ADVANCE HEALTH CARE DIRECTIVES FOR MENTAL HEALTH

A Trainer's Manual

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I. INTRODUCTION

Advance Directives provide an exciting way to work with mental health consumers to promote self-determination and choice. This manual is written for people who are interested in learning about Advance Directives for Mental Health and helping others understand and complete Advance Directives for Mental Health. It includes an explanation of the basic concepts related to Advance Directives, information on filling out the Advance Directive form and a discussion of some of the problems or questions that may arise around the use of Advance Directives. The attachments to this manual contain materials for conducting Advance Directive workshops for consumers.

II. ADVANCE DIRECTIVES

a. What is an Advance Directive for Health Care?

An Advance Directive is a legal document that allows people to direct their own health care even when they are in a coma, have dementia or are mentally incapacitated or unable to communicate. A person can use an Advance Directive to spell out his/her wishes regarding physical and mental health care and to select someone to make health care decisions when he/she is unable to do so. Advance Directives **cannot** be used to force treatment.

In California, an Advance Directive includes (1) Appointment of an Agent for Health Care and (2) Individual Health Care Instructions. A person may choose to complete either one or both of these parts. Either part is legally binding by itself.

b. Advance Directives are recognized in both state and federal law.

1. <u>Federal “Patient Self-Determination Act” (PSDA)</u>

Federal law requires hospitals participating in Medicaid (Medi-Cal) and Medicare to provide information to all adult patients regarding their right to make advance directives concerning health care

decisions. This law is called the Patient Self-Determination Act (PSDA) and is found at 42 U.S.C. §§ 1395cc(f) and 1396a(w). Regulations written pursuant to the PSDA are found at 42 C.F.R. §§ 489.100 and 489.102.

This law –

- Requires that facilities give written information about Advance Directives to people when they are admitted.
- Requires facilities to document in the person's record if they have an Advance Directive.
- Prohibits the facility from discriminating against a person based upon whether or not he/she has made an Advance Directive.

2. California's "Health Care Decisions Law"

California law sets out the requirements for making an Advance Health Care Directive, including who can make an Advance Directive, who can be an Agent and what health care providers must do to comply with Advance Directives. This law is called the Health Care Decisions Law and is found at California Probate Code § 4600 et seq.

c. Advance Health Care Directives have three primary components:

- Designation of a Health Care Agent (or Power of Attorney for Health Care)
- Individual Health Care Instructions
- Signature Pages

It is not necessary for the person to name an agent or write Individual Health Care Instructions in order to complete an Advance Directive, but the person must complete the signature section in order to make a valid Advance Directive.

i. Designation of a Health Care Agent (or Power of Attorney for Health Care)
This part of an Advance Directive allows the person to name a Health Care Agent. An agent is responsible for making health care decisions for the person should he/she lose the ability to make these decisions.
[Starts on page 7 of the Advance Directive]

ii. Individual Health Care Instructions
This part of the Advance Directive allows the person to write specific instructions about the care and treatment he/she would want in certain situations. This form covers both physical and mental health treatment.
[Starts on page 20 of the Advance Directive]

iii. Signature pages
In order to be valid an Advance Directive must have the person's signature, the date the Advance Directive was made and the signature of either two witnesses or an acknowledgement by a notary public.
[Starts on page 28 of this form]

III. MAKING AN ADVANCE DIRECTIVE

a. Who can make an Advance Directive?

Any adult[1] who has the "capacity" to make health care decisions and is acting of his/her own free will may make an Advance Directive.

b. What is Capacity?

"Capacity" means the person's ability to understand the nature and consequences of a decision and to make and communicate the

[1] Emancipated minors who have capacity may also write a valid Advance Directive. Family Code §§ 7002 (emancipation), 7050 (emancipated minor considered as an adult for consent to medical, dental, or psychiatric care).

decision, and includes in the case of proposed health care, the ability to understand its significant benefits, risks and alternatives.[2]

The issue of capacity to make health care decisions comes up in three ways:

- A person must have capacity to make an Advance Directive.
- An Advance Directive goes into effect when the person is found to lack capacity.
- A person with capacity may revoke his/her Advance Directive.

c. How can a person prove he/she has capacity?

Legally, everybody is presumed to have capacity to make health care decisions and to make an Advance Directive for health care.[3] Neither the existence of a mental disability nor hospitalization, in and of themselves, means a person lacks capacity to make an Advance Directive.

However, it is still a good idea for the person to explain the reasons for his/her choices in the Advance Directive. Many sections in this document leave space to write out the reason for decisions. The more the person explains the reasoning behind his/her choices, the more difficult it will be for someone to argue that the person lacked capacity when he/she wrote the Advance Directive.

d. Free will

People making Advance Directives are usually making some very important decisions for themselves. When a person is making these decisions, he/she should be acting freely, without pressure from anyone.

This does not mean that the person cannot discuss his/her decisions with health care providers, family or friends, if he/she chooses.

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[2] Probate Code § 4609.
[3] Probate Code § 4657.

People often seek advice and input from trusted friends, family and providers. But ultimately, the person should be comfortable with every decision he/she makes. A person who is feeling pressured or pushed into decisions should be advised not to make an Advance Directive.

IV. WHEN AN ADVANCE DIRECTIVE GOES INTO EFFECT

An Advance Directive for Health Care goes into effect when the person's primary physician determines that the person lacks capacity to make health care decisions.[4] The primary physician must note this determination in the person's health care record and tell the person and his/her agent of the determination. An Advance Directive is no longer in effect when the primary physician determines that the person has regained capacity.

V. HEALTH CARE AGENTS

A person may use an Advance Directive to appoint a Health Care Agent. An Agent is responsible for making health care decisions if the person loses the ability to make these decisions. A Health Care Agent is responsible for carrying out the person's wishes as stated in the Advance Directive or in discussions with the Agent.

It is not necessary to name a Health Care Agent in order to complete an Advance Directive. If the person has not chosen a Health Care Agent, the health care provider is still required to follow the person's wishes, as expressed in the Individual Health Care Instructions.

If both parts of the Advance Directive are filled out, the Health Care Agent must follow the specific wishes spelled out in the second part of the document which is called the Individual Health Care Instructions

[4] Probate Code §§ 4631, 4658.

a. Appointing an Agent

Part I of the Advance Directive form [page 7] is the appointment of an Agent for Health Care. There are several important considerations for people to understand before appointing an Agent. First and foremost is that no one *has* to appoint an Agent. An Advance Directive can be completed without an Agent. If the person decides not to appoint an Agent, the Individual Health Care Instructions in Part II of this form stand on their own.

b. Limiting the Agent's Power

If the person decides to appoint an agent, the person has the right to limit the Agent's power, in other words, allow the Agent to make some decisions on his/her behalf, but not others. [see page 9 of the Advance Directive]

If the person decides to appoint an Agent and does not limit the Agent's power, then his/her Agent will have the authority to:

(a) Consent or refuse consent to any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a physical or mental health condition.

(b) Select or discharge health care providers and institutions.

(c) Approve or disapprove diagnostic tests, surgical procedures, and programs of medication.

(d) Direct the provision, withholding, or withdrawal of artificial nutrition and hydration and all other forms of health care including cardiopulmonary resuscitation.[5]

If the Agent is called upon to make any of these decisions, the Agent must make those decisions in the way the person would have himself/herself. This is often referred to as "substituted judgment."

In California, the law prohibits Health Care Agent from making certain decisions:

[5] Probate Code § 4701

An Agent cannot authorize treatment over the person's objection;

An Agent cannot authorize placement in a mental health facility, authorize Electro Convulsive Therapy (ECT), psychosurgery, sterilization, or abortion.[6]

c. When does the Agent's power go into effect?

Normally, an Agent's authority to make health care decisions would go into effect only when the person was determined to lack capacity to make health care decisions. However, the person does have the option of authorizing his/her Agent to begin making health care decisions immediately.[7] [On page 7 of the Advance Directive form there is a box to check in the "Statement of Intent" paragraph that relates to this decision].

Because of the potentially far-reaching powers that a Health Care Agent can have, it is essential that the person choose an Agent that they know and trust. Furthermore, no one should appoint an agent if they are feeling pressured to do so. The decision to name an agent must be made freely.

d. Who cannot act as a Health Care Agent?

Certain people are prohibited by law from acting as Health Care Agents. The general rule is that the following people *cannot* be named the person's Agent:

1. The person's supervising health care provider.
2. An employee of a health care institution where the person is receiving care.
3. An operator or employee of a community care or residential care facility where the person receives care.

However, there are exceptions that apply to #2 and #3 above:

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[6] Probate Code §§ 4652, 4689.
[7] Probate Code § 4682.

- If the employee is related to the person by blood, marriage or adoption, or is the person's registered domestic partner[8], then he/she may act as the person's agent
- If the employee is employed by the same health care or community care, facility as the person. (In other words, if the person filling out the Advance Directive is an employee of a facility, he/she may name a co-worker at the facility as his/her agent).

Note that if the person names his/her spouse as the Agent and later divorces his/her spouse, then the Agent's designation is *automatically revoked*. In other words, the person's ex-wife or ex-husband is automatically NOT the Agent anymore. If the person wants to keep his/her ex-spouse as the Agent, the person will have to write a new Advance Directive making their ex-spouse the Agent.

Also note that the person cannot name his/her LPS conservator as his/her agent, unless certain specific requirements have been satisfied. These requirements are found at Probate Code 4659(c).

e. Information for Health Care Agents

Just as the decision to appoint an agent needs to be made after careful consideration and without outside pressure, the decision to accept that Agent appointment also requires consideration. Being an agent is a big responsibility and people who are considering becoming agents should be informed of scope of these responsibilities. Before naming an Agent, the person should take the time to discuss with the potential Agent what his/her wishes are regarding health care. [Information for Agents and a worksheet for choosing an Agent are in the attachments to this manual].

f. Appointing a surrogate

In addition to designating an agent, a person may designate an adult as a surrogate.[9] Choosing a surrogate, like choosing an agent, is

[8] The law was amended in 2001 to add registered domestic partners. Probate Code § 4659(b)

optional. Surrogates are different from agents in that their appointment is more temporary, but they are still required to carry out the wishes of the person, as an agent is. The designation of a surrogate lasts only during the course of treatment or illness, or during the stay in a health care institution when the surrogate designation is made, or for 60 days, whichever is shorter. The person may specify a shorter time if they choose.

If a person elects to have both an agent and a surrogate, and then becomes incapacitated, the surrogate has priority over the agent to make decisions during the relevant period.[10] If the person who is elected as a surrogate also happens to be the agent, expiration of the surrogate status will not affect the status as agent.

Example:
Suppose Sarah is Michael's agent. During his hospital stay, Michael also designates Sarah as his surrogate. After 60 days, Sarah will lose her status as Michael's surrogate, but not lose her status as Michael's agent. Therefore, she will still be able to make decisions for him in line with his directives.

To appoint a surrogate, a person must personally inform his/her supervising health care provider. The designation of a surrogate must be promptly recorded in the medical record.

An individual with capacity may at any time disqualify his/her surrogate (including a family member) by a signed writing or by personally informing his/her supervising health care provider.

VI. NOMINATION OF A CONSERVATOR

A person may also use an Advance Directive to nominate someone to act as conservator should one become necessary. [see page 9 of the Advance Directive] If a conservator becomes necessary, the court

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[9] Probate Code § 4711 et seq.
[10] Probate Code § 4711(d)

will appoint the person nominated, unless the court finds that it would not be in the person's best interest to do so. [11]

VII. INDIVIDUAL HEALTH CARE INSTRUCTIONS

Individual Health Care Instructions are the way in which a person can tell his/her doctor, family or Agent what his/her decisions are regarding physical and mental health treatment. A person can use these Individual Health Care Instructions to plan now for the treatment he/she would want when in crisis. Individual Health Care Instructions tell the health care provider and Agent what the person wants done and under what circumstances. This may include agreeing to certain treatments or refusing specific treatments or services.

The person can either put these decisions in writing using an Advance Directive form or the person can tell his/her doctor and/or Agent what his/her decisions are, but either way, the person will need to think through his/her decisions carefully. Clearly worded Individual Health Care Instructions can help a person keep some control over what happens in a crisis; poorly worded instructions can complicate matters.

PART II(a) of the Advance Directive form can be used to write out Individual Health Care Instructions for mental health treatment.

Several of the sections in Part II(a) have space to write out the reason for decisions. The person making the Advance Directive should explain the reasons for his/her choices in the Advance Directive as much as possible. As mentioned above, the more the person explains the reasoning behind his/her choices, the more difficult it will be for someone to argue that the person lacked capacity when he/she wrote the Advance Directive.

Example:
Section 5 "My Choice of Treatment Facility" gives the person the

[11] Probate Code §§1810, 4672.

option of saying which facilities he/she would or would not like to go to in a crisis.

X B. In the event I am to be admitted to a hospital for 24-hour care, I would prefer to receive care at the following hospitals:

Facility's Name: ***Alpha Hospital***

Reason: ***This is the hospital where my regular psychiatrist works. I want to go there so I can be treated by the doctor who knows me best.***

X C. I do not wish to be admitted to the following hospitals or programs/facilities for psychiatric care for the reasons I have listed:

Facility's Name: ***Beta Hospital***

Reason: ***I have been to Beta Hospital in the past and I know that they do not have a patio area for smokers. When I am not allowed to smoke, I start to suffer from nicotine withdrawal. (I get irritable and restless). This makes my symptoms worse and my recovery takes longer.***

If the person needs additional space to complete any instruction or explanation, he/she may attach additional sheets to the Advance Directive document, but each of these additional sheets must be signed and dated at the same time as the Advance Directive.

The person does not have to fill out each section of the Individual Health Care Instructions to complete the Advance Directive. If there are certain sections for which the person has no instructions, he/she may put a line through the entire section and initial and date the page.

a. Treatment Facilities and Notification of Others

Part II(a) Section 4 allows the person to list individuals other than his/her Agent that he/she would like notified when admitted to a

psychiatric hospital. [12] California law prohibits psychiatric hospitals from telling anyone about a patient's admission without that patient's consent. For a person who knows that he/she becomes confused or disoriented when in crisis, this is a way the person can help ensure that friends, family or health care providers will be able to locate him/her.

Section 5 allows the person to identify specific facilities where he/she would or would not like to receive treatment. Section 5, part A refers to non-hospital facilities that provide 24-hour supervision, such as crisis houses or crisis residential services. Section 5, parts B and C refer to acute psychiatric hospitals.[13]

b. Primary Physician

Section 6 allows a person to designate who he/she wants to act as his/her primary physician. A primary physician is the doctor chosen by the person or the person's agent or conservator, to have primary responsibility for the person's health care.[14] As mentioned above, the primary physician also determines if the person has capacity to make health care decision and, thus, determines when the person's Advance Directive goes into effect.

Section 7 allows the person to specify who he/she wants (or does not want) to act as primary physician if his/her regular doctor is unavailable. For example, a person designates his/her outpatient psychiatrist as his/her primary physician, but is then admitted to a hospital where his/her outpatient psychiatrist does not have admitting privileges. Section 7 allows the person to name alternate doctors who are on staff at the hospital to act as primary physician.

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[12] Part I, Section 1 of the Advance Directive instructs psychiatric facilities to notify the person's Agent of admission.
[13] People making Advance Directives should be aware that there may be situations in which their choice of treatment facility cannot be honored, because of emergency or insurance coverage.
[14] Probate Code § 4631.

c. Emergency Interventions

Sections 8 and 9 are related to emergency interventions in inpatient psychiatric facilities. “Emergency” is defined in different places in the law,[15] but generally means a situation in which the staff believes that a person has become so upset or confused that his/her behavior poses a threat of physical harm to him/herself or to other people. When an emergency arises, the law allows the staff to take steps to stop the person’s behavior. Typically, when staff feels that a person’s behavior is “out of control,” they physically restrain the person by strapping him/her to a bed and/or give the person powerful medication. These interventions can be frightening, degrading and even dangerous for the person who is subjected to them. While an Advance Directives may not prevent a person from receiving emergency intervention over his/her objection, it may help the person keep more control over the type of treatment he/she receives. Staff often has several options for dealing with a particular emergency situation.

Section 8 allows the person to explain what will help him/her regain control **before** staff decides that the situation has turned into an emergency. Section 9 refers to situations in which the staff has already decided that emergency intervention is needed. This section allows the person to say which intervention they would like the staff to try first.

d. Psychiatric Medications

Section 9(a) has to do with routine psychiatric medication. Routine medications are those that a person would take on a daily basis to maintain their health or decrease symptoms. There are seven

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[15] “Emergency” means a situation in which action to impose treatment over the person’s objection is immediately necessary for the preservation of life or the prevention of serious bodily harm to the patient or others, and it is impracticable to first gain consent. It is not necessary for harm to take place or become unavoidable prior to treatment. Welfare and Institutions Code § 5008(m) …An emergency exists when there is a sudden marked change in the patient’s condition so that action is immediately necessary for the preservation of life or the prevention of serious bodily harm to the patient or others, and it is impracticable to first gain consent…California Code of Regulations, Title 9 § 853

subparagraphs in this section [A - G] and the person should read through all of them carefully before trying to fill out this section.

Section 9(b) [page 18] allows the person to specify his/her choices around emergency psychiatric medication. Under certain circumstances, medications may be administered to a person in an emergency without the person's consent or the consent of the person's Agent.[16] Emergency medications are quick-acting medications designed to calm the person and help him/her regain control of his/her behavior. These medications may or may not be the same medications the person takes routinely. Here again, while an Advance Directive may not prevent an emergency intervention, consideration should be given to the person's preferences when determining what intervention to use. If emergency medication is administered, it must be given in the manner least restrictive to the person's liberty.

Decisions about routine medications and emergency medications may be difficult to make if the person has little experience with psychiatric medications and their effects. If the person is comfortable with the idea, he/she should consider discussing these decisions with his/her mental health provider before completing these sections.

e. Electro-Convulsive Therapy (ECT)

What is Electro-Convulsive Therapy (ECT)?
Electro-Convulsive therapy, also known as "ECT" or "shock treatment," is applying an electric current to a person's head when he/she is under anesthesia to produce a controlled seizure. Electro-Convulsive Therapy is sometimes used in the treatment of severe depression. Section 10 is related to decisions about ECT.

[16] A physician may take "appropriate action in and emergency…If antipsychotic medication is administered during an emergency, such medication shall be only that which is required to treat the emergency condition and shall be provided in ways least restrictive of the personal liberty of the patient." California Code of Regulations, Title 9 § 853.

Under California law, there are special requirements for consenting to ECT.[17] These requirements were put in place to make sure that people do not receive unnecessary treatment. Doctors must follow the requirements set out in law before giving a person ECT, even if that person wants that treatment. Therefore, in California, an Advance Directive cannot be used to consent to ECT.

Section 10(a) of the Advance Directive form does allow a person to specify that he/she does *not* want ECT. If the person filling out the Advance Directive wants ECT, or would not object to having ECT if his/her doctor felt it was necessary, the person should leave section 10(A) on this form blank.

If the person filling out the Advance Directive wants ECT, or would not object to having ECT if his/her doctor felt it was necessary, he/she can specify the maximum number of treatments (shocks) he/she want to receive by filling out section 10 (B).[18]

What are Drug Trials and Experimental Studies?

Drug trials and studies are the use of people as the subjects of research to test the effectiveness of a new medication or treatment. Recent changes in California law allow a surrogate decision-maker to consent, under specific circumstances, to drug trials and other medical experiments on behalf of an individual who has lost capacity to consent and who does not express dissent or resistance to participation in the experiment.[19] The surrogate decision-maker must have "reasonable knowledge" of the individual and be one of the following persons in the following descending order of priority:

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[17] Welfare and Institutions Code, sections 5326.1 through 5326.91 describe the requirements that must be met before a person can be given Electro-Convulsive Therapy. For more information, see Disability Rights California publication # 5398, *Electroconvulsive Treatment.*

[18] The law prohibits the doctor from giving a person more that 15 treatments in a 30-day period or more than 30 treatments in a 1-year period without meeting additional specific requirements. These requirements are found at California Code of Regulations, title 9, section 849.

[19] AB 2328 (Wayne, 2002), codified at Cal. Health and Safety Code, section 24178.

(a) The person's agent pursuant to an advance health care directive;

(b) The conservator or guardian of the person having the authority to make health care decisions for the person;

(c) The spouse of the person;

(d) The domestic partner of the person;

(e) An adult son or daughter of the person;

(f) A custodial parent of the person;

(g) Any adult brother or sister of the person;

(h) Any adult grandchild of the person; or,

(i) An available adult relative with the closest degree of kinship to the person.

The surrogate may consent only to medical experiments that relate to the cognitive impairment, lack of capacity, or serious or life threatening diseases and conditions of research participants.

This new provision does not apply to individuals who are either voluntarily or involuntarily admitted to a psychiatric facility. In other words, a Health Care Agent or family member may not provide surrogate consent to medical experiments for individual who is currently in a psychiatric facility.

Section 15 lets a person specify that he/she does *not* want to participate in *any* drug trials or studies. If the person leaves this section blank, there is a possibility that a surrogate may under very specific circumstances, consent to participation in drug trials or experiments the person's behalf.

VIII. GENERAL POWER OF ATTORNEY

People who are unexpectedly hospitalized may need to make important decisions about things other than their own health care. For example, who will take care of their children or pets, who will have access to their bank account to pay their rent and utilities, who will be able to move their car to a safe location.

Under California law, these decisions cannot be included in an Advance Health Care Directive, but can be included in a general Power of Attorney. This document (Uniform Statutory Form Power of Attorney) is completely separate from the Advance Health Care Directive. Like an Advance Health Care Directive, a general Power of Attorney must be signed, dated and witnessed.

IX. SIGNING AND WITNESSING THE ADVANCE DIRECTIVE

In order to be "legally sufficient" an Advance Directive must have all of the following:

1. The date it was executed (made),
2. The signature of the person making the Advance Directive, and
3. The signature of two witnesses or the acknowledgment of a notary public.

a. Witnessing the Advance Directive

If the Advance Directive is signed by witnesses, the witnesses must be adults who either witnessed the person signing the document or the person's acknowledgement of the signature or the Advance Directive.

Each witness must either know the person making the Advance Directive or have the person's identity proven to them by "convincing evidence." This evidence might include the person's driver's license, California Identification Card, Green Card or Passport. Each witness must also attest to the fact that the person making the Advance Directive appears to be of "sound mind" and acting freely and without pressure.

b. Who cannot be a witness?

Under California law, the following people are prohibited from witnessing an Advance Directive:

- The person's health care provider or an employee of the health care provider.
- The operator or employee of a community care facility or a residential care facility for the elderly.
- The person's Health Care Agent.

Additionally, at least one of the witnesses must *not* be related to the person making the Advance Directive.

Note that even though this list looks similar to the list of people who are prohibited from being Agents, it is not the same. All operators and employees of all community care facilities and residential facilities for the elderly are prohibited from witnessing an Advance Directive, regardless of whether the person is receiving care at those facilities or the employee is a relative of the person.

c. Witnesses or Notary Public?

As mentioned above, an Advance Directive may either be signed by two witnesses or acknowledged by a notary public. There are at least a couple advantages to using witnesses rather than a notary. First, notaries usually charge for their services. Second, when a notary notarizes an Advance Directive, the notary is simply verifying the identity of the person signing the document. However, when witnesses sign the Advance Directive, the witnesses are attesting to the person's "sound mind." This is extra protection against someone later saying that the person did not have capacity and challenging the Advance Directive.

d. Special Witness Requirements

If the person making the Advance Directive is a resident of a skilled nursing facility, a patient advocate or ombudsman must sign the document either as one of the two witnesses or in addition to notarization.[20]

[20] Probate Code § 4675

X. DISTRIBUTION OF THE ADVANCE DIRECTIVE

Who should have a copy of the Advance Directive?

- **The person making the Advance Directive**

The person making the Advance Directive should keep a copy in a safe, but *accessible* place. It is not a good idea to keep an Advance Directive in some place like a safe deposit box. If the person is unexpectedly hospitalized, nobody will be able to access the Advance Directive.

- **The person's Agent and Alternate Agents**

The person's Agent and Alternate Agents should have a copy of the Advance Directive. First, the Agent needs to know what the person's wishes are and what they have written in the Advance Directive. Second, the Agent needs the Advance Directive to show that he/she is authorized to make decisions on the person's behalf.

- **The person's treating health care professional and other health care providers**

The person's health care providers should have a copy of the Advance Directive. A provider cannot be expected to follow an Advance Directive if he/she doesn't know one exists. When a health care provider is given a copy of the Advance Directive, California law requires that he/she maintain a copy of the Advance Directive in the person's health care record.[21] [A sample cover letter to providers and wallet card are in the attachments to this manual].

- **Mental health facilities and mental health programs**

The person should consider giving a copy of the Advance Directive to hospitals and programs where he/she is receiving services or where he/she would most likely be taken in an emergency.

[21] Probate Code § 4731(a)

- **Family members or friends**

If the person feels comfortable with the idea, he/she should also consider giving a copy of the Advance Directive to family members or close friends.

It is also important that the person keep a list of everyone who has a copy of his/her Advance Directive. If at some later time, the person decides to revoke or change his/her Advance Directive, he/she needs to ensure that the previous versions of the Advance Directive are destroyed to avoid any confusion.

XI. REVOKING OR CHANGING AN ADVANCE DIRECTIVE

a. Revocation

A person with capacity may revoke all or part of an Advance Directive, *other than the designation of an Agent*, at anytime, in any manner that communicates the intent to revoke.[22] "Communication" of the intent to revoke does not have to be oral or written, one of the most common ways to revoke an Advance Directive is to simply tear it up.

A person with capacity may revoke the designation of an agent with a signed written statement or by personally telling his/her supervising health care provider that he/she wants to revoke the designation. [23]

b. Changing an Advance Directive

A person with capacity may also change his/her Advance Directive by making a new Advance Directive with the desired changes. The new Advance Directive will revoke earlier Advance Directives to the extent that they conflict.

If the person writes a new Advance Directive he/she must complete all the same steps she did in writing the first Advance Directive, including having it witnessed. A person may change his/her Advance

[22] Probate Code § 4695(b)
[23] Probate Code § 4695(a)

Directive as often as he/she likes. As a practical matter, however, changing the Advance Directive too frequently may cause confusion as to what the person's wishes are and may cause others to questions the person's capacity.

XII. PROBLEM SOLVING

While Advance Directives for Health Care have been around for a long time, the use of Advance Directives for mental health care is a relatively new application. Consequently, a number of problems or concerns may arise when writing or enforcing an Advance Directive.

This section reviews some of those problem areas and suggests strategies for solving problems.

a. What if a facility refuses to honor an Advance Directive on the basis that the person created the Advance Directive did not have capacity to make one?

A person is presumed to have capacity to make an Advance Directive. The two witnesses who signed the Advance Directive attested to the person's "sound mind." This witnessing procedure meets the legal requirements for documentation of capacity to create an Advance Directive.

Because people are presumed to have capacity to make Advance Directives, the burden is on the facility to prove in court that the person lacked capacity to make the Advance Directive. [24]

If the person making the Advance Directive is concerned that someone might later try to challenge his/her capacity, he she can take the following steps to help prevent future challenges:

- Talk with health care provider(s) about the Advance Directive when filling it out. Ask him/her to conduct a mental status exam and note in the record that he/she is of "sound

[24] Probate Code § 4657

mind." Ask for a copy of this note to attach to the Advance Directive.

- When filling out the Advance Directive, use the space available to explain the reasons for the decisions. The more the person explains his/her reasoning, the harder it will be to argue that the person lacked capacity.
- Choose witnesses who know the person and know how he/she is doing and who can be easily located should the Advance Directive be challenged.

b. What if a facility does not permit the Agent to consent to or refuse treatment?

Under the Federal Patient Self-Determination Act and the California Health Care Decisions Law, people have a right to appoint a Health Care Agent to carry out their wishes regarding physical and mental health care if they become unable to make those decisions for themselves or are found legally incapable of consenting to physical or mental heath treatment. If the Advance Directive appoints an Agent, and the person has been found to lack the capacity to make treatment decisions, then that person's appointed Agent must be permitted to consent or refuse proposed treatment.[25]

If the Agent is not permitted to consent or refuse treatment by the facility, make sure that the facility is aware of the specific provisions of the Advance Directive and has a copy. Review with the appropriate treating and administrative personnel the legal obligation of the facility to comply with those provisions. The person, or a third party on the person's behalf, may petition the court to compel a health care provider to honor an Individual Health Care Instruction or the authority of the agent.[26]

[25] Probate Code § 4671, 4683, 4733.
[26] 4766(e)

c. What if a facility does not consider the person's Advance Directive in a psychiatric "emergency"?

Individual Instructions for emergency intervention should be considered in determining which form of intervention is least restrictive of the person's liberty.[27] An Advance Directive may not prevent a person from receiving emergency intervention over his/her objection, but it may help the person keep more control over the type of treatment they receive. Staff often has several options for dealing with a particular emergency situation. In considering which intervention or combination of interventions is the least restrictive to the person's liberty, consideration should be given to what that person considers the least objectionable.

If the facility does not consider the Advance Directive in a psychiatric emergency, ensure that the treating and administrative staff is aware of the specific provisions in the Advance Directive related to emergency interventions. Review the legal requirements to utilize the least restrictive alternatives and the person's Individual Health Care Instructions regarding emergency intervention with the treating staff.

d. What if the Agent cannot be located or is unable or unwilling to make treatment decisions?

If the Advance Directive appoints an Alternate Agent, that person should be contacted. If no Agents are available or able/willing to be an Agent, the health care provider must still recognize and comply with the Individual Health Care Instructions in the Advance Directive.

---

[27] Welfare and Institutions Code section 5332(d) and Cal. Code of Regs, Tit 9 section 853 specify that when antipsychotic medications are used in an emergency, the medication *"shall be provided in the manner least restrictive to the personal liberty of the patient."*
Cal. Code of Regs., Tit 9 section 865.4(a) and Cal. Code of Regs. Tit 22 sections 70577(j)(1), 71545(a) specify that seclusion and restraint may only be used when lesser restrictive alternatives are not sufficient to protect the patient or others.

e. What if the Agent is making decisions that are not consistent with the person's wishes?

The Agent may not make any decisions that he/she knows are not accordance with the person's wishes. If a third party believes that the Agent may not be following the person's instructions, the party may file a petition with the court to determine if the Agent's decisions are consistent with the person's instructions as expressed in the Advance Directive.[28]

A third party may also petition the court for removal of the Agent if the Agent has violated his/her duty to act in a way consistent with the person's desires.[29]

f. What if the Agent is asked to make a decision upon which the person has given no specific instructions?

Before making any decision, the Agent must determine if the decision he/she is being asked to make is within his/her authority as Agent. The Agent is prohibited by law from making some decisions. For example, an Agent may not consent to Electro Convulsive Therapy (ECT) on behalf of the person. Further, the person writing the Advance Directive may also have limited his/her Agent's power.

If the decision is within the scope of the Agent's authority, the Agent must make decisions based on the person's expressed desires. If the person's specific desires are not known, the Agent must make decisions based on substituted judgment: [30]

1. **Expressed desires.** The Agent must make decisions in accordance with the person's **expressed desires** as the person has stated them in his/her written Individual Health care Instructions or in conversation with the Agent.
2. **Substituted judgment.** If the person has left no instructions on a particular decision, the Agent must make decisions on behalf

[28] Probate Code § 4766(c)
[29] Probate Code § 4766(d)
[30] Probate Code § 4684

of the person in the way the person would have him/herself. This means the Agent must take into account what he/she knows about the person and the person's values and make the decision based on those values.

g. What if the person changes his/her mind about a treatment decision after he/she has lost capacity and the Advance Directive is in effect?

As mentioned above, only a person with capacity may change or revoke an Advance Directive. However, an Agent may not make any health care decision over the person's objection. The Agent should try to keep in frequent contact and open communication with the person when he/she is hospitalized. Prior to making health care decisions, the Agent should always make sure the person agrees with the decision. Additionally, before implementing a health care decision made for the person, the health care provider must promptly inform the person about the decision and the identity of the person making the decision. [31]

If the person objects to the Agent's decision or to the implementation of an Individual Health Care Instruction, the matter concerning that particular procedure shall be governed by the law that would apply if there were no Power of Attorney for Health Care or Individual Health Care Instruction regarding that procedure. [32]

Example:

> John makes an Advance Directive. In his Advance Directive he names Sarah as his Agent. He also writes Individual Health Care Instructions that says he would like Lithium and Ativan to be his routine psychiatric medications.
>
> John is hospitalized and John's doctor (primary physician) determines that John lacks the capacity to make health care decisions. John's doctor wants to give John Ativan

[31] Probate Code §§ 4689, 4730.
[32] Probate Code § 4689

and Lithium so he contacts Sarah and asks her to consent for the medication.

Sarah reads John's Advance Directive and the instructions related to routine psychiatric medication and consents to Lithium and Ativan. The doctor then goes to John and explains that Sarah his Agent has consented these medications for him. John tells his doctor that he has changed his mind and does not want to take Lithium, Ativan or any other medication.

The doctor discusses the medication with John and goes over his Advance Directive with him, but John is adamant he will not take any medication.

Because John objects to Sarah's decision about routine psychiatric medication, it is as if he had no Agent or Instructions for this issue. In other words, John would be treated like another person who was refusing psychiatric medication. If John's doctor feels he does not have capacity to make decisions about medication, his doctor can petition the court for a capacity hearing (*Riese hearing*). If it is found at the hearing that John lacks capacity to consent to medication, he can be medicated over his objection.

h. Can a person on an LPS Conservatorship make an Advance Directive for Mental Health?

Placement on conservatorship under the Lanterman-Petris-Short (LPS) Act does not, in and of itself, prevent a person from making an Advanced Directive. Adults are presumed to have capacity to make an Advance Directive. An otherwise legally sufficient Advance Directive is presumed valid absent a determination that the individual lacked capacity at the time it was made. It is well settled under California law that a person who is on LPS conservatorship retains the right to make treatment decisions absent a specific finding of

incapacity to do so.[33] The law expressly provides that any adult is presumed to have capacity to make an Advance Directive.[34]

i. What if an Advance Directive is lost?

Try to locate other copies of the Advance Directive by checking with the Agent/Alternate Agent or any mental health providers or others that have copies. If no other copies are available, complete a new Advance Directive as soon as possible. Disability Rights California has Advance Directive forms available online at www.disabilityrightsca.org or by calling 1(800) 776-5746.

If you have other questions or concerns about the implementation or enforcement of Advance Directives for Mental Health contact your county patients' rights advocate or Disability Rights California at www.disabilityrightsca.org or by calling 1(800) 776-5746.

[33] An LPS conservatee does not forfeit any legal right nor suffer legal disability by reason of the LPS commitment alone. Welf. & Inst. Code §§ 5005, 5327; *see also Riese v. St. Mary's Hospital & Medical Center,* 243 Cal.Rptr. 241, 246 (1987) (involuntarily committed individuals retain the right to make informed decisions regarding treatment with antipsychotic medications absent an emergency or judicial determination of their incapacity); *Conservatorship of Moore,* 229 Cal.Rptr. 875, 884 (1986) (LPS conservatees are not considered incompetent by reason of conservatorship).
The Uniform Health Care Decision Act expressly envisions that LPS conservatees may develop an advance directive. A conservator may not be designated as an Agent unless the Advance Directive is otherwise valid, the conservatee is represented by legal counsel, and the lawyer signs a certificate of advisement. Probate Code § 4659[c]; *see also* Section 4770 (LPS conservatorship court may issue temporary order prescribing health care of principal pending filing and determination of a petition under Section 4766).
[34] Probate Code § 4657

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Attachment # 1

Health Care Agent Worksheet

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Advance Health Care Directive
Health Care Agent Worksheet

This worksheet is to help you prepare to complete the Advance Health Care Directive form. You do not have to complete this worksheet in order to make an Advance Health Care Directive, but you can use these questions to help you think through some of the decisions you will have to make when choosing a Health Care Agent.

1. Are you feeling pressured by anyone to name a specific person as your agent?

   ____ No *(Go to step 2*).

   ____ Yes (Stop, do not continue. Your choice of a Health Care Agent is yours alone).

2. Who do you want to represent your wishes (be your agent)?

   _____

3. Is this person any of the following?

   a. Your healthcare provider ----------Yes / No

   b. A non-relative employee of your healthcare provider ----------Yes / No

   c. An operator of a community care facility in which you live ----------Yes / No

   d. A non-relative employee of a community care facility in which you live ----------Yes / No

   e. An operator of a residential facility for the elderly in which you live----------Yes / No

   f. A non-relative employee of a residential facility for the elderly in which you live ----------Yes / No

If you answered NO to all of the above, go to step 4.

If you answered YES to any of the questions above, do not continue. This person may not serve as your agent under California law.

4. Will this person understand your Advance Directive and how to use it ----------Yes / No
5. Will this person be able to speak up on your behalf and advocate for your decisions with healthcare providers? ----------Yes / No
6. Will this person be available and easy to contact? ------Yes / No
7. Have you *talked* with this person about becoming your agent? ----------Yes / No
8. Has this person *agreed* to become your agent? ----------Yes / No
9. Have you discussed your wishes regarding your health and mental health treatment with this person and answered any questions he/she has about your wishes? ----------Yes / No
10. Do you have any hesitations about this person being your agent? What are they and will they interfere with this person acting as your agent?

_____

_____

_____

Attachment # 2

Individual Health Care Instruction Worksheet

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Advance Health Care Directive

Individual Health Care Instruction Worksheet

This worksheet is to help you prepare to complete the Advance Health Care Directive form. You do not have to complete this worksheet in order to make an Advance Health Care Directive, but you can use these questions to help think through some of the decisions you may want to make about your physical and mental health treatment.

Medications

1. What are the medications you are currently taking? How often? At what dosages?_____

   _____

   _____

   _____

2. Do you want to take medication in the hospital? ----------Yes / No
3. What kinds of medication would you prefer if you were hospitalized? Which medications? At what dosages?

   _____

   _____

   _____

4. Are there medications you would not want under any circumstances? _____

   _____

   _____

5. What time of day do you prefer to take medication?

_____

_____

_____

6. Do you prefer pills or injections? ----------Yes / No
7. Which medications would you prefer in an emergency situation?

_____

_____

_____

Electro-Convulsive Therapy (ECT or Shock Treatment)

8. Do you want ECT or would you consider having it if your doctor recommended it? ----------Yes / No

   If yes, under what circumstances? Describe the circumstances when you want or would consider having ECT:

_____

_____

Emergency Situations

9. What kinds of things help you regain control when you start to feel upset, agitated or frightened? _____

_____

_____

_____

10. If you are in the hospital and the staff decides that there needs to be some kind of intervention (against your will), which would you prefer staff try first, medication, seclusion or restraint?

_____

_____

Other Mental Health Treatment

11. What other kinds of mental health treatment do you want and not want (e.g. outpatient therapy, group therapy, family therapy, substance abuse counseling)?_____

_____

_____

_____

_____

_____

12. Are there specific hospitals you prefer? Specific community programs you prefer? Specific outpatient therapists/centers you prefer? _____

_____

_____

_____

_____

_____

Nomination of a Conservator

13. Who do you want to be appointed by the court to be your conservator, if necessary? _____

    _____

14. Will he/she be willing and available to speak to health and mental health providers? ----------Yes / No
15. Have talked with him/her about being your conservator? ----------Yes / No
16. Has he/she agreed to become you conservator, if necessary? ----------Yes / No
17. Have you discussed with this person your wishes regarding physical and mental health treatment? ----------Yes / No
18. Do you have hesitations or concerns about him/her acting as your conservator? ----------Yes / No
    What are they and will they interfere with his/her acting as your conservator?

    _____

    _____

    _____

    _____

Physical Health Treatment

19. List any physical conditions for which you receive on going treatment:

    _____

    _____

_____

20. Do you have any specific instructions regarding your physical health care? _____

_____

_____

_____

_____

21. Do you have other instructions regarding your health care in the event you become terminally ill and/or are in an irreversible coma or persistent vegetative state? _____

_____

_____

_____

_____

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Attachment #3

How to Be an Effective Health Care Agent

PAI Publication #5407.01 December 2005

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How to Be an Effective Health Care Agent

As an agent, you have important responsibilities:

- **Be knowledgeable**
  Your role is to represent your friend/relative's wishes regarding mental health and/or physical health treatment. Read the Advance Directive of the person you are representing. Discuss treatment options and scenarios with that person to familiarize yourself with his/her general and specific wishes regarding health care. Try to keep in frequent communication with the person if they should become hospitalized. Remember, your responsibility is to consent or refuse treatment based on *that person's* wishes, not your own.
- **Don't be afraid to ask questions**
  As an agent, you have the *right* to access information from the health care provider regarding the person you are representing. Get all the information you need to make fully informed decisions.
- **Ask for full explanations**
  If there is anything that you don't understand, ask staff to explain it in terms that you can understand. Ask for details. If you feel uncomfortable… like you don't have "the whole picture," say so! Don't be pushed into making a decision before you feel you have enough information.
- **Be firm and persistent.**
  Don't hesitate to insist that you be fully heard, and don't be afraid to argue for everything that the person is entitled to.
- **Keep your cool**
  Getting upset and yelling only serves to alienate health care providers, undermine your credibility and, ultimately, decrease your effectiveness as an advocate. The best approach is calm, polite and firm.
- **Keep things written down**
  Make notes of conversations you have with providers. Include the date, time, type of contact (i.e. meeting, telephone call), name of the person, his/her title, telephone number and address so you can contact him/her again if necessary. Make notes of what you discussed and what the outcome of the discussion was. Ask the

provider to give you written confirmation of any decisions or promises that were made. Get copies of any signed consents for treatment.

Attachment # 4

Sample Provider Letter

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(Date)

_____
(Director/Health Care Provider)

_____
(Mental Health Program/Facility)

_____
(Address)

_____
(City, State, Zip)

Dear Mr./ Ms./Dr. _____,

Enclosed is a copy of my Advance Health Care Directive. Please place this document in my medical record, as required by California Probate Code § 4731(a).

In this document, I have written Individual Healthcare Instructions and/or designated an agent to make health care decisions, including mental health treatment decisions, for me in the event I become or am found legally incapable of making health care decision for myself. This document is to be regarded as the vehicle through which I have expressed my decisions for healthcare, including mental health treatment.

Sincerely,

_____
(Name)

Blank

Attachment # 5

Wallet Card

(Print two sided)

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NOTICE TO HEALTH CARE PROVIDERS

I have signed an Advance Health Care Directive **pursuant to California Probate Code § 4600 et seq. This document contains a Power of Attorney for Health Care and/or Individual Health Care Instructions. If I become or am found legally incapable to make decisions regarding my health care, this document is to be seen as the vehicle through which I have expressed my decisions regarding health care, including mental health treatment.**

_____ _____

SIGNATURE DATE

_____

PRINT NAME

_____

ADDRESS

NOTICE TO HEALTH CARE PROVIDERS

I have signed an Advance Health Care Directive **pursuant to California Probate Code § 4600 et seq. This document contains a Power of Attorney for Health Care and/or Individual Health Care Instructions. If I become or am found legally incapable to make decisions regarding my health care, including mental health treatment, This document to be seen as the vehicle through which I have expressed my decisions regarding health care, including mental health treatment.**

_____ _____

SIGNATURE DATE

_____

PRINT NAME

_____

ADDRESS

NOTICE TO HEALTH CARE PROVIDERS

I have signed an Advance Health Care Directive **pursuant to California Probate Code § 4600 et seq. This document contains a Power of Attorney for Health Care and/or Individual Health Care Instructions. If I become or am found legally incapable to make decisions regarding my health care, including mental health treatment, This document to be seen as the vehicle through which I have expressed my decisions regarding health care, including mental health treatment.**

_____ _____

SIGNATURE DATE

_____

PRINT NAME

_____

ADDRESS

➢ NOTICE TO HEALTH CARE PROVIDERS

On _____ 20_____, I have signed an Advance Health Care Directive pursuant to California Probate Code § 4600 et seq. I have designated the following person(s) as my agent to make health care, including mental health treatment, decisions:

1. _____ Tel. ( ) .

2. _____ Tel. ( ) .

The following persons also have copies of Advance Health Care Directive:

1. _____ Tel. ( ) .

2. _____ Tel. ( ) .

*NOTE: Even if I have not named an agent or my agent is unavailable at the time of execution of my Advance Directive, the Individual Health Care Instructions contained therein express my decisions regarding health care, including mental health treatment.

➢ NOTICE TO HEALTH CARE PROVIDERS

On _____ 20_____, I signed an Advance Health Care Directive pursuant to California Probate Code § 4600 et seq. I have designated the following person(s) as my agent to make health care, including mental health treatment, decisions:

1. _____ Tel. ( ) .

2. _____ Tel. ( ) .

The following persons also have copies of Advance Health Care Directive:

1. _____ Tel. ( ) .

2. _____ Tel. ( ) .

*NOTE: Even if I have not named an agent or my agent is unavailable at the time of execution of my Advance Directive, the Individual Health Care Instructions contained therein express my decisions regarding health care, including mental health treatment.

➢ NOTICE TO HEALTH CARE PROVIDERS

On _____ 20_____, I signed an Advance Health Care Directive pursuant to California Probate Code § 4600 et seq. I have designated the following person(s) as my agent to make health care, including mental health treatment, decisions:

1. _____ Tel. ( ) .

2. _____ Tel. ( ) .

The following persons also have copies of Advance Health Care Directive:

1. _____ Tel. ( ) .

2. _____ Tel. ( ) .

*NOTE: Even if I have not named an agent or my agent is unavailable at the time of execution of my Advance Directive, the Individual Health Care Instructions contained therein express my decisions regarding health care, including mental health treatment.

Attachment # 6

ADVANCE DIRECTIVE COMPLETION CHECKLIST

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ADVANCE DIRECTIVE
COMPLETION CHECKLIST

❑ 1. I have completed this document.

❑ 2. I have reviewed each section to make sure there are no errors.

❑ 3. For any sections I chose not to complete, I have drawn a line through the section and initialed the page.

❑ 4. I have signed and dated page 25.

❑ 5. ___ Two witnesses have signed and completed the form on page 26 (and page 27 if necessary);

or

___ The form has been notarized on page 28.

❑ 6. I have attached pages 1-28 and any additional pages.

❑ 7. I have made at least 5 copies of this document.

❑ 8. I have given a copy of the completed document to those people who may need this form if I am found or become unable to make my own healthcare decisions. These people include (check all that apply):

- ❑ my agent;
- ❑ my alternate agents;
- ❑ my family members;
- ❑ friends;
- ❑ my health/mental health care providers;
- ❑ mental health facilities and programs;
- ❑ patients' rights advocate
- ❑ other _____

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