

## **MULTIDISCIPLINARY END-OF-LIFE CARE ISSUES**

### **NATIONAL AND WEST VIRGINIA END-OF-LIFE CARE STATISTICS and END OF LIFE CARE ISSUES**

Nearly 2.5 million Americans die each year, with the majority of deaths in the United States being over the age of 65. Nationally, about fifty percent of all deaths occur in hospitals; in West Virginia, more than 58% of deaths occur in hospitals, with only seven states reporting higher in hospital deaths. Nationally, more than twenty percent of the U.S. population dies in nursing homes; in West Virginia, that figure is reduced to 14% of all deaths, with only four states reporting lower in nursing home deaths. Although West Virginians state they would prefer to die at home, only 13% of our state's population dies at home with hospice involvement.

In the last decade, use of home care by Medicare beneficiaries has grown rapidly. According to a recent report on end-of-life care by the Institute of Medicine of the National Academy of Sciences, home care visits jumped from 37.7 million in 1988 to 208.6 million in 1994. Increasingly, medical technology, incentives in medical payment systems, and patient preference combine to make home care for the terminally ill not just possible, but necessary. We need to improve quality of life for the patient and family by improving factors that contribute to suffering and impair physical, psychological, and existential functioning. The question

arises: how do we create a multidisciplinary team of knowledgeable physicians, nurses, social workers, pharmacists, and clergy who will coordinate holistic comfort care and be able to address with patient and family members alike the four major areas of suffering associated with the end of life, namely physical, social, emotional, and spiritual needs?

## **END-OF-LIFE CARE**

What has caused an interest in end-of-life care issues on both a national and state level? Experts in end-of-life care recognize that the field itself must grow in order to meet the public's demand for greater access to quality care at the end of life. In West Virginia, a series of community dialogue meetings throughout the state and surveys of health care professionals revealed the key concerns in end-of-life care as follows:

- Inability to talk about death - a cultural stigma exists that says it is wrong to talk about death;
- Mindset among health care providers and community members that death means failure; general denial of death and fear of death;
- Inadequate physician services to patient and family, including unnecessary aggressive treatments provided to terminally ill patients and the inability to treat the whole person (treatment of symptoms and disease only);

- Poor physician involvement in pain control, symptom management, and knowledge about end-of-life care options;
- Lack of knowledge and understanding of end-of-life care options by citizens and professionals alike;
- Hospice regulations are often too restrictive and Medicare regulations for hospice are too narrow;
- Patients are required to give up curative measures to access hospice;
- Lack of completion of advance directives - patients' wishes are not respected/advanced directives are not adhered to;
- Not enough support for family and caregivers - the present health care system does not recognize the tensions and conflicts between the person dying and members of their family and support system;
- Poor communication in the continuum of care by health care professionals.

## **WHAT WEST VIRGINIAS WANT**

What kinds of care do the dying want? How do people experience a 'good death'? Professionals and citizens alike have asked these and similar questions. With the move to hold down and cut back on health care costs, programs for the care of the dying will involve trade-offs and sometimes difficult decisions about the types of and extent of care provided. Many people think that the dying ought to have access to all the health care that's available, including life support systems; the debate

arises generally around responsibility for payment. Often we combine the chronically ill – those with the potential for dying within a year or two - with those who know they are actively in the process of dying. We must remember that the chronically ill are hypothesizing about dying whereas people in hospice programs have a closer view of their mortality and may be more likely to agree to DNR orders. The definition of who is categorized as ‘dying’ could perhaps be expanded. At present, those who are conventionally labeled as dying are ICU patients in their last day or two, cancer patients, and AIDS patients; the current definition does not include congestive heart failure patients or Alzheimer’s patients.

In West Virginia, community dialogues and surveys have identified the following to be key concerns about end-of-life care:

- pain and other symptoms are minimized;
- the patient’s preferences for end-of-life care are elicited and respected and the dignity of the patient preserved;
- companionship and support from family and friends are received and time is allowed for the patient to say his/her good-byes;
- attention is paid to the patient’s spiritual goals in the dying process;
- the burden to the family and others is minimized;
- the bereaved are assisted through the early stages of mourning and adjustment;
- the costs of end-of-life care are covered by insurance.

The exact point at which a patient’s end-of-life care should begin remains a subject of discussion. Several leaders from various disciplines

in the field of end-of-life care believe that palliation and cure are not mutually exclusive and that palliative care should be practiced during all stages of serious illness, even while aggressive curative treatment continues. This way, compassionate and effective end-of-life care for patients is a balance between attention to their physical and emotional needs. The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) adopted the *Core Principles for End of Life Care*, which helps to define roles and responsibilities as providers of end-of-life care, and address the physical and psychological standards of care that the dying and their caregivers should expect and receive from the medical establishment.

These *Core Principles for End of Life Care* are:

1. Respecting the dignity of both patient and caregivers;
2. Being sensitive to and respectful of the patient's and family's wishes;
3. Using the most appropriate measures that are consistent with patient choices;
4. Encompassing alleviation of pain and other physical symptoms;
5. Assessing and managing psychological, social, and spiritual/religious problems;
6. Offering continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers);
7. Providing access to any therapy which may realistically be expected to improve the patient's quality of life, including alternative or nontraditional

treatments;

8. Providing access to palliative care and hospice care;

9. Respecting the right to refuse treatment;

10. Respecting the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences;

11. Promoting clinical evidence-based research on providing care at the end-of-life.

## **CARE FOR THE DYING**

What kinds of care do the dying need? As interest in end-of-life care has developed, researchers have begun to explore patients' psychosocial needs at the end of life. Many other symptoms of advanced illness (poor appetite, fatigue, shortness of breath, constipation, and pain related to the heart, gastrointestinal tract, urinary tract, and female reproductive organs) have received relatively little basic or clinical research. What role do these symptoms play in a patient's choices regarding end-of-life care? What role does depression play in this process, and how often do health care providers recognize depression? What is the impact of treatment of depression on patients' quality of life at the end of life, on desires for hastened death, and on the bereavement outcomes of family members? In general, this is new and unexplored territory with major implications for the provision of high quality, comprehensive end-of-life care. As a result of community and professional involvement and

interest in developing statewide improvements in end-of-life care, the West Virginia state legislature passed H.B. 2815 in March 2001, which states mandatory continuing education around end-of-life care and pain management issues for all physicians, physician's assistants, nurses, and pharmacists holding licenses in West Virginia. This action will result in West Virginia health care providers being able to provide up to date information and end-of-life care options to patients and caregivers.

As with many other types of medical care, the patient's emotional needs and concerns play a major role in their physical health and the health care choices they make. Educating health care professionals to know how to provide good end-of-life care entails teaching ethical decision making and good practitioner-patient communications, symptom and pain management, and recognition and effective treatment of suffering for the patient and family members. Health care providers who offer the majority of health care in West Virginia's communities are in a unique position to engender trust in their patients, but only if they are aware of end-of-life care options. The West Virginia Center for End-of-Life Care was created to provide information and education to health care professionals and the citizens of West Virginia on issues related to end-of-life care. There is a need for all disciplines to not only communicate in a language that conveys mutuality, respect, and interdependence, but also recognize the multidimensional nature of suffering, and respond with appropriate attention that addresses the care of patients with active, progressive, and

advanced disease for which the prognosis is limited and the focus of care is quality of life.

## **ADVANCE DIRECTIVES FOR HEALTH CARE DECISIONMAKING**

How can you remain in charge of your health care, even after you can no longer make decisions for yourself? By creating a document called an "advance directive." In West Virginia, the state law recognizes two types of written advance directives for health care decision-making: the Living Will and the Medical Power of Attorney. Both forms have a special section for you to write in specific comments about circumstances in which you would not want certain life-prolonging interventions. You should discuss these comments with your family and doctor so they can better understand what is important to you in receiving medical treatment, and you can use these forms to document your decisions for health care if you become unable to speak for yourself. You can appoint someone you know and trust as your Medical Power of Attorney representative to ensure that your choices and decisions are honored.

The living will is a document that tells your doctor how you want to be treated if you are terminally ill or permanently unconscious. You can use a living will to tell your doctor that your choice is to avoid life-prolonging interventions, you want to be kept pain-free and comfortable at the end of your life, and give any special medical directives or limitations to your doctor.

The medical power of attorney (sometimes referred to as the durable power of attorney for health care) is a document that allows you to name another

person to make certain medical decisions for you if you are unable to make them for yourself. This is very important, particularly for those who are not likely to be terminally ill. If you are unable to speak for yourself, your medical power of attorney is the person who will be your 'voice' to your doctor for health care.

You should give your written instructions to your doctor, hospital, nursing home or other health care provider as well as anyone else involved in your health care decision-making. In addition, you should talk to your doctor and discuss your health care wishes, desires and fears. Your doctor will be able to help you understand what health care options may be available for you, and also can talk with you about end-of-life care options. As an adult, you have the right to make your own health care choices and decisions. You have the right to know about treatments and alternative treatments, their risks and benefits. You have the right to ask questions, and you also have the right to decide whether you want the treatment or not; your right to accept medical or surgical treatment includes the right to refuse it.

## **RELATED LINKS TO END-OF-LIFE CARE ISSUES**

West Virginia Center for End-of-Life Care [www.hsc.wvu.edu/chel/wvi](http://www.hsc.wvu.edu/chel/wvi)

WV Center for Health Ethics and Law [www.hsc.wvu.edu/chel/index.htm](http://www.hsc.wvu.edu/chel/index.htm)

Project on Death in America [www.soros.org/death/index.htm](http://www.soros.org/death/index.htm)

National Hospice and Palliative Care Organization [www.nhpco.org](http://www.nhpco.org)

Health-related Law Issues [www.findlaw.com/01topics/19health/index.html](http://www.findlaw.com/01topics/19health/index.html)

## **GLOSSARY OF END-OF-LIFE TERMS**

**Advance Directive**

A legal document in which people state their wishes regarding medical treatment and preferences in case they are incapacitated. Advance directives include living wills, medical power of attorney, and a combined living will/medical power of attorney form.

### **Advance Care Planning**

Thoughtful family-based discussions about health care wishes and goals when someone faces end-of-life decision making. The goals of advance care planning are three-fold:

- To elicit clear understanding of the kind of care a person facing a life-threatening or life-limiting illness would want;
- To determine who would speak for that person if he were unable to speak for himself ;
- To complete a written health care directive

### **Cardiopulmonary Resuscitation (CPR)**

Refers to a group of treatments used when a person's heart stops beating or a person stops breathing. It can include any of the following: mouth-to-mouth breathing, chest compressions (pressing on the chest to push blood through the heart), electric shock, (paddles), and drugs used to stimulate the heart.

### **Comfort Care**

Care that relieves pain and suffering and controls debilitating symptoms but does not prevent dying. These cares include, but are not limited to:

- Administration of medications or other treatments such as radiation to relieve pain;
- Administration of medications for anxiety, constipation, breathing difficulty and other symptoms;
- Provision of personal care such as bathing and turning;
- Provision of emotional and spiritual support to the dying person, family and friends;
- Administration of other treatments that enhance comfort.

### **Decision-Making Capacity**

The ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.

### **Do Not Resuscitate (DNR)**

DNR is a physician's order to **not** attempt to restart a failed heartbeat or to apply cardiopulmonary resuscitation (CPR) to restore normal breathing.

### **Hospice**

A philosophy of care for people who are dying that emphasizes comfort over cure. Hospice care is available in a wide variety of settings including the home, hospitals, nursing homes, and residential hospices. Hospice care is provided by an interdisciplinary team of health care professionals who:

- Attend to the physical, emotional and spiritual needs of the patient and family ;
- Have expertise in pain and symptom management ;
- Follow up with grief support services for the family.

### **Hospice Medicare Benefit**

A special benefit under Medicare Part A that covers hospice services. Criteria for hospice admission include:

- A terminal illness with a prognosis of six months or less as certified by a physician;
- Patient consent to pursue a "hospice philosophy of care" that includes a focus on comfort rather than either cure or prolonging life.

The hospice Medicare benefit includes:

- Interdisciplinary team support from nurses, social workers, chaplains, volunteers, home health aides and therapists;
- Coverage for all prescriptions and treatments related to the terminal illness. In patient respite care;
- Medical equipment to maintain patient comfort such as oxygen or a hospital bed;
- 24 hour hospice on-call service;
- Bereavement follow-up for the family.

### **Living Will**

A Living Will only applies if you are terminally ill or permanently unconscious AND too sick to make decisions for yourself. A Living Will only tells your doctor what you do not want unless you write in other specific instructions. A Living Will is a written record of health care choices and health care decisions that you have made yourself.

### **Medical Power of Attorney**

Use of a Medical Power of Attorney form allows you to choose someone else to make health care decisions for you if you are too sick to make them for yourself. This person is called your Medical Power of Attorney representative. Your representative can make any health care decision that you could make if you were able. A Medical Power of Attorney allows you to give specific instructions to your representative about the type of care you would want to receive.

Completion of the Medical Power of Attorney form allows your representative to respond to medical situations that you might not have anticipated and to make decisions for you with knowledge of your values and wishes.

### **Palliative Care**

Palliative care focuses on relieving symptoms rather than curing a disease. Like hospice care, it addresses the physical, emotional and spiritual needs of a patient and family. The definition of palliative care, according to the World Health Organization, is as follows:

"Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families."

### **Terminal Illness**

An illness or condition that is incurable and irreversible. When a person is diagnosed as terminally ill, death is expected in a relatively short period of time.