

ADVANCE DIRECTIVES

End-of-Life Issues and Policies

Introduction

Improvements in medical technology have allowed healthcare providers to prolong life and delay the dying process, sometimes presenting seriously ill patients, their families, and their doctors with difficult, painful decisions. In an effort to protect the right of personal autonomy and promote end-of-life discussions prior to a medical dilemma, policymakers have enacted laws that provide individuals the means to direct their treatment decisions. However noble these efforts are, only about one in three U.S. adults take advantage of the opportunity to direct these decisions.¹ This explainer provides information on creation of advance directives, their benefits and issues, and laws that govern them.

What Are Advance Directives?

An advance directive is a legal document that protect a patient's right to refuse or request medical treatment in the event the patient becomes terminally ill, mentally incapacitated, or permanently unconscious. An advance directive also allows for the designation of a healthcare proxy, or surrogate, to make decisions on behalf of the patient when these circumstances arise.

There are two primary documents that establish advance directives: a living will, also known as a treatment or instruction directive, and durable power of attorney for health care, also known as a proxy directive. Living wills are used to protect the requests of individuals, allowing them to determine the course of life prior to their becoming incapacitated. Living wills also play an important role in alleviating the burden of end-of-life decisions on families. An individual with

durable power of attorney for health care has decision-making power to control medical treatment for another individual who is incapacitated.

How Is an Advance Directive Created?

Competent adults and emancipated minors may create advance directives. Many states provide planning tools to help people make decisions about matters such as conditions that would result in what they deem an unacceptable quality of life; treatment, e.g., desiring or not desiring long-term life support with a ventilator; the appointment of a person permitted to make healthcare decisions; and organ donation. To be legally binding in Arkansas, an advance directive must be notarized or witnessed by two adults, one of whom cannot be related to the individual who is the subject of the advance directive or entitled to any portion of the individual's estate. An individual with capacity, defined as the ability to understand proposed care and make healthcare decisions, may revoke all or part of an advance directive at any time. An advance directive become effective when an individual lacks capacity. In the absence of an agent identified in an advance directive or a guardian, a surrogate may be appointed to make healthcare decisions. If a surrogate has not been identified by the individual, a supervising healthcare provider — a provider who has the primary responsibility for an individual's health care — may identify a surrogate. If no one is eligible to act as a surrogate, the supervising health care provider may make decisions for the patient after certain conditions are met. A healthcare provider or institution may decline to comply with an individual's advance directive for reasons of conscience or if the directive would require providing care that is medically inappropriate or contrary to generally accepted standards. If a healthcare provider or institution declines to comply, reasonable efforts must be made to transfer the patient to a provider who can.

What Are the Laws Governing Advance Directives?

Arkansas

Enacted in 1987, the Arkansas Rights of the Terminally Ill or Permanently Unconscious Act (ARTIPUA) allows an individual to execute an advance directive, known as a “declaration” under the act, to govern decisions pertaining to life-sustaining treatment.² Prior to the Health Care Decisions Act of 2013, Arkansas retained separate statutory provisions relating to a living will and durable power of attorney for health care. The Health Care Decisions Act brought the two under a single statutory provision but did not explicitly repeal other advance directive statutes.³

It also required the Arkansas State Board of Health to adopt three healthcare decision forms: 1) the Advance Care Plan Form, which is equivalent to a living will; 2) the Appointment of Health Care Agent Form, which is equivalent to naming a durable power of attorney for health care; and 3) the Acceptance of Surrogate Form, which acknowledges the authority to make all medical decisions on behalf of the patient. Act 947 of 2017 repealed the Durable Power of Attorney for Health Care Act of 1999 and merged provisions into the Health Care Decisions Act. It also amended ARTIPUA in order to conform with the Health Care Decisions Act.

The Arkansas Physician Order of Life-Sustaining Treatment Act of 2017 provides for a Physician Order for Life-Sustaining Treatment (POLST) Form that complements advance directives and serves as a translation tool by taking an individual's intentions and converting them into a medical order.⁴ The POLST does not replace an advance directive. Unlike an advance directive, this form is completed when a person has an advanced progressive illness and is making end-of-life decisions with that illness in mind. The POLST also differs from an advance directive in that it is signed by the individual's physician. Healthcare providers are required to treat a patient in accordance with their POLST form unless care is contrary to accepted standards or inconsistent with the provider's religious or moral beliefs. Most states have developed POLST programs, and some, like Arkansas, have enacted legislative guidelines.⁵ Having end-of-life preferences in a medical order is beneficial because medical personnel may be more likely to honor them.

Federal

Federal legislation regarding advance directives has been minimal. The Patient Self-Determination Act (PSDA) of 1990 requires certain healthcare facilities receiving Medicare or Medicaid funding to: 1) inform patients of their rights under state law to make decisions concerning their medical care; 2) ask patients if they have executed an advance directive and document their wishes regarding their medical care; 3) not discriminate against persons who have executed an advance directive; 4) ensure that legally valid advance directives and documented medical care wishes are implemented; and 5) provide education.⁶ Though organizations like the American Bar Association have called to amend the act to implement stronger mechanisms and protocols, the PSDA has seen little legislative interest.⁷

The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 introduced the "Welcome to Medicare" exam, which provides information about preparing advance directives

and the services offered by Medicare.⁸ On Nov. 29, 2010, the final rule regarding annual Medicare wellness exams was issued, allowing payment to providers who offered “voluntary” end-of-life planning. The rule was rescinded a few days after it became effective when it met political opposition, e.g., fear of “death panel” controversies.⁹ However, with increasing recognition of the value and importance of provider-patient discussions regarding end-of-life planning, the Centers for Medicare and Medicaid Services issued new billing codes to pay for these conversations in 2016.

Who Creates Advance Directives?

Anyone 18 or older should consider creating an advance directive and prepare for unexpected medical situations. The key is getting individuals to consider the topic of end-of-life care and ultimately engage in these discussions earlier in life, before they become terminally ill. For older adults, discussions regarding end-of-life decisions have been shown to be therapeutic. Seventy-two percent of all deaths in the United States occur after the age of 65.¹¹ Twenty percent of all deaths occur at home, 60% occur in a hospital, and 20% occur in a nursing home.¹² Estimates show that 80% of patients do not wish to be hospitalized or utilize intensive care during the terminal phase of illness.¹³ Many individuals have interest in executing an advance directive but are either confused about the process or do not know where to go for help. The forms referenced in the Health Care Decisions Act and Act 504 of 2017 are available at <https://www.healthy.arkansas.gov/programs-services/topics/health-care-decision-forms>. Figure 1 is a table that shows which individuals are more or less likely to have prepared an advance directive.

Figure 1: Characteristics of Individuals with Advance Directives¹⁰

- Generally older
- Women
- More education
- Higher income
- More likely to be white
- Have a chronic disease
- Have a regular source of care

Currently, many nursing homes discuss advance directives upon admission. The PSDA requires nursing homes that receive Medicare or Medicaid funds to provide written information regarding advance directives to all residents upon admission. This is frequently a stressful period for an entering resident, so while federal regulations must be met upon admission, a follow-up conversation with the resident and the resident’s family may be beneficial.

What Are the Benefits of Advance Directives?

Advance directives can provide peace of mind and relieve some of the pressure of making critical medical decisions during a time of stress. Absent an advance directive, an agent or surrogate may encounter several issues when deciding on end-of-life care. First, healthcare providers may approach care for terminally ill patients differently. Thus, shared treatment goals between a patient and provider cannot be assured. Also, terminal care may be unanticipated early in the hospitalization or may go unmentioned in an attempt to spare the family pain or additional emotional distress. As a result, families and decision-makers are not emotionally prepared to make end-of-life decisions.

In addition to helping decision-makers make informed decisions and eliminating confusion about a loved one's wishes, advance directives are important for avoidance of costly, futile care. Experts believe lowering the use of high-technology interventions and excessive treatment for terminally ill patients will produce significant cost avoidance.¹⁴ The majority of the cost avoidance — between 25% and 40% of healthcare costs — occurs during the last month of life.¹⁵ Dying in a hospital can be very expensive. The average cost for terminal ICU hospitalizations is \$24,541 (the average length of stay is 12.9 days).¹⁶ Many nursing home patients would prefer not to be transferred to a hospital for end-of-life care. In Arkansas, an individual on Medicare experiences an average of 1.3 hospital stays in the final six months of life.¹³ Studies show that patients who have executed an advance directive have lower hospitalization rates than those who have not. However, there are still high transfer rates for end-of-life care.¹⁷

What Are Issues with Advance Directives?

Regardless of advance preparation, an inherent weakness of advance directives is the inability to cover all unforeseen medical events. There are also problems with vague drafting, lack of communication to decision-makers, and reluctance of physicians to honor advance directives. As previously mentioned, the Health Care Decisions Act attempts to address these problems by providing a single uniform process to execute an advance directive and the POLST by incorporating preferences into the medical order. There has also been a lack of training for medical professionals to communicate with patients regarding end-of-life planning. Sixty-eight percent of physicians report they have not received this training.¹⁸

Another issue is the racial and ethnic disparity in advance directive completion. A 2017 study showed whites had the highest completion rate at 51.7%, while the completion rate was 18.0% for Hispanics and 15.0% for blacks.¹⁹ Mistrust of medical providers or the healthcare system has often been cited as the reason for lower completion rates among blacks, but a recent study has called into question this common assertion.²⁰ Over the past decade, the completion rate for blacks has increased, which may be a result of focused education programs on advance directives. The study suggested language barriers may hamper education of Hispanics on the issue. It also cited close family ties within the Hispanic community as a reason advance care planning is viewed as unnecessary.

A major criticism of advance directive laws is that the documentation is not available at the critical time of implementation, forcing decision-makers to make decisions presumed to be in line with the patient's wishes. Advance directives are useless if not available at the time decisions need to be made. To increase the likelihood that advance directives are enforced, individuals should have conversations about their wishes with their healthcare providers and family members. In addition, a copy of the advance directive should be sent to the following:

- Person with durable power of attorney for health care or other authorized decision-maker
- Primary care physician
- Close family members
- Treating physicians and nurses upon hospitalization

Several states, including Arkansas, now have legislation in place that allows individuals to electronically store their advance directives, allowing health care providers easy access to important documentation in the event of an urgent or critical situation. Nursing homes need to make sure advance directives stay with the patient. In the event the patient is transferred to the hospital, the advance directive should follow and the doctor should be notified that the advance directive exists. In the absence of electronic storage, copies of the advance directive should be stored in vehicles likely to be used for hospital transport.

Conclusion

There tends to be a disparity between what individuals would like their end-of-life treatment to be and what actually occurs. The COVID-19 pandemic has exposed a need to have these conversations with healthcare providers and prepare these documents earlier, as complications

form the virus can happen quickly and patients with severe complications may be isolated, alone, and unable to share their wishes. Advance directives give individuals the right to decide how their end-of-life care is to be provided. Encouraging participation in advance directives earlier in life, providing resources to execute these forms, and educating individuals on the importance of communication may allow individuals to obtain peace of mind in dealing with the end phases of life.

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