New Challenges in End of Life Planning

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How Did We Get Here and What's Next?

Florida law on end of life care dates back to the mid-80s and some may argue much before to the Karen Quinlan case. However, our view of end of life care clearly is founded on two big cases from the late 1980s to early 90s. Chapter 765 of the Florida Statutes came along in 1992 after the cases that shaped Florida and much of Federal law in this area.

Now we are in a world of new challenges and opportunities dealing with end of life care decision making. I will discuss two developments that I believe will impact future decision-making.

Nancy Cruzan

Nancy Cruzan at age 25 lost control of the car she was driving one night in 1983. She was alone in the car and was discovered lying face down in a ditch without pulse or respiration. She had brain stem activity only and was later diagnosed to be in a persistent vegetative state. After several years of exhausting all resources and hope her parents went to court in Missouri to remove her life support. The trial court approved the request but the Missouri Department of Health appealed to the Supreme Court of Missouri. The Missouri Supreme Court reversed the trial court and the case went to the United States Supreme Court.

The question as stated by the US Supreme Court was "Did the Due Process Clause of the Fourteenth Amendment permit Cruzan's parents to refuse life-sustaining treatment on their daughter's behalf?

The Supreme Court in a 5-4 decision with concurring and dissenting opinions galore, decided that while individuals enjoyed the right to refuse medical treatment under the Due Process Clause; incompetent persons were not able to exercise those rights unless there is "clear and convincing" evidence that Cruzan desired treatment to be withdrawn. The case may be found at 497 US 261 (1990). The Missouri Supreme Court decision was confirmed and Nancy remained on life support. Fortunately, a new witness was found who testified that Nancy had specifically told her that she would not want to live on life support so the feeding tube was removed and Nancy died quietly.

Estelle Browning

In 1985 at the age of 85, Estelle Browning went to visit a friend in the Sunset Point Nursing home. Her friend had suffered a stroke and Estelle was so upset about her friend's condition, she went to her

attorney to have him prepare a living will. Florida Statute 765.07 at that time allowed removal of life support if the patient had a ”terminal condition” and “death was imminent.” Removal of “sustenance” was specifically forbidden under the statute until 1990.

On November 19, 1985, Mrs. Browning executed a declaration that provides, in part:
“If at any time I should have a terminal condition and if my attending physician has determined that there can be no recovery from such condition and that my death is imminent, I direct that life-prolonging procedures be withheld or withdrawn when the application such procedures would serve only to prolong artificially the process of dying.”

In addition, Mrs. Browning stipulated that she desired not to have “nutrition and hydration (food and water) provided by gastric tube or intravenously.”

As luck would have it, Estelle had a major stroke in 1986.Doctors concurred that Estelle’s brain damage was permanent and there was no chance for recovery and that she would die within 7-10 days if her nasogastric feeding tube were removed. However, she was not comatose and seemed to follow someone in the room and cried out if she was in pain.

Her guardian, who had lived with Mrs. Browning for several years and had numerous conversations with her about her wishes took no action for around two years and filed a petition to remove the feeding tube in Circuit Court. There was plenty of evidence to clearly show her wishes. A friend went with Estelle to her attorney’s office and testified that right after signing the living will quoted Estelle as saying ”oh Lord, I hope this never happens to me…thank God I’ve got this taken care of. I can go in peace when my time comes.”

Judge Penick, the trial judge determined that death was not imminent and that under the living will statute he could not grant the relief sought.

Mrs. Browning’s case bounced back and forth between the Circuit Court and the Second District Court of Appeal until the Florida Supreme Court finally took jurisdiction when the case was certified by the second District as a question of great public importance even though the outcome was moot due to Mrs. Browning” death in 1989.

The Florida Supreme Court did not release its decision until the United States Supreme Court published the Nancy Cruzan decision.

The Supreme Court decided that the FS 765.07 did not apply to this case and followed the reasoning of the Second District Court of Appeal that the real basis for decision is the constitutional right of privacy under the Florida Constitution, passed by the voters in 1980.

Florida Probate Rule 5.900, often referred to as the “Browning Rule” provides for an expedited hearing choice of treatment in end of life cases where there is a need for expedited procedures.

Law Following Cruzan and Browning

The high profile case following Browning is Schindler v. Schiavo 851 So. 2d 182 (Fla Dist. Ct. App. 2d Dist, 2003). There is no need at this time to rehash this case and the judicial bravery of Circuit Judge George Greer.

Chapter 765 was rewritten from scratch following Cruzan and Browning in 1994 with many amendments and refinements along the way.

Advance Directives

We are all familiar with significant changes to the Durable Power of Attorney effective October, 2011 and a discussion of these changes is beyond the scope of this presentation.

Note the amendments to Chapter 765 in the 2015 legislative session allowing for an immediate health care surrogate in lieu of the springing surrogate designation under prior law. It is hard to believe that the original Health Care Surrogate statute required that the Health Care Surrogate designation had to be updated every two years. The effective date of the new surrogate designation is October 1, 2015. Also note the statutory availability of a parental surrogate designation for minors under Chapter 765.

A New Era of Health Care Decision Making

Care Planning Act of 2015 (S. 1549

The purpose of the act is to provide for advanced illness care coordination services for Medicare beneficiaries. The context is a conversation (reimbursable by Medicare) between the care provider and patient or patient representative (Agent, Surrogate,

Findings

Congress makes the following findings:

(1)The population of the United States is estimated to age rapidly, with the number of people over the age of 65 set to double to more than 72,000,000, or 1 in 5 Americans, over the next two decades.

(2)Americans today are living longer and healthier lives than ever before in the history of the United States yet are also facing increased incidence of multiple serious conditions as aging progresses.

(3)Americans with advanced illness face a complicated and fragmented system of care delivery that puts them at risk for repeat hospitalizations, adverse drug reactions, and conflicting medical advice that may be overwhelming to individuals and families.

(4)The progression of advanced illness leads to the need for increasingly intensive decision support, health care services, and support from family caregivers.

(5)The complexity of care needed by individuals with advanced illness may result in uncoordinated care, adverse health outcomes, frustration, wasted time, and undue emotional burdens on individuals and their family caregivers.

(6)Numerous private sector leaders, including hospitals, health systems, home health agencies, hospice programs, long-term care providers, employers, and other entities, have put in place innovative solutions to provide more comprehensive and coordinated care for Americans living with advanced illness.

(7)Hospice programs, as one of the longest standing Medicare care coordination benefits that offer a comprehensive set of services via an interdisciplinary team working to provide person- and family-centered care to the frailest and most vulnerable individuals in our communities, can serve as a model for advanced illness care delivery.

(8)Palliative care programs that serve patients beginning at diagnosis with advanced illness and provide care designed to reduce the symptom burden of illness can serve as a model for interdisciplinary team care planning based on the individual's goals of care.

(9)The Government of the United States, as the Nation's largest purchaser of health care services, must learn from these innovators and encourage health care providers to furnish more supportive and comprehensive advanced illness care to improve the efficacy and quality of health care delivered for generations of Americans to come.

(10)Health care providers who serve individuals with advanced illness face complicated care systems and legal concerns that may result in over- or under-treatment of individuals with advanced illness.

(11)Individuals have the well-established right to accept or reject medical treatment that is offered, as well as the well-established right to document their preferences for how treatment decisions should be made if, at some point in the future, they lose the ability to make health care decisions.

(12)Too often, individuals with advanced illness do not understand the conditions they are facing or their treatment options, and they do not receive the information or support they need to evaluate treatment options in light of their personal goals and values and to document treatment plans in a manner that allows providers and facilities to follow their plans.

(13)Providing quality services and planning support to individuals with advanced illness will protect and preserve their dignity. For purposes of this subsection, the term planning services eligible individual means an individual that meets at least one of the following criteria:

(A)The individual is diagnosed with metastatic or locally advanced cancer.

(B)The individual is diagnosed with Alzheimer's disease or another progressive dementia.

(C)The individual is diagnosed with late-stage neuromuscular disease.

(D)The individual is diagnosed with late-stage diabetes.

(E)The individual is diagnosed with late-stage kidney, liver, heart, gastrointestinal, cerebrovascular, or lung disease.

(F)The individual needs assistance with two or more activities of daily living (defined as bathing, dressing, eating, getting out of bed or a chair, mobility, and toileting) not associated with an acute or post-operative conditions that are caused by one or more serious or life threatening illnesses or frailty.

(G)The individual meets other criteria determined appropriate by the Secretary, including criteria that are designed to identify individuals with a need for planning services due to a serious or life threatening illness or risk of decline in cognitive function over time.

Medicare Choice Model Awards

Ordinarily, when hospice is chosen, the patient is no longer able to receive curative care. Under the Medicare Choice Model, the patient is eligible to receive both palliative and curative care at the same time. CMS has invited over 140 Medicare-certified hospices to participate in a five year demonstration project that will allow up to 150,000 eligible Medicare and dually eligible beneficiaries to participate. Beneficiaries must fall into the following categories:

- Must be diagnosed with the illnesses listed above
- Must meet hospice eligibility requirements under the Medicare or Medicaid Hospice benefit.
- Must not have elected hospice benefit with n the last 30 days prior to participation
- Must receive services from a hospice that is participating in the model: and
- Must have satisfied the model's other eligibility criteria.

New Advance Directives/Orders?

As we look at the Care Choice program and see a hybrid developing for a condition sometimes referred to as "frailty"(a patient suffering from conditions including those defined in the Care Choice program where the physician wouldn't be surprised if the patient died in the next year.) The frailty concept leads to a discussion of whether or not the durable power of attorney for healthcare, the designation of health care surrogate and the surrogate chosen to act under the patient's living will are sufficient tools to make sure the patient's wishes are being followed.

The POLST Paradigm

POLST, an acronym for "Physician's Order for Life Sustaining Treatment", started in Oregon in 1991 and has been statutorily adopted in a number of states. Some states use the acronym I prefer of POST "Physician's Order for Scope of Treatment", or MOST "Medical Order for Scope of Treatment."
The POLST document at its best is the result of a conversation between a doctor and patient to document what the physician recommends and that reflects the values of the patient. The POLST form is signed by the health care provider and the patient and ends up as a physician order similar to the DNR.

A number of agencies have been using POLST without the need for statutory authority and the leader has been the Center for Innovative Collaboration in Medicine and Law at the Florida State University College of Medicine.

A POLST statute for Florida was introduced by Senator Brandes as part of the Right to Try Act in 2015 but was removed from the bill.

Senator Brandes drafted a new bill (SB 664) to make POLST a statutory paradigm in Florida in the 2016 Legislative Session. The Real Property, Probate and Trust Law Section of the Florida Bar assembled an ad hoc committee to deal with some of the complex issues presented not just by POLST but also by this new set of pre end of life decision making. It is important that we make sure that due process and transparency are part of any new statute.

The RPPTL Section will introduce a new version of POLST in the 2017 legislative session so stay tuned as this may require a change in our advance directives.