

Life Care Planning

... a beginning

Provided by DecideYourCare.org

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UJA Federation of New York - Jewish Healing & Hospice Alliance

Veterans Health Administration – VISN 3

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ACKNOWLEDGEMENTS

Hospice Alliance of Downstate New York – for the funding to write and print *Life Planning...a beginning* and general support

AARP – for operating support

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Second edition, 2006.

USING THIS PUBLICATION

There are many guides to the various aspects of life planning in print and on the internet. This *Life Planning...a beginning* seeks to introduce the reader to these issues in basic language and simple concepts.

Life planning shouldn't be done in a hurry – spend some time with this guide, check out the listed resources and give some quiet thought to what you really want as you age and face some important decisions. In years to come, you'll be glad you did.

Most importantly, we hope you will express your life planning wishes to your loved ones and learn about theirs. A healthcare crisis is no time to *start* a conversation. The way to get the healthcare you *need* is to say and write down what you *want*, then *tell someone you trust* to help you when the time comes.

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WHY LIFE PLANNING?

Planning is all about making choices. If you want to send your kids to college or buy a home or retire early, you'll need to make some careful choices. You plan ahead, and when the time comes, you hope your life will unfold as you've planned.

Rarely do we think about our final years and rarely do we plan how we want them to go -- some topics are just a lot harder to think about than others. The result is that sometimes we're unprepared for the financial, legal, or health-care situations that arise in our later years or when we develop chronic, even life-threatening illness. We lose control over our lives just when we are most vulnerable.

Life planning is about making choices *now*, while you are fully capable. As you grow older you will be confronted with an urgent new set of questions:

- Who should speak for your interests if you grow too ill to speak for yourself?
- What sort of medical care do you want if you fall ill—and what care *don't* you want?
- Where do you want to be cared for if you grow frail?
- Where do you want your estate to go when your life is over?
- What sort of memorial service do you want?

These are important questions and many of us care deeply about how they are answered. Yet it's hard to think about them because they involve thinking about the end of our lives. But formulating your plans now, while you're able to weigh your choices carefully, can give you peace of mind and the certainty that your wishes will be respected.

You can let things unfold as they may, but for most people, it's best to plan ahead. Delay rarely helps in life planning or health care planning. Refusing to think about death doesn't deny death. It may, however, deny you the special help or services that will make the end of your life easier and more peaceful.

This guide can help you *start* thinking about life planning and the health care choices you have. Legal, financial and housing issues come into play, so we review these as well. “Where to Find Help” at the end tells you where to turn for further information on all of these subjects.

GETTING STARTED

Life planning involves thinking about several areas of your life — medical, legal, residential, financial — but planning in all these areas can be guided by these suggestions:

- Start by thinking carefully and realistically about your own needs and wishes.
- Financial considerations often determine what you will be able to do, so review retirement, insurance, and financial plans with a trusted family member or advisor. Then you can make realistic decisions about what you can afford.
- Discuss your plans with knowledgeable people: doctors, lawyers, clergy, or financial advisors.
- When you've decided what you want, leave a paper trail. Putting everything in writing can save a ton of grief for you and your loved ones.
- Keep all your life planning papers — instructions about your care choices, insurance policies, powers of attorney, will and trust papers — in an accessible place and tell a trusted person where they are. Making a list of them can help, too.
- Tell your plans to family members or close friends — they need to understand your decisions so they can support them.

Legal and Financial Planning

Sometimes the easiest place to begin life planning is with your estate and your finances. Many people draw up their wills as soon as they have children; others wait until they are much older, but most of us see the importance of having a will. For your earthly possessions to end up where *you* want them, make out a detailed will and have it signed. Specify your keepsake items, properties and investments. If you have an old will, be sure to have it updated. In most states, you can create your will by yourself, but help from a lawyer is usually a good idea.

Other legal documents can make life much easier in the event of illness. You may reach the point that you cannot handle your affairs yourself. In that case, it will help if you have given the legal power to handle your business (paying bills, filing taxes, etc.) to a trusted and responsible relative or friend. A durable power of attorney for financial affairs is a legal document that designates a trusted person to act for you if you become too ill. A lawyer can help you complete these documents.

Finally, be sure your health insurance is in order. While many people will be eligible for Medicare, a Medicare supplemental policy or membership in a Medicare managed care organization will help cover services not fully paid for by Medicare. Long term insurance can also be useful. This covers home care, nursing homes, and certain other services not always covered by Medicare or private health insurance.

If you have not accumulated much wealth, you may want to learn how one becomes eligible for Medicaid (government support for health care for the poor) and plan appropriately. An insurance broker, a financial planner, or a group that provides assistance with these services can be consulted.

Housing Arrangements

As your condition changes over the years, your housing needs may change, too. Mobility, safety, nutrition, and companionship are all issues that are strongly affected by your living arrangements. Housing choices include:

- Staying at home and hiring support services as needed.
- Moving to an assisted living complex, which can provide both independence and medical care as needed.
- Staying at home until intensive treatment is required and then moving to a nursing home.

When you consider housing choices, recognize that your needs may change over the years. A situation that works when you're strong and active may present a hardship if your health weakens. In addition, be sure to look at the cost of different housing choices and factor that into your larger life plan.

Medical Planning

Most of us cannot know what health care support we will need as we grow older, but if you understand your choices, your preferences can be followed as much as possible. Health care options include:

- Family caregiving, which allows you to stay in your home
- Adult day care
- Assisted living
- Nursing homes.

All states have adopted laws that make it easier to plan for the medical care we wish if we become incapacitated. These documents, called "advance directives," allow you to say where you want to be cared for and how you wish to be treated in the event you are unable to make treatment decisions. You can get free copies of living wills and other advance directives from some organizations (see "Where to Find Help"), or you can consult a lawyer.

Helping Others Plan Ahead

Even if you are comfortable planning your own life, you may have loved ones who find it awkward to face these issues. A spouse, a parent, a sibling, or a friend might need some diplomatic and loving assistance thinking about the future. You can open up the conversation and be supportive in working through these decisions.

Approaching the conversation is often the most difficult part. Talking about your own choices can help get things started. You might tell your parents, for instance, that you've decided that if you had a bad accident and became brain dead, you wouldn't want to be hooked up to machines – you could then ask your parents what they might prefer. Adult children sometimes insist that their parents face the hard issues, but it can be more effective to look for a good excuse to discuss life planning, such as:

- The illness or death of a friend, colleague, or celebrity (or news articles about illness or funerals)
- Annual medical checkups
- Routine discussions about bills or financial planning
- Family events such as births, weddings, and (especially) funerals
- A movie, magazine articles, sermons, or books.

Be patient, and remember that it's a lot easier to think about the end of life if the life in question isn't *your own*. Move slowly, provide lots of support, and you can help your loved ones make some of the most important decisions of their lives.

LIVING AND CARE CHOICES

Where will you live as you get older? What sort of care facility do you want? These are two of the most important questions facing aging Americans.

Finances play a major role in deciding what your housing and care options are, so it is important to develop realistic plans of what you can afford. You might want to stay in your own home, for example, but it might be safer to move to an assisted living facility or a nursing home.

Those who face serious illness confront more complex housing and care choices. You'll need to find out which care programs are covered by your insurance. But you may also think about what *sort* of care you want in your last days and what setting can provide that best.

Care at Home

The comfort of your own home may be something you cherish greatly. If so, you may prefer to stay at home for as long as possible, even up until the end. Home-based care works best if you have close family members who can share the caregiving when you need special attention — a situation that can sometimes last for years. If you can afford to hire home healthcare assistance — someone to help oversee your care — your family caregivers may not become overburdened.

But you should recognize that as you age, even before major health issues arise, you are likely to need more and more help with shopping, cooking, cleaning, transportation, and other daily tasks. Assistance with these things can be planned for, as well as more serious health issues. If illness strikes, you may not be able to stay at home, but often recovery can happen at home. And if you are facing progressive or advanced illness, you may also prefer to end your days at home with your family, in the care of family caregivers. You have several options in staying at home:

Family Caregiving

Even for patients receiving complex medical care for serious illness, family caregiving is important at the end of life. Families play major roles in patient care, both practically and emotionally. Better than anyone, your loved ones know how to make you feel safe and comforted -- so you may prefer as much family care as possible.

But patients may feel differently than families about the intense personal involvement in caregiving at home. As a patient, you may fear being a burden to your family, despite your family's willingness to help. In truth, there is great emotional strain in caring for a loved one who is very ill, but many caregivers find a deep satisfaction in providing support. If your choice is to remain at home as much as possible, it may help to have detailed talks with your family about this plan. The following questions could get you started:

- How much at-home care can family and friends realistically provide, and for how long? (Consider issues such as time and logistics, physical tasks, financial costs, and emotional needs.)
- Can your family caregivers assist with medical treatments or will a health aide be needed?
- Can you afford to hire home health aides to assist your family?
- What should you and your family do if your illness is an extended one?

Home Healthcare

After an illness or injury, most of us return home to recover, but we may still need services to help restore health and independence. If you are homebound, you can receive home healthcare benefits for the treatment of illness or injury under private insurance plans and under Medicare. Home health care can provide a range of services in your home, including:

- Skilled nursing (on a limited basis)
- Home health aide assistance (on a limited basis to support nursing services)
- Physical therapy
- Speech language therapy
- Occupational therapy
- Medical social services such as counseling
- Certain medical supplies and equipment, such as a wheelchair or walker.

Adult Day Care

Another form of support is available to those who need some medical and therapeutic assistance but who are living at home. *Adult day care* provides care during the day—this is not an in-patient or home-based program. Its aim is to help people who need some assistance to remain in their homes and communities. Adult day health facilities offer a range of health-care services and activities, among them:

- At least one meal daily and necessary additional nourishment
- Planned activities such as recreation and community outings
- Nursing services
- Social services
- Health status checks.

The medical services offered by adult day health programs are generally paid for by Medicaid (with a referral by a doctor), as are certain long-term care services (such as assistance with walking or using the bathroom) and will vary by state. Many other social and recreational services must be paid for privately. Some adult day health programs are designed for people with specific conditions such as dementia or Alzheimer's.

Hospice Care

Hospice is a special way of caring for people who have advanced illness. Emphasizing the *quality* of life rather than the length of it, its goal is to care for people through comfort, rather than attempts at cure that only add burden for many patients.

Proven methods of pain and symptom control can allow patients to live more fully and comfortably. Hospice workers ask patients to tell them in detail about their pain and symptoms so they can make them comfortable.

You don't have to go anywhere for hospice care — hospice comes to you. Hospice care is delivered wherever the patient lives. If you qualify for hospice care, Medicare, Medicaid or private insurance will generally cover hospice services. (Room and board is not generally covered as part of hospice's services, although the Medicaid hospice benefit often includes room and board in a nursing home.) Hospice help can be provided:

- at home
- in a nursing home
- at a "hospice residence"
- in a hospital.

Hospice care, based on an approach known as *palliative care*, can be provided if a patient has an advanced, life-threatening illness.

Hospice services for each patient are determined by the hospice in the plan of care it develops for each patient. Items included in the plan relate to the illness and are provided by the hospice, which considers many items in creating the plan of care:

- Medications to control symptoms and pain
- Medical equipment (such as wheelchairs and walkers) and supplies
- Physician services
- Nursing care
- Counseling
- Home health aide and homemaker services
- Physical, occupational, and speech therapy
- Nutrition counseling
- Counseling for the family
- Volunteer companionship and family support.

Care in the Community

For personal, medical, or practical reasons, you may find that your home is not the right place to spend your senior years. You may seek out assisted living facilities, or turn to nursing homes if illness becomes severe. Either choice is influenced by medical, financial and personal preferences. It is easier to make the necessary changes in living arrangements when you are still well, rather wait for a crisis to occur.

Assisted Living

Increasingly unable to get out of the house, isolated from friends your own age, or concerned about growing old without reliable support, you may decide to leave your home in favor of an assisted living facility. These residential programs have become popular in recent years because they allow you to remain independent and still receive necessary services. They also answer some of the social needs of seniors. Typically assisted living facilities arrange for daily medicines, personal support services (such as housekeeping), healthcare, and full-time oversight. They bridge the gap between living on your own and living in a nursing home.

Nursing Homes

If you need help with many activities of daily life and family caregivers cannot do the job, you may consider moving to a nursing home. Providing housing, nursing care, and rehabilitative services, nursing homes serve patients with incurable chronic conditions such as heart disease or cancer.

Entering a nursing home can be a difficult experience. New residents have probably lost a lot already: a spouse, a home, health, independence. The family may feel guilty about not being able to keep their loved one at home, regardless of the improvements in caregiving at the nursing home. Whatever the different struggles, everyone who enters a nursing home has reached the point when one's medical condition requires long-term and intensive care.

Nearly half of Americans who live to 65 years will enter a nursing home at some point, typically when illness has become serious. Patients in the final stages of this sort of illness often prefer treatment that emphasizes pain management and supportive care while limiting the use of life-extending therapy.

Rehab

Physical medicine and rehabilitation or "rehab" aims to return you to the highest level of independent functioning. A multidisciplinary team led by a doctor involves nurses, physical and occupational therapists, social workers, nutritionists, and speech-language pathologists.

Rehab serves patients across their entire life span and is provided in many different settings. You can receive rehab at hospitals, outpatient rehab centers, acute care facilities, your home, or in specialized hospital settings such as cardiac rehab units. Rehab is also used along with other care options such as hospice to improve the patient's quality of life. In every instance, team members work together to establish a treatment plan, teach family members, and give you the skills you need to function as independently as possible.

COMFORT CARE vs. CURATIVE CARE

All of us hope that medicine can provide a cure, or at least improve health. Yet when a severe illness, an accident, or advanced old age occurs, it may no longer be possible to make a person well. At that point, continued treatment may be able to support life but it may cause or prolong suffering. Or the time may come when treatment to cure is no longer likely to succeed.

At this point the patient, family, and doctor should talk about what the patient wants and what is in the patient's best interests. It is very important for the patient to be involved in this discussion as much as possible — healthy family members may come to a different decision than a very sick patient. The patient and family should talk about how many side effects the patient is willing to accept as the illness advances, and let the doctor know. Without communication, treatment to cure may go on well past any useful point, because the doctor doesn't want to take away the family's hope. Ask the doctor to tell you if and when curative treatment is inappropriate and decide together whether to begin the transition to comfort care and hospice.

Comfort care aims at controlling pain and other symptoms while preserving dignity and addressing the emotional and spiritual needs of patient and family. Providing comfort and allowing the patient to maintain the highest quality of life is the goal, not battling illness. Comfort care (or "palliative care") can be a good transition to hospice when the time comes.

If a loved one is under serious medical treatment, ask plenty of questions so you can make decisions about health care:

- Will any treatment help regain health? Are there side effects?
- Is there treatment to sustain life? What kind of life will it be?
- Is comfort care the best choice at this time?
- What will be provided if we decide to focus on comfort care?
- Is hospice or another comfort-care provider available?
- What other help is available for the family at this time?

A common fear about dying is that the person will suffer greatly. Many of us are more afraid of dying in pain than of death itself. In most cases, severe pain can be managed effectively by medications and non-medical means such as relaxation therapies, biofeedback, massage, and good nursing care.

Comfort care emphasizes a team approach. Doctors, nurses, pharmacists, clergy, social workers, personal caregivers, and others should be involved, but patients and their families are perhaps the most important members of the team. Care should address the needs and wishes of patient, requiring frequent feedback between the healthcare team and the patient. If pain increases, appetite diminishes, depression sets in, symptoms worsen or activity levels decline, the care plan should be modified. Staying constantly in touch with the team means that health care responds to what a patient needs from week to week and even day to day.

ADVANCE CARE PLANNING

Most of us want *our* wishes, not someone else's, to guide our medical care. Now, while you are capable, you can take steps to make that happen by creating documents known as *advance care directives*. This is a general term that refers to your oral and written instructions about your future care.

Advance care planning and directives give you the chance to make choices about your future personal care. They can make things easier for everyone concerned:

- Easier for you, because you'll know that your wishes are known.
- Easier for your family, because they can reduce the strain of making decisions on your behalf.
- Easier on your care providers, because they'll be able to act in an emergency, knowing they are fulfilling your wishes.

Advance care planning is a process that allows you to think about important issues when you don't need to make immediate decisions or aren't under great emotional stress. It's also good to know that your loved ones understand your wishes should you become unable to speak for yourself. Likewise, if you become the decision-maker, you won't have to guess what your loved one wants: you're prepared to act based on what you know.

Starting to Think about What Care You Want

There are many ways to handle advance care planning. The process calls for careful thought and communication. You may want to start by considering these questions:

- How do you want to be treated at the end of life?
- Is it important for you to live at home as *long* as possible, or as *well* as possible?
- If you are unlikely to recover from an illness, do you want to receive medical care that will prolong your life?
- What are you afraid might happen if you can't make decisions yourself?

When you've thought through these initial—and very difficult—questions, you can start coming up with more specific directions. You might want to think about these issues before you decide on your advance directives:

- Who do you want to make medical and financial decisions for you if you are not able? (The same person may not be right for both jobs.)
- 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?
- Where do you want to be treated if you are seriously ill—in the hospital, at home, or somewhere else?
- How will your care be paid for? Do you have adequate insurance or savings?
- What sort of funeral might you want when you die?

Your advance directives do not have to specify decisions for all possible situations — that would be impossible. But the person you choose to represent you should know your values, your beliefs, and your choices, to be sure healthcare decisions about *you* reflect *your* values.

How Detailed Should Advance Directives Be?

You can give broad or specific instructions, but most advance care directives cover your wishes about life-sustaining treatments. Think about artificial feeding, mechanical ventilators, resuscitation, antibiotics, dialysis, and other invasive procedures. Are there situations when you might want these treatments — or not? Your

advance directive can cover these things. You can also state if you want to receive hospice care or other comfort care when cure is no longer an option.

There is much that you can plan in advance of your own illness, and you can make your wishes known. But some day other people will have to implement your wishes and live with the results. For that reason, your plans should allow for flexibility and trust in your representatives.

Whom Should You Tell?

Advance planning is all about communicating. Probably the most important person with whom you should discuss your wishes is your “proxy” — a trusted person who can act if you become unable. (Depending on which state you live in, this person may be called a proxy, agent, attorney-in-fact, or surrogate, but they will have many of the same functions.) You might want to let close family and friends know your wishes as well. Not everyone wants to hear about death, but talking through possible disagreements now may prevent problems later.

Discuss your plans with your doctor, who will be in charge of your health care. Medical professionals can also provide a good idea of what you can expect from treatments, and that information may be helpful with your decision-making.

Can I Change My Mind?

One comfort of making advance directives is that they are legally binding, even if they are not put formally into writing. You can tell your proxy in person, or write a note, or leave a phone message. If you change your mind about any aspect of your health or personal care, however, you can change your directions. Just be sure to explain your change clearly to your representative.

Completing an advance directive is particularly useful if you think that family members may not know what you want, if they are not readily accessible, or if they may not agree on the care you should receive. Anyone in a nontraditional family needs to pay special attention to arrangements for the end of life, for without specific instructions, state law will normally assign decision-making to your next-of-kin.

ORGAN AND TISSUE DONATION

Every year, thousands of people wait for organ transplants and thousands die without a donor. If tragedy strikes and your doctors are not able to save your life, your organs and tissues can be donated to give life to another. Heart, kidneys, liver, lungs, corneas, even skin and bones can all be transplanted. If you are interested in serving as a donor, talk to your doctor and your family and be sure that your wish is registered in your medical record. Most religious groups support organ donation, but you might want to discuss this with your clergy. Your power of attorney for healthcare should also indicate that you want to be a donor, and you can fill out a wallet-sized donor card.

FUNERAL PLANNING

When death occurs, immediate choices must be made. These choices are based on personal preferences, religious beliefs, and budgets, as well as certain legal requirements. Planning and paying for a funeral ahead of time (“pre-need”) is a choice many families make and it can provide peace of mind.

Pre-funding is particularly important for those on SSI/Medicaid. Those programs are based on the level of your assets, but pre-paid funeral costs are not included among those assets. Pre-need laws vary from state to state. Ask a funeral director about refund policies, how a prepaid funeral will be funded, and portability between funeral homes. The most common way to fund a funeral is through Funeral Planning Choices™ in New Jersey and The PrePlan in New York. Consult with your local funeral director for further information.

Connecticut: Connecticut State Funeral Directors Association, 350 Silas Deane Highway, Suite 202, Wethersfield, CT 06109, (800) 919-2332, www.ctfda.org.

New Jersey: New Jersey State Funeral Directors Association, P.O. Box L, Manasquan, NJ 08736, pre-need (732) 449-4003, general information (732) 974-9444, www.njsfda.org.

New York: New York State Funeral Directors Association, 426 New Karner Rd., Albany, NY 12202, (800) 291-2629, www.nysfda.org.

Medical Decisions

Some people find that all sorts of day-to-day decisions become hard to handle as they age or become ill. But the technical and scientific nature of medical decisions usually makes them the toughest of all.

A *durable power of attorney for healthcare* is the most common form of advance directive and it can prove invaluable during illness. This legal document names a proxy—a trusted friend or family member—to make medical decisions for you if you cannot do it yourself.

You will want to select a responsible person as your healthcare proxy, one who shares your values and beliefs about medical care and dying. Your proxy will be able to make decisions about your treatment, even down to deciding what to do about life-sustaining procedures. So you should speak as frankly and honestly as possible with your proxy about your wishes, and you may want to tell your family as well. There is often a lot to be said for naming someone other than a spouse, parent, or child if you think they may have trouble following your wishes. Surprisingly often, family members disagree over what a very ill relative would prefer. Your instructions can make your wishes clear ahead of time. The durable power of attorney for healthcare must be signed to be valid, and it is wise to get the help of an attorney.

Living Wills

In many states, the durable power of attorney for health care includes special instructions about how you want the end of your life handled, medically. These instructions are commonly called *living wills*. They provide directions to your doctors about your desires regarding life-sustaining or life-prolonging treatment (for example, what you would like done in the case of prolonged unconsciousness).

Life Care Planning---A Deliberative Process

Life care planning is a deliberate process and should not be rushed. It is important to understand your options, the decisions that must be made and your rights in making choices. Give yourself some time to think about your values and wishes and to relay your thoughts to the people you choose. Consider the issues presented in this booklet, discuss them with your health care provider, your clergy person, and loved ones. Then put those decisions into writing using the forms provided by your particular state. Finally, give copies to your health care provider and loved ones. And don't forget to keep a copy for yourself. **You** can make the decisions that are best for you and represent **your** values and beliefs.

SUPPORTIVE ORGANIZATIONS & RESOURCES

Advance Directives

Caring Connections, a service of NHPCO; Helpline 800-658-8898, www.caringinfo.org provides a variety of free resources and information about advance care planning, caregiving, pain, financial issues, hospice and palliative care and grief and loss, including free advance directives for each state.

State of New York, Office of the Attorney General, www.oag.state.ny.us and regional offices throughout New York State. (Brooklyn 718-722-3949, Harlem 212-961-4475, NYC 212-416-8345, Nassau 515-248-3300, Suffolk 631-231-2424, Westchester 914-422-8755). Publishes the guide, *Planning Your Health Care in Advance: How to Make Your End-of-Life Wishes Known and Honored*, includes health care proxy forms for New York State and a resource directory with toll free government helplines.

Aging

American Association of Retired Persons (AARP), 601 E St. N.W., Washington, DC 10049, (800) 424-3410, www.aarp.org. Services and information about health care, entitlements, legal issues, and life planning.

National Council on the Aging, 300 D St. SW, Suite 881, Washington, DC 22024, (202) 479-1200, TDD (202) 479-6674; regional office 50 Clinton St., Suite 507, Hempstead, NY 11550, (516) 485-5431, www.ncoa.org. Information on a range of senior issues including health care, housing, insurance.

U.S. Administration on Aging, (202) 619-0724, eldercare locator (800) 677-1116, www.aoa.gov. Multilingual nationwide information and services for elderly on caregiving, legal rights, nutrition, and medical questions. Regional offices provide direct support:

- *Connecticut*: John F. Kennedy Building, Rom 2075, Boston, MA 02203, (617) 565-1158.
- *New Jersey and New York*: 26 Federal Plaza, Room 38-102, New York, NY 10278, (212) 264-2976.

Family Caregiving

National Family Caregivers Association, 10400 Connecticut Ave., # 500, Kensington, MD 20895, (800) 895-3650, www.nfcacares.org. Information to support caregiving by families.

National Organization For Empowering Caregivers, 425 West 23rd Street, Suite 9B, New York, NY 10011, 212-807-1204, www.care-givers.com. Information and programs to support family caregivers.

Hospice and Palliative Care

Hospice Alliance of Downstate New York, PO Box 245, Port Jefferson Station, NY 11775, (631) 474-4040, (845) 561-6111. Contact information for hospice organizations in New York City, Long Island, and the Hudson Valley.

Hospice and Palliative Care Association of New York State, 21 Aviation Rd., Suite 9, Albany, NY 12205, (518) 446-1483, www.hpcanys.org. Information on hospice care and hospice agencies throughout New York State.

Hospicelink, (800) 331-1620, www.hospicelink.com. Information on hospice care and referrals.

National Hospice and Palliative Care Organization, 1700 Diagonal Road, Suite 625, Alexandria, VA 22314, (800) 658-8898, www.nhpc.org. Information on hospice care and hospice agencies throughout the U. S.

New Jersey Hospice and Palliative Care Organization, 175 Glenside Ave., Scotch Plains, NJ 07076, (908) 233-0060, www.njhospice.org. Information on hospice care and hospice agencies throughout New Jersey.

General Resources

Alzheimer's Association, 225 N. Michigan Ave., Fl. 17, Chicago, IL 60601, (800) 272-3900, www.alzhi.org, info@alz.org. Information and referrals to local chapters for specific services.

American Pain Society, 201 N. Charles St., Suite 710, Baltimore, MD 21201, (888) 615-7246, www.painfoundation.org. Patient information and resources for people with pain.

Cancer Information Service, (800) 422-623 (English and Spanish), www.cis.nci.gov, live help at www.cancer.gov. Information about cancer, treatment, referrals for home care, support, and hospice groups.

Friends and Relatives of Institutionalized Aged (FRIA)- provides a free Helpline for questions and concerns about long term care in nursing homes, assisted living facilities and at home. 212 732- 5667
(Tues-Fri 10am-5pm)

Social Security Administration (SSA), (800) 772-1213, www.ssa.gov. Information on government entitlement programs for seniors and disabled people.

Visiting Nurse Association of America, 99 Summer St., Suite 1700, Boston, MA 02110, (617) 737-3200, www.vnaa.org. Provides referrals to visiting nurses and agencies nationwide.

Health Insurance Assistance

Center for Medicare and Medicaid Services (CMS) Medicare, (800) 633-4227, (877) 486-2048 (TTY), www.medicare.gov. or www.cms.gov, Information on government entitlement programs for the elderly, disabled and indigent.

Every state has a State Health Insurance Assistance Program with counselors who will give you free health insurance information. You can call them about Medicare plan choices; for help filing an appeal; and with questions about home health and what Medicare, Medicaid, and other types of insurance pay for.

- *Connecticut*: (800) 994-9422
- *New Jersey*: (800) 792-8820
- *New York*: (800) 333-4114

GLOSSARY

Adult day health: Healthcare services and activities provided during the day to help people with functional difficulties maintain their health and remain in their communities.

Advance directives: Legal documents that give instructions about the medical treatments you want to receive should you become too ill to make decisions. Typically the documents include living wills and healthcare powers of attorney.

Assisted living: Residential programs offering health and support services for those who need some help with daily life but do not need a nursing home.

Comfort care: Care designed to allow you to live your final days with the greatest comfort and to the fullest. The emphasis is on comfort rather than curative care, quality rather than quantity.

Durable powers of attorney: A legal document in which you appoint someone to act for you if you can no longer make decisions. A *durable healthcare power of attorney* (also known as a healthcare proxy or durable power of attorney for healthcare) appoints someone to make medical decisions for you and a *durable power of attorney for financial affairs* appoints someone to make financial decisions for you if you cannot

Family caregiving: Care provided by family members, beyond what is normally expected as a part of normal family life, when a loved one is ill.

Home healthcare: Health services provided in your home during the treatment of illness or injury.

Hospice: Palliative care for people who have progressive, life-threatening or advanced illness, focusing on physical, emotional and spiritual support for the patient and family. The emphasis is on caring, not curing.

Living will: A legal document that provides instructions about the use of medical treatments at the end of life. The purpose is to guide family and doctors in deciding how aggressively to use medical treatment intended to delay death, in the event that you cannot tell them your wishes.

Medicare: Federal health insurance primarily for people 65 or older.

Medicaid: Joint federal and state program that helps with healthcare costs for some low-income people.

Nursing home: Residential alternative for patients with chronic conditions that require intensive treatment and services.

Palliative care: Care that eases the symptoms of a disease for patients whose illnesses don't respond to curative treatment. Similar to comfort care, but intended for patients with chronic or life-threatening illness such as heart disease, rather than terminal illnesses such as cancer.

Proxy: An agent or representative whom you legally appoint and who is empowered to make decisions for you under certain circumstances. A healthcare proxy, for example, can make decisions about medical issues.

Rehab: Rehabilitation or "rehab" refers to medicine the primary goal of which is to return a person to the highest level of independent functioning.

We would appreciate your feedback about this guide.
Please indicate whether you have used it alone, with your family or friends,
with a larger group in your community, or in some other way.
Feedback may be provided to DecideYourCare@yahoo.com at any time.

Formerly known as the Caring Coalition of Metro NY, DecideYourCare.org is an alliance of healthcare organizations to promote advance healthcare decision-making. Our members share the common goal of enhancing access to quality end-of-life information, education and services. The coalition seeks to provide networking opportunities, strengthen collaborative initiatives and promote life care planning for all residents of the Metro New York and New Jersey area. DecideYourCare.org sponsors National Healthcare Decisions Day every April 16, encouraging every local organization to sponsor a seminar for its members, clients or constituents on the importance of planning for one's future healthcare needs.

Organizations are encouraged to contact DecideYourCare.org for further information. Copies of this guide may be downloaded from our website: www.DecideYourCare.org.

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