Most Americans have strong views on end-of-life care and, when asked, say they would not want to be kept alive artificially by medical interventions if they suffered from a terminal illness or had severe dementia. A 2003 study by the Agency for Healthcare Research and Quality (“AHRQ”) found that upwards of 72% of respondents would refuse cardiopulmonary resuscitation, mechanical respiration, intravenous fluids, and artificial nutrition if they had dementia. Those numbers rose to 82% or higher when respondents were asked to assume they had dementia and a terminal illness.

Ironically, however, relatively few Americans plan for end-of-life issues by expressing their wishes through advance directives. The AHRQ study found that less than 50% of severely or terminally ill patients execute advance directives. Only 12% of people who execute advance directives discuss them with their doctors, and over 65% of physicians are unaware of the advance directives that actually have been executed by their patients. See “Advance Care Planning: Preferences for Care at the End of Life” www.ahrq.gov/research/endlifedia/endria.htm.

These problems are compounded by the fact that both family members and health care providers often guess wrong about what their loved ones or patients would want if faced with incurable, terminal illnesses, permanent comas, or severe dementia. The AHRQ study found that doctors were accurate in predicting patient preferences only about 65% of the time and tended to provide less treatment than their patients otherwise would have requested. Surrogates who were family members, on the other hand, tended to authorize more treatment than the patient would otherwise have preferred, even if the patient and the surrogate had previously reviewed or discussed the patient’s advance directive. A 2007 study by the University of Wisconsin found that even husbands and wives make poor prognosticators. When asked to predict what their spouses’ wishes would be regarding end of life care, such as whether or not they would want artificial nutrition and hydration, 33% of study participants guessed wrong. See “Do Older Adults Know Their Spouses’ End-of-Life Treatment Preferences?” Center for Demography and Ecology, University of Wisconsin-Madison, CDE Working Paper No. 2007-05. http://www.ssc.wisc.edu/cde/cdewp/2007-05.pdf.

The message is clear. Fifteen years after passage of the federal Patient Self-Determination Act (42 U.S.C. § 1395 cc(a) (1990)), which was designed to ensure that patients are informed about their end-of-life decision-making rights, many Americans still do not adequately plan for and communicate their preferences regarding end of life care.

The 2007 North Carolina General Assembly took steps to address this concern by enacting House Bill 634, which significantly overhauls the state’s advance directives laws. The changes are designed to clarify prior law and to provide additional choices for North Carolina citizens. The changes affect existing state laws governing living wills (N.C.G.S. §§ 90-320 et seq.), health care powers of attorney (N.C.G.S. §§ 32A-15 et seq.), and the so-called “statutory living will” laws that govern the withholding of life-prolonging care in the absence of a living will (N.C.G.S.}
§ 90-322). HB 634 also authorizes a new portable advance directive called a Medical Order for Scope of Treatment (“MOST”).

House Bill 634, as enacted:

- Replaces the term “extraordinary means” with the term “life-prolonging measures”, which it defines as medical procedures or interventions that serve only to postpone artificially the moment of death by supplanting, restoring or sustaining a vital life function. N.C.G.S. § 90-320(a). The term specifically includes mechanical ventilation, dialysis, antibiotics, artificial nutrition and hydration, and “similar forms of treatment.” N.C.G.S. § 32A-16(4). Comfort measures are not included in this term.

- Replaces the terms “persistent vegetative state” and “terminal and incurable condition” as the triggers defining when life-prolonging measures may be withheld under a living will. The new triggers are: 1) an incurable or irreversible condition that will result in death within a relatively short period of time; 2) the patient is unconscious and it appears to a high degree of medical certainty that the patient will not regain consciousness; or 3) the patient has advanced dementia or other substantial loss of cognitive ability and it appears to a high degree of medical certainty that the condition is not reversible. The maker of the living will can select any or all of these conditions as triggering the withholding of life-prolonging measures. N.C.G.S. §§ 90-321(b) and (c).

- Allows the maker of a living will to state that health care providers shall withhold or withdraw life-prolonging measures when the trigger conditions are present or may withhold such care in those situations. N.C.G.S. § 90-321(b).

- Allows the maker of a living will who has appointed an agent under a health care power of attorney either to direct that agent to follow the living will or to authorize the agent to override the living will instructions. N.C.G.S. § 90-321(d1).

- Includes a revised living will form reflecting the changes described herein and providing patients additional choices regarding the types of life-prolonging measures that they will receive. (Although these additional choices promote patient choice, they also have the potential to increase confusion and result in patients selecting mutually-inconsistent choices. Patients will need additional guidance with the new forms.) N.C.G.S. § 90-321(d1).

- Clarifies that health care providers who rely upon a revoked living will (N.C.G.S. § 90-321(e)) or health care power of attorney (N.C.G.S. § 32A-24(d)) are not liable absent actual notice of the revocation.

- Clarifies that paid facility employees may not serve as witnesses for living wills (N.C.G.S. § 90-321(c)(3)) or health care powers of attorney (N.C.G.S. § 32A-16(6)) but does not preclude facility volunteers from doing so.
• Clarifies that paid facility employees may serve as notaries for living wills (N.C.G.S. § 90-321(c)(4)) and health care powers of attorney (N.C.G.S. § 32A-16(3)) but are not required to do so.

• Continues the “conscience exception” for health care providers but states that physicians who refuse to honor an advance directive based on their own conscience or the conscience-based policies of the facility where the patient is being treated must assist in the transfer of the patient to a facility or physician who will honor the directive. The new legislation also allows a provider to refuse to honor an advance directive if he or she has a good faith belief that the document is not valid. N.C.G.S. § 90-321(k).

• Clarifies that a guardian may not revoke a valid living will or health care power of attorney. N.C.G.S. § 90-321(e). The new law also states that where a guardian is appointed, a health care agent appointed pursuant to a valid health care power of attorney retains her power over those decisions covered by that document unless a court suspends the agent’s powers, in which case the court must state whether the guardian is then required to act consistent with the health care power of attorney or may deviate from it. Providers may continue to rely upon a valid health care power of attorney, without liability, until they receive actual notice of a revocation of the document by a court. N.C.G.S. § 32A-22(a) and N.C.G.S. § 35A-1241(a)(3).

• Clarifies further who may give consent for medical treatment where a patient lacks capacity to make or communicate health care decisions by listing individuals, in order of priority, who can make such decisions for the patient. N.C.G.S. § 90-21.13. This same list is used later in the legislation to identify surrogates who can make decisions regarding the withholding of life-prolonging measures in the absence of a living will. N.C.G.S § 90-322(b).

• Provides additional protections from civil liability, criminal prosecution or professional discipline for providers who act pursuant to a living will or health care power of attorney, unless the provider has actual knowledge of the revocation of that document or has reason to question its validity. N.C.G.S. §§ 90-321(e) and (h) and N.C.G.S. § 32A-24.

• Allows providers to rely upon an oral or written statement of counsel that an advance directive executed in North Carolina or another state is valid. N.C.G.S. § 90-321(h). The law also stipulates that advance directives created in other states are valid in North Carolina if they are valid under the law of either this state or the state where they were created. N.C.G.S. § 90-321(l) and N.C.G.S. § 32A-24(d).

• Clarifies that living wills created before the new law becomes effective are “grandfathered” in, and thus remain valid without being revised or recreated. N.C.G.S. § 90-321(i).
The New MOST Legislation

• Creates the new Medical Order for Scope of Treatment ("MOST") form, which allows patients to request, and doctors to order on a standing basis, a range of treatments, or the withholding of such treatments, including life-prolonging care and less drastic care such as antibiotics, among others. N.C.G.S. § 90-21.17. A MOST form containing instructions that are consistent with the patient’s previously-executed living will or health care power of attorney allows providers to immediately initiate or withhold care covered by the documents without further physician intervention since the MOST form is a standing physician’s order.

• Provides that the MOST form must have the consent of the patient or his representative, the basis of which must be documented in the medical record. The patient or the patient’s representative is required to sign a completed copy of the MOST form; however, where it is not practical for a patient representative to sign the original (e.g., where the patient representative lives in another state, and the discussion about the options on the MOST form and the provision of the representative’s consent occur over the telephone), the patient representative may be provided an electronic copy of the completed form to sign and return. In such a case, the signed copy of the form is to be included in the patient’s medical record, and the patient/patient representative signature field on the original MOST form should indicate “on file.” N.C.G.S. § 90-21.17(b).

• Designates information that must be included on the MOST form, including information about the patient, the licensed health care professional completing the form, the designated health care choices of the patient, the effective date of the form, and dates on which the was reviewed, among other information. N.C.G.S. § 90-21.17(c).

• Requires a statement warning patients that a valid MOST form may, while the MOST is in effect, suspend or supersede conflicting directions in a patient’s previously-executed living will, health care power of attorney or other similar instrument. (This creates the potential for confusion and will require careful discussion with patients or their surrogates.) N.C.G.S. § 90-21.17(c).

• Requires a statement that patients are not required to have a MOST to receive medical care. N.C.G.S. § 90-21.17(c).

• States that the MOST form should be a universal, portable form similar to the universal Do Not Resuscitate form. N.C.G.S. § 90-21.17(c).

• Requires that the Department of Health and Human Services develop a standardized MOST form, which is expected to be closely based on one already developed by the N.C. Medical Society and the N.C. Bar Association. N.C.G.S. § 90-21.17(c).
States that no provider may be found civilly or criminally liable, or face professional disciplinary action, for relying upon a valid MOST form, absent actual knowledge of its revocation or reasonable grounds to doubt its validity. N.C.G.S. § 90-21.17(d).

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