End of Life Care

**Purpose:**
End of life care refers to the interventions and treatment given to an individual in the final stages of their life following either disability or a disease process. It is sometimes referred to as palliative care, hospice care, comfort care or even supportive care. As the population ages, health care professionals will need to become well acquainted with caring for individuals at the end of their life. The care of the dying patient, like all medical care, should be guided by the values and preferences of the individual patient. Independence and dignity are central issues for many dying patients, particularly the elderly. Maintaining control and not being a burden can also be relevant concerns. A major focus of end of life care is the relief of pain and suffering and interventions that help improve the individual’s quality of life. Many of these important principles/interventions are reviewed in throughout this overview of end of life care.

**Learning Objectives:**
1. The learner will understand an overview of some of the important principles surrounding end of life care
2. The learner differentiate between clinical death and brain death
3. the learner will understand the difference between palliative care and hospice care and will examine aspects of the history and current state of hospice care
4. The learner will identify the various stages of dying as defined by Dr. Kubler Ross.
5. The learner will review and contrast the varying attitudes of family members, medical professionals, community members as well as the attitudes of the dying individual themselves
6. The learner will review the 5 “A”s of palliative care according to the World Health Organization: Assess, Advise, Agree, Assist, Arrange
7. The learner will understand other important aspects of managing palliative care such as: management of pain, institution of preventative measures, and the management of key symptoms.
8. The learner will recognize the key signs of impending death noted in the last hours of life.
9. The learner will understand key legal aspects of death including living wills, durable power of attorney for health care and do not resuscitate orders (DNR), as well as key ethical aspects of death including euthanasia and physician assisted suicide.
10. The learner will review and have a general knowledge of key positions of the American Geriatric Society for the dying individual in areas of patient care, health care delivery, education and research.

Outline

1) Introduction
2) Definitions Related to End of Life Care
3) The Hospice Movement
4) Stages of Dying
5) Attitudes of the Dying, Their Family and Caregivers
6) World Health Organization – Approach to Palliative Care
7) What Happens in the Last Days/Hours of Life
8) Legal and Ethical Issues Surrounding End of Life
9) 2007 Position Paper of the American Geriatrics Society

Introduction

“The rhythm and meaning of human development eventually wend their way to late adulthood, when each of us stands alone at the heart of the earth and “suddenly it is evening”. We shed the leaves of youth and are stripped by the winds of time down to the truth. We learn that life is lived forward but understood backward. We trace the connection between the end and the beginning of life and try to figure out what this whole show is about before it is over. Ultimately, we come to know that we are what survives of us.” (Santrock, 2006)
End of life care refers to the interventions and treatment given to an individual in the final stages of their life following either disability or a disease process. It is sometimes referred to as palliative care, hospice care, comfort care or even supportive care. There are some important principles/interventions that have been studied over recent years and found to be important related to end of life care. Some of those include:

- Managing symptoms, in particular, pain
- Dealing with grief (in both the dying individual as well as family)
- Utilization of advanced planning for end of life, including when and when not to provide or withdraw life sustaining treatments
- The importance of communication between patient, family and health care providers
- The importance of spirituality during end of life
- The valuable role of family caregivers

The care of the dying patient, like all medical care, should be guided by the values and preferences of the individual patient. Independence and dignity are central issues for many dying patients, particularly the elderly. Maintaining control and not being a burden can also be relevant concerns. (AGS, 2007) Many if these important principles/interventions are reviewed in throughout this overview of end of life care.

**Definitions Related to End of Life Care**

**What is death?**
A common term for death is sometimes referred to as clinical death. Clinical death is defined as the cessation of breathing, circulation and brain activity. This begins at the moment of, for example, a cardiac arrest, and lasts for 3 to 7 minutes. It is during this time that a person can be resuscitated. In years past, this ceasing of breathing and one’s heart beat, was considered “death”, however as medical resuscitation efforts became more widely used and successful, death began to be defined by neurological means or “brain death”. Brain death is defined as when
electrical activity has ceased in both the higher (cortical) and lower (brain stem) areas of the brain. This usually occurs within a few minutes after clinical death and can be measured by an electroencephalogram (EEG). Santrock, 2006)

What is Palliative Care vs. Hospice Care?
Palliative care is generally care that is aimed at reducing the symptoms and providing relief from an illness. Although palliative care and hospice care share many similarities including their aim to provide comfort care, there are some areas that differ and they are outlined as follows:

1. **Treatment** – In hospice care, the individual receives comfort care for a life threatening illness and aggressive treatment aimed at curing the illness is not utilized. In palliative care, the individual may have a life threatening illness or just a chronic or major illness. The person may continue to receive aggressive treatment for their illness in addition to comfort care.

2. **Place** – Hospice care is most often given in the home with a home caregiver whereas palliative care is usually given in a hospital or nursing home.

3. **Timing** – Hospice care is generally given when a person is within 6 months of dying whereas palliative care is given at any stage of an illness.

4. **Payment** – Hospice care is usually paid for by Medicare and most of the cost is covered. Palliative care is generally covered by your medical insurance and is subject to co-pays and restrictions set forth in individual policies.

As stated above, not all palliative care refers to end of life care. In contrast, all care given by hospice, is both end of life and palliative. (National Caregivers Library, 2009)

**The Hospice Movement**
In medieval times, “hospice” referred to a type of rest station for weary and hungry travelers. It evolved over the years into a rest station for the sick and dying. The first modern hospice was opened in 1969 in England. It utilized a model of palliative care to serve the terminally ill. Palliative care is most
broadly defined as treatment that focuses on control of symptoms of a disease but is not aimed at treating the underlying condition. This care model was further defined by physician Dame Cicely Saunders of London in 1969 as having its foundation on 5 tenants or principles as follows:

- Control of pain and other distressing symptoms
- The provision of diagnostic honesty
- 24 hour care, including a system of caregiver support
- Improving patient quality of life
- Grief support to survivors

This became the model upon which all hospice services were built. The first hospice in the United States opened its doors in 1971. Hospice care can be provided in a variety of settings. (Lewis, 2003)

Medicare and Hospice
Hospice services were added as a paid benefit to Medicare clients in 1983 as part of Part A services. Most hospice care in the U.S. is paid for by Medicare. Only 10% are paid for by other resources such as private insurances. The reason for this is that 80% of individuals who use hospice care are 65 or older. The majority of costs are covered by Medicare and therefore the patients/families themselves have little to no financial burden for the care. Eligibility for Medicare Benefits are as follows:

- Have Medicare Part A Coverage
- Physician certification of life threatening illness where, without treatment, death is within 6 months
- Patient election of hospice care versus routine medical care for the illness
- Utilization of hospice organization approved by Medicare

The services covered by Medicare include physician, nursing, occupational, speech and physical therapy, social services, medications for symptom and pain control, medical equipment and supplies and short term hospital and respite care. Medicare will not cover any treatment that is aimed at curing your illness. In addition they will not pay for any duplication of services, i.e.; any care from another health care provider that is the same care you are getting from your hospice provider. (Caring Connections)

Hospice Statistics from 1998 to 2008
According to the Centers for Medicare and Medicaid Services, among the top 20 diagnoses that are cared for by hospice are the following:
- Cancers (with lung cancer being the most common of the cancers)
- Congestive Heart Failure and other Heart Disease
- Chronic Kidney Disease
- Stroke
- Parkinson’s
- Pneumonias
- Chronic Liver Disease
- Dementias (Alzheimer’s and other related dementias)

One of the major changes that has occurred in this area over the past 12 years has been the decrease in the number of cancer patients cared for by hospice and the increased in non-cancer patients under hospice care. Leading the non-cancer patients being cared for by hospice are those with a diagnosis of dementia. Other “diagnoses” that have increased markedly in the past few years are Debility, not otherwise specified (NOS) and Failure to Thrive.

The average length of stay for hospice patients has increased over the past 10-12 years form 48 days in 1998 to 71 days in 2008. In 2008, the “top twenty” diagnosis with the lowest length of stay was chronic kidney disease, 28 days, and the highest length of stay was Alzheimer’s Disease and other degenerative diseases with 105 days. (Hospice Center, 2009)

**Dr. Kubler-Ross Stages of Dying**

Dr. Elisabeth Kubler-Ross was a physician who, after being dismayed by hospitals treatment of the dying patient, began to study death and dying by interviewing individuals with terminal illnesses. It was from these interviews that her famous work on the stages of death and dying emerged. It was her goal to “encourage others not to shy away from the ‘hopelessly sick’ but to get closer to them, as they can help them much during their final hours.” (Kubler-Ross, pg. 11) She identified the following emotional reactions to death as a means that many individuals experience as a way to cope with death.
Stage 1 – Denial and Isolation

The most common initial reaction to a terminal diagnosis is, “This cannot be true.” Many feel that the diagnosis must be a mistake and it is not unusual for them to get second, third and even fourth opinions. People will sometimes refuse treatment during this stage. At times, they move in and out of denial, at one moment talking as if the end is near and at other times talking about plans for the future, no matter the improbability. Most individuals will eventually move through this stage, however, denial tends to re-emerge at various times during the terminal process as it is difficult for any individual to face death 24/7. It is very unusual for a person to remain in denial until their death, although it does occur.

Stage 2 – Anger

The second stage of dying is the anger stage. The anger may be either rational or irrational. The anger may be directed at God, at family, the medical community and caregivers, or even at themselves. A common reason for anger is the simple loss of control. This may be one of the few areas that an individual has ever had little to no control in. They may react angrily, for example, to being told what to do by others. They may be demanding and hard to manage. It may be that the person alienates and pushes others away temporarily. Caregivers need to be aware of this and not take the anger personally and not respond with their own anger. It is important to listen to the individual and even maybe to even accept the irrational anger as this may actually help the person to better deal and cope with their illness.

Stage 3 – Bargaining

The third stage of dying is referred to as bargaining. It is an attempt to put off the inevitable. When the anger has not worked to reverse the situation, some may begin to negotiate or make promises. The bargaining usually occurs in private with God and therefore, most often, the caregiver may be unaware exactly when the individual is in this stage.
Stage 4 – Depression

The fourth stage of coping with dying is depression. It is in this stage that the person begins to accept that they are dying. This brings on a state of sadness. Depression is a normal state of being when one is losing and separating from those things and people that he/she loves. Trying to “cheer up” the person, is often a poor idea, as they need to mourn the loss, even the loss of themselves. It is a necessary step of “emotional preparation” for the dying individual as they begin to separate themselves from this life. It is a good idea to just spend time with them, even if it is just silent time, they will most likely appreciate your presence.

Stage 5 – Acceptance

Often, in this fifth stage of dying, the person appears happier and more at peace. They may become more matter of fact and begin to “put their affairs in order”. During this stage they may want to write letters to children or even try to comfort the living with words of reassurance. (Kubler-Ross, 1969)

It is important to note that not everyone will exhibit all of the above stages of dying. Some will move in and out of one stage or another, or even appear to get “stuck” in certain stages. The important idea to embrace is that although everyone reacts somewhat differently toward death, there are some common emotions that can be identified that are in and of themselves a means of coping with the end of life.

Attitudes of the Dying Patient, Their Family and Caregivers
In a study done in 1997 by the organization, Supportive Care of the Dying: A Coalition for Compassionate Care, attitudes of dying patients, their families and their health care providers were examined. The following are some of the most common attitudes discovered:

The person with the life threatening illness
"I think it's made me a stronger person. I think it's made me appreciate life a lot more, appreciate people a lot more. I try not to take things for granted. I was going to work, coming home, cooking supper, and then doing the wife thing. I just never really took time to enjoy life. I was enjoying life because it was the life that I was in, but I think you need to take time to... I love the moon, and I love sunsets, and I love stuff like that. I think if you can even take the time just to appreciate the beauty that there is, the flowers that people plant, just take a little extra time or give somebody an extra hug."
(McSkimming, 1997)

Common attitudes of the person with the life threatening illness included,
- Wanted to continue to live until it was time to die
- Saw their illness as an opportunity for personal growth
- Wished that doctors would take their symptoms seriously
- Wanted information form their doctors to make educated choices on their treatment options
- Wanted to know form their doctors what was going to happen to them as they died
- Feared losing independence and being a burden more than dying
- Depended heavily on their family for support

The family caregiver
"There [were] times I was up with her every hour, you know, [every] 45 minutes to one hour, getting up with her and sitting on the pot. So it's constant--and then to get up and go to work and work a full day. You think, 'Oh, I am so tired!' And then the other thing that's so hard is like when you're not allowed to be sick. You can't be sick!"
"[You can feel cut off from life] when you have [only] an hour or two hours in a week, or a total of maybe four hours in a week that you're not at the house or wherever the person is that you're caring for. If you're there 22 hours for two days,
and then 24 hours a day for the rest of the time, you don't really get a chance to shut off for a bit." (McSkimming, 1997)

Common attitudes of the family caregiver included,

- Saw the illness as their “illness” as well as the family members
- Wanted doctors to respect their “expertise” in knowing what their family member needed and wanted
- Wanted doctors to respect their choice to try alternative therapies along with traditional therapies
- Expressed that care giving was burdensome and led to isolation and exhaustion
- Appreciated when friends and family pitched in and helped without being asked
- Saw care giving as a way to give respect and honor to the dying person’s life

The professional caregiver

"Just last night, there was a trauma patient that came in that just died, and there was no--it's scary almost, how we're desensitized to that. I mean, I walk in, the patient is there, we work on him for a while and he dies. Then I walk out, go get a cup of coffee, and I go home. There's not a real grieving process, because there is more work to be done." (McSkimming, 1997)

Common attitudes of professional caregivers included,

- Acknowledge that the current healthcare system is set up to reward productivity and not quality time spent with the dying patient
- Often don’t have the time to “attach” to the dying patient and address their psychosocial needs as well as physical needs
- Often feel inadequate to do their job well
- Are afraid that they are sometimes “too de-sensitized” to death and dying
- Acknowledge that sometimes the medical “machinery” forges past patients wishes related to their own
health care

- Often become more sensitive to their patients when they themselves experience a personal loss
- Those professionals that have learned good supportive care principles understand the value of the spiritual, emotional and relational needs of their patient, and that these will come to take precedence over the physical needs

The community

"In your living you don't be so wrapped up in yourself that you aren't able to reach out and help somebody along the way." (McSkimming, 1997)

- Community healthcare systems were usually not very helpful in assisting the grieving family after a death
- Churches and some volunteer groups can be important in helping individuals through the grieving process
- Neighbors, friends, other family are the most important community support for the grieving family

The bereaved (after the loss)

"There for a while, they were sort of stand-offish. They didn't ask me because they're afraid they don't know how you're going to react. If I started talking about it, it was okay, but at first they didn't want to. They don't know what to say. If they see you cry, they think they may be upsetting you and they don't realize that those tears are okay and this is what you need. If other people see you cry, they don't know how to react to this and they don't want to see them cry."

(McSkimming, 1997)

Common attitudes of family members after the death of a loved one include,

- Often saw the final days coming before the healthcare professional saw it
- Was thankful for opportunities in the final days to say their goodbyes
- Saw healthcare workers as sometimes prolonging the dying process by instituting routine medical procedures even when they were asked not to
- Has a roller coaster of emotions from one day to the next
• Sometimes becomes depressed, even to the point of wishing to also die
• Can take offense at well intentioned words of condolence, and sometimes prefer just a simple, “I’m sorry” or a friend silently standing by their side as an acknowledgement of their pain and grief
• Don’t want family and friends to avoid talking about the deceased person
• Sometimes benefit from a support group, but some people prefer to grieve alone
• May have to learn new skills to take over tasks that the loved one used to do
• Never really gets over the loss, but the loss does get easier

( McSkimming, 1997)

Being aware of the above attitudes can assist the health care worker in developing a comprehensive plan of care for the individual facing end of life.

World Health Organization – Approach to Palliative Care

The World Health Organization (WHO) describes their approach to palliative care with the 5 “A’s”: Assess, Advise, Agree, Assist and Arrange.

• Assess - It is important to assess both the patient’s status and current symptoms as well as the family caregiver’s knowledge and concerns.
• Advise – The healthcare worker becomes a teacher to both the patient and the family caregiver – teaching them the important skills they will need to manage symptoms and increase quality of life.
• Agree – Make sure that the patient and family caregiver are in agreement with whatever course of self management has been decided. In other words, do not impose care that they are not in agreement with.
• Assist – Assist them to get any supplies they may need for their care.
• Arrange – Arrange support for them in the community, if that is wanted, or by having a place to call if help is needed.
In addition, the World Health Organization identifies other important aspects of managing palliative care as: management of pain, institution of preventative measures, and the management of key symptoms.

**Management of Pain** – It is important to assess the source and the type of pain. Pain can be assessed using the Faces Pain Scale or using a number rating system. Treatment of pain may be with medications and/or non-medical treatments. Common non-opioids utilized are aspirin and ibuprofen while opioids commonly used are codeine and morphine. There are some common side effects to opioids including constipation, nausea, drowsiness, twitching, itching and urinary retention. Additionally, it is important to teach family members how to administer pain medication on a routine basis (as opposed to waiting until the person begins to complain of pain). The ultimate goal is to manage the pain without the person becoming too lethargic or un-alert. Additional methods for pain control include massage, rocking, ice or heat, relaxation breathing, music, imagery and prayer.

**Institution of Preventative Measures** – Some areas that may require preventative care include oral care, prevention of bedsores, adequate bathing, prevention of stiffness and contraction. Below are some strategies to help prevent common problems in these areas:

**Oral Care**

- Use a soft toothbrush to clean mouth with either baking soda or toothpaste
- Rinse the mouth with salt water occasionally (especially after eating)

**Bathing**

- Dry skin well after bathing
- Keep skin moist with oil or creams
- Keep skin folds clean and dry
- Use petroleum jelly to create a moisture barrier as necessary
Prevention of bedsores
- encourage the person to sit in a chair when able
- encourage shifting/changing of position while in bed
- use pillows and towels for extra padding
- lift instead of sliding the person in bed
- make sure bed is clean and dry
- check for changes in skin color/condition daily

Prevention of stiffness and contractures
- Encourage movement
- Do active, active assisted or passive range of motion on major joints two times daily
- Offer/use massage

Management of Key Symptoms

Weight loss
- Encourage eating of favorite foods
- Offer small meals throughout the day
- Treat diarrhea and mouth ulcers

Nausea and Vomiting
- Offer fluids throughout day
- Ginger and other teas may help
- Use anti-nausea medications

Mouth Ulcers
- Remove food particles that remain in mouth
- Rinse mouth with salt water or baking soda
- Rinse mouth with aspirin that has been dissolved in water
- Utilize soft foods
- Avoid extreme temperatures of food or spicy food
- Give pain meds as needed

Dry Mouth
- Give frequent drinks of liquids
- Moisten lips with liquids
- Try decreasing medications as able that contribute to dry mouth

Constipation
- Frequent fluids
- Keep fiber in diet as able
• Give tablespoon of vegetable oil before meal
• Use Vaseline on rectum
• Use laxatives

Diarrhea
• Encourage fluids, soups, hydration drinks
• Avoid sweet drinks
• Monitor for blood in stools
• Give foods that add bulk such as potatoes, rice
• Replace potassium with rehydrating drinks, bananas
• Give stool hardening medications as indicated

Anxiety and depression
• Converse and listen to person, provide emotional support
• Use music and relaxation tapes, massage
• Use anti-anxiety or anti-depressant drugs as needed
• Monitor for suicide risk

Insomnia
• Limit caffeine
• Treat pain
• Keep noise and light at a minimum

Confusion
• Keep familiar things/people around them
• Stick to a routine
• Remove items that could be dangerous
• Keep communications simple

Itching
• Keep skin moisturized
• May add small amount of vegetable oil to bathing water
• Utilize medicated creams for fungi or infections

Cough
• Use honey or lemon to help sooth cough
• Utilize steam inhalations for thick mucus
• Codeine can be helpful for dry cough
• Treat underlying respiratory infections with antibiotics

Fever
• Give fluids
• Cool body with damp cloth/sponge baths
• Avoid heavy clothing and blankets
• Treat with fever reducers

Hiccups
• Can try some traditional hiccup remedied (eat 2 tablespoons of sugar, breath into a paper bag, eat crushed ice, pull knees to chest and lean into them)

(World Health Organization, 2004)

What Happens in the Last Days/Hours of Life

It is important to understand and recognize the symptoms of what happens both physically and psychosocially when a person is nearing the very end of life. This is sometimes referred to as “active dying”. In addition, there may be important ways that the caregiver can intervene during the process of active dying. Both of these are outlined in the following chart.

<table>
<thead>
<tr>
<th>Dying Process</th>
<th>Possible Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition:</td>
<td></td>
</tr>
<tr>
<td>• Decrease in appetite – a person can live for a month or longer when they do not eat but continue to drink</td>
<td></td>
</tr>
<tr>
<td>• Decrease in thirst – a person can only live a few days to a few weeks with little to no hydration</td>
<td></td>
</tr>
<tr>
<td>Nutrition:</td>
<td></td>
</tr>
<tr>
<td>• Do not try to force foods or liquids if the person does not want to eat or drink.</td>
<td></td>
</tr>
<tr>
<td>• Sometimes ice chips can be helpful – may be best palced under the tongue or in the cheek</td>
<td></td>
</tr>
<tr>
<td>• Moisturize the lips</td>
<td></td>
</tr>
<tr>
<td>Energy Level:</td>
<td></td>
</tr>
<tr>
<td>• Increasing lethargy is seen in the 1-2 weeks before death</td>
<td></td>
</tr>
<tr>
<td>Energy Level:</td>
<td></td>
</tr>
<tr>
<td>• Allow the person to stay in bed if that is their desire</td>
<td></td>
</tr>
<tr>
<td>Cardiovascular:</td>
<td>Cardiovascular:</td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>• Heart rate can be very irregular – may decrease or begin to beat very rapidly</td>
<td></td>
</tr>
<tr>
<td>• Blood pressure decreases</td>
<td></td>
</tr>
<tr>
<td>• Person may feel cold but be sweating at the same time</td>
<td></td>
</tr>
<tr>
<td>• Fever is common</td>
<td></td>
</tr>
<tr>
<td>• Skin and nails may become bluish or purplish in color</td>
<td></td>
</tr>
<tr>
<td>• Possible increase in edema</td>
<td></td>
</tr>
<tr>
<td>• Have plenty of blankets available for the person</td>
<td></td>
</tr>
<tr>
<td>• Avoid use of ice packs</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Respiratory:</th>
<th>Respiratory:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Increased congestion in the lungs and may be difficulty breathing sometimes referred to as “death rattle”</td>
<td></td>
</tr>
<tr>
<td>• Increase in carbon dioxide</td>
<td></td>
</tr>
<tr>
<td>• Irregular respirations – can sometimes be quick and sometimes slowed</td>
<td></td>
</tr>
<tr>
<td>• Pneumonia is a common occurrence at end of life</td>
<td></td>
</tr>
<tr>
<td>• May need suctioning but be cautious as this can cause discomfort and also can lead to increased congestion</td>
<td></td>
</tr>
<tr>
<td>• The “death rattle” often distresses caregivers more than the dying individual</td>
<td></td>
</tr>
<tr>
<td>• Low doses of morphine</td>
<td></td>
</tr>
<tr>
<td>• Proper positioning for ease of breathing</td>
<td></td>
</tr>
<tr>
<td>• Light tapping on chest can loosen mucus</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gastrointestinal:</th>
<th>Gastrointestinal:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• May be nauseous</td>
<td></td>
</tr>
<tr>
<td>• Decreased urination</td>
<td></td>
</tr>
<tr>
<td>• Incontinence of bowel and bladder</td>
<td></td>
</tr>
<tr>
<td>• May be constipated</td>
<td></td>
</tr>
<tr>
<td>• Use of anti-emetics</td>
<td></td>
</tr>
<tr>
<td>• Avoid use of catheter as able</td>
<td></td>
</tr>
<tr>
<td>• Use of suppositories for constipation</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Nervous System:</th>
<th>Nervous System:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• May be restless at times</td>
<td></td>
</tr>
<tr>
<td>• Increased periods of sleeping</td>
<td></td>
</tr>
<tr>
<td>• Periods of unresponsiveness</td>
<td></td>
</tr>
<tr>
<td>• An anti-anxiety is often helpful</td>
<td></td>
</tr>
<tr>
<td>• Senses are still present – person can often still hear, so talk to them, touch them</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional and Spiritual:</th>
<th>Emotional and Spiritual:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• May be a “letting go” period</td>
<td></td>
</tr>
</tbody>
</table>
| • Caregivers may need to let the
• May have “visions” or talk to persons not present
• May be a period of increased lucidity

person know it is okay to “let go” – it is okay to say good-bye
• Know that the visions are rarely disturbing but rather comforting
• Might want to play music or read to them
• Do not try to force the person to talk, sit quietly at the bedside

(Barnes, 2006)

Legal and Ethical Issues Surrounding End of Life Care

A large part of the ethics surrounding end of life care revolves around the belief that patients know what is best for themselves, or patient autonomy. This means that sometimes what an individual desires may be in direct conflict with what their family members or their health care team desires. What is the health care worker’s responsibility in this area? Their responsibility lies in making sure the person is fully informed about all aspects of their care so that they can make an informed decision about their medical care. What further complicates the issue of patient autonomy is the deterioration that occurs at end of life which may make the individual unable to communicate their desires. For this reason, some legal avenues have been designed that allow persons to communicate those desires in advance. They are called advance directives. Advance Directives are a way to communicate your wishes about end of life care while you are still capable of making those decisions. They usually can be communicated in three ways which are legally binding.

• Living wills
• Durable power of attorney for health care
• Do not resuscitate order (DNR)
Living wills are a legal document that outlines your desires surrounding medical care. (Savory, 2009) They can be general or very specific. The legal definition for a living will is as follows:

“A Living Will is a document that allows a person to explain in writing which medical treatment he or she does or does not want during a terminal illness. A terminal illness is a fatal illness that leads ultimately to death. A Living Will takes effect only when the patient is incapacitated and can no longer express his or her wishes. The will states which medical treatments may be used and which may not be used to die naturally and without the patient’s life being artificially prolonged by various medical procedures. Although the term Living Will may indicate that it is a Will, in reality, it is more similar to a Power of Attorney than a Will. Therefore, don't be confused by the title of the document. The purpose of a living will is to allow you to make decisions about life support and direct others to implement your desires in that regard.” (UU Legal, Inc., 2009)

Some people are under the misconception that only the elderly need to have a living will, but it is a document that can be established at any time. Additionally, a person does not need to have a lawyer in order to draw up a living will. Different states have varying laws, so it is important to know your state laws concerning any type of advanced directive.

Durable power of attorney for health care involves choosing an individual that will make health care decisions for you in the event that you cannot make them for yourself. This is often a spouse or family member, but this is not imperative. (Savory, 2009) The legal definition for a power of attorney over health care in the U.S is:

“A Health Care Power of Attorney (HCPOA) is a legal document that allows an individual to designate another person to make medical decisions for him or her when he or she cannot make decisions for himself or herself. In other words it names someone who stands in your shoes and tells the doctors what to do or what not do for you. A person need not be terminally ill, elderly, or facing high risk activities to execute a HCPOA. Health care decisions include the power to consent, refuse consent or withdraw consent to any type
of medical care, treatment, service or procedure. A HCPOA is also referred to as health care proxy, medical power of attorney and Durable Power of Attorney for Health Care.” (US Legal, Inc., 2009)

In order for the advance directive to function properly, one would need to discuss your desires concerning medical care with this individual prior to becoming incapacitated.

Finally, do not resuscitate orders are another way of making your wishes known. This is a more complex set of instructions than one would imagine. Many individuals have differing wishes on resuscitation depending on factors such as age, health, and what health care setting they are in. (Savory, 2009) The legal definition for Do Not Resuscitate Orders are:

“A patient with a DNR Comfort Care-Arrest Order (DNR-CC-ARR) will receive all the appropriate medical treatment, including resuscitation, until the patient has a cardiac arrest (heart has stopped beating) or pulmonary arrest (patient has stopped breathing), at which point only comfort care will be provided. Under a DNR Comfort Care Order (DNR-CC), a patient rejects other resuscitative measures, such as drugs to correct abnormal heart rhythms. A DNR-CC order is restricted to providing only comfort care or other requested treatment at a point even before the heart or breathing stops. Comfort care involves keeping the patient comfortable with pain medication and providing bereavement care.” (US Legal, Inc., 2009)

An Act was passed in Congress in 1990, called the Patient Self Determination Act with the intent being to better educate individuals on the role and purpose of advance directives. Unfortunately, there is still much confusion regarding the implications of the 3 advanced
directives named above. Reports show that only 10-30% of people actually put advance directives into place and even less than that have it appropriately documented. For this reason, it is important for the health care provider to help their patients navigate this area of end of life care. (Savory, 2009)

Euthanasia and physician assisted suicide are also hotly debated ethical topics. In the United States, what is sometimes termed “passive euthanasia” is commonly practiced, but “active euthanasia” (assisted suicide) is hotly debated. The terms are legally defined as follows:

“Euthanasia is the act of mercifully and painlessly ending a person or animal’s life. It may involve withdrawal of life support systems or extraordinary medical care, rather than an affirmative action. In the U.S., committing suicide or attempting to commit suicide is no longer a criminal offense. However, helping another person commit suicide is almost always a criminal act. Living wills and Do Not Resuscitate orders are legal instruments that make a patient's treatment decisions known ahead of time; allowing a patient to die based on such decisions is never considered euthanasia.” (US Legal, Inc., 2009)

“Physician assisted suicide is the voluntary termination of one’s own life by taking lethal medication with the direct or indirect assistance of a physician. Physician-assisted suicide is also referred to as active euthanasia. It differs from withholding or discontinuing medical treatment in circumstances that will result in death. Withholding or discontinuing medical treatment is sometimes called passive euthanasia. Passive euthanasia is generally accepted, although not without controversy, in the United States as an individual's right to refuse medical treatment.” (US Legal, Inc., 2009)

Most of us became aware of these issues in the 1990’s with the well-publicized practices of Dr. Jack Kevorkian who engaged in physician assisted suicides. Currently in the United States,
there are only two states where physician assisted suicide is legal and those are in the states of Oregon and most recently, Washington (law went into effect March 2009).

Another ethical issue surrounding end of life care is the amount of resources that should be spent in order to sustain or prolong life. The utilization of resources when the outcome is predictably poor, may be ill advised. On the other hand, withholding life sustaining treatments when a person has what is defined as a “terminal illness”, must also be measured in terms of quality and length of remaining life, ie; we cannot uniformly take a passive approach to care. (Savory, 2009)

Summary

In summary, because death is something that we all must face, providing supportive care at the end of life is an issue that should be of interest to all. It is of particular interest to the elderly population and for this reason the American Geriatrics Society has issued a position paper that addresses patient care, health care delivery, as well as education and research of how we provide care to the dying individual. We will finish this course on end of life care with those positions and rationale which summarize many of the ideas presented in this course:

2007 Position Paper of American Geriatrics Society

“Patient Care Issues
**Position 1**
The care of the dying patient, like all medical care, should be guided by the values and preferences of the individual patient. Independence and dignity are central issues for many dying patients, particularly in the elderly. Maintaining control and not being a burden can also be relevant concerns.

**Rationale**
Optimal medical care of all patients, not just those who are dying, rests on frank and sensitive communication between patients and physicians. For dying patients, this ordinarily entails recognition and discussion of the facts surrounding prognosis and the likely course with a palliative plan of care. The conversations throughout must continue to elicit and respond to the patient's needs. Physicians sometimes face the challenge of being asked to respect patients choices which may maximize the quality of life and independence at the expense of optimal safety. This tension requires particular thoughtfulness and sensitivity to each patient's needs and values. When the patient loses decision-making capacity, care should be guided by previous conversations as well as by written advance directives, if available. Decisions made by surrogates should be guided by the patient's known and previously expressed wishes.

**Position 2**
Palliative care of dying patients is an interdisciplinary undertaking that attends to the needs of both patient and family.

**Rationale**
In caring for dying patients, physicians must themselves develop a broad array of knowledge and skills and an attentiveness to comprehensive care. In addition, whether or not the patient is enrolled in a formal hospice program, physicians most often should function as members of a team. The team may include nurses, social workers, home health aides, physical therapists, personal caregivers, chaplains, volunteers, and the patient's family. Each team member contributes the special knowledge and skills of his or her discipline to help meet the needs of dying patients. Together, team members provide care for the patient and assist the family in coping with the patient's dying and death. Family members (with "family" defined by the individual patient) usually play a critical role in both providing care for dying patients and in making decisions for dying patients who have lost decision-making capacity. Providing support for the patient's family,
including a period after the patient dies, is an important aspect of the care of dying patients.

**Position 3**
Care for dying patients should focus on the relief of symptoms, not limited to pain, and should use both pharmacologic and non-pharmacologic means.

**Rationale**
Pain, anxiety, depression, dyspnea, constipation, and other symptoms can all be significantly ameliorated, if not eliminated, in the vast majority of dying patients. Symptoms should be treated as vigorously as is appropriate to the patient's situation and preferences to maximize comfort, even if the unintended effect of these efforts is, on rare occasions, the hastening of death.

**HEALTH CARE DELIVERY ISSUES**

**Position 4**
Dying patients should be guaranteed palliative care as part of any health care coverage, without care being conditioned on the financial status of the patient. Reimbursement and administrative arrangements should encourage continuity across sites and time, so that commitments to patients can be honored regardless of point of care.

**Rationale**
Palliative care is often provided most appropriately in the patient's own home, a setting where reimbursement is inadequate under many existing insurance plans. Dying patients should be able to receive palliative care in the home, the hospital, and the nursing home, depending on the needs and preferences of the patient, without a disruption in the continuity of the patient's care. Patients and families are presently faced with major financial obstacles to choosing palliative care, while payment for continued highly technological, acute care (e.g., dialysis, ventilator care, etc.) is readily available. Physician reimbursement should also be modified to promote palliative care. Like other forms of primary care, palliative care is time-consuming, does not involve highly reimbursed procedures, and requires substantial counseling of patients and families.

**Position 5**
Administrative, regulatory, and reimbursement structures often serve as barriers to palliative care and should be reshaped.
Rationale
Current arrangements for care make it difficult to provide symptom management, continuity, or advance planning. Indeed, current reimbursement structures make it financially problematic to gain a reputation for excellent care of the very sick, except perhaps in hospice. Conventional fee-for-service payments make sustaining team care over time very difficult, and managed care in Medicare pays no more for very sick persons than for healthy ones. Requirements regarding availability of family and a home for care giving regularly prevent some patients from receiving palliative care through hospices. Uncertain or unavailable estimates of prognosis also may serve inappropriately to exclude patients from hospice care. Many laws and regulations made for other purposes end up making good palliative care difficult. For example, regulations intended to promote adequate nutrition for nursing home residents can cause great hardship for dying nursing home residents. Laws intended to make it more difficult to divert narcotics into abuse can also make it very difficult to ensure adequate supplies for persons who need pain relief. Laws and regulations like these should be rewritten or revised. In addition, laws and regulations could place responsibility for good service upon specified service providers. At present, most shortcomings in care are unnoticed and never addressed. Care systems should be judged on the basis of performance with regard to issues like pain management, advance planning, and continuity. This information should be available to patients and families as well as professionals, and it may well be appropriate to mandate data collection and suitable corrective action for the shortcomings that are identified.

EDUCATION ISSUES

Position 6
Physicians and other health care professionals, at all levels of training should receive in-depth, insightful, and culturally sensitive instruction in the optimal care of dying patients.

Rationale
More attention has been paid in recent years to improving education in the care of dying patients. This instruction can still be expanded and targeted to reach a broader audience. Health care professionals, in training and in practice, need adequate knowledge of symptom management (especially pain control and adequate use of opioid
analgesics), ethical issues relevant for end-of-life care, and use of multi-disciplinary teams. They ought to have adequate training in communication skills necessary for delivering bad news, discussing advance directives, and exploring patient wishes and goals. They should know their own attitudes towards and reactions to death and care of the dying, and have a personal process for grief over the loss of patients cared for. Instruction in the physician's role during the dying process and in guiding the family through bereavement are necessary. The importance of knowledge about the care of dying patients should be reinforced by evaluating it on board exams and other specialty certification exams.

Position 7
The public, including our patients and our colleagues, needs to be educated regarding the availability of palliative care as an important and desirable option for dying patients. The AGS (American Geriatrics Society) should be active in this education.

Rationale
It is the position of AGS that this kind of educational effort would benefit many by dispelling the notion that the only options available to dying patients are continued futile therapy in a medical setting or turning to assisted suicide or euthanasia (see related position paper).

RESEARCH ISSUES

Position 8
Adequate funding for research on the optimal care of dying patients is essential to improving end of life care.

Rationale
Much of the information base needed to inform patients and physicians regarding optimal care of dying patients does not yet exist. Studies documenting the outcomes of various models of care delivery, medications, and treatment settings, focused on the experience of the dying patient and significant others, should take place. Although traditional biomedical research on symptom relief is needed, much of what is already known about symptom relief is not implemented effectively because of professional ethical concerns about aggressive symptom management and institutional barriers to the provision of palliative care. Research to identify these barriers and to evaluate educational approaches and interventions to promote palliative care, is needed.” (American Geriatrics Society, 2007)
Resources:


Barnes, Irene. End of Life Care for Residents with Dementia. Canadian Nursing Home – Volume 16, Number 1. (March/April, 2006).


