



Advance Directives: What You Need to Know

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Now and again, a story hits the news that regenerates discussions and controversy surrounding end-of-life decision making. These conversations often leave health care professionals concerned and consumers confused. Written advance directives are not the answer to all questions. However, they can make a positive difference and enable AL residents to communicate and preserve their wishes for times when they are no longer able to communicate this information.

Back to the Beginning: PSDA and ADs

The Patient Self-Determination Act, enacted in 1991, federally mandated

that people have the right to accept or refuse treatment. Toward this end, advance care directives—documents that communicate these preferences and decisions—came into being. With advance directives, a person informs family, friends, and health care practitioners about how to care for them when they can no longer speak for themselves. The ability to know and follow plans that reflect a person's values and preferences can comfort family members in the event of serious illness and/or death.

In some states, creating an advance directive may simply mean having a conversation with one's physician. The specific information from such a discussion, sometimes

referred to as an oral advance directive, then should be placed in the person's medical records.

More often, an advance directive takes the form of one of two documents:

- A living will enables a person to specify this or her choices for medical care in advance of times when such decisions might have to be made.
- A durable power of attorney for health care (sometimes referred to as a proxy) appoints another person (referred to as the health care agent) to make decisions on behalf of the person should he or she become incapacitated.

Wishes in Writing: Living Wills and More

A living will allows people to define what treatment they want to receive in certain situations. They also can indicate any treatment they do not want to receive, such as cardiopulmonary resuscitation (CPR). The living will also can define what to do if an accident or serious illness puts an individual in a comatose state, and it can spell out what treatments the person wants withheld or stopped if he or she is dying without hope of recovery. These treatments may include:

- CPR
- Feeding tubes
- Ventilators
- Intravenous lines
- Antibiotics

The durable power of attorney (DPOA) for health care or health care power of attorney (HCPA) allows people to designate someone to make their health care decisions for them if they are incapacitated.

Frequently Asked Questions about the Health Care Power of Attorney

- Do I need a lawyer to write a HCPA?
 - A HCPA sometimes is prepared by a legal professional, but such preparation is not required. However, some states do require that signatures be notarized. The decisions made by the agent may be guided by specific written or spoken instructions from the person. An HCPA may include a living will provision—a description of health care choices—but the living will in such cases serves as guidance for the agent rather than as a binding directive. To ensure this, the living will should state that in the event of any differences between the living will and the agent, the agent should have final say in decisions.
- Who decides whether I'm incapacitated?
 - You can specify how you wish to have your incapacity and mental status determined if the need should arise. For example, in your HCPA you can name a physician to make this determination, or you can say that two doctors must decide whether you have capacity. Any physician or clinical psychologist who makes evaluations of capacity should have experience in this area. If you provide no instructions, a court ultimately might decide the issue, guided by generally accepted standards used by other courts in making these determinations.
- How are my wishes carried out?
 - When you have a HCPA and become incapacitated, the agent discusses treatment alternatives and outlook for recovery with the health care team. The agent then makes decisions based on current circumstances and on what is known about your preferences and values. The agent is also an advocate for you and can argue for aggressive care or for withholding care as your diagnosis, condition, and outlook change. The agent's flexibility while making decisions makes a HCPA preferable to a living will for many people.

Navigating the Maze of End-of-Life Definitions

Advance directive, living will, power of attorney. The plethora of legal and medical terms that get thrown out to residents, family members, and others when discussions turn to end-of-life decision making or advance care planning can be overwhelming. Here are some of the most common terms and their definitions that can be used to help residents, family members, and staff alike understand the issues, make informed choices, and know that they are on the same page when they communicate with each other.

Advance directive: This is a broad term describing both living wills and durable powers of attorney, which enable residents to provide written instructions about future medical care. Advance directives vary significantly from state to state, but many enable individuals to include instructions for specific situations such as when they are temporarily unconscious or impaired by Alzheimer's disease. These documents also may include instructions on options for organ or tissue donation.

Artificial nutrition and hydration: This encompasses a variety of therapies whose goals are to prevent dehydration or malnutrition in patients who cannot swallow. Most common interventions include intravenous therapy, total parenteral nutrition, and tube feeding.

Assisted suicide: This term commonly refers to situations in which people with an incurable and ultimately terminal disease or condition ask others (often a physician) to help them end their lives.

Cardiopulmonary resuscitation (CPR): This refers to procedures used to revive a person who has stopped breathing or whose heart has stopped beating. It may include mouth-to-mouth breathing, chest compressions, electric shock, and drugs to stimulate the heart.

Do-Not-Resuscitate (DNR) order: This is a physician's written order instructing health care providers not to attempt cardiopulmonary resuscitation if a resident's heart or lungs stop working. While residents and their family members may request this order, it must be signed by a physician.

Do-Not-Hospitalize (DNR) order: This involves written instructions regarding a resident's wish not be hospitalized if he or she gets seriously or acutely ill or if an illness takes a turn for the worse. This often is part of an individual's advance directive.

Durable power of attorney: This is type of advance directive that provides power of attorney to others in case of incapacitating medical condition or illness. However, it goes beyond medical care and enables a resident to give someone else the legal ability to make bank transactions, sign Social Security checks, apply for disability, or write checks to pay utility and other bills.

Futile care: This refers to treatments or therapies that will not cure the resident or increase comfort but will only prolong the vegetative or dying state.

Health care proxy: This is a legal document that enables a resident to appoint another person to make health care decisions if he or she is rendered incapable of making his or her preferences or wishes known. The proxy generally has the same legal rights to request or refuse treatment that the resident would if he or she could communicate this information.

Hospice care: This refers to medical care at the end of a resident's life where the focus is on comfort, not cure. Hospice care encompasses palliative care (see definition below) and also includes support for family members.

Living will: This is a legal document designed to control a resident's future health care decisions only when he or she becomes unable to make his or her own decisions and choices. The living will details the resident's wishes and preferences about future medical treatment and generally addresses such issues as stopping life-sustaining treatment in the case of terminal illness or persistent vegetative state.

Medical power of attorney: This is a legal document in which a competent adult designates another person to make health care decisions on his or her behalf in cases where the adult is unable to make such decisions.

Palliative care: This refers to a comprehensive approach to treating serious or terminal illness that is designed to meet the resident's quality of life, comfort, spiritual, and emotional needs. Palliative care involves relief from suffering, pain management, and activities and programs to meet the individual's spiritual and emotional needs (such as music or animal-assisted therapy).

Proxy: This is a person who has been granted the authority to act on behalf of a particular individual.

Ventilator: This is a machine that helps a person breathe. It is used temporarily until the person can breathe on his or her own or as a permanent breathing aide (often used in individuals who are in a permanent vegetative state).

It can cover any health care decision, and the person does not need to be dying or unconscious for it to take effect.

The HCPA is a document executed by a competent person to appoint another to make health care decisions for him or her if he or she becomes incompetent to make these decisions. It allows the ALF resident, whose autonomy is at stake, to

decide who shall make his or her health care decisions. This, in turn, allows the resident to choose the decision maker most likely to understand and apply his or her values.

A resident's advocate only has the authority to act for that person while he or she is unable to communicate his or her wishes. If the resident gets better, the advocate's authority ends. Further, the advocate does not

have the authority to end medical treatment if it is likely to cause the resident's death unless the resident specifically has given the advocate the authority also to make life and death decisions. This must be spelled out in the resident's HCPA.

It is important that residents understand the details of a HCPA and how to complete one properly. Toward that end, here are some tips:

- The resident must understand the form he or she is signing.
- The resident's signature must be witnessed by at least two other adults. Certain people are not allowed to be a witness to a HCPA because of a possible conflict of interest. These include the resident's spouse, child, grandchild, brother, sister, parent, possible heir, person benefiting from the resident's will, his or her physician, the person he or she is appointing patient advocate in the document, and/or an employee of the resident's life or health insurance carrier or of the resident's ALF.

In the process of determining who to designate as their HCPA, residents can ask themselves several questions:

- Who do I want to make decisions about my health care?
- Is quality of life more important than longevity?
- How important is physical and/or mental functioning in decisions to accept, refuse, or limit medical treatment?
- What are my spiritual beliefs, and how do they fit with my choices?
- Are the intake of food and water basic human rights, regardless of delivery (ie, tube, mouth, or vein)?

The resident's HCPA should address the answers to these questions.

Residents should give copies of their living will or HCPA to their physicians. A copy of the HCPA should also be given to the person appointed to carry out the wishes and another placed with important papers. The resident's lawyer should hold a copy of all documents, and the person should keep copies at home. ALC

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The Interdisciplinary Team

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rehabilitation and evaluations for durable medical equipment. Since these are the only occupational therapy evaluations and interventions that are reimbursed by Medicare, the cost of any other type of occupational therapy services must be covered by the facility or individual residents.

Some more progressive facilities either have hired occupational therapy consultants to provide these services or funded grant projects to have occupational therapists provide demonstration projects within their facilities.^{8,9} Hay et al¹⁰ found that preventative occupational therapy was cost-effective for independent living older adults, and it seems plausible that similar results would occur for ALF residents.

The use of an occupational therapy consultant to develop and implement such a program would potentially present a win-win situation by providing residents with improved function while enabling them to utilize lower levels of care. Further, many ALFs view part of their mission as enhancing quality of life; for them it would be important to explore potential programming identified through documented research to meet that objective. Unfortunately, the economics of current health care in this country have not provided adequately for the concepts of prevention and quality of life improvement.

A secondary barrier might be caregivers' and providers' cultural values and possible biases. Some cultures focus on caring for the older adult, rather than promoting their independence. Fortunately, this is less common in assisted living facilities. Care providers should be encouraged to explore their biases and not let them interfere with the promotion of resident independence.

Conclusion

Occupational therapists can provide many varied services to ALF residents. Currently, only a few of these

services are widely utilized. ALF administrators and managers should commit themselves to exploring the broader range of interventions that occupational therapists may provide to enhance their programs. While costs present a significant barrier, OT services can make a real and viable difference in residents' independence, quality of life, and functioning. ALC

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