

# Advance Directives: *A Short Primer*

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As health care providers expand the availability of hospice services and palliative care services to assist severely or terminally ill patients in transitioning to end-of-life care, there is a concurrent need to encourage and expand conversations on advance directives, the important role they play, and impact they can have not only on end-of-life care, but also on unexpected medical care episodes. The beginnings of a move to increase awareness can be seen in recent media attention on the importance of advance care planning.<sup>1</sup>

Advanced care planning can be seen, simply, as a fundamental aspect of patient self-determination. As the United States Supreme Court Stated in 1891, “no right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.”<sup>2</sup> This fundamental right of self-determination (which includes the right to informed consent and to refuse treatment), developed first in common law and professional ethical standards, has since been codified into statutory law, both on the federal and state level. With respect to advance care planning in particular, the Patient Self Determination Act of 1990<sup>3</sup>, CMS Conditions of Participation<sup>4</sup>, Florida Statutes<sup>5</sup>, and the Joint Commission standards<sup>6</sup> all require hospitals to inform patients of their right to formulate advance directives. Despite this strong regulatory support, studies continue to indicate that the number of adults (with and without serious illnesses) that have completed an advance directive remains relatively low. For example:

- Both the Centers for Disease Control and Prevention (“CDC”) and the Agency for Healthcare Research and Quality (“AHRQ”) report that, even among severely or terminally ill patients, fewer than 50 percent had an advance directive in their medical record.<sup>7</sup>
- A survey of nearly 1,700 California adults showed that 76% of those responding did not have a written advance directive (and less than 40% had heard of the term “advance directive.”)<sup>8</sup>

Additionally, despite the fact that most states’ laws strongly support respecting patient’s wishes as expressed through their advance directives, implementation of supportive processes to assure that an individual’s wishes are known, and that care



is provided in accordance with those wishes, continues to present a challenge. A study sponsored by the Robert Wood Johnson Foundation found that nearly a third of terminally ill participants did not want cardiopulmonary resuscitation (CPR), but less than half of their physicians knew of their preference.<sup>9</sup> AHRQ has reported that between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed.<sup>10</sup>

Fortunately, healthcare providers throughout the country - and of particular interest here in Florida - continue to discuss the importance of improving, and finding ways to increase, the public’s knowledge about advance directives and end-of-life planning.<sup>11</sup> For example, the UF Health system recently convened a task force to improve dissemination of information regarding advance directive not only to hospital and clinic patients, but throughout the community. The Florida legislature recently considered legislation to recognize the Physician Order for Life-sustaining Treatment (“POLST”), currently endorsed in at least 13 states.<sup>12</sup> And CMS is considering reimbursing physicians for advance care planning, including the explanation and discussion of advance directives.<sup>13</sup> All of these efforts recognize the fact that the best time and place for advance care planning is probably not upon admission to the hospital, the only currently ‘legally’ required time that such information be provided.

There is clear consensus that in order to assure that health care providers are delivering care in accordance with their patient’s wishes we must improve the number of individuals with advance directives. Less discussed is that it is also

important to educate not only patients and potential patients (a.k.a. the public) regarding the different kinds, requirements, applications and limitations of each advance directive under the applicable law, but also health care providers. A 2012 article in the AMA's American Medical News reported that "[m]isunderstandings among physicians about living wills, advance directives and do-not-resuscitate orders are common.... A series of surveys by QuantiaMD, an online physician learning collaborative, found that nearly half of health professionals misunderstood the components of living wills. Ninety percent of those surveyed were physicians."<sup>14</sup> Despite very detailed policies regarding advance directives, the legal department of UF Health Shands Hospital routinely receives questions regarding the implementation, effect and/or validity of different kinds of advance directives. Following is a brief summary of the most commonly recognized advance directives and the requirements for each under Florida law<sup>15</sup> that I hope will provide Risk Rx readers a basic foundation for continuing education in this very important area:

## Living Will

Originally designed by attorney Luis Kutner and the Euthanasia Society of America/Euthanasia Educational Council in 1967<sup>16</sup>, the Living Will is probably the best known 'advance directive.' Generally, a Living Will sets forth an individual's wishes regarding withholding and/or withdrawal of life-prolonging procedures in the event that s/he has lost the ability to express her/his wishes and is suffering from a terminal illness, end-stage condition, or persistent vegetative state.

How is it properly executed?<sup>17</sup> A Living Will must be signed by a competent adult (the "principal") in the presence of two subscribing adult witnesses, at least one of whom cannot be the spouse or a blood relative of the principal. If the principal is physically unable to sign, one of the witnesses must sign for the principal at her/his direction and in her/his (and the other witness') presence.<sup>18</sup>

When does it become effective? A Living Will becomes effective only during an end-of- life situation. Before withholding/withdrawal<sup>19</sup> of life-prolonging procedures can be done in accordance with a patient's Living Will, the patient's attending physician must determine that the patient is incapacitated, and s/he and another consulting physician must each determine and document that:

1. the patient is suffering from a terminal condition, end stage condition or persistent vegetative state, and
2. the patient is unlikely, within any reasonable medical probability, to regain capacity (and thereby be able to directly exercise his/her right to refuse treatment).

Florida law provides the following definitions for the above referenced conditions precedent to implementation of a Living Will:<sup>20</sup>

- Terminal condition - "a condition caused by injury, disease, or illness from which there is no reasonable medical probability of recovery and which, without treatment, can be expected to cause death."
- End-stage condition - "an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective."
- Persistent vegetative state - a permanent and irreversible condition of unconsciousness in which there is:
  - the absence of voluntary action or cognitive behavior of any kind [and]
  - an inability to communicate or interact purposefully with the environment.

A person may designate an individual – a 'surrogate' – to carry out their wishes as expressed in the Living Will, but does not have to; a Living Will stands on its own to represent the patient's wishes. Once the two physicians have made the requisite findings and documentation, a patient's wishes regarding which life-prolonging procedures s/he does or does not want in specific end-of-life circumstances can be implemented.

In the Florida statutory "suggested" Living Will<sup>21</sup> form, a patient directs "that life-prolonging procedures be withheld or withdrawn when the application of such procedures would serve only to prolong artificially the process of dying, and that [s/he] be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide [her/him] with comfort care or to alleviate pain." While such general guidance helps, the more detail provided in a Living Will, the better guidance a health care provider and the patient's loved ones have to assure that the patient's exact wishes can be fulfilled. For example, the form available through UF Health hospitals and clinics prompts the patient to give more specific direction regarding artificial nutrition and hydration and cardiopulmonary resuscitation. It also encourages additional instructions regarding not only specific treatments desired (or not), but also "conditions that are important to making life acceptable to [the patient]" in order to "help your doctor know exactly what [the patient's] wishes are."

While a Living Will form may provide directions regarding a patient's preferences relating to CPR, it is important

to distinguish a Do Not Resuscitate Order from a Living Will. QuantiaMD (cited by American Medical News above) performed a survey wherein it provided characteristics of a patient who had a living will and asked survey respondents to identify the patient's code status. "Of about 10,000 respondents, 44% incorrectly identified the patient as having a DNR, and 16% did not know the code status. About 41% correctly identified the patient's status as a full code."<sup>22</sup> Similarly, The Realistic Interpretation of Advance Directives (TRIAD III) nationwide study reported in The Journal of Emergency Medicine concluded that most physicians misinterpret a living will as a DNR designation, and that the more sub-specialized the physician, the less understanding there is regarding the role and differences of each.<sup>23</sup>

A Living Will may provide directions regarding the patient's desire to forego CPR, but in order to implement those wishes, a physician medical order must be entered. Regardless of the Living Will instructions, without the physician's Do Not Resuscitate Order, CPR must be initiated. Furthermore, prior to issuing a DNRO on an incapacitated patient that is based on a Living Will or an incapacitated patient's surrogate or proxy's request, a physician must document the conditions precedent to implementation of the Living Will discussed above. (N.B. - a DNRO may be entered on a capacitated patient's request without the existence of any of the three conditions required for a Living Will to take effect.) Moreover, a DNRO simply addresses the withholding of cardiopulmonary resuscitative efforts in the event of cardiac or respiratory arrest. It has no impact on any other care to be withheld or withdrawn from a patient.

### **Designation of a Health Care Surrogate**

All too often discussions regarding Advance Directives focus primarily on Living Wills. While undoubtedly an important advanced care planning tool, it is by no means the only one, and perhaps not even the most important one. A Living Will is important for an end-of-life event, but there are many potential health care encounters that do not require a decision on the provision of life-prolonging procedures, but which require guidance from the patient – at a time when the patient cannot her/himself provide that direction. Clearly, written instructions for every contingency is impossible. For example, a healthy, active 65 year old patient who has a bad car accident receives emergent life-saving treatment, but once stabilized must remain in an induced coma while they recover, during which time several invasive procedures are required. How can one assure that one's preferences for care at such times are communicated and respected?

A Designation of a Health Care Surrogate ("HCS") permits a person to appoint a trusted individual with knowledge

regarding her/his health preferences (and life philosophy) to speak for a patient during unanticipated episodes of care when a patient cannot speak for her/himself. Unless specifically restricted, a HCS can also make withholding/withdrawal decisions for a person during end-of-life. Thus a well-informed HCS can provide more than a Living Will alone; that is they can help health care providers respect your wishes in more circumstances that the Living Will can alone, and potentially with more detail than usually provided in a Living Will.

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<http://www.amednews.com/article/20121029/profession/310299941/4/>

How is it properly executed? Like the Living Will, a Designated Health Care Surrogate must be signed by the principal in the presence of two subscribing adult witnesses. If the principal is physically unable to sign, s/he should direct one of the witnesses to sign on her/his behalf. As with a Living Will, only one witness may be a spouse or blood relative. Additionally, the HCS is prohibited from being a witness. A copy of the designation must be provided to the HCS. If the principal desires, s/he may name an alternate HCS on the same instrument in case the primary HCS is unable or unwilling to serve in that capacity when needed.<sup>24</sup> Whether written or oral, documentation used to designate the HCS should have contact information for the HCS (and alternate where appropriate). Unless limited by the principal in the designation, an HCS has the authority to: give, or refuse informed consent for medical care<sup>25</sup>; make end of life decisions; apply for public benefits to help pay for the cost of the principal's care; consent admission or transfer of the principal to or from a health care facility; obtain all medical records needed to carry out her/his duty; authorize release of information and medical records to provide for the principal's health care.

When does it become effective? A Designation of Health Care Surrogate becomes effective at such time as the patient's attending/treating physician determines that the patient lacks capacity to make health care decisions regarding her/his own health care, or to give informed consent for her/his care. Such incapacity must be documented in the patient's record before turning to the HCS for decisions regarding the patient's care. It remains effective until such time as the patient's attending/treating physician determines that the patient has regained capacity.<sup>26</sup>

### Health Care Durable Power of Attorney

A Health Care Durable Power of Attorney ("Health Care DPOA") serves the same purpose as the Designation of Health Care Surrogate – it appoints a person who will speak on behalf of the patient in the event of incapacity.

How is it properly executed? A Health Care DPOA must be executed with the same formality as any other power of attorney. Therefore, it requires not only two subscribing witnesses to the principal's signature, it also must be notarized.<sup>27</sup> Additionally, unlike a "regular" power of attorney, which is not valid if the principal is incapacitated, a 'durable power of attorney' must contain the following (or similar) words: "This durable power of attorney is not terminated by subsequent incapacity of the principal except as provided in chapter 709, Florida Statutes."<sup>28</sup> Finally, the Health Care DPOA must specifically grant the power to make health care decisions to the agent.<sup>29</sup> Individuals who are DPOAs often mistakenly assume that they have the authority to make health care decisions; however, most DPOAs with which UF Health Shands Hospital is presented are limited to financial matters. Therefore, it is important for health care providers to carefully read the DPOA upon which a purported "health care" DPOA is relying to claim s/he has authority to speak for the patient. A bona fide Health Care DPOA has the same authority, unless otherwise stated or limited, as a Designated Health Care Surrogate.

When does it become effective? Like the HCS, a Health Care DPOA becomes effective upon a determination, and documentation, by the patient's attending/treating physician that s/he is incapacitated, and ends upon a finding that s/he has regained capacity.

### Mental Health Advance Directive

A less commonly known, but potentially very valuable advance directive is the Mental Health Advance Directive. The Florida Department of Children and Families has designed a "Mental Health Advance Directive" that not only allows the patient to designate a mental health HCS, but also provides

a patient with numerous prompts in order to provide very detailed direction on the kinds of treatments, medications, facilities, and physicians that s/he would or would not find acceptable, as well as directions regarding persons to whom information may be disclosed.

How is it properly executed? A Mental Health Advance Directive is executed in same manner as a Designated Health Care Surrogate form, requiring that the principal execute in the presence of two subscribing witnesses, neither of which is the named surrogate or alternate, and only one of which may be the spouse or blood relative of the principal.

When does it become effective? A Mental Health Advance Directive becomes effective if the principal has been admitted to a facility on an involuntary basis, and the treating physician has determined that the principal is incompetent to make his/her own treatment decisions, and remains effective until principal regains competency (or, if for some reason a court grants the authority to a Guardian Advocate).

### Health Care Proxy

A Health Care "Proxy" is not an advance directive – it is what happens when an individual has NOT provided guidance – through a HCS or Health Care DPOA - on who should speak for her/him if s/he is incapacitated and requires healthcare. In a recent study, Yale researchers reviewed the records of more than 100,000 veterans who received care between 2003 and 2013 and found that 7% of the time the patient identified people outside their immediate family as their next of kin.<sup>30</sup> However, unless that person was specifically designated as a HCS or Health Care DPOA, Florida law, and most other state laws, would not have permitted that person to make health care decisions for the patient if an alternate decision-maker was needed. Under Florida law, if an incapacitated patient has not designated a surrogate, the person(s) who the hospital must turn to for decisions, in descending order of priority is/are:<sup>31</sup>

1. a court appointed guardian, if one already exists (but note, in the case of a need for mental health consents for an involuntary patient under the Baker Act, a court must appoint a Guardian Advocate if the patient has not designated an surrogate)
2. the patient's spouse
3. an adult child of the patient, or if there is more than one, a majority
4. a parent of the patient
5. a sibling of the patient, or if there is more than one, a majority
6. an adult relative who has exhibited special care for the patient



7. a close friend of the patient
8. a clinical social worker not affiliated with the provider

While this may be the patient's own preference order, it may not be. Part of the conversation health care providers should be having with their patients is to let them know who the law provides will make decisions for them in the event of an unanticipated health care crisis (including decisions regarding withholding/withdrawal of life-prolonging procedures) if the patient has not provided directions.

### Anatomical Gifts

Under Florida law, an anatomical gift made by the decedent her/himself in advance is considered an "advance directive." A competent adult may arrange for the donation of all or part of her/his body through an organ and tissue donor card, a Living Will or other advance directive (in addition, s/he make such designation in a regular will, on a driver's license, or by registering online with a donor registry).<sup>32</sup>



How is it properly executed? Like the Living Will or surrogate designation, the donor card or other advance directive regarding an anatomical gift must be signed by the principal in the presence of two subscribing witnesses.

When does it become effective? The donation becomes effective upon the principal's death, and is irrevocable at that time. The donation cannot be revoked, modified or denied by a family member, guardian, or a designated health care surrogate after the principal's death.<sup>33</sup>

While the above listing discusses the more common forms of advance directives, a person may leave instructions regarding any aspect of health care that they wish; there is nothing in Florida law that limits the content of an advance directive to only end-of-life, mental health, or alternate decision-maker instructions. And while this article has focused on the options for advance care directives, it is important to remember that having advance directives is just part of addressing end-of-life care or other unpredictable health care circumstances. Equally (if not more) important is having discussions with your physician(s) and family, so that they are aware of your thoughts on these important issues. CMS's recently proposed reimbursement codes for advance care planning is an import-

ant step in supporting the discussion with physicians; some insurance plans already provide reimbursement for the conversation. Providing reimbursement should help encourage physicians to initiate these discussions in an office setting, which is much better than waiting until a patient is admitted to a hospital, which is currently where most patients first encounter an advance directive form. The more we encourage advance care discussions and planning, and written directives which can be readily available, the more we can assure that we are providing care consistent with our patient's wishes when they are unable to express their wishes directly.

1 See e.g. End-of-life debate hinder "Right to Try" legislation, Lloyd Dunkelberger, Gainesville Sun April 6, 2015, 1b; Advance care planning is essential, Timothy C. Flynn and Randy Harmatz, Gainesville Sun April 13, 2015; Milan organizations to present workshop on living wills, advance care planning, The Milan News-Leader, April 13, 2015 [http://www.heritage.com/articles/2015/04/13/milan\\_news\\_leader/news/doc5527ffa66f0c8651692126.prt](http://www.heritage.com/articles/2015/04/13/milan_news_leader/news/doc5527ffa66f0c8651692126.prt), accessed 4/13/2015.

2 Union Pacific Railway Company v. Botsford, 141 U.S. 250, 251 (1891)

3 42 USC §1395cc (f)

4 42 CFR §482.13 (3)

5 F.S. §765.110

6 The Joint Commission Hospital Standards Manual, Standard RI.01.05.01

7 See e.g. Advance Care Planning; Ensuring your Wishes are Known and Honored If You Are unable to Speak for Yourself, <http://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf> accessed 4/3/2014, and Kass-Bartelmes BL. U.S. Agency for Healthcare Research and Quality. Advance Care Planning: Preferences for Care at the End of Life in Research in Action Issue 12. March 2003. [www.ahrq.gov/research/endliferia/endria.htm](http://www.ahrq.gov/research/endliferia/endria.htm)

8 76% of patients neglect end of-of-life care planning" by Kevin B. O'Reilly, Feb 27, 2012; <http://www.amednews.com/article/20120227/profession/302279943/6/> accessed 3/31/2015

9 Supra note 6, CDC article pp2-3

10 See id at p.2

11 See e.g. Hospitals teach being 'conversation-ready' for end-of-life care, by Kevin B. O'Reilly, April, 2013, <http://www.amednews.com/article/20130415/profession/130419978/6/> accessed 3/31/2015

12 SB 1052

13 79 FR 219 at 67670-67671, November 13, 2014

14 Clearing up confusion on advance directives, by Alicia Gallegos, October 29, 2012; <http://www.amednews.com/article/20121029/profession/310299941/4/> accessed 3/27/2015; see also "Triad III: Nationwide Assessment of Living Wills and Do Not Resuscitate Orders," F.L. Mirarchi, E. Costello,

J. Puller, T. Cooney, and N. Kottkamp in *The Journal of Emergency Medicine*, Vol. 42, No. 5 pp. 511-520, 2012, at 512: “Evidence from other institutions reveals that there are vast differences in the understanding of living wills among patients, family members, and physicians. Additionally, evidence suggests that the majority of those interpreting advance directives are poorly trained or untrained in the interpretation of these documents.”

15 Note, however, that Florida law permits recognition of an advance directive that is valid in accordance with the laws of the state within which it was executed. F.S. §765.112

16 Personal note: The author worked at Euthanasia Educational Council the summer of 1977, sending Living Will forms to individuals in response to their requests.

17 Unless otherwise stated herein, Florida law recognizes both written and oral advance directives. While providing clear directions for proper execution of written advance directives, the law provides no concrete guidance on documentation requirements for ‘oral’ directives. While oral directives are probably rare, there are circumstances in which a patient provides clear instructions that can be interpreted (usually in hindsight) as an advance directives. Such instructions should be witnessed in the same manner required for a written Advance Directives (two witnesses in presence of principal when uttering the directive, with same persons excluded from being witnesses). In order to avoid conflict of interest, it would seem prudent to have at least one of the witnesses be a person who is not affiliated with the hospital. The witnesses’ names and contact should be documented in the chart along with the instruction given by the patient.

18 F.S. §765.302

19 Under Florida law, there is no ‘legal’ distinction between withholding and withdrawal of life prolonging procedures. Nevertheless an individual may make a distinction when giving instructions regarding her/his personal preferences at end of life.

20 F.S. §765.101

21 F.S. §765.303

22 Supra note 13.

23 “Triad III: Nationwide Assessment of Living Wills and Do Not Resuscitate Orders,” supra note 13. See also “Understanding Living Wills and DNR Orders” in *Pennsylvania Patient Safety Advisory*, Vol.5, No. 4, pp 111-117 December 2008: “Despite the prevalence of living wills and DNR orders, [Pennsylvania Patient Safety Reporting System] reports received between June 2004 and September 2008 have revealed that healthcare providers, as well as patients and families, may not understand the differences between living wills and DNR orders.”

24 F.S. §765.202

25 Certain procedures require that the principal specifically have granted authority (abortion, sterilization, refusal of

life-prolonging procedures if patient is pregnant with viable fetus, and non-FDA approved experimental treatment.)

26 F.S. §765.204

27 F.S. §709.2105

28 F.S. §709.2104

29 F.S. §709.2201

30 Many Very Ill Patients Choose ‘Next of Kin ‘Who Aren’t, Study Finds by Dennis Thompson, *HealthDay News*, April 2015, <http://consumer.healthday.com/senior-citizen-information-31/misc-death-and-dying-news-172/many-veterans-choose-next-of-kin-who-aren-t-kin-study-says-698155.html%5B4/8/2015>, accessed 4/8/2015, citing Andrew Cohen, M.D., D.Phil., postdoctoral fellow, Yale University School of Medicine, New Haven, Conn.; Jonathan Keyserling, senior vice president for health policy and in-house counsel, National Hospice and Palliative Care Association; April 7, 2015, *Journal of the American Medical Association* 2015, <http://consumer.healthday.com/senior-citizen-infor>

31 F.S. §765.401

32 F.S. §765.514

33 F.S. §765.512