

Decision-making and Advance Directives

Life Is A Gift Conference

Sacred Heart Major Seminary

Archdiocese of Detroit

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- **The Need for Advance Directives**
 - The Law is a Fundamental Baseline Only
 - The Social and Legal Pressures
 - Progress, Policy Failure or Just Emotionally Difficult?
 - Better Assessment Tools and Legal Language Have Developed.

- **Completing the Right Advance Directives**
 - The Different Types of Advance Directives (both formal and informal);
 - The Law Surrounding Advance Directives;
 - The Fundamental Medical Conditions, Medical Treatments and Medical Systems; and,
 - The Resident's Personal Capabilities, Wishes and Preferences
 - Your Family's Values and Preferences as the Next of Kin

Exhibits:

Exhibit A: Excerpts from USCCB's Statement on Medically Assisted Nutrition and Hydration

Exhibit B: Gift of Life Registry Form

Exhibit C: Values History Form

Exhibit D: Michigan Statutory DNR

Exhibit E: Wallet Identification Card

Exhibit F: Sample HIPAA Release Form

I. Advance Directives from a Legal and Religious Perspective¹

A. The Law is a Fundamental Baseline Only.

The Michigan Supreme Court has recognized the enormity of decisions surrounding end-of-life care:

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The decision to accept or reject life-sustaining treatment has no equal. We enter this arena humbly acknowledging that neither law, medicine nor philosophy can provide a wholly satisfactory answer to this question.

To err either way has incalculable ramifications. To end the life of a patient who still derives meaning and enjoyment from life or to condemn persons to lives from which they cry out for release is nothing short of barbaric. ***If we are to err, however, we must err in preserving life.***² (Emphasis provided.)

Regarding end-of-life care decisions, the Catechism of the Catholic Church instructs:

2278 Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of “overzealous” treatment. Here one does not will to cause death; one’s inability to impede is merely accepted. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected.

2279 Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed as either an end or a means, but only foreseen and tolerated as inevitable. Palliative care is a special form of disinterested charity. As such it should be encouraged.

Although there are some parallels to Catholic teachings, especially in terms of honoring the dignity of individual preferences, Michigan law regarding Advance Directives and end-of-life decision-making is only a starting point. An informed Catholic will be aware of Church teachings and legal requisites, both when setting forth their own wishes regarding end-of-life care in legal documents, as well as when carrying out end-of-life decisions on behalf of others entrusted to their care. (See **Exhibit A**, Committee for Pro-Life Activities, National Conference of Catholic Bishops, “Questions about Medically Assisted Nutrition and Hydration”, *Nutrition and Hydration: Moral and Pastoral Reflections* (Washington, D.C.: United States Catholic Conference, 1992). See also, Committee on Doctrine, National Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services, 4th Ed*, (Washington D.C.: United States Conference of Catholic Bishops, 2001) part 5.

There is considerable tension in law and society regarding decision making on end-of-life care issues. Attempts to resolve these tensions have produced the law on what is *permissible* in our society (for example, in Michigan, assisted suicide is illegal). Particularly with respect to surrogate decision-making, it is extremely important that legal power and authority for decisions-making are clear; both the U.S. Supreme Court and the Michigan Supreme Court have emphasized that there must be “clear

² *In re Martin*, 450 Mich 201; 538 NW2d 399 (1995).

and convincing” evidence of what the patient would have wanted if able to choose for herself or himself. These statutes and court decisions are merely a baseline for authority, akin to a stoplight. They should not determine one’s ethical framework for actual decisions regarding end-of-life care.

B. The Social and Legal Pressures.

1. **Society continues to confuse a disability with legal incapacity.** A disability is a functional limitation. It depends on that functional limitation whether the person is unable. Persons are presumed legally capable unless there is clear and convincing evidence of incapability. Only when there is clear incapability is a Guardianship established – and only for those decisions the person is unable to conduct. A Guardianship does not mean the person loses their voice on basic preferences.
2. **Increasing legal complications involving incapacity and privacy laws.** We are also witnessing increased litigation and concerns about end of life decisions, privacy laws, placement and care decisions. The Probate Courts in Macomb, Oakland and Wayne Counties have restricted Guardians from issuing Do Not Resuscitate Orders without prior court approval.
3. **External pressures for refusal of care due to determinations of “futility.”** Be sensitive to the effect of subtle (if not overt) pressures of economics and the influence over determinations of withdrawal of care. We increasingly witness inappropriate discharges of patients quicker and sicker due to lack of Medicare or health insurance determinations about coverage. Consider the subtle forms of “rationing” care as financial considerations dominate much of care decisions today in the health industry. Hospitals have the right to define and determine clear standards on “futility of treatment.”³
4. **Prevalence of boilerplate power of attorney forms.** In addition, there is a prevalence of boilerplate forms presuming uniformity of thinking. Many of these forms lack the necessary powers to deal with the particular hardships of chronic illness, costs, accountability and preferences about care – especially in the mental health setting. Generic forms have fallen short to provide the specific legal authority required to address the specialized needs of the elderly, persons with disability and the incapacitated.
5. **Substantial recent statutory and case law developments surrounding incapacity and durable powers of attorney.** Durable powers of attorney and advance directives are relatively new legal tools – since 1991 in Michigan. Most of the case law in Michigan surrounding advance directives has been in the last twenty years.
6. **Ethical dilemmas for Guardians, Care Providers and Professionals and does not exist or is unclear.** When the individual’s preferences about life support are unclear, and family guidance is absent, there is a presumption that all means must be taken to keep the person alive. Ethical dilemmas arise in

³See Andrew Broder, “Between a Rock and a Hard Place: Hospital and Physician Refusal to Honor P.A.D.s”, ICLE, *1997 Medicaid and Health Care Planning Update*.

hospice decisions, palliative care, communications and even conflicts of interest.

C. Progress, policy failure or just emotionally difficult?

1. Clear communications during the time of capacity are the key to preparing for the time of diminished capacity. Although progress has been made since the advent of advance directives in the early 1990's, statistics show most adults have not adequately prepared advance directives,⁴ nor financial arrangements for incapacity.⁵
2. Studies have blamed these problems on lack of sufficient information, confusion due to different state laws and lack of proactivity from professionals and family members. Interestingly enough, studies have shown at least as to advance directives that "there is considerable evidence 'that the elderly's action of delaying execution of advance directives and deferring to others is a deliberate, if not an explicit, refusal to participate in the advance directives process.'"⁶

D. Sophisticated assessments and planning language have developed.

1. While it is clear that there have been major stumbling blocks surrounding planning for incapacity, sophisticated tools involving incapacity have evolved over the past ten years. Elder law attorneys, psychologists and care managers have developed specialized incapacity assessments and planning language, particularly for advance directives.
2. To address the legal and ethical dilemmas with incapacity, the American Bar Association (ABA) and American Psychological Association (APA) have teamed up to create a practice handbook discussing the if, why, when, and how an attorney should conduct a preliminary assessment of screening of a client with diminished capacity. The *Assessment of Older Adults With Diminished Capacity: A Handbook for Lawyers* provides a list of red flags for incapacity and provides a format to structure observations, documentation and conclusions about capacity
3. In addition, elder law and special needs attorneys across the country have concentrated on developing specialized language treating the particular medical problems for incapacitation.

⁴ There apparently has been slow progress in preparation of advance directives since the Cruzan case in 1991:

- A Gallup survey in 1991 showed only 20% of persons surveyed had an Advance Directive.
- The New York Times on April 21, 2009 reports: "A [Pew Research Center survey in 2006](#) found that only 29 percent of people had a living will; in 2007, a [Harris Interactive study \(PDF\)](#) put the proportion with advance directives at two in five. Even among "severely or terminally ill patients," the majority had no advance directives in their medical records, researchers for the federal [Agency for Healthcare Research and Quality reported](#) a few years ago."

⁵ The AARP reports that in a survey approximately 45% of persons over 50 had executed a DPOA and approximately 70% of persons over 70 had completed one. *Where There Is a Will ... Legal Documents Among the 50+ Population: Findings from an AARP Survey*, AARP Research Group, April 2000.

⁶ See Carl E. Schneider and Angela Fagerlin, "The Death of the Living Will," *University of Michigan Law School Quadrangle Notes* (Spring 2005).

4. The best results come from clear understandings of preferences in personalized documents providing specific help in times of incapacity.

II. Completing the Right Advance Directives–

Essential Terms and Provisions

A. Understand the different types of Advance Directives

Advance Directive: a statement (written or oral) made by a patient before the onset of decisional incapacity which indicates the direction for the patient's treatment when the patient is no longer able to participate in health care decisions for his/her care.

Each type of advance directive serves a purpose. Use of a combined approach overcomes the particular disadvantages of each format and will provide the most powerful protection for a patient during times of incapacity.

1. **Living Will** – Document for specific care and treatment to be provided or declined under specific circumstances during incapacity for health care decisions. Ordinarily directs restraint on life support and treatments in the event of terminal or irreversible condition. Michigan is one of three states without a statute specifically authorizing living wills.
Weaknesses: (1) Not recognized in Michigan. (2) Does not involve a specific person or agent with authority to assess the particulars of the situation or adjust to unanticipated conditions and treatments.
2. **Medical Durable Power of Attorney (“MDPOA”) / Patient Advocate Designation (“PAD”)** – Designates an Agent who the person trusts to make health care decisions during any time of incapacity. Recognized in Michigan under the Patient Advocate Act of 1990, effective January 1, 1991, see below.
Weaknesses: (1) Requires specific guidance for the agent to represent the patient's wishes and to meet legal standards for end-of-life decisions. (2) On its own may not provide a sufficient portrait of the patient's values, wishes and communications.
3. **Family Consent / Informal Agreements** – Allows respect and dialogue for the persons closest to the patient without cumbersome formalities, especially when other advance directives are missing. Quite often the actual operation of hospitals and hospice systems where the closest relatives agree with the treating physician or nurse on the course of action for an incapacitated patient or patient with diminished capacity. Formally recognized only under limited circumstances with the Michigan Dignified Death Act of 1996, see below.
Weaknesses: (1) Patient's wishes may become subject to disagreements of a committee, conflicts of interest and inadvertent omission of relevant persons. (2) No clear priority established for the patient's decision maker.
4. **Oral Directives** - Nine states now recognize oral directives of a patient recorded in the medical record. Generally not recognized in Michigan. The Michigan Supreme Court sent a clear message with the In re Martin case, discussed below, that mere general oral directives are insufficient, although it

left open the possibility for a clear, explicit oral statement addressing the particular situation.

Weaknesses: (1) Lack of recognition; (2) difficulty of proof; and, (3) high probability of error.

5. **Physician's Orders** - Orders entered by the physician in a hospital or hospital-like setting directing or denying medical treatments. Hospitals have patients sign-off about risks and contingencies in anticipation of treatment.

Weaknesses: (1) Physician's records may be inaccessible when needed. (2) Statements made to multiple physicians may conflict.

6. **Hospital Policies Regarding Withdrawal of Treatment** - Hospitals must have an ethics committee to set policies on refusal of additional treatment. In the absence of an advance directive, treatment decisions are to be made in the patient's "best interests."

Weaknesses: (1) Financial pressures for hospitals due to limited resources, limitations by insurance and Medicare may influence decision. (2) Sets a personal decision to an outside committee.

7. **Do Not Resuscitate Order ("DNR")** - An order requesting not to initiate medical interventions in the event of an impending or actual cardiac arrest (when the heart stops beating and breathing ceases). Stops CPR and other medical procedures performed in an attempt to re-start the heart (eg. defibrillation, medications and artificial ventilation). Extended from hospital-like settings to the home by the Michigan Do-Not-Resuscitate Act of 1996, see below.

Weaknesses: (1) Contemplates only one form of life support. (2) Misunderstandings by most people. About the efficacy of CPR and need for a DNR.

8. **Organ Donation Registry** - Allows for a central registry to insure wishes about anatomical gifts are honored, especially when an individual dies suddenly and the Medical Durable Power of Attorney is not on file with the hospital where death occurs. Helpful when the Medical Durable Power of Attorney or driver's license registration cannot be found. "The Gift of Life Registry" in Michigan was established by the First Person Consent legislation passed in Summer 2003 (discussed below). **See Exhibit B.**

Weaknesses: (1) There is a general lack of awareness and education by the public. (2) It is irrevocable by family members or Patient Advocate even if they decide it is not what the donor would have wanted. (3) It should be consistent with other advance directives.

9. **Values History Form** - Allows a person to reflect their background and preferences about health care, treatment and end-of-life decisions. The best example through the years has been the University of New Mexico Values Clarification form developed by the University of New Mexico Center for Health Law and Ethics. It is intentionally not copyrighted, unlike other more recent forms. **See Exhibit C** for a copy.

Weaknesses: (1) It is not a binding legal document. (2) It generally lacks specificity. (3) It is cumbersome to fill out.

- 10. Plan of Care** – “Long Term Care/Chronic Illness Advance Directive” – Sets forth the preferences and logistics on placement, care, access, safety and supervision. Primarily used for an at home or other long term care setting. Recognizes the specifics of how the person wishes their long term care needs to be met.

Weaknesses: (1) Lack of awareness about this essential role of geriatric care managers. (2) Not a legally recognized document.

- 11. Five Wishes Form** - A booklet attempting to combine the separate functions of the living will, the medical durable power of attorney, the values history form in plain English. Substantially complies with the legal requirements in 35 states and the District of Columbia, including Michigan. Popular movement signed by over one million Americans provided by Aging with Dignity (www.agingwithdignity.com).

- **Wish 1:** Provides for a health care agent and specific powers (MDPOA);
- **Wish 2:** Sets forth desires on life support (Living Will);
- **Wishes 3-5:** Sets forth personal, spiritual and emotional preferences primarily about comfort, treatment and communications during end-of-life care (Values History form).

Weaknesses: (1) Lacks clarification of duties and acknowledgement by the Patient Advocate as required under Michigan law. (2) It is a form document not necessarily tailored under medical or legal professional advice. (3) By language of the form, “As soon as you sign it, it takes away any advance directive you had before.”

- 12. Lifeline Registration** - Offers registration of Advance Directive documents for their subscribers. Provides fax forwarding of documents including allergies, current medications, medical conditions and contact persons to the specific institutions in a time of emergency. See www.lifelinesys.com or call 1-800-543-3546. Usual enrollment fee of \$75.00.

Weakness: Lack of awareness about this wonderful service.

B. Understanding the Law

1. Federal Constitutional Law

Cruzan v. Missouri Department of Health, 497 U.S. 261 (1990) –

- Recognized a competent person’s right to refuse medical treatment as a protected “liberty interest” under the due process clause.
- Balanced this liberty interest with the state interest in protecting life, protecting minor children, prevention of suicide, and maintaining the integrity of the medical profession.
- Allows states to require “clear and convincing” evidence of an incompetent patient’s desires before removal of nutrition and hydration from a permanently unconscious patient.

Washington v. Glucksberg, 521 U.S. 702 (1997) – Rejects a federal constitutional right to assisted suicide under due process clause.

Vacco v. Quill, 521 U.S. 793 (1997) –

- Denied that there is a constitutional right to assisted suicide.
- Allowed for states to ban assisted suicide with exception of statutes violating the equal protection clause when they lack a rational basis for distinguishing physicians withdrawing life support and assisting suicide.
- Considered as “similarly situated” physicians who responded to requests of terminally ill, competent patients for self-administered prescribed drugs and physicians who at the request of the patient actively removed life support and administered pain relief drugs which themselves contributed to death.
- Impacts end-of-life health care decisions beyond assisted suicide debate by **questioning whether there is a tangible difference between (1) withdrawal of life support, administration of palliative drugs contributing to death and (2) self-administration of prescribed drugs**

2. Federal Legislation

Patient Self Determination Act of 1990, 42 USC §§1395 and 1396 - an information and education mandate about advance directives:

- Requires hospitals, nursing homes and Medicare/Medicaid providers to give all adults upon admission written information about their state law rights on health care decisions;
- Requires requesting about advance directive at admission and noting in medical record; and
- Prohibits discrimination against persons without advance directives

Health Insurance Portability and Accountability Act of 1996 (“HIPAA”), 42 USC 1320d; 45 CFR 160-164 –

- Creates uniform, national standards for maintaining privacy of health-related information (“PHI”).
- Required health professionals to have specific policies and procedures to maintain confidentiality of PHI by April 2003

3. Michigan Legislation

Patient Advocacy Act of 1990. MCL 700.5006, *et. seq.*, effective January 1, 1991 –

- Establishes the right of a *competent* adult to designate an agent to make health care decisions in the event the person is unable to participate in medical treatment decisions.
- Allows a statement of the patient’s desires on *care, custody and medical treatment*.
- Permits the patient advocate to make a decision to withhold or withdraw treatment which would allow the patient to die *only if the patient has expressed in a clear and convincing manner that the patient advocate is authorized to make such a decision and that the*

patient acknowledges that such a decision could or would allow the patient's death.

Dignified Death Act of 1996, MCL §333.5651, *et. seq.* –

- Requires disclosures by doctors to terminally ill patients.
- Established a limited family consent law when the patient has a “reduced life expectancy due to an advanced illness.”
- A “patient surrogate” then has the right to (1) make an informed decision regarding receiving, continuing and refusing medical treatment and (2) choose palliative care treatment, including hospice care and pain management.
- Provides no clear priority for the patient’s surrogate decision-maker other than a mixture of family members including a parent, a member of the immediate family or next of kin.
- Provides physicians immunity for prescriptions of narcotic drugs in such circumstances.

Do-Not-Resuscitate Procedure Act of 1996, MCL §333.20192, *et. seq.* –

- Permits an adult person of sound mind to sign an order (“DNR”) with a doctor directing emergency personnel not to perform CPR in an out-of-hospital setting.
- Stops not only resuscitation, but also de-fibrillation, medications and artificial ventilation implicit with CPR.
- A statutory form is required and found at MCL 333.1055. **See Exhibit D.**
- It may be executed by “another person who, at the time of the signing, is in the presence of the declarant and acting pursuant to the direction of the declarant.” This has been interpreted to include a patient advocate.
- Individuals who for religious reasons against physician assistance need not obtain the signature of a physician for a valid DNR.

Ban on Assisted Suicide effective September 1, 1998, MCL §750.329a –

- Provides for felony when knowledge that an individual intends to kill himself and (a) provision of means or (b) participation in act or (c) helps the individual to plan to kill himself.
- Does not apply to refusing, withholding or withdrawing medical treatment.

Amendments to EPIC regarding Patient Advocate’s relation to Guardian effective January 1, 2001

For Patient Advocate Designations executed *before* the determination of legal incapacity:

- Removed discretion of a court to grant a guardian the same powers of a patient advocate upon awareness of a validly executed patient advocate.

- Set strict terms for the court-appointed guardian not to override the medical treatment decisions of a Patient Advocate absent specific Petition alleging (1) invalid execution, (2) non-compliance with terms of designation or (3) not acting in the ward's best interests. MCL §700.5306(5).

After the determination of legal incapacity and appointment of a guardian a Patient Advocate Designation is not possible:

- Bars the ability of a legally incapacitated individual with a guardian appointed for medical treatment decisions to “trump” the guardian by appointing another individual to make treatment decisions.
- Prevents an end-run around the process of the Petition for Removal of Guardian.

End-of-Life Care Amendments of December 2001 and January 2002,

Public Acts 216, 219, 231, 234-240 –

- Broadened access to end-of-life care for chronic illness by re-defining “terminal illness” from the last six months of life to “limited life expectancy due to advanced illness.”
- Broadened access to pain relieving medication by lowering threshold from “intractable pain” to a finding that the patient is in “pain.”
- Requires hospitals and nursing homes to inform and educate about availability of palliative and hospice care.
- Provides for a sticker to be placed on a driver's license/senior citizen's ID informing about the designated patient advocate; provides also for an emergency medical card. **See Exhibit E for a copy of the card.**

First Person Consent Legislation of Summer 2003, HB 4479 –

- This bill specifies that an anatomical gift made by a will or a document of gift (e.g. donor registry card) would not be revocable after the death of the donor, making the donor's wishes paramount.
- Adds state ID cards and driver licenses to the list of acceptable documents authorizing an anatomical gift.
- Deletes the requirement on the hospital's organ donor log sheet for the name and signature of the person making a donation request.

Amendments to Mental Health Code effective January 3, 2005, (Senate Bills 1464-1472) –

- Allows a Patient Advocate to make certain mental health care decisions on behalf of an individual.
- Recognizes the authority of a Patient Advocate to execute an application for formal voluntary hospitalization.
- Requires informing a Patient Advocate with such authority of a transfer to another hospital.

- Allows waiver by the patient for a 30-day period of the power to revoke the Patient Advocate designation when the Patient Advocate is making mental health care decisions.
- Requires specific statutory language in the Acceptance of Designation by the Patient Advocate recognizing such right of waiver.

4. Michigan Common Law

In re Martin, 450 Mich 399, 538 NW2d 399 (1995):

- Provided that a court may not authorize a surrogate decision-maker to waive the person's right to continued life-sustaining medical treatment unless it is established by clear and convincing evidence that the person, while competent, stated a desire to refuse life-sustaining medical treatment under the specific circumstances present. Id. at 233.
- After a serious injury from a 1987 car accident, Michael Martin could respond to stimuli, but could not communicate, nor process information. He was dependent on a gastronomy tube, colostomy and substantial supportive care.
- Case did not involve a medically defined persistent vegetative state or terminal illness, but rather a conscious patient of seriously diminished capacity.
- The withdrawal of gastronomy tube by his wife as Guardian was contested by his mother and sister, ultimately denied by the Michigan Supreme Court and denied cert. by the U.S. Supreme Court.
- The court rejected an objective, "best interests" standard except under the limited circumstances where there is no explicit evidence of what the patient would choose; then it would allow evidence of the patient's value system, and attitude toward sickness, medical procedures, suffering and death. Id. 220.

5. Other Michigan Case Law

In re Joelle Rosebush, Minor, 195 Mich App 675, 680; 491 NW2d 633 (1992): parents were allowed to withdrawal their minor daughter's life-sustaining treatment.

People v. Messenger, No. 94-2487FY (Ingham County Circuit Court, February 2, 1995): medical doctor acquitted for withdrawing his infant's life-sustaining medical treatment.

Osgood (Young) v. Genesys Regional Medical Center, No. 94-26731 (Genesee County Circuit Court, February 16, 1996) jury award of \$16 million against hospital not honoring advance directive directing termination of life sustaining treatment; jury verdict subsequently reduced to undisclosed amount.

6. Instructive cases and laws of other states or legal movements:

In re Quinlan - (the “Karen Ann Quinlan case”) the first case to focus national attention on the problems created by artificial life support systems, incapacity, prolongation of suffering and permanent unconsciousness. The New Jersey Supreme Court affirmed that Karen’s father as her adult guardian could withdraw her ventilator. She continued to breathe spontaneously for an additional nine years while maintained on artificial feedings.

In re Guardianship of Schiavo - (the “Terri Schiavo case”) the most recent end-of-life struggle over the withdrawal of artificial nutrition and hydration ultimately ending Terri Schiavo’s life. National attention centered on the end-of-life litigation, involving legislative intervention temporarily staying the withdrawal in the form of Terri’s law, a declaration of unconstitutionality of the intervening legislation by the Florida Supreme Court and the decline of the U.S. Supreme Court to hear requests for appeal. Contests arose about her medical status of “persistent vegetative state” as well as her state of responsiveness and possibility of improvement. Nine days after the withdrawal of life artificial nutrition and hydration, Terri Schiavo died on March 31, 2005.

Uniform Health-Care Decisions Act - approved by the National Conference of Commissioners on Uniform State Laws, 1993, adopted in seven states and endorsed by the ABA, AARP and ABA Commission on Law and Aging. Not yet adopted in Michigan. Creates a comprehensive family consent law (without the necessity of terminal illness) with statutory priority among family members.

Oregon’s Assisted Suicide Statute – Allows for self-administered procedures which will prematurely end a life under limited circumstances. No states allow for direct physician assisted suicide and Oregon is the only state to allow self-administered suicide.

C. Understand the Basic Medical Terminology, Medical Treatments and Medical Systems

It is impossible to contemplate all medical conditions and treatments a patient may or may not desire as the list of possibilities gets longer every day. We generally remind clients that our Patient Advocate Designation is not a Living Will; it appoints generally a person they trust – and to whom they can impart their values and preferences. However, the client is charged with giving that Patient Advocate directions, especially about end-of-life decisions. Consider the Michigan Supreme Court’s dicta in the Martin case treating a patient advocate’s powers:

“A proper designation allows a third person to execute the patient’s treatment decisions, even if the decision will result in death, *provided the patient is in the condition delineated in the patient advocate designation.*”

Although the court acknowledged that the question of specific expression in the patient advocate was not the question before it, it certainly set a strong signal to the legal community to move toward clear and convincing expressions about end-of-life conditions and treatments.

1. **Understanding and clarifying medical conditions.**

a. **Understand and clarify what is “terminal illness”**

Many Patient Advocate Designations still define the standard for hospice coverage under Medicare or less than six months to live for a “terminal illness”. This Medicare definition was developed around acute, hospital-like conditions.

The Michigan Dignified Death Act of 1996 and the “End of Life Care Amendments” of 2001, effective 2002 contemplate a more extensive definition: “limited life expectancy due to advanced illness”.

This definition considers chronic, long-term conditions such as Alzheimer’s disease, Parkinson’s disease, strokes and diabetes, in which it is more difficult to determine when patients are “terminally ill”.

As this is the new default statutory definition in Michigan for “end-of-life” care when a surrogate is appointed, we should offer it as an option to our clients in the end-of-life instructions within the Patient Advocate Designation. We may still want to have the clarity of the “six month” standard when acute illnesses are involved. A more refined approach would use a standard differentiating between acute and chronic terminal illnesses.

Option #1: Medicare hospice definition (which focuses on acute terminal illnesses -- as terminal cancer)

“Terminal condition” means a condition which is reasonably expected to result in my death within six (6) months whether I receive medical treatment or not.

Option #2: Michigan statutory default standard for “end-of-life” care (which is broadened to contemplate chronic illness)

“Terminal condition” means a condition which involves a limited life expectancy due to advanced illness.

Option #3: Combination-standard differentiating between acute illnesses and chronic illnesses

“Terminal condition” means a condition: in the case of acute illness, a condition which is reasonably expected to result in my death within six (6) months whether I receive medical treatment or not; and in the case of chronic illness, where there is a limited life expectancy due to advanced illness.

b. **Know the difference between “loss of cognitive/sapient state,” “coma,” “vegetative state” and “brain death” – your client likely doesn’t.**

A recent study found approximately 37 percent of patients after more than one month with a brain injury were diagnosed with a coma or persistent vegetative state *inaccurately*. The errors in diagnosis were believed to be the result of confusion in terminology, lack of extended observation of patients, and lack of skill or training in the assessment of

neurologically devastated patients. N.L. Childs, et. al., “Accuracy of Diagnosis of Persistent Vegetative State,” 43 *Neurology* 1465-67 (1993).

If doctors are confused, how can we and our clients understand these terms in our advance directives? Reliance on general parlance from the news, etc. surely is not sufficient. Fortunately, there have been some clarifying efforts. **Here are some specific definitions.**⁷

- **Loss of cognitive/sapient state:** a qualitative state involving the loss of the ability to understand and reason. This could include later stages of dementia and Alzheimer’s disease, a person in a coma or a person in a vegetative state; the key is the loss of self-awareness and intellectual capacity to interact humanly with one’s family and friends.
- **Coma:** a clinical state of **unarousable** psychological **unconsciousness** in which the patient lies with his or her **eyes closed**.⁸ Appears **unawake**, but distinguishable from sleep in that the person **does not respond** to external stimulation (e.g. sound, light or touch), nor to his or her inner needs (e.g., a full bladder.)
- **Vegetative State:** a clinical state in which the patient **lacks** evidence of any **adaptive response** to the external environment, i.e. the absence of any evidence of a functioning mind which is either receiving or projecting information in a patient who has **long periods of wakefulness**. Patients in a vegetative state are able to open and move their eyes, have normal sleep/wake cycles, and may even spontaneously smile, chew and swallow. Motor movement is limited to posturing and reflexive withdrawal responses. *The difference between a coma and vegetative state is that a coma is a closed-eye state of unresponsiveness, whereas a vegetative state is an open-eyed condition with no evidence of **conscious** awareness.*
- **Brain death** refers to a **complete failure** of the functioning of the cerebral cortex of the brain (responsible for consciousness, emotions, higher mental functions) and the lower brain stem (responsible for vital automatic body functions as independent breathing, heart rate, coughing and swallowing).⁹ *Versus* a vegetative state involves the loss of the functioning of the higher functions in the cerebral cortex of the brain. *Versus* a coma

⁷For the definitions under this section, we relied largely on John B. Oldershaw, M.D., J.D., Jeff Atkinson, J.D. and Louis D. Boshes, M.D., F.A.C.P., “Persistent Vegetative State: Medical, Ethical, Religious, Economic and Legal Perspectives,” 1 *DePaul J. Health Care L.* (Spring 1997) 495. This article compiled numerous medical treatises, ranging from government councils, to positions by the AMA and American Academy of Neurology.

⁸See *Id.*; see also the *American College of Physicians Complete Home Medical Guide*; see also *The AMA Home Medical Encyclopedia*.

⁹The Uniform Determination of Death Act specifies that a patient can be determined to be dead if the person has sustained **irreversible cessation of all functions of the entire brain including the brain stem**. See President’s Commission for the Study of Ethical Problems in Medicine and BioMedical Behavioral Research, *Defining Death: Medical, Legal and Ethical Issues in the Determination of Death* (U.S. Gov’t Printing Office, 1981).

involves damage to the “reticular-activating system,” which results in an inability to arouse the patient. A person in a vegetative state or coma may eventually lose vital automatic brain functions irreversibly, causing death without the assistance of life-support machines and place them in a condition of brain death.

Providing for more exacting definitions in your Advance Directives can assist the Agents and caregivers in discerning the intentions of the patient:

Definition #1: *“Irreversible loss of awareness” means a loss of consciousness or other condition from which there is no reasonable likelihood that I will recover to a cognitive (capable of understanding) or sapient (capable of reasoning) certified by two physicians who have personally examined me, one of whom shall be my attending physician.*

Definition #2: *“Irreversible coma” means an unarousable state of unconsciousness in which there is no reasonable likelihood that I will recover responsiveness to external stimuli as certified by two physicians who have personally examined me, one of whom shall be my attending physician.*

Definition #3: *“Persistent vegetative state” means the absence of any evidence of a functioning mind which is either receiving or projecting information (whether or not there are periods of wakefulness) in which there is no reasonable likelihood that I will recover conscious awareness as certified by two physicians who have personally examined me, one of whom shall be my attending physician.*

c. Understand and define what makes a coma “irreversible” and a vegetative state “persistent”.

Clients regularly relate stories of the person who awoke from the coma or regained awareness after a vegetative state. The “time” element of this determination is often crucial for even the most life-support adverse clients (“give me at least some time to come out of it before they pull the plug” or “allow me to go if I’m ever in that state”).

This is one of the most important issues impacting their care, costs, prolongation of suffering and potential contests. The American Academy of Neurology recommends a waiting period of three months to establish the diagnosis of “persistent vegetative state”. The American Medical Association recommends a twelve month waiting period to confirm the diagnosis and prognosis of “persistent vegetative state”.

The Schiavo case illustrates that medical experts can disagree well after a year into the onset of the vegetative state.

Because the decision to refuse and withdraw life support in Michigan is based on a subjective standard, the client has the opportunity define this

time element and consider the degree of confirmation necessary for the trigger.

For example, the legal form may require certification by two physicians of the irreversible nature of the coma or persistent nature of the vegetative state

- d. **Consider a definition based on loss of quality of life or functional abilities, but beware of vagueness or overly-broad authority which would be mistaken with euthanasia.**

Most states permit the removal of life-sustaining treatment only if the patient is in a terminal condition or is permanently unconscious. A few states – Hawaii, Maryland, New Jersey and Oregon – permit withdrawal of life support based on functional criteria and quality of life.

Michigan’s Health Care Power of Attorney statute has no express limitation on this trigger for withholding or withdrawing treatment, other than ensuring clear and convincing expression and the acknowledgement it could result in the patient’s death. MCL §700.5507(4). In addition, there is a restriction on this authority insofar as it would condone suicide or homicide. MCL §700.5512(4).

The statewide form circulated by the Michigan Bar and Michigan Hospital Association has provided for an option for refusal or termination as follows:

Sample language:

Under any circumstances where my medical condition is such that the burdens of the treatment outweigh the expected benefits. In weighing the burdens and benefits of treatment, I want my Patient Advocate to consider the relief of suffering and the quality of life as well as the extent of possibly prolonging my life.

Weakness: The danger is understanding with enough specificity for what constitutes “quality of life” according to the subjective standard mandated under medical ethics, the Cruzan case and the Martin case. According to Martin there must be some form of explicit statement that meets the standard of “clear and convincing evidence”. Mere general statements are insufficient.

Commentators have criticized the “quality of life” criteria suggesting an inordinate frequency of “bargaining down,” in which many patients upon actually experiencing the condition, are willing to accept far less than what they originally would accept.¹⁰

Solution: Consider a more functional definition, which provides specific measurable abilities as “recognition” and “interaction” with others and “total physical dependence.” In addition, note that the

¹⁰ See Carl E. Schneider and Angela Fangerlin, “The Death of the Living Will,” *University of Michigan Quadrangle Notes* (Spring 2005).

withholding or withdrawal of treatment merely allows death through natural causes:

Sample language:

If I am cognitively impaired to the extent that I have irrevocably lost my ability to recognize and interact meaningfully with my family and other loved ones and I have become totally dependent on others for my physical needs, as certified by two physicians who have personally examined me, one of whom shall be my attending physician, I desire to be permitted to die of natural causes.

e. Understand that Alzheimer's is a condition, not a cause of death.

“Strictly speaking, no one dies of Alzheimer’s. Rather, they die of a condition created by Alzheimer’s. Most often this is pneumonia. The reason for this is that a person with advanced Alzheimer’s loses the ability to swallow, causing aspiration problems.” From Thomas J. Murphy, “Recent Developments in End-of-Life Decision Making,” *NAELA News* 10 (October 2004).

2. Understand generally medical treatments, interventions and levels of care

a. The contentious issue: refusal or withdrawal of artificial nutrition & hydration

– There are various medical mechanical means to provide food and hydration when the person is unable to participate in manual drinking and feeding. Examples are:

- **IV** – a regular IV generally providing hydration with basic mineral/vitamin supplement.
- **Naso-gastric tube** – a feeding tube through the nostril into the stomach (long term health risk is infection and pneumonia)
- **Peg tube (gastrostomy)** – permanent opening through the abdominal wall inserting feeding tube
- **Total parenteral nutrition** – a solution of water, protein, fat, vitamins and minerals through a more permanent IV.

The client may want to differentiate between manual feeding used to provide nutrition and hydration and these mechanical means.

The U.S. Supreme Court in the Cruzan decision recognized artificial nutrition and hydration as a “medical treatment” subject to the right to withhold or withdraw. The Michigan Health Care Power of Attorney statute does not exclude hydration and nutrition as a treatment.

Significant moral and religious differences exist in this area. See statement issued by Pope John Paul II in March 2004:

I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use, furthermore, should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory, insofar as

and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.

This issue was the primary battle in the Martin case, as well as the Schiavo case.

Because of the hot contests in this area, specific authority again is key. Use a values history form to allow guidance under the client's moral and religious perspective.

My Patient Advocate shall ensure provision of manual feeding used to provide me with nourishment and hydration, and if this is not medically possible, then institute artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion, if medically appropriate. I do not wish to have the withholding or withdrawal of artificially provided fluids and nutrition unless medically inappropriate.

b. Access to pain relief and palliative care – to what degree?

International guidelines recommend the types of painkillers that are most effective for different levels of pain. This is known as the “analgesic ladder” and recommends specific types of painkiller for mild pain, moderate pain and severe pain.

- **Mild pain** -- Mild painkillers or anti-inflammatory drugs (e.g. aspirin or ibuprofen) in conjunction with other drugs
- **Moderate pain** -- Weak opioid painkillers (e.g. codeine) in conjunction other drugs
- **Severe pain** -- Strong opioid painkillers (e.g. morphine) in conjunction with other drugs.

There is a point where the administration of morphine and other severe pain relief medications will be addictive and may hasten death. Unconventional pain-relief therapies may cause legal controversy.

Allow the client to clarify his or her viewpoint on maximum levels of pain control and unconventional therapies in a values history form. Specify authority in the Patient Advocate. Consider requiring frequent assessments when the client is unable to communicate.

Option #1 (Maximum pain relief; unconventional authorized):

To consent to and arrange for the administration of pain-relieving drugs of any kind or surgical or medical procedures calculated to relieve my pain, including unconventional pain-relief therapies, that my Agent believes may be helpful to me, even though such drugs or procedures may lead to permanent physical damage, addiction, or an earlier death, although not intentionally caused.

Option #2 (limitation on hastening death): same as above, except striking the italicized phrase and providing “*except insofar as such pain relief would hasten death.*”

Option #3 (frequent assessment): *I request my Patient Advocate ensure that frequent assessments are made of any condition which may cause pain in the event I am unable to communicate directly the experience of such pain.*

Option #4: (painful treatments): *I request my Patient Advocate to refuse treatments which may cause me chronic pain.*

c. Consider how the client will address other “life-sustaining treatments”

Artificial respiration, kidney dialysis, antibiotics, chemotherapy, blood transfusion, surgery and invasive diagnostic tests are current examples of other “life-sustaining” treatment.

The Health Care Power of Attorney statute and the Martin decision encourage specificity, especially as to withholding or withdrawing life-sustaining treatments.

Since the Martin decision, there have been various suggested means for clients to provide directions to their Patient Advocate.

Option #1: Attach a chart delineating different life-sustaining treatments and the client’s perspective.

Weaknesses:

The client will not be able to conjure up preferences for unspecifiable future circumstances and treatments. The chart is a “static” time capsule for the client and likely to change. Studies show elderly clients change preferences depending on the description of the treatment. See Fagerlin and Schneider, supra, at 33.

Option #2: Give direct authority about the decision of life support with an accompanying definition of “life-sustaining treatments” supplemented by a values history form clarifying perspectives on various treatments.

“Life-sustaining treatments” means the use of any medical device or procedure, drugs, surgery, or therapy that uses mechanical or artificial means to sustain, restore, or supplant a vital body function and thereby increases the expected life span of a patient.

d. Other questions for the client’s preferences (which can also be addressed in a supplementary values history form). Does the client wish:

- to refuse life-sustaining if it is unproven and/or experimental when it would only prolong an imminent dying process?
- to limit blood transfers to family members?
- to refuse chemotherapy if death imminent?
- to have an informal duty of consultation with other family members (as the client’s child)?

Option: Consultation. *I would prefer that, if circumstances allow, my Patient Advocate discuss any decision to withhold or terminate life support with my children. However, this expression is precatory and my Patient Advocate shall be my sole representative.*

e. Consider that most persons misunderstand the efficacy of CPR and need to be informed when to trigger a Do-Not-Resuscitate Order (DNR)

Studies show that people overestimate the effectiveness of CPR and in fact do not know what it is.¹¹

In fact, one study of long term care residents showed that 0%-4% of patients survive to leave hospital if high burden of chronic disease and 12%-32% of patients survive to leave hospital if little accompanying pathology.¹²

Provide guidance on executing and registering a DNR for both the hospital and non-hospital setting (including home), especially for the frail elderly client

Many Medical Durable Powers of Attorney still lack specific authority of the Patient Advocate to sign a DNR order in accordance with Michigan law.

f. Discuss organ donation, “Gift of Life” registration and the Patient Advocate’s role after death.

Option: Anatomical Gift. *As authorized by the Michigan Uniform Anatomical Gift act (M.C.L. Section 333.10101, et al.), and in the hope that I may help others, I hereby make an anatomical gift of any of the useable and needed organs and parts of my body for the purposes of transplantation, therapy, medical research or education, without limitation. I make this gift without specifying a donee. I also authorize my Patient Advocate, pursuant to MCL Section 700.5506(1), et seq., to take whatever action is needed at or near my death to coordinate and facilitate the timely execution of my anatomical gift upon my death.*

g. Specifically treat authority on mental health treatment

Prior to the recent amendments to the mental health code, discussed above, Patient Advocates had little, if any, recognition of authority in the mental health setting. Inevitably the Patient Advocate had to seek court intervention through guardianship. This meant a public declaration of incapacity.

New powers allow the client suffering from bouts of depression, paranoia, schizophrenia or other mental illnesses, who acknowledges

¹¹See K.M. Coppola, et. al., “Perceived Benefits and Burdens of Life-Sustaining Treatments: Differences among Elderly Adults, Physicians, and Young Adults,” 1 *Journal of Ethics, Law and Aging* 4, 3-13 (1998).

¹²Murphy, “Do-Not-Resuscitate Orders: Time for Reappraisal in Long-Term-Care Institutions,” 260 *JAMA* 2098-2101 (1988)

the need for help, to waive the right of revocation of the Patient Advocate for periods of involuntary hospitalization.

In addition, the Patient Advocate can have authority to deal with administration of medications, assisted outpatient treatment and release of information in the mental health setting.

Mental Health Treatment Provisions.¹³

In this document, the term “medical treatment” includes “mental health treatment.”

- a. *I authorize my Patient Advocate to obtain all information about my mental health treatment and I consent to the releases of such information to my Patient Advocate.*
- b. *I authorize my Patient Advocate to make a petition for an Assisted Outpatient Treatment (AOT) as an alternative to hospitalization.*
- c. *I authorize my Patient Advocate to consent to forced inpatient hospitalization for mental health treatment.*
- d. *I authorize my Patient Advocate to consent to the administration of medication for mental health treatment.*
- e. *I waive my right to revoke this designation of my Patient Advocate for up to thirty days as permitted by Michigan statute.*

h. Discuss the effects of acute and chronic illnesses on the different routes of care in light of the client’s condition and concerns

For acute (hospital-like) care, our medical systems provide an array of covered treatments and supports, largely covered by Medicare and health insurance. A statement about advocacy for sufficient hospital-stays and sufficient skilled therapies is increasingly useful to empower the Agent as Advocate.

Option: *I request and empower my Agent to appeal inappropriate discharges and denials of coverage necessary for my recovery and to take steps to ensure continued provision of skilled care, including directing continued provision of such care, even if it results in private payment pending determination by Medicare or health insurance.*

Chronic illnesses have suffered from lack of insurance coverage, as well as lack of adequate and appropriate access to pain and symptom management. Exhaustion of financial resources is much more likely, and quite often feared by clients.

Option: *Before undergoing expensive treatments or care which would merely prolong my life and not cure my chronic conditions of diabetes, multiple strokes, etc., I direct my Agent consider the*

¹³ From Robert Anderson, Esq. per Elder Law Listserve.

impact on my financial resources, especially those assets I have saved for my dependent child/spouse.

Understand your family member’s capabilities, wishes, preferences and pressures.

1. **Is your family member capable? Assessing capacity:** This legal phrase has deeper roots in determinations of testamentary capacity for a will. It is presumed that an individual has the legal capacity to execute such a document. At the time of execution, the client must be of “*sound mind*”. However, the specifics of possessing a “*sound mind*” are not defined under the Michigan Health Care Power of Attorney Act. The operative questions presumably are similar to the medical-ethics standards for determinations of capability of *informed consent*, specifically:
 - Understanding – Does the patient comprehend the nature of the decisions the patient is authorizing and to whom these are being delegated?
 - Appreciation – Does the patient her own situation and appreciate the role of the Patient Advocate in this situation?
 - Reasoning – Can the patient evaluate options involved in the decision delegated?
 - Expression of choice – Can the patient communicate the decision to delegate? The more serious the more important to describe, discuss and document in specific terms:¹⁴
 - Easy, effective treatments and ineffective, useless treatments have the least stringent standard. There is a presumption of capacity.
 - Less certain treatments require that the client understand the risks and outcomes of different options and be able to make a decision based on this understanding.
 - Dangerous treatment decisions which violate reasonableness and are counter to professional and public rationality involves the most demanding standard of competence. The client must appreciate with the highest degree of understanding the medical options, implications and be able to give personal reasons involving critical reflection.
2. **Consider your own values statement among the next of kin.** Consider providing a values clarification form and/or letter of instruction. This treats the religious, moral and quality of life preferences of the family member that might not be able to be captured through the structure of the Patient Advocate Designation.
 - Implement steps to resolve disagreements and future ones
 - Clarify family viewpoints about life support as feeding tubes and life support
3. **Consider incorporating into the document an evolving Plan of Care.** Consider an advance directive about long term care – expressing preferences about care and placement in the event of chronic illness and loss of

¹⁴ Hastings Center Report, Vol. 15:2, April 1985 and Laretta Murphy, “Who Decides? Health Care Decision Making After In Re Martin,” ICLE, 1996 *Medicaid and Health Care Planning Update*.
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functioning. A geriatric care manager's interview of the family member's preference and development of a letter of intent about care can forestall problems about placement and care.

Sample language engaging instruction and periodic evaluation of geriatric care manager for plan of care: *I direct my Patient Advocate seek instructions from _____, my geriatric care manager, or equivalent person, as selected by my Patient Advocate, about my preferences on placement, care, psycho-social functioning, safety and visitors in the event I am unable to care for myself or function independently. I intend for an evaluation of my condition and the appropriateness of my placement at least every six months or sooner, depending on any changes identified by my Patient Advocate.*