting additional time spent over the typical length of a hospital visit.

Exhibit 22. Evaluation and Management Codes for Prolonged Hospital Services

Prolonged Hospital Service Face-to-Face	
CPT E&M Code	Time
99356	Additional 30 min (after initial 35 minutes)
99357	Each subsequent 30 min (after initial 65 minutes)

Current Procedural Terminology (CPT) Codes for Consultations

A consultation is a type of service provided by a physician whose opinion or advice regarding evaluation and/or management of a specific problem is requested by another physician/nurse practitioner or another appropriate source. A physician consultant may initiate diagnostic and/or therapeutic services. The physician requesting the consultation and its purpose must be documented in the medical record. The opinion and any services ordered or performed must also be documented. A consultation initiated by a patient and/or family and not requested by a physician should be reported using the codes for hospital or office **visits**, not consultation.

The consultation follow-up codes should not be used for subsequent inpatient palliative care visits if the consultant assumes responsibility for management of any portion (or all) of the patient's condition(s). Instead, subsequent hospital visit codes for Attendings (99231-99233) should be used. Exhibit 23 provides the E&M CPT codes for consultations in the hospital. Follow-up consultations are only applicable when the consultant's recommendations are delayed pending a test result or other information not available at the time of the initial consult.

**Exhibit 23. Summary of Some CPT Evaluation and Management Codes
Consulting Physician; Hospital Setting**

Initial Hospital Consultation		Follow-up Hospital Consultation	
CPT E&M Code	Time	CPT E&M Code	Time
99251	20 min	99261	10 min
99252	40 min	99262	20 min
99253	55 min	99263	30 min
99254	80 min	99255	110 min

Diagnosis Codes

As mentioned above, in addition to the CPT code, physicians/nurse practitioners describe the reasons for their services by using diagnosis codes from the International Classification of Disease-Clinical Modification codes (ICD-9-CM). Many symptom codes exist in addition to the disease-specific ICD-9-CM codes. Exhibit 24 outlines commonly used ICD-9-CM codes used in palliative care. However, to ensure the highest degree of accuracy, use the full-published list of ICD-9-CM codes. For accurate and regularly updated billable diagnosis codes, use web-based ICD-9 code indexes.

Exhibit 24. ICD-9 Codes* Commonly Used in Palliative Care

Anorexia	783.0	Cachexia	799.4	Pain: non-specified	780.99
Agitation	307.9	Insomnia	780.52	Pain: abdomen	789.07
Anxiety	300.02	Malaise	780.79	Pain: arm	729.50
Confusion	298.9	Mental status change	780.09	Pain: back	724.2
Coma	780.01	Nausea	787.02	Pain: bone	733.90
Cough	786.2	Nausea & vomiting	787.01	Pain: chest	786.50
Debility	799.3	Vomiting	787.03	Pain: foot	729.50
Delirium	293.0	Weakness	780.7	Pain: hip	719.45
Dyspnea	786.05	Weight loss	783.21	Pain: leg	719.45
Diarrhea	558.9	SOB	786.05	Pain: muscle	729.1
Fatigue	780.7	Unconscious	780.09	Pain: sacroiliac	724.60
Fever	780.6	Sleep disturbance	780.52	Pain: throat	784.1
Headache	784.0	Pruritus	698.9	Pain: neck	723.1
Hemorrhage	459.0	Constipation	564.09		
Inanition	263.9	Hiccups	786.8		

*ICD-9 Codes updated annually

Concurrent Care

Many physicians, particularly internists, are concerned about reimbursement for concurrent care. That is, if an internist physician sees a patient on the same day as another internal medicine specialist or sub-specialist, there is concern that only one of the physicians will be reimbursed. However, in October of 1995, the Health Care Financing Administration (now the Centers for Medicare & Medicaid Services, or CMS), published new rules that permit concurrent care by two or more physicians on the same day, even if they are of the same specialty. To describe the legitimate differences in evaluation and management services that multiple physicians may provide to a single patient, physicians need, as appropriate, to use different ICD-9-CM diagnosis codes. Palliative care services that physicians/nurse practitioners provide typically focus on symptoms rather than disease labels. Since other physicians rarely use the symptom codes, their use by palliative care physicians/nurse practitioners will decrease the chances of submitting identical ICD-9 code requests for reimbursement.

5

MEASURING PROGRAM QUALITY AND IMPACT

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SECTION 5

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MEASURING PROGRAM QUALITY AND IMPACT

Palliative care program success rests on an ability to demonstrate results. Before taking steps to establish a program, the planning team should develop a plan for measuring and monitoring program impact. This will ensure the establishment of baseline measurements prior to program launch, as well as the development of systems needed to track the palliative care program's effect on those measurements over time.

Overview of Measurement

Four categories of measurement are recommended to ensure an appropriate, effective, and efficient palliative care program. These are:

1. Pain and symptom control
2. Patient, family, and health care provider satisfaction surveys
3. Program operational measures such as volume and type of referrals and team workload
4. Financial impact such as professional billing revenues, hospital and ICU length of stay, and cost per day

The sophistication and comprehensiveness of the measures will vary with the goals and scale of the specific program and setting, but simple proxies should be established in each category. In each category, gather baseline data (the current state of things BEFORE the program is initiated). Ideally, baseline data is gathered before active discussion and education efforts on the need for palliative care begin, providing the most accurate basis for a “before and after” comparison. If no baseline measures are collected, it will be impossible to attribute improvements in performance measures to palliative care team interventions. A sound sustainability strategy for funding requires demonstration of meaningful results.

Depending on the needs of the institution, the palliative care team may put significantly more effort and emphasis into some measures than others. Choices should be made with input from key advocates and sponsors, not solely from the clinical team perspective.

For example:

- ▶ A hospital primarily focused on building market share which also has empty beds may be most interested in how the program can increase community physician referrals into the hospital, and less interested in reducing length of stay and cost per day
- ▶ A hospital with recent adverse outcomes in high visibility cases, or with chronic quality problems may be most interested in the quality measures of pain and symptom control and satisfaction surveys
- ▶ A hospital in stable financial condition with focus on market leadership and innovation may also emphasize the quality measures
- ▶ A hospital at full capacity and with significant variation in length of stay, as well as frequent lengthy readmissions from local nursing homes, may be interested in LOS reduction, cost avoidance, and reductions in unnecessary admissions for low reimbursement DRGs
- ▶ An academic medical center may be focused on how the program can support medical education and research, and therefore interested in the volume and demographics of patients and the program impact on other departments and initiatives

Our recommendation is to establish at least rudimentary measures in EACH category, and then put effort into the development of more extensive tools in the categories of primary importance to the institution and from which program continuation decisions (for team staff, beds, budgets) will be made.

Few settings will have all the data needed to measure program impact, and data gathering requires time and resources. The following steps should be followed when developing measures:

1. Develop a clear understanding of what the problems are now (the gaps the program hopes to close), and the desired outcomes.
2. Brainstorm possible measures and review available instruments (see the “Tools” section of www.capc.org) including instruments already used in the institution.
3. Review measures with knowledgeable administrative staff, such as “decision analysts,” the CFO, quality improvement managers, and the medical director; get their input into what will be feasible, what analytical resources are available, and what is likely to be most persuasive retrospectively.
4. Test the measurement process through the gathering and analysis of baseline data, and revise to maximize usefulness and feasibility, and to minimize effort.

5. Establish clear processes and accountability for ongoing measurement, including measurement tools, systems for data storage and analysis, frequency of and sample size for data collection, and report design.
6. Compile data each quarter, and adjust processes or measures to ensure that year-end results are meaningful to targeted audiences, and actionable for program staff.
7. Use results, including interim results, in team meetings for quality improvement efforts, and to modify program activities.

Doing this systematically and *using* the results will ensure that the program achieves stated objectives, demonstrates professionalism, engenders support within the administration, and serves as a useful “insurance policy” that may help ensure sustainability.

Measuring Quality of Care

The program should track two types of impact: clinical and financial. The palliative care team’s clinical impact includes:

- Decrease in severity of pain and other symptoms
- Number and type of palliative care interventions and their impact
- Changes in prescribing
- Patient and family satisfaction
- Referring physician satisfaction
- Nurse retention and satisfaction
- Hospice referral numbers and length of stay in hospice
- Advance care planning/DNR discussions
- Number of DNR orders
- Transfers out of the ICU
- Number of readmissions from long-term care institutions

Financial outcomes include:

- Length of stay (hospital and ICU)
- Length of stay after palliative care consultation
- Total cost per day before and after consultation
- Pharmacy costs per day before and after consultation
- Invasive and routine testing before and after consultation

To monitor these outcomes, the palliative care program will need to collect data from patients and/or proxies (family members, friends, health care professionals), medical records, and hospital databases. Basic patient service data should be tracked and reported at least quarterly. Basic patient service data are:

- Number of patients seen
- Mean/median lengths of stay in the hospital, in the ICU, and on the palliative care service
- Diagnostic categories
- Services provided
- Percent of patients discharged alive
- Discharge location(s)

In addition, track and evaluate any educational and research activities provided by program staff including:

- Contact hours for residents, medical students, and other health profession students
- Departmental rounds and conferences for medical and nursing staff
- Community lectures
- Academic contributions (grants, publications, invited lectures)
- Time and effort spent in conducting clinical research

The palliative care planning team may find that not all identified data are readily available. Unfortunately, most hospitals do not gather or store all the information required to build and sustain a successful palliative care program. In creating a measurement and monitoring system:

- Identify the data elements needed
- Identify the variables currently collected or stored in existing hospital databases
- Choose or develop standardized tools to gather information that cannot be obtained from hospital databases
- Work with an appropriate professional (many palliative care programs employ a graduate student or a finance intern) to build a database or spreadsheet for data storage

Data Needed to Measure Quality of Care

The following chart summarizes the data, data sources, and relative importance of the data the program may collect.

Data Element(s)	Source*	Where Stored †	Importance
Patient Characteristics (date of consult, religion, ethnicity, education)	PPI	PCD	Required
Patient Characteristics (age; sex; medical record number; DRG; primary, secondary, tertiary diagnoses (ICD-9 code); insurance; procedure codes)	HD	HD	Required
Functional status (e.g., Karnofsky score)	PPI	PCD	Required
Advance directive status	PPI	PCD	Important
Surrogate/NOK contact information	PPI	PCD	Required
Pain and symptom assessment	PPI	PCD	Required
Palliative care interventions	PCR	PCD	Important
Post-discharge/death satisfaction	PPI	PCD	Important
Site of discharge	MR	PCD	Required
Documentation of advance directives‡	MR/HD	PCD/HD	Important
Length of stay (hospital and ICU)	HD	HD	Required
Pharmacy information**	MR/HD	PCD/HD	Important
Cost measures	HD	HD	Required
Reimbursement rates by payer category	HD	HD	Important
Philanthropy and grant funding	PCR	HD/PCD	Required

* PPI—patient/proxy interview; PCR—palliative care records or palliative care team interview; MR—medical record; HD—hospital database

† PCD—palliative care database; HD—hospital database

‡ Some hospital database systems store this information.

** If pharmacy information is readily accessible from a hospital database, it can become a very powerful data element. If only available by chart review, the data may not be worth the labor required to gather it.

Selecting Clinical Assessment and Evaluation Tools

Several valid instruments are available to track symptom burden over time. Two examples of these instruments, the Condensed Memorial Symptom Assessment Scale (CMSAS) and the Modified Edmonton Symptom Assessment Scale (ESAS), are provided in Appendix G. Tools have been developed by various programs to help compile information from multiple types of clinical assessments and data sources. These tools are used to report both clinical and program outcomes. Examples of important data are date of referral, first contact, and last visit. See Appendix E-5 for a sample tool. Numerous tools are available for assessing quality of life and patient/family satisfaction, which can be found at www.capc.org.

Systems for Storing and Analyzing Data

The clinical, patient satisfaction, and financial data collected should be kept in a computerized database that permits easy analysis and standardized reporting. Options include a simple Access database or Excel tracking sheet.

Systems for Reporting Outcomes

Well-presented data will help the palliative care program demonstrate that:

- ▶ The program improves clinical care, including treatment of pain and other symptoms
- ▶ Patient/family satisfaction is high
- ▶ The program is fiscally responsible, due to a positive effect on length of stay in the hospital and ICU, use of hospice, and pharmacy/ancillary costs

6

MARKETING THE PALLIATIVE CARE PROGRAM

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MARKETING THE PALLIATIVE CARE PROGRAM

A solid marketing strategy is as essential to planning and growing a palliative care program as a sound business plan. It ensures that the palliative care team will win support for the program, gain referrals to its services, serve patients well, and be best positioned to stimulate and manage growth in the number of patients served.

In the process of establishing the palliative care program and showing how it benefits the institution, the planning team has, in essence, marketed to hospital administrators. Now the palliative care program must be marketed to physicians, other health providers, and to patients and families. The program will need to show benefits meaningful to these audiences so that they will seek the services the program has to offer.

Leaders of successful programs understand the need to shift between roles. For example, creating a compelling business plan to start a program requires a clinical leader to think like a hospital decision-maker and a marketer. Program leaders will want to devise a business plan that reflects institutional priorities, financial realities, and benefits relevant to the most pressing concerns of hospital administration. Likewise, a leader working to generate physician referrals will need to design a program perceived by clinician colleagues to be of service to them.

Effective marketing requires an in-depth understanding of the people served, often referred to as the audience. Knowledge of the audience allows the team to offer desired, easily accessible services and to deliver messages that promote these services. Leaders must often put aside their role as clinical palliative care advocates and recognize that personal reasons for promoting palliative care may not reflect reasons others may have for wanting palliative care for themselves or for their patients.

Information on marketing strategy is intentionally integrated throughout this *Guide* because marketing should not be an afterthought, but a key element of every step of planning, implementing, and promoting palliative care services. A compelling case for palliative care must be made in the earliest stages onward to ensure a successful and sustainable program.

Elements of a Marketing Plan

There are four key elements of a marketing plan:

- ▶ Service being offered
- ▶ Price or cost to the audience (e.g., patient, family, or referring physician) for accessing the service
- ▶ Place or distribution channels for delivering the message
- ▶ Promotion that delivers compelling messages about the service

Successful services offer the audience a benefit that they perceive as valuable. The value of the benefit is subjective, as different audiences will perceive different benefits from the same product or service. For example, physicians may find the palliative care service valuable because of support offered with difficult or time-consuming family interactions. Nurses may find value in the validation of their important caregiving role. Administrators may value the efficient use of resources and contribution to meeting The Joint Commission accreditation. The key to successful marketing is offering a set of benefits that the audience perceives as so valuable that they are willing to pay the associated cost. For palliative care, the major drivers of costs are intangible factors, such as fear of the implications of palliative care, inconvenience (seeing yet another doctor), conflicts in self-image (does this mean I am not doing a good job for my patient?), and difficult behavior changes (such as incorporating palliative care into an active treatment plan). Palliative care leaders seek to minimize these costs in order to facilitate the audience's willingness to pay the price in exchange for receiving palliative care services.

The audience must be able to access the service when and where they need it. Effective marketing helps audiences find the services as well as promote benefits relevant to the audience.

Strategic Questions for Audience-Based Communication and Marketing of Palliative Care¹⁵

As has been stressed throughout this *Guide*, effective communications require an understanding of the palliative care program's various audiences, both within the hospital and in the larger community. The following seven questions will help the palliative care team to research these audiences to get the information needed to form the basis of the marketing plan.

¹⁵ Source: Sutton Group/LLC, 2000 and LDM Strategies, 2014

Who is the audience for palliative care services?

To successfully market the palliative care program, the palliative care team must be able to profile the target audience; that is, to create a specific and vivid stereotype of what the audience is like. What is important to this person? What are his/her priorities? Values? What are the perceived benefits and barriers to supporting, referring to, asking for, or receiving palliative care? Most importantly, the team should develop an understanding of the audience's current behavior, in essence a "map" of the steps toward or away from supporting, referring to, or asking for palliative care. Research and reconnaissance conducted as part of the needs assessment can help to do this.

Target audiences for a palliative care program will fall into three broad categories: 1) administrators and decision-makers, 2) clinicians, and 3) seriously ill patients and their families. Understanding as much as possible about each of these audiences is important to effective utilization of the program.

What does the palliative care program want the audience to do?

Effective communication requires specifying the actions we want the audience member to take after hearing our message. Depending on the target audience's knowledge levels, perceptions, current behavior, and receptiveness to change, the proposed actions could be very different. Examples of desired actions include:

Audience	Desired Action
Hospital administrator	Commit money to the palliative care program
Clinician	Call for referral when patient's family needs to understand and choose between treatment options
Patient/family	Ask for palliative care when patient has difficulty with symptoms

Why would the audience want to access palliative care?

This question focuses on which rewards the target audience might find the most appealing and motivating. What do they get in exchange for taking the desired action? The reward needs to motivate the audience to take action. Examples of rewards include:

Audience	Reward
Hospital administrator	Palliative care results in cost savings for the hospital
Clinician	Ability to focus on patients' disease-specific therapies because palliative care team takes care of time-consuming communications and symptom management
Patient/family	Decreased symptoms and lessened anxiety about multiple sources of treatment and care; comfort knowing family member is getting the best care

Getting Referrals

Success = Comprehensive, continuous coverage. Create a coverage system in which the palliative care team or someone covering is available and responsive at all times. The first time a patient, family member, or colleague calls and gets no response is probably the last time he or she will try to use the palliative care service.

What supports the palliative care message?

One task is to promise the audience a reward, another is to make that promise credible. What will make the audience believe they will get the promised rewards? Support is built through use of relevant and credible information sources, such as statistical data or testimonials from peers. Graphic illustrations and personal stories can bring the facts or feelings to life. Examples of supports include:

Audience	Supports
Hospital administrator	Data, including the Goldsmith, Morrison study (Archives of Internal Medicine, Sept. 2008); IOM Report 2014; Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer (Jama 2010); Program data showing savings from palliative care
Clinician	Recommendation from a trusted colleague
Patient/family	Testimonial from satisfied patient and family

Where are the openings for the palliative care message?

The key to reaching the target audience is to determine when and where the audience can best receive the message—not when and where we can best send it. Openings are the times, places, and circumstances in which the audience is most receptive to the message. They may be the places where the audience is thinking about palliative care (or has a need for these services). To determine the best communications vehicle for reaching each audience, think about the reading, listening, work, and communications habits of that audience. Vehicles convey messages along established channels such as regular meetings, personal conversations, or strategically placed brochures, or through other venues such as list serves and conferences. Communication vehicles need to be selected that are suited to and fit the openings. Examples of openings include:

Audience	Openings
Hospital administrator	Budget cycle when administrators are thinking of ways to reduce LOS and pharmacy costs; crisis crunch in throughput
Clinician	Morning report; CME course; Discharge planning rounds; Grand rounds; One-on-one encounters; Physician department meetings; Nursing in-service; ICU or ED
Patient/family	Brochure in waiting room; suggestion from nurse; discussion in ICU or ED

What are the best communications vehicles for the palliative care message?

To determine the best communications vehicle(s) for reaching each audience, think about the reading, listening and communications habits of that audience. Communication vehicles convey messages through established channels like meetings or personal conversations. Pocket pain cards for clinicians, or literature for patients and families, are examples of communication vehicles. Other examples include word-of-mouth, web and social media, print advertising, public relations and direct mail. Vehicles need to be selected that are suited to and fit the openings. Examples include:

Audience:	Communication Vehicles:
Hospital administrator	Discussion at budget meeting; Presentation at department meeting
Clinician	Word-of-mouth; academic detailing (one-on-one discussion); discussion in morning report, discharge planning rounds, grand rounds; pain pocket cards; presentation at physician department meetings
Patient/family	Word-of-mouth; literature in waiting room; in-house television; media coverage; local media publicity

What is an appropriate image for palliative care?

Image allows an audience to quickly process the information and know that we are talking to them. The overall image answers the audience's implicit question, "Is this action something that I can see myself doing?" An effective image is appealing and relevant, makes the action seem feasible, and tells the audience, "I'm speaking to you." Examples of images include:

Audience	Image
Hospital administrator	Palliative care programs are part of every leading hospital; they are cost-effective, improve quality, and support the hospital's mission
Clinician	The palliative care team will save you time; will work with you to handle pain and symptom management, intensive family meetings, goal-setting and care transitions; team is responsive to physician needs, pragmatic, and helpful; will work to vigorously treat patient's pain and symptoms; is a resource that serves the busy clinician
Patient/family	Palliative care is the medical care every seriously ill person needs, wants, and deserves

In marketing the program, remember that educating any of these audiences about the evidence-based value of palliative care alone is not enough. How palliative care relates to their personal priorities and perceived needs must also be demonstrated. This is one reason to start the reconnaissance at the earliest stages of program planning. The questions posed here are simple, but the answers are not. They are based on audience research to ensure that services provide desired benefits and that communications are specific, actionable, and targeted. By keeping the team focused on the approach and the language that is most likely to appeal to their different audiences, palliative care is repositioned from a request or a demand to an offer that is hard to turn down.

Request/Demand	Offer
“You should support us to...”	“We believe this can help achieve our goals of _____”
“This hospital must address deficiencies (we care about) ...”	“We know the situation (you care about) and we can help...”
“Will you commit money to...?”	“We have a plan to accomplish _____, and we would like your advice and perspective...”
“I need your support to...”	

Then we must make good on the offer. The biggest mistake a program can make is to promise a reward and then not deliver.

Messages for Key Palliative Care Program Audiences

The marketing section has thus far outlined some audiences that the palliative care program must reach, as well as means of researching and marketing services to those audiences. The next step is to communicate the messages to these audiences. To help the team effectively communicate, the following pages outline key messages that successful palliative care programs have used with their audiences.

Talking Points For Administrators

Why Hospitals Want Palliative Care Teams

What is it? Palliative care, also known as palliative medicine, is focused providing relief from the symptoms and stress of serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care teams work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

- **Better clinical outcomes**—Numerous studies show palliative care relieves pain and distressing symptoms in all stages of treatment, assists patients and their families with difficult decision-making, and helps patients complete life-prolonging or curative treatments. A 2010 study published in JAMA showed that palliative care may also extend life.
- **Strengthened patient satisfaction**—Research shows palliative care increases patient and family satisfaction with hospitals and health care teams. Patients are able to get palliative care without forgoing other treatment.

How does it help hospitals? Hospitals can afford to provide palliative care to their patients given the tremendous impact it can have on the hospital's bottom line through:

- **Increased efficiency**—Palliative care programs lead to more appropriate use of hospital resources. Through coordinated care and goal setting with the patient and family, palliative care programs facilitate transitions between care settings, decrease length of hospital and ICU stays, lower costs, and increase capacity.
- **Improved staff retention**—Palliative care improves staff retention and morale by supporting doctors and nurses in the care of complex patients with round-the-clock needs.

Who is doing it? Palliative care is a rapidly growing trend in American medicine.

- Leading U.S. hospitals and marketplace leaders are in the forefront of hospital-based palliative care.
- As of 2012, two-thirds (1,734) of hospitals with more than 50 beds had a palliative care team. By 2015, eight in ten U.S. hospitals with 50 or more beds are expected to have a team.

Why now? Hospitals need palliative care teams for a number of reasons:

- **Patient demographics are changing**—The number of Americans living with complex, serious illness is growing exponentially. To meet the needs of these patients, hospitals must find a way to successfully deliver high-quality care while remaining fiscally viable.
- **Seriously ill patients want the best care**—Health consumers are demanding high standards of care and an active role in their treatment. Numerous studies of people with serious illness show that patients and their families want the types of services that palliative care provides: pain and symptom relief, communication about their plan of care, and coordinated care over the course of their illness. These people do not want to have to choose between curative and comfort care.
- **Accreditation standards mandate quality**—Palliative care programs are a systems approach to quality enhancement. They improve patient outcomes and help hospitals meet pain and other quality standards developed by The Joint Commission.
- **Hospitals need a strong bottom line**—Given these demands, hospitals are increasingly seeking effective ways to manage their most complex patients. Palliative care is a systematic and rational approach as it lowers costs, increases capacity, and raises quality, all at the same time.

Talking Points For Clinicians

Why Physicians Refer to Palliative Care Programs

What is it? Palliative care is a medical specialty that supports the primary physician's care of patients with serious illness.

- Palliative care specialists treat complex pain and symptoms, handle intensive patient-family communication, and manage after-hours needs and questions.
- Palliative care specialists support the primary physician's plan of care by making the patient as comfortable as possible at all stages of illness, simultaneously with curative care or any other medical treatment.
- Patients can have palliative care along with curative and life-prolonging treatment.
- Palliative care is offered at any stage of a serious illness and can be delivered along with curative treatment. Unlike hospice, it is not dependent on prognosis.

How does it help attending physicians? Physicians with seriously ill patients who require complex pain and symptom management or have a high demand for patient/family communication can refer to palliative care specialists. Palliative care programs offer attending physicians:

- **Time**—by helping with care coordination and time-intensive patient/family communication about the goals of care and treatment options
- **Expertise**—in pain and symptom management, particularly for complicated cases where relief of symptoms is hard to achieve
- **Support**—for the physician's plan of care, by helping coordinate the treating physician's orders, including safe and effective discharge planning
- **Satisfied patients**—because patients who receive palliative care as part of their overall medical treatment have a high level of satisfaction with their physicians, health care team, and hospital.

Why now? Palliative care is in greater demand because it addresses stronger emphasis on quality of care and the stresses on the medical system from the aging population while helping hospitals remain fiscally viable.

- The number of Americans living with debilitating chronic and serious illness is growing exponentially. To meet the needs of these patients, leading hospitals are turning to palliative care programs as a successful systems approach to delivering high-quality care.
- Palliative care has been shown to significantly lower pain and discomfort, improve patient outcomes, and boost patient and family satisfaction.
- Palliative care programs support the primary care physician. The palliative care team focuses on serving the primary physician and supplementing and facilitating the plan of treatment.
- Palliative care is care patients are demanding. Research shows that people want what palliative care provides. The Baby Boomer generation will expect much more from the health care system for their parents and themselves.

Talking Points for Patients and Families

What Seriously Ill Patients Should Know About Palliative Care

What is it? Palliative care, also known as palliative medicine, is focused providing relief from the symptoms and stress of serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care teams work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

- Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support.
- **Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.**

Why is it important?

- **Many patients need palliative care.** Americans are living longer with many advanced, chronic illnesses and need relief of their pain and symptoms so they can enjoy a good quality of life for as long as possible. Because their medical care is complex, these patients also need help coordinating their care.
- **Palliative care works.** Palliative care programs have been shown to provide the best possible care for serious illness, effectively relieve pain and distressing symptoms, increase patient and family satisfaction with their care, and make transitions between hospitals and other health care settings easier.
- **Palliative care is a growing specialty.** More and more hospitals are providing palliative care to meet the needs of their seriously ill patients, but the specialty is still fairly new. More programs are needed. To ensure all patients can access palliative care when and where needed, hospitals that do not have a program should start one, and more physicians should receive training—including generalists. Seriously ill patients should look for hospitals and physicians with access to palliative care expertise.

How does palliative care help patients and their families?

- It makes patients feel better throughout illness by:
 - *Vigorously treating pain and symptoms such as nausea, fatigue, depression, and anxiety*
 - *Keeping patients as comfortable and active as possible while fighting an illness so as to remain independent and live fully*
 - *Benefiting patients at all stages of illness, at the same time as receiving curative treatment or any other medical care*
- It supports patients and families to navigate the medical system by:
 - *Assisting patients and families in making decisions about care and treatments—and then ensuring that care is received*
 - *Providing answers, assistance, and emotional support to patients and families making difficult medical decisions*
 - *Identifying services to support patients after leaving the hospital*

Talking Points for Potential Donors

Opportunities to Support Palliative Care

What is it? Palliative care is a medical specialty focusing on expert treatment of the pain, discomfort and stress that can occur with serious illnesses. Seriously ill patients receive exceptional care at _____ hospital because we offer them special medical attention from the _____ Palliative Care Program. The palliative care specialists at _____ hospital are among the best in their field. They work with patients' primary doctors to deliver this vital care at the same time patients are receiving other treatments, at all stages of an illness.

How does _____ Palliative Care Program help patients and families?

- Makes patients feel better throughout illness by:
 - *Vigorously treating pain and symptoms such as nausea, fatigue, depression, and anxiety*
 - *Keeping patients as comfortable and active as possible while fighting an illness so they can enjoy their daily activities and live fully*
 - *Benefiting patients at all stages of illness, at the same time as they are receiving curative treatment or any other medical care*
- Helps patients and families to navigate the medical system by:
 - *Being on call around-the-clock to answer questions or provide treatment*
 - *Assisting patients and families in choosing the care and treatments desired—and then ensuring that care is received*
 - *Providing answers, assistance, and emotional support to patients and families making difficult medical decisions*
 - *Identifying services to support patients after leaving the hospital*

How can you help?

- Provide stories and examples of real situations from the hospital's program. This is the best way to illustrate the impact and importance of palliative care and demonstrate how palliative care makes a difference for patients and families.
- The specialized care provided by the palliative care program involves significant costs. The hospital funds many aspects of the program, but additional resources are needed to ensure that all patients who need palliative care can receive it. Philanthropic support would help us to (these talking points need to be tailored to an individual palliative care program):
 - *Describe very specific ways philanthropic dollars would be used (to fund an inpatient unit, to add a staff physician, etc.)*
 - *Provide examples of met and unmet patient need to illustrate the palliative care program's positive impact on human suffering*
 - *Provide examples of how other philanthropic gifts have made a difference in the lives of real patients and families*

Marketing Plan

The marketing plan is a part of the business plan. The business plan tells the story of the palliative care program and the need it meets; the marketing plan describes how the palliative care program will assure that the services reach the proper audiences and position, promote, and communicate effectively over time. The marketing plan is based on the research outlined here, as well as the research that went into creating the overall business plan.

The following are components of an effective marketing plan:

- ▶ **Target Audiences**—Defines the various audiences for palliative care, including hospital leaders, potential referring physicians, nursing and social work leaders, case management leaders, other clinicians, community agencies, and patients and families.
- ▶ **Marketing Objective**—Describes, by audience, the action or result that will be achieved if marketing is successful (e.g., referring physician calls for a palliative care consultation).
- ▶ **Benefits of Services Offered**—Details what benefits the services offer to each audience.
- ▶ **Cost Exchange**—Defines the “costs” to each audience of accessing the palliative care service, and considers how to make the program seem worth that price.
- ▶ **Communications Plan**—Outlines the message strategies for reaching each key audience. Defines the types of communications activities to be employed (e.g., personal relationships, presentations, mailings, newsletter articles, advertisements, public relations, etc.) and the associated budget.

The marketing plan also names the parties responsible for carrying out the plan, and describes the timeline for executing the plan.

Working with a marketing or communications professional to prepare this plan may prove beneficial. The planning team might consider including some time from the hospital’s marketing or communications staff in the budget.

Creating Program Promotional Materials

With a clear message strategy for each audience, execute the strategy by creating promotional materials such as brochures or flyers. Not only does each audience require different messages (and therefore unique materials), but also the method of translating into physical materials will need to differ.

The messages must be translated into the understood audience perspective and language. The perspective and the language are essential, but commonly overlooked. Too often, materials define palliative care in abstract terms and describe a program with words and concepts of primary interest to the palliative care team, not the patient. Terms like “interdisciplinary team,” “psychosocial support,” and “empowering care,” may be important and relevant to a palliative care professional, but are not necessarily meaningful to a patient.

The talking points in this section will help in developing materials for different programs and different audiences. In addition, the following pointers will help a program avoid common pitfalls:

- ▶ **Decide who the literature is for**—Cancer patients? Parents of pediatric patients? Seriously ill hospital patients? What do these patients and the families care about? What type of care are they looking for? This information will establish the audience perspective for the brochure and the palliative care benefits to cover for that specific audience.
- ▶ **Start from the patient's vantage point** rather than beginning with a description of the program. Consider an opening that conveys why the audience should care. Why is it relevant? What is in it for them? How will they know we are talking to them? For example, consider opening with: "If you are seriously ill, you should know that _____ hospital has a special program to help you."
- ▶ **Emphasize the immediate benefits that palliative care can offer** such as what patients and families are seeking in the face of serious illness:
 - *Relief of pain, discomfort, and stress at the same time as curative care is continued; help in making difficult medical decisions at every stage of illness*
 - *Assistance in finding the right care outside the hospital*
- ▶ **Discussing aspects of palliative care not of immediate interest to the audience is not necessary**—for example, bereavement resources or care that "affirms the role of death." Once in a program, a patient can obtain these services when ready or needed. For the purposes of a marketing brochure, the program should focus on the initial reasons why a typical patient might be willing to consider palliative care. Talk of death might make many patients feel they are "not ready for that yet" or that palliative care is "not currently relevant."
- ▶ **Talk about the specific elements of a palliative care program in concrete, everyday language.** Avoid jargon like "goal-setting," "psychosocial," "existential," "coordinated," and "interdisciplinary team." Those outside of the palliative care field do not easily understand these terms, and such abstraction does not effectively convey what palliative care will offer from this audience's perspective.
- ▶ **Provide a clear action the audience can take to get palliative care**—a phone call to the program, a drop-in location, a request for a referral to their primary physician, etc. Feature this contact information prominently.

The messages outlined in this section can help the team create their own materials. Also, sample brochures from successful palliative care programs can be viewed and downloaded by members at www.capc.org.

Leveraging Hospital Channels to Get the Word Out

In addition to brochures or printed matter, there are many other ways to reach the palliative care audiences. Consider the following outlets and how the program might use them to communicate:

- Grand rounds
- Hospital brown-bag lunches
- Department meetings
- Continuing education programs
- Board meetings
- Board and employee orientation materials
- Hospital newsletters, both internal and for the community
- Hospital-sponsored community events
- Health care system and partner community events and materials

Launching the Program

The marketing plan specifies the timing of marketing activities in order to ensure that marketing supports each step in program development, from seeking approval to launching services. Distribute communication materials and use hospital communication channels ahead of the program launch, through the launch, and as the program continues.

In launching the palliative care program, consider taking a limited number of patients as part of a “pilot trial run” to help staff prepare for the full launch and to ensure that operations are running smoothly. Once the program has completed its trial run, and is ready to care for patients, the marketing and communications plans can be fully implemented to generate interest, support, and referrals to the team.

Measuring and Monitoring Marketing Activities

The marketing plan and marketing efforts should be reviewed and renewed over time so as to reflect the evolving clinical and fiscal context of the palliative care program. The reasons why various audiences will support or need a palliative care program are likely to change, as will the demand for services, and the methods and messages used to market palliative care should be adjusted accordingly.

By monitoring program development, the palliative care team can also gauge how well marketing efforts are working. Continually solicit feedback from all audiences to improve marketing messages and materials. More information on marketing the program for the long-term is included in Section 7 of the *Guide*.

7

SUSTAINING AND GROWING THE PROGRAM

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SECTION SEVEN

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SUSTAINING AND GROWING THE PROGRAM

Ensuring Long-term Success

A number of successful palliative care programs have been challenged by poorly managed growth, with high demand outstripping team capacity. Conversely, if monitoring and marketing efforts have flagged, a program may soon discover a dwindling support base with a future in question due to the hospital's fiscal constraints.

The goal of this section is to ensure that the growth of the palliative care program is successful and that the steps necessary to sustain and build on the support that allowed its establishment in the first place are taken.

Managing Growth

Palliative care programs provide needed high quality care to the sickest, most complex patients in the hospital. Once this is recognized, referral volume grows rapidly. Programs make two common mistakes when interest begins to grow in palliative care services. One error is failing to plan for growth, causing the program to turn away patients based on a lack of capacity to meet increased demand. Another error is declining certain kinds of patients because of a fear of excessive demand. Even if capacity is not a problem, a palliative care team may worry that accepting a broad array of patients from referring physicians will be unmanageable. As a result, the program may be tempted to turn down referrals that do not fit narrowly defined criteria.

Both of these scenarios can undermine a program. Physicians often will stop referring patients if the palliative care program turns them away, whether the reason is lack of capacity or confusion about which patients are “appropriate” palliative care candidates.

The solution is to plan prospectively for growth and to hire more staff as demand for palliative care services increases. The palliative care team should avoid turning away referring physicians at all costs. A clinician whose request for help is turned down, whatever the reason, is highly unlikely to make another referral. A successful program is always accessible and available to every clinician or patient needing services.

When planning and implementing the palliative care program, project and monitor program growth and develop an updated business plan for managing that growth. Areas to consider in managing growth are as follows:

Changes in patient need/demand

- ▶ Are the number of referrals increasing or decreasing? From which referral sources? From which diagnostic groups?
- ▶ Is there unmet patient need due to palliative care staffing limitations or an increase in hospital admissions of patients needing palliative care?
- ▶ Are there new departments or hospital focus areas that would benefit from knowledge of and coordination with the palliative care program?
- ▶ What outreach steps could be taken to encourage referrals from services that do not currently refer patients for palliative care?

Changes in the hospital environment

- ▶ Have there been changes in hospital services that might complement or otherwise affect the palliative care program (i.e., a new pain service)?
- ▶ Are there disparities in access to palliative care or issues to address concerning ethnicity, diagnostic categories, socioeconomic status, or spiritual preferences?
- ▶ Are there new clinical champions or barriers for the program?
- ▶ How are new staff members and health professions students informed about palliative care services? And how are they reminded of it?

Changes in the community environment

- ▶ Have changes in relationships with community providers, such as hospice, home health, or other agencies occurred?
- ▶ Are there new referral sources outside the hospital?

Growing financial impact

- ▶ What financial impact is the program having on LOS, pharmacy and ancillary costs, revenues, and cost avoidance?
- ▶ Does the financial impact (i.e., cost avoidance) justify additional resources for the program?

The business plan should be revised to reflect each change that may have significant implications for the palliative care program. In revisiting the business plan, the palliative care team may need to adjust the program model (i.e., add an inpatient unit or outpatient services), the composition and number of staff, the budget, and the marketing plan.

The program must remain highly responsive to the needs and circumstances of the hospital, the referring physicians, and patients and families. A program that cannot serve certain types of patients because of understaffing, or fails to demonstrate an effect on cost avoidance, risks an unnecessarily jeopardized future.

The program should also maintain support to its own leadership. Palliative care program leaders have heroic tendencies, and supporters and colleagues are needed to share that workload over time to ensure sustainability for the long term.

Tracking and Reporting Outcomes

If the palliative care program has established an effective measurement and monitoring system as described in Section 5, it should be relatively easy to regularly track and report outcomes. This process is crucial to:

- ▶ Demonstrate accountability
- ▶ Keep hospital leaders updated on the positive clinical and fiscal impact of the program, constantly reinforcing the case for the palliative care program
- ▶ Demonstrate to clinicians, especially referring physicians, the positive effects of palliative care on patients and families, and their satisfaction levels
- ▶ Allow the palliative care team to detect and address any quality problems
- ▶ Help alert the palliative care team to any necessary clinical or financial adjustments to the program

Measurable clinical and financial success for a palliative care program is vital, as is the ability to monitor and measure outcomes and convey them to key audiences in a clear and compelling manner. As a number of programs have discovered, demonstrating the potential financial impact of a program at the outset is not enough. Monthly or quarterly data may be necessary to demonstrate financial benefits, with palliative care patients compared to a DRG-matched control group. Tracking increasing numbers of referrals on a regular basis is important, because the more and the earlier the referrals, the greater the quality and financial impact of the program.

Marketing for the Long Term

Marketing is sometimes misunderstood as a one-time effort associated with launching a palliative care program. In fact, marketing and communications efforts should be continually reviewed and renewed. As the clinical and fiscal context of the palliative care program evolves over time, so must its marketing plan.

The reasons why various audiences will support a palliative care program are likely to change over time, and the messages used to reach them should be adjusted accordingly. For example, a clinician might initially refer patients to a palliative care program to relieve the burden of intensive, time consuming communication with patients and families. Later, as the effects of the program become evident, the clinician may find the best reason to refer is because of improved clinical outcomes or patient and family satisfaction. Initially, a hospital leader may support a program to meet The Joint Commission accreditation requirements. They may also achieve The Joint Commission (TJC) Advanced Certification for Palliative Care. As the financial and quality impact of the program becomes clear, cost avoidance and philanthropic potential may become the chief reason for the leader's support.

The palliative care program should keep updated on the perspectives of all target audiences. Audience viewpoints are not static and, as such, the program must be responsive to any shifts in priorities or areas of interest. The best vehicles to communicate with target audiences also may change over time, and the communications plan must reflect any shifts to remain effective.

Ensure that marketing and communications efforts are consistent and constant. One highly useful tool for maintaining administrative and financial support can be an advisory committee. Many leaders of palliative care programs have reported that if anything should have been done differently, advisory groups would have been formed earlier. The composition and role of an advisory group will vary according to the circumstances and needs of each program, and careful thought should be given to how and when to convene and nurture new advisors. Types of advisory committees might be:

- ▶ **Key departmental or administrative leaders**—This group can help keep the program aligned to the needs and perceptions of hospital leaders, act as liaisons to their departments, and encourage staff support of the program.
- ▶ **Physician leaders**—A number of programs gained vital support through a physician advisory board that developed champions from each clinical service in the hospital. This board was key to gaining initial support and growing referrals to the program over time.
- ▶ **Community leaders**—A board of business and community leaders that advises hospital executives on palliative care can help sustain fundraising and long-term program growth. If the hospital already has an active board focused on philanthropy, identify potential champions among board members and include palliative care information in board orientation materials.
- ▶ **Community agencies**—Representatives of community agencies that serve the seriously ill or older patients can help identify unmet community needs, generate referrals, and encourage community awareness of palliative care services.

Consider additional methods that successful programs have used to maintain and increase their bases of support:

- ▶ Revision of marketing plan to reflect changes in the hospital or community.
- ▶ Consistent cultivation of supporters (hospital leaders, leaders of institutional strategic planning efforts, development and public affairs offices, clinicians, patients, families, and philanthropic supporters) through program impact updates, delivering messages that reflect current priorities, and asking for continuing support.
- ▶ Ongoing outreach efforts within the hospital, including staff presentations, newsletters, orientation materials for new staff, and patient brochures.
- ▶ Outreach to professionals outside the hospital, such as presentations to local medical and nursing societies and articles in professional newsletters and trade journals.
- ▶ Outreach to the public, such as presentations through the hospital's community outreach programs, articles in hospital newsletters for the community, and stories in academic or alumni magazines. A well-established program may want to interest a reporter in a feature story. Targets might be major newspapers, community newspapers, or periodicals for specific audiences such as support groups, senior citizens, or ethnic groups.

Conclusion and Resources

While establishing and operating a successful palliative care program requires effort on the part of committed advocates, ample rewards are paid by the striking difference made in patient care. Programs around the country are reporting enormous, positive impact on pain and suffering, and the number of palliative care programs is rapidly rising each year. Palliative care is becoming part of the gold standard of health care for the seriously ill.

In undertaking the process of building a palliative care program, users of this *Guide* will have the opportunity to join this growing movement and see first-hand the transformations that can be made in the lives of patients and their families. The growth of palliative care in the United States is cause for great optimism about the future of our health care system.

The Center to Advance Palliative Care provides numerous resources for hospital-based palliative care programs:

- ▶ CAPC member institutions can take advantage of CAPC tools, training, and technical assistance for their entire staff at www.capc.org.
- ▶ Palliative Care Leadership Centers™, a network of six exemplary palliative care programs that host site visits for peer institution learning
- ▶ Twice yearly two-day management training seminars on building palliative care programs
- ▶ Monthly Grand Rounds audio conferences
- ▶ The IPAL Project, an initiative sponsored by the Center to Advance Palliative Care, focuses on improving palliative care in various settings. These include the ICU, emergency department, and the outpatient setting:
 - *IPAL-ICU*
 - *IPAL-EM*
 - *IPAL-OP*

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SECTION EIGHT

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CLINICAL PRACTICE GUIDELINES FOR QUALITY PALLIATIVE CARE

Source: National Consensus Project for
Quality Palliative Care: The Development of Guidelines

Full Document is Available at www.nationalconsensusproject.org

Excellence in specialist-level palliative care requires expertise in the clinical management of problems in multiple domains, supported by a programmatic infrastructure that furthers the goals of care and supports practitioners. Eight domains were identified as the framework for these guidelines (structure and process, physical, psychological, social, spiritual, cultural, care of the imminently dying patient, and ethical/legal). These domains were drawn from the work of the previously established Australian, New Zealand, Canadian, Children's Hospice International, and NHPCO standards efforts.

The guidelines rest on fundamental processes that cross all domains and encompass assessment, information sharing, decision-making, care planning, and care delivery. Each domain is followed by specific clinical practice guidelines regarding professional behavior and service delivery. These are followed by suggested criteria for assessing whether or not the identified expectation has been met.

Domains of Quality Palliative Care

1. Structure and processes of care
2. Physical aspects of care
3. Psychological and psychiatric aspects of care
4. Social support
5. Spiritual, religious, and existential aspects of care
6. Cultural considerations
7. Care of the imminently dying patient
8. Ethics and law

Domain 1: Structure and Processes of Care

Guideline 1.1 The plan of care is based on a comprehensive interdisciplinary assessment of the patient and family.

Criteria:

- ▶ Assessment and its documentation is interdisciplinary and coordinated.
- ▶ Initial and subsequent assessments are carried out through patient and family interview, review of medical records, discussion with other providers, physical examination and assessment, and relevant laboratory and/or diagnostic tests or procedures.
- ▶ Assessment includes documentation of disease status; comorbid medical and psychiatric disorders; physical and psychological symptoms; functional status; and social, cultural, spiritual, and advance care planning concerns and preferences. Assessment of children must be conducted with consideration of age and stage of neurocognitive development.
- ▶ Patient and family values, expectations, goals for care and for living, their information preferences and understanding of the disease, prognosis, management options, as well as preferences for the type and site of care are assessed and documented.
- ▶ Initial and ongoing assessment data are reviewed on a regular basis.

Guideline 1.2 The care plan is based on the identified and expressed values, goals, and needs of the patient and family, and is developed with professional guidance and support for decision-making.

Criteria:

- ▶ The care plan is based upon an ongoing assessment, determined by goals set with the patient and family, and with consideration of the changing benefit/burden assessment at critical decision points during the course of illness.
- ▶ The care plan is developed through the input of the patient, family, caregivers, involved healthcare providers, and palliative care team with the additional input, when indicated, of other specialists and caregivers, such as school professionals, clergy, friends, etc.
- ▶ Care plan changes are based on the evolving needs and preferences of the patient and family over time, and recognize the complex, competing, and shifting priorities in goals of care.
- ▶ The interdisciplinary team coordinates and shares the information, provides support for decision-making, develops and carries out the care plan, and communicates the palliative care plan to the patient and family, to all involved health professionals, and to the responsible providers when patients transfer to different care settings.

- ▶ Treatment alternatives are clearly documented and communicated and permit the patient and family to make informed choices.
- ▶ Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence, and patient/family preferences. Re-evaluation of treatment efficacy and patient-family preferences is documented.
- ▶ The evolving care plan must be clearly documented over time.

Guideline 1.3 An interdisciplinary team provides services to the patient and family, consistent with the care plan.

Criteria:

- ▶ Specialist-level palliative care is delivered by an interdisciplinary team
- ▶ The team includes palliative care professionals with the appropriate patient population-specific education, credentialing, and experience, and ability to meet physical, psychological, social, and spiritual needs of the patient and family. Of particular importance is hiring health professionals appropriately trained and ultimately certified in hospice and palliative care.
- ▶ The interdisciplinary palliative care team involved in the care of children has expertise in the delivery of services for children with life-threatening conditions, and the care of younger children in the family of a dying adult.
- ▶ The patient and family have access to palliative care expertise and staff 24-hours per day, 7-days per week.
- ▶ The interdisciplinary team communicates regularly (at least weekly, more often as required by the clinical situation) to plan, review, and evaluate the care plan. The team meets regularly to discuss provision of quality care, including staffing, policies, and clinical practices.
- ▶ Team leadership has appropriate training, qualifications, and experience.
- ▶ Policies for prioritizing and responding to referrals in a timely manner are documented.

Guideline 1.4 The interdisciplinary team may include appropriately trained and supervised volunteers.

Criteria:

- ▶ If volunteers participate, policies and procedures are in place to ensure the necessary education of volunteers and to guide recruitment, screening, training, work practices, support, supervision, performance evaluation, and the responsibilities of the program to its volunteers.

- ▶ Volunteers are screened, educated, coordinated, and supervised by an appropriately educated and experienced professional team member.

Guideline 1.5 Support for education and training is available to the interdisciplinary team.

Criteria:

- ▶ Educational resources and continuing professional education focused on the domains of palliative care contained in this document are regularly provided to staff, and participation is documented.

Guideline 1.6 The palliative care program is committed to quality improvement in clinical and management practices.

Criteria:

- ▶ The palliative care program must be committed to the pursuit of excellence and highest quality of care and support for all patients and their families. Determining quality requires regular and systematic measurement, analysis, review, evaluation, goal setting, and revision of the processes and outcomes of care provided by the program.
- ▶ Quality care must incorporate attention at all times to:
 - *Safety and the systems of care that reduce error*
 - *Timeliness, care delivered to the right patient at the right time*
 - *Patient-centered, based on the goals and preferences of the patient and the family*
 - *Beneficial and/or effective care, demonstrably influencing important patient outcomes or processes of care linked to desirable outcomes*
 - *Equity, available to all in need and who could benefit*
 - *Efficiency, designed to meet the actual needs of the patient and not wasteful of resources*
- ▶ Quality improvement policies and procedures are established by the palliative care program.
- ▶ Quality improvement activities are routine, regular, reported, and are shown to influence clinical practice.
 - *The clinical practices of palliative care programs reflect the integration and dissemination of research and quality improvement evidence.*
 - *Quality improvement activities for clinical services are collaborative, interdisciplinary, and focused on meeting the identified needs of patients and their families.*
 - *Patients, families, health professionals, and the community may provide input for evaluation of the program.*

Guideline 1.7 The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with serious illnesses, and their families.

Criteria:

- Emotional support is available to staff and volunteers as appropriate.
- Policies guide the support of staff and volunteers, including regular meetings for review and discussion of the impact and processes of providing palliative care.

Guideline 1.8 Palliative care programs should have a relationship with one or more hospices and other community resources in order to ensure continuity and highest quality palliative care across the illness trajectory.

Criteria:

- Palliative care programs must support and promote continuity of care across settings and throughout the trajectory of illness.
- As appropriate, patients and families are routinely informed about and offered referral to hospice, and other community care resources.
- Referring physicians and health care providers are routinely informed about the availability and benefits of hospice and other community resources for care for their patients and families as appropriate and indicated.
- Policies for formal written and verbal communication about all domains in the plan of care are established between the palliative care program, hospice programs, and other major community providers. Policies enable timely and effective sharing of information between teams while safeguarding privacy.
- Where possible, hospice and palliative care program staff routinely participate in each other's team meetings to promote regular professional communication, collaboration, and an integrated plan of care on behalf of patients and families.
- Palliative care teams, hospices and community providers routinely seek opportunities to collaborate and work in partnership to promote increased access to quality palliative care across the continuum.

Guideline 1.9 The importance of the physical environment in which care is provided is recognized.

Criteria:

- When feasible, care is provided in the setting preferred by the patient and family.

- ▶ The care setting addresses safety and, as appropriate and feasible, provides space for families to visit, rest, eat, or prepare meals; opportunities to meet with the palliative care team and other professionals; flexible or open visiting hours; privacy; and other needs identified by the family. The setting should address the unique care needs of children whether they are patients, family members, or visitors.

Domain 2: Physical

Guideline 2.1 Pain and other symptoms, and treatment side effects are managed based upon the best available evidence, which is skillfully and systematically applied.

Criteria:

- ▶ The interdisciplinary team includes professionals with specialist-level skill in symptom control.
- ▶ Regular, ongoing assessment of pain, non-pain symptoms (including but not limited to shortness of breath, nausea, fatigue and weakness, anorexia, insomnia, anxiety, depression, confusion, and constipation), treatment side effects, and function occurs, and is documented. Whenever possible a standardized instrument should be used. Symptom assessment in children uses age-appropriate measures.
- ▶ The outcome of pain and symptom management is the rapid reduction of pain and symptom levels for as long as the symptom persists, to a level that is acceptable to the patient.
- ▶ Response to symptom distress is prompt and tracked, through documentation in the medical record.
- ▶ Barriers to effective pain management should be recognized and addressed including inappropriate fears of the risks of side effects, addiction, respiratory depression, and hastening of death in association with opioid analgesics.
- ▶ Patient understanding of disease and its consequences, symptoms, side effects, functional impairment, and treatments is assessed. The capacity of the patient to secure and accept needed care and to cope with the illness and its consequences is assessed.
- ▶ Family understanding of the disease and its consequences, symptoms, side effects, functional impairment, and treatments is assessed. The capacity of the family to secure and provide needed care and to cope with the illness and its consequences is assessed.
- ▶ Treatment of distressing symptoms and side effects incorporates pharmacological, non-pharmacological, and complementary/supportive therapies. Approach to the relief of suffering is comprehensive, addressing body, mind, and spirit.

- ▶ Referrals to health care professionals with specialized skills in symptom management are made available when appropriate (e.g., radiation therapists, anesthesia pain management specialists, orthopedists, physical and occupational therapists, child life specialists).
- ▶ The family is educated and supported to provide safe and appropriate comfort measures to the patient. The family is provided with back-up resources for response to urgent needs.
- ▶ A process for quality improvement and review of physical and functional assessment and effectiveness of treatment is documented and leads to change in clinical practice.

Domain 3: Psychological and Psychiatric

Guideline 3.1 Psychological and psychiatric issues are assessed and managed based upon the best available evidence, which is skillfully and systematically applied.

Criteria:

- ▶ The interdisciplinary team includes professionals with patient population-appropriate skill and training in the psychological consequences and psychiatric comorbidities of serious illness for both patient and family, including depression, anxiety, delirium, and cognitive impairment.
- ▶ Regular, ongoing assessment of psychological reactions (including but not limited to stress, anticipatory grieving, and coping strategies) occurs and is documented. Whenever possible, a standardized instrument should be used.
- ▶ Psychological assessment includes patient understanding of disease, symptoms, side effects, and their treatments, as well as assessment of caregiving needs, capacity, and coping strategies.
- ▶ Psychological assessment includes family understanding of the illness and its consequences for the patient and the family, as well as assessment of family caregiving capacities, needs, and coping strategies.
- ▶ Family is educated and supported to provide safe and appropriate psychological support measures to the patient.
- ▶ The team will include professionals with knowledge of and skills in identifying and treating common psychiatric disorders that arise in the context of life-threatening and chronic debilitating illnesses, including delirium, anxiety, and depression.
- ▶ Regular, ongoing assessment of psychiatric symptoms/disorders associated with life-threatening illness occurs and is documented. Whenever possible a standardized instrument should be used.

- ▶ Pharmacologic, non-pharmacologic, and complementary therapies are employed in the treatment of psychological distress or psychiatric syndromes, as appropriate. Treatment alternatives are clearly documented and communicated, and permit the patient and family to make informed choices.
- ▶ Response to symptom distress is prompt and tracked through documentation in the medical record. Re-evaluation of treatment efficacy and patient-family preferences is documented.
- ▶ Referrals to healthcare professionals with specialized skills in age appropriate psychological and psychiatric management are made available when appropriate (e.g., psychiatrists, psychologists, and social workers). Identified psychiatric comorbidities in family or caregivers are referred for treatment.
- ▶ Developmentally appropriate assessment and support is provided to pediatric patients, their siblings, and the children or grandchildren of adult patients.
- ▶ Communication with children occurs using verbal, non-verbal, and/or symbolic means appropriate to the child's age, experience, maturity, and condition.
- ▶ Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence, and patient/family preferences. The goal is to address psychological needs, treat psychiatric disorders, promote adjustment, and support opportunities for emotional growth, healing, reframing, completion of unfinished business, and support through the bereavement period.
- ▶ A process for quality improvement and review of psychological and psychiatric assessment and effectiveness of treatment is documented and leads to change in clinical practice.

Guideline 3.2 A grief and bereavement program is available to patients and families, based on the assessed need for services.

Criteria:

- ▶ The interdisciplinary team includes professionals with patient population-appropriate education and skill in the care of patients and families experiencing loss, grief, and bereavement.
- ▶ Bereavement services are recognized as a core component of the palliative care program.
- ▶ Bereavement services and follow-up are made available to the family for at least 12 months, or as long as is needed, after the death of the patient.
- ▶ Grief and bereavement risk assessment is routine, developmentally appropriate, and ongoing for the patient and family throughout the illness trajectory.

- ▶ Clinical assessment is used to identify people at risk of complicated grief and bereavement, and its association with depression and comorbid complications, particularly among the elderly.
- ▶ Information on loss and grief and the availability of bereavement support services are made routinely available to families before and after the death of the patient, as culturally appropriate and desired.
- ▶ Support and grief interventions are provided in accordance with developmental, cultural, and spiritual needs as well as expectations and preferences of the family, including attention to the needs of siblings of pediatric patients and children of adult patients.
- ▶ Staff and volunteers who provide bereavement services receive ongoing education, supervision, and support.
- ▶ Referrals to healthcare professionals with specialized skills are made when clinically indicated.

Domain 4: Social

Guideline 4.1 Comprehensive interdisciplinary assessment identifies the social needs of patients and their families, and a care plan is developed in order to respond to these needs as effectively as possible.

Criteria:

- ▶ The interdisciplinary team includes professionals with patient population-specific skills in the assessment and management of social and practical needs during a life-threatening or chronic debilitating illness.
- ▶ Practitioners skilled in the assessment and management of the developmental needs of children should be available for pediatric patients, and the children of adult patients.
- ▶ A comprehensive interdisciplinary social assessment is completed and documented, to include family structure and geographic location; relationships; lines of communication; existing social and cultural network; perceived social support; medical decision making; work and school settings; finances; sexuality; intimacy; living arrangements; caregiver availability; access to transportation; access to prescription, over-the-counter medicines, and nutritional products; access to needed equipment; community resources including school and work settings; and legal issues.
- ▶ Routine patient and family meetings are conducted with members of the interdisciplinary team to assess understanding and address questions; provide information and help with decision-making; discuss goals of care and advance care planning;

determine wishes, preferences, hopes, and fears; provide emotional and social support; and enhance communication.

- ▶ The social care plan is formulated from a comprehensive social and cultural assessment and re-assessment, and reflects and documents values, goals, and preference as set by the patient and family over time.
- ▶ Interventions are planned to minimize adverse impact of caregiving on the family, and to promote caregiver and family goals and well-being.
- ▶ Referrals to appropriate services are made that meet identified social needs and promote access to care; help in the home, school, or work; and provide transportation, rehabilitation, medications, counseling, community resources, and equipment.

Domain 5: Spiritual, Religious, and Existential

Guideline 5.1 Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied.

Criteria:

- ▶ The interdisciplinary team includes professionals with skill assessing and responding to the spiritual and existential issues that pediatric and adult patients with life-threatening illnesses and conditions, and their families, are likely to confront.
- ▶ Regular, ongoing exploration of spiritual and existential concerns occurs and is documented (including, but not limited to, life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness, and life completion tasks). Whenever possible a standardized instrument should be used.
- ▶ A spiritual assessment is utilized to identify religious or spiritual/existential background; preferences; and related beliefs, rituals, and practices of the patient and family.
- ▶ Re-evaluation of the impact of spiritual/existential interventions and patient-family preferences is documented.
- ▶ Spiritual/existential care needs, goals, and concerns are addressed and documented, and support is offered for issues of life completion in a manner consistent with the individual and family's cultural and religious values.
- ▶ Pastoral care and other palliative care professionals facilitate contacts with the spiritual/religious communities, groups or individuals, as desired by the patient and/or family.
- ▶ Patients have access to clergy in their own religious traditions.
- ▶ Professional and institutional use of religious symbols is sensitive to religious and cultural diversity.

- ▶ In institutional settings, the patient and family are encouraged to display their own religious/spiritual symbols.
- ▶ The palliative care service facilitates religious or spiritual rituals as desired by patient and family, especially at the time of death.
- ▶ Referrals to professionals with specialized knowledge or skills in spiritual and existential issues are made available when appropriate. (e.g., to a chaplain familiar with or from the patient's own religious tradition).
- ▶ A process for quality improvement is documented and leads to change in clinical practice.

Domain 6: Cultural

Guideline 6.1 The palliative care program assesses and aims to meet the culture-specific needs of the patient and family.

Criteria:

- ▶ The cultural background, concerns, and needs of the patient and family are elicited and documented.
- ▶ Cultural needs are identified by team and family and addressed in the interdisciplinary team care plan.
- ▶ Communication with patients and families is respectful of their cultural preferences regarding disclosure, truth-telling, and decision-making.
- ▶ The program aims to respect and accommodate the range of language, dietary, and ritual practices of the patients and their families.
- ▶ When possible, the team has access to and utilizes appropriate interpreter services.
- ▶ Recruitment and hiring practices strive to reflect the cultural diversity of the community.

Domain 7: Care of the Imminently Dying Patient

Guideline 7.1 The imminence of death is recognized, and care appropriate for this phase of illness is provided to patient and family.

Criteria:

- ▶ The patient's transition to the actively dying phase is recognized when possible, and is documented and communicated appropriately to patient, family, and staff.
- ▶ The changing needs of the family and other caregivers during this stage of illness are recognized and assessed.
- ▶ End-of-life concerns, hopes, and expectations are addressed openly and honestly in the context of social and cultural customs in a developmentally appropriate manner.

- ▶ Symptoms at the end of life are assessed and documented with appropriate frequency and are treated based on patient-family preferences.
- ▶ The care plan is revised to meet the needs of the family and other caregivers during this stage of illness, including higher intensity and acuity of support services, communications, and education about what to expect.
- ▶ Patient and family wishes regarding care setting for the death are documented. Any inability to meet these needs and preferences is reviewed and addressed by the palliative care team.
- ▶ As patients decline, the hospice referral option will be introduced (or re-introduced) for those who have not accessed hospice services.
- ▶ The family is educated regarding the signs and symptoms of approaching death in a developmentally-, age-, and culture-appropriate manner.
- ▶ Emotional and spiritual support for the patient and family is provided during the dying process and bereavement period.
- ▶ Appropriate and sensitive care to patient and family occurs in the hours following death including physical care of the body in accordance with spiritual needs, cultural expectations, keepsakes, and rituals.
- ▶ Staff are trained in the pronouncement of death; completion of the death certificate; and relevant policies and procedures on organ and tissue donation; and offer of an autopsy.
- ▶ Families are offered guidance and information regarding memorial or funeral arrangements.

Domain 8: Ethics and Law

Guideline 8.1 The patient's goals, preferences and choices are respected and form the basis for the plan of care.

Criteria:

- ▶ The interdisciplinary team includes professionals with knowledge and skill in ethical, legal, and regulatory aspects of medical decision-making.
- ▶ The patient or surrogate's expressed wishes, in collaboration with the family and the interdisciplinary team, form the basis for the care plan.
- ▶ The adult patient with decisional-capacity determines the level of involvement of the family in decision-making and communication about the care plan.
- ▶ Evidence of patient preferences for care is routinely sought and documented in the medical record. Failure to honor these preferences is documented and addressed by the team.

- ▶ Among minors with decision-making capacity, the child's views and preferences for medical care, including assent for treatment, should be documented and given appropriate weight in decision-making. When the child's wishes differ from those of the adult decision-maker, appropriate professional staff are available to assist the child.
- ▶ The palliative care program promotes advance care planning in order to understand and communicate patient or appropriate surrogate's preferences for care across the healthcare continuum.
- ▶ When patients are unable to communicate, the palliative care program seeks to identify advance care directives; evidence of previously expressed wishes, values, and preferences; and the appropriate surrogate decision-makers. The team must advocate for the observance of previously expressed wishes of patient or surrogate when necessary.
- ▶ Assistance is provided to surrogate decision-makers on the ethical bases for surrogate decision-making including honoring the patient's known preferences, substituted judgment, and best interest criteria.

Guideline 8.2 The palliative care program is aware of and addresses the complex ethical issues arising from the care of people with serious, debilitating illness.

Criteria:

- ▶ Ethical concerns commonly encountered in palliative care are recognized and addressed, using ethical principles to prevent or resolve ethical dilemmas, including beneficence; respect for persons; self-determination and associated regulatory requirements for truth-telling; capacity assessment; confidentiality; assent and permission for persons not of legal age to consent; informed consent; and attention to justice and nonmaleficence and associated avoidance of conflicts of interest. The team recognizes the role of cultural variation in the application of professional obligations including truth-telling, disclosure, decisional authority, and decisions to forego therapy. Attention must be paid to the role of children and adolescents in decision-making.
- ▶ Care is consistent with the professional codes of ethics and the scope, standards, and code of ethics of palliative care practice are modeled on existing professional codes of ethics for all relevant disciplines.
- ▶ The palliative care team aims to prevent, identify, and resolve ethical dilemmas related to specific interventions such as withholding or withdrawing treatments (including nutrition and hydration), instituting DNR orders, the principle of double effect, and the use of sedation in palliative care.
- ▶ Ethical issues are documented and referrals are made to ethics consultants or committee, as appropriate.

Guideline 8.3 The palliative care program is knowledgeable about legal and regulatory aspects of palliative care.

Criteria:

- ▶ Palliative care practitioners are knowledgeable about legal and regulatory issues, including federal and state statutes and regulations regarding medical decision-making, advance care planning and directives, and the roles and responsibilities of surrogate decision-makers; appropriate prescribing of opioids and other controlled substances; pronouncing death; request for autopsy and organ transplant; and associated documentation in the medical record.
- ▶ Patients and families are routinely advised of the need to seek professional advice on creating or updating property wills and guardianship agreements.

Conclusion

Palliative care programs support patients of all ages with debilitating serious illness, and their families, through the full course of illness, regardless of its duration. Palliative care is delivered through skilled, interdisciplinary attention to pain and other symptom distress; emotional, spiritual, and practical support; assistance with complex medical decision-making; and coordination across the continuum of healthcare settings. The goal is to help the patient and family achieve the best possible quality of life in accordance with their values, needs, and preferences. These guidelines for quality palliative care programs represent a consensus opinion of the major palliative care organizations and leaders in the United States, and are based both on the available scientific evidence and expert professional opinion. Clinical practice guidelines are required to encourage a level of consistency, comprehensiveness, and quality that patients and families can come to expect and rely upon, whatever their age, their diagnosis, or their needs, wherever they may live, and regardless of the setting in which they receive care. The widespread adoption of these guidelines in the United States will promote access to consistent and high quality clinical services, and help to establish palliative care as the norm and the expectation for the health care of people living with serious illness.

DESCRIPTION OF CORE COMPETENCIES IN PALLIATIVE CARE

Source: Center to Advance Palliative Care

COMPETENCY FOCUS	DESCRIPTION OF COMPETENCY
Pain and Symptom Management	Appropriately manages patient pain and other distressing physical symptoms of disease, illness or treatment in a timely manner and achieves outcomes acceptable to the patient/family. Management may include referral to appropriate specialist and/or acceptance and support of the patient's decision to include complementary therapies in treatment.
Emotional	Supports patient and family expression of emotional needs. Listens actively, supports as appropriate, and refers to support groups, other patients and families with similar conditions, and/or professionals with expertise in this area. May use open-ended questions such as "How are you doing? How are things going in your life? What, if anything, are you feeling anxious about?"
Psychosocial	Provides an environment to support patient and family expression of psychosocial needs. Listens actively, supports as appropriate, and refers to support groups, other patients and families with similar conditions, and/or professionals with expertise in this area. Integrates this area with each interaction. May use open-ended questions such as "How are you doing? How are things going in your life? How have things changed for you in your life? How are your spirits?"
Spiritual/Cultural	<p>Manages interactions to support patient and family expression of spiritual needs and strengths and cultural practices. Creates environment that allows integration of dialogue about spiritual issues within care experience. Refers to spiritual care staff and community resources as congruent with patient/family values.</p> <p>Communicates cultural care preferences of patients/families to others. May use questions such as "What is the meaning of this illness to you and for your life? What lessons would you want to share? How has your sense of time changed? What strength have you called upon as you go through this illness? Are there specific religious or family traditions you would like us to consider?"</p>

COMPETENCY FOCUS	DESCRIPTION OF COMPETENCY
Relationship—Family	Addresses desires and needs for support from family and friends. Determines if there has been a change in family communication. Facilitates family communication of specific issues by structure of interactions. Provides anticipatory guidance for family as they focus on their relationships. This may include reconciliation of relationships. Provides helpful tools and/or refers for assistance with family communication. May use questions such as “How have things been within your family? Are there things you would like to say to your family or things you would like them to know? Friends? Colleagues? How much change has occurred with your social relationships outside the family?”
Honoring Patient Care Wishes	Understands and communicates patient and family wishes prior to crises or impending death. Honors wishes as care goals change. Carries out interventions that make a difference for patient comfort and/or recovery. Supports patient and family when they refuse treatment. Provides welcoming environment for family to stay with patient.
Dying and Death	Identifies those who are approaching last days of living. Communicates honestly to patient/family about approaching death and helps make the most of the last days. Determines patient/family wishes regarding place of death and seeks to have death occur where desired. Assists family to give patient permission to die, to say “good bye,” and to bring reconciliation to family relationships.
After Death	Prepares family for events that occur immediately following death, i.e., select funeral home, make funeral arrangements, notify agencies such as SRS, Medicare, attorney who handles estate, financial issues, canceling appointments, etc. Hint: This could be presented to the family in a packet of information.
Bereavement	Manages interactions with the bereaved that support communication of clinical concerns and questions as appropriate. Actively initiates referrals for support during bereavement.
Relationship	Establishes rapport with patient and family. Is viewed as “present, really listening, caring, and trustworthy.” Initiates contact with bereaved family as appropriate to relationship (e.g., call to family to express condolences).
Communication	Is available physically and mentally for patient and family communication. Delivers difficult information in honest clear manner. Maintains hope by focusing on palliative care when cure or life prolongation is no longer possible. Focuses on helping patient/family live in way meaningful to them.
Teaching	Assesses for patient and family knowledge and questions. Refers to appropriate resources for additional information and support. Provides anticipatory guidance about illness, treatments, possible outcomes, and health system issues.
Team Collaboration	Provides care with a team approach that includes patient and family as integral and essential members of the care team.

SYSTEM ASSESSMENT TOOL

Source: Center to Advance Palliative Care

The following is a chart to identify your system's strengths for a hospital-based palliative care program. The characteristics listed are designed to focus on palliative care for patients facing serious illness and their families. These characteristics may be in place in your institution but they may not specifically address palliative care. This tool is to be used during the system assessment as you communicate with direct caregivers, quality and risk management staff, and patients and their families. It is designed to be helpful as you focus on your infrastructure to improve palliative care. Although your institution may not offer all of the characteristics listed, this tool can be used to assess partnerships and other health care resources within your system that make these characteristics available to your staff and people you serve.

SYSTEM CHARACTERISTICS	P = PRESENT NP = NOT PRESENT	RATE ITS EFFECTIVE IMPLEMENTATION 0 = NOT AT ALL 10 = FULLY IMPLEMENTED AND EFFECTIVE	RATE PRIORITY FOR ACTION PLAN 0 = NOT AT ALL 10 = UNDERTAKE WITHIN YEAR
Vision and Management Standards			
Organization's strategic plan and annual objectives include focus on excellence in palliative care			
Performance improvement plans include focus on improvement of all aspects of palliative care for those with serious illnesses			
Educational resources are designated to support development of competencies and practices in palliative care (See Appendix B, Description of Core Competencies in Palliative Care)			

SYSTEM CHARACTERISTICS	P = PRESENT NP = NOT PRESENT	RATE ITS EFFECTIVE IMPLEMENTATION 0 = NOT AT ALL 10 = FULLY IMPLEMENTED AND EFFECTIVE	RATE PRIORITY FOR ACTION PLAN 0 = NOT AT ALL 10 = UNDERTAKE WITHIN YEAR
Practice Standards (Procedures, Policies, Care Protocol)			
Holistic comfort care or palliative care standard(s) are implemented. Standards specify population to be served			
Interdisciplinary palliative care consult services are available			
Advance care planning supports are available			
Cultural/religious guidelines are integrated			
Organ/tissue donation guidelines are implemented			
Complementary or integrative therapies are supported			
Space and Visiting Standards			
Patient room is comfortable, home-like, and supports family visiting and confidentiality			
24 hour visiting for close friends/family as defined by ill person/family. No age limits to visitors and pets accommodated			
Family participate in care as desired			
Family space is home-like and is supportive of families and their ADL needs			
Spiritual, Religious, and Cultural Standards			
Support is available 24 hours a day for patient, family, and professional caregivers			
Links/communication are established with spiritual care providers			
Bereavement Support Standards			
Active follow-up available for 100% of bereaved families whose loved ones have died within your facility or practice environment 2-4 weeks following death			
Bereavement support groups and 1:1 support available and offered for families and professionals			

SYSTEM CHARACTERISTICS	P = PRESENT NP = NOT PRESENT	RATE ITS EFFECTIVE IMPLEMENTATION 0 = NOT AT ALL 10 = FULLY IMPLEMENTED AND EFFECTIVE	RATE PRIORITY FOR ACTION PLAN 0 = NOT AT ALL 10 = UNDERTAKE WITHIN YEAR
Psychosocial and Emotional Standards			
Referral and individual support is available 24 hours for patients/families and professional caregivers			
Support groups for patient/families are available regardless of diagnosis(es)			
Waiting time to join a support group is less than 2 weeks			
Patients/families are given information about support groups			
Communication Standards			
Patient care preferences; values; spiritual, emotional, and relationship needs; and treatment decisions are consistently and accurately communicated across care settings and professional providers			
Patient care preferences are honored across care settings and professional providers			
Frequent physician communication occurs throughout the course of the serious illness			
Communication with community spiritual care providers is routine			
Professional Experiential Education during Orientation and as Continuing Education			
<i>Education on palliative care provided for all leadership teams, employed staff and physicians in the following areas:</i>			
Organization values and strategic objectives			
Ethics			
Palliative care practice standards			
Palliative care quality standards			
Communication			
Grief and bereavement			
Patient/family supports			
Professional caregiver/staff support			
Spiritual/religious/cultural standards			
Individual performance expectations			

SYSTEM CHARACTERISTICS	P = PRESENT NP = NOT PRESENT	RATE ITS EFFECTIVE IMPLEMENTATION 0 = NOT AT ALL 10 = FULLY IMPLEMENTED AND EFFECTIVE	RATE PRIORITY FOR ACTION PLAN 0 = NOT AT ALL 10 = UNDERTAKE WITHIN YEAR
Individual Performance/Competency Standards Established and Monitored at Least Annually <i>(See Appendix B, Description of Core Competencies in Palliative Care)</i>			
Volunteer Program Standards (If Applicable)			
Training program for volunteers required			
Volunteers available to visit seriously ill patients and/or maintain vigil with dying person if appropriate			
Quality Improvement Standards			
Routine feedback from patients, family caregivers, bereaved family members, and community partners is obtained			
Annual objectives and priorities include focus on palliative care and respond to feedback from above			
Employee Support Standards			
Human Resources policies for employees support bereavement leave for those the person defined as close or family and is at least 7 days			
Human resources policies allow others to “give” vacation time or time off to support other employees			
Acuity and patient assignments provide time to “be with” the patient and family throughout the course of the serious or life-threatening illness			
Professional caregiver is supported to attend memorial/ funeral service of patients			
Community Network and Partnerships			
Care offered by faith-based ministries (including parish nursing) is coordinated with patient needs			
Hospital partners with formal and informal community organizations to meet support needs for patient and family caregivers			
Hospice/home care services are available and linked to other hospital palliative care services			
Education about accessing palliative care is integrated within schools, workplaces, faith-based organizations, and other community formal and informal gatherings			

PALLIATIVE CARE SERVICE SCOPE OF CARE

Source: Adapted from Palliative Care Center of the Bluegrass
Lexington, Kentucky

Department: _____ Policy #: _____

Manual: _____ Effective Date: _____

Distribution: _____ Supersedes #/Date: _____

TITLE: Palliative Care Service—Practice Guidelines on Scope of Care

Definition—Palliative care:

- Palliative care is specialized medical care focused on providing patients with relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.
- Palliative care is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Purpose—For the palliative care team to work with the existing care team: attending physician, nursing, case management, and clinical support staff to provide patient-focused, family-centered care which:

- Defines immediate and long-term goals of care and promotes advance care planning
- Optimizes symptom control
- Optimizes functional status when appropriate
- Promotes the highest quality of life for the patient and family
- Educates the patient and family to promote understanding of the underlying disease process
- Establishes an environment that is comforting and healing
- Plans for discharge to the appropriate level of care in a timely manner
- Assists actively dying patients and their families in preparing for and managing self-determined life closure

Palliative care consultation:

- Requires a written order by the patient’s physician

Palliative Care Team—MD, RN, MSW, MDiv:

- Serve as **educators** and mentors for hospital staff
- Promote timely access to Palliative Care Services
- Collaborate with primary care professionals in developing plan of care
- Provide physical, psychological, social, and spiritual support to patient and family
- Facilitate **care planning** with patient and family to meet multidimensional care needs caused by advanced or life-threatening illness
- Facilitate **patient understanding** of diagnosis and prognosis to promote informed choices
- Assist patients in establishing **goals of care** and establishing priorities
- Encourage **advance care planning**

Criteria for identifying appropriate palliative care referrals:

- Team/patient/family needs help with complex decision-making and determination of goals of care
- Patient has unacceptable level of pain or other symptom distress > 24 hours
- Patient has uncontrolled psychosocial or spiritual issues
- Patient has frequent visits to Emergency Department (>1 x mo for same diagnosis)
- Patient has more than one hospital admission for the same diagnosis in last 30 days
- Patient has prolonged length of stay (> five days) without evidence of progress
- Patient has prolonged stay in ICU and/or transferred from ICU to ICU setting without evidence of progress
- Patient is in an ICU setting with documented poor prognosis

Nurse Executive

Date

Chairperson, Patient Care Council

Date

Medical Executive Committee Chair

Date

PALLIATIVE CARE SCREENING TOOL

Source: Adapted from Palliative Care Center of the Bluegrass, Lexington, Kentucky

Criteria—Please consider the following criteria when determining the palliative care score of this patient																														
1. Basic disease process a. Cancer (Metastatic/Recurrent) b. Advanced COPD c. Stroke (with decreased function by at least 50%)	d. End stage renal disease e. Advanced cardiac disease—i.e., CHF, severe CAD, CM (LVEF<25%) f. Other life-limiting illness	SCORING SCORE 2 POINTS EACH																												
2. Concomitant disease processes a. Liver disease b. Moderate renal disease c. Moderate COPD	d. Moderate congestive heart failure e. Other condition complicating care	SCORE 1 POINT OVERALL																												
3. Functional status of patient Using ECOG Performance Status (Eastern Cooperative Oncology Group)		SCORE AS SPECIFIED BELOW																												
<table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left; width: 10%;">ECOG</th> <th style="text-align: left; width: 10%;">Grade</th> <th style="text-align: left; width: 80%;">Scale</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">0</td> <td></td> <td>Fully Active, able to carry on all pre-disease activities without restriction</td> </tr> <tr> <td style="text-align: center;">1</td> <td></td> <td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work</td> </tr> <tr> <td style="text-align: center;">2</td> <td></td> <td>Ambulatory and capable of all self-care but unable to carry out any work activities, up and about more than 50% of waking hours</td> </tr> <tr> <td style="text-align: center;">3</td> <td></td> <td>Capable of only limited self-care; confined to bed or chair more than 50% of waking hours</td> </tr> <tr> <td style="text-align: center;">4</td> <td></td> <td>Completely disabled, cannot carry on any self-care, totally confined to bed or chair</td> </tr> </tbody> </table>	ECOG	Grade	Scale	0		Fully Active, able to carry on all pre-disease activities without restriction	1		Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work	2		Ambulatory and capable of all self-care but unable to carry out any work activities, up and about more than 50% of waking hours	3		Capable of only limited self-care; confined to bed or chair more than 50% of waking hours	4		Completely disabled, cannot carry on any self-care, totally confined to bed or chair		<table style="width: 100%; border-collapse: collapse;"> <tbody> <tr> <td style="text-align: right; width: 10%;">SCORE 0</td> <td style="width: 80%;"></td> </tr> <tr> <td style="text-align: right;">SCORE 0</td> <td></td> </tr> <tr> <td style="text-align: right;">SCORE 1</td> <td></td> </tr> <tr> <td style="text-align: right;">SCORE 2</td> <td></td> </tr> <tr> <td style="text-align: right;">SCORE 3</td> <td></td> </tr> </tbody> </table>	SCORE 0		SCORE 0		SCORE 1		SCORE 2		SCORE 3	
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SCORE 3																														
4. Other criteria to consider in screening <ul style="list-style-type: none"> • Team/patient/family needs help with complex decision-making and determination of goals of care • Patient has unacceptable level of pain or other symptom distress > 24 hours • Patient has uncontrolled psychosocial or spiritual issues • Patient has frequent visits to emergency department (>1 x mo for same diagnosis) • Patient has more than one hospital admission for the same diagnosis in last 30 days • Patient has prolonged length of stay (> five days) without evidence of progress • Patient has prolonged stay in ICU and/or transferred from ICU to ICU setting without evidence of progress • Patient is in an ICU setting with documented poor prognosis 		SCORE 1 PT EACH _____ _____ _____ _____ _____ _____ _____																												
TOTAL SCORE		_____																												
SCORING GUIDELINES: TOTAL SCORE = 2 No intervention needed TOTAL SCORE = 3 Observation only TOTAL SCORE = 4 Consider Palliative Care Consult (requires physician order)																														

Signature of Staff Member Completing Form _____

Date _____

PALLIATIVE CARE INITIAL ASSESSMENT/CONSULTATION REPORT

Source: Hertzberg Palliative Care Institute, Mount Sinai School of Medicine, New York, New York

<p>Mount Sinai School of Medicine New York, New York Palliative Care Consultation Report</p>	<p>Date: _____ Name: _____ Unit #: _____ Sex/DOB: _____ Physician Service: _____</p>
---	--

REQUESTING PHYSICIAN

Requesting MD: (last name) _____ (first name) _____

Consultant MD: _____

Reason for Consultation: Pain Non-pain Symptoms Plan of Care

Consultation Requested to Evaluate: _____

Problem List: _____

Recommendations:

(1) _____

(2) _____

(3) _____

(4) _____

(5) _____

HPI Summary: _____

Review of Systems and Symptoms Assessment:

System	Neg.	System	Neg.	System	Neg.	System	Neg.	System	Neg.
Constitutional		Endocrine		GU		Musculoskeletal		Respiratory	
Cardiovascular		Eyes		Hem/Lymph		Neurologic		Skin	
ENMT		GI		All/Immunology		Psychiatric			

Patient unable to communicate because of disease severity/cognitive impairment and review of systems unobtainable

Abnormalities:

ESAS (0-none, 1-mild, 2-moderate, 3-severe):

___ Pain ___ Depression ___ Anorexia ___ Inactivity ___ Dyspnea

___ Nausea ___ Drowsiness ___ Constipation ___ Agitation ___ Physical

Discomfort

Dementia: Yes No Delirium: Yes No Coma: Yes No

Karnofsky: _____ %

CONSULTING PHYSICIAN

Mount Sinai School of Medicine New York, New York Palliative Care Consultation Report	Date: _____
	Name: _____
	Unit #: _____
	Sex/DOB: _____
	Physician Service: _____
Date/Time: _____	

PMHx: _____ Family Hx: _____

Social HX: _____ Home Care Services: _____

Contact Person: Name _____ Telephone (_____) _____

DNR: Yes No Living Will: Yes No

Health Care Proxy: Name _____ Telephone (_____) _____

Physical Examination: BP _____ Pulse _____ RR _____ Temp _____ O2 sat _____

	nl		nl		nl		nl
Appearance		Respiratory/Chest		GI/Abdomen		Skin/Integumentary	
HEENT		Cardiac		GU		Neurologic	
Neck		Pulses		Musculoskeletal/ Strength		Psychiatric	
LN							
Abnormalities							

Laboratory and Other Data Review: _____

Fellow/Resident (please print): _____ Dictation Code: _____

Fellow/Resident (signature): _____ Date: _____

Choose Appropriate Documentation (either 1 or 2):

1. Attending Documentation	2. Documentation of Attending Physician Counseling Coordination
	I, as the attending physician, personally provided:

Attending time spent in face-to-face patient contact: _____ minutes

Attending time spent on unit in counseling, care coordination: _____ minutes

Total time: _____ minutes

Attending (please print): _____ Dictation Code: _____

Attending (signature): _____ Date: _____

CONSULTING PHYSICIAN

PALLIATIVE CARE PROGRESS NOTES

Source: Hertzberg Palliative Care Institute, Mount Sinai School of Medicine, New York, New York

<p>Mount Sinai School of Medicine New York, New York Palliative Care Consultation Report</p>	<p>Date: _____ Name: _____ Unit #: _____ Sex/DOB: _____ Physician Service: _____</p>
---	--

CC: _____

Objective Findings (location, quality, duration, timing, context, modifying factors, signs/sxs): _____

Current Symptoms (0-none, 1-mild, 2-moderate, 3-severe):

- | | | | | |
|------------|----------------|------------------|----------------|-------------------------|
| ___ Pain | ___ Depression | ___ Anorexia | ___ Inactivity | ___ Dyspnea |
| ___ Nausea | ___ Drowsiness | ___ Constipation | ___ Agitation | ___ Physical Discomfort |

Delirium: Yes No Coma: Yes No

Counseling Session Participants: _____

Patient unable to participate because of illness severity or cognitive impairment: Yes No

Location: Patient's room Nursing unit conference room Other (specify) _____

Summary of Patient/Family Counseling Session: _____

Assessment/Recommendations: _____

Past History: Not pertinent Family History: Not pertinent Social History: Not pertinent

Current Medications: _____

Review of Systems and Symptoms Assessment:

System	Neg.	System	Neg.	System	Neg.	System	Neg.	System	Neg.
Constitutional		Endocrine		GU		Musculoskeletal		Respiratory	
Cardiovascular		Eyes		Hem/Lymph		Neurologic		Skin	
ENMT		GI		All/Immunology		Psychiatric			

Patient unable to communicate because of disease severity/cognitive impairment and review of systems unobtainable

Abnormalities: _____

Mount Sinai School of Medicine
New York, New York
Palliative Care
Consultation Report

Date/Time: _____

Date: _____

Name: _____

Unit #: _____

Sex/DOB: _____

Physician Service: _____

Physical Examination: BP Pulse RR Temp O2 sat

	nl		nl		nl		nl
Appearance		Respiratory/Chest		GI/Abdomen		Skin/Integumentary	
HEENT		Cardiac		GU		Neurologic	
Neck		Pulses		Musculoskeletal/ Strength		Psychiatric	
LN							
Abnormalities							

Laboratory and Other Data Review: _____

Fellow/Resident (please print): _____ Dictation Code: _____

Fellow/Resident (signature): _____ Date: _____

Choose Appropriate Documentation (either 1 or 2):

1. Attending Documentation	2. Documentation of Attending Physician Counseling Coordination
	I, as the attending physician, personally provided:

Attending time spent in face-to-face patient contact: _____ minutes

Attending time spent on unit in counseling, care coordination: _____ minutes

Total time: _____ minutes

Attending (please print): _____ Dictation Code: _____

Attending (signature): _____ Date: _____

Palliative Care Pager Number XXX-XXX-XXXX

Palliative Care Office Number XXX-XXX-XXXX

INITIAL ASSESSMENT AND PLAN OF CARE

Source: Adapted from Palliative Care Center of the Bluegrass, Lexington, Kentucky



Patient Name Plate

8.28

APPENDIX E-4

Palliative Care Consult Service

Initial Assessment/Plan of Care

Reason for referral: _____

Referred by: _____

Location of patient: _____ Date of consult: _____

History: _____

Evaluations:

Medical: _____

Psychosocial: _____

Spiritual: _____

Nursing: _____

Diagnoses/Problem List:

Psychosocial: _____

Spiritual: _____

Nursing: _____

Recommendations:

Medical: _____

Psychosocial: _____

Spiritual: _____

Nursing: _____

Goals:

Signatures of staff members completing form:

Medical: _____

Psychosocial: _____

Spiritual: _____

Nursing: _____

CONSULTATION TRACKING FORM

Source: Adapted from Transitions and Life Choices, Fairview University Health Services

Unit: _____ Service: _____

Patient name: _____ SS#: _____

DOB: _____ Pt ID: _____

B#: _____

Gender: Male Female

Ethnicity: European American Latino Asian Somali African American Native American
 Other _____

Marital status: Single Married/partner Divorced Widowed

Spiritual and faith community: Christian Jewish Muslim Other _____

Date of referral: _____ Date of first contact: _____

Date of last visit: _____

TLC team member making first contact: Nurse Social Worker Spiritual Health Medical Director MD

Name: _____

Reason for patient referral (check all that apply):

- | | |
|---|--|
| <input type="checkbox"/> Team/patient/family needs help with complex decision-making and determination of goals of care | <input type="checkbox"/> Has more than one hospital admission for the same diagnosis in the last 30 days |
| <input type="checkbox"/> Pain and symptom management | <input type="checkbox"/> Has prolonged length of stay (> than 5 days) without evidence of progress |
| <input type="checkbox"/> Has frequent visits to the emergency room | <input type="checkbox"/> Has prolonged stay in ICU and/or transferred from ICU to ICU setting without evidence of progress |
| <input type="checkbox"/> Psychosocial, spiritual, or cultural issues | <input type="checkbox"/> Is in an ICU setting with documented poor prognosis |
| <input type="checkbox"/> Family/patient request | |

Did a specific event trigger referral? _____

Who particularly needed education during this consultation? (check all that apply)

- Attending Other consulting services House staff Medical students Nurses
 Other hospital personnel Family

Team estimation of life expectancy: <24 hours Days, but <1 week Weeks, but <1 month
 Months, <6 Months, 6-12 >1 year

ECOG performance status at first contact: No symptoms, fully functional <50% of day in bed
 >50% of day in bed Bed-bound

Who initially contacted the team? Housestaff Staff nurses Social worker Spiritual health

Care coordinator: _____ Other: _____

Physician making referral: _____

Specialty: _____

Primary diagnosis (that triggers team involvement—please check):

- | | | |
|---|--|---|
| <input type="checkbox"/> Cancer—head and neck | <input type="checkbox"/> Cancer—pancreas | <input type="checkbox"/> Dementia |
| <input type="checkbox"/> Cancer—lung (small cell) | <input type="checkbox"/> Cancer—prostate | <input type="checkbox"/> Cardiac _____ |
| <input type="checkbox"/> Cancer—lung (non-small cell) | <input type="checkbox"/> Cancer—ovary/uterus/cervix | <input type="checkbox"/> Renal _____ |
| <input type="checkbox"/> Cancer—breast | <input type="checkbox"/> Cancer—lymphoma _____ | <input type="checkbox"/> Neurologic _____ |
| <input type="checkbox"/> Cancer—esophagus/GE junction | <input type="checkbox"/> Cancer—brain/neuro _____ | <input type="checkbox"/> Pulmonary _____ |
| <input type="checkbox"/> Cancer—stomach | <input type="checkbox"/> Cancer—unknown primary cell type: _____ | <input type="checkbox"/> Multi-system _____ |
| <input type="checkbox"/> Cancer—colon | <input type="checkbox"/> Cancer—other _____ | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Cancer—renal | <input type="checkbox"/> AIDS | |
| <input type="checkbox"/> Cancer—liver | | |

If patient died while on consultation service, what was quality of death?

Patient: excellent good fair poor

Family: excellent good fair poor

Secondary diagnoses:

- | | |
|--|---|
| <input type="checkbox"/> Hepatic disease _____ | <input type="checkbox"/> Diabetes _____ |
| <input type="checkbox"/> Cardiac _____ | <input type="checkbox"/> Renal _____ |
| <input type="checkbox"/> Pulmonary _____ | <input type="checkbox"/> Neurological _____ |
| <input type="checkbox"/> Psychiatric _____ | <input type="checkbox"/> Other _____ |

Indicate any extraordinary conditions (e.g., dialysis, intubation, dopamine, etc.): _____

Disposition:

- | | |
|---|--|
| <input type="checkbox"/> Died (date) _____ | <input type="checkbox"/> D/C from service |
| <input type="checkbox"/> D/C to home | <input type="checkbox"/> D/C to home with Palliative Care outpatient follow-up |
| <input type="checkbox"/> D/C to home with Hospice | <input type="checkbox"/> D/C to home with other home care or Hospice services |
| <input type="checkbox"/> D/C to long term care (LTC) facility | <input type="checkbox"/> D/C to LTC with Hospice partner |
| <input type="checkbox"/> D/C to LTC with other Hospice | <input type="checkbox"/> Residential Hospice |

Edmonton Symptom Assessment 0-3 Scale

0=none, 1=mild, 2=moderate, 3=severe

DATE								
Pain								
Activity								
Nausea								
Depressed								
Anxious								
Fatigue								
Appetite								
Well-being								
Dyspnea								
Constipation								
Drowsiness								
Confusion								
Agitation								
Diarrhea								
Sore or dry mouth								
Cough								
Insomnia								

Other: _____

8.32
APPENDIX E-5

Outcomes: Impacted by team (check all that apply):

- Patient/family conference occurred
- Code status clarified
- Affected early discharge—Approx. # days saved: 1-2 3-5 6-10
- Health care agent identified
- Discharge to less acute setting: _____
- Health care directive clarified
- Diagnostic tests reduced: _____
- Pharmaceuticals reduced: _____
- Additional sheet attached with further outcome information or story
- Pain and symptom managed: Significant recommendations made that altered course
- Provided primary psychosocial support
- Provided primary spiritual support
- Provided significant education and support to staff
- Affected withdrawal life prolonging therapies

Staff adoption of recommendations:

- minimal some/early some/late full/early full/late

Patient/family adoption of recommendations:

- minimal some/early some/late full/early full/late

GUIDELINES FOR STAFF ABOUT PATIENT AND FAMILY CONFERENCES/CONFERENCE RECORD FORM

Source: Adapted from Transitions and Life Choices, Fairview Health Services

8.34

APPENDIX E-6

Guidelines for staff about patient and family conferences

Definition: Family conference

A meeting among the patient, family, and health care team to facilitate communication about the plan of care, transition or discharge plan, and patient and family goals and resources. Most conferences will be held to prevent or address communication issues and to resolve identified or anticipated issues.

Definition: Care conference

A formal or informal meeting of health care professionals involved in the care of a patient to communicate and/or develop the plan of care. The patient/family are not present.

Indicators for family conference and care conferences

Family Conference (may also indicate need for care conference)	Care Conference only
Change in patient status/changing goals of care	No clear physician leader Need for coordination among multiple specialties
Health care provider/family miscommunication or conflict	Health care team disagreement
Unusually long length of stay	No primary (or consistent) assignment of nurse to patient
Blanket, absolute direction, e.g., "Do everything for the patient," including when treatment is of minimal benefit	Nurses request to not care for the patient
Differing messages from family members	Patient and/or family seen as "difficult"
Boundary conflicts	Acute or chronic mental health condition complicating plan of care
Family conflict or mistrust of caregivers	
Uninvolved family/adult orphan	
Alternative sites of care are indicated	
Health care providers need information about patient/family cultural and spiritual beliefs	
Debriefing after a death	

How to request

Any staff member may suggest a family conference. This typically occurs during rounds or interdisciplinary discussions.

Who attends

Patient, family, others the patient wishes to invite; attending and consulting physicians; nurse; care coordinator; and other team members involved in the care or whose expertise is needed. This might include a social worker, chaplain, rehabilitation therapists, pharmacists, home care staff, and/or clinical nurse specialists.

Health care team

Some members of the team may need to meet prior to the conference to:

1. Discuss need and purpose
2. Make sure the right people will be at the table
3. Identify lead physician to present medical information from all services
4. Identify facilitator
5. Identify goals
6. Resolve or identify team conflicts around plan of care. All parties need to be at the team conference, if involved in conflict
7. Come to consensus on plan of care

Facilitator's role

Facilitator's roles can vary depending on group facilitation skills of attendees and relationship with the patient and family. Facilitators may include any of the disciplines. Tasks include:

1. Facilitate introductions
 - *Explain purpose and goals of conference*
 - *Review ground rules*
2. Ask patient and family to identify their questions, concerns, and goals
3. Invite review of medical status
4. Facilitate discussion among those present

5. Clarify understanding, especially of medical terminology
6. Summarize discussion, identify follow-up and document on **Patient/Family Care Conference Record**

Format of Conference:

1. Set atmosphere for collaborative, respectful discussion
 - a. *Discuss purpose of and need for patient/family conference*
 - b. *Identify goals and desired outcomes of family conference*
 - c. *Identify family needs and wishes*
2. Provide setting for discussion of diagnosis, implications of illness, and treatment options
3. Identify current and anticipated issues and stressors
4. Identify resources among patient, family, staff, and community that can support patient and family coping
5. Explore and identify hopes and goals beyond current issues (this frequently cannot be addressed until feelings about presenting concerns and problems have been expressed)
6. Identify follow-up, documentation on **Patient/Family Care Conference Record**, need for additional meeting

PATIENT/FAMILY CARE CONFERENCE RECORD (Front)

Fairview Health System

Date: _____ Care Conference Coordinator: _____

Patient: _____ Conference Date, Time, and Location: _____

Diagnosis: _____

Purpose: _____

How are the patient's wishes known?

- Patient cognitive/verbal
- Patient's previous request
- Advance health care directive
- Other _____

If patient is a child (8-18), requires assent.

Who is the decision-maker for the patient?

- Patient
- Proxy (specify) _____
- Parents (if child is under 18)

Issues to be addressed (consider patient update, current problems/stressors, needs and goals of patient/family, desired outcome of conference):

Discussion/Outcomes/Follow-up: _____

Kardex updated to reflect care plan: Date: _____ Initials: _____

Tentative date for next patient planning session: _____

PATIENT/FAMILY CARE CONFERENCE RECORD (Back)

	Notified?	Attended?
Family Members:		
Care Coordinator:		
Primary Nurses:		
Primary Service:		
Attending:		
Fellow:		
Resident:		
Secondary Service:		
Other Services:		
Cardiopulmonary Services:		
Pharmacist:		
Clinical Nurse Specialist:		
Social Worker:		
Physical Therapist:		
Chaplain:		
Psychologist:		
Dietician:		
Patient Representative:		
Child Family Life Specialist:		
Other:		
Signature:		

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APPENDIX E-6

USE OF PENTOBARBITAL FOR SEDATION AND VENTILATOR WITHDRAWAL

Adapted from Guidelines For Physician Staff, Froedtert Hospital, Milwaukee, Wisconsin
Developed by the Palliative Care Committee

These guidelines will outline the use of pentobarbital (Nembutal) as a sedative agent for use in ventilator withdrawal of the dying patient or for so-called “terminal sedation.”

1. Definitions

- a. **Terminal (dying) patient**—A patient who’s disease has progressed beyond the point at which care aimed at cure, remission, or rehabilitation is feasible
- b. **Total sedation**—A medical procedure to alter a patient’s level of consciousness, with the intent to relieve suffering for a dying patient, until the time of death
- c. **Refractory symptom**—A symptom that cannot be controlled, despite aggressive efforts that do not compromise consciousness

2. Clinical situations in the care of dying patients, where use of pentobarbital is appropriate

- Sedation for refractory symptoms—dyspnea, pain, delirium, when all other modalities for symptom control have proven ineffective. The goal of this sedation is to relieve intolerable symptoms until the time of death. This treatment is not equivalent to assisted suicide or euthanasia.
- Sedation for the awake patient, who has requested withdrawal of mechanical ventilation, with the expectation that such removal will result in death. (example: metastatic lung cancer who cannot be weaned from ventilator support).

3. Procedure—Pre-sedation

- a. Patient selection
 - *Dying patient with intolerable symptoms or awake ventilator-dependent patient requesting withdrawal*
 - *Palliative care service attending physician consultation and/or ICU/pulmonary attending physician consultation in cases of ventilator withdrawal*
 - *Review of medical records, patient interview, and examination to determine suitability for terminal sedation*
- b. Family meeting (with patient if patient is decisional)
 - *Discussion of prognosis, treatment options and goals of total sedation*
 - *Review of decision-making authority/advance directive information*
 - *Completion of advance directive if not already done (decisional patient)*
- c. Meeting with hospital staff: primary physician team, nurses, social worker, and chaplain
- d. Write DNR order if not already completed
- e. Review current treatment plan, medications, etc.—discontinue treatments not contributing to comfort (note: discontinuing artificial hydration/nutrition is recommended but not required)
- f. Establish time for beginning sedation; coordinate family, chaplain visits in relation to timing of sedation
- g. Document plan in medical record: reason for decision to use sedation, who is the legal agent making the decision (patient or surrogate), who participated in discussion, alternatives and expected prognosis

4. Procedure—Sedation

- a. Order pentobarbital to be present on floor in time for beginning sedation:
 - *Pentobarbital 50-100 mg for IV push administration at 50 mg/min by physician, followed by*
 - *Pentobarbital 1-2 mg/kg/hr IV for continuous infusion to begin after bolus dose*
- b. Discontinue heart monitors, pulse oximetry
- c. Begin pentobarbital administration
- d. Remove mechanical ventilation once desired level of sedation is achieved (see below)
- e. Assess sedation hourly x 4, then q 2h. to ensure desired effect consistent with goals of care
- f. Document in medical record dose of pentobarbital, titration guidelines, monitoring guidelines

5. Dose titration guidelines

The goal of terminal sedation is provide first stage anesthesia; the eyelash reflex is used to assess level of sedation. First stage anesthesia is achieved when a soft-tactile stroke over a close eyelid causes a small flicker/reflex; deeper anesthesia will cause loss of this reflex.

- ▶ Clues to the need for an increased dose of medication are arousal to verbal or tactile stimulation; frequent body movement, signs of agitation
- ▶ Clues to the need to decrease dose of medication are loss of eyelid reflex, apnea, snoring, vomiting, fixed/pinpoint pupils

When dose escalating, the drip rate of a continuous infusion can be increased in intervals of 0.5-1.0 mg/kg/hr, every hour. If significant arousal or agitation develops, re-bolusing with 50-100 mg. IV push may be necessary.

References

Greene WR and David WH. Titrated intravenous barbiturates in the control of symptoms in patients with terminal cancer. *South Med J* 84:332-337, 1991.

Truog RD et al. Barbiturates in the care of the terminally ill. *NEJM* 327:1678-1681, 1992. Letters in response: *NEJM* 328: 1350-1351, 1993.

Cherney NI and Portenoy RK. Sedation in the management of refractory symptoms: Guidelines for evaluation and treatment. *J Pall Care* 10:31-38, 1994.

Rousseau P. Terminal sedation in the care of dying patients. *Arch Int Med.* 1996;156: 1785-1786.

Smith GP. Terminal sedation as a palliative care: revalidating a right to a good death. *Cambridge Quarterly of Health Care Ethics.* 1998;7:382-387.

Policy guideline: Use of barbiturates in the control of symptoms in terminally ill patients, St. Joseph's Hospital, Milwaukee (#17220-22).

ARTIFICIAL HYDRATION AND NUTRITION IN ADVANCED DEMENTIA OR AT THE END OF LIFE

Adapted from Guidelines for Physician Staff, Froedtert Hospital, Milwaukee, Wisconsin
Developed by the Palliative Care and Ethics Committees in consultation with faculty from
departments/divisions of neurology, geriatrics, radiology, gastroenterology

Source: Froedtert Hospital, Milwaukee, Wisconsin

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APPENDIX F-2

Of particular concern to patients, families, physicians, nurses, and other staff are guidelines about the responsible, ethical, and legal use of artificial hydration and nutrition in patients who are dying.

These guidelines provide a framework for decision-making about the use of non-oral feeding and hydration in patients who are dying, taking into consideration medical, legal, and ethical principles, as well as cultural and religious values.

Definitions

Non-oral feeding—provision of food by nasogastric tube (NG), gastrostomy tube (G-Tube) or Gastro-jejunostomy (G-J tube) or Total Parenteral Nutrition (TPN).

Artificial hydration—provision of water or electrolyte solutions by any non-oral route (intravenous, hypodermoclysis, NG/G/G-J tube).

Advanced late stage dementia or “brain failure”—a progressive, terminal illness caused by one of a number of conditions including Alzheimer’s disease, cerebrovascular disease, congenital or acquired neuro-degenerative diseases, brain tumors, AIDS, Parkinson’s disease, etc. Diagnostic features include:

- Loss of higher cognitive function including memory and judgement
- Loss of intelligible speech
- Inability to interact meaningfully with family/friends
- Inability to maintain oral nutrition due to loss of swallowing reflex
- Inability to ambulate
- Increasing need for medical attention due to complications of dementia

Natural history—progressive dementia is a terminal illness; when patients can no longer eat, speak, or ambulate, the median survival is approximately 6-12 months, depending on the level of medical intervention for intercurrent illnesses (e.g., urosepsis).

Identifying the dying patient—Who is dying? How can this population of patients be identified? There are two groups of patients who can be thought of as dying: 1. Patients entering the Syndrome of Imminent Death, and 2. Patients who have a progressive, incurable, chronic medical condition.

1. Syndrome of Imminent Death

The *Syndrome of Imminent Death* (SID) is the final common pathway to death for virtually all patients except those dying from a sudden catastrophic event (e.g. acute MI). SID is characterized by the following stages:

- ▶ **Early stage:** Bed bound; loss of interest and ability to drink/eat; cognitive changes: either hypoactive or hyperactive delirium, or sedation.
- ▶ **Mid stage:** Further decline in mental status—obtunded; “death rattle”—pooled oral secretions that are not cleared due to loss of swallowing reflex; fever is common.
- ▶ **Late stage:** Coma, cool extremities, altered respiratory pattern—either fast or slow, fever is common.
- ▶ **Time course:** The time to traverse the various stages can be less than 24 hours or up to 14 days. Once entered, it is difficult to accurately predict the time course, which may cause considerable family distress, as patient seems to “linger.”

2. Progressive, incurable, chronic medical condition

Patients in this category can be thought of as dying when most of the following features are present:

- ▶ A progressive disease that no longer responds to life-prolonging treatments
 - *Heart failure or COPD that is refractory to all medications*
 - *Metastatic cancer that is progressing despite chemotherapy, with no further available treatments*
 - *Chronic aspiration pneumonia in the setting of dementia where the patient/surrogate has declined use of artificial feeding*
- ▶ Progressive decline in functional ability
 - *Increasing need for medical attention with little improvement in functional ability (ability to do self-care, mobility)*
 - *Increasingly frequent ER visits, hospital admissions*
 - *Steady weight loss*
- ▶ Psychological acceptance of imminent death
 - *A major depression is excluded*

The medical effectiveness of non-oral feeding/hydration in advanced dementia and/or in the dying patient

Benefits—Psychological benefits for family members and caregivers include:

- Maintaining appearance of life-giving sustenance
- Maintaining hope for future cognitive improvement
- Removal/avoidance of guilt about making a decision to withdraw/withhold non-oral feedings

Unproven benefits—There is no medical evidence to confirm that provision of non-oral feeding or hydration in patients with late-stage dementia will meet the following goals:

- Reduction in aspiration pneumonia
- Reduction in patient suffering
- Reduction in infections or skin breakdown
- Improved survival duration (in a population of similar patients)

Burdens:

- Risk of aspiration pneumonia is the same or greater than without non-oral feeding
- Increased need to use physical restraints
- Wound infections, abdominal pain, and tube-related discomfort
- Cost, indignity

Ethical principles:

- There is no medical or ethical mandate to provide non-oral feeding/hydration to a dying patient when the burden/risk of feeding is greater than the benefit.
- Non-oral feeding/hydration is considered a medical treatment, not “ordinary care.” “Ordinary care” includes provision of oral food and water; bathing; dressing; and keeping a patient safe, warm, and comfortable.
- The decision to withhold or withdraw non-oral feeding/hydration in this setting is **not euthanasia** (the active administration of a drug/procedure by a physician to induce death).
- The decision to withhold or withdraw non-oral feeding/hydration in this setting is **not assisted suicide** (the provision of a lethal drug/procedure to a patient, with their full knowledge that the drug/procedure can be used by the patient to induce death at the time/place of the patient’s choice).

- ▶ Patients who do not have decision-making capacity (non-decisional) may have non-oral feeding/hydration withdrawn or withheld in the following situations:
 - *If the patient has indicated approval of withholding/withdrawing food on a valid advance directive (POAHC or Living Will) and the physician feels that withholding/withdrawal will not incur added suffering; or*
 - *If the patient is in a Persistent Vegetative State (PVS); or*
 - *If the patient has no advance directive but had expressed **clear evidence** in the past that they would not want non-oral feeding/hydration continued and/or if the burden/risk of feeding/hydration is greater than the benefit.*

Religious/cultural values concerning food/water

- ▶ The act of eating and the provision of food to the sick are important cultural symbols signifying life and hope. Thus the withdrawal or withholding of food often appears contrary to normal societal values. Families will often mistakenly equate withdrawal or withholding of food with starvation, euthanasia, or murder.
- ▶ Many, but not all, religions recognize that death is a normal aspect of life and that non-oral feeding/hydration may be discontinued when the burden exceeds the benefit. However, this is not a universally held religious belief; when in doubt, clinicians should consult with the hospital chaplain staff or spiritual leader.
- ▶ Physicians themselves have deeply held cultural and religious values surrounding the issue of feeding. Such personal feelings must be respected, but not allowed to interfere with the presentation of all reasonable facts and options to families or surrogate decision-makers.

Information for physicians when counseling families or surrogate decision-makers

Alternatives to non-oral feeding

When a decision is being made to either discontinue non-oral feeding or not to begin such feeding, alternatives do exist:

- ▶ Hand-feeding, using food/liquids prepared in such a manner that will lessen the aspiration risk (e.g., thickened liquids); or
- ▶ No oral or non-oral food, with the expectation that death will result within 14 days.

Note: There is no data that withdrawal/withholding of non-oral food from patients causes suffering when adequate comfort measures are instituted. **Note:** The dying patient typically has no or little appetite, moreover ketosis will blunt the symptom of hunger. Moistening the lips and good mouth care will alleviate the symptom of a dry mouth. There are good data that provision of non-oral hydration, by itself, will not correct the symptom of dry mouth among the terminally ill.

► Aggressive comfort measures will always be provided

- *Pain and symptom management*
- *Moistening agents to lips and mouth*
- *Frequent change of body position*
- *Keeping warm and dry*
- *Family support*

Discussions with family and surrogates—Key points

- An advance directive should be completed by patients at the earliest onset of a serious illness. Once completed, physicians are legally obligated to follow the patient's expressed wishes.
- Once a medical determination has been made that adequate oral nutritional intake to sustain life is not possible and there are no prior expressed wishes, all reasonable options must be discussed with families/surrogates.
- The option of withholding/withdrawing feeding must be done **in a manner that minimizes guilt for the family/surrogate.**
 - *If available, review patient wishes expressed in an advance directive with family/surrogate. **Note:** if a patient has expressed wishes not to have non-oral feeding/hydration in an advance directive, emphasize to the surrogate(s) that they do not need to make the choice about withdrawal or withholding as the choice has already been made by the patient; the decision by the surrogate is about honoring a previously made decision*
 - *Inquire about patient and family religious or cultural values*
 - *Ask the family/surrogate, "what would (name) want if he/she could tell us?"*
 - *Give permission to withhold/withdraw feeding—patients/families/surrogates will be looking to the physician for clear permission and leadership to make this decision*
 - *Offer consultation input (palliative care, ethics, chaplaincy, psychology)*
 - *Offer families/surrogates time to make a decision; suggest they contact their spiritual leader, friends, or other family for further discussion*
 - *Provide patient/family with educational material*
- If a decision is made to begin non-oral feedings, establish a time frame (e.g., 4-8 weeks) for re-evaluation, to establish if the goals of feeding are being met (e.g., weight gain, improved function). Reassure families/surrogates that if goals are not being met, non-oral feeding can be discontinued.

- ▶ If a decision is made to discontinue/not begin non-oral feedings, and hand-feeding is not an option (e.g., diminished level of arousal), and intravenous hydration is not started, families/surrogates should be advised that death will likely ensue within 14 days and that all comfort measures will be continued.

Discussing artificial feeding/hydration—Suggested phrases

- ▶ I am recommending that the (tube feedings, hydration, etc.) be discontinued (or not started); this treatment will only prolong his/her dying, it will not improve his/her quality of life.
- ▶ Your (relation) will not suffer; we will do everything necessary to ensure comfort.
- ▶ Your (relation) is dying from the (insert terminal disease); they are not dying from starvation.
- ▶ Almost all dying patients lose their interest in eating and drinking in the days to weeks leading up to death; this is the body's signal that death is coming.

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PRINCIPLES FOR TERMINAL WITHDRAWAL OF MECHANICAL VENTILATION

Source: Hertzberg Palliative Care Institute, Mount Sinai Medical Center, New York, New York

Prepared at Mount Sinai with incorporation of materials including protocols posted at www.promotingexcellence.org by the Critical Care Peer Workgroup of the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care Project

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APPENDIX F-3

1. Death occurs as a complication of the underlying disease. The goal of the care outlined in these orders is to relieve suffering in a dying patient, not to hasten death.
2. Dosing of medications is to be determined by patient comfort needs; any dose needed to achieve patient comfort is acceptable, even if death is unintentionally hastened as a secondary effect.
3. Withdrawal of mechanical ventilation is a medical procedure that requires the same degree of physician participation, skill, and quality as other procedures.
4. A senior physician, respiratory therapist, and nurse should be present at the bedside when mechanical ventilation is withdrawn.
5. When mechanical ventilation is to be withdrawn, consideration should be given to the appropriateness of other concurrent life-sustaining treatments.
6. Continuity of care (including caregivers and care setting) is an important consideration when mechanical ventilation is to be withdrawn.
7. Mechanical ventilation should not be withdrawn during the administration of neuromuscular blocking medication, as these will mask signs of distress. Mechanical ventilation can be withdrawn after discontinuation of neuromuscular blockade when clinicians conclude that the patient has motor activity sufficient to demonstrate discomfort.
8. Comfort medication is unnecessary for withdrawal of mechanical ventilation from a brain dead patient.

Protocol for “terminal” withdrawal of mechanical ventilation

- ▶ **Conduct and document discussion with family** to confirm decision to withdraw mechanical ventilation, explain process of ventilator withdrawal, consider which hospital unit is most appropriate, address presence of family during withdrawal process, and assess individual family needs.
 - *If family wishes to be present, explain the patient’s expected condition during the process as clearly as possible.*
 - *If family will not be present, obtain contact numbers and make plans for notification of changes in the patient’s condition.*
- ▶ **Document basis for determination that withdrawal of mechanical ventilation is appropriate**, including discussions with family, advance directive, prognosis for recovery in condition acceptable to patient, discussion with primary MD, and resolution of any legal and/or ethical issues.
- ▶ **Discuss basis and plan for withdrawal of mechanical ventilation with primary nurse, nurse manager, and respiratory therapist.**
 - *The 24/7 beeper for the respiratory therapy supervisor is 2244.*
- ▶ **Assess need for pastoral care** presence and coordinate with chaplaincy, as appropriate.
- ▶ **Enter DNR order.** (Do not reintubate, defibrillate, or use vasoactive medications.)
- ▶ **Reevaluate all other orders**, including routine vital signs, medications, radiographs, and laboratory testing.
- ▶ **Alert NY Gift for Life**, as appropriate. (1-800-GIFT4NY)
- ▶ **If the patient is to be transferred to a different hospital unit** before or after the withdrawal of mechanical ventilation, there must be **clear communication with and assumption of responsibility by the care team in the receiving unit**, including a commitment to attend closely to the needs of the patient and family.
- ▶ **Hold enteral feedings. Aspirate from feeding tube. Remove temporary feeding tubes** unless there is a compelling, comfort-related reason to continue them (e.g., intestinal obstruction, brisk upper GI bleeding).
- ▶ **Remove other devices not necessary for comfort**, including monitors, blood pressure cuffs, and leg compression sleeves. (Intravascular catheters can be left in place if excessive bleeding is expected with discontinuation.)
- ▶ **Begin glycopyrrolate 0.2 mg IV q 8h.**

- ▶ **Enter appropriate orders for comfort medications** (unless brain dead patient). Choice of specific medications and dosing, and decision whether to medicate (or increase dosing above baseline levels), is to be determined on an individualized basis with attention to prognosis for comfortable spontaneous breathing, previous exposure to these medications, and evidence of patient discomfort. Treatment with opioids for pain and dyspnea is appropriate for almost all patients; addition of benzodiazepine or propofol (for sedation) is appropriate for many. Sufficient medication should be available at bedside for relief of distress without delay. Medication needed for comfort should not be held for hypotension, bradycardia, depression of consciousness, or respiration. When administering medications for acute distress, bolus dosing should be used to ensure rapid relief, with or without an increase in a continuous infusion.
- ▶ **Document rationale for medications given** (e.g., appearance of dyspnea, air hunger, labored respirations, tachypnea).
- ▶ **Discontinue ventilator alarms** (as possible—note that some ventilators have a “protective mechanism” that prevents disabling of ventilator alarms).
- ▶ **Discontinue previous ventilator orders.**
- ▶ **Reduce FIO₂ to room air and PEEP to 0 over about 5 minutes**, titrating opioid and sedative medications as indicated for relief of distress. Maintain level of ventilator support until comfort is achieved. **Set ventilator to either PS 5 or, in patients not breathing spontaneously, to low IMV rate (e.g. # 4), and continue this level of support for 5 minutes**, again titrating opioid and sedative medications by bolus as needed to achieve comfort.
- ▶ With attending and housestaff MDs and respiratory therapist at bedside, **extubate** patient (wrapping endotracheal tube in a readily-available pad or towel for disposal) and shut off the ventilator. If the patient has a tracheostomy, leave it in place when the ventilator is discontinued. In rare cases when upper airway obstruction is a significant risk, the attending physician may choose to discontinue mechanical ventilation but leave an orotracheal tube in place; if this is done, the reason should be discussed with the family and team members, and documented in the chart. Supplemental oxygen or humidified air is not needed after extubation/discontinuation of mechanical ventilation.
- ▶ **Continue close MD, RN, and respiratory therapist observation of patient** with further titration of opioid and sedative medications (boluses, with or without increase in continuous infusion) as indicated for relief of distress.
- ▶ **Continue frequent contact between MD (and RN) and family** (whether present or not), with provision of emotional support as appropriate.
- ▶ **When the patient dies, notify the family and the primary physician.** Provide appropriate family support, including assistance with decision-making about autopsy, explanation of the post-mortem process, and contact information for bereavement resources.

CONDENSED MEMORIAL SYMPTOM ASSESSMENT SCALE (C-MSAS)

Source: Chang, Victor. Condensed Memorial System Assessment Scale (C-MSAS)
Predictors of Survival in VA Cancer Patients. *Cancer Investigation*, 2004 ____ in Press.
Forthcoming from Marcel Dekker, Inc. www.dekker.com/servlet/product/productid/CNV

How much did this symptom bother or distress you in the past 7 days?

Symptom	Present	Not at all	A little bit	Somewhat	Quite a bit	Very much
Lack of energy*	Y N	0	1	2	3	4
Lack of appetite*	Y N	0	1	2	3	4
Pain*	Y N	0	1	2	3	4
Dry mouth*	Y N	0	1	2	3	4
Weight Loss*	Y N	0	1	2	3	4
Feeling drowsy*	Y N	0	1	2	3	4
Shortness of breath*	Y N	0	1	2	3	4
Constipation	Y N	0	1	2	3	4
Difficulty sleeping*	Y N	0	1	2	3	4
Difficulty Concentrating*	Y N	0	1	2	3	4
Nausea	Y N	0	1	2	3	4

How frequently did these symptoms occur during the last week?

Symptom	Present	Rarely	Occasionally	Frequently	Almost constantly
Worrying	Y N	1	2	3	4
Feeling sad	Y N	1	2	3	4
Feeling nervous	Y N	1	2	3	4

The scoring is similar to that for the MSAS Short Form

For the top box (physical symptoms), weights of zero for N, 0.8 for not at all, 1.6 for a little bit, 2.4 for somewhat, 3.2 for quite a bit, and 4.0 for very much. The average of the starred symptoms would be the PHYS subscale.

For the bottom box (psychological symptoms), weights of zero for N, 1 for rarely, 2 for occasionally, 3 for frequently, 4 for almost constantly. The average of the 3 symptoms would be the PSYCH subscale.

MODIFIED EDMONTON SYMPTOM ASSESSMENT SCALE

Source: Adapted from Bruera E, Kuehn N, Miller MH, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care* 1991; 7:6-9.

1a. Please rate your pain now.

1. No pain
2. Mild pain
3. Moderate pain
4. Severe pain

1b. Please rate your pain over the past 3 days.

1. No pain
2. Mild pain
3. Moderate pain
4. Severe pain

1c. Is your pain control acceptable to you?

1. Very acceptable
2. Acceptable
3. Not acceptable

2. How would you describe your activity level during the last 3 days?

1. Very active
2. Somewhat active
3. Minimally active
4. Not active

3. How would you describe the amount of nausea during the last 3 days?

1. Not nauseated
2. Mildly nauseated
3. Moderately nauseated
4. Very nauseated

4. How would you describe your level of constipation in the last 3 days?

1. No constipation
2. Mild constipation
3. Moderate constipation
4. Severe constipation

4a. When was your last bowel movement?

1. Today
2. Yesterday
3. 2-3 days ago
4. More than 4 days ago

5. How would you describe your feelings of depression during the last 3 days?

1. Not depressed
2. Mildly depressed
3. Moderately depressed
4. Very depressed

6. How would you describe your feelings of anxiety during the last 3 days?

1. Not anxious
2. Mildly anxious
3. Moderately anxious
4. Very anxious

7. How would you describe your level of fatigue during the last 3 days?

1. Not fatigued
2. Mildly fatigued
3. Moderately fatigued
4. Very fatigued

8. How has your appetite been during the last 3 days?

1. Very good appetite
2. Moderate appetite
3. Poor appetite
4. No appetite

9. How would you describe your sensation of well-being during the last 3 days?

1. Very good sensation of well-being
2. Moderately good sensation of well-being
3. Not very good sensation of well-being
4. Poor sensation of well-being

10. How short of breath have you been during the last 3 days?

1. No shortness of breath
2. Mild shortness of breath
3. Moderate shortness of breath
4. Very short of breath

11. How has your physical discomfort been during the last 3 days?

1. No physical discomfort
2. Mild physical discomfort
3. Moderate physical discomfort
4. Severe physical discomfort

INPATIENT HOSPICE CARE

Source: Amber B. Jones, M.Ed., Health Care Consultant
Hospice Liaison Consultant for the Center to Advance Palliative Care

Palliative care programs may be led by or developed in partnership with hospice(s). Given that the focus of this Guide is on providing hospital-based services, it is important for program planners to understand how hospice can be integrated within the in-patient palliative care continuum. Specific clinical, financial, and regulatory considerations of hospice care provided in the hospital setting are summarized briefly below.

Background

Many hospice patients are insured by the Medicare Hospice Benefit (MHB), a federal program that defines the terms and conditions under which services are rendered and for which reimbursement is authorized. The MHB specifies four levels of care: routine home care, continuous home care, inpatient respite care, and general inpatient care. Each level of care is reimbursed at a different daily rate inclusive of all elements reflected in the plan of care except physician professional services, which are billed separately.

Both inpatient respite care and general inpatient care may be provided in the acute care setting. In-patient services provided for either level of care must conform to the written hospice plan of care.

When a hospice provides inpatient services, there must be a written agreement between the hospital and the hospice that meets specific regulatory requirements (see sample contract on the CAPC website).

Note: Medicaid and other non-Medicare providers also offer coverage of inpatient hospice services; specifications of these payers are beyond the scope of this paper although many of them mimic MHB provisions.

General Inpatient Hospice Care

General inpatient hospice care may be used as necessary for pain control or for acute or chronic symptom management including medication adjustment, observation, or other stabilizing treatments. The caveat for this level is care is that the inpatient admission should be primarily for services that cannot be provided in other settings. So, for example, a brief period of general inpatient care may be needed when a patient elects the hospice benefit at the end of a covered hospital stay. In this case, the patient may be discharged from the hospital on paper, elect hospice and remain in a hospital bed. There is no requirement for the patient who needs continuing inpatient care to physically leave the hospital in order to begin receiving hospice services. The average daily reimbursement rate for general inpatient hospice care from October 1, 2003-September 30, 2004 is \$525.28, modified to reflect area wage considerations.

Inpatient Respite Care

Inpatient respite care is designed to provide skilled nursing care for the patient for whom it is no longer feasible to furnish needed care in the home setting. This level of care may also be used to provide respite for the patient's family or other persons caring for the patient at home. The average daily reimbursement rate for this service from October 1, 2003-September 30, 2004 is \$122.15, modified to reflect area wage considerations. Inpatient respite services may be provided in acute care hospitals, Medicare participating skilled nursing facilities or in nursing facilities that meet special hospice standards.

Financial Considerations

While the hospice inpatient reimbursement rates noted above are considerably lower than hospital daily rates, it is often true that inpatients who elect hospice have exceeded the DRG payment for their hospital stay. Under these circumstances, once the hospitalized patient elects hospice, there is once again an avenue for daily hospital reimbursement.

Billing for Conditions Unrelated to the Primary Hospice Diagnosis

There may be times when a hospice patient requires medical care for one or more conditions unrelated to the primary hospice diagnosis. Any covered Medicare services not related to the treatment of the terminal condition for which hospice care was elected and not included in the hospice plan of care are billed to the intermediary or carrier for regular (non-hospice) Medicare payment. These services are billed by the provider, in accordance with existing procedures as a new admission with appropriate query and billing actions.

HOSPICE HOW-TO: BECOMING A PART B SUPPLIER

Source: National Association of Home Care and Hospice (NAHC)

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APPENDIX I

Many hospices ask how to go about structuring palliative care outreach beyond the Medicare Hospice Benefit. The document below is a copy of a newsletter article released in July 2003 by the National Association of Home Care and Hospice following a meeting with the Association and staff at the Centers for Medicare & Medicaid Services (CMS).

When reviewing this newsletter article, three cautions and one recommendation are key.

1. Each State has the authority to tailor its requirements and/or preclusions relative to clinic establishment. For this reason, it is important to review the relevant state laws and regulations to determine whether a proposed structure is permissible.
2. Each hospice seeking to obtain a Part B supplier number will need to correspond with its local Part B carrier to identify the information the carrier requires and the scope and timeframe of the application process.
3. Care must be taken to ensure that the proposed arrangement is consistent with federal and state physician self-referral and anti-kickback laws.

Recommendation: obtain advice from experienced health care legal counsel.

We have also set forth several explanatory footnotes in the attached newsletter.

Note: to review the formal Arent Fox legal opinion on proposed hospice arrangements involving the provision of palliative care services, visit the CAPC website at www.capc.org. The opinion, prepared by Connie Raffa and Mark Langdon, includes as an attachment a chart which will allow the reader to determine which states have a corporate practice of medicine law which will in turn influence both organizational structuring options and regulatory/approval requirements.

In January 2003, the National Association of Home Care and Hospice (NAHC), an affiliate of Hospice Association of America (HAA), received information from the Centers for Medicare and Medicaid Services (CMS) on how hospices may become Part B suppliers. CMS has now added some additional clarifications to the original guidelines (their additions are in italics). As some hospices are still seeking to become Medicare Part B suppliers in order to bill for non-hospice palliative care for Medicare beneficiaries who are not on the Medicare hospice benefit, we offer below the full instructions on steps to take to become Part B suppliers.

In order to do this, CMS stated that a hospice has to enroll with the local carrier as a single or multispecialty physician clinic. All state licensure requirements for a physician clinic must also be met. The hospice has to enroll as an organization and each physician or other practitioner associated with the hospice must enroll individually. The organization must complete a CMS 855B and the individuals must complete a CMS 855I.

With the exception of physician assistants, the physicians and other practitioners that work for the clinic (hospice) will have to reassign their benefits in order for the clinic to receive payments directly from Medicare. If the clinic employs staff (paid via an IRS W2) there are no restrictions where the services can be rendered. If the clinic contracts with staff (paid via an IRS 1099), benefits can only be reassigned for services rendered on premises owned or leased by the clinic.

For physician's assistants, the clinic has to bill for the services because physician assistant services have to be paid to their employers and not directly to the physician assistants.

Included along with the enrollment application should be a cover letter to the carrier explaining that the hospice is requesting a part B supplier billing number.

There was discussion about how a hospice may become a Medicare Part B supplier. Below are the steps to take and some clarifying questions and answers.

Steps for Hospice to Become a Medicare Part B Supplier

Check state requirements for a physician clinic to be sure you are qualified:

- ▶ Go to website: www.cms.hhs.gov
 1. *Choose Medicare*
 2. *Choose Provider/Supplier Enrollment*
 3. *Choose How Does a Supplier/Provider Enroll*
 4. *Choose Clinic/Group Practice*
 5. *Choose Enrollment Forms*

- ▶ Choose the 855-B Form for the Clinic (hospice), 855I for individual physicians and other practitioners and 855R to reassign benefits to the clinic¹
- ▶ Register as a physician clinic, not a hospice
- ▶ Write a cover letter to go with your registration application explaining your intent to become a physician clinic

Enroll all the physicians and nurse practitioners (NPs) individually to allow them to reassign their benefit payments to the clinic. Physician assistants also have to individually enroll but only their employer can bill and receive payment for their services.

Clarifying Q & A

Q: What services may be billed to a Part B carrier for Medicare hospice benefit patients?

A: 1. Services related to the terminal condition that were furnished by the hospice patient's "designated attending physician."² These services are billed with the "GV" modifier. The attending physician may also bill for services that were furnished by a substituting physician by coding the service with the "Q5" modifier, in addition to the GV modifier; and

2. Services unrelated to the terminal condition (furnished by any Medicare-enrolled physician practitioner or supplier). These should be billed with the "GW" modifier.

Q: If a hospice enrolls as a Part B "clinic," what services would be billable to Medicare Part B?

A: This hospice would be able to bill for any covered physician and nurse practitioner services furnished to Medicare patients who are not enrolled under the hospice benefit.

Q: Does this clinic have to be separately incorporated from the hospice?

A: No, but the hospice must still primarily be providing hospice services to continue its certification as a hospice.³

Q: May the Hospice medical director also be an employee of the clinic?

A: Yes

Q: How do the "Stark" restrictions for physician referrals apply?

A: They do not apply to hospice.

Q: May all of the employees of this clinic also be employees of hospice?

A: Yes

Q: How does this affect care plan oversight under Part B?

A: It doesn't.

Q: May the physician and NP reassign their Medicare payments to the clinic?

A: Yes, regardless of whether they are employed by the clinic (W2 relationship) or contracted by the clinic (IRS 1099 relationship). However, if the relationship is contractual, for the clinic to be eligible for payment, all services provided must be on premises owned or leased by the clinic.

Q: What are the state requirements of a clinic related to the hospice Medicare Part A provider?

A: Determined on a state-by-state basis.

¹ Note that the 855I Form is also used for physician assistants. However, the 855R Form is not applicable to physician assistants.

² To the extent that the physician is an employee, contractor, or volunteer of the hospice, such services would not be billed to Part B.

³ However, for liability purposes, it might be preferable to separately incorporate the clinic.

⁴ When an employee works for two different programs, such as hospice and a non-hospice palliative care program, the issue of cost allocation needs to be examined. Hospices are required to file a cost report, even though they are reimbursed on a per diem methodology. Therefore, cost report rules apply to shared hospice employees. The costs of their salaries and fringe benefits must be allocated on the hospice cost report between the hospice program and a non-reimbursable cost center for the palliative care program. The Provider Reimbursement Manual requires that the hospice obtain prior approval of a cost allocation methodology from their fiscal intermediary prior to the hospice employee performing duties for a non hospice provider. Usually, a time sheet which records time spent on hospice versus the palliative care program is acceptable, but the FI must approve it before implemented.

⁵ However, the Stark Law might apply to Medicare or Medicaid referrals of the following non-hospice services: clinical laboratory; DME; prosthetics, orthotics, and prosthetic devices and supplies; home health services; outpatient prescription drugs; inpatient and outpatient hospital services; physical, occupational and speech therapy services; and certain radiology and radiation therapy services.

⁶ The discussion in footnote 4 related to cost allocation is equally applicable here.

*Although the world is full of suffering,
it is also full of the overcoming of it.*

Helen Keller | Optimism, 1903

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