

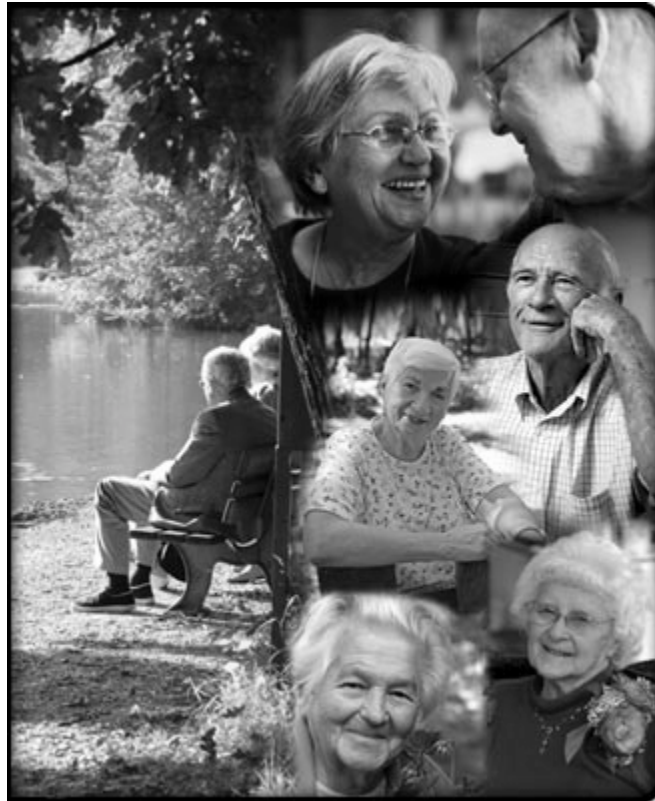
# EMERGENCY MEDICAL CONSULTANTS INC.



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## End-of-Life Care



### Objectives:

- ✓ Discuss the concept of end-of-life care.
- ✓ Differentiate between palliative care and hospice services.
- ✓ Describe the importance of symptom management in terminal care.
- ✓ Explain the value of advanced directives in end-of-life care.
- ✓ Identify common medications used for symptom management.
- ✓ List comfort measures utilized in terminal care.
- ✓ Summarize the nursing care priorities in active death.
- ✓ Discuss children and infant deaths.
- ✓ Understand the process of family bereavement.

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**I'm not afraid of death; I just don't want to be there when it happens."**

**----Woody Allen**

## **Introduction:**

There is no 'one size fits all' when it comes to death. The only guarantee is that it *will happen* to all of us. Yet Americans remain strangely reluctant to discuss the concept of their own end-of-life preferences. In 2010 the National Hospice and Palliative Care Organization (NHPCO) stated that less than one third of Americans have placed their wishes in writing and the other two thirds have not thought about the issue at all, or have not shared their thoughts with others. This unfortunate avoidance of topic is compounded by a medical community that often feels uncomfortable discussing a terminal diagnosis with a patient and may associate death with the "failure of treatment."

Prior to 1974, in the United States, there was not an established system geared towards specific end-of-life care goals. When the doctor approached the patient and family with the news that nothing more could be done, it often closed the door to the possibility for a cure and was associated with a loss of hope as well. In those days, the majority of people died at home with the family doing the best they could to provide care. With limited medical resources available to prolong life or even effectively treat chronic illness, death often rapidly ensued.

Fortunately, there have been extraordinary advances in medical science, which has significantly extended the potential life span of individuals diagnosed with chronic illness or even a terminal condition. End-of-life care is now a recognized discipline that plays a major role in offering support and medical care, which is administered during the time that precedes death. The goal is to prevent or relieve suffering in a dying individual while respecting their values and beliefs. This educational offering is intended to educate the healthcare professional in the role they play in supporting a person through the dying process. Due to the advances in medical technology and symptom management; weeks, months or, in some cases, years of care may be necessary before death ensues.

In the United States, approximately two and a half million people die annually. According to the Census Bureau this rate will double by 2040. This increase is partly due to the estimate that 1 in 5 Americans will be over the age of 65 by 2030. This aging of America will pose significant issues, as it is evident that 40% of physicians are currently over 55 years old and 30% of the nursing force is over 50 years old. As this large volume of healthcare professionals retire, it will become increasingly difficult to obtain qualified medical services. In other words, less doctors and nurses and more patients will make it especially important for individuals to plan in advance how they would like to receive care in their final months and days.

Cultural issues often play a significant part in end of life care decisions. A Medicare survey indicated that blacks were more inclined to choose to have life prolonging medications and procedures administered in their final days, which are usually spent in a hospital setting. And although most people would rather not spend their final days in a hospital attached to a variety of tubes and monitors, research indicators have shown that the majority of black and Hispanics were much more likely than whites to die in a hospital facility.

The need to educate the public regarding end-of-life care options has become increasingly evident. One of the biggest obstacles to overcome is the public's belief that if their doctor initiates a discussion with a patient or family member it means the health care team is "giving up" on them and this attitude will decrease their survival time, when in fact, the opposite is true. Studies have shown that people who are enrolled in a hospice program live longer than those who have the same diagnosis who are not receiving hospice care. The average survival rate is actually thought to be about 30 days longer for individuals who receive this specialized type of care. This is probably due to the fact that the care goal shifts from curative procedures and treatments to focusing on making the patient comfortable while providing symptom management and offering spiritual, emotional and psychological support to the patient and their loved ones. This environment helps patients to accept the next stage of life and to spend their time comfortable and surrounded by people who care deeply about them and transition peacefully into death. Ultimately, it is up to the patient and family to make these difficult decisions but this can only be accomplished through the use of education to inform the public of those options for terminal care exists.

**“It's only when we truly know and understand that we have a limited time on earth -- and we have no way of knowing when our time is up -- that we will begin to live each day to the fullest, as if it was the only one we had.” ----*Elizabeth Kubler-Ross***

#### Defining Hospice and Palliative Care:

It is important to note that Hospice and Palliative Care are not the same, although people often believe that it is simply 2 different names for the same service. Palliative care is provided to individuals who suffer from life alterations of a physical disease or long-term illness. These individuals may live for several years and wish to have their symptoms controlled for the duration of their life. Some examples of illnesses that often benefit from palliative care are:

- ✓ Congestive heart failure
- ✓ Chronic obstructive pulmonary disease (COPD)
- ✓ Parkinson's Disease
- ✓ Cancer
- ✓ Diabetes associated with complications (renal/heart failure)
- ✓ AIDS
- ✓ Pain – must be related to a confirmed diagnosis

Ideally, palliative care should be initiated after a patient receives a diagnosis of a severe life-limiting illness. The goal of this multidisciplinary approach is to provide supportive care aimed at preventing or treating the *symptoms that cause suffering* associated with various chronic ailments. The diagnosis that leads the client to seek palliative care will often lead to death but it is not yet eminent. This allows the individual to live more comfortably while awaiting the transition stage to Hospice or end-of life care. In addition to the life expectancy being longer than 6 months, the main difference between Hospice and Palliative Care is that individuals often choose to continue treatment for their illness while receiving the supportive care of the palliative team. For example, a client may still be undergoing chemotherapy or radiation for cancer if desired, while also obtaining the benefits of a well-structured palliative care program. The program utilizes a multidisciplinary approach that consists of doctors, nurses, social services and chaplains, which is also consistent with the services that Hospice provides. Most insurance programs cover payment for Palliative Care services if the patient has an approved diagnosis, although some treatments or medications may not be covered depending on the specific limitations of the individual policy. Medicare and Medicaid may also cover costs associated with Palliative Care but this would depend on the diagnosis and may have time limits applied for length of service. At this time Palliative Care programs are providing comfort, relieving pain and coordinating long-term treatment efforts of more than 1.2 million Americans and their families.



Hospice care is the next step in the transition phase and may be offered if the client has been given an end-stage life prognosis of six months or less. At that point the attempts at curative treatment have stopped and the focus now shifts to assisting the individual to die pain free and with dignity. This is still a relatively new concept in medical science. The first Hospice in the United States was started in 1974 and Hospice Care models are now practiced in most states. There remains, however, a divide between the availability of service and the people who take advantage of this program. Fewer than half of Americans who are eligible for end-of life care (life expectancy-6 months, or less) are utilizing it at all. Those who are under Hospice care average only 20 days of care versus the 180 days they are eligible for. One third of these patients only receive care for one week or less. It is widely recognized that optimum benefit of the end-of life care programs are seen when the individual has access to the full scope of the service for 60 or more days.

The Hospice care approach is designed to provided a variety of settings, which include:

- ✓ A patient's home, or the home of a family member (most common)
- ✓ Hospital
- ✓ Nursing Home or Assisted Living Facility
- ✓ Hospice Residence



The goal of hospice care is to involve a team access to expert medical care, pain management, emotional and spiritual support to the individual and their family. The team that is assigned to each patient consists of a doctor, nurses, social worker, clergy, counselors and trained volunteers. A physician must verify that the patient meets criteria for admission by having 6 months or less to live. The patient must also agree to decline aggressive treatment plans such as chemotherapy or radiation, unless it will be used to provide symptom relief. Medicare, Medicaid and most insurance plans pay for hospice benefits. After admission the plan of care is tailored made for each client depending upon their expressed wishes. It is also important to note that while treatments aimed at curative measures are discontinued – it does not mean that the client does not receive medical care. For example a person dying from cancer would still get medicine to treat high blood pressure, if he wishes.

### **Advance Directives:**

The time to consider what type of end-of life care a person would like to participate in is when they are still healthy and can make informed choices on the path they would chose to follow in the event they are no longer able to speak for themselves. The easiest way to accomplish this is for clients to have conversations with those around them to let them know what choices are preferred when death is imminent. This obviously can be a very difficult conversation to have but it opens the doors to family members and friends understanding the values, wishes and types of care that a loved one prefers. Knowing and upholding a loved one's wishes can be very comforting to family as it gives them a sense of peace realizing they are informed and able to properly carry out the wishes of a loved one.

Ultimately, the most effective way to ensure that one will receive the care they want is accomplished through the use of advance directives. These documents provide clear written instructions regarding the specifics of their medical care if they become incapable of making medical care decisions on their own. Advanced directives include a living will and a health care power of attorney, which includes the name/names of the individual who will be making the care decisions. Some topics that are covered in the living will include information on patient preferences such as:

1. Mechanical ventilation
2. CPR
3. Tube feedings
4. IV hydration
5. Antibiotic use
6. Blood products
7. Comfort measures

In addition to the directives mandated in the living will, it is also important to designate a healthcare proxy who understands the client's wishes and will be able to evaluate the circumstances and make responsible decisions for the patient when necessary. A health care proxy could be a relative, friend or a lawyer. The person appointed as proxy must have a clear understanding of the wishes of the patient in advance of having to make these often difficult decisions.

A lawyer can complete these forms or people can prepare them on their own. Forms are readily available to the public from local advocacy groups or even off the Internet. If the forms are not prepared by an attorney, they will need to be witnessed by people who are not related to the client as they observe the signing and dating of the paperwork and then the witness must also sign and date the paperwork as proof of the client's signature. It is important that the doctor and healthcare facility have copies of the advance directive paperwork as well as the appointed proxy. These forms should be reviewed and revised as needed.

Additional information regarding Advanced Directives can be found at:

- American Bar Association  
[www.americanbar.org](http://www.americanbar.org) 1-800-285-2221
- Caring Connections  
[www.caringinfo.org](http://www.caringinfo.org) 1-800-658-8898
- MedlinePlus.gov  
[www.medlineplus.gov](http://www.medlineplus.gov) (go to advance directives)
- National Cancer Institute  
[www.cancer.gov](http://www.cancer.gov) 1-800-422-6237



End-of-Life Care:

**“Everyone dies alone. That's what it is. It's a door. It's one person wide. When you go through it, you do it alone. But it doesn't mean you've got to be alone before you go through the door. And believe me; you aren't alone on the other side.”**

**---Jim Butcher**

Patients and their loved ones often want to know how long a person is expected to live as they enter the final stages of an illness. It's a hard question to answer. Doctors are hesitant to predict when death will occur because they are concerned about over or underestimating the information and are also reluctant to destroy an ill person's sense of hope. And although they can't pinpoint when a person will die, they can usually tell them how they will die. Although it sounds morbid to discuss; the actual event of death can be managed in the best possible way with clearly directed interventional support. When a patient understands that the fears associated with the process of dying (pain, respiratory distress, anxiety and agitation) can be controlled with proper symptom control, they have much less anxiety overall and are better able to enjoy their remaining life. In the event that a return to health is no longer an option, a peaceful death becomes the goal. Death is a profound event in a person's life. This transition is best accomplished with the assistance of a Hospice program. It is considered the gold standard for end-of-life care because the healthcare team brings extensive science based techniques to the client for symptom control and psychosocial support.

Not all dying individuals receive Hospice care. In some cases, it is not offered as an option by the physician or the services may be offered; but refused by the client because they believe it signals the end of medical care and the end of hope. Hospice services are still not available in many rural areas, which further limits the access to this type of expertise. Regardless of where the dying individual receives end-of-life care, there are generally four areas that need to be addressed:

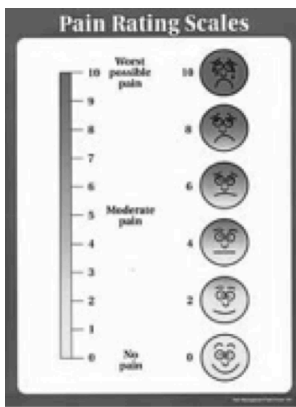
1. Physical Comfort
2. Emotional Needs
3. Spiritual Issues
4. Practical Tasks



#### **PHYSICAL COMFORT:**

*The number one concern of dying people is pain control.* This fear is justified as it has been estimated that approximately 75% of people experience pain with the death process and that individuals who die in nursing homes have the highest numbers of unrelieved pain. Once again, this is another reason to seek specialty care, as almost all patients would benefit from proper pain management, as it is very treatable, if managed correctly at the end of life. There are various levels of pain relief that can be obtained with the proper treatment depending on the patient's wishes. Some individuals would prefer to be comfortable to the point where they can still interact with loved ones and continue to function with some degree of alertness while others want to be pain free to the point of sedation.

The Joint Commission has advocated that patients have a right to be free from pain and requires healthcare professionals to consistently assess, monitor and treat individuals who are experiencing discomfort. It is also at this juncture that the medical community ceases to worry about addiction of the client to powerful pain medications. One of the main purposes for opioid narcotics is to eradicate needless suffering. If drug dependence or tolerance develops, the medication dosage can be adjusted to continue to meet the challenge of ongoing relief from pain.



Assessment of pain is crucial to providing the correct type of relief. It has become the 5<sup>th</sup> vital sign in the medical profession and healthcare workers are trained to utilize objective assessment tools that assist the client to describe their pain's location and intensity, often with a pain scale-rating device. It is important to medicate the patient for pain regularly to maintain pain control because when pain is allowed to become overwhelming, it can be very difficult to treat. Administer the correct amount of pain medication as prescribed by the physician to avoid trying to "catch up" with the pain, which can be difficult to do. If the client continues to suffer from pain after administering the prescribed medications, the physician will need to be notified to adjust the intervals, doses or to order additional break through medications. Frequent re-evaluation is indicated.

Obviously, the pain measures should start on the lower dosing end and be adjusted according to tolerance when initiating a pain control plan. The World Health Organization supports a 3-tier approach to the medical management of pain. It starts with providing step 1 medications and can be increased as follows:



In Step 1, commonly used medications include the following non opioids:

- Aspirin
- Acetaminophen
- Nonsteroidal anti-inflammatory drugs (NSAID'S)

Step 2 includes the medication in the Step 1 and adds the following opioids:

- Codeine
- Hydrocodone
- Oxycodone
- Dihydrocodeine
- Tramadol

In Step 3 the following medications are added for pain relief:

- Morphine
- Hydromorphone
- Methadone
- Levorphanol
- Fentanyl
- Oxycodone



In many instances the health care team will have a prescribed comfort kit available containing a mixture of prescribed medications that the family or caregivers can administer to keep the patient comfortable (See Appendix A). In these circumstances, it is important to keep a log on the type and severity of the patient's pain as well as the medication that was given and if it was effective. This helps the caregivers to keep track of the amount and efficacy of the medications that have been administered. It is also worthy to note that many of these drugs also have side effects that should be documented as well.

The most common side effects experienced from pain medications include drowsiness, dry mouth, excessive sedation, diminished appetite, nausea and constipation. It is vital to notify the physician if the patient is suffering from adverse effects of pain medicine as they can be successfully treated.

Many of the opioids are available in time released form so the caregivers/family must be cautioned not to break open the capsules and sprinkle the granules in food as this can cause a rapid release of the medication and overdose the patient. Liquid solutions are available if the patient has trouble swallowing pills. Fentanyl patches deliver powerful pain medication through the skin and the caregiver must be instructed NOT to cut the patches in half and to be sure to remove one patch before another is applied. When proper guidelines are followed, effective pain relief can be made available to most individuals. This makes the journey much easier for clients and their families alike. Other adjuncts that have been helpful in pain management include massage, guided imagery, aromatherapy, biofeedback and music.

Another issue in maintaining physical comfort is dyspnea or shortness of breath, which is common in a dying person. There are many causes of dyspnea, (pneumonia, pleural effusion, COPD, congestive heart failure and tracheal obstruction) so it is important to establish what is causing the event in order to best treat it. The following methods are commonly used to alleviate respiratory distress:

- Oxygen therapy
- Elevate the head of the bed
- Anti-anxiety medications – bronchodilators (see appendix A)
- Low-dose immediate release morphine
- Open windows for a breeze effect or use a fan
- Nebulizer treatment



Efforts to decrease oxygen demands on the body include providing frequent periods of rest and maintaining good pain control. Proper repositioning of the client can make the work of breathing easier. It is important to remember that additional measures like keeping the patient at a comfortable temperature and hydrated also helps to maintain adequate oxygenation.

Digestive issues can be bothersome complaints to a healthy individual but are exceedingly so to a dying person. Nausea, vomiting, constipation and loss of appetite are the most widely reported symptoms. The causes and treatments for these symptoms are varied but interventions are available to ease the distress. Nausea and vomiting can be controlled through the use of anti-emetics, anticholinergics or even benzodiazepines. It can be helpful to control the strong odors associate with certain foods (onions, garlic, and fish) that have been known to induce nausea. Severe constipation may occur secondary to narcotic usage for pain control and can contribute to nausea and vomiting in the dying patient. Stool softeners and stimulant laxatives can help to limit the side effects caused by narcotic use and general lack of intestinal motility. The patient should also be encouraged to increase their activity level and fluid intake if they are able to. These measures should be instituted soon after narcotic therapy is started for best results.



Lack of appetite is normal as a person approaches death. It can be helpful to offer frequent smaller meals rather than 2 or 3 large ones. If a patient does not want to eat, they should not be forced to do so. Lack of appetite or thirst is not painful and forcing food or liquids can actually add to their discomfort. The patient should be offered small sips of liquids or a few bites of a favorite food if indicated for comfort.

Dry mouth is often caused by medications, oxygen therapy and refusal of food or liquids. Symptoms can be alleviated by using mouth swabs moistened with water or an alcohol free mouthwash. These swabs can also be used to clean the gums, oral mucosa and teeth to keep the tissues moist. Mouthwashes that contain alcohol

should be strictly avoided as they are very drying to the oral mucosa and can promote breakdown of the delicate tissues in the mouth. Individuals who wear dentures will need to be observed for signs of pressure areas due to weight loss that usually accompanies the dying process. Open areas in the mouth will predispose the patient to infection, which is painful and may be difficult to adequately treat.

Skin breakdown can be avoided by routine cleaning of the skin with a gentle cleanser with tepid water while avoiding applying friction or pressure to the skin. All instances of urinary or fecal incontinence need to be immediately cleansed to avoid irritation and breakdown of the perineum and buttock areas. Moisturizers are very helpful to combat dryness and also provide soothing relief to the skin. If the patient is no longer able to turn over on their own, they will need to be turned and properly positioned every 2-3 hours to prevent pressure sore development. Foam pads may be used to provide additional padding to bony prominences like elbows and heels.

## EMOTIONAL NEEDS:

Individuals who have been given a terminal diagnosis may experience the following range of emotions:

- ✓ Depression
- ✓ Anxiety
- ✓ Anger
- ✓ Fear
- ✓ Grief

Most people who are nearing the end of life are understandably fearful, anxious and depressed as the gravity of the situation sinks in. It takes time and patience to help a person move through these feelings as these are all normal reactions and they need to be addressed. Unfortunately, in most cases, the family members feel very uncomfortable talking to the terminally ill individual about their feelings regarding dying. It's like the proverbial white elephant on the dining room table. Everybody sees it there but no one wants to discuss it. Family members and close friends often think that they are sparing the individual undue distress by avoiding discussing these feelings, when in fact, the opposite is true. Even when curing an illness is no longer possible, *healing of the inner person* can still occur. Individuals who are encouraged to talk about their feelings and anxieties are more likely to have a sense of peace and closure that comes from within in their final days.

Loved ones by simply asking the dying person to talk about their fears and concerns can initiate these discussions. The individual often has specific concerns such as if their pain will be relieved, fear of being alone during death or worries about leaving their family members behind. Encouraging and facilitating these conversations can be just as useful to the patient as relief of uncomfortable symptoms. If the family is unable to open up this line of discussion with the patient, then a trained counselor should be contacted. One of the many strong points of a hospice program is they recognize this need for emotional healing and provide skilled social workers who have experience in facilitating family discussions as well as addressing any counseling issues that may arise. True depression and unresolved anxiety can be treated with medications if they are not resolved after the lines of communication are opened up.

Patients who are facing death tend to feel isolated as they sense that people they love are starting to withdraw from them. Sometimes family and friends simply feel that they don't know what to say and so they stop visiting or just sit in uncomfortable silence when they do. Unfortunately, even the doctor might appear to be avoiding the patient because they are discouraged that they can't cure the patient and they feel helpless. Some medical professionals are not trained in any aspects of end-of-life care and view death as a failure of the medical model rather than a natural aspect of life. This is another reason individuals are encouraged to seek hospice care, as the entire healthcare teams are well versed in this subject and their focus is on the *patient as a whole being*.

In addition to encouraging final conversations, it can be comforting to people to have someone simply hold their hand and sit quietly with their loved ones. As death becomes near, soft music and low lighting can provide a soothing environment. Always talk to the person who is dying and don't assume that they cannot hear or understand what the conversation is about.

## **SPIRITUAL ISSUES:**



When faced with death many individuals will question the meaning of their life. This becomes a time for self-reflection and contemplation. Patients want to feel like their life had meaning and often wish to resolve unsettled matters or conflicts with family and other loved ones. Many individuals find great strength and comfort in their faith. Individuals seek reassurance from their spiritual leaders (priests, rabbi, ministers etc.) and often wish to pray or speak to them during this trying time for encouragement and peace of mind. Sometimes medical decisions are based on religious beliefs so it is helpful to have a cultural understanding of different faiths.

For example, Jehovah Witnesses believe the Bible prohibits them from receiving a blood transfusion, or the donating their blood – even if it is for them to store for a future surgery. Their religion also prohibits them from accepting blood in an emergency situation as well. This is a non-negotiable religious stand and if a Jehovah decided to accept a blood transfusion, they would be disassociated from the religion and shunned by its other members.

Family members and friends should be encouraged to spend time with the patient to remind them of their importance in those relationships. This sharing of memories can be comforting to both the patient and their family. Religious individuals are more likely to continue to see friends and have less depression than those who are nonreligious. They are also more likely not to have a living will and to prefer to utilize life-sustaining measures such as mechanical ventilation and CPR up until the end. Understanding and supporting these patterns can improve the quality of life for dying individuals. Once again, authentic hospice programs will provide spiritual counseling options as part of the interdisciplinary team service.

## PRACTICAL TASKS:

Most people require assistance with their tasks of daily living as they approach the end of their lives. This assistance can be in the form of:

- Grocery shopping, cooking meals
- General cleaning of the home
- Laundry
- Assistance with personal hygiene
- General errand running
- Walking the dog
- Bringing meals to the individual

As the individual becomes weaker, there will be additional tasks that others will need to assist with that may include bathing, feeding and positioning. In many instances, the dying individual is cared for in the home by family members who may require help in order to free them up to give their full attention to the dying individual. Family caregivers actually are a major force in the care of the dying patient as many individuals prefer to stay at home and remain the “family environment.” This places an incredible strain on those who are tasked with this care. It can be a very time consuming endeavor that is often physically demanding as well. Most family members are not trained on the specifics of patient care and can even suffer physical injury from the strenuous demands of lifting or moving the weakened patient. It may be necessary for the family member who is caring for a dying individual to give up their job to care for the patient which further compounds their burden as it has been estimated that up to one third of family caregivers end up losing most, if not all of their savings while trying to provide care for a loved one. Being exhausted, mounting financial concerns and a disrupted daily routine can all lead to depression, anxiety and feelings of hopelessness in the caregiver. It is important for the healthcare team to be alert for caregiver burnout and to provide support services to the caregiver as well as the patient.

The Dying Process:

**“I maintained that everyone has to die – I still do. The hospice gives a person the opportunity to die with dignity. It provides care, help and as much comfort as possible. In spite of the fact that I have been staying in a hospice, I’m not going to heaven immediately. My doctor informs me that I can stop over in Martha’s Vineyard on the way there.”---Art Buchwald, *Too Soon to say Goodbye*.**

The following signs may indicate that death is imminent:

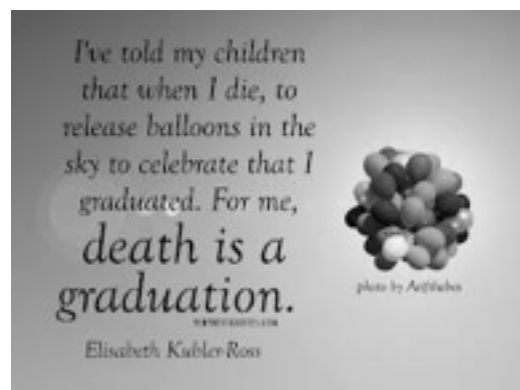
- Confusion
- Withdrawal from family/friends
- Refusal to drink or eat
- Dark or decreased urine output
- Dyspnea (shortness of breath)
- A gurgling or rattling sound in the chest
- Changes in heart rate
- Lowered body temperature
- Darkened or grey skin color
- Incontinence of urine or stool
- Terminal restlessness

This stage is called active dying and individuals may or may not experience the above symptoms. Always remember that the individual may still be able to hear conversations and to speak to them in a calm tone. Do not force the patient to eat or drink fluids at this point but keep their lips and mouth moistened with swabs or a wet cloth. Offer sips of water or ice chips to the patient as tolerated. Use blankets to keep the patient warm and if incontinent, use disposable pads on the bed and remove them when soiled while cleaning the patient. Prescribed medications are available to diminish airway secretions and control pain. Keeping the patient turned to the side with the head elevated often helps to control excessive secretions. Oxygen may be used continuously via nasal cannula or mask as indicated for dyspnea. The goal now becomes keeping the dying person as comfortable and calm as possible. Many families will hold vigil, while they take turns staying in the room with their loved one to comfort them.

The following signs indicate that death has occurred:

- Pulseless, for over 1 minute
- No respirations
- Pupils are dilated and fixed
- No response to touch, or voice
- Relaxed jaw
- Pale, cool waxen skin

If death has occurred outside of a healthcare facility, the appropriate authorities will need to be notified. If the patient is on hospice service, they will pronounce the death and initiate care of the body. If the patient is not on hospice care, the family will need to notify the doctor and the local authority to notify them of a death at home. The funeral home is notified as well. Sometimes family members panic and feel helpless when the patient is in the active dying process and call 911. This can cause confusion, as most 911 responders are required by law to initiate CPR and other aggressive treatments. It is vital for the patient to have completed a non-hospital DNR if they intend to die at home. Depending on the state, the responders may or may not be able to honor this paperwork.



The family may wish to sit and spend some time with the deceased individual to console each other, talk or pray. Equipment and supplies should be removed from the bedside and the body should be placed in a supine position with a pillow under the head to avoid facial discoloration. Close the eyelids and hold them shut for a few seconds to ensure they remain closed. Dentures should be placed in the mouth to maintain facial structure. If necessary a rolled towel may be placed under the chin to keep the mouth in the closed position. Reduce the lighting and encourage the loved ones to take their time with the deceased.

When the family has left the room, the body will have 2 identification tags secured to the body on the wrist and ankle. Remove all jewelry, except for a wedding band and that should be taped to the finger. The body is then wrapped in a covering, or shroud, and another ID tag is secured on the outside. The body is then ready for disposition to the funeral home or morgue.

## **Grief:**

For many individuals the grieving process starts when they learn of a loved one's terminal diagnosis. After death, individuals will continue the grieving process until the frequency and severity of the pain of loss gradually decreases in intensity. There is no specific time frame allotted for the grieving process, as it will vary from person to person. Some people are able to resolve their feelings of grief in a few months but for others it can take years.



Generally people who are grieving are attempting to understand and work through feelings of despair and isolation. Loved ones often say that it feels like a hole has been placed in their heart. Although individuals do not have a time limit set on the grieving process, most will experience the following normal stages:

- ✓ An initial feeling of numbness or shock
- ✓ Yearning or longing for the presence of the deceased
- ✓ Periods of despair
- ✓ Finally, a sense of closure and rebuilding a life without the deceased

As healthcare providers, it is important to recognize the signs of grief and to urge the family members to continue to work through emotional issues that may arise such as feelings of guilt, hopelessness and isolation. The Medicare Hospice benefit allows organizations like Hospice to follow the progress of the family members and loved ones for up to a year after loss. Skilled individual and group bereavement sessions are made available to help people cope with their response to the death of the loved one. Many people are totally unprepared for the amount of effort that is required to work through the stages of active grief. Physical symptoms include loss of appetite, extreme fatigue, depression and difficulty concentrating. Individuals need appropriate support and encouragement to move through the stages and not become stuck in a pattern of unresolved grief, which makes it difficult to move forward. Often the grief is not only for the lost person but also for the loss of plans, dreams and accomplishments shared with the deceased.

## **Death of a Child:**

It is universally understood that the death of a child is one of the most traumatic and challenging event that a person can endure. In the United States approximately 57,000 children die under the age of 19 annually – 28,000 will die before their first birthday. These deaths occur to a variety of reasons; the most common being:

- Prematurity
- Life threatening birth defects
- Accidents
- Cancer (#1 disease killer in children)
- Metabolic illnesses
- Murder



Some of the causes of death are sudden and others, like cancer, are often prolonged. Over 500,000 children in the U.S are coping with the profound effects of a chronic, life-limiting illness. Treatment is well directed when palliative care can be initiated in the early stages of illness, as this will help the child and family to focus on the wellness strategy offered in comprehensive programs. It is very difficult for a family to attempt to manage a child's serious illness without a structured service that can provide physical, psychological and spiritual focused care.

Children who suffer from a terminal illness need to have a sense of normalcy in their measured time. Healthcare professionals should encourage appropriate social interactions for these children that include education and play structured time for the child. Most children would prefer to remain in the school environment for as long as possible. Healthcare professionals should also encourage the parents to be honest with the child (age appropriate) regarding the diagnosis and what types of procedures will be necessary to face in the future. The child will sense when the news is not good and needs the opportunity to be able deal with the truth in an open and honest manner. Some children are able to communicate their feelings through the use of play therapy, which involves drawing and playing with puppets or dolls to express their concerns and questions.

The physical care of the child is similar to the end-of-life care for the adult. It is focused on providing comfort measures and relief of distressing symptoms. A variety of medications is available for secretion control, pain relief and other symptoms and is dependent upon the physician's treatment plan. Children are also afraid of being in unrelieved pain and need reassurance that their pain will be successfully managed. The care plan of a terminally ill child focuses on:

- ❖ Pain management
- ❖ Respiratory care
- ❖ Maintenance of bowel and bladder function
- ❖ Nutritional status
- ❖ Socialization
- ❖ Promotion of rest and normal sleep patterns

Parents will need to be kept well informed of the progression of the stages of terminal illness so they can participate appropriately in their child's care. They will also need help coping with the feelings of anger, fear, sadness and frustration that often hinder the enjoyment of the time they have left with their child. After the death of a child, people may experience a deeper grief than even the loss of a parent or spouse. The care of the family should extend beyond the period that follows initial death. Clients who are receiving hospice care may continue to have follow-up calls, visits and supportive counseling for up to one year following the death of a child.



**“I held her close for only a short time, but after she was gone, I’d see her smile on the face of a perfect stranger and I knew she would be there with me all the rest of my days.” --Brian Andreas, *Strange Dreams***

## Appendix A - Pharmaceutical Interventions:(Generic List)

The following medications are commonly used to treat symptoms that may occur during end-of-life care for both adults and children. The dosage and route will vary according to patient tolerance, age and physician preference. There are also other drugs that may be utilized which are not found on this list. Each medication profile is designed to meet a standardized approach for symptom management and is individualized according to established criteria.

### **AGITATION:**

- ❖ Haloperidol
- ❖ Chlorpromazine
- ❖ Risperidone
- ❖ Lorazepam

### **ANXIETY:**

- ❖ Alprazolam
- ❖ Clonazepam
- ❖ Diazepam
- ❖ Lorazepam
- ❖ Buspirone
- ❖ Hydroxyzine

### **ASCITES:**

- ❖ Spironolactone
- ❖ Bumetanide
- ❖ Furosemide
- ❖ Hydrochlorothiazide

### **CACHEXIA:**

- ❖ Dexamethasone
- ❖ Megestrol
- ❖ Dronabinol

### **CONSTIPATION:**

- ❖ Biscodyl
- ❖ Senna
- ❖ Docusate calcium
- ❖ Magnesium citrate

### **COUGH:**

- ❖ Promethazine (may add codeine)
- ❖ Bezonatate
- ❖ Dextromethorphan
- ❖ Guaifenesin (may add codeine or dextromethorphan)



**DEPRESSION:**

- ❖ Trazodone
- ❖ Mirtazapine
- ❖ Duloxetine
- ❖ Paroxetine
- ❖ Imipramine
- ❖ Bupropion

**DYSPNEA:**

- ❖ Albuterol
- ❖ Beclomethasone
- ❖ Ipratropium bromide
- ❖ Dexamethasone
- ❖ Morphine
- ❖ Theophylline

**EDEMA:**

- ❖ Bumetanide
- ❖ Furosemide
- ❖ Spironolactone
- ❖ Hydrochlorothiazide

**HICCUPS:**

- ❖ Valproic acid
- ❖ Baclofen
- ❖ Haloperidol

**MUSCLE SPASMS:**

- ❖ Clonazepam
- ❖ Diazepam
- ❖ Carisoprodol
- ❖ Metaxalone

**NAUSEA/VOMITING:**

- ❖ Hydroxyzine
- ❖ Meclizine
- ❖ Scopolamine
- ❖ Promethazine

**PAIN:**

- ❖ Acetaminophen
- ❖ Ibuprofen
- ❖ Naproxen
- ❖ Codeine
- ❖ Morphine
- ❖ Oxycodone
- ❖ Fentanyl transdermal patch

**SECRETIONS:**

- ❖ Atropine
- ❖ Hyoscyamine
- ❖ Scopolamine transdermal patch
- ❖ Glycopyrrolate

**SEIZURES:**

- ❖ Phenobarbital
- ❖ Clonazepam
- ❖ Diazepam
- ❖ Phenytoin
- ❖ Valproic acid

**URINARY INCONTINENCE:**

- ❖ Doxazosin
- ❖ Oxybutynin
- ❖ Tolterodine
- ❖ Prazosin
- ❖ Tamsulosin

## Appendix B - Resources

Additional information regarding end-of-life care can be found at:

### **AARP**

601 E Street, NW  
Washington, DC 20049  
1-888-687-2277 (toll-free)  
[www.aarp.org](http://www.aarp.org)

### **Aging with Dignity**

P. O. Box 1661  
Tallahassee, FL 32302  
1-888-594-7437 (toll-free)  
[www.agingwithdignity.org](http://www.agingwithdignity.org)

### **Alzheimer's Association**

225 N. Michigan Avenue, Floor 17  
Chicago, IL 60601  
1-800-272-3900 (toll-free)  
[www.alz.org](http://www.alz.org)

### **American Academy of Pain Medicine**

4700 W. Lake Avenue  
Glenview, IL 60025  
1-847-375-4731  
[www.painmed.org](http://www.painmed.org)

### **American Geriatrics Society**

#### **Foundation for Health in Aging**

40 Fulton Street, 18th Floor  
New York, NY 10038  
1-800-563-4916 (toll-free)  
[www.healthinaging.org](http://www.healthinaging.org)

### **American Hospice Foundation**

2120 L Street, NW, Suite 200  
Washington, DC 20037  
1-800-347-1413 (toll-free)  
[www.americanhospice.org](http://www.americanhospice.org)

### **Centers for Medicare and Medicaid Services**

7500 Security Boulevard  
Baltimore, MD 21244-1850  
1-800-633-4227 (toll-free)  
[www.medicare.gov](http://www.medicare.gov)

### **Center for Practical Bioethics**

Harzfeld Building  
1111 Main Street, Suite 500  
Kansas City, MO 64105  
1-800-344-3829 (toll-free)  
[www.practicalbioethics.org](http://www.practicalbioethics.org)

### **Center for Advanced Palliative Care**

1255 Fifth Avenue, Suite C-2  
New York, NY 10029  
1-212-201-2670  
[www.getpalliativecare.org](http://www.getpalliativecare.org)

### **Compassion and Choices**

P. O. Box 101810  
Denver, CO 80250  
1-800-247-7421 (toll-free)  
[www.compassionandchoices.org](http://www.compassionandchoices.org)

### **Family Caregiver Alliance**

785 Market Street, Suite 750  
San Francisco, CA 94103  
1-800-445-8106 (toll-free)  
[www.caregiver.org](http://www.caregiver.org)

### **Hospice and Palliative Care Nurses Association**

One Penn Center West, Suite 229  
Pittsburg, PA  
1-412-787-9301  
[www.hpna.org](http://www.hpna.org)

### **Well Spouse Association**

63 West Main Street, Suite H  
Freehold, NJ 07728  
1-800-838-0789  
[www.wellspouse.org](http://www.wellspouse.org)