

Since the publication of the first edition of The Medical Care of Terminally Ill Patients, the field of palliative care has progressed significantly, both socially and scientifically. In this new edition, Dr. Robert Enck reviews the results of clinical studies devoted to the care of dying patients.

Sign up now Hospice care: Comforting the terminally ill Hospice care might be an option if you or a loved one has a terminal illness. Understand how hospice care works and how to select a program. Find out how hospice care works and how it can provide comfort and support to you or your loved one, as well as to your family and friends. What is hospice care? Hospice care is for people who are nearing the end of life. Hospice care services are provided by a team of health care professionals who maximize comfort for a person who is terminally ill by reducing pain and addressing physical, psychological, social and spiritual needs. To help families, hospice care also provides counseling, respite care and practical support. The goal of hospice care is to support the highest quality of life possible for whatever time remains. Who can benefit from hospice care? Many people who receive hospice care have cancer, while others have heart disease, dementia, kidney failure or chronic obstructive pulmonary disease. Enrolling in hospice care early helps patients live better and live longer. In addition, there is a unique benefit of hospice that allows a patient to be cared for at a facility for a period of time, not because the patient needs it, but because the family caregiver needs a rest in order to continue to care for his or her loved one. This is known as respite care. Where is hospice care provided? Most hospice care is provided at home – with a family member typically serving as the primary caregiver. However, hospice care is also available at hospitals, nursing homes, assisted living facilities and dedicated hospice facilities. Hospice staff is on call 24 hours a day, seven days a week. A hospice care team typically includes: Each patient gets to decide who his or her primary doctor will be while receiving hospice services. This can be your prior doctor or can be one of the hospice doctors. Nurses are also responsible for coordination of the hospice care team. Home health aides can provide extra support for routine care, such as dressing, bathing and eating. Chaplains, priests, lay ministers or other spiritual counselors can provide spiritual care and guidance for the entire family. Social workers provide counseling and support. They can also provide referrals to other support systems. Pharmacists provide medication oversight and suggestions regarding the most effective ways to relieve symptoms. Trained hospice volunteers offer a variety of services depending on your needs, from providing company or respite for caregivers to helping with transportation or other practical needs. Speech, physical and occupational therapists can provide therapy, if needed. Trained bereavement counselors offer support and guidance after the death of a loved one in hospice. How is hospice care financed? Medicare, Medicaid, the Department of Veterans Affairs and private insurance typically pay for hospice care. While each hospice program has its own policy regarding payment for care, services are often offered based on need rather than the ability to pay. Be sure to ask about payment options before choosing a hospice program. How do I select a hospice program? To find out about hospice programs, talk to doctors, nurses, social workers or counselors, or contact your local or state office on aging. Consider asking friends or neighbors for advice. To evaluate a hospice program, ask questions about the services offered. Is the hospice program Medicare certified? Is the program reviewed and licensed by the state or certified in some other way? Is the hospice program accredited by The Joint Commission? Who makes up the hospice care team, and how are they trained or screened? Is the hospice medical director board certified in hospice and palliative care medicine? Is the hospice program not-for-profit or for profit? Does the hospice program have a dedicated pharmacist to help adjust medications? What services are offered to a person who is terminally ill? How are pain and other symptoms managed? How are hospice care services provided after hours? How long does it take to get accepted into the hospice care program? What services are offered to the family? What respite services are available for the caregiver or caregivers? What bereavement services are available? Are volunteer services available? If circumstances change, can services be provided in different settings? Does the hospice have contracts with local nursing homes? Is residential hospice available? Are hospice costs covered by insurance or other sources, such as Medicare? Remember, hospice stresses care over cure. The goal is to provide comfort during the final months and days of life.

Chapter 2 : The Medical Care of Terminally Ill Patients

Since the publication of the first edition of The Medical Care of Terminally Ill Patients, the field of palliative care has progressed significantly, both socially and scientifically.

We live in a death-denying culture that favors life-prolonging interventions rather than admit hard truths and focus on quality of life. Physicians are human, too. Even they prefer to explore all their options with the hope of finding a miracle. Jessica Zitter, a palliative care physician and author, this is a mistake. To willfully ignore or delay a terminal diagnosis, no matter how good the intention, only prolongs suffering. Ample data support a clear reluctance, even opposition, to this kind of harsh treatment. Zitter wrote about one particular case that highlights the pervasiveness of this trend. She tells the story of a woman named Marcia Green. Zitter met with her, Green had been diagnosed with end-stage lung cancer. Yet, she did not know or realize that her diagnosis was terminal. Zitter sites several reasons for why this happened. In general terms, physician lack training in end-of-life decisions. They also face time constraints that prevent them from spending adequate time with patients to discuss their options. Zitter admits that there is an underlying cultural trend in the medical community that encourages life-prolonging treatment. But this all poses a tremendous problem for patients. Not only is the tendency to favor life-prolonging treatment with terminally ill patients harsh, it is also expensive. It places an unnecessary burden on patients and their families. In order to change this tendency, Dr. Zitter says the underlying culture in the medical community needs to change. The earlier training in end-of-life issues is implemented, the better outcomes will be for patients. Zitter is not alone in her observations. The Massachusetts Coalition for Serious Illness Care has successfully lobbied to improve physician training on how to ask more personal questions to make better decisions in end-of-life care. Their program is a shining example of how education and awareness of issues in end-of-life care are effecting positive change across the country. This is important because many patients elect lower levels of intervention after having these discussions with their doctors.

Chapter 3 : Nurses play vital role in care of terminally ill patients

The Medical Care of Terminally Ill Patients by Robert E. Enck MD Since the publication of the first edition of The Medical Care of Terminally Ill Patients, the field of palliative care has progressed significantly, both socially and scientifically.

End-of-life care By definition, there is not a cure or adequate treatment for terminal illnesses. However, some kinds of medical treatments may be appropriate anyway, such as treatment to reduce pain or ease breathing. Others continue aggressive treatment in the hope of an unexpected success. Still, others reject conventional medical treatment and pursue unproven treatments such as radical dietary modifications. Hospice care, which can be provided at home or in a long-term care facility, additionally provides emotional and spiritual support for the patient and loved ones. Some complementary approaches, such as relaxation therapy, massage, and acupuncture may relieve some symptoms and other causes of suffering. They can also assist the individual with daily living activities and movement. Caregivers may call the physician or a nurse if the individual: Caregivers reassure the patient and honor all advance directives. Palliative care can also help patients make decisions and come to understand what they want regarding their treatment goals and quality of life. Additionally, it lowers hospital admissions costs. However, needs for palliative care are often unmet whether due to lack of government support and also possible stigma associated with palliative care. For these reasons, the World Health Assembly recommends development of palliative care in health care systems. However, hospice care is specifically for terminal patients while palliative care is more general and offered to patients who are not necessarily terminal. A common misconception is that hospice care hastens death because patients "give up" fighting the disease. However, patients in hospice care often live the same length of time as patients in the hospital. A study of liver cancer patients found that patients who received hospice care, and those who did not, survived for the same amount of time. In fact, a study of adult lung cancer patients showed that patients who received hospice care actually survived longer than those who did not. Additionally, in both of these studies, patients receiving hospice care had significantly lower healthcare expenditures. Since patients are in the company of other hospice patients, they have an additional support network and can learn to cope together. Hospice patients are also able to live at peace away from a hospital setting; they may live at home with a hospice provider or at an inpatient hospice facility. The specific medication prescribed, however, will differ depending on severity of pain and disease status. To ease this symptom, doctors may also prescribe opioids to patients. Some studies suggest that oral opioids may help with breathlessness. However, due to lack of consistent reliable evidence, it is currently unclear whether they truly work for this purpose. For example, if patients develop depression, antidepressants will be prescribed. Anti-inflammation and anti-nausea medications may also be prescribed. Rather than to "give up fighting," patients spend thousands more dollars to try to prolong life by a few more months. What these patients often do give up, however, is quality of life at the end of life by undergoing intense and often uncomfortable treatment. A meta-analysis of 34 studies including 11, patients from 11 countries found that less than half of all terminal patients correctly understood their disease prognosis, or the course of their disease and likelihood of survival. This could influence patients to pursue unnecessary treatment for the disease due to unrealistic expectations. In PAS, physicians, with voluntary written and verbal consent from the patient, give patients the means to die, usually through lethal drugs. Reasons as to why patients choose PAS differ. These often depend on the organization and the stance they take on the issue. In this section of the article, it will be referred to as PAS for the sake of consistency with the pre-existing Wikipedia page: In the United States, PAS or medical aid in dying is legal in select states, including Oregon, Washington, Montana, Vermont, and New Mexico, and there are groups both in favor of and against legalization. They believe that allowing PAS is an act of compassion. According to Sulmasy et al. For example, the Death with Dignity Act in Oregon includes waiting periods, multiple requests for lethal drugs, a psychiatric evaluation in the case of possible depression influencing decisions, and the patient personally swallowing the pills to ensure voluntary decision. They state that instead of using PAS to control death: The International Association for Hospice and Palliative Care issued a position statement arguing against considering legalizing PAS unless comprehensive palliative care systems in the country were

in place. It could be argued that with proper palliative care, the patient would experience fewer intolerable symptoms, physical or emotional, and would not choose death over these symptoms. Palliative care would also ensure that patients receive proper information about their disease prognosis as not to make decisions about PAS without complete and careful consideration. Doctor-patient relationships[edit] Doctor-patient relationships are crucial in any medical setting, and especially so for terminal patients. There must be an inherent trust in the doctor to provide the best possible care for the patient. However, being overly optimistic about outcomes can leave patients and families devastated when negative results arise, as is often the case with terminal illness. The six-month standard is arbitrary, and best available estimates of longevity may be incorrect. Though a given patient may properly be considered terminal, this is not a guarantee that the patient will die within six months. Similarly, a patient with a slowly progressing disease, such as AIDS , may not be considered terminally ill if the best estimate of longevity is greater than six months. However, this does not guarantee that the patient will not die unexpectedly early. Patients may experience grief , fear , loneliness , depression , and anxiety among many other possible responses. Terminal illness can also lend patients to become more prone to psychological illness such as depression and anxiety disorders. Insomnia is a common symptom of these. Depression causes quality of life to go down, and a sizable portion of patients who request assisted suicide are depressed. These negative emotions may be heightened by lack of sleep and pain as well. Patients may feel distressed when thinking about what the future may hold, especially when considering the future of their families as well. It is important to note, however, that some palliative medications may facilitate anxiety. Different forms of psychotherapy and psychosocial intervention, which can be offered with palliative care, may also help patients think about and overcome their feelings. Taking care of sick family members may also cause stress, grief, and worry. Additionally, financial burden from medical treatment may be a source of stress. Interventions may also be offered for anticipatory grief. In the case of more serious consequences such as Depression , a more serious intervention or therapy is recommended. This must be done while the patient is still able to make the decisions, and takes the form of an advance directive. DNR orders are medically and legally binding. Recognizing these symptoms and knowing what will come may help family members prepare. During the final hours, patients usually will reject food and water and will also sleep more, choosing not to interact with those around them. Their bodies may behave more irregularly, with changes in breathing, sometimes with longer pauses between breaths, irregular heart rate, low blood pressure, and coldness in the extremities. It is important to note, however, that symptoms will vary per patient. Education about death and its aftermath, especially as it relates to decision-making. Completion of any significant goals, such as resolving past conflicts. Palliative sedation is not intended to prolong life or hasten death; it is merely meant to relieve symptoms.

Chapter 4 : Terminal illness: Supporting a terminally ill loved one - Mayo Clinic

Assessing and managing depression in the terminally ill patient. Ann Intern Med. "A clear, well-written review on the diagnosis and treatment of depression in the terminally ill.

Sign up now Terminal illness: Find out how to offer support and deal with grief. By Mayo Clinic Staff

Knowing how to offer comfort and support to a loved one who has a terminal illness can be challenging. What can you say or do? How can you help your loved one cope? How will you deal with your own grief? Get the facts about supporting a loved one who is terminally ill. My loved one has been diagnosed with a terminal illness. How might our relationship change? Your relationship with your loved one might not necessarily change because he or she has a terminal illness. Or unresolved conflicts might present new challenges. Remember that your loved one is still the same person and will still have the same needs and desires as he or she had before the terminal illness. Many people facing terminal illness want to be treated as normally as possible, without always focusing on the illness. How can I help my loved one cope with a terminal illness? Is there a typical emotional process that a person who has a terminal illness experiences? It might not happen that way. Acceptance or accommodation might be the most desirable outcome of the grieving process "learning to live as fully as possible while accepting the presence of a terminal illness. But does your loved one have to accept that he or she has a terminal illness? Does your loved one have to accept that he or she is going to die before he or she expected? Denial is an important coping mechanism. Your loved one might be in denial because reality is too frightening, too overwhelming, or too much of a threat to his or her sense of control. Denial is a form of natural protection that can allow your loved one to let reality in bit by bit and continue living as he or she contemplates death. Your loved one might be afraid of pain. Perhaps your loved one is afraid of losing control of his or her bodily functions, mind or autonomy. Your loved one might also fear failing family or becoming a burden to others. To provide emotional and spiritual support to your loved one, invite him or her to talk about his or her fears. When is denial harmful? This can be most effectively handled by a professional who has expertise in the care of the dying. Examples of professionals in this area include hospice, palliative care nurses, physicians and social workers. Clergy may also be of great help if religion is important to the patient. What else can I do for my loved one? You can encourage your loved one to talk about his or her life. For instance, ask your loved one to talk about how he or she met his or her mate. You might be amazed at the stories your loved one has to share. Consider recording your conversations as a way of honoring the memory of your loved one. Keep in mind that your loved one is still the same person he or she was before becoming ill. Your loved one will likely still have the same needs, desires and interests. Is it important to keep a vigil by my loved one when he or she is near death? Start by asking your loved one what he or she would want. Most people wish to die with family nearby, but others might prefer to go privately. Let the dying person be your guide. Keeping a vigil by your loved one before his or her death can be a sacred experience. Remember, however, that keeping a vigil can be exhausting. Constant, physical presence is not required as part of being loving and supportive. If you choose to keep a vigil, be sure to take breaks, drink plenty of fluids, eat balanced meals and accept support from others. Sometimes it might appear that your loved one is having trouble letting go. What advice do you have for people who are grieving? Grief is a natural response to loving and feeling loss that often comes in waves. Emotions can sometimes feel overwhelming, making even simple tasks difficult. Right now you need to grieve. Hospice or palliative care experts can be a great resource. What do you tell people who are struggling with guilt? After your loved one dies, you might question whether you did enough or said the right things. Guilt is a normal part of grieving. Often, we come to peace and guilt gradually fades.

Hospice care is for a terminally ill person who's expected to have six months or less to live. This doesn't mean that hospice care will be provided only for six months, however. Hospice care can be provided for as long as the person's doctor and hospice care team certify that the condition remains life-limiting.

The assurance that you will be able to carry on—perhaps to help children grow or to fulfill another shared dream—may offer enormous relief. How to talk about death Talking about death is often difficult. Your own anxiety, sadness, and discomfort may make the words choke in your throat. But clinicians who work with people with a terminal illness point out the following: Some people at the end of life are comforted by the thought that they will be embraced, not abandoned, no matter what happens. Some want to talk. They may tire of keeping up a good front or talking around a topic that looms so large that every other conversation strikes false notes. Some are afraid—and want empathy. They may be stifling their own numerous fears: Many people dread a painful death or the reflected fears of others. Sharing such fears and expressing beliefs about death can help people feel less overwhelmed and alone. It can also diminish physical pain, which is aggravated by fear. Approaching this difficult conversation Clearly, not everyone who is terminally ill is ready to talk about death. So how will you know when to talk and what to say? Below are some words that may help you. Your task in this difficult time is merely to open the door to this conversation and promise to stay for it if the person you care for wishes to talk. Broach the topic gently. What do you worry about? How can I help? Is there anything you want to talk about? Try not to rebuff tentatively expressed fears with hearty assurances, such as: It might help instead to ask specific questions. What are you thinking about? What would be a good death? Sharing your own thoughts on the nature of a good death may help. Talk with your religious leader or counselor. Priests, rabbis, and other religious leaders can offer real comfort to believers. Even people who do not regularly attend religious services may turn toward their faith as an illness progresses. Ask advice about hospice. Hospice workers and hospital social workers can also help you and the person who is ill grapple with the issues surrounding death. Even if you have chosen not to use a full range of hospice services, some resources are often available. Ask a doctor to help. Some doctors can ask gently about fears, as well. Some feel determined to try everything and view death as a failure. Being human, they have their own fears and discomfort to deal with, too. Let your loved one end conversations that feel too difficult. Allow him or her to hold on to comforting thoughts and fantasies. A New England Journal of Medicine study reported that longer, more empathetic end-of-life conferences eased stress, anxiety, and depression in family members of people who died in intensive care units ICUs. Conducted in 22 ICUs in France, this randomized trial divided families of patients into two groups; those in one group had short, standard conferences, and those in the other engaged in longer sessions and received a brochure on bereavement. During the longer sessions, staff focused on listening, acknowledging and valuing feelings, encouraging and responding to questions, and gaining an understanding of the patient as a person. When the researchers contacted a representative in each family 90 days later, they found that those who attended longer end-of-life conferences had significantly lower scores on measures of stress, anxiety, and depression than did family representatives from the control group. The practical aspect of end-of-life planning Few of us wish to think about practical matters at difficult times. The sections below address the topics of advance care directives which set forth how a person hopes to be treated medically toward the end of life , hospice services, and organ donation. These documents address how aggressively doctors should pursue life-sustaining measures and whether quality of life or comfort should be paramount concerns. Two common advance directives are: This sets forth medical wishes that will guide health care if a person becomes mentally or physically unable to make decisions Health care power of attorney or health care proxy. State laws vary, so it is important to make sure any advance directive complies with local regulations. Or have your loved one discuss this with a lawyer qualified in elder law. Rather than sidestepping this difficult issue, though, consider that mulling over wishes for end-of-life care can help people sort out values and feelings about medical measures often taken at the end of life. A frank talk with a doctor about possible medical scenarios can provide guidance. It may help to know that if the person who wrote the

advance directive has a change of heart at any time while under medical care, his or her spoken wishes override any written ones. These wishes should be communicated fully with everyone involved. Make sure you or your loved one takes the following steps: Anyone named as proxy in a durable power of attorney for health care should have a copy of the document and know the goals for medical care. The proxy, a family member, and a lawyer, if any, should know where additional copies of the form are kept. Talk with medical staff. Talk with the doctors to be sure the wishes are understood and can be followed. Discuss wishes for end-of-life medical care with family members. Acknowledge that this is a difficult topic. It may help to begin by talking about a recent case in the news or the treatment of someone you know. Have discussions with family and medical staff more than once to be sure wishes are understood. This is especially important as circumstances change. This document is written only when these measures are unlikely to revive a dying person or to prolong meaningful life. Generally, during the last stage of a terminal illness, CPR is not very likely to result in successful resuscitation. Here is some advice about making the best use of DNR documents: Decide when a DNR is needed. Discuss the need for a DNR with your loved one and the doctors. Understand that medical care will still be available. It may be reassuring to know that even with a DNR, the patient will continue to receive appropriate medical care to treat short-term illnesses or injuries and relieve pain or other troubling symptoms. Know why putting it in writing matters. Keep the originals handy. Have some on file. Mistakes do occur, so ask if this has been done. A machine called a ventilator or respirator forces air into the lungs for people who are unable to breathe under their own power. A tube inserted into a vein supplies a solution of water, sugar, and minerals for people who are unable to swallow. Artificial nutrition tube feeding: A tube inserted through the nose into the stomach supplies nutrients and fluids for people who are unable to swallow. Blood is circulated through a machine to maintain the balance of fluids and essential minerals and clear waste from the bloodstream for people whose kidneys are unable to perform this function. Hospice comfort and care Once a word that evoked shelter for tired and ill religious pilgrims, the term hospice has come to describe a concept of end-of-life care centered on quality of life. Hospice careâ€”which encompasses physical, emotional, and spiritual needsâ€”may take place at home or at a nursing home, assisted living center, or hospice residence. The hospice team works with the patient to develop a personal plan of care. Family, partners, and close friends may be invited to help in many ways, such as by assisting with daily tasks like feeding and bathing and offering comfort by reading, sharing music, holding hands, and simply being present. Hospice programs vary greatly but generally share certain characteristics: Hospice staff can administer pain medications, provide nursing care, and offer emotional support. Before and after a death, emotional support is extended to caregivers, too. Many programs offer bereavement counseling for a year after a death. The hospice team typically includes specially trained doctors, nurses, aides, social workers, counselors, therapists, people who offer spiritual care, and volunteers, according to the Hospice Foundation of America. Licensing, certification, and accreditation. Hospices must be licensed in most states. Those providing services covered by Medicare or Medicaid must be certified by the Centers for Medicare and Medicaid Services. Hospice programs may also be accredited by the Joint Commission or the Community Health Accreditation Program, but there is no national requirement for this. Hospice services are covered nationwide under Medicare and in at least 45 states and the District of Columbia under Medicaid for anyone who has a prognosis of six months or less to live. Many private insurers and health maintenance organizations also offer coverage. As you consider hospice programs, the Hospice Foundation of America suggests you ask whether each is licensed and Medicare- or Medicaid-certified, or certified by other organizations. Find out what services are available, whether insurance or Medicare or Medicaid covers these costs, and what out-of-pocket expenses are typical. Sometimes a sliding-scale payment plan is available for services that insurance will not cover. It is wise to investigate hospice programs well in advance, as there may be a waiting list for some facilities. And ask about support programs for caregivers and availability of inpatient services. Locating a Hospice Program Near You To locate a hospice program near you, ask a doctor for a referral or contact:

Qualifications include either a doctor of medicine or osteopathy, licensed in PA with expertise in the medical care and pain management of terminally ill.

Chapter 7 : Medical Marijuana for Terminal Illness - Marijuana Doctors

Tomorrow's Doctors identifies palliative care, including care of terminally ill patients, as one of the core content areas for undergraduate medical education. 18 Indeed, the palliative care component is increasing in medical schools across the United Kingdom; the mean number of taught hours in a recent survey was 19 The educational.

Chapter 8 : When a Loved One is Terminally Ill: Talking About Death and Making End-of-life Decisions

Hospice offers pain management and palliative care for patients who are terminally ill. Hospice is not tied to a particular place. It can be offered at home or in an assisted living facility nursing home, hospital or hospice center.

Chapter 9 : The Cost of Dying - CBS News

Terminal illness or end-stage disease is an incurable disease that cannot be adequately treated and is reasonably expected to result in the death of the patient. This term is more commonly used for progressive diseases such as cancer or advanced heart disease than for trauma.