

# PASSAGES

June 2008

SPECIAL  
POINTS OF  
INTEREST:

- > **New Physician's Order, MOST**
- > **Changes in NC Statutes**
- > **Upcoming planning clinics**
- > **NC License Plate Option for Advocacy**



- > **Kitty Askins Fund Raiser**

INSIDE THIS  
ISSUE:

<b>Medical Update</b>	<b>1</b>
<b>Legal Update</b>	<b>1</b>
<b>"What can happen"</b>	<b>2</b>
<b>Focus on Culture</b>	<b>2</b>
<b>Peter Keese Award</b>	<b>3</b>
<b>Highlight on Services</b>	<b>5</b>

## THE NEW MEDICAL ORDERS FOR SCOPE OF TREATMENT (MOST)

by Susan Redding, MSN,  
FNP-C

Mr. L., age 89, has advanced dementia due to the effects of multiple strokes on his brain. Prior to his first stroke, he executed a living will and appointed his son, who lives out of state, as his health care power of attorney (HCPOA). The patient now resides in a nursing home and has a Do Not Attempt Resuscitation Order (DNAR) on his nursing home chart. The patient's dementia has advanced and he is no longer able to make

his own decisions. His son has communicated to his father's physician that Mr. L's previously expressed wishes were to not begin artificial nutrition or hydration should he stop being able to take nutrition by the normal route. Neither would Mr. L want to return to the hospital for aggressive treatment of other health problems due to the fact that he now has end-stage dementia. His father had previously expressed that, when he came to the last stages of a disease, he would want to be allowed to die peacefully and naturally

in a hospice program of care.

Mr. L. develops a severe infection and is sent to the Emergency Department (ED) of a large teaching hospital near his nursing home. Although the nursing home has communicated that Mr. L is a DNAR to the Emergency Medical Personnel, a portable DNAR is not in place when Mr. L. arrives at the hospital, and

Continued on page 4

## RECENT CHANGES TO NORTH CAROLINA'S END-OF-LIFE CARE PLANNING STATUTES

by Kristin L. Burrows, J.D.  
Elder Law Attorney

In 2005, Terri Schiavo became a household name when members of her family were forced to go to court to determine her wishes regarding end-of-life treatment, particularly whether she would want to be kept alive on feeding tubes when she was severely brain-damaged and had been in a persistent vegetative state (completely unaware of her surroundings) for years. Her case brought the issue of end-of-life care planning to the forefront of many peoples' minds. In fact, it caught the attention of the North Carolina state legislature, which began its first com-

prehensive review of our state's Living Will and Health Care Power of Attorney laws. A workgroup, which included both the North Carolina Bar Association and the North Carolina Medical Society, determined that the state's laws needed revision and, together with representatives from the Carolinas Center for Hospice and End-of-Life Care, the North Carolina Health Facilities Association, and the North Carolina Hospital Association, they drafted a bill to clarify and improve the state's Living Will and Health Care Power of Attorney laws and forms. When this bill passed in 2007, it was the first major revision to North Carolina's end-of-life health care planning

laws.

Prior to the 2007 revisions, the Living Will statute was enacted in 1977. Then, not until 1991, the Health Care Power of Attorney statute was enacted. Due to the time lapse between the enactment of the Living Will and Health Care Power of Attorney, and the fact that many thought the new Health Care Power of Attorney form would essentially replace the Living Will form (which it did not), there were many discrepancies between the two documents.

One big problem under the old laws was that it was unclear whether the Living Will or the Health Care Power of Attorney controlled when the

Continued on page 5

## WHAT CAN HAPPEN WHEN THERE IS NO PLANNING

by Chaplain Dick Tucker, M.Div.

**“To suddenly be confronted with an array of such choices without preparation is traumatic.”**

I vividly remember attending a death in an intensive care unit. The woman had suffered a massive, devastating, and completely unexpected stroke the previous day and death was near. Her breathing was starting to slow down and time was running out. As her daughters rushed breathlessly into the room – one having just arrived from out of state – the nurse asked, hesitantly and as gently as possible, “If your mom stops breathing, do you want us to put in a breathing tube?” The

respiratory therapy team was waiting outside the room, ready to begin their work.

Their mother, not yet 50 years old, had never told her daughters what kind of treatment she would want if something like this happened. As her next-of-kin, legally the daughters were the only ones who could spare their mother that final futile and undignified “treatment.” However, they were totally unprepared to make that decision, and suffered much guilt as they finally told the medical people to let her go.

As I stood there, I felt sadness and anger. Sadness for that family, and anger that we have not done a better job as a society in preparing each other to deal with end-of-life care issues. To suddenly be confronted with an array of such choices without preparation is traumatic. That is why the End of Life Care Coalition of Eastern Carolina was created, to help people make and communicate decisions that can prevent the kind of tragic scene I witnessed at the hospital that day.

## FOCUS ON CULTURE: NATIVE AMERICANS

by Belinda F. Bagan, RN

The Native American today has merged so peacefully into society where there are no reservations. They have had to become part of the mainstream to try to survive, or have they? Who are these people and what do they look like?

In North Carolina there are eight State-Recognized Indian Tribes and two Associations. There is also a tribe, with blood ties to both the Cherokee and another tribe, that has petitioned for state recognition but has not yet gained it! It is not unusual to meet someone on the street and ask them to name the Indian tribes in North Carolina, and they can only name one or two, the Cherokee and the Lumbee. I will list them all for you:

- Coharie Intra-Tribal Council (State Recognized)
- Cumberland County Association of Indian People (State Recognized)
- Eastern Band of Cherokee Indians (State Recognized)
- Guilford Native American Association

Haliwa-Saponi Tribe (State Recognized)

Lumbee Tribe of North Carolina (State Recognized)

Meherrin Indian Tribe (State Recognized)

Metrolina Native American Association, Inc.

Nuluti Equani Ehi Tribe

Occaneechi Band of the Saponi Nation (State Recognized)

Sappony (State Recognized)

Waccamaw-Siouan Tribe (State Recognized)

How do Native Americans handle the end of life, and how can caregivers facilitate this phase of life for Native American patients? To the Native Americans, it is believed that in order to survive as individuals and communities, it is necessary to acknowledge spiritual powers in every aspect of their lives, generally by addressing the powers in prayer and song. When working with Native Americans who are facing an end-of-life situation, the first step would be to assess their belief system because every Native American may not practice or worship the same. Many Native Americans prac-

tice monotheism, whereas others practice Wiccan or what is believed to be closest to nature worship in organized religion.

When addressing a Native American’s spiritual needs at the end of life, ask if there is anything you may assist with, such as finding or providing a quiet place to pray. If prayers are offered in a traditional Native American way, smudging may be done, which is a practice that requires briefly lighting a mixture of sweet grass, sage and cedar for purification prior to praying. The items used in smudging are for cleansing of evil spirits and allowing the Great Spirit to enter and heal. Remember the person will have to light with a match briefly and then blow it out so that the items are allowed to smoke. This prayer ritual is extremely sacred to the participant, but it may not abide by your facility’s guidelines, so please check if your facility can or will accommodate this practice.

## EOLCCEC PRESIDENT RECEIVES NOMINATION FOR PETER KEESE AWARD

At the March meeting of the Coalition *Susan Redding*, Coalition President was presented with a certificate noting her nomination for the Peter Keese award by Jody Riddle, North Carolina Family Caregiver Support Program Consultant and former board member. The Carolinas Center for Hospice & End of Life Care chooses a recipient for this award based on having devoted significant time to promoting hospice care; having vision and thinking forward; having been involved in hospice care throughout North Carolina; and having an active involvement in all stages of hospice development. In nominating Susan, Mrs. Riddle described her as a “fearless leader.”

The success and growth of the Coalition are due in no small part to Susan’s drive and commitment to the cause of comfortable and compassionate end of life care. We congratulate Susan on this recognition of her effort and talent!

## HOSPICE LICENCE PLATE PROJECT

The Carolina’s Center for Hospice & End of Life Care is pleased to partner with the North Carolina Department of Transportation in offering this beautiful license plate – a chance to support hospice care in a very visible way!

Applications for the license plate can be accessed on the Carolina’s Center’s website listed below.

For more information on the Carolina’s Center for Hospice & End of Life Care you may call (800) 662-8859, e-mail [info@carolinasendoflifecare.org](mailto:info@carolinasendoflifecare.org) or visit their website at:

<http://www.carolinasendoflifecare.org/>



**Get your Hospice Care License Plate to show everyone that you support caring and compassionate end of life care!**

## COMMUNITY HOME CARE AND HOSPICE

*by Chaplain Elizabeth Yarbrough, M.Div.*

Community Home Care and Hospice is the largest Hospice Provider in North Carolina, serving 76 of 100 counties, as far east as Currituck and Dare, and as far west as Wilkes and Catawba. Community Home Care and Hospice also serves 12 of 46 counties in South Carolina.

At Community Home Care and Hospice, we believe that it is all about living. It is a common misperception that hospice is about death; but at

Community Home Care and Hospice, it is about living well and living fully until the end of life. We offer heartfelt physical, emotional, and spiritual care to individuals and families living with a life-limiting illness. We focus on comfort, support, choice, enriching the quality of life, and bereavement care.

A patient is appropriate for hospice when his physician determines that he has a life-limiting prognosis of six months or less should the disease follow its normal course, and the patient and family have chosen a

palliative plan of care, rather than curative treatment. If it is necessary for a patient to enter the hospital while on hospice services, Community Home Care and Hospice can continue to visit and manage the patient’s care.

Every day, the staff of Community Home Care and Hospice strives to improve the lives of our patients with life-limiting illnesses. We focus on controlling pain and managing symptoms while maintaining the highest quality of care. We seek to allow patients to stay home with their families while receiv-

## M E D I C A L   U P D A T E   ( c o n t i n u e d   f r o m   p a g e   1 )

(actual form is printed on pink paper)

“The MOST provides a mechanism for patients to communicate their wishes to either provide or withhold certain medical interventions”

he is placed on a ventilator, and aggressive treatment is initiated for his respiratory tract infection. He is then admitted to the Medical Intensive Care Unit (MICU). It is not until Mr. L’s son can be reached that the hospital personnel become aware of Mr. L’s wishes for care at what may be the end of his life. Mr. L’s son is now faced with difficult decisions regarding how much care should be continued and if he is violating his father’s previously stated wishes by continuing this level of medical care.

In 2007, the North Carolina legislature approved the use of a document called Medical Orders for Scope of Treatment (MOST) that might have helped Mr. L. to receive the kind of care he had desired at the end of his life. If a MOST form had been completed for Mr. L., his son might also have been spared some very painful decision-making at the end of his father’s life.

The MOST form is a medical order, signed by both the medical provider and the patient or the patient’s surrogate, that outlines, for any medical provider who may be caring for the patient, the kind of care he would want. Although the form is intended for those with advanced disease, anyone can request a MOST form from their medical provider. The MOST addresses not only a per-

son’s wishes regarding resuscitation attempts (CPR), but also if a person would want to return to a hospital for intensive levels of medical care. The form also addresses issues of artificial nutrition and hydration (feeding tubes and IV fluids) and whether a person would want antibiotic treatment. The MOST provides a mechanism for patients to communicate their wishes to either provide or withhold certain medical interventions and should be completed in a setting where these options for care can be discussed.

The MOST, like the current portable DNR, which addresses only resuscitation status, should remain with the patient wherever he is residing or receiving medical care. Because it is a medical order, it may be followed by any medical provider. Healthcare providers must see the original form. Copies may be made for the medical chart for documentation purposes, but the original should always remain with the patient.

The MOST does not replace an advance directive (living will and/or HCPOA). Rather, it is a tool available to persons in NC to ensure that wishes for care at the end of life are honored by health care providers. In a time where multiple healthcare providers in a number of settings may provide healthcare, the communication of a person’s wishes can be challenging. The MOST form, which is bright pink in color, was designed to help ensure this appropriate

communication.

The MOST form must be reviewed at least annually and should be verified each time a person changes the location of their care, i.e., transfers from the nursing home to the hospital or to any other location of care. The form remains effective for a period of one year from the date it was last reviewed.

How might a MOST have helped Mr. L.? Mr. L. would most probably have been receiving hospice case management in the nursing home. When he developed his infection, the nursing home and hospice staff would have provided symptom control so that he could remain in the nursing home where he wanted to be. If his symptoms could not be controlled there, he might have been admitted to a palliative care unit at the hospital or to an inpatient hospice facility if available, rather than rushed to the ED and admitted to MICU, until his symptoms were controlled. If death were not imminent, then he could have been brought back to the nursing home to die.

If you are interested in talking about a MOST form, ask your healthcare provider. The form is available from the North Carolina Department of Health and Human Services to physicians, nurse practitioners or physician assistants, and healthcare facilities or agencies.

## C O M M U N I T Y   H O M E   C A R E   ( c o n t i n u e d   f r o m   p a g e   3 )

ing the care they need, and we follow patients into nursing facilities should the illness progress beyond the point where staying home is the best option. In fact, Community Home Care and Hospice has two inpatient facilities, one in Lillington, NC and the other

in Fayetteville, NC. As much as possible, we help patients face the conclusion of life on their own terms.

Referrals for Hospice can be made by patient, family, physician, social worker, nurse, clergy, or advanced care facility. Any

additional questions regarding Hospice may be answered by contacting Community Home Care and Hospice at 1-800-569-1348, or

visit us at

[www.communityhch.com](http://www.communityhch.com)

## LEGAL UPDATE (continued from page 1)

agent named in the Health Care Power of Attorney wanted to make a decision that conflicted with the Living Will. For instance, if the patient stated in his Living Will that he did not want to be placed on feeding tubes under his current medical condition, but the health care agent told the doctor to insert feeding tubes, which was the doctor to follow? There was not a clear answer under the old laws.

To resolve this issue, the new Living Will allows a person to choose whether his Living Will controls, or whether his health care agent may override his Living Will. If no choice is made in the Living Will, the statutory form specifies that the Living Will controls. One thing that is important to note, however, is that the new law is not retroactive; that is, the new law does not resolve the potential conflict between Living Wills and Health Care Powers of Attorney executed under the old laws.

Another problem with the old Living Will and Health Care Power of Attorney forms was the use of inconsistent, ambiguous, and outdated medical terms. Therefore, the new laws attempt to clarify the forms with new terms to describe medical conditions and treatments.

Examples of Inconsistent Terms:

1. The old Living Will authorizes withholding or withdrawing certain treatments when the person's condition is "terminal or incurable". The old Health Care Power of Attorney gives the agent the power to withhold treatment when the patient is "terminally ill". Is a person who is "terminally ill" also a person who is in a "terminal and incurable" state?

2. The old Health Care Power of Attorney gives the agent the power to withhold treatment if the patient is suffering severe dementia. The old Living Will made no mention of dementia as a condition for withholding treatment.

Example of Outdated Medical Term: Both the old Living Will and Health Care Power of Attorney authorize withholding treatment if the patient is in a "persistent vegetative state". However, physicians now use the new term "permanent vegetative state" to refer to a more prolonged vegetative state that is probably not reversible, and use the old term "persistent vegetative state" to refer to an *intermediate*

condition of being vegetative for longer than one month.

Under the new Living Will terminology, a person can now choose whether certain treatment can be withheld when he: (1) has an incurable or irreversible condition that will result in death within a relatively short period of time, or (2) is unconscious and, to a high degree of medical certainty, will never regain consciousness, or (3) has advanced dementia or any other condition resulting in the substantial loss of cognitive ability and that loss, to a high degree of medical certainty, is not reversible.

The hope of the drafting group is that the above terminology is clearer to both patients and physicians. First, the terms are not tied to current medical jargon, so there is less chance that the terms will become outdated, like the term "persistent" vegetative state did. Second, they are less confusing to the average person; for instance, the phrase "unconscious and ... will never regain consciousness" paints a clearer picture than a medical term like "coma". Plus, the new terms are tied temporally to imminent death ("death within a relatively short period of time"), and make it clear that, to a "high degree of medical certainty", the patient's condition is irreversible.

The new Health Care Power of Attorney form does NOT include the new terms used in the Living Will. Rather, the drafting group determined that a person chooses a health care agent whom they trust to make decisions, so the form did not need these explicit standards. This also helps to eliminate the potential for conflicting instructions in the two documents.

Regarding the types of treatment that can be withheld or withdrawn, both forms also now use the term "life-prolonging" measures rather than "life-sustaining" procedures because the verb "prolong" connotes the concept of artificial postponement of death better than does the verb "sustain". "Life-prolonging measures" are defined as medical procedures or interventions which, in the judgment of the attending physician, would serve only to postpone artificially the moment of death by sustaining, restoring, or supplanting a vital function, including mechanical ventilation, dialysis, antibiotics, artificial nutrition and

hydration, and similar forms of treatment. Life-prolonging measures do not include care necessary to provide comfort or to alleviate pain.

Another change to the Living Will involves artificial nutrition and hydration. Although artificial nutrition and hydration is included in the definition of "life-prolonging measures", a person may give special instructions in the documents indicating that he wants to receive such interventions. However, because many people do not understand that administering artificial nutrition and hydration is a very invasive procedure, the drafters attempted to make it clear on the form that choosing artificial nutrition and hydration entails inserting tubes or other invasive mechanisms down one's throat.

Lastly, a significant change to the Living Will is that it now includes a "shall" option that requires a physician to withhold certain treatments. The old Living Will provided that the attending physician had the *option* to withhold certain treatments in accordance with the patient's Living Will. It is important to note, though, that (1) the physician still retains the discretion to determine whether the conditions required for withholding treatment under the Living Will actually exist, and (2) a physician has the right to object to withholding treatment on moral or conscience grounds (the physician may decline to participate but must cooperate to allow a non-objecting physician to carry out the patient's wishes). This new "shall" option is helpful, though, because it can relieve the pressure placed on both the physician and the family when faced with these end-of-life decisions for a patient or loved one.

It is important for you to have these documents because they give you control over decisions about your health care, and they can alleviate some of the pressure on your loved ones and health care professionals by preventing confusion and conflict over your end-of-life treatment. This article addresses just a few of the changes and clarifications that the new laws made to the Living Will and Health Care Power of Attorney. If you have questions about these documents, or are considering signing or updating your advance directives, please get in touch with your health care provider or an elder law attorney.

**"they can alleviate some of the pressure on your loved ones and health care professionals by preventing confusion and conflict over your end-of-life treatment"**

END OF LIFE CARE  
COALITION OF  
EASTERN CAROLINA

P.O. Box 33  
Greenville, NC 27835  
Phone: 252-847-0868

*The mission of the End of Life Care Coalition of Eastern Carolina is to provide education and support to help area residents have conversations and make decisions that lead to compassionate and comfortable care at the end of life. The Coalition will also support services that serve to facilitate compassionate and comfortable end of life care.*

**KITTY ASKINS HOSPICE CENTER ANGEL  
FUNDRAISER**

In support of the expansion of the Kitty Askins Hospice Center in Goldsboro, lovely handmade angels can be purchased for \$10. Names can be attached to the angels in memory or honor of a loved one. The angels will be placed on the Christmas tree at Kitty Askins during the Christmas season and returned to the purchaser after the 2008 holiday season. This is a volunteer effort to allow more families to have access the facility in their time of need. Please contact April Brantham at 1-800-260-4442 ext. 1072.



**EOLCC 2008 MEETINGS**

**All meetings of the EOLCC are held  
in the Maple Room  
at Pitt Memorial Hospital,  
on the second Tuesday of the month  
from 12:00 noon– 1:00 p.m.**

(with exception of the annual meeting held in  
January)

June 10  
July 8  
August 12  
September 9  
October 14  
November 11  
December 9

**EOLCC MEMBERSHIP**

For information on becoming a member of the Coalition contact Susan Redding at (252) 847-0868 Or visit the website at [www.endoflifecarecoalition.org](http://www.endoflifecarecoalition.org)