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The Good, The Bad, and The Ugly: Evolution of the Law Affecting End-of-Life Planning

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Over the last thirty years there have been significant changes to end-of-life-planning. The changes were initiated as a result of "ugly" scenes played out on national television when grieving families were forced to sue health care providers in order to withdraw life-support systems from family members whose medical conditions would never improve. As a result of these lawsuits, Health Care Power of Attorney and Declaration of a Desire for a Natural Death ("Living Will") statutes were enacted that recognized an individual's right to control medical decisions, even when the individual lacked the ability to make or communicate those decisions.

In 2007 substantial changes were made in North Carolina's statutory Health Care Power of Attorney form as well as the statutory Living Will form. Although many improvements were made in North Carolina's statutory forms, for the reasons expressed below we have decided to recommend that, in lieu of the new statutory forms, our clients execute an alternative form that we have drafted combining the health care power of attorney and living will provisions. This alternative combined form appears in the 2007 supplement to the BB&T ESTATE PLANNING FORMS MANUAL and as a PDF document on the Robinson Bradshaw & Hinson website, www.rbh.com, that can be downloaded from the MenuForms page .

Historical Background

Historically, the presumption in the law favored the continuance of life under all circumstances. However, a movement to change the law and grant individuals the right to decide end-of-life medical treatment gained momentum in response to the legal challenges brought by family members after the tragic accidents of two young women Karen Ann Quinlan and Nancy Cruzan.

Beginning in 1975, when Karen Ann Quinlan suffered irreversible brain damage following complications from mixing alcohol and valium at a party, the movement to extend the common law right of an individual to refuse medical treatment in non-emergency situations to the right of an individual to elect to die a natural death without the intervention of life-prolonging measures began to gain national acceptance. In 1976, after Karen Ann Quinlan's parents secured the New Jersey Supreme Court's permission to disconnect their daughter from life support systems (*In re Quinlan*, 70 N.J. 10, 355A. 2d 647, cert. denied *sub nom.*, *Garger v. New Jersey*, 429 U.S.

92 (1976), States began adopting Natural Death Acts. In 1978 North Carolina became one of the first States to pass a Right to A Natural Death Act, creating the first statutory "Living Will" form in North Carolina codified in Article 23 of Chapter 90.

Fifteen years later in 1990 the issue of end-of-life treatment was addressed by the United States Supreme Court in the case involving Nancy Cruzan who in January 1983 suffered irreversible brain damage as a result of an automobile accident. Unlike Karen Ann Quinlan, Ms. Cruzan was able to breath on her own but needed a feeding tube to receive the necessary nutrition and hydration to sustain her life. When the hospital refused to remove the feeding tube, her parents sued. The State of Missouri appealed the local probate court's order allowing the parents to remove the tube, and the Missouri Supreme Court, while recognizing an individual's right to refuse medical treatment based on the common-law doctrine of informed consent, overruled the probate court's decision.

On appeal to the United States Supreme Court, the constitutional question presented was not whether a surrogate could act on behalf of an incompetent patient to elect to have artificial nutrition and hydration withdrawn, but whether a State could establish procedural safeguards to assure the action of the surrogate conformed to the expressed wishes of the patient while competent. The State of Missouri required the Cruzan family to establish by clear and convincing evidence that their daughter would not want life pro-longing measures under the circumstances that existed. The State maintained the family had failed to meet its evidentiary burden. Even though the Supreme Court upheld the decision of the Missouri court, it concluded that it was indisputable that the "Due Process Clause protects an interest in life as well as an interest in refusing life-sustaining medical treatment." *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261 (1990). The case was retried in the Missouri probate court where the family ultimately established by clear and convincing evidence that Nancy Cruzan would not want her life prolonged and the feeding tube was removed.

As a result of the Supreme Court's decision in *Cruzan* that individuals have a constitutionally protected interest in refusing life-sustaining treatment within State mandated procedural safeguards, States began enacting health care power of attorney statutes that established procedural requirements for delegating medical decisions to surrogates and authorizing the discontinuance of life-sustaining treatment. North Carolina's law, codified in Article 3 of Chapter 32A of the General Statutes, was enacted in 1991. It recognized an individual's right to control decisions relating to his medical care by designating an agent to make such decisions on his behalf. The specific purpose of Article 3 was to establish an additional, nonexclusive method for an individual to exercise his rights concerning medical treatment when he lacks the capacity to make or communicate heath care decisions.

Conflicts Between the Statutory Forms

There was a significant time lapse between the enactment of North Carolina's Living Will statute and the Health Care Power of Attorney statute. Many thought use of the Living Will statutory form would be discontinued when the new statutory Health Care Power of Attorney form was enacted. However, many clients continued to execute both forms. The two statutory forms contained several discrepancies that proved to be confusing.

First, the Living Will statutory form allowed an individual to state that he did not want his life prolonged if it was determined that he met one of two statutory conditions: (i) his condition was terminal and incurable or (ii) his condition was a persistent vegetative state. On the other hand, the Health Care Power of Attorney statutory form extended the conditions under which the health care agent was permitted to discontinue life sustaining measures to " terminally ill, permanently in a coma, suffer severe dementia, or in a persistent vegetative state."

It was not clear why the two forms provided for different statutory conditions for the withdrawal of life-sustaining procedures. Did the fact that the Living Will form omitted "severe dementia" imply that condition was not grounds for withholding treatment unless the patient had a valid Health Care Power of Attorney form? The answer was not clear. In addition, the statutory forms did not define the relevant terms. There was no guidance

under the statute for when a coma would be deemed "permanent," or whether "terminally ill" under the statute inferred imminent death.

Moreover, it was not clear which directive, the Living Will or the Health Care Power of Attorney, took precedence if an individual signed both statutory forms. Could the health care agent refuse to follow the directions in the Living Will and continue life sustaining measures? The statutes did not address this question.

In addition, the Living Will statute provided either that "*extraordinary means* or artificial nutrition or hydration" could be withheld under the stated conditions. While the term "extraordinary means" was defined as "any medical procedure or intervention 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," the term "artificial nutrition and hydration" was not defined. Thus, it remained unclear whether artificial nutrition and hydration fell within the definition of "extraordinary means."

On the other hand, the Health Care Power of Attorney statute allowed an individual to grant an agent the authority to withhold "*life-sustaining procedures*" which was defined as "those forms of care or treatment which only serve to artificially prolong the dying process and may include mechanical ventilation, dialysis, antibiotics, artificial nutrition and hydration and other forms of treatment which sustain, restore or supplant vital bodily functions, but do not include care necessary to provide comfort or to alleviate pain."

Use of "extraordinary means" under the Living Will statute and "life-sustaining procedures" under the Health Care Power of Attorney statute created further confusion. The different treatment of artificial nutrition and hydration under the two statutes was particularly bothersome.

Following the national media attention surrounding the death of Terri Schiavo in Florida, the North Carolina Bar Association and the North Carolina Medical Society established a joint committee to consider changes that would clarify and improve North Carolina's laws on Health Care Powers of Attorney and Living Wills. The result was House Bill 634 that made significant changes to the laws governing end-of-life health care planning in North Carolina. These changes, which were effective October 1st, include new statutory Health Care Power of Attorney and Living Will forms.

Changes Under House Bill 634

There were "good" changes under House Bill 634. One of the most significant improvements to the health care law is the newly defined term "life-prolonging measures" in both the statutory Health Care Power of Attorney and Living Will forms which brings consistency to the terminology between the statutes. Now, under both statutes "life-prolonging measures" is defined to include artificial nutrition and hydration.

House Bill 634 also clarifies in the *Living Will statute and statutory Living Will form* the conditions under which life-prolonging measures may be withheld or withdrawn. These conditions include: (i) the patient has an incurable or irreversible condition that will result in death within a relatively short period of time, (ii) the patient is unconscious and the health care providers determine that, to a high degree of medical certainty, the patient will never regain consciousness and (iii) the patient suffers from advanced dementia or any other condition which results in the substantial loss of cognitive ability and the health care providers determine that, to a high degree of medical certainty, this loss is not reversible.

However, some of the changes in the new statutory forms, in our opinion, are "bad" because the structure and content of the new forms may prove too complicated and confusing to clients, particularly to those who desire to execute both forms. Moreover, we think there are several problems with the new statutory forms as addressed below.

1. Unlimited authority of the health care agent with respect to withdrawal of life-prolonging measures. Perhaps the most significant problem with the new statutory Health Care Power of Attorney form is that, unless the individual expressly provides otherwise, the form grants the health care agent unlimited authority to withhold or discontinue life-prolonging measures. For individuals not wishing to give their health care agents such unlimited authority to withhold or discontinue life-prolonging measures, the new statutory form requires that individual to include his "own definition of when life-prolonging measures should be withheld or discontinued." We think that most clients would have neither the inclination nor the medical knowledge sufficient to formulate such a definition.

If asked for guidance in completing the statutory Health Care Power of Attorney, we would suggest inserting the three conditions under which life-prolonging measures may be withheld or withdrawn that are specified in the Living Will statutes and statutory form and, as in the statutory Living Will form, giving the client the choice of withholding or withdrawing life-prolonging measures as to each condition.

2. Too many choices in the statutory forms with respect to artificial nutrition and hydration. We think that both the statutory Health Care Power of Attorney and Living Will forms give the client too many choices to initial with regard to artificial nutrition and hydration, at least one of which is nonsensical. Both forms permit the client to initial that he wants artificial nutrition without initialing that he wants artificial hydration. Based on discussions with physicians it is clear that tube feeding cannot occur without hydration being involved. Our experience has been that the vast majority of clients who want this type of intervention want both artificial nutrition and hydration.

More importantly, we think any options concerning artificial nutrition and hydration should appear in the part of the form where the client is asked to choose that he does not want life-prolonging measures. The statutory Health Care Power of Attorney form, however, asks the individual to make choices concerning artificial nutrition and hydration in Paragraph 5.A when, for example, the individual in Paragraph 5.B may decline to give the health care agent the authority to withhold or withdraw life-prolonging measures altogether.

3. Giving the client the option to express a desire to have his or her life prolonged. We also think a client should have the option to express a desire to have his life prolonged within the standards of acceptable medical practice. As noted above, historically statutory Health Care Powers of Attorney and Living Will forms developed to allow individuals who did not want their life prolonged artificially to express this desire because the presumption was that life would be prolonged. The North Carolina statutes do not expressly authorize an individual to state a desire that his life be prolonged. Consequently, the statutory forms provided in House Bill 634 do not give the client that option.

As a result, if a client decides not to execute a living will and does not authorize the health care agent to withhold or withdraw life-prolonging measures, there is only a weak inference that the client desires his life to be prolonged. In such a situation under section 90-322 of the General Statutes the decision to withhold or withdraw life-prolonging measures devolves on another individual in the order prescribed by that statute. On the other hand, we note that section 90-322 provides a strong statutory presumption that the individual does not want life-prolonging measures withheld or withdrawn in the case of advance dementia. The statute contains two conditions specified in the living will as conditions permitting others to withhold or withdraw life-prolonging measures when there is no declaration but omits the third condition relating to advance dementia. This omission was apparently based on the assumption that an individual may not want life-prolonging measures withdrawn or discontinued if the individual has advanced dementia.

We think an individual, rather than having to rely on statutory presumptions, should be able to clearly express a desire that his life be prolonged as to each of the three conditions specified in the living will statute. We

recognize that there is no North Carolina law specifically requiring the health care provider to honor the request to provide life-prolonging measures and that there is a legislative research commission which may result in the law being amended in this regard.

4. Choices concerning disposition of the body in the statutory Health Care Power of Attorney form. Another problem with the statutory Health Care Power of Attorney form is that it grants the health care agent the authority to make decisions with regard to the principal's body in certain situations and not others. The health care agent has the authority to make decisions regarding autopsies and burial or cremation of the body *unless* the client drafts his own specific limitations on that authority; and yet the opposite approach is taken with "organ donation" where the health care agent does not have authority to make such gifts unless the client specifically initials one or more options in the statutory form.

Our experience has been that a client makes decisions regarding the disposition of his remains or organ donations in other documents such as wills or anatomical gift instruments. While it is clear in paragraph 4.1 of the statutory Health Care Power of Attorney form that directives in such other documents validly executed *prior* to the execution of the Health Care Power of Attorney control, it is not clear which document controls if a will or anatomical gift instrument is executed subsequent to the execution of the Health Care Power of Attorney.

We think all options concerning disposition of the body should be grouped together in one place in the Health Care Power of Attorney form and that the preferred approach is not to grant the health care agent authority to make decisions regarding the body unless the client specifically initials the options. Furthermore, the Health Care Power of Attorney form should be very clear that all valid documents executed by the client before or after execution of the Health Care Power of Attorney relating to disposition of the body take precedence over the authority given the Health Care Agent.

5. Use of "Shall" and "May" Choice in Statutory Living Will form. The Living Will statute provides in section 90-321(b) of the General Statutes that if a person has expressed a desire that his life not be prolonged and other requirements of that subsection are met, life prolonging measures "shall or may as specified by the declarant" be withheld or discontinued upon the direction of the attending physician. Section 90-321(c) provides that the attending physician "shall" follow a declaration subject to subsection (b), subsection (e) regarding revocation of the declaration and subsection (k) regarding conscientious objection. The Statutory Living Will form then requires the client to choose whether the health care provider "may" or "shall" withhold or withdraw life-prolonging measures. We question the necessity of such choice. We think that most clients would want their direction to be followed subject to the exceptions provided by statute, and what the physician should consider as a result of an individual choosing "may" as opposed to "shall" is not at all clear. The choice of "may" seems tantamount to no direction at all.

Alternative Form - Combined Health Care Power of Attorney and Advance Directive Regarding a Natural Death

For the reasons expressed above, we concluded that an alternative form is advisable. Since our firm has South Carolina clients, we are familiar with the South Carolina statutory form combining both Health Care Power of Attorney and Living Will provisions. We have thought for some time that such a combined form is preferable to separate forms. The combined form eliminates any conflicts between separate forms and is the best document that we can offer our clients because it encourages thoughtful consideration at one time to all the possibilities, including whether the decision of the health care agent or the instructions of the client as to life prolonging measures should prevail. Section 90-321(j) of the General Statutes specifically authorizes combining the Living Will form with the Health Care Power of Attorney form meeting the requirements of the statute so long as the resulting form is signed, witnessed and proved in accordance with the Living Will statute. *See also* N. C. Gen. Stat. §32A-26.

The alternative form limits the authority of the health care agent to make decisions regarding withdrawal or discontinuance of life-prolonging measures to the three medical conditions contained in the new statutory Living Will form. The alternative form gives the client the only three choices available with respect to each condition: (i) Let the health care agent decide whether to withhold or withdraw life-prolonging measures; (ii) State affirmatively that the client does not want life-prolonging measures; or (iii) State affirmatively that the client does want life-prolonging measures.

These alternative form provisions giving the three choices to the individual or similar to those in the South Carolina Statutory Health Care Power of Attorney form which in this respect we used as a model.

The specific language of the third choice, that the individual does want life-prolonging measures was derived from the South Carolina Health Care Power of Attorney. As indicated above, we think a client should be given this choice even though there is currently no North Carolina law that specifically requires health care providers to honor the request to provide life-prolonging measures. The request is limited by the language that life be prolonged "within the standards of acceptable medical practice." We also made a subtle change in the name of the alternative form so that it is a Health Care Power of Attorney and Advance Directive Regarding a Natural Death. By using "regarding" rather than "for" in the title of the form, we are indicating that the client may choose to have his life artificially prolonged or not.

As mentioned previously, the term "life-prolonging measures" includes, unless the client says otherwise, "artificial nutrition and hydration." Therefore, in the alternative form at the point where an individual chooses that he does not want life-prolonging measures, the client can initial that he nevertheless wants artificial nutrition and hydration. This close placement is in contrast to the new North Carolina statutory Health Care Power of Attorney form in which the client is given the choice to initial paragraphs as to whether the agent has authority to withhold artificial nutrition and artificial hydration that are not linked to the paragraphs where the client expresses his choice as to withholding or withdrawal of life-prolonging measures. Moreover, the alternative form eliminates the improbable choice of requiring artificial nutrition but not hydration.

The alternative form is intended to revoke all prior Health Care Powers of Attorney and Living Wills. However, the alternative form is not intended to revoke the client's instructions with respect to disposition of his body. To the extent the client has not made valid provisions for the dispositions of his body, the individual in the alternative form can authorize the health care agent to make decisions regarding disposition of the body, including the authorization of an autopsy, the donation of tissue or organs for transplantation or therapy, the donation of the body for anatomical study and the direction of the disposition of the remains which is defined as a decision to bury or cremate human remains. Absent specific authorization, the health care agent has no authority to make decisions regarding the disposition of remains or to make anatomical gifts on behalf of the individual.

Conclusion

In conclusion, we think the alternative form combining Health Care Power of Attorney and Living Will provisions will prove simpler and less confusing to clients, require less explanation and guidance by the practitioner and should be acceptable to health care providers. We think the choices offered by the alternative form will be complete and satisfactory to most, if not all of our clients.