Physicians and Patients Will Benefit from New Legislation on End-Of-Life Care Decisions

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One of the most difficult challenges physicians are experiencing is the treatment of a patient who is at the end-of-life. Physicians must be aware of the current medical, ethical and legal options and they must be able to effectively communicate all of those options to the patient. Certainly, there is no more difficult message for a physician to deliver to a patient than: "You are going to die."

More than thirty years ago, New Jersey's policymakers and Courts attempted to resolve end-of-life issues as a result of the Karen Ann Quinlan case. Family members and medical providers had differing opinions on how to treat Ms. Quinlan. As a result of the Karen Ann Quinlan case many state legislatures, including New Jersey's, enacted laws that allow an individual to set forth his or her end-of-life health care intentions in an advance directive.

In the intervening years policymakers have determined that additional laws are needed to make end-of-life decisions easier for families and healthcare providers. Therefore, two important new bills were signed into law during the 2010-2011 legislative session. A third bill has been reintroduced into the new 2012-2013 legislative session.

The first bill establishes the New Jersey Council on End-of-Life Care in the Department of Health and Senior Services' ("DHSS"); the second bill creates a form entitled the "Physician Order for Life-Sustaining Treatment ("POLST") so that patients can indicate their preferences for health care; and the final bill establishes a system to assist patients who lack decision-making capacity and who have no one available to make certain decisions for them. The need for this type of legislation has been well documented for many years by federal and state health care policymakers.

POLICYMAKERS AND STUDIES FIND DEFICIENCIES IN END-OF-LIFE CARE SYSTEM AND RECOMMEND THAT PHYSICIANS AND OTHER HEALTHCARE PROFESSIONALS RECEIVE EDUCATION AND TRAINING

According to an article by Alan Meisel and Bruce Jennings on "Ethics, End-of-Life Care, and the Law: Overview" the factors that complicate end-of-life discussions by physicians are "our legal traditions; the traditions of ethics in medicine and in moral philosophy more generally; and cultural, and social and religious values, which are quite diverse in the United States and may vary subtly from one state or region of the country to the next." The changes in medical technology are certainly the major factor in complicating these discussions. "Most of the cases and dilemmas that have shaped the law on end-of-life care have involved patients whose lives could be prolonged by new medical treatments and technologies, but whose health, functioning, quality of life, and even conscious awareness itself could not be restored."

In view of these factors it is understandable that *physicians need assistance in communicating with patients who are at the end of their life.*

A report of the Institute of Medicine's (IOM) Committee on Care at the End-of-life (Field & Cassel, 1997) identified five areas of deficiencies in current care for people with life-threatening and incurable illnesses. The third major area of deficiency cited in the IOM Report states that "the education and training of physicians and other health care professionals fails to provide them with the attitudes, knowledge, and skills required to care well for dying people and their families."

This finding is backed up by a new study published in the *Journal of Clinical Oncology*, which assesses the first program designed specifically to improve physicians' communication skills when faced with patients at the end of life. The study demonstrates that a short training program assists physicians to communicate better to their patients about terminal cancer, how to provide the patient emotional support and the importance of involving the patient's significant others.

Tanja Goelz, of the University Medical Center in Freiburg, Germany, and her colleagues developed the program to see if it was effective in improving the physicians' communication skills. They first videotaped 41 physicians performing consultations with actors pretending to be sick patients. Half of those physicians who were randomly chosen underwent training, while the others didn't.

After five weeks, the physicians who had been trained in communications skills were better at explaining the

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transition to end-of-life care, at communicating well in general and at asking about the actor-patients' families.

A study from the University of Pittsburgh School of Medicine and the Graduate School of Public Health ("Study") found that "family caregivers who had not discussed life support measures with critically ill patients took nearly two weeks longer to decide to forego further medical intervention than those who had prior conversations about the issue." The researchers determined that "caregivers who hadn't had a prior conversation with patients about treatment preferences took 40 percent longer – 33 days versus 21 days – to decide to discontinue life support."

"Teaching doctors to be better communicators may be an important step in improving end of life decisions for patients." The Study also "reinforces the value of patients, families and friends having prior conversations about the end of life so that they can feel comfortable with their decisions about medical care," said Senior Investigator Douglas B. White, M.D., associate professor and director of the Program on Ethics and Decision-Making in Critical Illness.

The New Jersey Hospital Association ("NJHA") recently released a "white paper" entitled, "End of life Care in New Jersey Hospitals: A Blueprint for Action," which calls for "standardized policies that will guide both patients and healthcare professionals through the difficult issues surrounding the end of life." The "white paper" supports a healthcare system "where patients are assured a pain-free death with dignity, where the choices of patients and their families are clearly heard."

This "white paper" also served as the basis for the new legislation on end-of-life issues, including the adoption of POLST – physician's orders for life-sustaining treatment – and the creation of a statewide advisory panel on palliative care.

OVERVIEW OF NEW END-OF-LIFE CARE LAWS AND PENDING LEGISLATION:

1. New Jersey Council on End-of-Life Care Created to Study Effective and Access to End-of-Life Services

The first bill, A-3839, sponsored by Assemblywoman Spencer and S-2199 sponsored by Senators Weinberg, Ruiz and Spencer, and cosponsored by Senators Vitale, Cunningham, Van Drew, Gordon , Beach, Beck and Stack established the New Jersey Advisory Council on End-of-Life Care ("Council") in the DHSS and it was signed into law on August 22, 2011. P.L. 2011, c.113. The Council is charged with conducting a thorough and comprehensive study relative to the quality and cost-effectiveness of, and access to, end-of-life care services for all residents in New Jersey. The Council is also required to develop and present policy recommendations relating to state agencies, policymakers, health care providers, and third party payers.

In developing its recommendations, the Council's overriding concern must be the promotion of an end-of-life care paradigm in which patients' wishes are paramount. The goal is to provide patients with dignified and respectful treatment that seeks to alleviate their physical pain and mental anguish as much as possible.

The Council is comprised of 21 members, including: the Commissioners of the Departments of Health and Senior Services ("DHSS") and Human Services, or their designees; two members each from the Senate and the General Assembly to be appointed by the President of the Senate and the Speaker of the General Assembly, respectively, who in each case are to be members of different political parties; the Ombudsman for the Institutionalized Elderly or his designee; and 14 public members who are residents of New Jersey, to be appointed by the Governor with the advice and consent of the Senate, with a wide variety of specified backgrounds related to end-of-life care. The Advisory Council must report to the Governor and the Legislature no later than 18 months after the date of its organization on the results of its activities.

"End-of-life care decisions are often very difficult for loved ones to make, and even more difficult for many to discuss," said co-sponsor Assemblywoman L. Grace Spencer, (D-Newark) "Hopefully, this Council will help offer the necessary guidance to make this process easier for families." At a 2011 presentation before the New Jersey Business and Industry Association, DHSS Commissioner Mary O'Dowd noted her commitments to the Council's work.

2. New Physician Orders for Life-Sustaining Treatment Form Enacted to Complement the Advance Directive Law

The second bill considered by the Legislature, A-3475 and S-2197, sponsored by Assemblypersons Quijano, Munoz, Wagner, Vainieri Huttle, Conaway and Senators Ruiz and Weinberg, and cosponsored by Senators Vitale, Cunningham, Gordon and Beck was signed into law by Governor Christie on December 20, 2011. P.L. 2011, c.145. This legislation has drawn the support of a variety of groups in the public health field. The law requires the State to create a new form called the Physician Orders for Life-Sustaining Treatment ("POLST") which enables New Jersey patients to indicate their preferences for health care. It also mandates that physicians and Advanced Practice Nurses must pursue continuing education in end-of-life care.

According to POLST.org, the POLST Paradigm program is designed "to improve the quality of care people receive at the end-of-life. It is based on effective communication of patient wishes, documentation of medical orders on a brightly colored form and a promise by health care professionals to honor these wishes."

The POLST form serves as a complementary form to the advance directive for health care. It may also be used in lieu of an advance directive if the patient has not signed an advance directive. Unlike an advanced directive (which the patient must enter into and have notarized) the POLST form is a standardized printed document available to all health care professionals and facilities for use with their patients.

The legislation provides that the Commissioner of the DHSS is responsible for instituting the program and the following actions:

- promoting awareness among health care professionals and the general public;
- encouraging ongoing training of health care professionals about the POLST form; and

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- prescribing additional requirements for the completion of a POLST form applicable to a patient with mental illness or a developmental disability.

Health care professionals and facilities are required to treat a patient who has completed a POLST form in accordance with the information contained in the form.

According to bill sponsor, Assemblywoman Nancy Munoz an Advanced Practice Nurse, "the POLST registry will help ensure that a person's medical treatment wishes are honored . . . Everyone deserves to be treated with dignity and respect regarding their medical care, especially as they enter the final phase of their lives."

3. New Decision Making Procedures for Patients Who Lack Decision-Making Capacity

The third bill, A-1835, sponsored by Assemblypersons Conaway and Vainieri Huttle creates a system through which patients who lack decision-making capacity and have no one available to decide for them could receive care in the most appropriate setting, with minimal delay, and without unnecessary cost. This bill allows healthcare facilities to make decisions for routine and major medical treatment for socially isolated, incapacitated patients, and for decisions to forgo life-sustaining treatment, when the treatment offers no medical benefit and violates accepted medical standards.

The bill provides explicit language authorizing facility-based transfer decisions as well as medical treatment decisions in order to expedite the healthcare decision-making process for these patients, reduce the time and expense of keeping these patients in inappropriate care settings, and eliminate the legal costs incurred by hospitals and nursing homes of securing a Special Medical Guardian to consent to medical treatment.

It also requires that specially constituted ethics committees in hospitals and nursing homes must have the authority to decide to forgo life-sustaining treatment for incapacitated patients who are terminally ill or permanently unconscious, and have no other decision-maker available. "This bill would ensure that those individuals who have no one else in their life to make medical decisions on their behalf, still receive the appropriate care and dignity during critical times," said Assemblyman Conaway. "These directives employ a compassionate, yet efficient, model for administering care to some of our most vulnerable residents." New Jersey is the twelfth state to authorize non-judicial decisions about medical treatment for such patients.

These end-of-life care bills will improve how New Jersey's healthcare providers and patients address these issues. National data shows that the level of medical care in the last six months of life is much more intense in New Jersey than in other parts of the country. "That means more physicians visits for patients, more tests and procedures, more days spent in the hospital and in the ICU — often times without medical benefit for the patient," said NJHA Spokeswoman Kerry McKean Kelly. "We want to make sure that it's the patients and their loved ones making those important care decisions."

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