Southern Caregiver Resource Center

Caring for those who care for others

Fact Sheet: Advance Health Care Directives and POLST

The Advance Health Care Directive (ADHC) allows you to appoint someone (health care agent, attorney-in-fact, proxy or surrogate) to make a decision for you if you cannot speak for yourself. It is also called the Durable Power of Attorney for Health Care, Natural Death Act, Directive to Physicians or a Living Will. (The living will is slightly different; check on what is recognized in your state.) Every state recognizes the ADHC, but states have their own forms, as laws vary from state to state.

Advance Health Care Directives

What does it do?

- Allows the person you appoint to have legal authority to make health care decisions for you if you are no longer able to speak for yourself
- Allows you to make specific written instructions for your future health care in the event of any situation in which you can no longer speak for yourself.
- You are in charge of your health care decisions, as long as you are able to make them, unless you specify differently
- Physicians and your agent are obligated by law to follow your health care instructions

Your agent has the right to:

- Make decisions regarding any treatment, not just life-sustaining treatment
    - You can give limited powers to agent or broad powers to agent
- Start helping you before you are incapacitated if you specify this is what you want
- Select or discharge care providers and institutions
- Accept or refuse specific treatments
- Withdraw or withhold life sustaining treatment
- Make anatomical gifts, e.g. tissue or organ donation
- Allow, restrict or forbid autopsy, unless required by law
- Direct the disposition of remains and make funeral or memorial plans

What your agent cannot do:

- Cannot make legal or financial decisions unless given that power through a Durable Power of Attorney for Property/Finance
- Cannot deny comfort measures to you
- Cannot be held responsible for your medical bills unless person also has Power of Attorney for Finance
- Cannot access your medical records as long as you are competent to make your own health care decisions. AHCD is not a release of information. The Health Insurance Portability and Accountability Act

(HIPPA) protects your privacy unless you sign a release of information with the treating physician. However, medical systems sometimes recognize the AHCD as a de facto release of information.

How do I choose an agent?

- Person must be over 18 years old
- Name one primary agent and two alternates in case the primary person is unavailable, unwilling or unable to act on your behalf
- Doesn't have to be someone who lives in your geographic area, but if agent doesn't, then you should have alternates who are nearby in case there is need for immediate decisions and/or long-term oversight of care
- Choose someone you trust; can be spouse, partner, family member, friend
- Does not have to be same person who has power of attorney for finance
- Someone who knows your personal values and beliefs
- Someone you have talked to about these issues
- Someone who is willing/able to do what you want them to do, who shares your values and beliefs about medical care and dying
- Cannot be your doctor, health care professional, someone working in a health care facility, such as a nursing home, in which you are receiving care

Where do I get the AHCD form?

- All hospitals and doctors' offices have the form.
- Long Term Care Ombudsman Program
- Senior Legal Services
- Senior Information and Referral (Usually under the Area Agency for Aging)
- State medical society
- Attorney

How do I complete the forms?

- You have to be 18 and mentally competent
- You can write out your health care wishes separate from the form and attach it to the AHCD in case your agent isn't available in an emergency.
- This will also help your agent when he/she has to make a decision and can help reduce family conflict if there is disagreement about a decision. Sign and date any sheets attached to the AHCD
- Does not require an attorney
- You must sign the form yourself
- It must be witnessed by two people not named as agents or it can be notarized
- Witnesses cannot be your agent or alternates, your physician or employee of residential or health care facility.
- One witness must not be a family member by blood, marriage or adoption and must not be entitled to any part of your estate
- If you are a resident of a skilled nursing facility, one witness must be a patient advocate or state designated ombudsman.

- Can be changed or revoked at any time you choose, as long as you are competent to make the decision
- Creating a new AHCD automatically revokes your previous one
- If you change it, inform concerned parties about your wishes or new agents

What happens if I don't have one?

- Someone has to make decisions when an ill person can't
- Doctors, hospital staff and loved ones will do the best they can
- Often that means disagreement over what you would have wanted
- If health care professionals make the decision, they will do all they can to keep you alive
- What they decide might not be what you want
- A conservator or guardian could be appointed by the court to decide for you

What choices do I have and not have regarding health care?

- Accepting or withholding life support measures, such as feeding tubes, ventilators, defibrillation, dialysis, CPR
- Specifying particular health care instructions, you might have regarding accepting or withholding treatment for such things as a UTI (urinary tract infection), pneumonia, pain medications, antibiotics, flu shots, surgery, etc.
- You can state that you do not want life prolonging treatments if you will never recover your physical and mental health so that you will be able to live without constant care and supervision
- You can also state that you wish to receive only palliative care or comfort care
- Or you can state that you want your life prolonged as long as possible
- You can address what you wish to occur in the event of trauma, a prolonged state of unconsciousness, a diagnosis of dementia, etc.
- You have the right to insist on treatment as well as the right to refuse treatment
- Each occurrence is considered a new treatment, such as taking a daily medication, going to dialysis, or breathing on a ventilator
- Doctors may present information on "medical futility"—the doctor informs you that further treatment will not change the outcome
- See fact sheets: *Advanced Illness: Holding on and Letting Go*, *Advanced Illness: Feeding Tubes and Ventilators*, and *Advanced Illness: CPR and DNR*
- Before making these decisions, they should be discussed with a well-informed health professional as well as family, clergy, etc.
- Ask what you can expect during the last days of your life and what your loved ones should expect if you are facing a life-limiting illness
- If your health care provider refuses to observe your stated wishes or the decisions of your agent because of conscience or the institution's policies or standards, the provider must inform you or your agent

immediately and arrange to transfer you to another provider

What do I do once I complete the AHCD?

- Make lots of copies
- If you have a vial of life, put a note in it to say where the form is kept
- Vial of Life is available from your local fire station or through the web at www.vialoflife.com
- Contains important medical information in case of emergency
- Keep one copy at home in a place you and your family/agents know where it is
- Give a copy to your agent and alternates
- Give a copy to family members who are not agents, so they know your wishes
- Give a copy to each of your physicians
- Give a copy to your lawyer (the AHCD may be part of a trust or other legal documents that you have completed)
- If you go to the hospital or other health care facility, take a copy with you and give it to the hospital staff
- Put a card or notation in your wallet or purse stating that you have an AHCD
    - List phone numbers of your agents
    - Take a copy with you when you travel or put it on your electronic devises under ICE (in case of emergency)
- If you live extended periods of time outside your home state, also complete an AHCD for the other state you are living in

DNR — Do Not Resuscitate

- This is a doctor's order that states that you do not want to be resuscitated, e.g. not have CPR (cardio-pulmonary resuscitation), in the event that your heart stops beating, or you stop breathing
- Discuss with your physician your health status and whether this is appropriate
- As a doctor's order, it must be heeded
- If paramedics are called and you do not have a DNR (or POLST—see below) in the house, they are legally required to do everything possible to resuscitate you
- If you go to the hospital, you can ask that you be "No Code" which means you do not want to be resuscitated as above

See fact sheet, *Advanced Illness: CPR and DNR*.

POLST — Physician's Orders for Life Sustaining Treatment

- Not in all states as of this time, but more states are accepting this form
- As a doctor's order, it must be heeded
- Follows you wherever you go; it's valid at home, in a nursing home, a long-term care facility, and in the hospital
- Discuss with your physician and complete in keeping with your current medical condition
    - Can be changed and updated as your health status changes

- Gives emergency and medical personnel orders, based on your wishes, on which actions to take in the event of an emergency
- There are three levels of care you can designate
    - "Comfort Measures Only"
    - "Limited Additional Interventions"
    - "Full Treatment."
- Says what you do and don't want in terms of end of life treatment, e.g. feeding tubes (artificial nutrition), CPR, ventilators, antibiotics, etc.

Talking About It:

- If we don't plan, and share our ideas with those we love, others will take over at the very time when we are most vulnerable, most in need of understanding and comfort, and most longing for dignity
- Find an opportunity to talk with family members about your wishes, and also about how you think about the decisions you or they might have to make. Use newspaper articles, movies, TV shows or the experiences of others as openers to these conversations
- Play the "What if…." Game—ask yourself and others what they want "if this or that happened", for example, "If you got hit by a bus crossing the street" or "If you had a stroke and couldn't feed yourself" etc.
- Have conversations frequently, as both you and your loved ones might change your thinking over time. Sometimes it is best to have shorter talks more regularly.

Some questions that might help start the conversation:

- What are your fears?
- What medical treatments and care are acceptable to you?
- What do you think about the care a friend received when facing a life limiting illness?
- Do you wish to be resuscitated if you stop breathing or your heart stops?
- What actually happens when a person dies? Do you want to know more about what might happen?
- Will your loved ones be prepared for the decisions they may have to make?
- Do you wish to be hospitalized or stay at home or somewhere else if you are seriously or terminally ill? Do you know your options, e.g. Hospice?
- How will your care be paid for? Does someone have the authority to pay the bills for your care if you can't sign your own checks?

Things to take into consideration:

- Beliefs about religion, pain, suffering, quality of life, death and afterlife
    - Talk with religious advisors about spiritual concerns
- Loss of dignity, not being understood, being overly sedated or in a lingering state of unconsciousness, being alone, dying in a strange place
- Leaving loved ones or unfinished projects behind
- Leaving your loved ones without adequate financial resources

- Are your legal and financial affairs in order?
- Do you have a will or trust?

See fact sheet, *Advanced Illness: Holding on and Letting Go*.

What if someone is already incapacitated?

- Depends on the degree of impairment the person has experienced and their legal ability to sign documents
- If you are the responsible person, the questions to ask yourself are:
- What is the prognosis?
- Knowing this person, what would he or she want in this situation?
- Are there others you should consult who might also have an idea of what would be wanted?
- Does the hospital have an ethics committee or other staff you can consult to help sort through options for care?
- What financial and insurance benefits can be accessed to provide care?

Resources

Southern Caregiver Resource Center
3675 Ruffin Road, Suite 230
San Diego, CA 92123
(858) 268-4432 | (800) 827-1008 (in CA)
E-mail: scrc@caregivercenter.org
Website: www.caregivercenter.org

Southern Caregiver Resource Center offers free support services to family caregivers of adults with chronic and disabling conditions in San Diego and Imperial counties. Services include information and referral, needs assessments, care planning, family consultation, case management, individual counseling, legal and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance
National Center on Caregiving
(415) 434-3388 | (800) 445-8106
Website: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers and assists caregivers nationwide in locating resources in their communities.

Five Wishes
www.agingwithdignity.org

Five Wishes is a document that helps you express how you want to be treated in the event you become seriously ill and unable to speak for yourself.

National Hospice and Palliative Care Organization
www.nhpco.org

POLST
www.polst.org

Objective information provided about this advance care planning tool. Offers a current POLST program map by state and a downloadable POLST form.

Nolo
www.nolo.com

Self- help publisher with many publications and sample documentation for POLST, AHCD, and related issues.

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