



**Advance Health Care Directive**

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# **Instructions**

**CANHR**

*Long Term Care Justice and Advocacy*

# Definitions

## **Principal**

The person who signs and executes the advance health care directive and subsequently receives or rejects health care treatment.

## **Agent**

The person selected by the principal to make health care decisions on behalf of the principal if the principal becomes incapacitated to make decisions. Principals do not have to select an agent to complete an advance health care directive (AHCD).

# Instructions for Completing CANHR's AHCD

## Selecting an Agent

Selecting the agent may very well be the most important component of the AHCD. There are several considerations regarding selecting the agent, many of which are covered in the “Selecting an Agent” document included at the end of these instructions.

One issue that frequently arises in the selection of an agent is the possibility of co-agents. Principals with more than one adult child, for example, often have difficulty selecting one to act as an agent – principals don't want to be seen as picking favorites. Co-agents are strongly discouraged. Co-agents can disagree on health care decisions and stall the provision of care, which can defeat the purpose of the AHCD. If a principal insists on having co-agents, the potential for problems can be minimized by giving one agent veto power or by inserting a third-person tie-breaker when the co-agents disagree.

Principals are encouraged to name alternate agents in case the first nominated agent cannot serve.

## Page 2 of the AHCD Form

**Section 1.15:** This language is added to assure consistency in terminology so that the agent may access otherwise protected health information to assist with decision-making.

**Section 1.2:** The AHCD form gives the agent vast decision-making authority – basically the agent may make any decisions that the principal could make.

**Section 1.25:** The AHCD form includes four limitations on an agent's power. If you do not agree with any of the limitations you should cross them out. The following is a brief explanation of why we included each limitation.

## Advance Health Care Directive Instructions

- (a) **Binding pre-dispute arbitration agreements** are promises to use arbitration - not courts - to resolve any future disputes. Once they are signed, the parties to an agreement may not sue each other in a courtroom, but must submit their dispute to a professional arbitrator. Businesses, including health care providers, are increasingly using binding pre-dispute arbitration agreements to prevent having to face lawsuits. They prefer to use arbitrators because they tend to side with businesses more often than consumers, primarily because of financial incentives. For more information about arbitration agreements, go to <http://www.canhr.org/arbitration/index.html>

Limiting your agent's power to enter into pre-dispute arbitration agreements on your behalf does not mean your agent would not be able to agree to arbitrate a claim you may have or use some other form of dispute resolution besides a lawsuit. Instead, your agent is limited to waiving your right to sue a health care provider that has caused you harm, *in advance of the dispute*.

Some health care providers require pre-dispute arbitration agreements as a condition of service. If you prohibit your agent from entering into such agreements, there is a chance you may not be able to receive services from those providers. For this reason, we recommend principals carefully consider this limitation and seek the assistance of an attorney if you have any questions.

- (b) California law is clear that a person cannot be placed in a **locked door long term care facility** unless they have consented or a court has determined that they do not have the capacity to make decisions. An overview of this law is contained in <http://www.canhr.org/reports/YourRightToLeaveGuide.pdf>. Despite this law, providers of locked door long term care often permit health care agents to place their principals in locked facilities. Section 1.25(b) clarifies that the agent shall not have such authority.
- (c) **Psychotropic drugs** are not FDA-approved for the treatment of dementia. They are often used to control behavior that stems from pain, discomfort, or fear but is conveyed through behavior due to confusion and impaired communication skills. For much more on this topic, please see CANHR's guide "Toxic Medicine" at <http://www.canhr.org/stop-drugging/download-the-guide>
- (d) By definition, **physical restraints** are initiated over the will of the restrained person. California law does not permit health care agents to authorize the use of physical restraints on principals. Section 1.25(d) clarifies that the agent shall have no such authority.

## Page 3 of the AHCD Form

Increasingly, long term care facilities or their residents are turning to video surveillance to monitor the care that is provided and ensure against abuse or neglect. However, the cameras can impose massive infringements on a resident's privacy rights. The principal is given the choice of whether to empower an agent to decide if video surveillance is permissible.

**Section 1.3:** This addresses the agent's authority "trigger." Generally, an AHCD is set up so the principal retains full decision-making authority until he or she becomes incapacitated. The agent's authority is dormant until then – often called a "springing" authority.

Defining incapacity, for purposes of triggering the agent's authority to make decisions, can be done in myriad ways. This form uses a declaration by the primary care physician, or in his or her absence, a declaration by two physicians.

The principal may elect to give the agent immediate authority to make decisions on his or her behalf. This form requires the principal provide a full signature in such a case. Generally, principals don't give immediate decision-making authority unless they have a chronic or degenerative condition that could lead to fluctuating capacity. Some attorneys recommend their clients give the agent immediate authority to spare them the sometimes considerable inconvenience of having to obtain a physician's statement regarding capacity.

Regardless of when the agent's authority becomes effective, the principal always has the right to override the agent's decisions unless a court has determined the principal is incompetent. (See Probate Code Section 4689.)

**Section 1.35:** This section gives the agent access to otherwise protected information at any time for the limited purpose of determining the principal's capacity. Otherwise, the agent could be in the tricky situation of having to prove incapacity to trigger decision-making authority but not being able to gather the information needed because he or she does not yet have that authority.

## Page 4 - 6 of the AHCD Form

The end-of-life care options in this AHCD favor simplicity over detail. Principals are free to address their end-of-life care options in greater detail if they want. Among the treatment options that may be questionable at the end of life but are not directly addressed in this form are:

- antibiotics in the case of infection,
- hospitalizations,
- pacemakers,
- fracture treatment,
- cancer treatment,
- dialysis,
- nutrition and hydration, such as feeding tubes and manual feeding assistance.

**Part 2** of the AHCD can be perhaps most effective if it represents a statement of overall values. Principals should use the space given, and additional space if necessary, to explain what is important to them when end-of-life care decisions are being considered.

**Section 2.15:** Expressing the desire to return home is not included in many AHCD forms but it is an issue about which many people have strong preferences.

**Section 2.25:** This section builds on section 1.25(c) to demand the use of comfort-focused care for dementia instead of psychotropic drugs.

Music and memory was featured in the documentary film "Alive Inside." For more information, go to [musicandmemory.com](http://musicandmemory.com).

**Part 3:** This health care directive makes anatomical gifts the default selection of the principal. If you do not wish to make anatomical gifts, be sure to initial the statement reflecting that preference.

## Page 7 of the AHCD Form

Sometimes, the principal may not be able to give a recognizable signature due to a physical disability. A written mark, if intended to act as a signature, will suffice if the principal can make one. If the resident cannot even make a mark, a surrogate signatory may work although the surrogate signer should not be a nominated agent or health care provider for the client. It might also be wise to have the surrogate signer detail in writing the indications the principal gave that he or she consented to the AHCD.

If the client is a resident of a nursing home, a Long-term Care Ombudsman must be one of the two witnesses; otherwise, the AHCD is not valid.

For additional information about signing the AHCD, please see “Instructions for the Use and Understanding of an Advance Health Care Directive” below.

# Instructions For The Use And Understanding Of An Advance Health Care Directive

## 1. **Signing and Witness Requirements.**

Your Advance Health Care Directive ("Directive") must be signed in the presence of two adult witnesses that are not disqualified. One of the witnesses must sign twice - once as a witness, once to certify that he or she is not related to you. You may sign before a notary public if you cannot find two witnesses. If you are living in a skilled nursing facility, a patient advocate or ombudsman must sign the form as well.

2. **Original Copy.** You should keep the original signed copy of your Directive and store it in an accessible location. You should inform the persons closest to you of the location of your Directive.

3. **Duplicate Copies.** You should make enough duplicate copies of your Directive so that one can be given to each of your physicians and to your agent and each of your alternate agents. You should distribute these copies as soon as your Directive is signed. Be sure that the copies given to your physicians are put into your official medical records. You should also discuss your Directive with the persons to whom copies are given. Your physician can decline to comply with your Directive so you should discuss whether your wishes conflict with your doctor's personal beliefs. It is important to keep a record of each person to whom a copy is given in case you revoke or change the form. Each person should be notified if you ever revoke or change the form.

You may also register your Directive with the California Secretary of State although this is not required. Call the Secretary of State at (916) 653-3984 for more information.

4. **Periodic Review.** You should review your Directive at least once a year to be certain that your views have not changed. If you wish to change your Directive, you should revoke your existing form and prepare and sign a new Directive. Do not write any changes on your original Directive. If you do make a new Directive, you should replace all copies of your old form with copies of the new form. If you change your mind about having a Directive, do not hesitate to revoke it.

5. **Revocation.** If you wish to revoke your Directive, you may do so at any time by a separate written document or by destroying the signed original copy of the form. If possible, you should also retrieve and destroy all copies of the revoked Directive and advise your physicians that you have revoked your Directive. You may revoke your Directive orally, but if you do, you should ask the person to whom you speak to make a written record of your oral revocation and, if possible, to retrieve and destroy the original and all copies of your Directive.

6. **Record of Copies.** Duplicate copies of my Directive have been given to the following persons or organizations:

## Record of Copies of Advance Health Care Directive

Name  Address

Name  Address

Name  Address

## Questions to Consider in Selecting an Agent

The following is a brief list of issues to consider in selecting an agent when executing an Advance Health Care Directive. While the ideal agent is often a spouse, domestic partner, or adult child, other individuals can also be good choices. These are a few of the more important questions to consider in choosing an individual to serve as your agent:

1. Is the proposed agent a person who knows you well, a person with whom you can easily discuss your health care wishes, and someone who you trust?
2. Does the proposed agent live near by?
3. Does the proposed agent have religious or other beliefs that would prevent him or her from carrying out your health care wishes?
4. Is the proposed agent in good health?
5. Can the proposed agent withstand tough pressure from relatives and friends?
6. Is the proposed agent willing to act as your agent?
7. Will the proposed agent benefit from your will or estate plan? (Such an individual may have potential conflicts of interest.)
8. Will the proposed agent be a forceful advocate on your behalf with your medical providers?