

The Advance Health Care Directive Act

Also Known as the Health Care Decisions Law



A Guide for Chronic Dialysis Facilities

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I. What is an Advance Health Care Directive?

An Advance Health Care Directive (AHCD) allows people to tell health care professionals and others close to them the health care they would like to receive, or not receive, should they ever become unconscious or too ill to communicate. If they are able to express their own wishes, their advance directives will not be used, and they can accept or refuse any medical treatment. In the absence of an AHCD, agents or others may make decisions based on their personal views, rather than those of the patient.

II. A Description of the Laws Concerning Health Care Decisions

Chronic dialysis patients in California are affected by two laws concerning their legal rights to make their treatment preferences known in the event that they become unconscious or too ill to communicate.

The California Advance Health Care Decisions Law (Assembly Bill 891)

This law, which became effective July 2, 2000, consolidates California's previous advance directive laws to make it easier for individuals to make their health care preferences known through written and oral communication. Previous laws were the *Natural Death Act Declaration*, the *Directives to Physicians*, and the *Durable Power of Attorney for Health Care*. Directives or other legal forms executed under these previous laws are still valid. The new law allows a person to do *either* or *both* of the following:

- Appoint a Power of Attorney for Health Care
- State instructions for future health care decisions

The Patient Self Determination Act (PSDA) of 1990

This federal law encourages communication between patients, families, physicians and professional staff on the issue of advance health care directives. It applies to hospitals, nursing facilities, hospices and most other health care providers. The PSDA requires that they give patients information concerning their legal right to make decisions about medical care and treatment that they may receive in the future. Although freestanding dialysis facilities are not specifically named in the federal law, it requires that most other health care providers do the following:

- Provide all adults under their care with written information about patients' rights under this law, which ensures patients of their right to make health care decisions including the right to accept or refuse treatment and the right to execute advance directives.
- Inform all patients of their institution's policy on implementing advance directives.
- Document in the patient's medical record whether they have executed an advance directive.
- Not discriminate against patients because they have or have not executed an advance directive.
- Provide staff and patients with education on advance health care directives.

III. Benefits of an Advance Health Care Directive

The AHCD is now the legally recognized form to appoint a health care agent in California, and allows people to specify more about their wishes than they can in a living will. An AHCD allows (competent) persons to state their wishes for medical care, or to name an agent to make those choices if they cannot. A traditional living will states a person's desire not to receive life-sustaining treatment only if terminally ill or permanently unconscious. An AHCD allows a person to state wishes about refusing or accepting life-sustaining treatment in any situation. A lawyer is not needed to complete an AHCD, (or a living will) and there are excellent kits and forms available (see "Additional Resources"). It can be revoked or changed at any time. **Residents in skilled nursing facilities** must have a patient advocate or ombudsman sign as a witness. Patients' instructions might also include their wishes regarding autopsy, funeral arrangements, and organ and tissue donation.

IV. Role of an Agent

When considering who to appoint as agent, people should select someone they are comfortable with, someone who knows them well, and someone with whom they have discussed their views. This person should be able to be present when needed. The agent should also be strong enough to advocate for them in the face of doctors or institutions that may disagree with their choices. This person has legal authority to make decisions for the patient about their medical care if the patient is unable to do so. The agent is immune from liability so long as he or she acts in good faith. The law does not allow the patient's doctor to act as agent. A person who operates a community care facility (board and care home) or a residential care facility where the patient receives care cannot act as an agent. Patients may not appoint anyone as their agent who works for the health facility in which they receive care unless the person is related to them. They may only name one agent, but may have one or more alternates if the agent is unavailable or unable to carry out the patient's wishes.

V. Special Issues and Considerations for Dialysis Patients

The age group with the largest number of patients with ESRD is now 60 to 79. Persons of this age and those with chronic illnesses are more likely to complete an AHCD. Some people want all that is medically available and possible, while others feel that the benefits and burdens of aggressive or active treatment must be weighed and possibly limited by a person's quality of life preferences.

Since dialysis patients receive a life sustaining treatment, they may be confused as to how to state their wishes within the context of an AHCD. For instance, dialysis patients who are in the process of developing an advance health care directive need to understand the implications of a decision to instruct their physician that they wish not to be resuscitated in certain situations. They should be assured that they will be treated for dialysis related complications that sometimes arise during treatment, and that are usually treatable (blood pressure changes, allergic reactions, heart rhythm changes). Cardiac arrest does not occur frequently during dialysis, and will be handled according to facility protocol. Patients who wish to decline cardiopulmonary resuscitation (CPR) should be informed about the type of comfort care usually provided by the facility such as clearing the airway, administering oxygen, control of bleeding, pain medication, and emotional support (see *Section VIII*).

VI. Dialysis Facility Responsibilities

A. Definitions

The definitions quoted below in AB891 clarify that nephrologists and chronic dialysis facilities are subject to the requirements described in this section.

Primary physician:

“a physician designated by a patient or the patient’s agent, conservator, or surrogate to have primary responsibility for the patient’s health care, or in the absence of a designation, or if the designated physician is not reasonably available or declines to act as primary physician, a physician who undertakes this responsibility.”

Health care provider:

“an individual licensed, certified, or otherwise authorized or permitted by the law of this state to provide health care in the ordinary course of business or practice of a profession”.

Health care institution:

“an institution, facility or agency licensed, certified or otherwise authorized or permitted by law to provide health care in the ordinary course of business”.

Supervising health care provider:

“the primary physician, or if there is no primary physician, or the primary physician is not reasonably available, the health care provider who has undertaken primary responsibility for a patient’s care”.

B. Duties of Health Care Providers

A health care provider who knows of the existence of an AHCD, a revocation of an AHCD, or a designation (or disqualification) of an agent must promptly record its existence in the patient’s health care record. If the AHCD is in writing, the provider should obtain a copy and arrange for it to be maintained in the patient’s medical record. It is a good idea to have the current names, addresses, and phone numbers of the patient’s agents and alternates.

Health care providers are required to:

Comply with the patient’s written health care instruction or those of the patient’s agent to the same extent as if the patient had made the decision while having mental and physical capacity.

Arrange for transfer of the patient if the AHCD instruction is contrary to institutional policy or for reasons of conscience. In such situations, there is a duty to inform the patient and/or agent.

Provide continuing care to the patient until a transfer can be made, or until it appears that a transfer cannot be made.

Note: A realistic assessment of the requirement to promptly transfer a patient to another provider must consider the shortage of dialysis stations in California, contract restrictions placed by insurance companies on covered beneficiaries, logistical and geographic difficulties, and financial burdens. It is important that your facility protocol includes complete information on such policies (see *Section E*).

C. Immunity of Health Care Providers

Providers are protected from civil or criminal liability and discipline for unprofessional conduct if they act in good faith and in accordance with generally accepted industry health standards. A health care provider that intentionally violates the law is subject to liability to the aggrieved individual, as is a person, who intentionally falsifies, forges, conceals, defaces or obliterates an AHCD.

D. Information Dissemination

Although **outpatient** dialysis providers are not specifically named in the Patient Self-Determination Act (see *Section II*), they are strongly encouraged to provide general information to patients on advance health care directives.

The ideal time to initiate a discussion of AHCDs is during the development of the patient long-term care program, and anytime thereafter that the patient's condition or life circumstances change significantly to warrant such follow-up.

Social workers might introduce the concept of the AHCD to *new* patients and then supply more detailed information to those interested. A note should be made on the chart for those patients who decline information, or do not wish to complete an AHCD. Physicians should participate in the discussions, particularly in those situations where a patient is contemplating DNR orders.

E. Policy Development

Every facility should have a policy on AHCDs. It must apply to all patients, and all patients must be informed. The policy must be consistent with applicable state or federal laws. You should work with your legal counselor in developing a policy. Suggested elements to be included in the policy are:

- A statement of commitment to patient involvement in medical decisions and that advance health care directives will be honored. It should also list any exceptions that apply in the facility. Examples include pre-existing institutional policy, reasons of conscience, or if the requested medical care would be medically ineffective or contrary to generally accepted standards.
- A statement that patients are presumed to have decision making capacity unless a determination has been made to the contrary (see *Section VI.A*).
- A statement that the provision of care will not be contingent upon or denied on the basis of the presence or absence of an advance directive.

- A description of resources available to patients who want information on AHCD.
- A description of how an AHCD is placed in the dialysis facility record.

VII. Physician Responsibilities

A. Determination of Capacity

A patient who wishes to execute an AHCD is presumed to have capacity to make such decisions, unless the primary physician determines otherwise. A primary physician who makes a determination regarding a patient's capacity, or knows that a patient lacks or has recovered capacity or has another condition that affects an individual instruction, promptly records the determination in the patient's record, and communicates this fact to the patient (if possible) or the patient's agent.

B. Compliance With Instructions

A primary physician is required to comply with the health care instruction of the patient or with a reasonable interpretation of that instruction made by the patient's agent. A physician may decline to comply with such an instruction for reasons of conscience, in which case the physician must promptly inform the patient and/or agent, make reasonable attempts to assist in the transfer of the patient to another provider willing to comply with the instruction, and provide continuing care to the patient until a transfer can be accomplished.

Oral directives by a patient are valid only if made to a physician.

C. Immunity and Liability of Physicians

A physician acting in good faith in accordance with generally accepted health care standards is not subject to civil or criminal liability, or to discipline for unprofessional conduct for actions in compliance with the California law. A physician who intentionally violates this law is subject to liability to the aggrieved individual. A physician who intentionally falsifies, forges, conceals, defaces or obliterates a patient's AHCD without consent is subject to liability.

VIII. Request to Forego Resuscitative Measures (DNR)

This is a written document, signed by the patient or the patient's agent, **and a physician**, that directs a health care provider to forego resuscitative measures for that individual. This includes a pre-hospital "Do Not Resuscitate" (DNR) form developed by the Emergency Medical Services Authority, or a similar form if it meets certain requirements. The form is valid whether the patient is within or outside a hospital or other health care institution.

A PATIENT WHO HAS CLEARLY STATED A WISH IN AN AHCD NOT TO BE RESUSCITATED SHOULD HAVE THOSE WISHES RESPECTED.

A facility policy on DO NOT RESUSCITATE (DNR) should include:

- Private space
- Return of blood
- Staff member to remain with patient
- Staff member to provide explanations to other patients or answer questions
- Notification of family
- Completion of incident report
- Notification to coroner and health department according to local or state requirements

IX. How to Work Effectively With Emergency Medical Services (EMS)

A. When you call 911, be ready to tell the dispatcher

- Your facility's address and phone number
- Your name
- What medical professionals are with the patient, and what is being done at this time
- The patient's age
- If the patient is breathing and/or conscious
- How long the patient has been receiving dialysis treatment this day

B. EMS Personnel (fire department or ambulance) will expect

- Safe and easy access to the patient upon arrival
- A concise verbal report and history from a physician or registered nurse
- Copies of any documents that provide useful patient care information, including demographics
- Assistance to move the patient and/or equipment

C. If the patient DOES NOT have a DNR order, the EMS personnel will

- **Perform** a complete patient assessment
- **Provide** any and all necessary basic and advanced life support (BLS and ALS) measures needed to restore cardiac rhythm (with adequate perfusion) and spontaneous respiration in the patient
- **Transfer** the patient to the ambulance and appropriate medical facility.

Usually, patients will have at least 10 minutes of ALS procedures performed prior to the paramedic making contact with a base physician. The base physician has the option to

declare the patient dead at the scene if the physician feels that continued efforts would be futile. In most cases in which there is no response to interventions, the patient will be transported from the scene and pronounced dead in the emergency department. In other instances, the patient may be left on scene for pick up by the coroner or funeral home.

- **Complete** an EMS Department Patient Contact Report of all actions and treatment performed.

D. If the patient DOES HAVE a valid DNR order, EMS personnel will:

- **Perform** a full and complete patient assessment
- **Do** a “good faith” review of all DNR Documentation to verify the patient’s wishes
- **Contact** the base physician as an added measure of assurance to confirm orders
- **Transport** the patient to the nearest emergency treatment facility IF there is still a pulse or respiration
- **Run** a cardiac rhythm strip in two leads to confirm systole if there is no pulse or respiration
- **Not transport** IF the patient is confirmed dead on scene.

E. DNR Emblems

California patients who have completed an approved DNR form may obtain a DNR bracelet or body medallion from the MedicAlert Foundation, a nonprofit foundation. MedicAlert is the only state approved provider of such medallions that California EMS personnel are authorized and trained to recognize. Emergency responders can honor the DNR order on the medallion without having to locate the actual written order.

X. PRACTICAL CONSIDERATIONS

The following are examples of frequently voiced questions and comments from dialysis providers when they are confronted with a situation that requires an emergency intervention.

- Q.** How can our staff tell the difference between a treatable dialysis related complication and an emergency non-treatable situation?
- A.** Clinical assessment by a physician or RN is critical in this situation, since such a determination cannot be made by unlicensed personnel.

- Q.** We have no place to store a deceased patient-where would we put a cadaver?
- A.** This is true in many instances, but improvisation is necessary. Some facilities screen off an area in the treatment center to hold the body until transportation is arranged, or use a vacant office.

- Q.** What will patients say if they see an emergency situation when staff do not appear to intervene aggressively?
- A.** Efforts should be made to review the facility policy with staff and patients who may have witnessed a medical emergency.

XI. ADDITIONAL RESOURCES

- California Hospital Association (CHA) Consent Manual 2000 contains a copy of a suggested form in both English and Spanish. Call 1-800-494-2001 or visit www.calhealth.org
- California Medical Association (CMA) has an Advance Health Care Directive Kit, including a new form. Call 1-800-882-1CMA or visit www.cmanet.org
- 10 Myths About Advance Directives www.abanet.org/elderly/myths.html
- Partnership for Caring. Visit www.choices.org/ad.html. Forms can be ordered by calling 1-800-989-9455
- About DNR Orders, Channing L. Bete Co., 1-800-628-7733, Item 396938-10-97
- MedicAlert Foundation, 1-800-432-5378, or visit www.medicalert.org
- Guidelines for EMS Personnel Regarding DNR Directives (EMSA #111) www.emsa.ca.gov
- Five Wishes – addresses medical, personal, emotional and spiritual wishes of seriously ill persons. \$5 per copy. Aging With Dignity, P.O. Box 166, Tallahassee, FL 32302, 1-888-5-wishes
- Finding Your Way – A guide for end of life decisions - \$1.50/copy CAHHS Sales Center, P.O. Box 340100, Sacramento, CA 95834 www.finalchoices.calhealth.org

SAMPLE

California Advance Health Care Directive

DESIGNATION OF AGENT: I designate the following individual as my agent to make health care decisions for me:

(name of individual you choose as agent)

(address) (city) (state) (zip code)

(home phone) (work phone)

OPTIONAL: If I revoke my agent's authority or if my agent is not willing, able, or reasonably available to make a health-care decision for me, I designate as my first alternate agent:

(name of individual you choose as first alternate agent)

(address) (city) (state) (zip code)

(home phone) (work phone)

OPTIONAL: If I revoke the authority of my agent and first alternate agent or if neither is willing, able, or reasonably available to make a health care decision for me, I designate as my second alternate agent:

(name of individual you choose as second alternate agent)

(address) (city) (state) (zip code)

(home phone) (work phone)

AGENT'S AUTHORITY: My agent is authorized to make all health care decisions for me, including decisions to provide, withhold, or withdraw artificial nutrition and hydration, and all other forms of health care to keep me alive, **except** as I state here:

(Add additional sheets if needed)

WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE: My agent's authority becomes effective when my primary physician determines that I am unable to make my own health care decisions unless I mark the following box. If I mark this box [], my agent's authority to make health care decisions for me takes effect immediately.

AGENT'S OBLIGATION: My agent shall make health care decisions for me in accordance with this power of attorney for health care, and my other wishes to the extent known to my agent. To the extent my wishes are unknown, my agent shall make health care decisions for me in accordance with what my agent determines to be in my best interest. In determining my best interest, my agent shall consider my personal values to the extent known to my agent.

AGENT'S POSTDEATH AUTHORITY: My agent is authorized to make anatomical gifts, authorize an autopsy, and direct disposition of my remains, except as I state here:

NOMINATION OF CONSERVATOR: If a conservator of my person needs to be appointed for me by a court, I nominate the agent designated in this form. If that agent is not willing, able, or reasonably available to act as conservator, I nominate the alternate agents whom I have named, in the order designated.

INSTRUCTIONS FOR HEALTH CARE

If you fill out this part of the form, you may strike any wording you do not want.

END-OF-LIFE DECISIONS: I direct that my health care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below: **(Initial only one box)**

(a) Choice NOI To Prolong Life

I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits,

OR

(b) Choice IQ Prolong Life

I want my life to be prolonged as long as possible within the limits of generally accepted health care standards.

RELIEF FROM PAIN: Except as I state in the following space, I direct that treatment for alleviation of pain or discomfort should be provided at all times even if it hastens my death

OTHER WISHES: (If you do not agree with any of the optional choices above and wish to write your own, or if you wish to add to the instructions you have given above, you may do so here.) I direct that:

(Add additional sheets if needed)

SIGNATURE OF PERSON COMPLETING THIS FORM:

(sign your name) (print your name) (date)

(address)

(city) (state) (zip code)

STATEMENT OF WITNESSES

I declare under penalty of perjury under the laws of California (1) that the individual who signed or acknowledged this advance health care directive is personally known to me, or that the individual's identity was proven to me by convincing evidence, (2) that the individual signed or acknowledged this advance directive in my presence, (3) that the individual appears to be of sound mind and under no duress, fraud or undue influence, (4) that I am not a person appointed as an agent by this advance directive, and (5) that I am not the individual's health care provider, an employee of the individual's health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of the individual's estate upon his or her death under a will now existing or by operation of law.

First Witness:

(sign your name) _____ (print your name) _____ (date)

(address)

(city) (state) (zip code)

Second Witness:

(sign your name) _____ (print your name) _____ (date)

(address)

(city) (state) (zip code)