

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.

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.
- **Heart to Heart Cards** – a communication card activity designed to make it easier for a family member, a caregiver, or a health provider to understand what a loved one wants done when life is ending. Available at www.caccc-usa.org/page157/index.html.
- **My Gift of Grace** – a conversation game for living and dying well. Available at www.mygiftofgrace.com.

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.

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.

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/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 are truly 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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