

WE ALL NEED TO PLAN FOR THE FUTURE

IN THE EVENT OF A LIFE-LIMITING CONDITION OR DEATH, EVERYONE NEEDS TO HAVE A PLAN

THE BASICS OF GOOD PLANNING INCLUDE...

You should collect and organize important documents in one location and tell your spouse, life partner, relative or friend the location of these documents. Additionally, you should write a Letter of Instruction that includes:

- The name and contact information of your physician, current prescription and non-prescription medications and medication allergies;
- The location of your Advance Directive;
- The name of your attorney and other advisors, such as a clergyman or stock broker;
- A list of all insurance policies, policy numbers and related identification cards;
- Information concerning your Social Security and Veterans Administration benefits;
- Who should be notified of your death, and how you would like them notified;
- Instructions concerning organ donation;
- Preparation of your obituary and where you would like it to appear;
- Funeral and burial desires or arrangements;
- The location of any safe-deposit box and its key;
- The location of your will, trust and related estate planning documents;
- A list and locations of bonds, deeds, home mortgage and other asset documents;
- Your wishes regarding the settlement of items not covered in your will or trust; and
- Your financial obligations involving periodic payments.



AN ADVANCE DIRECTIVE SPEAKS FOR YOU WHEN YOU CANNOT SPEAK FOR YOURSELF

An Advance Directive is a means of making your medical care and end-of-life wishes known through a legal document such as a Living Will or a Durable Power of Attorney.

- A Living Will instructs your family and healthcare providers what you wish them to do if you are unable to speak for yourself.
- A durable Power of Attorney for healthcare allows you to appoint someone to make healthcare decisions for you when you are incapacitated or unable to make them yourself. State law governs its enforceability.

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- In the absence of an advance directive or a durable Power of Attorney, some states permit the designation of a surrogate decision-maker. State law determines who serves in that capacity if a surrogate has not been previously designated.

CONSIDERING LONG TERM CARE INSURANCE

Long Term Care Insurance can help protect you from the catastrophic costs of long term care. It also may allow you to remain in control of your assets, and maintain your independence and dignity. In considering such policies, you should be aware that:

- Benefits differ from policy to policy, providing coverage for care offered by facilities across the continuum of care.
- Annual premium increases can be significant, particularly if you are on a fixed income.
- Before you purchase Long Term Care Insurance, you should carefully analyze your ability to pay these increasing premiums for the balance of your life.

THE FAMILY AND MEDICAL LEAVE ACT

The Family and Medical Leave Act requires employers with fifty or more workers to allow eligible employees to take up to twelve weeks of unpaid leave in a twelve-month period for one or more of the following reasons:

- Childbirth and care of a newborn;
- Adoption or foster care of a child;
- A serious healthcare condition that involves inpatient care or continuing treatment and makes the employee unable to perform the functions of her job; or
- A serious healthcare condition that involves inpatient care or continuing treatment of an employee's child, parent, spouse, or domestic partner requiring the employee's care.

YOUR EMPLOYER MAY OFFER ELDER-CARE BENEFITS

As the population ages, more employees will be caring for their elderly relatives.

- People who care for parents, relatives, or other loved ones with life-limiting conditions struggle with practical and emotional issues that can affect their performance at work.
- Some employers are expanding their employee benefits to include offerings that range from simple referral services and flexible work schedules to workshops and more-personalized assistance.
- Check to see whether or not your employer offers Elder-Care benefits



CHOOSING AN INDEPENDENT LIVING ARRANGEMENT

MAINTAINING AN INDEPENDENT AND ACTIVE LIFESTYLE MEANS MAKING CHOICES

THERE ARE TWO BASIC MODELS FOR INDEPENDENT LIVING...

You may choose to remain at home and in the community with which you are most familiar. This is called aging-in-place. Or you may choose to rent or buy in a retirement community. A retirement community is usually restricted to residents aged 55 or older. Models range from houses or condominiums, to apartments, to suites of rooms in communal residences. In either case, you may eventually need the assistance of medical professionals and other trained health workers to help you maintain your independence. These services are known collectively as Home Health Care.

GETTING THE HOME HEALTH CARE YOU NEED

There are three primary ways of getting the Home Health Care staff that you need.

1. HOME HEALTH AGENCIES

You may decide to contract with a Home Health Agency to provide you with necessary healthcare workers. These workers include non-physician professionals such as nurses and therapists, as well as trained non-professionals like home health aides, personal care assistants and chore workers. Home Health Agencies differ in the quality, range of services and associated costs. When choosing a Home Health Agency:

- Ask for references from past or current clients;
- Request information about licensure, insurances, accreditation, client privacy, and quality surveys;
- Discuss staffing levels, competencies, bonding and criminal background checks;



- Get detailed information about costs, services and response to complaints;
- Get a written agreement that reflects your understanding of what was discussed; and
- Before signing the agreement, review it with legal counsel.

2. DIRECT EMPLOYMENT

You may choose to directly employ all nursing and non-professional personnel, though you may decide to still contract with a Home Health Agency for other health professionals such as physical and occupational therapists. In this model, workers are not attached to Home Health Agencies, and

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your relationship with them will be either as an Employer/Contractee purchasing services from an Independent Contractor, or as an Employer employing an Employee. In either relationship, you must gather or develop basic information including the following:

- Understand the legal difference between an Independent Contractor and an Employee;
- Know your legal responsibilities in each case;
- Develop a job description that reflects your expectations;
- If you are contracting with or employing more than one type of worker, such as a nurse and a home health aide, develop different job descriptions for each;
- Request references, including training and education, and check all of them;
- Check the worker's licensure, insurance liability status and driving record;
- Establish a plan for problem resolution; and
- Develop an employment agreement, and have it reviewed by legal counsel.

3. HOME HEALTH AGENCY AND DIRECT EMPLOYMENT

You may choose to obtain the services of certain health professional workers, such as nurses and therapists, from a Home Health Agency, but directly employ non-professional workers like home health aides and chore workers. In this case, you will need to understand both how to choose a Home Health Care Agency and how to be an appropriate Employer.

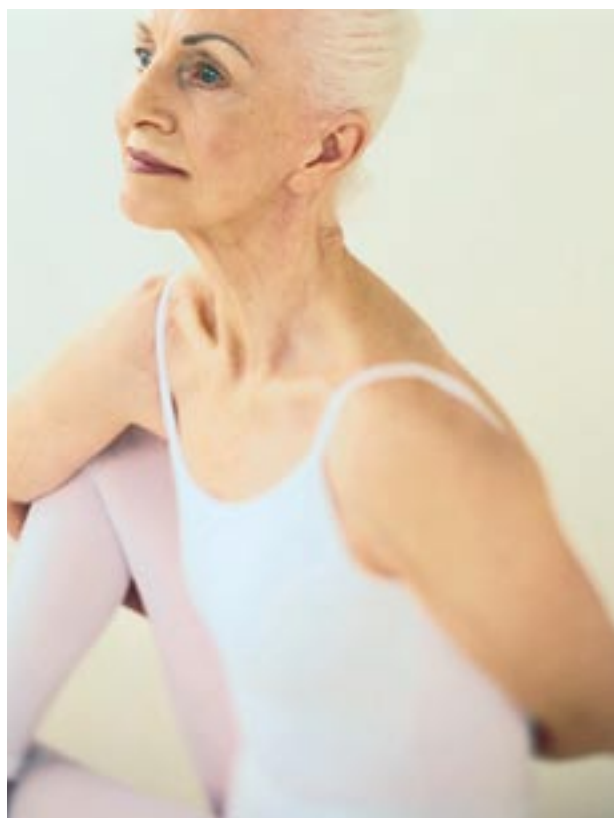
FAMILY AND FRIENDS AS CAREGIVERS

The aging population has given rise to a new class of workers—the Informal Caregiver. Because there are currently more elderly people than health workers trained in geriatric health, much of today's daily care for the ill, infirm, and housebound elderly is performed by Informal Caregivers. Informal Caregivers are usually family members like spouses,

children, or siblings. Sometimes they are old friends. You may receive Home Health Care from an Informal Caregiver, or you may be an Informal Caregiver yourself. The Family and Medical Leave Act and the rise of employer initiated Elder Care benefits both reflect a growing understanding of the stresses that Informal Caregivers face.

If you are an Informal Caregiver:

- Understand your rights under the Family and Medical Leave Act;
- Determine if your employer offers Elder Care benefits;
- Seek out and attend Informal Caregiver training classes;
- Seek out and participate in live and online support groups for Informal Caregivers; and
- Consider consulting a geriatric case manager.



LONG TERM CARE OPTIONS

CHOOSING YOUR LONG TERM CARE

TODAY'S LONG TERM CARE OPTIONS ARE VARIED...

When you can no longer live independently, you must consider your Long Term Care options. In the past, a nursing home was the only Long Term Care choice, but today there are new types of services available. Your primary options include:

- Adult Daycare;
- Assisted Living; or
- Skilled Nursing Facilities (i.e., Nursing Homes).

Some hospital systems and other large healthcare organizations have developed locations or campuses, called continuum-of-care facilities, that combine all three of these services. Alternatively, some retirement communities offer a range of living options across the continuum of care. You and your family need to understand your options when considering Long Term Care.

1. ADULT DAYCARE

Adult Daycare centers provide health, social-support, and recreational services to adults with life-limiting conditions for longer than four hours in a given day. You do not stay in the center overnight, but rather return home at the end of each day. If you can live at home under the minimal supervision of Informal Caregivers during the hours the center is closed, then you likely are a candidate for Adult Daycare services. Since Adult Daycare centers differ from one another, you must understand the range of services each center provides. These can include, among others:

- nutrition and social services;
- personal and hair care services;
- physical, occupational and speech therapy;



- therapeutic activities; and
- escorted trips to medical appointments, and more

2. ASSISTED LIVING

The definition, and even licensing requirements, of Assisted Living facilities differ from state to state. Nevertheless, the concept of Assisted Living generally is to provide a living option for people who cannot live by themselves, but who do not yet need twenty-four-hour care. If you live in an Assisted Living residence, you have your own room or apartment within a building, but have some or all of your meals with the other residents in a communal dining room.

LONG TERM CARE OPTIONS

If you or your loved one is an appropriate client for Assisted Living, you must ask questions to determine the specific services provided, such as:

- Does the facility provide twenty-four hour supervision and security?
- Are minimal healthcare services available?
- How many meals per day are provided?
- Are transportation arrangements available?
- Are social, religious, exercise and educational activities available?
- Are housekeeping, maintenance and laundry services provided?
- What is the cost of the services provided?
- What are the discharge criteria, and can a discharge be appealed?
- Are personal pets allowed?
- Is Internet access available?

3. NURSING HOMES

Nursing Homes provide twenty-four-hour skilled health care and other services to those who have a life-limiting condition and need round-the-clock medical or nursing care. The question of whether an individual needs the services of a Nursing Home usually relates to his or her ability to function, especially the ability to perform activities of daily living such as eating, bathing and dressing.

If you or your loved one is an appropriate client for admission to a Nursing Home, you should ask if the Nursing Home under consideration provides the following services:

- Medically necessary services including dispensing of medications;
- Dietary services such as dietary supplements and medically prescribed foods including tube feeding and oral feeding;
- Nursing services—including an appropriate number and mix of professional and non-professional staff, and the Nursing Home's round-the-clock staffing levels, and social services;

- Routine personal hygiene and access to a hair stylist;
- Laundry and housekeeping services;
- Transportation to medical and dental appointments and/or therapy sessions;
- Activities within and outside the facility; and
- Patient security mechanisms like patient monitoring systems and door alarms.



CHOOSING A LONG TERM CARE FACILITY

LONG TERM CARE FACILITIES SERVE A WIDE RANGE OF INDIVIDUALS

LONG TERM CARE IS NOT JUST FOR THE ELDERLY...

Long Term Care Facilities serve a wider group of people than just the elderly. Many of them provide care to otherwise healthy people who are recuperating from a serious injury or illness, and/or to those individuals whose chronic disabilities make independent living impossible. A young adult with advanced multiple sclerosis would fall into this second category.

PLACEMENT IS A DIFFICULT DECISION

Placing a relative or friend in a Long Term Care Facility is a stressful process, not only for your loved one, but also for you, your family and friends. To help relieve immediate concerns and ease the transition, you should involve both your loved one and family members in facility selection. While this task initially may seem overwhelming, some important basic knowledge will help you through the facility selection process.

BASIC CONSIDERATIONS

Although Long Term Care Facilities share a common set of goals and purposes regarding resident care, each one has certain areas of expertise, offers specific services, and specializes in serving a particular clientele. In other words, one Long Term Care Facility may be better suited to your loved one than another. There are some basic issues to consider when exploring your options, including the following:

- Who will pay for long term care services?
- Does the state Medicaid program pay for assisted living care?



- Does the facility accept Medicare and Medicaid?
- Will a Medicare/Medicaid bed be available after personal funds are depleted?
- Does the facility require that assets be assigned or held in escrow (sometimes called a Life-Care Contract)?
- Is the location convenient for family and friends?
- Does the location reflect the loved one's preference (i.e., urban vs. rural)?
- Are specialized services offered for certain disabilities (e.g., Alzheimer's Disease)?
- Are hospice services available?

CHOOSING A LONG TERM CARE FACILITY

BEYOND THE BASICS

There are thirteen important steps that you, your loved one, and family or friends should take to ensure that the Long Term Care Facility selected is the most appropriate placement possible. These steps are:

- Obtain **references** from people who have a good knowledge of the facility, such as a physician, hospital discharge planners and social workers, long term care professionals, and others.
- **Visit** the facility. If scheduled tours or visits are offered, take advantage of those opportunities. Unscheduled visits also are advised, particularly to observe the interaction between staff and residents.
- Check the **licensing and accreditation** status of the facility, as well as the training, licensing and credentialing requirements of medical professional and non-professional staff.
- Determine **appropriateness of location**. Does your loved one like the location of the facility? Is the location a convenient one for family and friends to visit?
- Look at the facility's **appearance and design**. Does it have a welcoming feel? Is it clean? Are there outdoor areas for residents to enjoy? Is parking available? Are safety and security measures in place?
- Check out the **attitude of staff**. Does staff make the facility warm and inviting? Are they respectful? Does staff take the time to answer questions, hear complaints and resolve problems?
- Examine the **bedrooms and bathrooms**. Does each bedroom have a window? Are the bathrooms clean, safe, convenient and handicap accessible? Is there a comfortable chair for every resident?
- Inspect the **dining facilities**. Is the dining room comfortable, and is the food tasty and attractively served? Are special dietary needs accommodated? Is oral and tube feeding available?
- Ask about the offerings for **resident activities**. What sort of planned activities are available? Can residents pursue their hobbies? Are outside trips planned?

- Understand **resident care services**. Is there an arrangement in place with a local hospital for transport and care if necessary? Are physical, occupational and/or speech therapy available?
- Understand **resident rights**. Does the facility have a written description of the residents' rights and responsibilities, and is it available for family review? Does the facility respect resident privacy?
- Understand the **cost structure**. Are most services covered in the basic daily rate? If not, is a list of non-covered services available? What are the policies concerning payment source?
- Assess **friend and family involvement**. Can family and friends ease your loved one's transition to a Long Term Care Facility by visiting regularly?



Excerpted by Elisabeth Belmont, Esq., MaineHealth, Portland, ME. For a checklist of questions to ask regarding these topics, please see the American Health Lawyers Association's *A Guide to Legal Issues in Life-Limiting Conditions* which can be downloaded on a complimentary basis at www.healthlawyers.org/LifeLimiting.

SETTLING INTO A LONG TERM CARE FACILITY

BEING ADMITTED INTO A LONG TERM CARE FACILITY IS A PROCESS

CHOOSING THE RIGHT FACILITY WAS THE FIRST BIG STEP...

After you, your loved one, and family or friends have chosen a Long Term Care Facility that provides the mix of services which you are seeking, the next step will be admission to the facility. The admission process can produce a great deal of anxiety in everyone concerned, but there are steps that you can and should take that will make the process more understandable and efficient.

LEVEL OF CARE REQUIRED

Check once again that the level of care provided by the facility is indeed the level of care that your loved one requires. For example:

- Does the individual need only assisted living services?
- Does the individual need nursing home care?
- Is the anticipated level of care consistent with the recommendations of the individual's physician?
- Is the facility part of a retirement community that offers different levels of care?

PAYMENT

There are a number of ways to pay for long term care, including self-pay, Medicare/Medicaid, or long term care insurance. You should review the facility's payment policies, and thoroughly understand how services will be funded.

- If your loved one is paying privately (i.e., is self-pay), what other types of contracts will be required? Some facilities require that assets be assigned or held in escrow to guaranty payment—this is often called a Life-Care Contract. All such contracts should be reviewed by legal counsel.



- If Medicaid is paying for services, has all additional paperwork been completed to ensure that the individual is Medicaid qualified?
- If payment is covered by long term care insurance, has all pertinent paperwork been completed?

ADMISSION POLICIES AND APPLICABLE LAWS

Laws that govern what a Long Term Care Facility is required to do at admission, may vary from state to state. Some states require the facility to provide guides to applicable state laws, so check with your state department of health. The types of contracts and forms that you or your loved one must sign also may vary. In addition, each Long Term Care Facility has certain types of forms that are unique to that facility.

SETTLING INTO A LONG TERM CARE FACILITY

ADMISSION AGREEMENTS

Although the admission process varies from facility to facility, some basic aspects will be the same, among them the signing of an Admission Agreement. The Admission Agreement should state clearly the following:

- The responsibilities of the Long Term Care Facility;
- The resident's responsibilities, obligations and required behaviors;
- If you or another family member or friend serves as co-signatory to the Admission Agreement, the document should state that person's responsibilities; and
- The services or items included in the fee that is being paid to the facility and any late charges.

ASK QUESTIONS AND ASK THEM AGAIN—UNTIL YOU UNDERSTAND EVERY ANSWER

Are there any additional charges for care? What services are **excluded** in the Admissions Agreement? Will there be additional charges if a different level of care is needed? Does the Admissions Agreement protect the confidentiality of personal and health information? What procedure does the facility have in place for the settlement of disputes? Does the Admissions Agreement contain information about how it (the Agreement) may be terminated? These questions and more must be asked and answered to the satisfaction of your loved one and/or you and family and friends.

ADDITIONAL FORMS

There are a number of other forms that you should expect upon admission, some of which will require a signature, some of which will not. Among these additional forms are the following:

- Admissions Record
- Choices of Professional Services
- Privacy Practices

- Management of Resident Funds
- Advance Directive Information or Form
- Nutritional Interview
- Clothing and Personal Property Inventory
- Resident Rights and Responsibilities
- Conditions on Asking a Resident to Leave
- Financial Assessment
- Privacy & Confidentiality Notification
- Consent to Release Information or Records
- Financial Agreement
- Social History/Resident Preferences
- Activities Interview
- Discharge/Readmission Record
- Facility Rules and Policies
- Penalties for Leaving Before an Agreed Time



CARE AND COMFORT AT THE END OF LIFE

LIFE PLANNING SHOULD INCLUDE YOUR WISHES ABOUT END-OF-LIFE CARE

KNOWLEDGE AND PREPARATION ARE IMPORTANT...

PALLIATIVE AND HOSPICE CARE

When we speak of, and begin to make arrangements for, the care of individuals who are approaching death, we enter the realm of what is known as “end-of-life” care. During this period, your loved one, you, family and friends may be offered Palliative Care and Hospice Care. Through a patient-centered and team-oriented approach, both Palliative Care and Hospice Care provide medical treatment and comfort to your loved one at life’s end as well as emotional support to you, your family and friends.

Palliative Care is medical treatment that enhances comfort and improves the quality of an individual’s life as his or her physical condition deteriorates. Palliative Care is an agreement between your loved one and his or her physician, primary caregiver (who may be you or a family member or friend) and the Hospice team about the extent of medical care that he or she wishes to have provided as life winds down. Ideally, Palliative Care segues into Hospice Care as a terminal illness progresses. The individual’s choices and decisions regarding care are paramount, and must be followed. These choices and decisions should be articulated in an Advance Directive such as a Living Will or a Durable Power of Attorney.

Hospice Care provides comfort and support to your loved one, you, family and friends when an individual’s condition no longer responds to curative treatments. Hospice is a philosophy of care designed to provide comfort as well as spiritual and emotional support for individuals in the final phase of a



terminal illness. While Hospice neither prolongs nor hastens death, it should be noted that when patients choose Hospice, they may give up their right to seek curative treatment depending upon the terms of their particular insurance coverage. For example, Medicare patients generally may be responsible for certain “out-of-pocket” Hospice costs.

PALLIATIVE CARE—ISSUES TO CONSIDER

In choosing a Palliative Care program that best meets an individual’s unique needs and situation, the following issues should be considered:



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CARE AND COMFORT AT THE END OF LIFE

- **Admission Criteria.** When is an individual eligible to have Palliative Care services paid for by insurance? What treatments, if any, must be discontinued, and which ones may remain? If the diagnosis changes, will contact with the Palliative Care team continue?
- **Setting.** Where will Palliative Care be provided, and how will it be maintained if the patient's setting changes?
- **Staffing.** What types of health care professionals will be necessary to provide Palliative Care? Where will they administer care? What is the role of the individual's own physician? Will volunteers play a role?
- **Family Involvement and Support.** How will the patient's family and friends be involved and supported during their loved one's end-of-life care?
- **Comfort and Pain Management.** How will the Palliative Care team manage pain medication? How will they provide spiritual and emotional support?
- **Contracts.** Are Palliative Care Services contracted with other facilities or providers, and if so, how does this process work?
- **Hospice Benefit Coverage and Duration.** What Hospice Care benefits are covered by insurance? Is supplemental insurance coverage available if Hospice Care is covered by Medicare/Medicaid? How long do benefits last? Is there a monetary cap? Can the individual change medical providers in the midst of receiving Hospice Care?
- **Selecting a Hospice Care Service.** Have you obtained references for the Hospice Care agency from health care providers and friends? Is the agency licensed? What is the agency's staffing level and accessibility? What support services are provided to the patient as well as to family and friends? What are the agency's payment policies?

HOSPICE CARE—ISSUES TO CONSIDER

When Hospice Care becomes the most appropriate option for your loved one, the following issues should be considered:

- **Hospice Team Membership.** Is the composition of the Hospice team appropriate for the needs of your loved one, family and friends? Does membership include a medical director, attending physician, nurse, patient care assistant, social worker, bereavement counselor, spiritual counselor and volunteers?

