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Fact Sheet **End-of-Life** **Decision-Making**

Americans are a people who plan. We plan everything: our schedules, our careers and work projects, our weddings and vacations, our retirements. Many of us plan for the disposal of our estates after we die. The one area that most of us avoid planning is the end of our life. Yet, if we don't plan, if we don't at least think about it and share our ideas with those we love, others take over at the very time when we are most vulnerable, most in need of understanding and comfort, and most longing for dignity.

Big issues confront us when we think about our own death or that of someone we love. Our attitudes and beliefs about religion, pain, suffering, loss of consciousness, and leaving behind those we love come into play. We can let things unfold as they may, and for some of us that's exactly right. For others of us, it is good to plan.

This Fact Sheet is not intended to provide a comprehensive planning tool. It outlines areas we need to think about and resources that can help, whether we are caring for someone who is already incapacitated, or making decisions for ourselves.

How to Begin

Begin simply... with yourself. Try to confront and understand any fears you might have: do they relate to the possibility of pain? Loss of dignity while undergoing treatment? Not being clearly understood by those around you? Being alone? Being overly-sedated or in a lingering state of unconsciousness? Leaving loved ones or unfinished projects behind? Leaving your loved ones without adequate financial resources? Dying in a strange place?

Once you know that you want to explore these topics and make some plans, most experts suggest that you begin by talking. Talk openly to family and friends

about your values and beliefs, your hopes and fears about the end stage of your life and theirs. Someone who is uncomfortable with the subject can be led to talk with indirect topics. Use "openings" in conversations, such as recalling a family event and talking about a future event where you might not be present. Talk about whom you wish to leave a possession to, whom you'd like to have near if you were seriously ill.

Ask your doctor for a time when you can go over your ideas and questions about end-of-life treatment and medical decisions. Tell him or her you want guidance in preparing advance directives. If you are already ill, ask your doctor what you might expect to happen when you begin to feel worse. Let him or her know how much information you wish to receive about your illness, prognosis, care options, and hospice programs.

Discuss with your lawyer and/or financial adviser whether your legal and financial affairs are in order. Talk to a religious adviser about spiritual concerns.

What do you need to talk about?

Specific issues relate to the end of one's life. They include:

- Whom do you want to make decisions for you if you are not able to make your own, both on financial matters and health care decisions? The same person may not be right for both.
- What medical treatments and care are acceptable to you? Are there some that you fear?
- Do you wish to be resuscitated if you stop breathing and/or your heart stops?
- Do you want to be hospitalized or stay at home, or somewhere else, if you are seriously or terminally ill?

How will your care be paid for? Do you have adequate insurance? What might you have overlooked that will be costly at a time when your loved ones are distracted by grieving over your condition or death?

- 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?

Taking Control

Financial Decisions

Sometimes the easiest place to begin taking control of planning is in your estate and finances because the content is more concrete. Make sure you have a valid, up-to-date *will*, or *trust documents* if desired or needed. A *durable power of attorney for financial affairs* is a legally binding document that you prepare, or have prepared for you to sign, that designates a trusted person to act for you if you become incapacitated. A lawyer should help you complete these documents.

Keep all your insurance information — medical, long-term care, life and special needs policies — in an accessible place. Tell a trusted person where these documents are located. You should also think about, and write out, instructions for your funeral, burial or cremation preferences, and how they will be paid for.

Keep a list of your documents in an accessible place, and either give a copy to a trusted relative or friend or let them know where they can find it when needed. (See *Where to Find My Important Papers* on FCA's web site, www.caregiver.org/work&eldercare/papers.html.)

Medical Decisions

Medical advances make it possible to keep a person alive who, in former times, would have died more quickly from the serious nature of their illness, injury or infection. This has set the stage for ethical and legal controversy about the patient's rights, the family's rights and the medical profession's proper role. To complicate matters further, the state also has an interest in protecting its citizens from harm.

Each American has the constitutional right, established by a Supreme Court decision, to request that medical treatment be withdrawn or withheld. The right remains valid even if you become incapacitated. Another aspect of end-of-life decision-making is the right to insist on receiving, rather than refusing, treatment. This issue relates to "medical futility," when medical personnel deem further treatment to be useless except if in the nature of comfort or palliative care.

To begin, understand that you have the right to make your own decisions about your care. You can also appoint an "agent" to be your proxy or surrogate should you become incapacitated. In the event you become legally incapacitated (which may require involvement of both medical experts and a court of law) very specific legal steps must be followed before decisions about your care are made.

All states have adopted laws that make it easier for you to plan for the care you wish to receive should you not be able to communicate these wishes in the future. These means are called "advance directives" and take different forms in different states. No one can force you to sign a directive, but they are a helpful tool for you and for those who must step in for you.

Care Options

Most people do not die traumatically. Instead, the last days of their lives are spent in a hospital, nursing home, or in their own home. In your advance directive (see below), you can state your preferences about where you wish to be in the event of terminal illness or during the process of dying. If you choose to be at home, many home care options are available, including home health and custodial care.

Hospice care — a program designed to aid the person who has been given only a short time to live and his or her family — can be provided in the home or in a facility, depending on the program. Hospice is an interdisciplinary approach that can enhance the quality of life. Pain control and emotional support for family members as well as the person who is ill are key elements of hospice. Contact your local hospice program or national association for more information.

Advance Directives

Advance directives are written instructions which communicate your wishes about the care and treatment you want to receive if you reach the point

where you can no longer speak for yourself. Medicare and Medicaid *require* that health care facilities that receive payments from them provide patients with written information concerning the right to accept or refuse treatment and to prepare advance directives. Every state now recognizes advance directives, but the laws governing directives vary from state to state.

Probably the most commonly used form of advance directive is the *durable power of attorney for health care*. A more limited type of advance directive is the *living will*. There are important differences between these two documents.

- The **durable power of attorney for health care** (also called the "medical power of attorney") names someone — a relative or friend — to make medical decisions for you when you are not able. Depending on the state where you live, the person you designate is called an agent, attorney-in-fact, proxy, or surrogate. (California uses the first two terms.) A durable power of attorney deals with *all* medical decisions unless you decide to limit it. You can also give specific instructions about treatments you want or don't want, or about other issues that concern you. For example, your agent will have access to your medical records unless you limit this right.

Because a durable power of attorney is a legal document, special forms are available and the power of attorney *must be signed to be valid*. Some states require witnesses and have specific rules about who can witness. It is important to select a proxy who knows you well and whom you trust. You should also name a backup proxy in case the first person is unavailable. A relative or friend can be your proxy, but an attending physician or hospital staff person usually cannot be.

The agent will be able to make all decisions regarding your health care, from flu shots to the need for surgery. And your agent or proxy can decide whether to withdraw or withhold life-sustaining procedures. While you can be as specific as you wish in the guidelines you give in the document, remember that your agent must also have the flexibility to make decisions in changing circumstances. You do not need a lawyer to complete a DPA-HC, nor can a nursing home require you to sign one before admission.

- The **living will**, in some states called "instructions," "directive to physicians," or "declaration," states your desires regarding life-sustaining or life-prolonging medical treatment. These instructions generally apply to specific circumstances that may arise near the end of your life, such as prolonged unconsciousness. They do not appoint a surrogate to make decisions for you. Most states include these types of instructions in their medical durable power of attorney forms. Not all states recognize separate living wills as legally binding; California does not.

California's new Health Care Decisions law, effective July 1, 2000, combines the durable power of attorney for health care and the instructions for health care decisions into one form called the Advance Health Care Directives. New forms are available from several agencies and web sites. (See Resources.) Older forms, executed before July 1, 2000, are still valid, however. Note that the durable power of attorney for health care *does not* authorize anyone to make legal or financial decisions for you. That is done through a separate financial durable power of attorney, as discussed above under "Taking Control - Financial Decisions."

Other forms or methods of instruction may also be available to you, including:

- A **Do Not Resuscitate** or **DNR** order, which instructs medical personnel, including emergency medical personnel, not to use resuscitative measures.
- A **preferred intensity of care** document, a form for your physician that outlines your preferences for care under special circumstances.

Check with the laws in your state regarding oral directives. Some allow you to designate a surrogate without a written directive, with some restrictions.

Why would I want to prepare an advance directive?

It is wise to prepare an advance directive so that medical personnel and your loved ones know what care and services you desire and what treatment you would refuse if you were able to communicate your wishes. You also can designate the person or more than one person who you would like to make decisions on your behalf. In a surprising number of families, there is disagreement over what a very ill relative would prefer. The advance directive makes your wishes clear.

What are the care or treatments covered by advance directives?

Most advance directives cover life-sustaining treatment such as artificial feeding, mechanical ventilators, resuscitation, defibrillation, antibiotics, dialysis and other invasive procedures.

You can give broad or specific instructions for care providers for each type of circumstance or treatment. For example, you can state that you *do not* want life-prolonging treatments if you will never recover your physical and mental health to live without constant care and supervision. 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, and so on.

You can also state that you wish to receive only *palliative* or comfort care. Such care is designed to manage terminal symptoms, including pain. It is important to understand these terms before making decisions about your preferences. Your surrogate should also become informed about the difference between comfort care and life-sustaining treatments. Health professionals and family members may disagree on the nature of a particular treatment. For example, a relative may become alarmed to see that fluids are being administered and think that this will extend life against the patient's wishes. However, the physician might believe fluids are making the dying person more comfortable and are appropriate palliative care. Another example could be the temporary need for a ventilator (mechanical breathing apparatus) and antibiotics following routine surgery.

Pain alleviation or management is among the most controversial end-of-life topics. Because of ethical concerns and the confusion over laws regulating

drug addiction, Congress is debating the role of habit-forming and potentially lethal drugs in the management of pain and discomfort at the end of life. Studies have found that addiction among seriously ill people is rarer than once thought. Some individuals, however, fear being over-sedated at the very time when they want and need to recognize and interact with others.

Before making decisions about these treatments they should be discussed with a well-informed health professional. You can also ask what to expect during the last days and hours of your life, and what your surrogate and other loved ones should expect.

What other decisions can my proxy make?

Depending on where you live and your written instructions, your proxy or agent can be authorized to decide where you will die (at home or in a facility), and can arrange for autopsy, organ donation, disposal of remains, and funeral or memorial plans.

Whom should I select to be my proxy or agent?

Choose a responsible person to be your surrogate who shares your values and beliefs about medical care and dying. You must also make sure that the person is willing to take on this responsibility before you name her or him in the directive. An alternate should also be selected (and informed of your choice). Some states do not allow certain people, such as health care providers or health facility operators, to serve as agents. Remember also that the person you select to be your surrogate does not have to be the same person who oversees your financial affairs.

Can someone take over making decisions before I'm ready?

Though laws vary by state, most states ensure that you remain in charge of your care as long as you are able. Usually laws are in place that require at least two physicians to declare you to be incapacitated. Agents/proxies are not allowed to commit you to a mental institution or to consent for experimental mental health research, psychosurgery or electroconvulsive treatment. Your proxy may not deny comfort measures for you.

Can a medical professional refuse to observe my wishes?

A health care provider may refuse 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 surrogate immediately and transfer to another provider should be arranged.

Advance directives must be reviewed periodically and kept current. Keep the original and give copies of the *signed* documents to your proxy/agent (including alternates), your physician, and your hospital. Put a card or notation in your wallet or purse stating that you have an advance directive. You may also leave a copy with your lawyer. Some people take their directives with them when they travel. If you spend extended time in another state you should also complete advance directives there, using that state's forms and rules. Advance directives remain in effect until they are revoked. Any written change you make on a directive may invalidate it, so consult with a professional or hospital if you wish to make changes.

Where to get forms and instructions

A local hospital, Long-Term Care Ombudsman program, senior legal service or senior information and referral program, a local or state medical society, or your physician usually have forms appropriate for your state. Some medical centers offer classes in preparing directives. Attorneys may also draft their own forms. Partnership for Caring, Inc., (formerly Choice in Dying) has forms and instructions for each state that can be downloaded from its web sites (www.partnershipforcaring.org or www.choices.org).

What if I don't sign an advance directive?

Someone has to make decisions when an ill person cannot. Without directives in the person's medical or hospital files, and without the appointment of a surrogate through the durable power of attorney, your doctors, hospital staff and loved ones will do the best they can. To your spouse or child or life-long friend, this might mean struggling with what they think you would want. To the medical staff, it means letting their training and professional experience guide them. Unfortunately, in a world of good intentions, that training has traditionally led health care professionals to do all they can to keep you alive. Recent laws are making it easier for these

able professionals to find the best ways to make you comfortable. But the ways all these wonderful people employ may not be what you want. Eventually, of course, a conservator (or guardian) could be appointed by a court. A public agency can request designation of a conservator and, if your family cannot be located, the conservator may be a public agency.

What if I *can't* sign a directive: What to do when someone is already incapacitated

What if you don't have a chance to plan for your own or a loved one's death? What if you are responsible for a person who has suffered a severe stroke, is already in late-stage dementia, or becomes severely disabled from a traumatic brain injury? Laws and programs exist for these situations, too.

If the impairment is gradual, it may be possible to employ many planning measures already discussed. This depends on the degree of impairment the person has experienced and their legal ability to sign documents. If the impairment or incapacity is sudden and permanent, it is imperative that the responsible person—spouse, child, grandchild, a favorite niece or nephew, long-time friend or companion or other individual—seek guidance quickly from an attorney, hospital social work staff, and accountant or financial planner. The person's own physician as well as the hospital medical personnel should also be consulted. Several legal mechanisms are available, the most common being the conservatorship.

Questions to ask if you are responsible for an incapacitated person include:

- What is the prognosis?
- Has the person prepared and signed advance directives?
- Who would the person most want to take responsibility?
- Would he or she want that responsibility shared, perhaps among more than one adult child?
- Does the hospital provide an ethics committee or other staff that can help you sort through options for care decisions?
- What are the person's financial assets?
- Do they have Medicare, medical or long-term care insurance or other specialized insurance plans for hospital or illness coverage?

- Are they eligible for Medicaid?

Some aspects of an incapacitated person's financial affairs could be handled through joint tenancy of property, community property (husband and wife) provisions, and representative payees. **Joint tenancy** is the registration of various assets, such as real estate or bank accounts, in the names of two or more joint tenants. Potential problems include the ability of one joint tenant to withdraw money from a jointly held account without the other's knowledge and possible adverse tax and estate planning consequences. While a spouse can manage the **community property** owned with an incapacitated spouse, court approval may be required for transactions including sales of real property, borrowing money, signing leases or giving gifts of property. Also, many states do not have community property laws. A **representative payee** can be named for a person who receives only governmental benefits, such as Social Security or SSI. The payee, who can be a trustworthy relative, friend or professional, manages the person's funds. The most effective means of handling an incapacitated person's affairs is the conservatorship or guardianship.

Conservatorships or Guardianships

A judicial procedure that appoints someone to take charge of an incapacitated person's legal, financial and personal affairs may be called a "conservatorship," "guardianship," or some other term in your state. The term "conservatorship" is used in this Fact Sheet.

A conservatorship may be established after a relative, friend or public official petitions the court for appointment of a "conservator." The petition must contain information on why the individual (the "conservatee") cannot manage his or her financial affairs or make decisions concerning his or her personal care. An investigation is conducted under the court's direction to determine if the individual is truly incapacitated and whether appointment of a conservator is justified. The court holds hearings and determines whether or not the conservatorship is required. The types of special powers to be granted to the conservator are decided.

Advantages of a conservatorship include a higher degree of protection for the conservatee than with other mechanisms. The conservator must file reports and inventories and accountings with the court. A court investigator also visits the conservatee regularly to determine if a conservatorship continues

to be necessary. Disadvantages include the costs of the legal proceedings and the cumbersome requirements to return to court for approval of various transactions. Also, the details of a conservatorship become part of a public record, a loss of privacy that many find intolerable.

The two types of conservatorship are "of the estate" and "of the person."

- **Conservator of the Estate:** In this type of conservatorship, the conservator handles the financial and legal affairs of the conservatee. The conservator collects the person's assets, pays bills, makes investments, etc. However, court supervision must be sought for some transactions, such as the purchase or sale of real property, borrowing money or "gifting" of assets.
- **Conservator of the Person:** Decisions about medical care, food, clothing and residence are made by this type of conservator. In the case of mental health facility placement, however, special requirements must be followed.

Mental illness or developmental disability

If the person for whom decisions must be made has a mental illness or developmental disability, various federal and state laws apply. No one can be committed to a mental institution, for example, without specific legal proceedings.

A special model for dementia

A study published in the Journal of the American Medical Association (July, 2000) reported that doctors often fail to acknowledge the final stages of Alzheimer's disease and other forms of dementia as a terminal illness. This can mean that patients are subjected to invasive procedures rather than comfort care. One problem area discussed in the study is the administration of pain medication to dementia patients. The study found that less pain relief is often prescribed for dementia patients than may be needed because the patient is unable to communicate the presence of pain. Treatment models developed for dementia patients suggest hospice and comfort care, rather than life-prolonging treatments, might be more appropriate in the end-stages of the disease. This would mean that in the event of a hip fracture, pneumonia, localized infection or other treatable condition, treatments might be withheld in

favor of medications and methods that bring comfort and ease.

There is much that we can plan and attend to in advance of our own death. We can make our wishes known about where we want to be, who we want to be with and what we want to happen to us and around us. We can set up ways to pay the costs of care and even pay for our own funeral. But financial and legal planning and medical advance directives must be made with the knowledge that some day other people will have to implement our wishes and live with the results. For that reason our plans should, when possible, allow for flexibility and trust in the discretion of our surrogates.

Credits

"Start the Conversation: The Modern Maturity Guide to End-of-Life care," and "The Last Taboo" by Mark Matousek, *Modern Maturity/AARP*, September-October, 2000.

"How to Talk about End-of-Life Concerns," by JoAnne Lynn, M. D., author, *WNET/PBS Program Guide*, "On Our Own Terms: Moyers on Dying in America."

"Issues: Background on the Right to Die" and "Advance Directives," Partnership for Caring, Inc. (formerly Choice in Dying), www.choices.org or www.partnershipforcaring.org. (See "Advance Directives Forms" below.)

Fact Sheets, Redwood Caregiver Resource Center: Legal Planning for Incapacity, Durable Powers of Attorney, Conservatorships, Grief and Loss.

"Advance Directives," California Department of Health Services, Licensing & Certification Division, Sacramento, CA. Contact State Ombudsman Program (916) 323-6681, or regional offices of the Licensing & Certification Division or the Ombudsman Program.

"California Health Care Decisions Law Fact Sheet," California Coalition for Compassionate Care.

"Ethical Considerations: Issues in Death and Dying," Alzheimer's Association, 1997. (800) 272-3900.

"The Living Will and The Durable Power of Attorney for Health Care," *APDA Educational Supplement No. 6*, American Parkinson's Disease Association, 1995. 1250 Hylan Blvd., Suite 4B, Staten Island, NY, 10305. (718) 981-8001 or (800) 223-2732.

"Power of Attorney for Health Care," *HealthSpan*, Buck Center for Research on Aging, 505A San Marin Drive, Suite 300, Novato, CA, 94945. (415) 899-1800.

Information on Pain Management and Palliative Care, Growth House, Inc., San Francisco, CA (415) 255-9045. www.growthhouse.org/pain.html and www.growthhouse.org/palliat.html

"Changing Care for End-Stage Dementia," *Washington Post*, July 5, 2000.

Resources

Family Caregiver Alliance
690 Market Street, Suite 600
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106
Website: <http://www.caregiver.org>
E-mail: info@caregiver.org

Family Caregiver Alliance supports and assists caregivers of brain-impaired adults through education, services, research and advocacy.

FCA's information Clearinghouse covers current medical, social, public policy and caregiving issues related to brain impairments.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating brain disorders that strike adults.

American Association of Critical-Care Nurses
101 Columbia
Aliso Viejo, CA 92656-1491
(800) 899-2226 or (949) 362-2000
www.aacn.org

American Hospice Foundation
2120 L Street, NW, Suite 200
Washington, D. C. 20037
(202) 223-0204
www.americanhospice.org

American Pain Society
4700 W. Lake Avenue
Glenview, IL 60025
(847) 375-4715
www.ampainsoc.org

Americans for Better Care of the Dying (ABCD)

4125 Albemarle St., NW
Suite 210
Washington, DC 20016
(202) 895-9485
www.abcd-caring.com

City of Hope Pain Resource Center

1500 E. Duarte Road
Duarte, CA 91010
http://mayday.coh.org

Education for Physicians on End-of-Life Care (EPEC)

American Medical Association (with Robert Wood Johnson Foundation)
515 North State Street
Chicago, IL 60610
(312) 464-5000
www.ama-assn.org/ethic/epec

Growth House, Inc.

San Francisco, CA
(415) 255-9045
www.growthhouse.org

Hospice Foundation of America

2001 S St., NW #300
Washington, D. C. 20009
(800) 854-3402
www.hospicefoundation.org

Last Acts Coalition

www.lastacts.org

Medicare Rights Center

(800) 333-4114 or (212) 869-3850
www.medicarerights.org

National Hospice and Palliative Care Organization

1700 Diagonal Road, Suite 300
Alexandria, VA 22314
(800) 658-8898 or (703) 243-5900
www.nhpco.org

Supportive Care of the Dying: A Coalition for Compassionate Care

c/o Providence Hospital System
4805 NE Glisan St.
Portland, OR 97213
(503) 215-5053
www.careofdying.org

U. S. Living Will Registry

523 Westfield Ave. (P. O. Box 2789)
Westfield, NJ 07091-2789
(800) LIV WILL (800-548-9455)
www.uslivingwillregistry.com

WNET/PBS Channel 13, New York "On Our Own Terms" Program Web Site

www.wnet.org/onourownterms
"Before I Die: Medical Care and Personal Choices"
www.wnet.org/archive/bid/index.html
Video available through (800) 424-7963 or
shop.pbs.org

Additional Reading

Hospice Care for Patients with Advanced Progressive Dementia

Edited by Ladislav Volicer and Anne Hurley,
Springer Publishing Company, 1998

Finding Your Way: A Guide for End-of-Life Medical Decisions

Sacramento Healthcare Decisions
(916) 484-2485 (www.sachealthdecisions.org)

Dying Well

Ira Byock, M. D., Riverhead Books, 1997

Books by Joanne Lynn, M.D.

Handbook for Mortals (with Joan Harrold, M. D.),
Oxford University Press, 1999

By No Extraordinary Means, Indiana University Press, 1990

Improving Care for the End of Life (with Janice Lynch Schuster), Getty Center for Education in the Arts, 1999

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