

Learning About Advance Directives

by Paula Johns

Advance Directives, Living Wills, Healthcare Directives—all of these terms refer to the same type of document regarding the personal healthcare desires of an individual who has executed the form. When completed and co-signed, either by witnesses or a notary public, these legal papers can be extremely influential in how the author's wishes are carried out by healthcare providers. Before completing an Advance Directive, it is imperative to learn the language of this valuable document so that the author fully understands what he or she is requesting.

Who is the author? It is any individual who is 18 or older and is mentally competent to make his or her own decisions, in particular, about healthcare wishes.

What does an Advance Directive do? It can do many things, depending on the complexity of the documents. Advance Directives can range from simple (i.e., identifying who is the chosen Health Care Agent) to more forward-thinking decisions (i.e., sentiments on how in-depth care should be in case of a health crisis; and it can include the author's wishes about embalming, cremation, autopsy, body donation, organ/tissue donation, and funeral home).

How are these directives carried out? That can depend on who has a copy of the most recent advance directive. If the hospital or clinic has an advance directive in its possession the hospital or clinic personnel will follow your wishes, unless there is strong family resistance to what has been proclaimed in the document. It is a good idea to inform your family of your thoughts. In a home setting it is advisable to keep an advance directive easily accessible versus placing the document in a locked bank safe.

When is it used? An Advance Directive is strongly advised for submission, completion, or revision any time a person is admitted into the hospital. Frequently providers will discuss the need for an Advance Directive during clinic appointments, especially if the person's health is failing, the person is getting older, or the person has complications from health issues. This document can guide any discussions that the healthcare provider will have with the author and individuals named as "healthcare agents" (HCA) for involvement with the healthcare matters.

Why is it so important? The Terri Shivo case in Florida greatly highlighted the reasons that every adult should have an Advance Directive. In 1990, this married 27-year-old woman suffered a cardiac arrest in her home. Even though she was resuscitated, she suffered brain damage and stayed comatose. One year after her debilitating event, she was considered to be in a "persistent vegetative state" despite multiple therapies and interventions. This is where the gigantic schism developed. Her husband of six years insisted that in prior discussions with his wife, Terri had stated that she would never want to be kept alive if she were not able to be functioning and participatory. Her parents, who were devout Catholics, felt as though life itself is precious and to be valued and, that no matter what, she should be kept alive. Had there been an Advance Directive, legal grounds would have been available. However, lawyers for both sides (her husband against her parents) argued repeatedly through 14 appeals in Florida courts, 5 suits in Federal District Court, and all the way to the Supreme Court for guidance. In the end, the courts sided with Terri's husband, as the legal next of kin (LNOK) that, as her spouse, he had more intimate knowledge of what her wishes

and desires were than her parents, who fell next on the hierarchy of kinship. Terri eventually died in 2005, 15 years after going pulseless in her own home. Considering these lengthy legal battles, the hundreds of thousands of dollars spent, the tears/fears/anger/grief/heartache that occurred for both sides of this family, it became a noteworthy event to all of us to be prepared for that "rainy day" when the unexpected might happen.

Considering this framework on Advance Directives, it is now time to delve deeper into two areas: (1) Who should assist the author in discussing the nuances of this valuable document, and (2) What verbiage should be included in these important papers. In my opinion, as an experienced Intensive Care Unit (ICU) and Emergency Room (ER) RN, an Advance Directive should be done with assistance from a healthcare provider. This does not mean that it needs to be your primary physician, as rarely will they have enough time at a clinic visit. Seek out a RN, who works in the trenches and who understands the complications and interventions that are used when someone's life is dangling precariously in front of the medical personnel. Make sure that the person has the time to explain terms such as health care agent, CPR, intubate, ventilator, persistent vegetative state, tube feedings, defibrillate, and brain death. Take time to spell out your wishes about your healthcare; you can always redo your Advance Directive at a later date if you change your mind about your care decisions. If you have the opportunity, please read Deborah



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Day Laxson's book, *The Gray Zone: When Life Support No Longer Supports Life*. She wrote this pocket-size book (an easy read for even those who are not avid readers) after her husband's death, reflecting on her range of emotions and the decisions she had to make as her husband dealt with his terminal diagnosis of cancer as well as her responsibilities.

Completing Forms Beyond POA

Many individuals think that, if they have completed forms for a Power of Attorney (POA), they have done enough. Wrong! POA can be helpful in many arenas; but at time of death, it becomes null. In an advance directive one designates a spokesperson a healthcare agent (HCA) and an alternative HCA. Without an Advance Directive, your legal next of kin (LNOK) will automatically become the representative if you are unable to state your own intentions, as long as the LNOK is mentally competent to do the duties. For many people, the spouse is whom they would choose to be their healthcare agent (HCA); however, for those who are in acrimonious relationships with their immediate family, or are in the process of a divorce/separation, being without an Advance Directive can pose many complications. Generally, the hierarchy of LNOK resides in the following order: (1) spouse, (2) adult children, (3) parents, (4) siblings, (5) adult grandchildren, (6) grandparents, (7) adult nieces or nephews, and (8) adults who have special relationships of care; this can vary though depending on which state you are in when you die.

Other Considerations

Other considerations for this document are your wishes about becoming an organ or tissue donor. Have you spent time reflecting on your thoughts about giving an altruistic gift of life that positively impacts people every

day because of generous souls and their families? Do you understand what this type of donation means? For instance, corneas, skin, heart valves, bones, and solid organs can be used in either transplant or research, depending on the situation surrounding the death. In addition, the health of the donor candidate, age, and health complications can also affect whether a donor may be used to help others with a very special organ donation gift. Individuals should have conversations with their loved ones about their wishes and then document their wishes in Advance Directives. Another form of gifting is that of donating one's entire body to science. Both the University of Minnesota and Mayo Clinic have an Anatomy Bequest Program allowing for individuals with pre-signed paperwork for releasing their bodies post-death to these organizations if the death does not fall under Medical Examiner jurisdiction. Bodies received into these programs are used for medical students, physicians, and mortuary sciences to expand knowledge and skills instead of relying only on textbooks and lectures. Once the University of Minnesota or Mayo Clinic has completed the use of the anatomical gift, the body is cremated and the ashes are returned to the family some months later, or there is an option of having the remains buried with other donors at a shared grave. For more information: <http://www.mayoclinic.org/body-donation/overview> or <http://www.med.umn.edu/research/anatomy-bequest-program>.

Topics of Cremation/Embalming

The topics of cremation and embalming are very personal subjects. When someone dies in the State of Minnesota, either the individual's body must be embalmed or cremated within 72 hours of release from the place of death, unless the body is under the jurisdiction of the Medical Examiner, <http://www.health.state.mn.us/divs/hpsc/mortsci/choices>.

pdf. The decision about what to do with the body after death is not limited only to embalming or cremation. There is a third option, a blending of the two: embalming for an open casket and funeral and cremation after the memorial services. Then there are choices about what to do with the cremains; they may be kept in a container, placed in a vault, buried, or scattered, depending on regulations in the location. Due to the sensitivity for individuals, whether cultural, religious or personal beliefs, having these types of choices documented in an Advance Directive can help guide remaining family members to follow the desires of the deceased person.

Other Important Factors

Advance Directives can spell out what factors are important to a person, such as music, friends, pets, family, and church, especially when the time is drawing near for that person's life on earth. The names of religious affiliations or spiritual guides/clergy may be mentioned so that they are notified in a timely manner if the individual is hospitalized and the Advance Directive is presented to the staff. Thoughts and desires about how one best wants their last moments, if they are able to participate, are valuable for family and healthcare providers to know. Truly, the Advance Directive can be the voice for the individuals who no longer can use their own voices to state their wishes. Make certain you speak up now, while you can, and document your decisions. Share the document with your family or significant loved ones, healthcare agents, physicians, and hospitals. Make a difference. Do it today!

Editor's Note: The author is a registered nurse with 17 years of experience; viewing and discussing many advance directives in her work in the ICU's, Emergency Rooms, and as a Death Investigator.