

The Dying Process: A Guide for Caregivers is also available in hardcopy. [Orders may be placed here.](#)

The Dying Process: A Guide for Caregivers



Physical Symptoms of Dying

3

LIFE-THREATENING ILLNESS 4

Physical Changes Associated with Dying

Nutrition and Hydration

States of Consciousness as Death Approaches

Myths about Dying

GOALS OF CARE 7

Needs of Dying Persons

Redefining the Goals of Care

Life-Support Measures

PAIN MANAGEMENT 10

Understanding the Nature of Pain

Barriers to Effective Pain Management

Consequences of the Failure to Manage Pain

The Patient's Right to Pain Relief

Understanding Pain Medications—Opioids

Common Myths about Pain

Pain Definitions

Psychological Concerns

17

ANXIETY 18

DEPRESSION 19

SUFFERING 20

SUICIDE 21

ANGER 23

CONCLUSION 24

About this Booklet

THE DYING PROCESS: A GUIDE FOR CAREGIVERS

INTRODUCTION

The Dying Process: A Guide for Caregivers, is intended for anyone who is caring for a dying person. Many of us who are caring for a terminally ill person have never done so before. This guide discusses both the physical symptoms of dying and the psychological issues that accompany the dying process. Even though each person is different, and the paths to death will vary, Hospice Foundation of America hopes to equip you, the caregiver, with enough knowledge and understanding to guide you through caring for your terminally ill loved one or patient.

- The first section will discuss the physical symptoms of dying, goals of care for the patient and caregiver, and pain management.
- The second section will deal with psychological issues that arise during the dying process and ways that you, the caregiver, can help the dying person in addressing these issues.

PHYSICAL SYMPTOMS OF DYING

An understanding of the physical changes and pain management issues that occur during illness and death are critical for any caregiver offering support to dying persons and their families.

Generally, patients portray specific physical symptoms that indicate they are approaching death. Many of us who are involved in the care for someone have never witnessed someone dying. It is hard, both physically and emotionally, to know and accept that someone we are caring for is near death. But if caregivers are aware of these symptoms, then they will be better prepared to give their loved one the best care possible in the final days. Knowing the signs of death will also help caregivers to prepare the rest of the family.

Whether you are the caregiver, or anyone who is involved in the life of the person dying, we hope that by knowing some physical aspects of the death process, you will be able to understand what is happening with your loved one, and what you can do to help.

After reading this booklet, the caregiver should be able to:

- Describe what may be expected as death occurs;
- Demonstrate an understanding of the issues related to withholding or providing nutrition and hydration as death approaches;
- Identify states of consciousness as death approaches;
- Identify some of the typical needs of dying person that will influence the goals of care;
- Demonstrate an understanding of the need for and value of effective pain management.

LIFE-THREATENING ILLNESS

Physical Changes Associated with Dying

What follows is a general description of what one may expect with an impending death. The picture will vary greatly according to the cause of death, the person's general health, medications and any other significant factors. However, the family can expect to see these physical events:

- Activity decreases, with less movement, less communication, less interest in the surroundings;
- Interest in food and water diminishes;
- Body temperature lowers by a degree or more;
- Blood pressure begins to fall, gradually;
- Circulation to the extremities is diminished so that the hands and feet begin to feel cool compared to the rest of the body;
- Breathing changes from a normal rate and rhythm into a new pattern of several rapid exchanges of air followed by a period of no respiration. This is known as “Cheyne-Stokes” respiration after the person who first described it;
- Skin color changes from normal to a duller, darker grayish hue;
- The fingernail beds become bluish rather than the normal pink;
- Verbalization (speaking) decreases. The person ceases to respond to questioning and no longer speaks spontaneously;
- Coma ensues and may last from minutes to hours before death occurs.

Nutrition and Hydration

Physicians and bio-ethicists who work with dying persons have grappled with the dilemma of what is reasonable care for a dying person. There comes a time in some cases where even nutrition and hydration are considered extraordinary means of prolonging life, and such ordinary nutrients are discontinued. This is never done without great and careful consideration. The decision to withhold food and/or fluid is made only when it is apparent to the caregivers and family that further prolongation of life would only extend discomfort. This decision should be made with the patient, if able to understand, and the family being fully informed of all considerations. Ideally, the family is then involved in making the decision to withhold food and fluids.

For persons in the final phase of illness, the withholding of food and fluids is not painful. To the contrary: the administration of food and fluids to dying persons can extend their general discomfort and frustrate their desire to let go and allow nature to take its course.

In cases where people cannot swallow, it is standard care to apply moisture in some form to the lips and mouth regardless of whether or not the patient is ever able to swallow again. This is basic oral hygiene. This is comfort care. Applying moisture should be done even if a person with advanced illness is able to take oral fluids.

In instances when it is determined that the person is dying and it is further determined that hydration would only prolong the patient's discomfort, dehydration is not a painful process. Even those with total bowel obstruction who had been unable to retain any oral fluids and who voluntarily declined intravenous fluids do not complain of thirst or hunger. There is a side effect of starvation and dehydration in which one's metabolism changes and the resulting elevated level of ketones produces a mild sense of euphoria, so that hunger and thirst are not the problem we would imagine.

It is this sort of information that underlies the bio-ethical support for withholding nutrition in those persons with advanced illness whose greatly impaired quality of life would not be improved, but only prolonged, by supplemental (intravenous or cut-down) methods of delivering nutrition and hydration.

States of Consciousness as Death Approaches

The individual's state of consciousness may fluctuate as the changes associated with dying affect the central nervous system. The patient may go in and out of a lower level of consciousness. It is not unusual for patients to experience sensory changes. Some important definitions:

- **Illusions**—misperceptions of ordinary sensations
- **Delusions**—misconceptions of reality—two major types:
 - Grandeur*—exalted sense of self
 - Persecution*—fear that others are trying to inflict injury
- **Hallucinations**—three major types of hallucinations:
 - Auditory*—hearing things (usually voices) not present
 - Visual*—seeing things not present
 - Tactile*—feeling things not present

Persons in a coma may still hear what is said even when they no longer seem to respond to verbal or even painful stimuli. Caregivers, family, and physicians should always act as if the dying patient is aware of what is going on and is able to hear and understand voices.

The pulse may change in rate and regularity. It may slow and become irregular. The blood pressure may fall. The extremities usually become cooler. Breathing may become labored. Fluid may accumulate in the lungs causing “rales” and “rattles.” The liquid sounds sometimes heard at the end of life are not an indication of pain or suffering. The secretions that cause these sounds can be dried up with a small injection of a specific medication (atropine) or the oral administration of a small amount of a common eye drop solution usually prescribed to reduce the amount of tears. Also running a vaporizer in the patient’s room can ease breathing when lung secretions are dry.

Periods of breathing may alternate with periods of no respiration. The skin may become pale, cool and moist. The skin of the feet and hands may become cooler than the skin of the trunk. Later, the skin may appear grayish or even a pale blue color.

A full discussion of the sequence of events leading up to the moment of death can be found in *How We Die*, Sherwin Nuland, M.D., Knopf, 1993.

Myths about Dying

Many pervasive cultural misconceptions about dying exist that can interfere with people receiving the best possible care at the end of life. Debunking these myths and understanding the realities can allow you to better support the dying person and loved ones.

“Death is too frightening to talk about... it’s not normal to talk about death.”

Death has been remote, hidden away in the back rooms of hospitals. There is a taboo about talking of death even though death is a normal part of life. Everything that lives dies. Death can be a positive experience not only for the dying person but also for family and friends. In order to be a positive experience we must recognize the needs of dying persons as well as the needs of their caregivers. The family must be aware that dying persons have special needs that can be met.

“People die as they have lived.”

This is generally true, yet it is also possible for people to change. If people receive excellent care during their last illness there can be great opportunity reminiscence, for forgiveness of past difficulties, and for spiritual growth. This is only possible if there is good communication and openness among patient, caregivers, and family.

“Dying is always painful.”

This is one of the most common misconceptions about dying. Pain can be relieved safely without any danger of death or addiction. Hospice caregivers and most doctors are familiar with the proper use of analgesic drugs. When given in the correct dose at the right time, pain can be relieved without sedating the patient. When pain is relieved, patients can experience a good quality of life until the time that death occurs. Good pain management does not shorten the course of life. On the contrary, patients who receive excellent pain management tend to live longer than expected.

“While dying, people see a white light, a tunnel, etc.”

In general, this is not true. As people die there are physical and chemical changes in the brain that result in a gradual loss of consciousness. Some people experience what are known as delusions, illusions, or hallucinations, similar to dreaming while still awake. Some persons relate seeing relatives who have previously died. In almost all instances, these last visions are usually pleasant and offer comfort to the dying person, especially regarding the prospect of reuniting with deceased loved ones.

GOALS OF CARE

In most cases, patients with advanced disease experience suffering from multiple origins. They have physical problems such as pain, nausea, shortness of breath, and they have psychological problems such as anxiety and depression. These problems can be handled by a variety of medical interventions and psychotherapy. But when the patient is dying, they have existential problems as well, which underlie the physical and psychological, and in many ways are more difficult to address. Moreover, all these elements extend to the family of the patient in one way or another. The list below has been compiled by hospice physicians, nurses, social workers and aides with more than 25 years of speaking directly to the dying. No one pretends that this list is complete, and it does not deal with individual variation, but it will help keep you focused on what should be the central point of caregiving: addressing the dying person's needs.

Needs of Dying Persons

- *Assurance* that they will be cared for, that they will not be abandoned.
- *Assistance* in developing and finalizing documents pertaining to terminal care.
- *Information* that will be accurate, timely, and reliable.
- *Communication* that is timely, honest, and open with family, friends, and caregivers; people who will listen. Opportunity to discuss their impending death (if desired) with selected family and caregivers.

- *Excellence* in the delivery of physical care, comfort, privacy, intimacy, sleep, and rest.
- *Management* of pain and other symptoms that is responsive to changing conditions.
- *Permission* to express feelings, both positive and negative; to say “thank you, I love you, I forgive you,” as well as to express dissatisfaction, anger, resentment.
- *Opportunity* to explore their finiteness and the spiritual dimensions of life.
- *Opportunity* to discuss preferences about funeral arrangements as well as the impact of dying on survivors.
- *Time* to reflect on the implications of the diagnosis and prognosis, to identify and attend to thoughts, feelings and needs, time to tell their story, to re-affirm their identity and value their life. Time to reflect on and to grieve prior as well as current losses. Time with selected family and friends. Time to attend to unfinished personal business. Time to plan for distribution of assets and to address their financial responsibilities.

Redefining Goals of Care

*Dying is not primarily a medical condition,
but a personally experienced, lived condition.*

—William Bartholme, M.D. 1997, Kansas City
(died of cancer of esophagus, 2001)

Once the needs of dying persons are understood and accepted, we are then able to refocus the goals of care. Instead of hoping for a cure, the dying person has a right to hope for a comfortable death, free of pain and discomfort. The dying person can retain the hope of finding or re-finding the value of his or her life; of resolving what was previously not able to be resolved; discovering or re-discovering spirituality. The dying person may renew a quest for answers to great existential questions. It is not unusual for the dying person to find deep reservoirs of faith that were never suspected before. There is much that a dying person can hope for.

Life-Support Measures

The following discussion of life-support measures is included here because an understanding of the effect of these interventions is necessary to set the goals of care. Families may wish for comfort care but due to misinformation may give confusing instructions on life-support measures.

Artificial nutrition and hydration

Artificial nutrition and hydration (or tube feeding) supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine, or a vein. Artificial nutrition and hydration can save lives when used until the body heals. Long-term artificial nutrition and hydration may be given to people with serious intestinal disorders that impair their ability to digest food, thereby helping them to enjoy a quality of life that is important to them. But long-term use of tube feeding frequently is given to people with irreversible and end-stage conditions. Often the treatment will not reverse the course of the disease itself or improve the quality of life. Some health care facilities and physicians may not agree with stopping or withdrawing tube feeding. Therefore, this issue should be explored with family and physicians, and the individual's wishes should be clearly stated about artificial nutrition and hydration in the advance directives.

Cardiopulmonary resuscitation

Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause blood to circulate. Electric shock and drugs also are used frequently to stimulate the heart. When used quickly in response to a sudden event like a heart attack or drowning, CPR can be life saving, but the success rate is extremely low for people who are at the end of a terminal disease process. Critically ill patients who receive CPR have a small chance of recovering and leaving the hospital. If a person is in the hospital and does not wish to receive CPR, the doctor must write a separate do-not-resuscitate (DNR) order on the chart. If the person is at home the properly executed DNR order will be honored in the emergency department and by the emergency medical technician or paramedic in a setting other than a health care facility.

Mechanical ventilation

Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea). Mechanical ventilation often is used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure exists due to injuries to the upper spinal cord or a progressive neurological disease. Some people on long-term mechanical ventilation are able to enjoy themselves and live a quality of life that is important to them. For the dying patient, however, mechanical

ventilation often merely prolongs the dying process until some other body system fails. It may supply oxygen, but it cannot improve the underlying condition. When discussing end-of-life wishes, the person should make clear to loved ones and the physician whether he or she would want mechanical ventilation if he or she would never regain the ability to breathe on his/her own or return to an acceptable quality of life.

The decision to forego life support is a very personal one. It is frequently influenced by cultural as well as religious beliefs.

Portions of the preceding section were abstracted from “Finding Our Way: Living With Dying in America” published by Knight-Ridder/Tribune.

PAIN MANAGEMENT

The information in this section was developed by William Lamers, M.D. and abstracted from “Patients in Pain: Casualties of the War on Drugs,” Kathleen M. Foley, M.D., “Ideas for an Open Society,” Open Society Institute, October, 2002.

Understanding the Nature of Pain

There are many ways to control pain. Increased knowledge of the numerous pain syndromes and utilization of radiologic, anesthetic and neurosurgical approaches has improved treatment. There have been important advances in the use of music, massage, aroma and other approaches to managing pain. For our purposes however, we will concentrate on the situation you are most likely to encounter—extreme pain in the terminally ill. That means focusing on opioid analgesics as the mainstay of treatment for severe pain.

Pain is a common complication of disease, surgery, injury and the aging process. Health care professionals and lay people alike have acquired mistaken assumptions about pain and pain management. Some people have needless fears about the medications used to provide pain relief.

From a public health point of view, pain is a serious issue in the United States. More than 50 million people live with chronic pain associated with various diseases. Between 70 percent and 90 percent of cancer patients with advanced disease experience pain, and pain is needlessly under-treated for AIDS, sickle cell disease, arthritis, and for nursing home residents. Yet studies show that over 95 percent of cancer patients could obtain relief with proper treatment.

The gap between the degree of relief that is possible and the suffering that persists is astonishing. There is always something that can be done to help relieve all types of pain, no matter what the cause.

Barriers to Effective Pain Management

There are several barriers to effective pain management in advanced disease, many of which are based on myths and misinformation:

- Inadequate education of health care professionals in the use of analgesics;
- Cultural fears about the use of narcotic analgesics;
- Fear of addiction; and
- Fear of overdose.

Consequences of the Failure to Manage Pain

Inadequately managed severe, chronic pain never occurs alone, but is accompanied by anxiety, fears, impaired sleep, reduced appetite, frustration, depression, memories of past pain, anticipation of pain yet to come and, in some instances, thoughts of suicide. Chronic pain has a strong emotional component that fades as soon as the pain is relieved.

Unmanaged pain interferes with the person's ability to address the existential questions of one's place on earth. The dying person cannot address issues of spirituality or unfinished business if pain is not effectively managed. Pain control must come first. Once pain is effectively managed, dying people can turn to the religious and spiritual issues of dying.

The Patient's Right to Pain Relief

Today, under new regulations of the Joint Committee on Accreditation of Health Care Organizations (JCAHO), hospitals and health care facilities must regularly assess, monitor and manage pain in all patients, or risk losing their accreditation. Pain has now been designated as a fifth vital sign to be recorded with blood pressure, pulse rate, respiratory rate and temperature. However, the sophisticated techniques of pain control developed by hospice physicians and others are not known throughout the medical system, and education of physicians has lagged behind.

Hospice experience shows us that some patients who were bedridden with severe, chronic pain have been able to return to a higher level of physical activity once their pain is properly managed.

Understanding Pain Medications—Opioids

Initially it was believed that patients would become tolerant to opioids, reducing the drug's effectiveness in controlling pain. Clinical experience shows that patients can take opioid drugs for months or even years, and still obtain adequate relief.

Patients can become physically dependent if opioids are taken for a long period of time. This simply means that they may show signs of withdrawal if taken off the drug abruptly. However, this is not an issue for the dying. Addiction is the term used to characterize the harmful behaviors of compulsive drug users. Tolerance and physical dependence are often confused with addiction. That confusion stigmatizes the patient and threatens quality pain management.

There is also the phenomenon of “pseudo-addiction.” Patients in pain may develop behaviors that are misinterpreted as drug seeking behaviors. They request increased doses or take more medicine than prescribed. Studies of cancer patients have linked these behaviors to inadequate dosages of pain medications. Once pain is properly managed, these behaviors stop.

Side Effects

Opioids and narcotic analgesics have different side effects when administered orally than through an IV:

- *Sedation.* When properly used, the onset of orally administered opioid analgesia brings with it a normal period of sleep. Narcotics exert a calming, relaxing effect through direct sedative action on the brain as well as through relief of pain. Patients often sleep after receiving pain relief because they have been sleep-deprived for days or weeks with recurrent episodes of pain. Such sleeping patients are easily roused by calling their name or touching them. Tolerance develops rapidly to this initial, sedative side-effect, and patients on even large doses of narcotic analgesics can be clear-headed, aware of all that is happening, and be involved in decisions affecting their care.

Intentionally sedated patients (from heavy IV doses) cannot be easily roused. To get such sedated persons back to clear consciousness, it may be necessary to administer one of the opioid antagonists that block the presence of opioids in opioid receptors. Resorting to this is rare.

- *Respiratory Suppression.* Another side effect of high-dose IV opioids is the risk of respiratory suppression. This does not occur with gradual increases in the oral dose of opioid analgesics. Too much respiratory depression can occur in persons who are new to opioids and have not developed the tolerance to the respiratory suppression side-effect of opioids that usually develops after several days of regular opioid use.
- *Slowed Breathing Rate.* Slowed rate of breathing is rarely a problem as a side effect, as the respiratory rate of patients in pain is usually higher than normal. Patients receiving narcotic analgesics usually breathe less frequently, but take deeper breaths. Like the sedative side effect, slowed respiratory rate is a transient side effect and if present, fades after several days.

- *Constipation.* A major side effect of narcotic analgesics is constipation which must be managed not only with stool softeners but with laxatives, like senna derivatives, that stimulate bowel activity. Laxatives must be provided on a regular basis as long as patients are receiving narcotic analgesics.

In summary, there is always something that can be done to relieve severe, chronic pain in advanced illness. Hospice work has taught us that chronic, severe pain is a complex psychophysiological process that is best treated by a number of approaches that includes narcotic analgesics, psycho-social support and the use of a wide variety of therapies ranging from massage to nerve block.

Common Myths about Pain

Myth: “Dying is always painful.”

Many people die without experiencing pain. If pain does occur, it can be relieved safely and rapidly.

Myth: “There are some kinds of pain that can’t be relieved.”

There are some types of pain that require “multi-modality” (combined approaches) pain relief. Recent advances in analgesia assure that all pain can be relieved by using commonly available medications and/or a combination of approaches that may include chemotherapy, radiation therapy, nerve block, physical therapies and whatever else is appropriate.

Myth: “Pain medications always cause heavy sedation.”

Most people with severe, chronic pain have been unable to sleep because of their pain. The opioid analgesics (morphine, codeine, et. al.) produce initial sedation (usually about 24 hours) that allows patients to catch up on their lost sleep. With continuing doses of medication they are able to carry on normal mental activities. Sedation often occurs because of other drugs, such as anti-anxiety agents and tranquilizers that have been prescribed for other reasons.

Myth: “It is best to save the stronger pain relievers until the very end.”

If pain is not relieved by the lesser strength analgesics (aspirin, non-steroidal anti-inflammatory drugs, codeine, hydrocodone, etc.) then it is best to change to a stronger analgesic to bring the pain under continuing (24 hour) control. Pain that is only partially or occasionally controlled tends to increase in severity. This leads to two mistaken assumptions: the patient mistakenly fears that the pain is so severe that it can never be controlled; the doctor mistakenly believes that the patient is becoming addicted or is developing tolerance to the analgesic medication. In most cases, an adequate dose of a stronger analgesic (e.g., morphine) prescribed on a regular basis usually brings the pain under control.

Myth: “Patients often develop tolerance to pain medications like morphine.”

When morphine and other opioid analgesics are prescribed for the management of pain, the dose is sometimes raised to be sure that pain is well-controlled 24 hours a day, seven days a week. Opioids given to relieve pain generally do not lead to the development of tolerance. As a disease, like cancer, progresses, more opioid may be needed to control the pain on a continuing basis.

Myth: “Once you start pain medicines, you always have to increase the dose.”

In fact, the converse is true. Once pain is under control and the dose of opioid held at a steady level for several days, the dose of opioid analgesic can be lowered without the pain recurring. Levels of opioid can be raised safely as needed to control increasing pain. Also, the dose can be lowered gradually if pain has been controlled on the same dose for several days. This change in dose to meet patient needs is known as “titration.” The fact that the dose of opioid can be lowered once pain is controlled is one of the paradoxes of treating severe, chronic pain.

Myth: “To get good pain relief, you have to take injections.”

Until the mid-1970s it was believed that morphine was not an effective analgesic when administered by mouth, so it was universally administered by injection. We now know that morphine is effective when given by mouth or by suppository. Patients generally do not like injections, as they are painful in themselves. There are several excellent long-acting opioid analgesic preparations. Morphine and related opioids are available that control pain for 12 hours when used on a regular basis twice daily. Other long acting opioid preparations available for trans-dermal (through the skin) delivery are available with a 72-hour (3-day) period of action.

Myth: “Pain medications always lead to addiction.”

When prescribed on a regular basis in a dose sufficient to relieve pain, there is no empirically based evidence that opioids lead to addiction.

Myth: “Withdrawal is always a problem with pain medications.”

When prescribed for managing severe chronic pain, there is no problem discontinuing the dose once pain is controlled. Withdrawal from the opioid analgesics is not a life-threatening condition as is withdrawal from a number of other commonly prescribed medications, such as barbiturates. The symptoms of withdrawal from opioids are generally mild and fairly easy to manage with commonly available medications. Many patients who receive opioids for severe pain have had their dose adjusted down without experiencing any withdrawal symptoms.

Myth: “Enduring pain and suffering can enhance one’s character.”

This myth developed in the years before we learned to provide excellent pain management, but is not appropriate today. Suffering does not enhance character or earn people a higher place in the life hereafter; it merely brings about a miserable life, a horrible death and needless anguish in all who see helpless dying people suffer.

Myth: “Once you start taking morphine, the end is always near.”

Morphine does not initiate the final phase of life or lead directly to death. Morphine provides not only relief of severe, chronic pain; it also provides a sense of comfort. It makes breathing easier. It lets the patient relax and sleep. It does not cloud consciousness or lead to death. When used properly morphine does not kill.

Myth: “Pain is a solitary phenomenon.”

Severe chronic pain never occurs alone, but is usually accompanied by a number of other symptoms including (but not limited to) anxiety, depression, fearfulness, insomnia, anorexia (loss of appetite), withdrawal and thoughts of suicide. All of these symptoms are compounded with memories of pain already experienced, currently perceived pain, and anticipation of more pain yet to come. Unmanaged (or inadequately managed) severe, chronic pain is a complex problem that needlessly aggravates the symptoms of the underlying disease.

Myth: “Heroin is needed to provide excellent pain control.”

Heroin is a derivative of morphine that is more soluble in water than morphine and therefore passes from the blood to the brain more rapidly, thus affording the ‘rush’ or ‘high’ desired by intravenous drug abusers. Morphine has a longer period of action. It can be safely taken by mouth. New preparations for sustained release make it possible to obtain excellent relief when taken by mouth only twice daily.

Myth: “People have to be in a hospital to receive effective pain management.”

It is easier to provide safe, effective relief of severe chronic pain at home than it is in the average hospital. There are fewer medication errors when there is only one patient to receive medications and no other patient emergencies to interrupt the care. Accurate messages regarding pain management can be shared on a regular basis by means of a ‘Comfort Control Chart’ on which the patient indicates the level of pain relief by using numbers (0 to 10) to let the doctor know the adequacy of pain management.

Pain Definitions

Acute Pain. The discomfort or warning signal that alerts us to the fact that something is wrong with our body. Pain is a result of stimulation of pain receptors in the body and may be caused by infections, injuries, hemorrhages, tumors as well as endocrine and metabolic problems. Once the underlying problem is corrected, acute pain vanishes.

Addiction. A primary, chronic neurobiological disease with genetic, psychosocial and environmental elements which influence its development and manifestations.

It is characterized by one or more of the following:

- Impaired control over drug use
- Compulsive use of drugs
- Continued use of drugs despite harm from them
- Craving for drugs

Chronic Pain. A persistent state of pain the underlying cause of which cannot be removed or otherwise treated. Such pain may be associated with a long-term incurable medical condition or disease.

Narcotic. A term reserved for derivatives of the opium poppy as well as other substances that are used in illicit drug trade and use.

Opioid. A medication derived from the naturally occurring opium poppy that has been purified and packaged for legitimate, prescribed use in health care.

Pain. A complex, unpleasant sensory and emotional experience associated with actual or potential tissue damage, or expressed in terms of such damage. This is the technical description developed by the International Association for the Study of Pain (IASP). The non-technical description is, “Pain is what the patient says it is.”

Pain and Suffering. A common phrase that indicates the close relationship between chronic physical pain and resultant emotional distress. Unrelieved chronic or intermittent physical pain has psychological manifestations that include, among other things, anxiety and depression.

Pain Management. The systematic study of clinical and basic science and its application for the reduction of pain and suffering. This newly emerging professional discipline emphasizes an interdisciplinary approach to treatment that includes tools, techniques and principles from all the healing arts to create a holistic paradigm for the reduction of pain and suffering.

Physical Dependence. A state of adaptation that is manifested by a drug class-specific withdrawal syndrome that can be produced by rapid cessation, rapid dose reduction, decreasing blood levels of the drug, and/or administration of an antagonist of that drug.

PSYCHOLOGICAL CONCERNS

Paying attention and learning about physical symptoms of approaching death is so important. But it is crucial to also understand the psychological journey that persons go through. By doing so, caregivers can help relieve the worries and stresses of the person who is dying, making the journey less painful, both physically and emotionally.

Caregivers who have not had formal training or who are inexperienced in dealing with psychological issues should bring in a trained professional to resolve serious issues. The intention of this section is to provide caregivers with an understanding of the psychological concerns of the dying.

We will deal primarily with anxiety and depression. As these disorders occur with some frequency in persons who are not dying, we will focus on the causes of anxiety and depression in dying persons and offer suggestions for their management. We will also discuss the question of suicide, as it is sometimes raised by dying persons. Further, we will look at related concerns including anger, dignity, and suffering that are raised when caring for persons at the end of life.

After reading this booklet, the caregiver should be able to:

- Describe the major psychological concerns that may occur during the dying process;
- Identify ways the dying person can be helped to address psychological concerns.

ANXIETY

Most people have experienced anxiety at some time in their lives. Anxiety is usually a transient phenomenon, vanishing after the fear that caused it has passed, been recognized as inappropriate, or has been surmounted.

The awareness that one is dying usually brings forth particular anxieties related to the dramatic awareness that one now has only a limited time to live. The anxiety of dying persons also relates to practical concerns about what will happen and how dependent survivors will be cared for, as well as spiritual concerns related to what happens after death.

Ways to Help

- Identify the causes;
- Establish clear communication;
- Present options;
- Consider social, psychological and spiritual needs.

The first step in relieving anxiety lies in identifying the causes of the anxiety. Most anxiety seen in dying persons is transient if they know that they have trusted people to answer all their questions, and they will be cared for and not abandoned.

The next step centers on establishing clear communication. This must include the treating doctor as well as all caregivers. Patients have a right to know their diagnosis, the prognosis, the treatment alternatives, the side effects of the proposed treatments, and the site of care. Most dying persons, given the choice, prefer to spend their last weeks and months at home. The matter of hospice care should be raised and discussed. The patient should be involved in this decision and should have all necessary information about hospice.

As communication is established and options are presented, much of the early anticipatory anxiety can be resolved. This passage from a supposedly healthy or 'non-dying' person to one who knows that he or she has a life-limiting diagnosis may take several weeks and considerable effort on the part of all involved. Anxiety may reappear as illness progresses.

Anxiety that is much more severe than the 'normal' anxiety described above may not be resolved without prescribed medication. Anti-anxiety medications come in a variety of forms. Some are more sedating than others. The 'sedating' anti-anxiety medications are usually reserved for persons with persistent, disabling anxiety.

DEPRESSION

Depression is “a mood disorder lasting at least several weeks in which there is depressed mood and loss of interest in nearly all activities plus several of the following: change in appetite, weight, and psychomotor activity; decreased energy, feelings of guilt or worthlessness, difficulty thinking, concentrating or making decisions; recurrent thoughts of death, or thoughts or plans of suicide.”

Depression in dying persons may be either “primary” (the person is pre-disposed to depression in response to stress) or “secondary” (depression is a result of the disease itself, the result of treatments designed to halt the disease or the result of medications prescribed to modify the side-effects of the treatments).

Sustained fear and anxiety may also result in depression. Sadness in anticipation of one’s own death is a normal and expected response. It is usually difficult to separate this normal sadness from true clinical depression.

Depressed persons have a negative outlook. They see no good in anything. They have given up. They see no reason to hope. They may experience shame, guilt, and self-recrimination. They may be overwhelmed by fear, exhausted from anxiety and unable to take comfort in the support provided them. They may express a desire to die or even talk about suicide.

The behavior of depressed persons includes withdrawal, isolation, decreased communication and lack of interest. They are slowed to the point that they are described as having “psychomotor retardation,” a generalized slowing of thinking and acting. They may exhibit weight loss.

Ways to Help

- Assess pain
- Identify the source and extent of depression
- Review medication
- Consider supportive psychotherapy
- Examine the way the person deals with loss
- Consider social, psychological and spiritual needs

Whenever depression is noted, the first thing to look for is physical pain that is not well managed. Be sure pain is under control and that other symptoms are managed. Unmanaged pain is the most common source of depression in dying persons. Identify the sources and extent of the depression. What else may be bothering the patient? Is there some unfinished business? Is there some unresolved conflict or dispute with another member of the family or other persons?

Get support from professionals: physicians, nurses, social workers, or clergy. Consider supportive psychotherapy sessions for affected persons in the family. Family members are influenced by depression in the dying person. They may need an opportunity to talk about their response to the depression.

Consider examining the way in which the person deals with loss. Dying persons grieve multiple losses. They grieve not only their own death but the loss of all that they leave behind. They may welcome the opportunity to talk about all their losses. Depression may be an equivalent for loss.

Consider the dying person's social, psychological, and spiritual needs. What is going on in the family? Who has unfinished business? What is being said? What is not being discussed? What worries and fears have not been addressed?

SUFFERING

We often hear the phrase, "pain and suffering." It is a catch phrase in that it is used without considering its origin or what it really means. Suffering is an old concept, a word used to describe something that had to be endured, that was associated with pain as being incapable of relief.

Somerville has defined suffering as:

“...the loss of control over what happens to you in a situation in which you perceive yourself as threatened or in danger of disintegration as a person. Any mechanism that provides you with a sense of choice, a sense of control, reduces the sense of suffering.”

Suffering is the emotional dimension of extended discomfort. It is an indication that something is seriously wrong. If unmanaged pain seems to be contributing to the patient's suffering and the suffering persists even after the pain is successfully managed, it is necessary to look elsewhere for the cause of the suffering.

Severe pain is not an essential ingredient of suffering. It often turns out that fear of the unknown contributes to suffering. The feeling that one deserves pain for punishment also accentuates the need to suffer. The most surprising aspect of suffering is

that if it is pain-related, an explanation of what is causing the pain can sometimes bring relief from suffering, hence the survival for hundreds of years of sayings like, “Suffering ceases to be suffering when it is given meaning.” There is also another mistaken assumption about suffering: that it can make you a better person or “enhance your character.” This is simply not true.

Ways to Help

- Check with the physician or nurse to see that proper pain management has been instituted.
- Encourage the patient to talk about his/her worries, fears, regrets, and hopes.
- Encourage the patient to identify any “unfinished business” that remains.
- Facilitate communication between the patient and doctor.
- Encourage the patient to develop a “personal history” or “life review.”
- Ask clergy to help identify and help resolve spiritual and religious concerns.
- Consider social, psychological and spiritual needs.

SUICIDE

Those who work with dying persons know that the subject of suicide comes up from time to time. Few people who are enrolled in hospice care actually commit suicide, yet a number of them have thoughts of killing themselves or of finding someone who will assist them in the act of ending their life. When patients ask about suicide, it is an indication that something is seriously wrong. They may be quite depressed. They may require psychiatric consultation and anti-depressant medications. More commonly, they have a problem that has been bothering them for some time and they do not know what to do about it.

The caregiver who encounters talk of suicide and does not have formal training in counseling and experience in dealing with suicide should immediately get in touch with someone who can give prompt assistance to the patient. Following are some things to know about dying persons who consider suicide.

Do not act surprised or afraid. Thoughts of suicide are not uncommon in persons facing the end of life, especially in those who feel they may be a “needless” burden to their family, who feel unworthy, who have unrelieved severe, chronic pain, or who feel that they are exhausting the financial resources they had hoped to pass on to survivors.

There are certain types of people who are extremely uncomfortable when they do not feel they have control over their destinies. For them, wanting to commit suicide is equivalent to saying, “I am going to take charge even if it kills me!” They do not know what to do when they are not in command. This is especially true if the person is in an institution where control has been taken from them.

There are some people who do not know how to deal with the fact that they are dependent. These are the people who are comfortable in caring for others, but are reluctant to have anyone care for them. The late Dame Cicely Saunders, founder of modern-day hospice, called them “the wounded Samaritans.”

Many persons with advanced illness see no value to their existence. They see no future, and the present is filled with discomfort and often, severe pain. Recurrent, severe, chronic pain can be treated. When this has been accomplished and the future still looks bleak, many dying persons respond well to someone who takes an interest in them and encourages them to develop an overview of their life for the benefit of others. Life review is included in the hospice plan of care. There are some commercially available life review self-help books including the Hospice Foundation’s *A Guide to Recalling and Telling Your Life Story*. (Details about the Guide can be found at <http://www.hospicefoundation.org>)

The greatest fear of dying persons is fear of abandonment. Many older persons have seen, or heard stories, about what happens to dying persons in some hospitals and nursing homes and they would rather consider killing themselves than be part of that distressing scenario.

Do not abandon those dying persons who, out of desperation, speak of suicide. See that they receive the timely, professional attention (counseling, medication, observation) they deserve. Offer them your hand.

Ways to Help

- Make yourself available to the person talking about suicide.
- Do not promise to assist in his/her desire to commit suicide.
- Do not put the person down because of his/her desire to end his/her life.
- See what you, together with others, can do to identify and resolve the problem that has caused the person to consider suicide.
- Maintain repeated contact with the patient to show that you are trying to help him/her.
- Let the person know that it is not unusual to have thoughts about suicide.

The most common reasons patients give for wanting to commit suicide are:

- Current pain and suffering;
- Fear of pain and suffering yet to come;
- Loss of control over what is happening;
- Fear of becoming even more dependent;
- Fear of abandonment, isolation, dying alone;
- Inability to cope with the impact of the illness on family and friends;
- Loss of personal integrity, fear of disfigurement;
- Economic impact of further expensive care; exhausted financial resources;
- Desire to “join” previously deceased spouse, parent, child.

ANGER

Anger is commonly observed by those who work with dying persons. Anger may be focused on one person or on the disease itself. Anger may also be diffused through many different situations. Some persons will seek excuses to express anger. There is sometimes an element of anger in the contemplation of suicide. Anger may be a reflection of the unfairness or powerlessness due to the underlying disease. The fear of pain and death may awaken latent feelings of worthlessness and anger.

Ways to Help

- Identify the sources of anger;
- Assess the use of anger as part of the personality;
- Assist in developing alternative expressions of anger.

It may be worth considering that:

- The patient may see the disease as punishment, and be angry at God.
Spiritual assessment may be in order.
- Anger may be a part of the underlying personality structure of the patient.
Anger may be the stance they have used in confronting the world.
- Psycho-social counseling is essential in helping patients look at the dynamics of their anger.

CONCLUSION

Caring for a dying person evokes myriad feelings and situations that can vary greatly depending on the caregiver, the dying person, and the relationship that the caregiver has with the dying person.

Hospice Foundation of America hopes that this booklet will serve to educate caregivers, whether professionals or family members, about the dying process, so that they are able to provide the best care possible to their patient or loved one. While many people consider death a frightening event, knowing the physical signs and symptoms, and awareness of the psychological implications, provides comfort.

Understanding what will occur during the dying process is the first step when it comes to providing excellent care.

About this Booklet

This booklet draws upon the Hospice Foundation of America curriculum developed for the clergy training program on care at the end of life, conducted on behalf of the Florida Department of Elder Affairs. The program was funded by the Florida Legislature and enacted by Florida Governor Jeb Bush.

The Advisory Committee to the project provided valuable insight in developing the curriculum, and included members of the clergy, physicians, hospice experts, and grief experts.

William Lamers, M.D., Medical Consultant, Hospice Foundation of America, and Kenneth J. Doka, Ph.D., Senior Consultant to HFA and Professor of Gerontology at the Graduate School of the College of New Rochelle, and a grief expert, were instrumental in the effort. Dr. Lamers provided medical expertise, information and review, and Dr. Doka provided guidance regarding spiritual and psycho-social issues.

HOSPICE FOUNDATION *of* **AMERICA**
exists to help those who cope personally or professionally
with terminal illness, death, and the process of grief and
bereavement.



1621 Connecticut Avenue, NW, Suite 300 ■ Washington, DC 20009
(800) 854-3402 ■ www.hospicefoundation.org

© Hospice Foundation of America 2005