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Federal Laws Concerning Advance Directives

An advance directive is a written statement by a competent person indicating his or her wishes regarding medical treatment in the event of future incompetence. In this context, incompetence means that a person cannot express his or her wishes which may be caused by mental infirmity, unconsciousness, or the inability to communicate. Advance directives may be used to address medical questions during any period of incompetence, including those periods associated with terminal illness.

In general, there are two types of advance directives: (1) a living will and (2) a health care power of attorney (also referred to as a "durable power of attorney"). A living will can inform health care providers about the type of medical care that an individual wants provided or withheld. This may include any type of medical treatment, including a life-sustaining procedure. Living wills typically take effect when the patient cannot communicate his or her wishes for medical care. In general, once a physician receives a living will, he or she either must honor its instructions or transfer the patient to another physician who will honor them. A health care power of attorney is a document that identifies a health care proxy or decisionmaker for the patient. This document typically takes effect when a physician decides that a patient is unable to make a health decision.

All 50 states and the District of Columbia have laws concerning advance directives and the appointment of a health care proxy. While generally a matter of state law, Congress has passed laws with respect to advance directives and advance care planning.

Patient Self-Determination Act

In 1990, Congress passed the Patient Self-Determination Act (PSDA; P.L. 101-508), which requires certain Medicare and Medicaid covered providers (hospitals, nursing homes, home health agencies, hospices, and Medicare Advantage plans) to follow specified policies and procedures in regard to advance directives. Covered providers are required to maintain written policies and procedures with respect to

- providing adults with written information regarding their rights under state law to make decisions concerning medical care, including formulating advance directives;
- documenting an advance directive in the individual's medical record;
- not conditioning the provision of care, or otherwise discriminating against an individual, based on whether or not there is an advance directive;
- ensuring compliance with requirements of state law respecting advance directives; and
- providing education for staff and the community on issues concerning advance directives.

The PSDA also mandated that certain covered providers distribute information about advance directives according to the timing of medical or health-related events such as at the time of admission, initial receipt of care, or plan enrollment. Medicare-certified providers that do not comply with these requirements may have payments withheld by the Secretary of Health and Human Services (HHS). Medicaid law does not contain a similar compliance requirement. Furthermore, the PSDA provides for the continued application of state laws that allow health care providers to object, as a matter of conscience, to implementation of an advance directive. To monitor implementation, a 2015 Government Accountability Office (GAO) report found that the Centers for Medicare & Medicaid Services (CMS) provides documentation to inform covered providers and describe agency monitoring activities (GAO-15-416). In doing so, CMS relies on outside entities such as state survey agencies and accrediting organizations, as well as internal contract review to monitor the advance directive requirement. GAO also found that while approaches to inform individuals about advance directives can vary by provider, similar challenges existed across settings, including provider discomfort in talking about end-of-life issues as well as lack of staff time for such discussions.

Other Federal Laws

Two other laws concerning advance directives and advance care planning are the National Defense Authorization Act for Fiscal Year 1996 (§748 of P.L. 104-106; 10 U.S.C. 1044c), which established a federal advance directive for military personnel that explicitly preempts state law, and the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA; P.L. 110-275). Among other things, MIPPA added "end-of-life planning" to the initial preventive physical exam that Medicare beneficiaries receive upon enrollment. MIPPA defines "end-of-life planning" to mean verbal or written information regarding an individual's ability to prepare an advance directive in the case that an injury or illness causes the individual to be unable to make health care decisions; and whether or not the physician is willing to follow the individual's wishes as expressed in an advance directive.

Health Reform and Advance Care Planning

The characterization of end-of-life or advance care planning as "death panels" during the health reform debate led policymakers to shy away from proposals to establish a Medicare covered advance care planning (ACP) benefit under the Patient Protection and Affordable Care Act (ACA; P.L. 111-148, as amended). However, some stakeholders saw opportunity to include more limited coverage of ACP under the ACA-established Medicare

annual wellness visit (AWV). The AWV includes a number of elements specified in the law, and authorizes the HHS Secretary to include any other element determined appropriate. Thus, the HHS Secretary could require the inclusion of ACP.

In 2010, CMS's proposal to implement the AWV requirement did not mention ACP (75 *FR* 40126). However, the final rule included "voluntary" ACP as part of the AWV, based on comments received on the proposal (75 *FR* 73170). This inclusion of ACP in the final rule generated controversy, and shortly after publication, CMS rescinded its addition as a specified AWV element (76 *FR* 1366). Since then, there has been interest in establishing a Medicare billing code for ACP. For 2016, CMS physician payment regulations finalized a proposal to allow payment for ACP under two new Current Procedure Terminology (CPT) codes:

- CPT Codes 99497/99498—Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health professional (first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate; add-on code for each additional 30 minutes).

The final rule also added ACP as an optional element to the AWV, at the beneficiary's discretion (80 *FR* 70886).

Constitutional Status

While the right to refuse medical treatment has been addressed in state law, even in those cases where no advance directive has been completed or where state law does not cover a particular medical circumstance, individuals or their guardians may still make medical decisions which will ultimately allow the death of the patient to occur. This was the litigation posture which led to the case of *Cruzan v. Director, Missouri Department of Health*. At the time of the litigation, Nancy Cruzan was hospitalized in a persistent vegetative state. Although Cruzan was able to take nutrition through spoon-feeding, it was determined that artificial nutrition and hydration were medically indicated. While Missouri now has a "Living Will" statute, Cruzan had not written out such a will. Even if she had, the statute specifically excluded the possibility that a patient's living will could provide for the withdrawal of nutrition or hydration tubes. As the Missouri legislature appeared to have made a decision that the withdrawal of nutrition and hydration was against public policy, the Missouri Supreme Court required that proof of Cruzan's wishes be subjected to a heightened evidentiary standard.

The *Cruzan* case presented two legal issues to the Supreme Court: first, whether Cruzan had the constitutional right, even absent legislative approval, to consent to the withdrawal of nutrition and hydration; second, whether this right could be exercised by a guardian, and furthermore what standard of proof would be required to show that such a course of action was the intent of the patient. The Supreme Court ultimately decided that the state could require clear and convincing evidence of her wishes, and as her guardians did not have sufficient proof, that nutrition and hydration could not be withdrawn. Although the Supreme Court did not specifically decide the issue as to whether the Missouri court could have acted contrary to a clear and convincing expression of Cruzan to withdraw medical procedures, it did presume that such a right existed under the Fourteenth Amendment. Thus, under *Cruzan*, an individual's right to refuse medical treatment may be broader than the rights granted by state statutes.

Use of Advance Directives

The *Cruzan* case and other high-profile cases involving an individual's right to refuse or terminate medical treatment in the absence of an advance directive (such as the Terri Schiavo case) have generated considerable public awareness about the issue. According to the Institute of Medicine's (IOM's) 2014 *Dying in America* report, about 47% of adults over the age of 40 had an advance directive. However, the likelihood that an individual has completed one can vary. A 2011 National Center for Health Statistics study found that 88% of discharged hospice patients had advanced directives, compared to 65% of nursing home residents and 28% of home care patients. According to GAO, factors that increase the likelihood of having an advance directive include presence of a chronic illness or condition (e.g., diabetes or dementia), as well as being aged 65 and older, white, female, or having relatively higher income and education levels.

Implementing Advance Directives

The boundaries of a seemingly clear-cut presumption to follow individuals' treatment wishes can become blurred. For example, a patient may be incapable of creating an advance directive because he or she is unconscious or suffering from dementia. An emergency provider might not know that a patient has an advance directive. A patient's advance directive may not be available when needed by the provider. Family members may threaten or pursue legal action against health providers for decisions with which family members disagree—even when those decisions accord with patient wishes. Patients may change their preferences after executing an advance directive, changes which might not be respected unless they are documented in an advance directive.

These possibilities can create challenges for the health care delivery system. According to the IOM, advance directives can be useful as part of a more comprehensive advance care planning discussion, but they must also be flexible for health care decisionmakers. Some see the need to articulate preferences through medical orders covering specific treatments (e.g., do-not-resuscitate, do-not-intubate). Moreover, inclusion of advance directives in a patient's electronic health record or storage in an external database such as a registry may address certain barriers to provider access.

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