

Chapter 1 : Hospice Vs. Palliative Care

PDF | This chapter provides an overview of the significant challenges imposed by admission of a patient to an in-patient setting in hospitals and palliative care units and strategies for.

Palliative Care The differences between hospice and palliative care. Hospice care and palliative care are very similar when it comes to the most important issue for dying people: Most people have heard of hospice care and have a general idea of what services hospice provides. Where palliative care programs and hospice care programs differ greatly is in the care location, timing, payment, and eligibility for services. Place Hospice Hospice programs far outnumber palliative care programs. Hospice often relies upon the family caregiver, as well as a visiting hospice nurse. While hospice can provide round-the-clock care in a nursing home, a specially equipped hospice facility, or, on occasion, in a hospital, this is not the norm. Palliative Care Palliative care teams are made up of doctors, nurses, and other professional medical caregivers, often at the facility where a patient will first receive treatment. These individuals will administer or oversee most of the ongoing comfort-care patients receive. While palliative care can be administered in the home, it is most common to receive palliative care in an institution such as a hospital, extended care facility, or nursing home that is associated with a palliative care team. Timing Hospice You must generally be considered to be terminal or within six months of death to be eligible for most hospice programs or to receive hospice benefits from your insurance. Palliative Care There are no time restrictions. Palliative care can be received by patients at any time, at any stage of illness whether it be terminal or not. Payment Hospice Before considering hospice, it is important to check on policy limits for payment. While hospice can be considered an all-inclusive treatment in terms of payment hospice programs cover almost all expenses insurance coverage for hospice can vary. Some hospice programs offer subsidized care for the economically disadvantaged, or for patients not covered under their own insurance. Many hospice programs are covered under Medicare. Palliative Care Since this service will generally be administered through your hospital or regular medical provider, it is likely that it is covered by your regular medical insurance. It is important to note, however, that each item will be billed separately, just as they are with regular hospital and doctor visits. If you receive outpatient palliative care, prescriptions will be billed separately and are only covered as provided by your regular insurance. In-patient care however, often does cover prescription charges. For more details, check with your insurance company, doctor, or hospital administration. Treatment Hospice Most programs concentrate on comfort rather than aggressive disease abatement. By electing to forego extensive life-prolonging treatment, hospice patients can concentrate on getting the most out of the time they have left, without some of the negative side-effects that life prolonging treatments can have. Most hospice patients can achieve a level of comfort that allows them to concentrate on the emotional and practical issues of dying. Palliative Care Since there are no time limits on when you can receive palliative care, it acts to fill the gap for patients who want and need comfort at any stage of any disease, whether terminal or chronic. In a palliative care program, there is no expectation that life-prolonging therapies will be avoided. It is important to note, however, that there will be exceptions to the general precepts outlined. There are some hospice programs that will provide life-prolonging treatments, and there are some palliative care programs that concentrate mostly on end-of-life care. Consult your physician or care-administrator for the best service for you. For additional caregiving information, visit www.

Chapter 2 : Hospice and Palliative Care | L.A. Care Health Plan

A number of actions should be considered by payers, providers, caregiver organizations, and the research community to improve support for family caregivers providing palliative care.

Family Caregiving and Palliative Care: Closing the Policy Gap Carol Levine: Closing the Policy Gap Release Date: It is re-posted here with permission. Family caregivers “what would we do without them? Many studies have demonstrated that family caregivers provide a wide range of essential care to people with serious chronic illnesses or disabilities” the same people who can benefit from palliative care applied as an ongoing approach to care, not just a hospital-based intervention. It is family caregivers who are responsible for much of the complex care at home, including managing pain and other medications, monitoring equipment, and communicating with the palliative care team. To say that most family caregivers are not prepared to take on this demanding role is an understatement. In theory palliative care practice supports the principle of person- and family-centered care, which addresses the needs of both the recipient of care and his or her caregiver, promotes communication and shared decision making as well as coordination and collaboration by health care delivery teams. But the practice arena is far ahead of the policy world. Support for family caregivers has largely been absent from policy discussions of palliative care, which focus on professional, clinical, regulatory, and financial issues. People are often introduced to palliative care during a crisis, when it is difficult to integrate and accept new knowledge. If they do know something, their knowledge may be incomplete or inaccurate. And even when they do get appropriate information, they may choose to reject it. Opening a discussion of palliative care brings up fears of abandonment, suspicions about financial reasons to reduce expensive treatments, concerns that death is imminent, guilt, and anger. Health care professionals themselves are often uneasy in these discussions; they too are unprepared. Reasons for Lack of Policy Support for Family Caregivers Family caregiving is a latecomer to the health care policy arena for a number of reasons. These measures were introduced in the s and s and a typical reaction has often been: These tasks are likely to be among those required in palliative care at home. A related reason may be the lack of standards and requirements for team-based care and a failure to appreciate its value in nonhospital settings. Interdisciplinary teams that include social workers are more likely to respond to the psychosocial needs of both patients and families and to be attuned to environmental and socioeconomic issues that affect caregiving. With the exception of integrated health care plans, the use of interdisciplinary team-based care is relatively rare, although there are some innovative models. Policymakers anxious to control health care costs are beginning to recognize the important role that caregivers play in transitions from hospital to home. Although designed for hospital discharges, it can be used in any setting and formalizes attention to family caregivers. Possible Future Actions A number of actions should be considered by payers, providers, caregiver organizations, and the research community to improve support for family caregivers providing palliative care. On the federal level, programs designed to improve care coordination such as Accountable Care Organizations and Patient-Centered Medical Homes, as well as Community Care Transition Programs, should add explicit attention to family caregivers in their protocols. Short of having Medicare adopt a palliative care benefit not a bad idea, just an unrealistic one, Medicare guidelines and conditions of participation for hospitals, skilled nursing facilities, and home health care agencies should explicitly recognize the need for training caregivers to provide the complex tasks that they are expected to do. Family caregivers should be brought into the planning process as early as possible, so that there are no surprises at discharge and while the disease progresses. Part of this planning should include discussion of palliative care, where appropriate, introduced by skilled clinicians who can address spoken and unspoken concerns. This is not a one-time conversation, but an ongoing discussion. At the state level, the expansion of Medicaid under the Affordable Care Act in some states is an opportunity to ensure that family caregivers are included in assessments of client needs. And as Medicaid Managed Long-Term Care plans are introduced, they should be accountable for including attention to family caregiver needs and limitations in developing care plans. Caregiver organizations as well as palliative care groups can play a major role in educating the public about palliative care “what it is and what it is not.

Professional education , as suggested in a previous Health Affairs Blog post on palliative care from Charles von Gunten and Betty Ferrell, must address the needs of an aging population with chronic illnesses. When presented as an option that relieves pain and suffering and that supports the patient and family in achieving the best quality of life possible, palliative care is more likely to be accepted, requested, or even demanded. Palliative care has much to offer people with serious illnesses and their families; it should be readily acceptable, available, and affordable.

Chapter 3 : Hospital-Based Palliative Care vs. Hospice Care at Home: How to Choose

Palliative care specialists are available at most major hospitals, and they can ease your pain, reduce your stress and perhaps even improve your chance of survival. Their services are typically covered by private insurance, Medicare or Medicaid.

Home-based plans typically integrate multidisciplinary care teams that include physicians and nurses, social workers, mental health professionals and chaplains who visit patients in their homes and offer tailored treatment plans focused on improving quality of life. The results can benefit patients and their caregivers and are cost-effective for the health care system, according to experts. About five years ago, Priority Health established the Tandem initiative, through which a multidisciplinary team provides free care to patients who are seriously ill and unable to seek outside medical help due to cost or immobility. The initiative has shown promising results, including: The big goal is to have that discussion with the patient of: Palliative is the low-tech, high-touch opportunity to learn what the patient wants and needs. They want to impress their doctors. Or that the patient is a hoarder with a fall risk when walking through the house. These social determinants of health can provide important context to their overall health care plan, Gadbois says. Retraining doctors to talk to their patients about end-of-life options is crucial. Death is seen as a failure. But the end is part of our journey. It is important to do a good job helping the person to transition from this world to the next with as much dignity as possible. However, the Center for Medicare and Medicaid Services is now paying for advanced care planning discussion, and some health plans are moving towards adopting a palliative care system. We are eliminating unwanted care, and we see fantastic outcomes. We are in the process of moving in that direction, but no where near where we need to be. Regence, which offers coverage in Idaho, Washington, Oregon and Utah, launched a palliative care program in that includes advance care planning, collaborative care coordination and in-home counseling. It is open to anyone with a serious medical illness and provides caregiver and psycho-social support, as well as non-medical needs such as transportation and food. The Coalition for Compassionate Care of California facilitates a shared community for palliative care learning, and foundations have provided strategic support. Patients and caregivers should ask whether or not palliative care is covered by their health plan and whether it requires a copay. This will allow patients and families to make the most informed choice about how to access palliative care," Fields says.

Chapter 4 : Caregivers Seek Home-Based Palliative Care Options

Palliative care can make a big difference in your family member's treatment and quality of life when he or she has cancer, heart disease, respiratory disease, kidney failure, or other serious illness.

This part of the guide gives answers to many questions family caregivers ask about hospice. When should we start thinking about hospice care? With hospice, the focus is on comfort and quality of life. Hospice may be the best option when you and your family member decide that treatment meant to cure is not worth its side effects, pain, and suffering. In hospice care, the patient and family are treated as the unit of care. It helps to make the choice for hospice sooner rather than later. This means that many patients receive hospice care for only a short period of time. Some patients and caregivers fear that choosing hospice means that nothing more can be done. But this is not the case. In fact, hospice patients often receive a lot of services to help improve their quality of life. Go to top Who decides about hospice care? As the family caregiver, you and your family member are the ones to decide about seeking hospice care. Many people find that it helps to make this choice only after talking with other family members, doctors, and caregivers. You must freely make the choice “ meaning that no one can force you to accept hospice care. Your doctor may be the first one to suggest hospice care. Or you may be the first to mention it. Please do not be afraid to talk about hospice. Some doctors do not like talking about hospice as they feel it is a sign of failure. Once in a while, a doctor may criticize family caregivers for asking about hospice. If this happens, ask why and then get a second opinion from another doctor. Sometimes a doctor and a hospice program do not agree on who should get hospice care. You can also try another hospice. Once the decision is made for hospice care, a doctor must sign an order requesting it. Go to top What if my family member cannot help make the choice? If your family member is too ill, unconscious, confused, or unable to speak, then you as the family caregiver may be the one to decide about hospice care. It helps if you have discussed this ahead of time with your family member. If not, you need to decide based on what your family member has said in the past or what you know about what he or she would want. Sometimes family members strongly disagree with each other. An advance directive is a very important legal document that can help. It is a way for patients to appoint someone to speak on their behalf if they no longer can speak for themselves. This person is known as a substitute decision maker or health care proxy. To learn more about advance directives, go to Advance Directives: What services are included in hospice care? Services vary but include: Care from a team of trained doctors, nurses, social worker, chaplain, home care aides and other health care providers. Hospice care does not include treatments and medications that are aimed to cure. Some programs offer more expensive comfort measures, equipment, or support and care because they have charity donations or special agreements with certain health insurance plans. The team may also include physical and occupational therapists. Access to the hospice team by phone 24 hours a day, 7 days a week. Medication to relieve nausea, pain, shortness of breath, agitation, and other symptoms. Medical supplies and equipment, such as a hospital bed or wheelchair. This includes emotional support as well as teaching how to do certain health care tasks such as giving injections and changing dressings. Short-term respite care “time off for family caregivers. Volunteers to provide companionship for the patient. Go to top Who pays for hospice care? If the patient has Medicare Part A coverage, the Medicare Hospice Benefit pays for most direct patient services listed in this guide including professional fees, medical equipment, and medication. Hospice patients can keep getting Medicare benefits to treat health problems other than the terminal illness. Most private health insurance plans pay for hospice and follow Medicare guidelines. Although not required, most state Medicaid programs pay for hospice services. You should check this to make sure. You may need to pay a small co-payment co-pay for some hospice services, such as some drugs and respite services. How should I choose a hospice? Hospices are not all the same. Some are large and some are small. Some are run by nonprofit agencies, others by corporations. You may have many hospices to choose from or just one. You can find out about hospices in your area by asking a doctor, hospital, state hospice organization, or health department, or by going to www. Make sure you check several sources to get a complete list. Here are some questions you may want to ask before choosing a hospice: Is the hospice certified by Medicare? This means that the hospice

meets state and federal guidelines. Can I speak with hospice staff 24 hours a day, 7 days a week? Is there a specific nurse or case manager I need to contact? How does the hospice manage medical emergencies, such as difficulty breathing or severe pain? How does the hospice manage complaints? How much and what kind of equipment will the hospice provide? What are the hospice policies about: Giving pain medication, antibiotics, chemotherapy to relieve symptoms, radiation therapy, anti-nausea medication, and blood transfusions? Using mechanical ventilator support breathing tubes? Taking out implanted heart devices pacemakers? The first few days of hospice care can be very busy and perhaps confusing. It takes a while to get to know the new team, understand who will be coming and when, and what your role is as a family caregiver. Go to top What happens once hospice services begin? A hospice staff member will set up a meeting with you after your family member has been referred for hospice. This meeting is a time for you and your family member to ask questions and confirm if hospice is the right choice. If so, you will be asked to sign consent forms. The hospice team then begins working with your family member within 1 to 2 days. If your family member had services from a home care agency, you may miss some staff with whom you had a good relationship. This is a common reaction to working with a new team. Calling is often not a good idea because ambulance rides or emergency department visits can be uncomfortable for your family member and are not always helpful. You may have to make some changes to the home such as moving furniture to make room for new hospice equipment. You will be assigned a hospice nurse. He or she will be your main contact and will visit regularly. The hospice team may also include therapists and a part-time aide or homemaker. You can keep working with other aides or helpers you pay for on your own. Hospice staff will talk with you about what to do in a medical emergency. Most often, this means calling the hour hospice number rather than This can be a difficult change if you are used to calling for an ambulance to take your family member to the hospital. Let the hospice team know if your family has any special religious, cultural, or other practices that may affect patient care. When you call the hour hospice number, the staff can help you decide what to do in a medical emergency. Maybe your family member is now at the end of his or her life and would be more comfortable at home. Or perhaps the hospital is the best place to manage his or her symptoms. If your family member does need to go to the hospital, the hospice nurse can assist with the admission and may be able to help you avoid the emergency room. Go to top What if we want to stop hospice care? Hospice care is voluntary. This means that you and your family member can leave the hospice program for any reason, for example, if he or she is getting better. Later on, you can again start working with the same or another hospice program. Go to top What if hospice stops working with our family member? Every hospice has its own medical director who oversees patient care.

Chapter 5 : Family Caregiver | Palliative Care | End of Life Nursing Care

Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers, as well as a toll-free call center for family caregivers and professionals nationwide.

See Making End-of-Life Decisions: What Are Your Important Papers? Palliative care is more likely to be suggested when there are: History The philosophy of palliative care in the US has evolved over time. Although palliative care is a natural practice in many cultures worldwide, the advancement of life-sustaining technology had charted a more cure-focused path in the United States. Life-prolonging measures such as a pacemaker early on in a condition, or a feeding tube or respirator as a disease progresses, are often assumed to be part of the treatment plan of care. Patients and their caregivers can question these assumptions, opting for a plan of care that recognizes and acts on their preferences. As with other medical specialties, physicians can become board certified in palliative care, and there is training and certification for other healthcare staff as well. The palliative philosophy of support, comfort, peace, and dignity is offered at any stage—even early in the diagnosis—of a chronic or serious illness that ultimately may or may not be life-threatening. Studies have indicated the benefits of palliative care: But not all patients have access to palliative care. Hospital staff may not have the right training. A doctor may feel it would not be beneficial in a specific case. Or, because it is more time-consuming than standard medical care, facilities may have concerns about reimbursement of costs. Medicare and Medicaid Medi-Cal in California will likewise cover many of the costs. Comprehensive hospice coverage is available for patients with Medicare Part A. This benefit is broader than the coverage for palliative care: Most private insurance programs pay for hospice programs, and state Medicaid programs cover costs as well. How are palliative care and hospice care different? Hospice is a specific kind of palliative care for patients approaching the end of life and focuses on death with dignity, not on seeking cure. In contrast, palliative care can start at any stage of a serious disease, and curative treatments can continue. With Advance Directives in place, families and healthcare professionals know that when someone is in hospice care, painful or intrusive treatments, admission to intensive care units, or frightening ambulance trips to emergency rooms, for example, may not be wanted or accepted. In fact, if a patient has a medical emergency, families or caregivers are instructed to call the hospice provider rather than Hospice staff are available for consultation 24 hours a day. In hospice, as in palliative care, the focus is on comfort and dignity, and spiritual concerns are addressed. How can patients access palliative and hospice care? Not all hospitals provide the services, but most do. There are different types of local hospice organizations—large and small, and nonprofit and for-profit. Care can be provided in the home, in assisted living or nursing home, hospital, or in a special hospice residence. In both palliative and hospice care, patients and families are gently supported as they are asked to do deep soul-searching about their values and beliefs during a very challenging time.

Chapter 6 : UHF Next Step in Care

The purpose of this review is to outline a succinct and empirically informed account of family caregiving within the context of palliative care and to propose an agenda for the future.

In this article, I will explore the topic in greater depth, discussing the similarities as well as the differences between the two primary options: For example, if the physician orders chemotherapy, it could be administered in the hospital—but not by the hospice—as chemotherapy is considered a therapy and precludes hospice admission. It is important to remember that hospitals are acute facilities that strive to restore patients to optimum function. Very simply, this means that they focus on therapeutic, rehabilitative measures. In this situation, the palliative care team might suggest an early hospice referral, as the patient would be leaving the hospital setting.

What to Expect from Hospital-Based Palliative Care The physician should expect the following from the hospital-based palliative care team: I have found that when working with physicians, patients and families who are considering hospice care in the last months, everyone appreciates a coordinated health care approach, which helps guide the patient to navigate the system, providing appropriate care at each stage. A hospice nurse on the hospital-based palliative team can advise as to when the patient would benefit more from hospice services, and advocate for the patient and his or her family regarding those services.

Hospice-Based Palliative Care Patients who are not hospitalized or are currently undergoing therapy can still access the expertise of the hospice nurse regarding pain and system management. Many hospices provide limited support to patients who are not yet eligible for hospice care or are not emotionally ready for hospice. These are non-reimbursed services that hospices provide as community outreach. Medicare stipulates all curative measures must be exhausted, and all therapies completed, before patients access hospice care benefits. So an early hospice referral from the hospital-based palliative team for these services can establish, and foster, a caring relationship with the case manager and the patient before any hospice care is actually needed. Establishing this relationship and making an early hospice referral helps alleviate fears on the part of the patient and family, and allows for a rapport to develop should the patient access hospice services at a later date.

How to Choose a Quality Hospice Agency Physicians who determine it is time for a hospice referral due to patient preference and disease trajectory may wonder how to select a competent hospice organization. Not all hospices are created equal: But, like choosing a hospital-based palliative care team, there are guidelines for determining high-quality hospice programs. To begin with, the physician can ask: Is the hospice accredited or certified through a national organization? Are staff members certified in hospice and palliative care medicine? Does each team member use a standardized assessment tool? Does each patient have one case manager and social worker assigned to them? How does the program monitor and improve its quality of care? Most hospice agencies are Medicare certified, as Medicare is the primary source of reimbursement for patient hospice care. But if the hospice is Joint Commission Certified, it is held to a higher standard and level of accountability. By voluntarily participating in this outside review and evaluation process, in addition to the mandated federal Medicare and state Department of Health annual reporting, a hospice demonstrates a commitment to quality care, continuous improvement and public accountability for the care and service of terminally ill patients and their families. When a hospice agency has this certification, both physician and patient can rest assured they have chosen a truly excellent hospice whose guiding principles focus on delivering competent, compassionate, and coordinated care. Following is a brief comparison of what each team offers:

Hospital-Based Palliative Care Team	Hospice Agency Services
Patients can be at any stage of illness, from months to years	Patients have a prognosis of 6 months or less and a terminal diagnosis
Services provided in the hospital	Services provided in home, nursing home, assisted living, or hospice house
Reimbursed through existing channels	Reimbursed per diem under hospice benefit
Length of stay varies based on identified needs, therapies involved	Length of stay is 2 months on average; all therapies must have been completed
No bereavement services	1 year of bereavement counseling
Does not use volunteers	Uses volunteers for family team members and bereavement support

The hospital-based palliative care team offers very important services for the patient, but those services vary from hospital to hospital, and not all hospitals have such teams. Hospice services and team

members are the same, however, from hospice agency to hospice agency, as mandated by Medicare. Whether a patient receives care from the hospital-based team or the hospice team, both must strive to provide patient and family-centered competent and compassionate care. This allows for a life closure with dignity and respect—hallmarks of all palliative care.

Chapter 7 : What is a family caregiver - NetofCare

Tips for Family Caregivers. May 2, ; Share ; Sixty percent of the estimated 44 Million caregivers in this country work full-time. In addition, they spend an average of 18 hours a week caring for an ill family member.*

The year-old cinematographer had been losing his voice for months. Then, one night last summer, he woke up gasping for breath. Doctors rushed Griffiths into surgery to place a breathing tube in his throat and, over the next few days, inserted a feeding tube in his stomach and a port in his shoulder for delivering medication. Griffiths would need five kinds of chemotherapy, plus radiation, to shrink the tumor and kill the cancer. The unrelenting pain in his neck made it nearly impossible to sleep. But unlike most people who enter the hospital with a severe illness, Griffiths had a secret source of strength: Comprising a specially trained doctor, nurses and other practitioners, the team helped Griffiths deal with the pain, stress and logistics of his treatment. In addition to making sure he was on the right dosage of morphine, his palliative care team helped him get rides to and from the hospital, provided a nutritionist, helped coordinate his care with all of his other doctors and answered any questions he had in between visits. Palliative care specialists are available at most major hospitals, and they can ease your pain, reduce your stress and perhaps even improve your chance of survival. Their services are typically covered by private insurance, Medicare or Medicaid. Hospice is reserved for when curative treatments have been exhausted and patients have less than six months to live. Palliative care, on the other hand, is a team-based medical specialty focused on providing relief from the symptoms and stress of a serious illness – care that you can get at any age and at any stage of your illness. Palliative care developed in the U. Today, three-quarters of U. Ninety percent of hospitals with beds or more offer it. And these specialists can have an enormous impact on the quality of your life and your outcomes. When adult patients with blood cancers saw palliative care clinicians at least twice a week during bone marrow transplant procedures, they experienced better symptom control during and after their hospitalization, according to a study in the medical journal JAMA. A New England Journal of Medicine study showed that lung cancer patients receiving early palliative care had less depression and better quality of life – and lived nearly three months longer. In fact, the American Society of Clinical Oncology now recommends that all patients diagnosed with advanced cancer receive palliative care within two months of their diagnosis. Communication is critical because one of the major issues people living with serious illness face is the fragmentation of our health care system. One reason is workforce shortages. Can you refer me to a palliative care specialist? You may need to be your own advocate and push to get the palliative care that you need or ask your health care proxy or another loved one to help you get it. For some, it may mean maximizing time with loved ones. Others may prioritize relief from pain and other symptoms. Or it may mean remaining independent and making your own decisions for care and where you want to be treated home versus hospital. Your religious, cultural or personal beliefs. Share anything that might be important to consider in your care and treatment decisions. Which treatments you may or may not want. Whether you have a living will or health care proxy. Give your doctor a copy.

Chapter 8 : Would You Know to Ask for Palliative Care at the Hospital?

ASCO Perspective "Caregivers provide critical support for patients with cancer, but it can take a heavy toll. This study shows that early palliative care, although designed for and directed at patients, can also help ease the burden on their caregivers," said ASCO President Julie M. Vose, MD, MBA, FASCO, ASCO President.

Chapter 9 : End of Life (Palliative, Hospice) | Family Caregiver Alliance

Caregiver Corner. Today, family caregivers provide about 80 percent of elder care. This includes lifting, bathing, delivering meals, taking loved ones to doctor's visits, handling difficult behaviors and managing medications and family conflicts.