End-of-Life Care

“We understand who we are-
We know where we came from-
We accept and understand our destiny
Here on Mother Earth-
We are spirit having a human experience”

Dianne M. Longboat*
(see complete citation at end of article)

Approaching one’s death remains one of the greatest emotional challenges for human beings. The Sioux people attempted to lighten the emotional burden of death by their daily greeting to one another: “Let this be a good day to die.” The implication is that if one lives everyday to its full and embraces the enjoyment of living, death becomes less of a terrifying experience.

In modern Western Culture the focus is different. The focus is on an internal locus of control where the individual is provided with all information and expected to be an active, and equal, partner in decision making. This concrete approach tends to move Westerners to a cure-orientated approach to the end of life as is stressed in the biomedical model of medicine. However, this approach often fails to accept the notion that just as there is a time for living, there is also a time for dying. This failure often creates major stresses in end-of-life care for both the patient and the health care professional.

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“The test of a people is how it behaves toward the old. It is easy to love children. Even tyrants and dictators make a point of being fond of children. But affection and care for the old, the uncurable, the helpless are the true gold mines of a culture.”

- Abraham Joshua Heschel, *The Insecurity of Freedom*

In the year when Bill Clinton and I, together with the first wave Baby Boomers, reach our sixtieth year and take our first tentative steps towards our golden years, I see all around me the ugly specter of ageism. Congress defunded the Geriatric Education Centers and cut the reimbursement for Medicare. Medicare Part D arrived as an uncertain blessing for aging Americans. Everywhere I look I hear the demographic imperative of the age wave mentioned but then ignored. In academic medical centers I see little movement towards increasing the teaching of geriatrics as the struggle continues to fill the curriculum with esoteric high technology and new pharmaceuticals of uncertain benefit. While everywhere the angels sing of the need to concentrate on the future care of our aging population, I fail to see a hardening of the public to the message. Even the Baby Boomers seem more inclined to look to maintaining their immortality rather than to providing an infrastructure which will allow them to maintain their function late into the twilight years. While none of us can write our true autobiography until we die, it seems to me that we are writing a future biography where disaster awaits us at the end of our journey of life.

So what needs to be done to improve the situation? In the United States, the flow of the mighty dollar often appears to be the only way to change the situation. For this reason, I recommend that in 2007 Congress gives up its ageist attitudes and passes the following legislation:

1. Increase the Medicare rate by 20% for those persons with geriatric certification. Because of the small number of certified geriatricians and geropsychiatrists, this will have little effect on the national budget but will increase the enthusiasm for young physicians to go into geriatrics.

2. Provide medical schools 50% of the salary of geriatricians on faculty to allow increased time for teaching.

3. Re-fund the Geriatric Education Centers at double their previous level. These centers have played the leading role in educating health care providers in the community and this remains a vital need for the foreseeable future given the low number of geriatricians now practicing medicine.

4. Increase funding for the National Institute on Aging.

5. Continue to move rapidly towards a universal computerized medical record as so ably championed by the Secretary of the US Department of Health and Human Services, Mike Leavitt.

You may legitimately ask me what I’ve been smoking or have I just developed premature mild cognitive impairment. However I strongly believe that it is time that America’s aging population begins to advocate for its own future by inundating Congress with letters, e-mails and phone calls (contact information can be found [http://www.senate.gov](http://www.senate.gov) and at [http://www.house.gov](http://www.house.gov)). Only in this way will our aging years be better than it was for who went before us.

As Rabbi Heschel said “Man lives in a spiritual order. Moments of insight, moments of decision, moments of prayer, may be insignificant in the world of space, yet they put life into focus.” It is time for decision and prayer, coupled with action, to reverse the ageist tendencies we are currently experiencing in our society.
Palliative Care
The Saint Louis University Experience

By Nabil S Kamel, MD, Oscar Cepeda, MD, Maria Renna, MD, Rafi T. Kevorkian, MD, and Joseph H. Flaherty, MD

For the last year and a half, Saint Louis University’s Geriatric team has run a Palliative Care Consult Service. As documented in the Fall 2004 Aging Successfully, Saint Louis University has been shown to have some of the best palliative care outcomes in the United States.

Ever increasing numbers of patients with advanced illnesses are challenging the health care system with increased demands for optimal medical care. Armed with medical information they or their family members have garnered from the Internet, these patients are well-informed about their illnesses and the range of treatment options available to them. Today’s patients have a more sophisticated understanding of diseases and they have higher expectations for pain and symptom management than did previous patients. It is with these growing patient demands that palliative care has started to flourish.

Palliative care is an interdisciplinary approach to medical care that focuses on patient-defined goals of care and works to relieve distress experienced by the patient and family. It also extends into the bereavement period that follows the patient’s death. The goal of palliative care is to relieve suffering and to promote the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Such care requires a unique approach that differs from the standard medical model of care. Palliative care assessment includes not only all the standard elements of a comprehensive medical history and physical examination, but also extends into domains far beyond the traditional medical approach.

The word palliative comes from the Latin word, “palliare” which means “to cloak or to cover.” So in the broadest sense, palliative care must cover all aspects of a person’s life and death.

Predictable palliative care issues can be remembered by the mnemonic “PAINS WISDOM.”

Palliative care also focuses on closure for the patient and the family near the end of life. Even experienced physicians often struggle when initiating complex, emotionally laden discussions about palliative care with seriously ill patients and their families. Oftentimes, it is the physician who must ask the most difficult questions, such as, “How long do you think you have to live?” or “Are you ready to die?” (continued on page 4)
Palliative Care

(continued from page 3)

1. Active palliation: Active and aggressive treatments which are directed towards symptom relief and may also prolong life (e.g., hormonal therapy, chemotherapy, aggressive antibiotic therapy, radiation therapy, and steroids);  

2. Comfort palliation: Noninvasive interventions such as drug therapies and other measures to relieve symptoms instead of modifying the disease (e.g., opioids, anxiolytics, antidepressants, steroids, NSAIDS, short term psychotherapy, grief counseling, and spiritual support); and  

3. Urgent Palliation: Treatments that are given when symptoms occur abruptly, when patients experience moderate to severe symptoms, or when sudden complications arise, in order that the patient does not have to endure uncontrolled symptoms for any significant time or die with uncontrolled pain.

Palliative care is often provided to patients whose disease no longer responds to curative treatment. This model is well-defined for patients dying with metastatic cancer. However, the majority of patients die of chronic diseases in which the prognosis is often uncertain, functional decline is nonlinear, and life-prolonging therapies coexist with, or are identical to, therapies directed at palliation and comfort.

Palliative care may be delivered in a variety of settings, including a hospital, nursing facility, or private home. The level of care required, the patient’s wishes and the level of commitment by the family will often dictate the choice of setting. However, the success of palliative care depends as much on the attitude of the clinician as on the setting.

Because so many people choose to die in the hospital, there is a strong need for hospital-based palliative care programs. Despite this increasing recognition for the need for palliative care, about three-fourths of hospitals lack such a program. As a result, the dying process is usually unsatisfactory and inadequate in acute hospitals. Improving end-of-life care requires both providing palliative care services to the patients and family and teaching the health care personnel how to best provide palliative care.

For the past year and a half, the Geriatrics Division of Internal Medicine has been running a palliative care consult service at the Saint Louis University Hospital. Upon review of the first five months of palliative care consults, it was discovered that 81% of the patients receiving palliative care consults had a non-cancer terminal illness, such as multi-organ failure and sepsis, stroke, or end-stage cardiac disease. Half of the consults were from the intensive care unit. Also, over half of the patients were discharged from the hospital to either their homes or to nursing facilities.

The three most common themes of palliative care concerns by patients and families in these consults were:

1. Fear that pain/comfort will not be adequately addressed when the patient is transitioned to comfort measures only (or therapeutic support level III status).  
2. Fear that patients will suffer when nutrition and/or hydration are withheld at the end of life.  
3. Belief that withholding further aggressive intervention/withdrawing support leads directly to death, rather than allowing natural progression of illness to death.

Saint Louis University Hospital is working to improve the level of understanding of what palliative care is and when it should be offered to patients in the hospital. The goal of the Geriatrics Palliative Care Consult Service is to offer families and patients a positive palliative-care experience that will allow the patient excellent pain and symptom management as well as compassionate and competent medical care.

REFERENCES


AAHPM. Pocket guide to hospice/palliative care medicine 2003.
Call to Action as Congress Eliminates Geriatric Training

On December 14, 2005, delegates to the White House Conference on Aging adopted 10 policy recommendations, including two that called for more training for health professionals who care for the elderly. Those two recommendations were:

- Support geriatric education and training for all healthcare professionals, paraprofessionals, health profession students, and direct care workers.
- Attain adequate numbers of healthcare personnel in all professions who are skilled, culturally competent and specialize in geriatrics.

Three days later, on December 17, Congress passed the Labor, Health and Human Services, and Education spending bill for 2006 which eliminated funding for the three federal programs that support training of healthcare personnel who treat older patients.

One program supported 60 medical school fellowships to train physicians, dentists and mental health professionals in geriatrics; another supported teaching opportunities for 103 geriatricians who are junior faculty members at medical schools; and the third program supported the infrastructure of 50 Geriatric Education Centers across the country that trained healthcare personnel from over 20 professions to care for elderly patients.

This elimination of the programs to train gerontologists and geriatricians is counterintuitive. For example, only 1% of the currently-practicing 650,000 physicians in the United States are geriatricians who specialize in treating the medical needs of the 12% of the nation’s population (36.3 million people) that is over the age of 65. That number does not include any of the 78 million Baby Boomers, all of whom will be 65 or older as of 2030. The Alliance for Aging Research estimates the United States will need 36,000 geriatricians by 2030. The 60 geriatric fellowships and the 103 geriatric faculty academic career awards that have now been eliminated were on track to help 11,000 doctors earn certification in geriatrics by 2030. The Geriatric Education Centers were training physicians as well as providers in many other healthcare professions, such as nursing, therapy, case management, and social work, in order to provide coverage for the increasing geriatric patient loads that are occurring for those professions as well.

Now, in one quick vote, Congress has eliminated the safety net that ensured that the frailest of our elders would receive the quality healthcare they deserve. The lost federal dollars mean inferior medical care for some of our country’s most vulnerable populations. The National Association for Geriatric Education will lead the charge to convince Congress to reinstate funding for geriatric education. Please consider joining in that fight. Our nation’s elders deserve no less.
On the other hand in non-Western cultures the focus is on interdependence and acceptance of the group’s needs and a belief in traditional ways. This often makes the dying process easier. However, cultural conflict arises when a Western physician insists on directly communicating with the dying person from a non-Western culture, rather than with the hierarchically appropriate person who should serve as the decision maker. Thus, in dealing with the end-of-life care, the health care professional needs to understand the cultural beliefs of the dying person and work within this context to help that person to a good death.

A History of End-of-Life Care

From the beginning of time people have developed rituals and sacred spaces to allow for the care of the sick and dying in order to facilitate their journey beyond this life. The concept of a place to care for persons at the end of life was first established during the time of the Byzantine Empire (the era following the Roman Empire and one driven by the ethics of Christian belief). The first of these infirmaries for care of the dying was established in Constantinople (modern Istanbul) by Saint Helen, the mother of the first Byzantine Emperor, Constantine the Great. These institutions were called genocomeia from the Greek words genos meaning old age and comein which is care. During the Middle Ages hospices proliferated as places that provided hospitality for pilgrims as well as care for the destitute and the dying. During the 19th century, a “Calvaire” was opened by Madame Garnier in Lyon, France to care for the dying, and the Irish Sisters of Charity started a hospice in Dublin. In 1905, the Irish Sisters of Charity also opened St. Joseph’s Hospice in London.

The Armatius Nursing Home in Constantinople (miniature from the Code Vaticanus Grecus, 1613).

The founder of the first nursing home in Constantinople, Saint Helen, with her son, Constantine the Great.

What is Palliative Care?
Palliative care is an approach that improves quality of life for anyone dealing with a serious illness. It not only provides appropriate care for the patient, but also support for the families.

What is Hospice Care?
Hospice care is a form of palliative care, specifically for individuals with a life expectancy of six months or less (as determined by their physicians), whose goals for care focus on palliation (comfort measures) rather than cure of the underlying disease.

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SLU Researchers Develop Drug for Alzheimer’s Disease

SLU researchers have continued their research into an antisense for amyloid precursor proteins. Antisense drugs block the ability of messenger RNA to be translated into the protein. In the SAMP8 mouse, a spontaneous model of Alzheimer’s disease, and in transgenic mice that overproduce the human beta amyloid, the antisense has been shown to reverse memory and learning deficits. The antisense also reverses the overproduction of free radical damaged proteins in the brain of the SAMP8 mouse and has been shown to cross the blood brain barrier. Recently it has been shown to be deliverable through the intraneural route. The antisense returns the slowed transport of beta-amyloid from the brain to the periphery. Overall these animal studies suggest that antisense is an excellent target drug for examining its potential for treating humans suffering from Alzheimer’s Disease. Saint Louis University has licensed the technology to Idunn Biotechnical Company for development in humans. Idunn was the Norse goddess who handed out apples to the gods to allow them to maintain their youth.

The Physiological Role of Beta-Amyloid

John Morley, MB, BCh, and his colleagues Susan Farr, PhD, and William Banks, MD, presented evidence at the Neuroscience Meeting in Washington, D.C., in November, 2005, that the physiological role of beta-amyloid is to act as a memory enhancing neurotransmitter. First, they showed that blocking access to the beta-amyloid receptors with the short peptide DFFVG (Asp-Phe-Phe-Val-Gly), inhibiting the effect of beta-amyloid with an antibody or lowering beta-amyloid production with an antisense to amyloid beta precursor protein (APP), all inhibited memory in young mice. They then showed that very low doses of beta-amyloid enhanced memory when injected into the brain. Scientists the world wide have been curious about the physiological role of beta-amyloid and questioned why the brain would make a substance toxic to its functions. These studies have clearly elucidated for the first time the physiological role of beta-amyloid.
Nursing home residents are vulnerable. We learned that lesson well in the hurricane season of 2005. An unofficial estimate is that 10% of the 1,322 people whose deaths have been attributed to Hurricane Katrina were nursing home patients. Although many of those residents who remained in their facilities initially survived the storm, some did not survive the aftermath. The heat and the lack of food, water, and proper medical care that followed were too much for them. Ironically, the lessons learned with Hurricane Katrina about how dangerous it is to protect patients in place were used in Hurricane Rita in Texas, with disastrous, and very public, results. Pictures of the infamous bus fire that killed 24 persons being evacuated from a nursing home will haunt us for years. More nursing home residents died during the evacuation ahead of Hurricane Rita than died in nursing homes in Texas during the hurricane. When Hurricane Wilma pounded Florida, the majority of victims were still elderly but this time, most of them were living in mobile home parks, not in nursing homes. What did Florida do differently to protect their nursing home residents? What went wrong in Texas, Louisiana, and Mississippi?

Lesson #1: Experience is the best teacher. Because Florida typically has two or three hurricanes annually, Florida takes emergency preparedness seriously. People there have worked hard to make sure that all nursing homes have multiple generators and sufficient gas to run them, food stuffs that do not require refrigeration or cooking, alternate locations of evacuation sites, multiple community partners to assist them in either an evacuation or at the residence, good communication to allow family members to find loved ones during and after the crisis, and room for the families of workers to stay on site during the crisis.

Lesson #2: Sometimes one cannot win, no matter what one does. For Hurricane Katrina, it would have been best to evacuate everyone. With Hurricane Rita, evacuation caused more deaths than protecting patients in place. All nursing homes, regardless of which state they are in, have emergency evacuation plans and all have plans that allow them to protect patients in place. Nursing home administrators are trained to make decisions about who can survive the rigors of evacuation and who cannot. They also make decisions about how many personnel to leave behind to care for those who are not evacuated and how many to send with those who are. These decisions are made in consultation with nursing staff, patients, family members, government employees, and public health officials. Some, as in the very public case of St. # continued on page 9
Rita’s in New Orleans, are made in consultation with a Higher Power. In Louisiana, Mississippi and Texas, although these methods all resulted in saving many lives, they also resulted in the loss of other lives. No solution is perfect all the time.

**Lesson # 3:** We need to increase education to the general public about emergency preparedness for the elderly. The more people you have who are aware of potential problems, the more people you have who can help solve those problems. Many elders can help others, as well as themselves, in an emergency; many need help. Those who need help are a diverse group with diverse problems. A well-educated workforce can offer appropriate assistance in a timely manner.

**Lesson # 4:** There is a need for special education about the physical and mental health needs of elders under stress, including, but not limited to:
- Dehydration
- Nutrition
- Frailty
- Gait and balance
- Sensory changes
- Chronic conditions
- Medications/vaccinations
- Incontinence
- Skin breakdown
- Hypothermia/hyperthermia

**Lesson # 5:** There is a need to educate healthcare and emergency workers about special communication strategies needed to communicate with elders during emergencies. Such communication should include methods to assist people with any or all of the following impairments:
- Vision
- Hearing
- Language/literacy
- Fear of authorities
- Level of cognition
- Physical limitations
- Fear of cost of evacuation/assistance

**Lesson # 6:** Transportation of elders away from emergency zones is complicated. Several important concerns include the answers to the following questions:
- Where do we evacuate to and what happens if that site is no longer safe?
- When do we evacuate?
- Who runs the evacuation?
- How can we safely evacuate patients who are bedridden or who need oxygen or a feeding tube?

**Lesson # 7:** There are currently public policy gaps in making coordinated preparedness training mandatory for (continued on page 10)
agencies that deal with frail elderly. Many questions remain unanswered and many opportunities remain unmet. For example, what role should fire and police have in planning for the evacuation of a nursing home; what priority do individuals in assisted living facilities have in receiving limited transportation away from an emergency site; what responsibilities do visiting nurses have towards home-bound elders in an emergency; and should we develop and use tracking systems that allow the authorities to know where an elder is before, during and after an emergency?

Lesson #8: A resource/training center is needed to coordinate training and certification of professionals in geriatric emergency preparedness. This Center would need to develop minimum standards of training, establish reasonable expectations for families about the care of a loved one, help determine the role of family members in emergencies, and work to develop policies that will minimize sensationalism and the individual profit that often comes with disasters. Public good is seldom served when individuals profit from honest mistakes made during a disaster. Good Samaritan rules do not commonly apply to those who help disaster victims who are being removed from the site of a disaster. In the case of elders, removing them from disaster sites is clearly better than leaving them there unattended but if this is at the expense of the rescuers, where is the greater good in this?

Lesson #9: There is a need to develop core competencies in geriatric emergency preparedness. The role of such competencies is to provide a measure against which training can be judged. Competencies identify key issues, set standards for training, and make evaluation possible. With evaluation comes the ability to determine which teaching strategies work and whether learning has taken place. Answers to the following questions can be determined when testing core competencies.

- Are lives being saved as a result of this training?
- Is the training making a difference in efficiency or efficacy of care?
- How can training be improved?

Lesson #10: Emergency Preparedness for the Aging training must be regulated. In order to be evaluated properly, training must be standardized by someone. Once the training is standardized, it must be provided. Education is not cheap. Someone must pay for it. Therefore, questions such as who will pay for this training and who will certify the training must be asked in order to ensure that training in emergency preparedness for the aging will make a difference in the lives of our elders.

It is our belief that, as Louis Pasteur once noted, “Chance favors the prepared mind.” Disasters are not predictable, but by being prepared we can hope to minimize the damage and survive the crisis. If this essay has encouraged you to become more educated about emergency preparedness, please let us know how we can help you attain that goal.
HEALTH CARE HERO

John E. Morley was nominated as a Health Care Hero by the St. Louis Business Journal in November 2005 in response to his work with Hurricane Katrina evacuees. Dr. Morley oversaw the development of a program in which the faculty in Geriatrics interviewed and examined 250 evacuees and provided them with medications and follow-up care. Despite the fact that the oldest person was only 59, the team’s expertise in geriatrics offered a good fit for the evacuees’ needs. “Geriatricians spend more time talking to people. We try to find out if they are depressed, then try to make them comfortable and feel that they are part of the process,” Morley says about his regular patients. This approach also works well for people who are displaced. The geriatricians took all of their special skills they normally use in treating frail and often demented elderly patients and applied them to confused and anxious evacuees. When people leave their homes in a hurry or are caught up in a disaster like Hurricane Katrina, they are in shock. Many have health problems such as diabetes or hypertension and many of them leave their medications behind. Special skills are needed to help displaced people remember what their medications are, as well as the dosages they had been taking.

In addition to volunteers from the Division of Geriatrics, Morley credits the NHC nursing home and Interlock Pharmacy with providing free medications for newly discovered medical conditions, as well as with also filling prescriptions for critically needed medications over the weekend – something that the Federal Emergency Management Agency (FEMA) has not yet determined how to do for victims of a disaster.

According to Dr. Morley, “The saddest part of it was that the people who evacuated ahead of time were the working poor. They kept being moved further north, and by the time they got to St. Louis they were out of money, out of everything. It was an extraordinary loss in their life.”
End-of-Life Care: Moving Toward the Medical Model

Management of End-of-Life Care

**Non-Pharmacological**

- **Fatigue**

- **Depression**
  - Provide psychological support and regular visitors/outings.
  - Trazodone if associated with poor sleep. Mirtazapine if associated with anorexia. Desipramine/Nortriptyline. Selective Serotonin Reuptake Inhibitors (SSRIs).

- **Anorexia/Cachexia**
  - Provide emotional support. Encourage small, frequent meals with calorie supplements between meals. Consider multivitamin. Consider glass of wine/beer.

- **Constipation**
  - Megestrol acetate (if anorexic use new formulation to enhance absorption). Dronabinol (causes munchies, use only when weight gain is not a major concern). Testosterone (effectiveness uncertain).

**Pharmacological**

- **Fatigue**
  - Treat depression. If anemic, use Erythropoietin or Darbopoietin X. Testosterone. Dexamethosone (4-6 week benefit). Methylphenidate.

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**Diagnosis**

- **Fatigue**
  - Consider drugs as cause. Increase fluid intake. Exclude fecal impaction. Toilet after meals with gastro-colic reflex.

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**Care**

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**End-of-Life Care**

- Physician: “I can’t cure you. You don’t need to see me anymore.”

Treat depression. If anemic, use Erythropoietin or Darbopoietin X. Testosterone. Dexamethosone (4-6 week benefit). Methylphenidate.

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Use mainly osmotic laxatives: Sorbitol, Lactulose, Polyethylene glycol.

Check to make sure it is not due to osmotic laxative. Rehydrate.

Use Kaopectate, Loperamide, Prostaglandin inhibitors, or Octreotide (somatostatin analog).
# End-of-Life Symptoms

## Non-Pharmacological

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<th>NAUSEA/ VOMITING</th>
<th>Pharmacological</th>
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<th>INSOMNIA</th>
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<th>ANXIETY</th>
<th>Pharmacological</th>
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<tr>
<td>Try supportive therapy and/or relaxation therapy. Consider various causes such as pulmonary embolus or myocardial infarction.</td>
<td>Lorazepam, Buspirone, Trazodone.</td>
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<th>PAIN</th>
<th>Pharmacological</th>
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<tr>
<td>Use WHO Analgesic Ladder. Try acetaminophen, NSAIDS, weak opioids, strong opioids, adjuvant drugs, e.g., Neurontin®, Gabapentin. All drugs scheduled by the clock and use PRNs for breakthrough pain. DO NOT USE MEPERIDINE due to seizure potential.</td>
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<th>GENERAL END-OF-LIFE ISSUES</th>
<th>Pharmacological</th>
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<td>Provide psychological support, help with social issues, and spiritual support. Limit loneliness. Increase activities within patient’s limitations. Keep out of bed.</td>
<td>Treat depression and anxiety. Consider dronabinol for general end-of-life care (enhances food intake and sleep, decreases nausea and pain, and improves general well-being). Use low doses and introduce first dose at bedtime to limit delirium.</td>
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In 1948, while working as a nurse and social worker, the founder of the modern hospice movement, Cicely Saunders, cared for David Tasma, a Pole who had escaped from the Warsaw ghetto and was dying of cancer. This taught her that end-of-life care was extremely inadequate. After graduating from medical school, she founded St. Christopher’s Hospice in London in 1967 – a place which would help the dying to live and die and their families to live on. Dame Cicely Saunders’ philosophy and timeless evangelism led to the creation of the medical specialty of palliative care and her vision has resulted in alleviating suffering and making death a more humane process for millions of persons throughout the world. In 1965, the Dean of the Yale School of Nursing invited Dame Saunders to visit and this eventually led to the establishment of America’s first hospice, The Connecticut Hospice, in New Haven, Connecticut, founded by Florence Wald. Last summer, Dame Cicely Saunders died at age 87 of cancer at St. Christopher’s Hospice, the hospice that she had created in London.

In 1969, Dr. Elisabeth Kubler-Ross published her book “On Death and Dying” which identified five stages of dying and made a plea for allowing patients to die at home. In 1972, during her testimony to the U.S. Senate Special Committee on Aging she stated, “We live in a very particular death-denying society. We isolate both the dying and the old.” This led eventually, after the National Cancer Institute and the Health Care Financing Administration had funded several hospice demonstration projects, to the establishment of the Medicare Hospice Benefit by Congress in 1982. In 1991, The Commission on the Future Structure of Veterans Health Care recommended the inclusion of hospice care as part of the veterans benefit package. Between 1984 and 1993, the number of hospices funded by Medicare increased from 31 to 1,288. Studies by the United States government have demonstrated that hospice care is cost effective. While hospice care has classically focused on care in the last six months of life, it has recently been recognized that quality of life for many patients with chronic diseases can be improved during their final two years of life if they are treated using the principles underlying palliative care. In addition to providing emotional and spiritual support, end-of-life care (be it palliative or hospice care) recognizes the importance of a team-oriented approach to pain and other psychological and physical symptoms management. Support is also provided to the patient’s family and continues beyond death throughout the bereavement process.

Understanding the Principles of End-of-Life Care

The first principle of end-of-life care is that appropriate disease-focused care (which may be life-prolonging) should continue throughout the process. Decisions to continue or discontinue certain treatments often need to be individualized based on considering the benefits and burdens of therapy. Treatment is...
only withdrawn when it is futile – a simple, but not always obvious example, is that lipid lowering therapy has little utility but can do harm in a person at the end stage of cancer or Alzheimer’s Disease. Furthermore, cost should never be an issue and pursuing a potentially curable diagnosis is always appropriate.

Singer and colleagues (JAMA 281:163, 1999) identified five components of quality end-of-life care based on the patient’s perspective:

◆ Adequate control of pain and other symptoms
◆ Avoidance of inappropriate prolongation of the dying process
◆ Maintenance of a sense of control
◆ Minimizing the burden associated with dying
◆ Strengthening of relationships with loved ones.

The overwhelming challenge to end-of-life care is that the process and the outcome are inherently bad. As appropriately phrased by Mike Harlos, Medical Director of the Palliative Care Sub Program of the University of Manitoba, “How can you tell when something inherently horrible goes badly?”

Cicely Saunders formulated the concept of “total pain,” which recognizes that end-of-life care must address not only physical symptoms but social, psychological, and spiritual issues as well. The process of dealing with the end stage of an illness and dying has a tremendous impact on those close to the individual, the so-called “collateral suffering.” This is why end-of-life care requires as much focus on the family as on the individual.

Care of patients nearing the end of life is moving away from a medical model with a prolonged period of aggressive medical management with patients being reassured that the side effects are essential to care followed by a few days of comfort-focused care. It is moving towards a more complex model where medical management equates to unavoidable suffering. They also must be provided with education about their disease processes and choices when this is culturally appropriate. Throughout the end-of-life care process, invasive investigations (even as minor as blood or urine testing) should be kept to a minimum and used only when the result would alter management. During the dying process, a diagnosis is not needed for the management of symptoms – whenever possible, treat the symptom, not the cause.

Fatigue is the major symptom experienced by patients with advanced cancer and other end-of-life conditions. Depression and anxiety are often associated with fatigue, as are two other major symptoms, anorexia/cachexia (wasting) and pain. An appreciation of how distressing the symptom is that drives management and 2) that help for symptom relief needs to be available around the clock. While fatigue and psychosocial factors may worsen symptoms, that does not allow the health care professional to ignore symptoms. Patients need to be taught that dying does not equate to unavoidable suffering.

The Five Stages of Dying

| Denial and isolation: “This is not happening to me.” |
| Anger: “How dare God do this to me.” |
| Bargaining: “Just let me live to see my son graduate.” |
| Depression: “I can’t bear to face going through this, putting my family through this.” |
| Acceptance: “I’m ready. I don’t want to struggle anymore.” |

The keys to appropriate symptom management are: 1) that the health care professional needs to recognize that it is the patient’s perception of how distressing the symptom is that drives management and 2) that help for symptom relief needs to be available around the clock.

Symptom Management

The keys to appropriate symptom management are: 1) that the health care professional needs to

Questions? FAX: (314) 771-8575 • email: aging@slu.edu •
The Edmonton Symptom Assessment System

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Scale</th>
<th>Worst Possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td>0-10</td>
<td>Pain</td>
</tr>
<tr>
<td>Not tired</td>
<td>0-10</td>
<td>Tiredness</td>
</tr>
<tr>
<td>Not nauseated</td>
<td>0-10</td>
<td>Nausea</td>
</tr>
<tr>
<td>Not depressed</td>
<td>0-10</td>
<td>Depression</td>
</tr>
<tr>
<td>Not anxious</td>
<td>0-10</td>
<td>Anxiety</td>
</tr>
<tr>
<td>Not drowsy</td>
<td>0-10</td>
<td>Drowsiness</td>
</tr>
<tr>
<td>Best appetite</td>
<td>0-10</td>
<td>Appetite</td>
</tr>
<tr>
<td>Best feeling of wellbeing</td>
<td>0-10</td>
<td>Wellbeing</td>
</tr>
<tr>
<td>No shortness of breath</td>
<td>0-10</td>
<td>Shortness</td>
</tr>
<tr>
<td>Other problem</td>
<td>0-10</td>
<td>Other Problem</td>
</tr>
</tbody>
</table>

Patient's Name ____________________________
Date __________ Time __________

Complete by (check one):
- Patient
- Caregiver
- Caregiver assisted
proach to management of various common end-of-life symptoms is provided in the Table at the bottom of pages 12-13.

The patient should be asked about symptoms at each contact with a health professional. The Edmonton Symptom Assessment System (ESAS) questionnaire (see page 16) represents a simple guide to follow. This can also be done by the patient or caregiver at home if they are not seeing a healthcare professional weekly.

Conclusion

While many physicians are poorly trained in end-of-life care, many patients can benefit from having the principle of palliative care used for them during the last two years of their life. Patients who may particularly benefit include those with end-stage congestive heart failure, chronic obstructive pulmonary disease, chronic renal failure, strokes, amyotrophic lateral sclerosis, Alzheimer’s Disease, cancer, and AIDS. The interdisciplinary team approach, with the focus on maintaining function and treating symptoms, makes geriatricians an ideal group of physicians to be involved in palliative care. Good end-of-life care requires health care professionals to listen very carefully to the patient and family and to help them make good decisions in a supportive psychosocial and spiritual environment. Finally, end-of-life care needs to continue beyond death as has been so well demonstrated by the Center for Grief Care and Education at the San Diego Hospice and Palliative Care (www.sdospice.org/cgefpc.htm).

The quote at the beginning of this article is reprinted from "Indigenous Perspectives on Death and Dying"
Author: Dianne M. Longboat
Publisher: Ian Anderson
Continuing Education Program in End-of-Life Care, University of Toronto
Year: 2002
The VA Focuses on End-of-Life Care

By Thomas Edes, MD, and Scott T. Shreve, MD

In recent years, the Department of Veterans Affairs (VA) has undergone a remarkable transformation in care at the end of life. In 2001, fewer than 40% of VA medical centers had a formal palliative care program. Now, by policy, all VA facilities have a Palliative Care Consult Team. And every VA Network, or regional cluster of VA facilities, has had an interdisciplinary team trained in hospice & palliative care program development.

Although VA offers to provide or purchase needed hospice care for all enrolled veterans, prior to 2001 half of all VA facilities did not purchase any hospice care because of inconsistent policies. VA now has a national policy and standardized practices for the purchase of comprehensive per diem hospice care, home hospice became a separate item in the 2004 VA budget for the first time in VA history, and all VA facilities now purchase hospice care. To promote collaboration between VA and the community agencies that directly provide hospice care to veterans, VA began the Hospice-Veteran Partnership initiative working within each state. VA also pioneered an innovation in training, by starting interdisciplinary fellowship programs in palliative care. (See www.hospice.va.gov for more information on fellowship sites).

As a result of these coordinated changes that addressed policy, workload capture, budget, performance measures, training, and community agency collaborations, VA has greatly increased access to hospice and palliative care for veterans. In the past two years, VA has tripled both the number of veterans receiving VA-paid home hospice care and the number of veterans receiving inpatient hospice care in VA facilities. While this progress is encouraging, VA’s efforts are accelerating. Keep an eye on VA care at the end of life – for advances in outcome measures, quality of care, staff competency, caregiver support, veteran and family satisfaction, and hospice care in nursing homes.

SLU to Organize Two Major International Nutrition Meetings in 2007

In May 2005, the International Academy of Nutrition meeting was held in St. Louis. The next meeting will be held in Adelaide, Australia on September 5-6, 2007. The meeting will be organized by Ian Chapman, John Morley, and Bruno Vellas. It will be held conjointly with the Australian Geriatrics Society Meeting. The Third International Cachexia Meeting was held in December, 2005, in Rome. Among participants from Saint Louis University were David Thomas, Matt Haren, and John Morley. The Fourth Cachexia Congress will be held December 6-8, 2007, in Florida. It will be organized by Stefan Anker, Bill Evans, and John Morley.
AGING SUCCESSFULLY IS ON THE WEB!

This issue and every issue is available at our NEW website:
http://aging.slu.edu

While you’re there, check out the screening tools, links to other useful sites, and information about our upcoming conferences.

If you need additional paper copies of a previous issue of Aging Successfully, please email aging@slu.edu.

SERVICES

Services of the Division of Geriatric Medicine, Saint Louis University Health Sciences Center include clinics at two locations in the following areas:

- Aging and Developmental Disabilities
- Bone Metabolism
- Falls: Assessment and Prevention
- General Geriatric Assessment
- Geriatric Diabetes
- Medication Reduction
- Menopause
- Nutrition
- Podiatry
- Rheumatology
- Sexual Dysfunction
- Urinary Incontinence

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or 314-966-9313
(at Des Peres Hospital)

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- Aging Successfully Newsletter

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- Emergency Preparedness CD
- Books

Call 314-977-8848 for more information about these products.
Dr. Wilson Elected to Executive Committee

Dr. Margaret Wilson has just been elected to a three-year term as a member of the Executive Committee of the School of Medicine Faculty Assembly.

Geriatric Medicine Fellows Receive Scholarship

Drs. Chris Espana, Ahmed Ali, and Oscar Cepeda have been awarded a scholarship to attend the 2006 American Medical Directors Association (AMDA) Future’s Program. Held during the AMDA Annual Symposium, this intensive learning experience is designed to expose residents and fellows to the numerous career opportunities available in long term care. Participants chosen for this program receive admission to the AMDA Futures Program on March 16, 2006, registration to the AMDA Annual Symposium, March 16-19, 2006 in Dallas, Texas, lodging and transportation to the meeting and a one-year membership to AMDA.

Drs. Hajjar and Kamel Awarded

Dr. Ramzi Hajjar and Dr. Nabil Kamel earned the American Academy of Hospice and Palliative Medicine (AAHPM) Award for Young Investigators for the poster they submitted, entitled, “Delay in Seeking Hospice and Palliative Care Services in Terminally Ill Patients - A pilot study of determinants of use and potential points of intervention.” This award recognizes a young investigator whose submission was considered outstanding by the program committee. The poster will be on display at the AAHPM/HPNA conference in Nashville, TN on February 8-10, 2006.

Doctors Receive Awards from AMDA

Drs. Julie K. Gammack and Zareen Syed have received a 2006 Pfizer Quality Improvement award through the American Medical Directors Association. This $14,000 award is designed to encourage the development of innovative projects that will help to make a distinct impact on the quality of patient care in the nursing home setting. The quality improvement project is titled “Oral Health Care in the Elderly Demented Patient in the Long-Term Care Setting.” The study will begin in Summer, 2006 and will continue until Spring, 2007. The purpose of the study is to improve oral care in older nursing home residents by providing education to the staff who care for these individuals.

I’m Fine, Thank You!

Author unknown

There is nothing the matter with me.
I’m as healthy as I can be.
I have arthritis in both my knees,
And when I talk
I talk with a wheeze.
My pulse is weak,
and my blood is thin,
But I’m awfully well for the shape I’m in.
Arch supports
I have for my feet,
Or I wouldn’t be able to be on the street.
Sleep is denied me
night after night,
But every morning
I find I’m all right.
My memory is failing,
my head’s in a spin
But I’m awfully well for the shape I’m in.
How do I know that my youth is all spent?
Well, my “get up and go” has got up and went!
But I really don’t mind when I think again
Of all the grand places that my “get up” has been.
Old age is golden,
I’ve heard it said,
But sometimes I wonder as I get into bed,
With my ears in the drawer,
my teeth in a cup,
My eyes on the table until I wake up,
Ere sleep overtakes me,
I say to myself,
“Is there anything else I could lay on the shelf?”
I get up each morning
dust off my wits,
And pick up the paper
and read the “Obits”.
If my name is missing,
I know I’m not dead,
So I have a good breakfast
and go back to bed!
Caring for the Vulnerable
June 6-7, 2006

IMPORTANT INFORMATION:
Due to increased postal rates and the loss of Federal funding, we will be making all of the conference details (including brochure and registration form) for the 2006 SUMMER GERIATRIC INSTITUTE available on the Internet at http://aging.slu.edu. Please visit this site for conference information and to register. If you want to be updated on conference details, send an email to: aging@slu.edu.

One of the workshops which will be presented at the Summer Institute is “Breaking Bad News: Do’s and Don’t’s.” This workshop will provide instruction on how to break bad news to patients, family members, and professional caregivers. The mnemonic on the left, created by the workshop presenter, Anupam Agarwal, MD, highlights major points to consider when talking about difficult medical diagnoses.
CyberKnife: Improving Care for the Older Cancer Patient

The CyberKnife Stereotactic Radiosurgery System (CyberKnife) is now being used at Saint Louis University Hospital.

CyberKnife radiosurgery is a noninvasive radiation treatment that can be used as an alternative to open surgery in certain cases. It uses image-guided robotics designed to destroy tumors with precisely directed beams of radiation. It may improve treatment outcomes and quality of life for some patients with malignant and benign lesions of the brain, spine and neck that may have been previously considered inoperable or inaccessible by radiation therapy.

The CyberKnife uses high doses of focused radiation beams delivered from multiple points outside the body to irradiate the tumor or lesion. Each individual beam is not sufficient to cause harm, but the convergence of all the beams at the target results in the tumor or lesion receiving a very high dose of radiation while sparing nearby normal tissue.

The CyberKnife’s targeting system may offer many patients improved tumor control with few side effects and fewer treatments. In fact, treatment that may have required as many as 30 sessions with conventional radiation therapy may be reduced to one to five sessions for 60 to 90 minutes each.

How does the CyberKnife work?

The CyberKnife, paired with other hospital imaging technology, allows specialists to customize a treatment plan for each patient. Physicists use a complex program to determine a treatment plan for each patient based on the unique shape and location of the tumor. The planning process determines the positions of the beams of radiation.

Through the use of technology, the CyberKnife system locates the position of the tumor and uses a robotic arm to deliver highly focused beams of radiation to the tumor. The robotic arm’s range of motion allows for radiation to be delivered to tumor sites that are unreachable when using most other stereotactic treatment procedures.

Potential Benefits of CyberKnife Treatment include:

- better quality of life during and after treatment
- better access to hard-to-reach, larger or previously inoperable tumors
- more accurate radiation targeting for minimal radiation exposure to surrounding tissue
- ability to treat multiple tumors in different locations during a single session
- treatment of lesions that have previously undergone the maximum allowed dose of traditional radiation therapy
- improved comfort due to the elimination of an invasive head frame
- no incision or scalp
- no blood loss
- no anesthesia required for treatment
- no recovery time
- immediate return to normal activities
- fewer complications than traditional surgery such as infection, hemorrhage or nerve damage.

Conditions Treated With the CyberKnife include:

- Malignant brain tumors
- Benign brain tumors
- Vascular malformations
- Extracranial tumors and lesions.

For More Information
If you are interested in the CyberKnife, you or your physician can contact us at 1-866-40cyber.
Upcoming CME Programs

SLU Geriatric Academy (SLUGA)
July 10-14, 2006

15th Annual Multi-Disciplinary Certificate Program in Geriatrics for Non-Physicians
In Effingham, Illinois on Wednesdays, March 15, 29, April 12, 26, May 10, and 24, 2006.
In Grayslake, Illinois on Thursdays, March 9, 23, April 6, 20, May 4, and 18, 2006.

17th Annual SLU Summer Geriatric Institute
Caring for the Vulnerable
June 6-7, 2006

4th Annual Rush Elder Rights Forum
April 7, 2006 at Rush University Medical Center in Chicago, Illinois

15th Annual Multi-Disciplinary Certificate Program in Dementia Assessment, Care, and Management

All of the conferences will be held at Saint Louis University, except as noted. For more information about any of these conferences, please call 314-977-8848.

Been Here? Done This?
Offering regular updates on geriatrics, Cyberounds, an internet-based educational program for physicians and other health providers, is edited by Dr. John E. Morley. The internet address for Cyberounds is:

www.cyberounds.com

A cybersite for seniors has been developed in collaboration with Saint Louis University and the Gateway Geriatric Education Center. Besides articles written by geriatric experts, this site provides health updates and an interactive question and answer section. The address for this site is www.thedoctorwillseeyounow. See you in cyberspace!
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Saint Louis University School of Medicine
Geriatric Research, Education, and Clinical Center (GRECC)
St. Louis Veterans Affairs Medical Center
Gateway Geriatric Education Center of Missouri and Illinois (Gateway GEC)
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John E. Morley, M.B., B.Ch.
Dammert Professor of Gerontology and Director, Division of Geriatric Medicine
Director, Gateway Geriatric Education Center
Department of Internal Medicine
Saint Louis University School of Medicine
and Director, GRECC, St. Louis Veterans Affairs Medical Center

Nina Tumosa, Ph.D.
Editor
Health Education Specialist, GRECC
St. Louis VAMC-Jefferson Barracks
and Executive Director, Gateway GEC
Professor
Division of Geriatric Medicine
Department of Internal Medicine
Saint Louis University School of Medicine

Carolyn E. Phelps
Assistant Editor

Please direct inquiries to:
Saint Louis University School of Medicine
Division of Geriatric Medicine
1402 S. Grand, Room M238
St. Louis, Missouri 63104
e-mail: agingsuccess@slu.edu

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