PRACTICAL AND SACRED DECISIONS AT THE END OF LIFE: ADVANCE HEALTH CARE DIRECTIVES

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I. INTRODUCTION

A. Quick Intro

1. We are delighted that so many people are interested in this very intriguing and complex subject. It is important to keep in mind that the issues we will be discussing are not abstract. They are very real and inevitably will touch each and every one of our lives both professionally and personally.

2. It is for this very reason why we would like to start this morning by framing the discussion with a real life hypothetical and get your personal reactions.

B. Hypothetical

1. Here is the hypothetical: You are all family members of Percy Harris. A 53 year old man diagnosed with painful terminal cancer. Percy is in the ICU ward of your local hospital. Percy is intermittently conscious, but sedated to alleviate his pain. The doctor arrives and asks all of you whether aggressive medical treatment should continue or whether the IV tubes providing artificial nutrition and hydration should be removed. None of you know whether Percy has signed an Advance Health Care Directive. The doctor wants and needs an immediate decision.

2. How many of you would advise the doctor to continue aggressive medical treatment to prolong Percy's life? How many of you would elect to withdraw artificial nutrition and hydration so as not to prolong Percy's inevitable death? How many of you wouldn't know what to do?

B. Why We Wrote Our Article

1. We know that the questions we just asked you are very difficult ones. We know because we were asked those very same questions a couple of years ago when my father was in the hospital. It was during the last few weeks of his life when the attending physician asked our family if my father had an Advanced Health Care Directive. Although he had executed one, we discovered that by its terms it had expired. But end of life decisions still had to be made. My father was 95 years old and my mother was 91. They had been married for 68 years. My father passed away on July 5, 2000 just five days after the California's Health Care Decisions Law became operative.

2. We researched and wrote the article handed out with this presentation ["Lasting Wishes"] during the last 3 weeks of his life to raise the awareness of these very personal and sensitive issues. We know that these are very difficult issues to discuss and even to think about. But as lawyers we must think of them. We must think of them to properly advise our clients but, before we can do so, we need to confront them ourselves.

3. As we go into this interesting and complex subject, we would like to know how many of you have completed and signed your own Advance Health Care Directive? How many customarily advise your clients to have one?

4. To get a sense of your various fields of practice, how many practice in the field of family law? How many here are estate planning lawyers?

<u>BRIEF HISTORY OF ADVANCE HEALTH CARE DIRECTIVES</u>

What are Advance Health Care Directives

1. Advance Health Care Directives now combine what used to be different health care instruments, including what is commonly termed a living will and what was termed a Durable Power of Attorney for Health Care.

2. A living will is a written expression by the patient indicating their end of life medical wishes in the event of a terminal illness, i.e., whether they would want to be treated aggressively or whether they would want life sustaining support withdrawn. Appointing an agent to carry out their medical wishes is another way a patient can express their end of life decisions should they become incompetent.

Legal History

1. Let's now give this important health care document some historical context. Review of case law in this area begins with the 1976 landmark case of *In re Quinlan* from the New Jersey Supreme Court.

2. *In re Quinlan* addressed whether a patient has a right to withdraw life support systems. In this tragic case, twenty-two year old Karen Ann Quinlan lapsed into a coma after she inexplicably stopped breathing and was put on a respirator. After an extended period on the ventilator, Karen Ann Quinlan's father requested that the doctors withdraw her life support. Although the doctors predicted that she would die without respiratory support, the New Jersey Supreme Court granted her father's request. The court determined that Karen Ann Quinlan had a right of personal privacy under both the New Jersey and the United States Constitutions and that this right encompassed the right to refuse treatment. The court emphasized that her personal autonomy and her right to decide to withdraw life support outweighed any compelling state interest in preserving human life. The court also determined that since Karen Ann Quinlan was not competent, her father could assert her right of privacy on her behalf. [*In re Quinlan*, 355 A. 2d 647 (N.J. 1976)]

3. In 1990, the United States Supreme Court affirmed the existence of a constitutionally protected right to refuse medical treatment when it decided its first right to die case in *Cruzan vs. Director, Missouri Dept. of Health*. In *Cruzan*, twenty-six year old Nancy Cruzan fell into a persistent vegetative state after a tragic car accident. After it became clear that she would not recover, her parents asked the hospital employees to terminate artificial nutrition and hydration procedures. When the hospital employees refused to terminate treatment, her parents sought and were granted a court order. Although the Missouri Supreme Court reversed by a divided vote, the United States Supreme Court affirmed the trial court, holding that Nancy Cruzan had a constitutional right to refuse life sustaining treatment. However, the high court left to the individual states the task of establishing their own standard of proof guidelines with respect to life or death treatment decisions for incapacitated persons. [*Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261(1990)]

4. In 1998, the California Court of Appeal decided *Conservatorship of Drabick*. In *Drabick*, the conservator sought court approval to remove a nasogastric feeding tube from a conservatee who was unconscious in a persistent vegetive state just like Karen Ann Quinlan and Nancy Cruzan. Although the trial court refused permission to remove the feeding tube, the court of appeal reversed and permitted such removal. The court based its decision on the premise that incompetent patients retain the right to have appropriate medical decisions made on their behalf. An "appropriate medical decision" is one made in the patient's best interest as distinct from one made in the interests of the hospital, the physicians, the legal system, or anyone else." The court, under Probate Code Section 2355, held that absent any formal health care directions from the conservatee, it was the conservator who had the exclusive authority to decide what was in the patient's best interests so long as the conservator's decision was made in good faith and was based on medical advice. The court further stated that the conservator should also consider any of the patients's prior informal statements regarding his or her end of life wishes. But the conservator would not have to prove by clear and convincing evidence the patient's desire to have medical treatment withdrawn because it was sufficient for the conservator to act in the patient's best interests and to consider the patient's expressed wishes in good faith. [Conservatorship of Drabick, 200 Cal. App. 3d 185 (1998)]

5. In 2001, the California Supreme Court decided *Conservatorship of Wendland*. In *Wendland*, forty-two year old Robert Wendland was in a tragic car accident which left him conscious, although severely physically and mentally disabled. Robert Wendland's wife, who was also his conservator, petitioned the trial court to withhold artificial nutrition and hydration. Robert Wendland's mother and sister, however, objected. The trial court refused permission to remove the feeding tube. The Court of Appeal reversed and granted permission to withdraw the artificial nutrition and hydration. When the case went to the California Supreme Court, the ultimate ruling

was to refuse permission to remove the feeding tube. The court refused to extend the holding in *Drabick* to a conscious patient. Remember that, in *Drabick*, the patient in a pvs state whereas Robert Wendland was conscious although incompetent. The Supreme Court held that a conservator may not withhold artificial nutrition and hydration from a conscious patient absent clear and convincing evidence that the conservator's decision is in accordance with the patient's own wishes, or in the alternative, the patient's best interests. The California Supreme Court, in reaching its decision, refused to treat a conscious patient the same as an permanently unconscious patient. First, the court held that interpreting Probate Code Section 2355 to permit a conservator to withdraw life support from a conscious patient based on a mere preponderance of the evidence created a serious risk that the conservator would make a decision with which the patient might disagree. Raising the standard of proof to one of clear and convincing evidence helps to ensure the reliability of a conservator's decision. Second, the court held that a conscious person, even though incompetent, is more likely to perceive the physical and emotional effects of dehydration and starvation than an unconscious patient. [*Conservatorship of Wendland*, 26 Cal. 4th 519 (2001)]

Reaction to the Wendland Decision

1. The Wendland ruling, denying the right to withdraw artificial hydration and nutrition, surprised most legal observers. The rather harsh tone of the opinion was also rather surprising. The case was argued when Justice Stanley Mosk was sitting on the high court bench. He died shortly thereafter. Six Justices approved the decision. One can only wonder if the reasoning of the court and the tone of the decision might have been altered had Justice Mosk participated in the ultimate decision.

2. The *Wendland* decision was not welcomed with open arms by the medical community either. An article in the New England Journal of Medicine in May of this year expressed concern and criticism of the ruling. The article mainly criticized the manner in which the court framed the issues. According to the article, the *Wendland* court sought to protect incompetent patients who would be unable to express a wish to remain alive. The court did not consider the other possibility – that incompetent patients might want to refuse life sustaining treatment, but be unable to state their refusal.

CALIFORNIA HEALTH CARE DECISIONS LAW, OPERATIVE JULY 1, 2000

A. Statutory Form

   1. The California Health Care Decisions Law, which became effective on July 1, 2000 made numerous revisions to prior law to promote the use of Advance Health Care Directives. The new statutory form improves on earlier forms by using simpler, more modern terminology that makes the directive easier to use and understand. The use of the statutory form is not mandatory. An individual who so chooses may complete or modify all or

any part of it and this flexibility allows for inclusion of personal, religious, and moral values in reaching critical decisions at the end of life. The form can be found in Probate Code Section 4701.

2. Reprints are available by the California Medical Association and California Hospital Association

B. Requirements For an Enforceable Advance Health Care Directive

1. Written Advance Health Care Directives need to contain the date of execution, to be signed by either the patient or in the patient's name by another adult in the patient's presence and at the patient's direction, and signed either by a notary public or by at least 2 witnesses. [California Probate Code 4673]

2. Oral Health Care Instructions are authorized by Probate Code Section 4623, but are subject to many uncertainties such as proof and capacity issues.

C. Important Questions to Consider: Quality of Life Issues

1. Now that we know what the requirements are for an enforceable Advance Health Care Directive, we must ask is it enough for us to merely advise a client to complete an Advance Health Care Directive that complies with the requirements just discussed ? The answer is no. What we should do is to open a dialogue with a client as to his or her own quality of life issues.

2. For example, as part of opening a dialogue with your client, you should ask the following hypothetical question: If you became severely burned, and that even with long and extremely painful treatment you would only have a 15% chance of surviving, would you want aggressive medical treatment to prolong your life or not. Another hypothetical question to ask your client is: if Alzemhers disease meant that you could not recognize your wife or children nor communicate with them in a meaningful way would you want to have your life prolonged by aggressive medical treatment in the event of a terminal illness? These are deeply personal and difficult decisions which would not even be contemplated, but for the sensitive questioning and counseling of the legal professional. This is an area, where we as legal counselors, need to do a much better job of helping our clients to consider and express their own personal feelings as to end of life decisions, particularly when the opportunity is afforded as part of the estate planning process or as part of a life transition such as a divorce. This is precisely the area where expanding the statutory form can embrace moral, religious, and personal decisions unique to the individual.

D. What to Do When a Patient Has A Change of Heart

1. As we just discussed, there are many important questions a person should consider when initially filling out their Advance Health Care Directive, but what should a patient do when they have a change of heart about their end of life wishes? California Probate Code Section 4695 addresses this issue.

2. A patient having capacity may revoke the designation of an agent only by a signed writing or by personally informing the supervising health care provider. [California Probate Code Section 4695].

3 Other than the designation of an agent, however, a patient having capacity may revoke all or part of an Advance Health Care Directive at any time and in any manner that communicates an intent to revoke. [Capacity issues have recently been addressed in a CEB Action Guide published in Fall 2001 entitled *Capacity and Undue Influence: Assessing, Challenging and Defending*.]

4 An important note for those of you who practice family law, is that divorce automatically revokes a former spouse's designation as an agent to make health care decisions. So, when representing a client in a divorce proceeding, you should advise your client that if they designated their former spouse as an agent that they should designate a new agent. [California Probate Code Section 4697.]

E. Discussion with Family Members & Others

1. Before designating an agent, the individual should discuss his or her personal feelings with those to be considered as designated agents so that the agent ultimately designated has adequate information to make decisions should that ever become necessary.

F. Distribution of Copies

1. Assuming that a patient has completed and signed an Advance Health Care Directive, it is crucial that they make copies of the signed Advance Health Care Directive and distribute it to the designated agent or agents, the primary treating physician, the personal family lawyer, close family members, and a copy kept readily available in the event of incapacity.

G. Benefits of Having an Advance Health Care Directive

1. We have covered many important topics during this discussion, but if there is one aspect we would like to emphasize for you and your clients, it's the major benefits of having an Advance Health Care Directive. Some of the most important benefits include the following:

2. They enhance the likelihood that the patient's medical and treatment wishes are known and followed.

3. They avoid conflict between competing family members in the midst of a crisis.

4. They allow a patient to appoint an agent rather than the court appointing a conservator, and according to the California Supreme Court decision in the *Wendland,* a designated agent is preferable to a court appointed conservator because a court appointed conservator is less likely to make decisions in accordance with the patient's best interest.

5. They allow designated agents to obtain medical records or any other health care information. [California Probate Code Section 4678]

6. Finally, associated issues such as nursing care, hospital costs, insurance coverage rehabilitation treatment etc., can all be vested in a designated agent to avoid uncertainty and confusion in the event of incapacity. [California Probate Code Section 4671]

H. Remaining Open Questions & Problems

1. As you can see there are many benefits to having an Advance Health Care Directive. However, there are still some gaps in the statutory scheme of the California Health Care Decisions Law. It is to these gaps, these remaining open questions to which we now turn.

2. The first open question is, California law is still unclear whether a designated agent has the right to consent to administration of experimental drugs.

3. The second open question is, California law does not address how conflicts between a patient's autonomy and a physician's right not to provide medically ineffective or futile treatment should be resolved. This unresolved issue, creates a problem because it is not clear whose desires and decisions are to be followed. [A recent law review article entitled, *Ethical Postures of Futility and California's Uniform Health Care Decisions Act,* discusses this open question in more depth. It can be found at 75 Southern Cal. L. Rev. 1217.]

IV. <u>QUESTIONS & ANSWERS</u>

V. <u>CONCLUSION</u>

There is a fine line between prolonging life or prolonging death. Choosing life is often preferable, but in the midst of end of life decisions which often lack bright line rules and clarity, prolonging certain death may be contrary to the personal desires and best interests of a patient. Please remember that these Advance Health Care Directives should be considered by people of all ages. Karen Ann Quinlan was twenty-two, Nancy Cruzan was twenty-six, Robert Wendland was forty-two. Any person at any time can contract a life threatening illness or be subject to a tragic accident.

We hope this review of California law, issues of bioethics, and personal values has been helpful to you in raising your consciousness of these issues and enabling all of us to better serve our clients. In that way, we are adhering to the highest ideals of our profession and serving the very best interests of our clients. They deserve no less. Thank you very much.