Huntington Hospital

Advance Care Planning

It's time to speak up!

Information About Advance Health Care Directives

It's time to start the conversation. It's time to speak up and make sure your voice is heard.

Advance care planning is the process of planning for a time when you could not make your own medical decisions.

What is an Advance Health Care Directive (AHCD)?

An AHCD is a way to make your healthcare wishes known if you are unable to speak for yourself or prefer someone else to speak for you. An AHCD can serve one or both of these functions:

- POWER OF ATTORNEY FOR HEALTH CARE (TO APPOINT AN AGENT)
- INSTRUCTIONS FOR HEALTH CARE (TO INDICATE YOUR WISHES)

Is the AHCD different from a Durable Power of Attorney for Healthcare?

Legislation enacted in July 2000 replaced the Durable Power of Attorney for Health Care and the Natural Death Act Declaration with the Advance Health Care Directive. However, if you had already completed a form that was valid before July 1, 2000, it is still valid.

Why should I complete an AHCD?

People of all ages may unexpectedly be in a position where they cannot speak for themselves, such as an accident or severe illness. In these situations, having an AHCD assures that your doctor knows your wishes about the kind of care you want and/or who the person is that you want to make decisions on your behalf.

Does this mean only one person can decide for me? What if I want others involved too?

Often many family members are involved in decision making, and most of the time, that works well. Occasionally, people will disagree about the best course of action, so it is usually best to name one person as the agent (with a back up, if you want). You may also indicate if there is someone who you do NOT want to make your decisions for you.

I thought the doctors make all those life-and-death decisions?

Doctors tell you about your medical condition, the different treatment options that are available to you and what may happen with each type of treatment. Though doctors provide guidance, you or your designated decision maker makes the decision to have a treatment, refuse a treatment or stop a treatment.

What if something happens to me and no form has been completed?

If you are not able to speak for yourself, the doctor and healthcare team will turn to one or more family members or friends. The most appropriate decision maker is the one with a close, caring relationship with you, is aware of your values and beliefs and is willing and able to make the needed decisions.

My "values and beliefs?" But I haven't talked with anyone about these!

It's a good idea to talk with family or close friends about the things that are important to you regarding quality of life and how you would want to spend your last days. Knowing the things that are most important to you will help your loved ones make the best decisions possible on your behalf.

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What if I don't want to appoint an agent? Or don't have one to appoint?

You do not have to appoint an agent. You can still complete the Instructions for Health Care, and this will provide your doctors with some basic information to guide your care.

How do I make a plan? Think about what's right for you.

Advance care planning is about making decisions about your medical wishes. It's about putting these decisions in writing by completing an advance healthcare directive.

What kinds of things can I write in my Instructions for Health Care?

You can, if you wish, write your preferences about accepting or refusing life-sustaining treatment (like CPR, feeding tubes, breathing machines), receiving pain medication, making organ donations, indicating your main doctor for providing your care, or other things that express your wishes and values. If you have a chronic or serious illness, you may also want to talk with your doctor about specific treatments that you could face and ask him/her to help you document your decisions on a POLST form.

What is a POLST form?

POLST stands for Physician Orders for Life-Sustaining Treatment and was adopted in California in 2009. It is a voluntary form, which must be signed by you (or your agent) and your physician, and indicates the types of life-sustaining treatment you do or do not want if you are seriously ill. POLST asks for information about your preferences for CPR, use of antibiotics, feeding tubes, etc. POLST doesn't replace your AHCD, but when you are seriously ill, it helps translate it into medical orders that must be followed in all healthcare settings.

If I appoint an agent, what can that person do?

Your agent can make all decisions for you, just like you would if you could. Your agent can choose your doctor and where you will receive your care, speak with your healthcare team, review your medical record and authorize its release, accept or refuse medical treatments and make arrangements for you when you die. You should instruct your agent on these matters so he or she knows how to decide for you. The more you tell your agent the better he or she will be able to make those decisions on your behalf.

When does my agent make decisions for me?

Usually the agent makes decisions only if you are unable to make them yourself – such as, if you've lost the ability to understand things or communicate clearly. However, if you want, your agent can speak on your behalf at any time, even when you are still capable of making your own decisions. You can also appoint a "temporary" agent – for example, if you suddenly become ill, you can tell your doctor if there is someone else you want to make decisions for you. This oral instruction is just as legal as a written one.

Are there other oral instructions that don't involve a written form?

Yes. You can make an individual healthcare instruction orally to any person at any time, and it is considered valid. All healthcare providers must document your wishes in your medical record. But it is often easier to follow your instructions if they are written down.

What is most important in your life? Living on your own? Having family nearby? Interacting with people?

Can I make up my own form or use one from another state?

Yes. Any type of form is legal as long as it has at least three things:

1. Your signature and date,
2. The signature of two qualified witnesses with their witness statements (see below), and
3. If you reside in a skilled nursing facility, the signature of the patient advocate or ombudsman.

Witness Statement: Witnesses must sign a statement on the AHCD indicating that they **a)** know who you are or have been shown proof of your identity, **b)** are 18 years old or more, **c)** are not your healthcare provider or working for your provider, **d)** are not your healthcare agent, and **e)** are not employed in the place where you live.

One of the two witnesses must sign a statement indicating that they are not related to you by blood, marriage or adoption and will not receive any property or money from you after your death.

Do I need an attorney to help with this?

No. Completing an AHCD isn't difficult, and an attorney is not necessary. But the most important part of this is talking to your loved ones. Without that conversation, the best form in the world may not be helpful!

What should I do with the form after I complete it?

Make copies for all those who are close to you. Take one to your doctor to discuss and ask that it be included in your medical record. Photocopied forms are just as valid as the original. Be sure to keep a copy for yourself in a visible, easy-to-find location – not locked in a drawer.

What if I change my mind?

You can revoke your form or your oral instructions at any time. Also, it's a good idea to try to find old forms and replace them with new ones.

Can doctors or hospitals require a patient to have an AHCD?

No, they cannot require you to complete one. But doctors and hospitals should have information available to you and your family about the form and your right to make healthcare decisions.

Resources

ADVANCE HEALTH CARE DIRECTIVE FORMS

- Download forms in English, Spanish and Chinese from the CCCC website at Coalitionccc.org. Click on Advance Care Planning.
- Forms are often available at no charge from your local hospital – call the Social Services or Patient Education department. Or ask your doctor.
- The California Medical Association has an Advance Healthcare Directive Kit available in English or Spanish for $5 that includes a form, wallet card and answers to commonly asked questions about advance directives. For single copies, visit cmanet.org.
- Five Wishes is a user-friendly advance directive that addresses the medical, personal, emotional and spiritual wishes of seriously-ill people. For more information, visit agingwithdignity.org.
- Caring Connections has state-specific forms that can be downloaded at caringinfo.org.

BOOKLETS FOR CONSUMERS

- Finding Your Way: A Guide for End-of-Life Medical Decisions. This 13-page, easy- to-read booklet helps those who are starting the advance care planning process. Also available in Spanish.
- *Mrs. Lee's Story: Medical Decisions Near the End of Life.* This 16-page booklet written in Chinese and English relates the story of 91-year old Mrs. Ming Lee and includes basic information on advance care planning and advance directives, pain management and hospice care.

These booklets can be viewed at CoalitionCCC.org. Click on Advance Care Planning.

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Choosing a Healthcare Agent

Role of a Healthcare Agent

An agent that you select has the authority to make any and all decisions you would make if you were able, including:

- *choosing your doctor or other healthcare provider and where you will receive your care.*
- *speaking with your healthcare team about your condition and treatment options.*
- *reviewing your medical record and authorizing its release when needed.*
- *accepting or refusing medical treatments, including artificial nutrition and hydration and CPR.*
- *consenting to tissue and organ donation, authorizing an autopsy and arranging for disposition of the remains after death.*

You should instruct your agent on these matters so he/she knows how to decide for you. The more you tell your agent, the better he/she will be able to make decisions on your behalf.

Selecting Your Agent

In choosing an agent, consider if he/she:

- *is legally able to serve as your agent (must be 18 years old; may not be a healthcare provider or her/his employee, unless this person is your spouse or close relative).*
- *will be available when needed.*
- *is willing to speak on your behalf.*
- *knows you well and understands your values and beliefs.*
- *will be comfortable asking questions of your healthcare team, particularly related to issues such as treatment options.*
- *will do his/her best to make the healthcare decisions that you would make (whether or not he/she agrees with you).*
- *will be able to "stand up" for you, be your advocate and handle conflict with others who might disagree with your wishes.*
- *can make difficult decisions under stress.*

Asking Someone to Be Your Agent

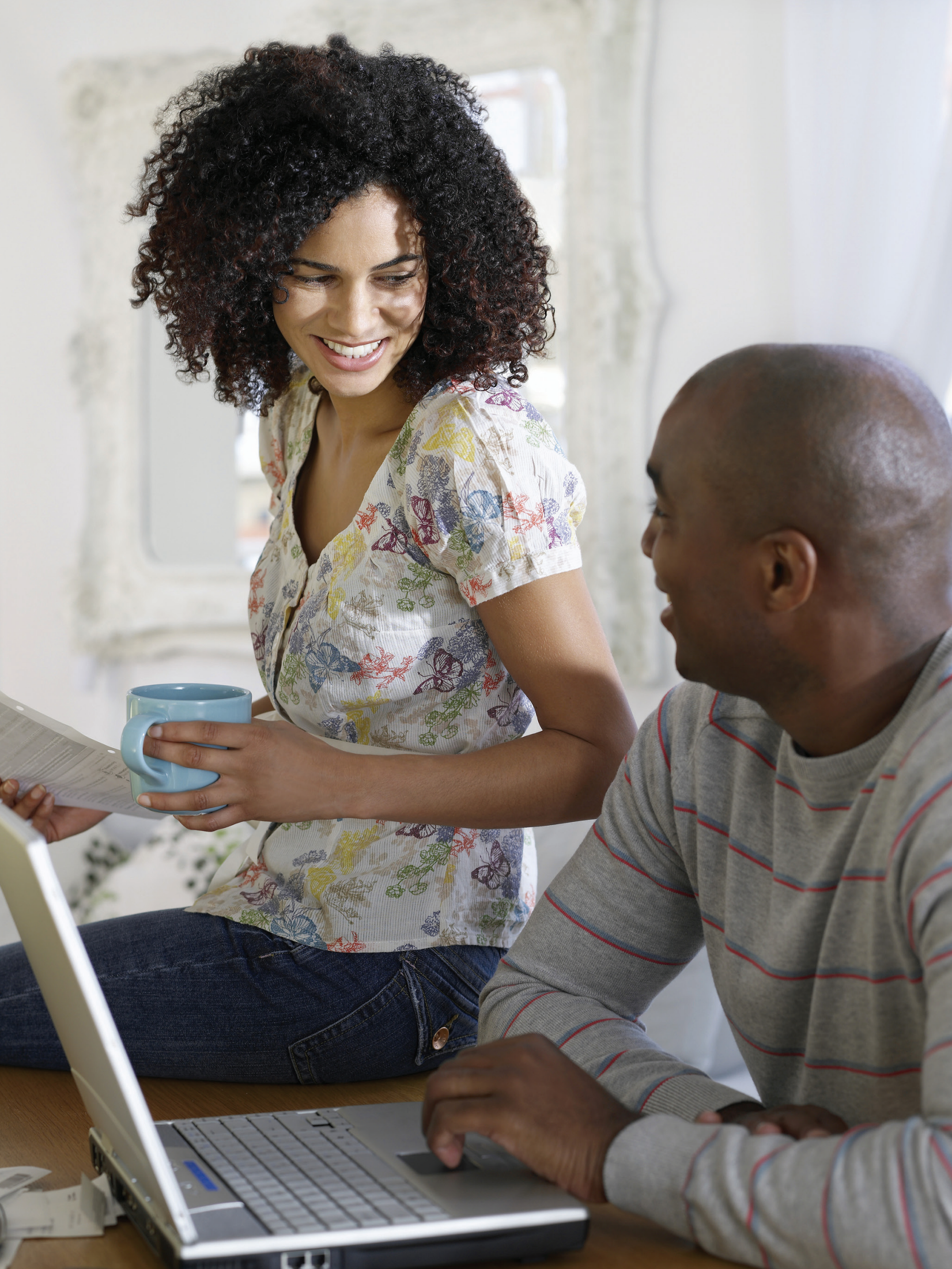
- *Do not assume someone will know that you want them to be your medical decision-maker. You have to ask them.*
- *Choose a quiet place and time to bring it up.*
- *Make sure the person understands what you are asking them to do.*
- *If the person feels uneasy, you may want to give them time to think about it, and ask them again later.*
- *Some people may say no. If so, you may need to think of someone else.*

Who will speak for you if you can't speak for yourself?

Additional Information

- *It is helpful to select at least one alternate agent, since your primary agent may be unreachable or unavailable (e.g., involved in a car accident with you).*
- *Talk with your agent about your wishes and give her/him a copy of your advance directive.*
- *To avoid confusion, tell your loved ones whom you selected as your agent(s).*
- *If circumstances change, you may select a new agent at any time. Make sure to give your new agent a copy of the revised advance directive, and tell family and friends of the change.*

Adapted from resources by Coalition for Compassionate Care of California and Center for Healthcare Decisions



Help for Healthcare Agents

A guide to help you understand your role as spokesperson for your loved one.

Your relative or friend has shown great trust in you by selecting you as her/his agent (sometimes called a surrogate or proxy). As the agent, you are being asked to make sure that your loved one's wishes for care are known and followed if she/he can no longer make medical decisions. To do so, you need to know her/his wishes and values. While making medical decisions for a loved one can be challenging, we hope the following information will help you in this role.

Advance care planning is about how we care for each other.

What You Can Do Before the Need Arises

Be an active participant. Talking about the end of life may be emotionally difficult for both you and your loved one. Anything you can do to encourage conversation about her/his values and preferences would be helpful to you both.

- *Ask your loved one to share views about how she/he describes a good quality of life; what concerns she/he has about dying or how she/he would want to spend the last month of life.*
- *Discuss with your loved one how she/he feels about her/his health problems. Focus on what goals of care near the end of life would be most important; for example, being free from pain or being able to die at home. This is often more helpful than stressing specific types of treatment (such as ventilation, dialysis and resuscitation), since it is difficult to predict what treatment a person might need and for what purpose.*
- *Periodically, revisit this topic with your loved one. People often change their end-of-life wishes as they age or have a change in health. Perhaps a birthday, first of the year or some other memorable occasion would be a good time to help your loved one make sure her/his Advance Directive reflects current wishes.*
- *Keep your copy of the most recent Advance Directive where it is easily accessible.*
- *Your role is to decide what your loved one, rather than yourself, would want. Situations may arise that you have not discussed. In such occasions you would decide based on your knowledge of her/his values. Your loved one has trusted you to do your best. Preparation through good communication can help.*

Some tools to help you and your loved one start talking

- ***Finding Your Way: Medical Decisions When They Count Most*** *– an easy-to-read booklet to help families and loved ones start discussions. Download a pdf at CoalitionCCC.org/Tools and Resources/Advance Care Planning (also in Spanish and Chinese).*
- ***Go Wish*** *– an online card game to help participants consider their end-of-life wishes. Available at gowish.org.*
- ***Advance Care Planning Conversation Guide*** *– ideas for talking with loved ones. Download for free at CoalitionCCC.org/Tools and Resources/Advance Care Planning.*

What to Do When You Need To Act

Your role as agent becomes active only when your loved one is unable to communicate or wants you to make decisions for her/him. Should your loved one regain the ability to make medical decisions, she/he can do so if she/he chooses.

Make sure your agent knows how you feel.

Without a plan your healthcare agent won't know your wishes.

1. ABOUT THE ADVANCE DIRECTIVE FORM

Retrieve the document and make sure you have the most recent one. As the agent, you are authorized to make healthcare decisions, including decisions to provide or withdraw artificial nutrition and hydration and other life sustaining treatments. You can select or change doctors and place of care, as well as review and release medical records. Often the agent has after-death powers to request an autopsy and donate organs or tissues. Consult your loved one's advance directive regarding these types of decisions.

2. BECOMING AN ACTIVE AGENT

As the advocate, become informed about her/his health situation and talk with the doctors. Let them know that your loved one appointed you as her/his decision maker. Make sure the doctors, hospital and / or care institution has a copy of the advance directive. As the decision-maker you are not alone in this process, but will receive guidance from the healthcare team to help you honor your loved one's wishes. Ask the doctors about your loved one's chances for improvement to help you decide the appropriate level of medical care. You may want a second opinion on this important matter. Don't be afraid to assert yourself with the medical team; take notes and ask questions when things aren't clear.

Make sure your agent can make decisions you would want.

3. MAKING DECISIONS

Remember you are deciding what you think your loved one would want, not what you would want. Your earlier conversations will be helpful, particularly if you focus on your loved one's goals of care. Ask the doctor: Is there treatment to help meet her goals? For example, to be able to interact with others, be free from pain, return home, live longer? Many people find ithelpful to talk with other loved ones about these decisions, but keep in mind that you have thelegal authority and responsibility to make decisions even if others disagree. In that case ask for a care team meeting or talk with a chaplain, social worker or ethics committee to help you and your family with these concerns and to solve any conflicts.

Sometimes these decisions can be difficult ones, even for an agent who knows their loved one very well. While it may not be possible for you to know exactly what she/he would want under the circumstances she/he faces, do your best to carry out your loved one's wishes as you believe them to be. In carrying out her/his wishes, you aretruly giving a gift of love.

Some tools to help you serve as agent

- ***Healthcare Agents: Choosing One and Being One*** *– Caring Connections website: caringinfo.org – click on "Planning Ahead".*
- ***Guide for Health Care Proxies*** *– from the Consumer's Toolkit for Healthcare Advance Planning developed by the American Bar Association Commission on Law and Aging: abanet.org/aging/toolkit/tool9.pdf.*

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Advance Care Planning Resources

ADVANCE CARE PLANNING GROUP OF LOS ANGELES

CALIFORNIA HEALTH CARE FOUNDATION
www.chcf.org/projects/2014/advance-care-planning-resources

CALIFORNIA MEDICAL ASSOCIATION
ADVANCE HEALTHCARE DIRECTIVE KIT
www.cmanet.org

CALIFORNIA PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT
www.capolst.org

CARING CONNECTIONS – FOR STATE SPECIFIC ADVANCE DIRECTIVE FORMS AND EDUCATIONAL MATERIALS
www.caringinfo.org

COALITION FOR COMPASSIONATE CARE OF CALIFORNIA – ADVANCE HEALTHCARE DIRECTIVE FORMS AND EDUCATIONAL MATERIALS
www.coalitionccc.org/tools-resources/advance-care-planning-resources/

CONSUMER'S TOOLKIT FOR HEALTHCARE ADVANCE PLANNING DEVELOPED BY THE AMERICAN BAR ASSOCIATION COMMISSION ON LAW AND AGING
www.abanet.org/aging/toolkit/tool9.pdf

FIVE WISHES ADVANCE DIRECTIVE
www.agingwithdignity.org

NATIONAL HEALTHCARE DECISIONS DAY
www.nhdd.org

NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION
www.nhpco.org