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# ASPEN

## Adult Services Practice Notes

Dedicated to providing information on excellent family-centered practice with adults and their families.

### Planning for the End of Life North Carolina Updates Its Statutes

As medical technology has made it easier to sustain life longer, people have become more concerned about making choices about their care at the end of life and helping family members and others make choices if they aren't able to do so. Three documents in particular help people make their preferences known about their health and mental health care: the Declaration of a Desire for a Natural Death 2007 (sometimes called a "living will"), the Health Care Power of Attorney 2007, and the Medical Orders for Scope of Treatment (MOST).

In 2005, North Carolina, like many other states, was feeling the ripple effects of the much-publicized Terri Schiavo case in Florida. State legislators, elder law and health law attorneys, hospice and hospital staff, and many health care professionals found themselves responding to a dramatic increase in interest, questions, and concerns about our state laws governing living wills and health care powers of attorney.

The state's end-of-life care statutes have responded to other landmark cases and contained the sometimes conflicting and ill-defined standards, couched in the terms of the times in which they arose. The living will statute (G.S. §§90-320-326), passed in 1977 in the wake of the Karen Ann Quinlan case in New Jersey, during the first wave of "right to die" cases, used such terms as "terminal and incurable," "persistent vegetative state," and withholding of "extraordinary means." The health care power of attorney law, passed in 1991 (G.S. §32A-15-26), came during a second wave of cases sparked by the Nancy Cruzan case in Missouri. This statute included terms such as "terminally ill," "permanent coma," "severe dementia," and withholding of "life sustaining procedures." The 1977 law defining the "Procedures for a natural death in the absence of a declaration" (G.S. §90-322) include yet a third group of terms, including "comatose with no reasonable possibility for a return to a

#### The Documents at a Glance

Three documents help people make their preferences known about their health and mental health care. The updated Advance Directive for a Natural Death 2007 and Health Care Power of Attorney 2007 are available on the Secretary of State's web site at: <http://www.secretary.state.nc.us/ahcdr/>. If you already have a North Carolina living will or health care power of attorney following the old format, they remain valid. You may choose to make a new document using these forms, but you are not required to do so.

The Medical Orders for Scope of Treatment (MOST) is not an advance directive for the general public. It is a physician's order form that must be completed and signed by a physician, physician's assistant or nurse practitioner and only after fully discussing the treatment options with the patient or resident of a long-term care facility or their representative. MOST forms may also be completed by a trained social worker under the direction of a physician. To see a sample of the MOST document go to: <http://www.ncdhhs.gov/dhsr/EMS/ems.htm>

cognitive sapient state.” The inconsistent language created confusion in what treatment could be withheld and under what conditions it was appropriate to withhold it.

The increased interest produced by the Schiavo case resulted in a comprehensive review and update of North Carolina’s end-of-life health care planning statutes, culminating in the passage of S.L. 2007-502, whose aim is to give individuals flexibility in end-of-life care decision making through enhanced choices, as well as clarifying the law and eliminating inconsistencies among different statutes. This update has also resulted in changes to statutes addressing procedures for withholding life-prolonging measures when there is no advance directive for guidance [G.S. §90-322]; informed consent to health care [G.S. §90-21.13]; use of a military advance medical directive [G.S. §90-320(a)]; and the role of a court-appointed guardian when there is an advance directive [G.S. §32A-22, G.S. §32A-25.1, G.S. §35A-1208, and G.S. §35A-1241(a)(3)]. Finally, the revisions also outline the new out-of-facility, portable medical order called the Medical Orders for Scope of Treatment or MOST.

## What are the major changes?

### When may treatment be withheld?

The 2007 revisions standardized terms among the statutes. The language describing when treatment may be withheld for both living will and health care power of attorney now reads that it is appropriate to withhold treatment when the declarant (patient who has an advance directive)

1. has an incurable or irreversible condition that will result in the declarant’s death within a relatively short period of time;
- or**
2. becomes unconscious and, to a high degree of medical certainty, will never regain consciousness;
- or**
3. suffers from 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.

In creating either document, people may select one, two, or all of these conditions as the trigger for following the directions of the document.

### What treatment may be withheld?

Instead of “life-sustaining procedures,” the language describing what treatment may be withheld now reads “life-prolonging measures” that include mechanical ventilation, dialysis, antibiotics, artificial nutrition, and hydration. The natural progression of a terminal illness includes a point where the body can no longer comfortably process food or take in water. Nonetheless, withholding nutrition and/or hydration remains a difficult choice for many. The new living will document takes this into account and allows one to choose to withhold life-prolonging measures but still receive nutrition and hydration.

### What if there is no advance directive?

When end-of-life treatment options need to be addressed *and* the person is unable to communicate *and* there is no living will or health care agent, what can the doctor and the family do? G.S. §90-322 lists the procedures to follow when a person’s wishes are not known. Two physicians must still determine that the person meets either the first or the second criterion (incurable disease with very limited life expectancy or almost no likelihood of regaining consciousness). However, the third condition—advanced dementia or substantial loss of cognitive ability—is not justification for withholding treatment when no declaration has been made.

### Who can consent to withdrawing treatment when there is no advance directive?

Another major revision to G.S. §90-322 is clarification of the priority list of individuals who may consent to withholding treatment after two physicians agree that it is time to consider it. In order of priority, physicians must consult

1. A guardian of the patient’s person or general guardian with powers over the patient’s person, if the clerk of court has revoked the health care agent’s authority
2. A health care agent appointed under a valid health care power of attorney
3. An attorney-in-fact with powers to make health care decisions
4. The patient’s spouse
5. A majority of the patient’s reasonably available parents and children who are at least 18 years of age
6. A majority of patient’s reasonably available siblings who are at least 18 years of age
7. An individual who has an established relationship with the patient, who is acting in good faith on behalf of the patient, and who can reliably convey the patient’s wishes.

### Guardianship and end-of-life care

The new health care power of attorney form continues to include a provision that enables a person to nominate a health care agent as guardian, if it becomes necessary to have one. Under the old law, if a county clerk of superior court appointed a general guardian or guardian of the person, that guardian became responsible for making health care decisions and the health care power of attorney ceased to be in effect, but this change in authority is no longer automatic. The health care agent may continue to make health care decisions unless the clerk determines that it is necessary to suspend the health care agent’s authority and give that power to a guardian. If the clerk determines the guardian shall have the authority to make health care decisions, the order removing the health care agent must include specific findings of fact and conclusions of law in the order, as well as stating whether the guardian must act consistently with the other declarations in the health care power of attorney.

## Revocation

People may remove their health care agent and revoke a health care power of attorney anytime while competent. However, if declared incompetent, only a clerk of court may remove the health care agent. You may revoke your living will at any time, regardless of your physical or mental condition. A health care agent only has the authority to revoke a living will if you explicitly grant that authority in the health care power of attorney document. A guardian never has the authority to revoke a living will.

## The MOST document

The Medical Orders for Scope of Treatment or MOST document is not an advance directive drafted by an individual, but a physician's order sheet similar to the out-of-facility or portable "do not resuscitate" (DNR) form (it is neon pink, rather than yellow with a red stop sign). It goes beyond DNR orders by including detailed end-of-life health care decisions—it records choices about the full scope of treatment (including transfer to a hospital) and a statement of whether the individual wants cardiopulmonary resuscitation (CPR), limited treatment (aimed at avoiding intensive care), or comfort measures only. It also documents whether the person wants antibiotics or medically administered fluids or nutrition.

Like the portable DNR, the MOST form is intended for use by people who have terminal illnesses or advanced degenerative diseases whose death is likely within a year. The form must be completed by a health care professional after a discussion of the options and implications of the choices, and it must be signed by both the doctor and the individual. It is designed to travel with the person among different health care settings and must be updated at least once a year or more often if the individual's condition changes. MOST documents will be available for health care professionals to order on the EMS web site beginning January 15, 2008, <http://www.ncdhhs.gov/dhsr/EMS/ems.htm>.

## How do I help clients or family members with this?

The best place to begin is to make an advance directive and appoint a health care agent for yourself, if you haven't already done so. None of us wants to think about doing this, but understanding what causes your own reluctance and what information you need to make these choices can prepare you to work with others. It's easy to believe (or hope) that you won't need someone to make these decisions anytime soon, but remember that Quinlan, Cruzan, and Schiavo were all in their 20s when they suffered catastrophic brain injuries, and all survived about 10 years more.

Start by learning more about the sort of interventions that can be made—CPR, artificial hydration and nutrition, treatment of infection, pain relief—and what might hap-

pen if you consent to or refuse them. Many websites for caregivers have information sheets—see, for example, the ones provided by the Family Caregiver Alliance (<http://www.caregiver.org/>) on CPR/DNR and feeding tubes and ventilators. Kathy Lowe at CARES recommends *Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care and the Patient with a Life-Threatening Illness*, by Hank Dunn (A & A Publishers, 2001), because it describes the various treatments and their consequences in detail in nonmedical language. For a more technical approach, the Merck Manual online has an article entitled "Symptom Control in the Dying" (<http://www.merck.com/mmpe/sec22/ch338/ch338d.html>). Although this article is aimed at medical professionals, it gives information about specific drugs, how they work, and when and why they might be prescribed.

While you're reading, remember that we are talking about treatment when you can't make your wishes known and when there is a very great likelihood that you won't survive, not about treatment that you can consider directly or that is likely to restore your health. Remember, also, that it is your right to have hope and fight on, and these documents allow you to convey that decision, too.

Next, get a copy of both documents, read them carefully, and fill them out, but don't sign them immediately. You must sign in the presence of two qualified witnesses and a notary public. No one who might benefit from your death may serve as a qualified witness, nor may a spouse or third-degree relative (grand relatives; parents, siblings, and children; aunts, uncles, and cousins, including step relationships), or your health care provider(s). Unpaid volunteers in health care settings may serve as qualified witnesses, and the notary may be a paid employee of a health care provider.

The new living will document clearly states that you intend for your health care providers to follow the directive no matter where you are. Once signed, you can register both your living will and your health care power of attorney online at <http://www.nclifelinks.org/ahcdr/>. It's also a good idea to give copies to your family members and health care provider(s).

### Starting the conversation with others

Completing these documents is a way to be more assured that you will be treated as you wish, but they are even more important to the people who may have to make these decisions on your behalf. It's not an easy topic, but if you have thought the issue through for yourself and discussed your own wishes with family and friends, you may have a better idea of how to begin. The National Hospice and Palliative Care Organization (<http://www.caringinfo.org/PlanningAhead.htm>) has some suggestions, and perhaps the most important is being prepared to listen.

**Thanks to Lynne Berry, Rosalyn Pettyford, Kate Walton, and Nancy Warren for preparing this article.**

# Mark Your Calendar for Continuing Professional Education!

## January 2008

- 8–10 Effective Social Work Practice with Adults: A Core Curriculum, Graham (and January 22–24)  
 15–16 Working with Older Adults, Winston-Salem  
 29 Beginning with the End in Mind, Mocksville

## February 2008

- 6–7 Working with Adults with Cognitive Disabilities, Pinehurst  
 12–13 Developing Effective Helping Relationships, Asheboro  
 19 Substance Use and Older Adults, Henderson  
 26–28 Effective Social Work Practice with Adults: A Core Curriculum, Washington (and March 11–13)

## March 2008

- 6–7 Geriatric Mental Health, Charlotte (and April 10–11; registration through AHEC)  
 18 Beginning with the End in Mind, Sylva  
 25–26 Working with Clients with Serious Mental Illness, New Bern

## April 2008

- 1–2 Working with Older Adults, Wilmington  
 7–10 DSS Supervisors' Curriculum, Modules 1, 2, and 3, Wilmington

- 15–16 Working with Adults with Cognitive Disabilities, Whiteville  
 22–23 Developing Effective Helping Relationships, Spindale  
 29 Substance Use and Older Adults, Mt. Airy

## May 2008

- 6–8 Effective Social Work Practice with Adults: A CORE Curriculum, Brevard (and 21–23)  
 13–14 Geriatric Mental Health, Greenville (and June 10–11; registration through AHEC)  
 29 Ethics and Everyday Practice, Bolivia

## June 2008

- 4 Ethics and Everyday Practice, Statesville  
 9–13 DSS Supervisors' Curriculum, Modules 4, 5, and 6, Wilmington  
 17–18 Working with Adults with Cognitive Disabilities, Boone  
 25–26 Working with Clients with Serious Mental Illness, Asheboro

For descriptions of these events, registration forms, and calendar updates, visit the CARES website, <http://ssw.unc.edu/cares/trnall.htm>. Also, you can register on line at <http://ncswlearn.org>.

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*The aspen is perhaps the world's largest organism. Although some aspen forests cover acres and seem to be composed of individuals in all stages of life, they share a common root system.*

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