WE ALL KNOW . . .

. . . that U.S. Copyright Law grants to the copyright owner the exclusive right to duplicate copyrighted, printed and recorded materials. Piracy involves the illegal duplication of copyrighted materials.

YOU MAY NOT KNOW . . .

. . . that every time you use or make an illegal copy of any printed material in any form or by any method you may be liable for further litigation.
. . . that your institution’s duplication or processing equipment may also be confiscated and destroyed if involved in illegal duplication.
. . . that the penalty for criminal violation is up to five years in prison and/or a $250,000 fine under a tough new law. (Title 17, U.S. Code, Section 506, and Title 18, U.S. Code Section 2319).
. . . that civil or criminal litigation may be costly and embarrassing to any organization or individual. We request you contact us immediately regarding illegal duplication of these copyrighted, printed materials. The National Center of Continuing Education will pay a substantial reward for information leading to the conviction of any individual or institution making any unauthorized duplication of material copyrighted by J.L. Keefer or The National Center of Continuing Education.
E	

xtraordinary efforts have been made by the authors, the editor and the publisher of the National Center of Continuing Education, Inc. courses to ensure dosage recommendations and treatments are precise and agree with the highest standards of practice. However, as a result of accumulating clinical experience and continuing laboratory studies, dosage schedules and/or treatment recommendations are often altered or discontinued. In all cases the advice of a physician should be sought and followed concerning initiating or discontinuing all medications or treatments. The planner(s), author(s) and/or editor(s) of each course have attested to no conflict of interest nor bias on the subject. The National Center of Continuing Education, Inc. does not accept commercial support on any course nor do they endorse any products that may be mentioned in the course. Any off-label use for medications mentioned in a course is identified as such.

No part of this publication may be reproduced stored in a retrieval system or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without the prior written permission of the publisher.
About the Authors

Angeline Bushy, PhD, RN, CNS, CHN, is the Bert Fish Endowed Chair, School of Nursing, at the College of Health and Public Affairs in Daytona Beach, Florida. She has practiced in a variety of rural health care settings including clinical as well as educational settings. She has published extensively, including textbooks, and presented various aspects of rural healthcare delivery at numerous national and international conferences.

Excerpts provided by Carolyn Hunter, RN, MA, Nursing Education Consultant for National Center of Continuing Education. She is Retired Assistant Dean for Continuing Education, Washington State University School of Nursing. Currently she is active with helping the elderly in her church with health related issues.

Purpose and Goals

The goal of the course is to present the basic concepts of palliative care, with emphasis on emotional, psychosocial, spiritual and family issues; pain management; and the rights of the patient to self determination and decision making.

Instructional Objectives

Upon completion of this course, the motivated learner will be able to:
1. Define and characterize palliative care.
2. State the role of palliative care and symptom management in end of life care.
3. Summarize nursing interventions that are useful in managing pain in a person having a terminal condition.
4. Define strategies to communicate effectively with client and family about death and dying.
5. Outline ways to address the emotional and spiritual concerns of the dying client.
6. Identify legislative changes that may be implemented in the future to aid the dying.

Introduction

Palliative Care: What is it? How does it relate to life and end of life issues? Many healthcare professionals subscribe to the notion that death is simply another dimension of life - a transition of living. This perspective of death as a major life transition should be the focus of care for a client in the last stages of life. The definition of Palliative care is: the comprehensive, specialized care provided by an interdisciplinary team to patients and families living with life-threatening, advanced illness or decline where care is particularly focused on patient and family directed goals of alleviating suffering and promoting quality of life. Major concerns are pain and symptom management, information sharing, advance care planning, psychosocial and spiritual support, and coordination of care.

Palliative care is care which is intended to relieve the symptoms of a disease that cause the patient to suffer, but which is not expected to cure the disease. This continuing education program focuses on the activities of health professionals that are involved in providing this type of care. For this program, we will focus on assisting and providing support to a person who is in the end stage of life, as well as to his or her family system. Please note that in all cases it is the client and his or her family system that establish priorities for care: the role of the health professional is to support the family system in achieving their unique goals. The term “family system” is broad and encompassing: it includes the client’s significant other(s), immediate and extended family members, friends, and in some instances even the community. Each person defines who is included in his or her family system, and this group will vary from person to person.

Health professionals in general, direct caregivers in particular, are in an ideal position to assist, and even provide alternative perspectives to a person in their care, and to allow their client to be open about feelings as well. Opportunities for meaningful interactions can be especially evident when administering personal care to the client in his or her home. A certain intimacy can be established while assisting a person with the usual and ordinary things of life such as preparing meals, doing housekeeping activities, and completing personal care.

Implementing Palliative Care

Palliative care is always goal centered. Components of the plan of care are centered around patient and family unique life goals. Discussion of symptoms and medical issues will affect the goals. It is centered in quality of life and whole person care. Another goal is alleviating symptoms so that patient has best experience possible in what time is left. The functional goals, with focus on hope tie the plan together. Evaluation of the goals will be ongoing, remembering that this plan is person based and family centered.

Palliative care and symptom management are the essence of care for a client experiencing end stage disease symptoms. They are directed toward promoting a high quality of life, relief of suffering, and supporting a peaceful death. They encompass the active and total care of people whose disease is not responsive to curative treatment.

Diagnostic procedures and special treatments such as chemotherapy, radiation, nutritional augmentation, pharmacotherapy, and in some cases even surgery, may have a place in palliative care. These interventions are ordered by the physician if the benefits in providing relief of symptoms outweigh the disadvantages of not having it. The goal of any intervention in palliative care is to improve the quality of life for the person by managing symptoms as opposed to controlling or curing the disease.

Palliative care focuses on the relief of suffering when the underlying disease cannot be cured. Suffering is described as a state of severe distress that often is associated with events that threaten a person’s intactness as a human being. Hence, suffering is viewed more broadly than simply experiencing physical pain. Rather, the whole person experiences suffering: having pain in the mind and spirit as well as one’s body. Moreover, the physical symptoms will vary with different diagnoses, affected body systems, progression of the end stage disease, and impact of these factors on the individual person. For example, nearly 75% of people with cancer experience pain at some time during their illness. But other conditions produce pain as well, including heart disease, AIDS, decubitus ulcers, and neuropathy. Different interventions may be needed to manage the pain experienced by different clients with different diseases.

In addition to pain, there may be other physical symptoms experienced by the client receiving palliative care. For example:

- Neurological symptoms including seizures, paralysis, or changes in mental status such as lethargy, confusion, agitation, or hallucinations; sensory and perceptual changes.
- Cardiovascular symptoms such as edema, syncope, hemorrhage, or angina.
- Respiratory symptoms such as dyspnea, cough, or congestion.
- Gastrointestinal symptoms such as nausea, vomiting, anorexia and cachexia, constipation, diarrhea, prolonged or continuous hiccups.
- Genitourinary symptoms such as incontinence, retention or dysuria.
- Musculoskeletal symptoms such as weakness, fatigue, pathologic fractures, contractures and spasms.
- Integumentary (skin and mucous membranes) symptoms such as pressure ulcers, ulcerative lesions, dry mouth, oral lesions, infections and pruritus.

Consequently, in addition to assisting with or
providing routine activities of daily living during care, special therapies may be ordered by the physician to relieve or manage symptoms. For instance, nutritional, physical, occupational, or speech therapy may be ordered for persons with a chronic disease or debilitating condition to maintain a certain quality of life during the end stages of the condition. Such interventions may also help to maintain a greater degree of mobility or enable one to participate in activities of daily living for a longer period of time. Medical supplies and durable medical equipment also can be helpful in palliative care and symptom management, such as hospital beds with special features; oxygen, intravenous, and enterostomy therapies; and wheelchairs and other comfort devices. In addition to improving comfort, durable equipment and medical supplies can help to provide a safer environment for the client as well as caregivers.

Management of Specific Symptoms

Symptom management in many cases is the most important activity in providing care to a client. Symptoms will vary from person to person, and his or her particular health problems or diagnosis. Likewise, the symptoms will change in intensity, frequency and duration as the disease progresses. Carefully listening to what the client is telling you, observing and assessing for changes from the baseline status, then intervening early on can go a long way to managing symptoms in the client.

Symptoms encountered in palliative care that cause an intense degree of discomfort include nausea, vomiting, anorexia, pain, skin breakdown and decubitus ulcers, urinary and bowel irregularities, and respiratory problems. If these cannot be managed at home, short-term inpatient care may be provided for symptom control, respite care, or terminal care (when death is imminent).

Pain Management

Pain management is an important component of palliative care. In recent years major contributions have been made to the nursing research literature regarding protocols for pain relief. The holistic view of pain and its management includes attention on the part of the caregiver to physical, emotional, social, and spiritual needs. Adequate availability and doses of analgesics, including narcotics; around-the-clock scheduling; and the use of co-analgesics and other non-drug interventions have made the control of pain an attainable goal. Throughout the care process, the client is central in making decisions about pain management. Judicious use of prescriptive and non-prescriptive drugs can greatly enhance the quality of life by providing relief from pain and other discomforts such as nausea, vomiting, and diarrhea.

Analgesia includes not only drug therapy, but also non-pharmacological interventions such as imagery, massage, therapeutic touch, music therapy, and meditation. The goal of therapy is to keep the client comfortable, as defined by the client, without overly clouding mental and cognitive functions necessary to the client’s participation in the activities of daily life. Fears of addiction to narcotics frequently are a concern to clients and families as well as healthcare professionals. Thus, teaching about pain management and facilitating the expression of beliefs about the use of medications are critical interventions if these are to be used effectively in palliative care and symptom management.

Measures of client comfort and function should be visible to caregivers as well as members of the family system on a documentation record, such as a bedside flow sheet specifically designated for rating pain. This information will provide an assessment of the success of the pain control regimen and also remind the caregiver that ratings above a specified number require intervention. Whether or not the agreed-upon goal has been achieved should also be routinely reported at the change of shift, along with other information about the person’s status such as vital signs. In fact, the American Pain Society suggests that pain rating be treated as the fifth vital sign (in addition to blood pressure, pulse, respiration, and temperature).

Emotional and Communication Support

Health professionals providing palliative care must be sensitive to the reality that depression, anxiety, and sleep disorders may be present and may cause physical or emotional symptoms. Furthermore, unique psychosocial issues accompany terminal illness. Emotional responses such as denial, anger, sadness, acceptance, and hope may vary from day to day and may differ between the client and the various members of the family.

Coping skills to deal with the loss of the loved one also may be limited, or dysfunctional, in some family systems. Moreover, even family systems that have effective coping abilities may find relationships strained at some time or another during a terminal illness.

Obviously, one of the most critical components of palliative care is effective communication between and among the client, caregivers and family members. Caregivers involved in terminal care must be aware of the opportunity and carefully listen for an opening for communication on the part of the client. Most dying persons want to talk about the process of their own death with loved ones. Oftentimes, family members feel extreme discomfort with the topic, and are unable to participate in discussions of death and dying. In these situations, health professionals can lead the way and assist the family system to feel that it is okay to talk about death and dying within the family.

Many times, actually saying the words “death” and “dying” provides an opening for communication to begin on the topic. If the caregiver is comfortable with those words, that in and of itself can help others to feel more comfortable talking about the highly sensitive topics of death, loss and grieving. In one case Mary, 72 years old, had end stage cardiac disease and was having trouble making a decision about continuing to live at home. Mary wanted to remain at home but her family was very concerned about her living alone. When asked what she believed their real concern to be Mary said, “I think my family is afraid they will come into my home and find me dead.” When asked if she was afraid to die at home or even alone, her response was, “Heavens, no! This is where I want to spend my last days. I want to die where I lived for the last 50 years with my husband and children. My husband died in our house 7 years ago. This is where I belong.”

Her case manager informed Mary, the client in this case, that she was capable of making her own decision. To help reduce the family’s anxiety, Mary agreed to carry a portable phone with automated dialing for quick access to her family and doctor. This strategy reassured the family, and it allowed Mary to live at home even with the seriousness of her illness. In the end, upon making a routine home visit, Mary’s nurse found her deceased in bed. In essence, the care plan for this woman focused on assisting her to live and die in the manner she desired.

Meeting the Spiritual Needs of the Dying

Often when health professionals talk about spiritual care, or the spiritual needs of their clients, they think of providing that person with the opportunity to participate in some specific religious ritual, such as the sacrament of communion or last rites. Or they offer to call the person’s rabbi, priest, or minister.

Yet, spiritual needs can be more concretely and broadly defined, if one will move from looking at the symbols of a person’s relationship to God to the essence of that relationship itself. The basic spiritual needs of all persons are:
1. the need for meaning and purpose
2. the need for love and relatedness
3. the need for forgiveness

Throughout history mankind has searched for the meaning of life, and this search has been the primary motivation for many of life’s richest and most satisfying experiences. For many, ultimate hope and meaning comes from a relationship with God (or however they conceptualize the higher spiritual power in their lives). This bond is especially important for the person searching for meaning in the face of death. Reliance on people and worldly achievements falls away as they will all be left behind, and the focus is increasingly on the unknown future. Those who have a relationship with their God can contemplate that future with hope and a sense of peace.

The need for love and to be in relationships with others is also a profound spiritual need. The dying person is no longer in a position to earn love from other people or try to meet the conditions required to obtain or maintain their love. The only true and lasting source of unconditional love is their God, and the dying person may turn increasingly toward God for their love. The only true and lasting source of love. Guilt is one of the biggest burdens the person may turn increasingly toward God for their love. The only true and lasting source.

The need for forgiveness is also a profound spiritual need. For example, you might forgive someone for a past wrong. Guilt is one of the biggest burdens the person may turn increasingly toward God for their love. The only true and lasting source.

The dying person is no longer in a position to earn love from other people or try to meet the conditions required to obtain or maintain their love. The only true and lasting source of unconditional love is their God, and the dying person may turn increasingly toward God for their love. The only true and lasting source of love. Guilt is one of the biggest burdens the person may turn increasingly toward God for their love. The only true and lasting source.

The Role of Advance Directives

In recent years, it has been increasingly recognized that an individual has the right to self-determination not only with regard to activities during life, but also in choosing services that will enhance the quality of life during her final days. People are encouraged to have chosen a personal representative to have the power to make health care decisions if the person is disabled and cannot make decision. If the person has shared his or her wishes prior to this need it will make it much easier for all concerned.

An important part of this process before this need is the preparation of advanced directives that may include a living will and a durable power of attorney for health care decision-making in the event of incapacitation. If the person decides that he does not want to be maintained by gastric feeding or mechanical ventilation, then those decisions can be conveyed to the physicians and others involved in his care. Most hospitals and other health care facilities require that they have this advance directive on admission or on file with physician.

Another important document is to have a Physician Orders for Life-Sustaining Treatment (POLST). This is primarily used to give directions to first responders (i.e. paramedics) the person’s wishes about CPR, limited additional interventions, or full treatment. It is usually posted in the person’s living unit. Each state may have different documents and names. Many people especially the elderly do not want to be resuscitated if found without pulse or respiration.

In addition, the person should also have a durable power of attorney for property management. This trusted person serves as Attorney-in-Fact to make decisions about financial concerns if the person is unable to make decisions.

Many individuals at the end of life have reported considerable comfort in knowing that they have expressed their wishes and are to be allowed a death with dignity according to those wishes. Healthcare professionals can assist their patients to achieve this level of peace by encouraging the preparation of advance directives.

Nurses are committed to providing care to the whole person throughout the life span, and to maintaining a holistic perspective on the needs of the person in their care. What could be more important than marshaling all the nurse’s personal strengths and professional skills to provide caring support to those facing one of life’s greatest transitions?

Tying It All Together

Effective public health strategies and medical treatment advances have resulted in a 30-year increase in life expectancy during the 20th century. As people are living longer, their expectations about quality of life throughout the lifespan, including at its very end, are increasing. Unfortunately, death itself is ultimately not preventable, and most people will die as a result of chronic disease. The public health field is aware of this issue and plays a critical role in helping Americans to maintain quality of life throughout their lives. Despite its demonstrable importance as a societal health concern, end-of-life has only recently captured the attention of the public health community. Although death itself is ultimately not preventable, much of the suffering that may accompany terminal illness is amenable to interventions that are often not accessible to everyone. For instance, studies point to disparities in hospice use, particularly among patients with certain types of cancer. It is uncertain whether these disparities are due to lack of awareness regarding the options for end-of-life care, or to differences in perspectives regarding end-of-life.

In recent years, members of CDC’s Healthy Aging Team collaborated with colleagues from the Division of Cancer Prevention and Control to develop public health priorities for end-of-life issues. This work involved key public health stakeholders and resulted in 103 short, intermediate, and long-term priorities.

Top Five Initial Priorities are:
1. Identifying a point of contact for end-of-life issues in state health departments
2. Collecting and analyzing data about end of life
3. Incorporating end-of-life principles into state comprehensive cancer control plans
4. Educating the public about hospice and palliative care
5. Educating the public about the importance of advance directives and health care proxies.

These top five initial priorities form the framework for our current projects that focus on EOL issues.

Understanding Palliative Care and Hospice Care

For the past several decades, the health care system has provided a number of options to ease the dying experience. Medical treatment has expanded to include palliative care and hospice care. The goal of palliative care is to achieve an optimal quality of life for patients by using a holistic approach that focuses on the alleviation of pain, symptoms, and other unique needs of the patient at any time during their experience with a serious or life-threatening illness. A combination of time during their experience with a serious illness, the focus on the relief of suffering and improvement of quality of life, is important throughout the course of the illness, and aspects of palliative care can be provided along with life prolonging treatment during earlier phases of a patient’s illness.

Hospice care is an organized program for delivering palliative care that involves an interdisciplinary team of specially trained health professionals and volunteers. Hospice care is delivered to dying patients in inpatient units, nursing homes, or, most often, in their own homes. In addition to providing palliative care and personal support to individuals at the end of their lives, hospice provides support to the family while their loved one is dying as well as during the bereavement period. In 1982, Medicare began reimbursing for hospice services. To qualify for the Medicare hospice benefit, terminally-ill patients must have a terminal diagnosis, a life-expectancy of 6 months or less, and is willing to forgo further treatments. Patients who live longer than 6 months can be “recertified” if their situation still meets the criteria for the hospice benefit. Currently Medicare rules are being reviewed (2016) to allow patients to continue with chemotherapy and radiation as these treatments may reduce pain (by reducing size of tumor) and will be allowed. Anything that reduces suffering should be given to the patient.

Working with the terminally ill is a demanding and emotionally draining position, especially if we confront death daily. In what ways can we learn to cope with the stress so that we do not lose control of our emotions or “burn out” and leave the profession.

1. Get to know yourself. Identify your emotional strengths and limitations.
2. Develop your own philosophy of life and death. Knowing what you believe decreases inner anxiety and frustrations.
3. Build a support system both at work and at home. Find people who will listen and care about you and the grief you experience when people you care for pass away. Communicate your feelings and frustrations, but do NOT dwell on them. Develop hobbies that will help to release emotional energy.
4. Develop a sense of humor and use it. Learn to laugh at yourself and at life in appropriate ways. When working with terminally ill people on a daily basis it is easy to get morbid and cynical about life and death.
5. Education can be of great assistance personally and professionally. Learn about the needs of the dying and how to meet those needs. You will find empowerment in knowing better how to intervene and assisting those facing death, and their families.

There are no easy answers or ‘magic bullets’. Even with this information, death remains difficult for us. However, working and caring for the dying individual can be exciting and rewarding if we realize that, as healthcare professionals, we can do mighty things to help them experience comfort and peace at the End-Of-Life.

Dr. Ira Brock wrote an editorial for the New York Times in February 1, 2015 regarding some of the legislative issues that should be addressed to help the dying. Read this document and determine what you as a nurse can do to help the people you care for at the end of their life.

Dying Shouldn’t Be So Brutal

By Ira Byock

“Travel safe!” It has become a nearly reflexive wish I give to friends who are coming or going. This fall, I noticed myself holding back from saying it to Michael, a dear friend who was wrestling with incurable cancer. The journey metaphor was too poignant.

I also avoided “Stay safe.” After all, dying is inherently precarious.

Instead I said: “Be well. I’ll be thinking about you.” That was true. I could have added, “and worrying about you.” That was true, too.

Michael was receiving state-of-the-art treatments at a renowned cancer center in New York City. As he became sicker, the treatments got more intense. Each decision came with more difficult trade-offs and uncertainties. Each step to stay alive risked making things worse.

He knew it. We’d talked openly about it. His life was precious and worth fighting for, so every option was worth carefully considering. But modern medicine has yet to make even one person immortal. Therefore, at some point, more treatment does not equal better care.

When Michael was out of standard options, they offered him a Phase I clinical trial - essentially an experiment. But his increasing pain and breathing problems were being poorly managed, sapping his strength and will to live. By phone I suggested to the nurse practitioner overseeing the study that Michael and his family would benefit from hospice services, starting with ensuring that he was correctly taking both long-acting and “as needed” pain relievers (and adjusting laxatives to counteract the pain relievers’ constipating effects). Hospice providers could also have responded to his wife and children’s questions about the details of caring for him at home.

“It’s his choice,” the nurse said, referring to Medicare rules that require patients to choose between cancer treatment and hospice care.

It was, but what a terrible choice to have to make.

Michael, who has since died, was suffering needlessly. Hospice care could have vastly improved the quality of his waning life, and eventually it did. But those rules mean that dying patients enrolled in Phase I studies, which aren’t intended to be treatments, are routinely denied access to hospice services. Caveat mortalis - let the die-er beware!

Our health care system is well honed to fight disease, but poorly designed to meet the basic safety needs of seriously ill patients and their families. We can do both. We must.

People who are approaching the end of life deserve the security of confident, skillful attention to their physical comfort, emotional well-being and sense of personal dignity. Their families deserve respect, communication and support. Exemplary health systems and healthy communities deliver all of this today. But they are few and far between.

Since 1997, the Institute of Medicine has produced a shelf of scholarly reports detailing the systemic dysfunctions, deficiencies and cultural blinders that make dying in America treacherous. Most people want to drift gently from life, optimally at home, surrounded by people they love. Epidemiological and health service studies paint an alarmingly different picture.

An American living with cancer has a roughly one in four chance of dying in a hospital and a similar chance of spending a portion of his or
her last month in intensive care. The chances are higher with chronic lung or heart disease. An American with Alzheimer’s disease will very likely spend most of his or her last months in a nursing home, yet many long-term care facilities are woefully understaffed and ill equipped to care for demented people.

Less than 45 percent of dying Americans receive hospice care at home, and nearly half of those are referred to hospice within just two weeks of death. Hospice was designed to provide end-of-life care, but this is brink-of-death care.

DYING is not easy, but it needn’t be this hard.

Most Americans don’t want to think about dying. There’s an assumption that dramatically improving how we die would be too complicated or costly.

Thankfully, the opposite is true. Over the past two decades the fields of geriatrics, hospice and palliative medicine have demonstrated that much better care is both feasible and affordable. Successful approaches share core attributes: meticulous attention to alleviating people’s symptoms and maximizing their independence, continuing communication and coordination of services, crisis prevention and early crisis management, and decision making rooted in patients’ and families’ values, preferences and priorities. Together these steps reliably improve people’s quality of life, modestly extend survival and save money.

Those of us who have been on a quest to transform care have been standing on a two-legged stool. We’ve demonstrated higher quality and lower costs. Missing is the visible, vocal citizen-consumer demand. Without it, large-scale change will not happen.

As a baby boomer, I wonder when we became inured to bad care. We’re the generation that transformed childbirth, creating the natural birthing movement over resistance from the medical establishment. As health outcomes when women were prepared for childbirth proved consistently higher than the status quo, the medical community gradually climbed onboard.

In the 1970s we supported hospice as a countercultural movement in response to the medical community gradually climbed onboard. The persistently unsafe state of dying in America should provoke a Howard Beale moment. We’ll find solutions in various white papers and Institute of Medicine reports. First, we need outrage.

With a citizen-consumer leg to stand on, we could write a Safe Dying Act. Let’s start by requiring medical schools to adequately train young doctors to assess and treat pain, listen to patients’ concerns and collaborate with patients and families in making treatment decisions - and test for those skills before awarding medical degrees. Let’s require nursing home companies to double staffing of nurses and aides, and the hours of care accorded each resident. Let’s set minimum standards for palliative care teams within every hospital. Let’s routinely publish meaningful quality ratings for hospitals, nursing homes, assisted living, home health and hospice programs for people to use in choosing care. And let’s repeal the Medicare statute that forces incurably ill people to use in choosing care. And let’s repeal the Medicare statute that forces incurably ill people to use in choosing care. And let’s repeal the Medicare statute that forces incurably ill people to forgo disease treatments in order to receive hospice care.

Medical school deans and corporate chief executives will vigorously testify against our bill, and opponents will try politicizing the matter as a means of paralyzing Congress. They will fail. When public safety is threatened and we become engaged as a national community, political action follows.

As the end of life approaches, whether death is welcomed or feared, there is a lot we can do to make the process of dying safer. Ira Byock, a palliative care physician and the director of the Institute for Human Caring of Providence Health and Services, is the author of “The Best Care Possible.”

EOL Resources and Toolkits

Center for Practical Bioethics Caring Conversations—www.practicalbioethics.org

Caring Connections—www.caringinfo.org

Aging With Dignity—Five Wishes—www.agingwithdignity.org/SWishes.html

Respecting Choices—www.gundluth.org/eolprograms

National Hospice and Palliative Care Organization—www.nhpco.org/templates/1/homepage.cfm


American Bar Association Commission on Law Aging—www.abanet.org/aging/

References and Suggested Readings

Brown T. Bringing It Home Explores Nursing Beyond the Hospital.

Am J Nurs, Jul 2015, 115(7) p49

Byock, Ira, “We Must—and We Can—Do Better, Health Progress, 2014, Jan-Feb

Byock, Ira, “The Best Care Possible: A Physician’s Quest to Transform Care Through the End of Life (Avery 2012).


Cimino NM, McPherson ML. Evaluating the impact of palliative or hospice care provided in nursing homes. J Gerontol Nrs, Oct 2014, 40(10) p10-4

Dacher JE. Nursing practice of palliative care with critically ill older adults.

Crit Care Nurs Clin North Am, Mar 2014, 26(1) p155-70

Di Bello KK. Grief and depression at the end of life. Nurse Pract, May 15 2015, 40(5) p22-8


Kostrzewa AS. Facing dementia: integrating palliation into all aspects of care.

Creat Nrs, 2013, 19(1) p12-5

Perrin KO, Kazanowski M. Overcoming Barriers to Palliative Care Consultation.

Crit Care Nurse, Oct 2015, 35(5) p44-52


Spicer S, Heller R, Troth S. Hospice clinical...
experiences for nursing students: living to the fullest. J Christ Nurs, Jan-Mar 2015, 32(1) p46-9

Uren SA, Grahamm TM. Subjective experiences of coping among caregivers in palliative care.

Online J Issues Nurs, 2013, 18(2) p8


"Embracing the End–of–Life"

by Shelda L. K. Hudson, RN, BSN, PHN

Creating an atmosphere and purposeful preparation can assist the patient and family through an oftentimes, difficult process. Theologian Megory Anderson says in her book Sacred Dying, “It takes great strength and courage to face death and to begin to move through it to the other side. And it takes great courage for the survivors to put aside their own fears and anxieties to help their loved ones die a peaceful death.” Anderson explores the idea of returning spirituality into the process of dying through attentiveness and the use of personalized tradition. In her research she has discovered beautiful and deep ways of helping people resolve issues and find a way to let go and die with peace.

Experiences gained while attending to the dying indicate that listening and respecting the dying person’s concerns are essential for end–of–life care. Pain management and physical concerns must be handled first. Then look for a way to address concerns of the spirit, no matter what form these may take. Begin by finding out about the patient’s religious and cultural background. Nearly everyone has religious and/or cultural images and beliefs that affect how they live and how they view death. Build upon common religious rites or teachings that have meaning for the patient in order to create a personalized touch. (Scriptures, sacred texts, poetry, and prayers can be used as starting points.)

Cultural awareness and identification are essential as health care professionals look at patients through both their own eyes and the eyes of the patient and family system. First, an understanding of one’s own perspective is needed. Knowing or thinking about how you feel will influence your care and how you handle each end–of–life situation. Family structure, belief systems, roles/decision making, how emotions are handled, response to illness and attitudes toward pain and procedures and communication styles may differ among cultural groups.

The dying need to be treated with absolute respect. If a person is conscious and able to talk, listen and take cues from him. The desires of the dying, however illogical or puzzling they may be, should try to be met. Make a point to reassure the patient that you understand and will do whatever you can to make the request happen. Do not diminish the patient’s reality. Instead, accept that the patient could be experiencing things we may be unaware of. To those who are unconscious or in a coma speak “as if he is able to hear and understand.” In addition to helping patients let go of this life, rituals can help them put things in order and resolve issues between family and friends. Sometimes the unfinished business is with God. By setting the stage, the releasing of emotions such as anger, fear, sorrow, guilt, and burdens can occur; these rituals can also help comfort. With the deepest respect and attentiveness, we can learn how to nurture peace and spiritual healing in those who are making this final transition.

Passage Matthew 28:20

Jesus said... “And be sure of this: I am with you always, even to the end of age.” (NLT)