

## Help for Healthcare Agents

**A companion piece to the Advance Health Care Directive to help you understand your role as the spokesperson for your loved one.**

Your relative or friend has shown great trust in you by selecting you as her\* agent (sometimes called 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 can no longer make medical decisions. To do so you need to know her 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.

(\*For ease in reading this material, we refer to a loved one as "her" or "she.")

### ***What You Can Do Before the Need Arises.***

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

- Ask your loved one to share views about how she describes a good quality of life; what concerns she has about dying or how she would want to spend the last month of life.
- Discuss with your loved one how she feels about her 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 ventilators, 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 status. 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 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 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*** – easy-to-read discussion-starter booklet for families; preview and order at: [www.chcd.org](http://www.chcd.org) (also in Spanish, Chinese)
- ***Go Wish*** – online card game to help participants consider their end-of-life wishes: [www.gowish.org](http://www.gowish.org)
- ***Advance Care Planning Conversation Guide*** – ideas for talking with loved ones: [www.coalitionforcompassionatecare.org](http://www.coalitionforcompassionatecare.org)

## ***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. Should your loved one regain the ability to make medical decisions, she can return to doing so if she chooses to.

### **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 health care 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 health situation and talk with the doctors. Let them know that your loved one appointed you as her decision maker. Make sure the doctors, hospital 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 health care 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.

### **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 it helpful to talk with other loved ones about these decisions, but keep in mind that you have the legal 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 would want under the circumstances she faces, do your best to carry out your loved one's wishes as you believe them to be. In carrying out her wishes you are truly giving a gift of love.

### **Some tools to help you serve as agent:**

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

The Alliance is a non-profit, regional coalition of healthcare professionals and community members encouraging dialogue about end-of-life issues. For more information, contact the Center for Healthcare Decisions at (916) 851-2828 or visit [www.chcd.org](http://www.chcd.org)