



NURSING HOMES AND ALTERNATIVES

WHAT NEW YORK FAMILIES NEED TO KNOW

HOME AND COMMUNITY-BASED HEALTH CARE

ADULT HOMES, ASSISTED LIVING AND OTHER OPTIONS ■ CHOOSING THE RIGHT NURSING HOME

PAYING FOR LONG-TERM CARE ■ REGULATIONS, RIGHTS AND REQUIRED SERVICES

MONITORING CARE AND PROBLEM SOLVING ■ STATEWIDE RESOURCES

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9TH EDITION Completely Revised and
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MFY LEGAL SERVICES, INC.



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MFY & FRIA

MFY Legal Services, Inc. (MFY) envisions a society in which no one is denied justice because he or she cannot afford an attorney. To make this vision a reality, for 50 years MFY has provided free legal assistance to residents of New York City on a wide range of civil legal issues, prioritizing services to vulnerable and under-served populations, while simultaneously working to end the root causes of inequities through impact litigation, law reform and policy advocacy.

On February 1, 2012, MFY launched its Nursing Home Residents Project (NHRP). The NHRP provides information, advice, advocacy, and legal representation for nursing home residents and their families who are struggling with abuse and neglect, civil rights violations, improper discharge planning, unfair consumer practices, and other problems. The NHRP also provides training and educational sessions to nursing home residents and family councils. **For help, call us toll-free at 855-444-6477 (NHRP), on Monday through Friday from 10:00 am to 5:00 pm.**

The NHRP tracks trends in the complaints that it receives to support policy advocacy and, where necessary, impact litigation. The NHRP is modeled on MFY's Adult Home Advocacy Project, which provides trainings, advice, and legal representation that has resulted in systemic reforms that have benefited thousands of New York's adult home residents.

The NHRP continues the work of **Friends and Relatives of the Institutionalized and Aged (FRIA)**, which suspended its operations in 2011. FRIA was an independent, non-profit, advocacy agency founded in 1976 in response to scandals that documented the severe neglect and physical and psychological abuse of elderly residents in a number of local nursing homes. For over 35 years, FRIA was the one-stop resource thousands of people turned to for answers to complex questions concerning long-term health care. FRIA was an authentic consumer voice and watchdog, which worked to improve long-term health care in New York.

MFY launched the NHRP to continue FRIA's vital work. As part of that effort, MFY has revised and updated this book, which FRIA created. *Nursing Homes and Alternatives*, which has been called "the bible of long-term care for the elderly and their caregivers," has been used by many families to ensure that their relatives receive the care that they deserve. Although friends and relatives of prospective or current nursing home residents are the target audience for this book, residents who are advocating for themselves will also find it to be a valuable resource.

PREFACE

You may be picking up this book in mid-crisis. Your mother or someone you love, who was doing so wonderfully at 69—or 89—fell, had a stroke, or almost died from a serious illness. Before you have had time to think, the hospital wants to discharge her to a nursing home. If you were lucky, they asked you to name her first five choices. Where do you start?

Or, maybe, you know your father's illness can only get worse. It won't be long before he needs more help than you yourself can give. You need a plan.

Or, you might be at the very beginning, worried about an elderly relative and preparing, just in case.

This is an emotional and stressful time, and you are probably finding emotional support hard to come by. Friends avoid the topic, as you used to do. It's common to find yourself at odds with siblings and other relatives, even in close families. As you struggle to help a relative, he may fight you all the way, unwilling to be "realistic."

Although a book can't give you the emotional support you need, we urge you to make sure you get it from friends, professionals, or support groups. You won't be there to help your relative if you don't take care of yourself. But you can't afford to get stuck with the emotions. There is too much to find out, to do, and to decide. Your relative might depend on you to find a good nursing home, but, first of all, to see if there isn't some way home care could work instead.

You have been thinking about your relative's financial needs. How will she pay for home care or assisted living? What will Medicare cover? How much money can your relative have when Medicaid pays for a nursing home? You remember skimming articles about financial planning, living wills, and health care proxies, but you can't remember the details. Should you see a lawyer?

Nursing Homes and Alternatives can help you with all the facts, figures and hard information you need right now and with all the tips and resources we could pack in. It will remain a valuable reference tool as your family's situation changes. Knowledgeable, empowered consumers make better decisions about long-term care and will improve care for all.

When you face a family health crisis, the specifics are important and are missing from the many general books about nursing homes. This book tells you what New York law and regulations require and how, for example, New York determines Medicaid eligibility.

DISCLAIMER

Nursing Homes and Alternatives is for educational purposes only, and it does not constitute legal advice. *Nursing Homes and Alternatives* is not intended to create, and does not create, an attorney-client relationship between MFY Legal Services, Inc. (MFY) and any person or entity. MFY does not accept any liability for any loss or damage caused to any person or entity relying on any information or omission in *Nursing Homes and Alternatives*. Legal advice must be tailored to the specific circumstances of each situation, so nothing provided in *Nursing Homes and Alternatives* should be used as a substitute for the advice of an elder law attorney. Readers with legal questions about long-term health care and their family's situation should consult with an elder law attorney.

IF YOU DON'T LIVE IN NEW YORK

No matter where you live, this book is a valuable resource. The information you need to get and the questions you need to ask will be the same. Knowing what to do first and what you need to find out gives you a big head start.

Much of the information in the book is useful everywhere. All families need to know how to help a relative make choices, for example, or how to work with long-term care professionals, plan for incapacity, participate in comprehensive care planning, monitor care, and learn to be effective advocates and caregivers.

Every state's regulations about nursing homes must comply with the basic framework set forth in the federal Nursing Home Reform Law of 1987. Although states do have some leeway to shape their rules and coverage, Medicare and Medicaid are national programs.

State laws vary in many minor ways and in a few significant ones. You should be aware of some examples:

- New York uses Medicaid to pay for long-term home health care more than most states;
- Many states have longer experience with assisted living and impose more extensive and coherent oversight than New York;
- "Board and care" homes is another term for adult homes; and
- New York does not allow Medicaid-only beds or nursing homes, but other states do.

New York and many states allow you to "spend down" monthly income that is over Medicaid-eligibility levels, so that you can pay part of health care bills with the excess income and Medicaid will pay the balance. Other states do not allow you to "spend down." If your monthly income is even a little above the eligibility limits set by the state, you cannot qualify for Medicaid. In many states, elder law attorneys can suggest ways to cope with these limits.

HOW TO USE THIS BOOK

When we say *family* in this book, we mean families of choice, as well as those that are actually related. Many domestic partners, close friends, neighbors, and others are regular caregivers and visitors to residents in long-term care facilities.

Most people do not read this book from start to finish. It covers every aspect of long-term health care. **Begin with the questions facing you right now.** As you learn more and your family's situation changes, you'll find yourself asking new questions and reading additional parts of the book. Readers tell us it's often only months later that they realize the book's full value as a comprehensive reference.

If you are considering assisted living or want to see if a nursing home is the only option, start with *Chapters 1 and 2* and consider alternatives.

If you need a nursing home today, go to *Chapter 5* to see what you should be looking for **and bring the CMS checklist** described in Chapter 5 when visiting nursing homes.

If paying for the nursing home is your first concern, look at the explanations of costs and ways to pay for care in *Chapter 4*. When you understand Medicaid-eligibility rules and legal ways to preserve assets, you may want to see an elder law attorney.

If Chapter 4's financial information overwhelms you as it moves from one confusing government program to the next, begin with **the chart appearing at the beginning of Chapter 4**. This chart is intended to introduce beginners to the government benefit programs for long-term care.

Once a nursing home has been found, anticipate your new role. Turn to *Chapters 3 and 6* for a description of the placement process and to learn to be the effective care monitor your relative might need after placement.

If your relative is currently in a nursing home and you're facing problems there, learn what you can do to help in *Chapter 7*.

Everyone should read Chapter 8 after dealing with immediate issues, to find out why all New Yorkers need **health care proxies**.

For specific questions (can you move your mother from Florida? Can you stop a premature hospital discharge? What is sub-acute nursing home care? A PRI? Medicaid eligibility limits?), check the *Table of Contents* and **skim the**

questions in the text. They are designed to indicate the topics being addressed.

**THIS CHAPTER
INCLUDES THE
FOLLOWING:**

Basic types of home care services available in New York and the agencies that provide them

How to apply for home care and how to evaluate home care workers and services

Paying for home care — through Medicare or Medicaid or privately

New York State's new rule requiring mandatory managed care for Medicaid home care services

How to appeal a denial of coverage for home care services from Medicare or Medicaid

Community-based services that supplement home care



**STAYING HOME: HOME AND
COMMUNITY-BASED HEALTH CARE**

Doesn't everybody dream of living independently as long as possible? Most men and women who are elderly want to stay in their own homes — even when they are in poor health and need help with daily routines. People who are elderly often suffer adverse consequences when they move from their familiar surroundings to a nursing home, including a loss of personal privacy and the ability to make independent decisions about their lives and medical care.

Placing your relative in a nursing home or other health care facility should be considered only as a last resort. Before you take that step, you should explore home health care — medical and non-medical support services, all provided in your relative's home. You might also want to consider services offered in the community, like adult day care; or less restrictive group residences, like those discussed in [Chapter Two](#). By using community services that offer your relative necessary care, you can maintain her quality of life and keep her in her own environment for as long as possible.

What can home care do for your relative?

It might supply all the services she needs — from skilled nursing and various types of therapies to personal care, such as housekeeping, shopping, and assistance with bathing, dressing, and cooking.

Will home care work for your relative?

That depends on her health care needs, the availability of regular help from family members and friends, the types of home care services and other programs found in her community, the cost of care services needed,

and her (or your family's) ability to supervise home care workers. Your relative's finances will also have to be considered: how much your relative can afford to pay for in-home services, how long she can afford to pay privately, and whether she qualifies for Medicare or Medicaid home care benefits.

New York State now requires mandatory enrollment into a Managed Long-Term Care Plan for anybody wishing to receive Medicaid Long-Term Home Care Services. This mandatory managed care requirement applies even if your relative already received Medicaid Long-Term Home Care Services before the rule change.

For more information about New York's mandatory managed long-term care rule, visit the New York State Department of Health website at [DOH MLTC](#).

TYPES OF HOME CARE SERVICES: AN OVERVIEW

New York State's complex system of long-term home care options encompasses many different types of home care agencies offering a variety of overlapping medical and non-medical services. Also, New York recently made an important change to the way long-term home care services will be delivered to New York Medicaid recipients. New York state now requires anybody receiving Medicaid home-based, long-term care services to enroll in a Managed Long-Term Care (MLTC) plan. From now on, the MLTC plan will control access to long-term home care services and will actually deliver these services for all New York Medicaid recipients.

What is Home Care?

Home care is a simple term that encompasses a wide variety of medical, personal, and social services that can be provided at home. These services range from complex skilled-nursing services, such as administering intravenous medications, to simple housekeeping services or assistance with the essential activities of daily living.

Who pays for home care services in New York?

Home care services are paid for privately, through Medicare, or through Medicaid. This chapter will discuss who qualifies for Medicare and Medicaid coverage for home care.

What kinds of home care services are available in New York?

For more information about home care, where to find care, how to pay for care, and what services may be available to your relative, see the New York State Department of Health’s guide to community-based, long-term care ([DOH Guide](#)).

New York State has many services and programs as alternatives to nursing home care. There are two basic kinds of home care services: medical services (also known as home health care services) and personal care services (or help with the activities of daily living, such as bathing or eating). Both home health care and personal care services can be received at home or in community-based settings such as assisted-living facilities. Other services that are not health-related, such as transportation and heavy cleaning, may also be necessary for your relative to stay at home. These supplemental community services are discussed at the end of this chapter.

HOME HEALTH CARE SERVICES	PERSONAL CARE SERVICES
INCLUDE: Nursing visits, intravenous drug therapy, artificial feeding and hydration, oxygen therapy, wound care, injections, catheter and colostomy care, administration of medication, and speech, occupational, and physical rehabilitation	INCLUDE: Help with the activities of daily living (ADLs) such as bathing, dressing, eating, walking, using the bathroom, moving from a bed to a chair to a wheelchair, light housekeeping, and cooking

Sometimes people receive home care within a specialized program that also addresses other needs. Hospice programs (for terminally ill patients) and Lombardi programs (“nursing homes without walls”) are explained later in this chapter.

What is the difference between CHHAs and LHCSAs?

CHHAs (Certified Home Health Agencies) offer skilled care or what is more commonly known as “visiting nurse” services. All CHHAs are certified and regulated by the New York State Department of Health and are also certified by the Federal government to receive Medicare and Medicaid payments. Many hospitals and

HOME CARE SERVICES ARE PROVIDED IN NEW YORK STATE BY THE FOLLOWING:

CERTIFIED HOME HEALTH AGENCIES (CHHAs) – provide nursing and home health aide services and arrange for other professional services, including physical, occupational, and speech therapy. Services may be reimbursed by Medicaid/Medicare.

LICENSED HOME CARE SERVICES AGENCIES (LHCSAs) – provide nursing care, housekeeper and personal-care attendants, and other health and social services for patients who pay privately or who have private insurance coverage. LHCSAs may also contract with CHHAs to provide services for Medicaid and Medicare recipients.

some nursing homes have CHHAs affiliated with them.

Licensed Home Care Services Agencies (LHCSAs), also licensed by the Department of Health, offer home care services for clients who pay privately or have private insurance coverage. LHCSAs are not certified to receive direct payments from Medicare and Medicaid but they may contract to provide services for Medicare/Medicaid beneficiaries. LHCSAs often contract with CHHAs to provide services for the CHHA's patients.

How do I get home care for my relative?

That depends on what she needs and how she will pay for it. This chapter discusses what you will need to do:

- If your family pays privately,
- If Medicare covers your relative's home care, or
- If your relative obtains home care through Medicaid.

ARRANGING HOME CARE PRIVATELY

Can home care be arranged privately?

Yes, if your relative can afford it or family members are willing to pay for it. First, figure out what services your relative needs and decide what support is available through family and community resources. Also check to see if Medicare, Medicaid, or any private insurance your relative has will pay for some or all of the services she needs. Since Medicare services are limited, you may want to supplement them with private care if your relative is not financially eligible for Medicaid.

How do I find qualified home care?

You can privately hire a CHHA or a LHCSA to provide home care services for your relative. The rates for service through a CHHA are higher, so you should determine whether your relative needs skilled home health services or just personal care services before deciding which type of agency to use. Medical and

social assessments by doctors, geriatric care managers, or by a CHHA can help you to determine your relative's home health needs.

To locate agencies in your area, consult your local Area Agency on Aging ([AAA Agencies](#)), the New York State Department of Health website ([DOH Agency Locator](#)), local hospitals, the Yellow Pages, or websites such as the Health Care Association of New York State ([HCA-NYS Locator](#)) or the National Association for Home Care and Hospice Locator ([NAHC Locator](#)).

Your relative may avoid an agency and hire medical professionals and personal care providers directly. In that case, she, or a family member, will have to supervise — perhaps help train — and pay the home health workers herself. She'll also have to find substitutes whenever regularly scheduled workers are unavailable.

If my relative or my family decides to hire an agency to provide care, what questions should we ask?

Ask for a written explanation of all services the agency promises to provide. Find out how the agency handles replacements for late, absent, or unacceptable home attendants. Even if you get services through an agency, you or your relative will still have to keep an eye on things to make sure she gets the hours of care and types of care promised.

Are there services my relative may need that I can't get through an agency?

Yes. Many of the supplemental community-based services discussed at the end of this chapter may be necessary to keep your relative at home.

Does private insurance cover home care?

Certain private insurance policies cover some home-based services, but many policies have restrictions. If your relative has a private insurance policy, check to see if home care is covered and what the limitations are. Long-term care insurance policies provide the broadest coverage of long-term care services. Many long-term care insurance policies cover all or some of the cost of nursing home care and in-home care.

What if my relative needs home care and is not eligible for Medicaid and can't pay privately?

For more information about EISEP service in your area, visit [EISEP](#) and contact your local Area Agency for the Aging ([AAA Agencies](#)).

The Expanded In-Home Services for the Elderly Program (EISEP) serves elderly people who need home care but are not financially eligible for Medicaid. It is operated and regulated by the New York State Office for the Aging (SOFA) and is run locally by county Area Agencies on Aging (known in New York City as the Department for the Aging or DFTA). The EISEP program is generally limited to part-time services, and it provides non-medical home care, housekeeper/homemaker services, and respite care for caregivers, among other services. EISEP services are provided by community agencies in many parts of the state at low or no cost, depending on income. Because of limited funding, however, there are often long waiting lists for this program.

DEMANDING QUALITY HOME CARE

For more information about selecting a home care agency, hiring a home care worker, and evaluating a home care service contract, visit the Family Caregiver Alliance ([FCA](#)). Also, The U.S. Administration on Aging has a helpful guide on choosing a home health agency and interviewing home health workers ([AOA Guide](#)).

How does a home care agency usually indicate what home care services will be performed?

The agency's service contract should describe your relative's plan of care and should list the services the agency will provide to her. Unfortunately, however, this contract language is often vague ("give meds four times a day") and fails to provide sufficient detail about your relative's care needs.

Review the service contract with both the home care worker and the supervisor. If the contract is unclear about the services to be provided, an informal agreement often can be made with the agency and the worker to cover the gray areas.

Both Medicaid and Medicare require that a nurse review the service contract and supervise the home care worker. Call this nurse/supervisor if you have questions about the care or the services provided.

How do I assess the quality of my relative's home care agency?

A good home care agency is flexible and willing to listen and to take your relative's individual needs into consideration. It is responsive and makes every effort to maintain quality of care. If, for example, a home attendant doesn't show up or does a poor job, a good agency will move quickly to correct these problems.

A good agency also fosters a relationship in which you, your relative, and the home care worker understand which services are to be given and which are not. This understanding should be established at the outset, to avoid confusion later on.

What is the procedure for filing complaints?

For home care not paid for by Medicare or Medicaid, if problems arise, first try to resolve them with the home care worker and her supervisor. If this doesn't work, send a written complaint directly to the home care agency that is providing the services. The New York State Department of Health regulations guarantee consumers the right to receive a written response from certified or licensed agencies to complaints about home care staff or services. If you are not satisfied with the agency's response, you can contact the New York State Department of Health, Division of Home and Community-Based Care, which is the agency responsible for investigating complaints and incidents concerning home care agencies in New York State. Call the Home Health Hotline (800) 628-5972 24-hours per day, seven days per week. Alternatively, you can send an e-mail to homecare@health.state.ny.us with an explanation of the nature of your complaint. Complaints and incidents can also be submitted by fax (518) 408-1636 or by mail to:

Bureau of Quality Assurance & Licensure
875 Central Avenue
Albany, New York 12206

Complaints against insurance companies regarding their failure to pay home health care benefits should

be addressed by filing an online complaint form ([NYS DFS Complaint](#)) or by calling the New York State Department of Financial Services at (800) 342-3736. In New York City, call (212) 480-6400.

Remember, Medicaid agencies must meet strict oversight regulations. If your relative is paying privately for home care, however, it's up to you to monitor the home care agency and the home care workers. Only by becoming an advocate, an active defender of your relative's rights, can you insure that she will get the quality of care she needs and deserves.

GETTING HOME CARE THROUGH MEDICARE

The U.S. Department of Health and Human resources has published a guide, [Medicare Home Care](#), to help you understand Medicare home health benefits.

You can get additional information about immigrant eligibility for Medicare and other government benefits from the New York Immigration Hotline, (800) 566-7636.

Medicare is the government health insurance program that covers seniors. Generally, your relative will be eligible for Medicare if she is at least 65 years old and she or her spouse paid Medicare taxes for at least 10 years. If your relative is not yet 65, she might also qualify for coverage if she has certain disabilities.

Generally, your relative must be a U.S. citizen in order to qualify for Medicare. Immigrants "lawfully present" in the United States who have paid Medicare taxes for at least 10 years in connection with legal employment are also qualified to receive Medicare. The eligibility rules are complex, so you may need to consult with an immigration attorney or other professional if your relative is not a citizen.

Medicare Part A is free and covers hospital care and some home health care and nursing home care. Part B requires a monthly payment, usually as an automatic deduction from Social Security payments. Part B covers doctor visits, laboratory charges, and other outpatient hospital services.

Does Medicare cover home health care?

Yes — but only a limited number of services and only under certain conditions. If a person is homebound and her doctor orders skilled nursing or therapy services, Medicare will cover the services if they are provided by a Medicare-certified CHHA.

How does a person qualify for Medicare coverage of home care?

A person may qualify for coverage if *all* of the following are true:

- The person receives services under a plan of care established and regularly reviewed by a doctor.
- A doctor certifies the person needs one or more of the following:
 - Intermittent skilled nursing care (care given on fewer than 7 days each week or less than 8 hours each day over a period of 21 days with some exceptions in special circumstances)
 - Physical therapy
 - Speech-language pathology services
 - Occupational therapy
- Medicare certifies the home health agency providing the services.
- The person is homebound – unable to leave the house because of illness or injury without the help of a person or device and with a considerable and taxing effort. Trips from home for medical reasons or short infrequent trips for non-medical purposes are acceptable if all the other requirements are met. Funerals and graduations are examples of situations that would not violate the homebound requirement. Another is regular attendance at an adult day program.

MEDICARE WILL COVER	MEDICARE WILL NOT COVER
<ul style="list-style-type: none"> • A combination of skilled nursing care and home health attendant services. Both must be part-time or intermittent (fewer than 7 days each week or less than 8 hours each day over a period of 21 days) • Physical, speech, and/or occupational therapy • Medical social work supervised by a doctor • Medical supplies and equipment 	<ul style="list-style-type: none"> • Full-time nursing care • Meals delivered to the home. • Homemaker services like shopping, cleaning, and laundry when this is the only care needed • Personal care given by home health aides like bathing, dressing, and using the bathroom when this is the only care needed

Is prior hospitalization required for Medicare to cover home health care?

To locate CHHAs in your area, consult your local Area Agency on Aging ([AAA Agencies](#)), the New York State Department of Health ([DOH Agency Locator](#)), local hospitals, the Yellow Pages, or websites such as the Health Care Association of New York State ([HCA-NYS Locator](#)) or the National Association for Home Care and Hospice Locator ([NAHC Locator](#)).

No. Many doctors, nurses and social workers don't know this and may tell you incorrectly that your relative cannot receive Medicare coverage for home care because she was not hospitalized. Prior hospitalization is required, however, in the case of nursing home care.

How do I apply for Medicare home care?

Your doctor or a hospital may call a CHHA to begin the assessment and application process for you. You may also choose to contact a CHHA near you directly.

What can I do if a CHHA refuses to provide my relative with the home care she needs?

If a CHHA believes that Medicare will not cover the home care your relative's doctor has ordered because the care: 1) is not "medically necessary and reasonable," 2) is considered "custodial," or 3) does not meet the "homebound" or "intermittent care" standards, the CHHA must give a Home Health

Advance Beneficiary Notice (“the Notice”) to your relative. The Notice should also be delivered to your relative before home care services are reduced or terminated.

The rules for Medicare coverage of home care services are complex. Even some Medicare-certified CHHAs may not understand them. If you try another CHHA, you may be successful in getting the home care services your relative needs. Your relative can also ask the CHHA to provide the services and to bill her for them. Before she pays the bill, though, she should ask the CHHA to submit the bill to Medicare, and then she should wait for the official response.

What do I do if Medicare denies coverage to my relative?

For more information on how to file a Medicare appeal, visit [Medicare Appeals](#).

Although your relative will be responsible for paying the bill for home care services, she also has the right to appeal Medicare’s denial. In fact, many Medicare home health care appeals are won. To get an official determination of whether Medicare will cover her home health services, she must continue to receive home health services, request the home health agency to file a demand bill with Medicare, and find some way to pay for those services pending a determination from Medicare.

What if Medicare will no longer pay for my relative’s home health care services?

The home health agency will give your relative a notice called the Notice of Medicare Provider Non-Coverage before your relative’s Medicare-covered services are completely terminated. If you think these services are ending too soon, you may have the right to a fast appeal. The Notice of Medicare Provider Non-Coverage will give you instructions on how to ask for an immediate, independent review of the proposed termination of your relative’s home care services. When you request a review, you will receive an additional notice that will provide a more detailed explanation as to why your relative’s Medicare home care coverage is ending.

New York State now requires mandatory enrollment into a Managed Long-Term Care Plan for anybody wishing to receive Medicaid Long-Term Home Care Services. For more information about New York's mandatory managed long-term care rule, visit the New York State Department of Health website at [DOH MLTC](#).

As of 2013, New York State will require mandatory enrollment into a MLTC plan in order to receive Medicaid CDPAP services.

Visit the website of the Consumer Directed Personal Assistance Association of New York State, [CDPAANYS](#), for more information about the CDPAP program and for help in finding a CDPAP fiscal intermediary in your county.

GETTING HOME CARE THROUGH MEDICAID

Medicaid is the government program that pays long-term and other health care costs for low-income people who have no other way to pay for them.

How does my relative qualify for Medicaid?

To qualify for Medicaid:

- your relative must be a citizen of the United States, a legal resident, or an alien permanently residing in the United States under color of law;
- your relative must present evidence that she resides in New York State (such as a driver's license, voter registration card, mail received at a New York address, or bank statements); and
- your relative must demonstrate that both her income and assets (savings) are low enough to qualify for Medicaid.

Is there any way for my relative to avoid an agency and hire her own home care workers whom Medicaid would pay?

Yes. Your relative can choose to participate in the Consumer Directed Personal Assistance Program (CDPAP). Unlike traditional home care programs where an agency employs home care workers, in the CDPAP program your relative will be responsible for recruiting, hiring, training, supervising, scheduling, and terminating, if necessary, her home care workers. If your relative is able to manage these responsibilities and she wishes to participate in the CDPAP program, she must first contact her MLTC plan. If your relative is eligible for the CDPAP program, her MLTC plan will conduct a nursing and social assessment to determine whether she requires skilled nursing tasks, home health aide services, or personal care services. In addition to working with her MLTC plan, your relative will also work with a CDPAP organization known as a "fiscal intermediary" that will provide administrative

services for your relative (such as collecting paperwork and paying home care worker salaries).

FINANCIAL ELIGIBILITY FOR MEDICAID HOME CARE

What are the New York State Medicaid income and asset limits for an adult who has a disability or is at least 65 years old?

The chart below shows how much income your relative can receive in a month and the amount of assets (savings and other assets) she can retain and still qualify for Medicaid. The income and asset limit amounts depend on the number of your family members who live with your relative. This chart applies to 2013 only (income and asset limits change every year):

2013 INCOME & ASSET LEVELS*			
FAMILY SIZE	NET INCOME FOR ADULTS WHO HAVE A DISABILITY OR ARE 65+		ASSET LEVEL FOR ADULTS WHO HAVE A DISABILITY OR ARE 65+
	ANNUAL	MONTHLY	
1	\$9,600	\$800	\$14,400
2	\$14,100	\$1,175	\$21,150
3	\$16,224	\$1,352	\$24,323
4	\$18,336	\$1,528	\$27,495
5	\$20,448	\$1,704	\$30,668
6	\$22,560	\$1,880	\$33,840
7	\$24,684	\$2,057	\$37,013
8	\$26,796	\$2,233	\$40,185
9	\$28,920	\$2,410	\$43,358
10	\$31,044	\$2,587	\$46,531
For each additional person, add:	\$2,124	\$177	\$3,173

***Effective January 1, 2013**

If your relative has assets above the limits at the time she applies for Medicaid, she must use the assets before she can become eligible for Medicaid. Detailed information regarding Medicaid and your relative's financial resources is found in [Chapter Four](#). Note that some of the rules differ for home care. The differences are discussed below.

What if my relative's income is higher than Medicaid allows but not high enough to cover the costs of home care?

If your relative's monthly income is higher than the allowable amount, she will still be eligible to receive Medicaid each month if she "spends down" her surplus money (the amount over the income limit) by using the money to pay for medical care. This money must be used to pay for medical expenses, including home care, medical transportation, health insurance, and her spouse's medical and medically related expenses. Your relative should keep receipts to show how she spends the money.

Consult an experienced elder law attorney if you are considering transferring assets or plan to use spousal refusal. We also urge you to consider the possibility of a future need for nursing home care even when applying for home care.

How are eligibility rules for transfer of assets different for home care and for nursing home care?

For the most part, the rules for home care Medicaid (also called "community Medicaid") and for nursing home Medicaid (also called "institutional Medicaid") are the same, but in some key ways Medicaid treats them differently. The following rules affect home care only. To determine eligibility for home care services, Medicaid considers only the resources available in the month of the Medicaid application. In New York City and some other counties, your relative will be asked only about her present financial status. In other parts of the state, she may have to report past financial transactions, but they do not affect her Medicaid eligibility.

A person may give away or transfer financial resources for less than market value at least a month before applying for Medicaid without harming home care Medicaid eligibility or triggering a penalty period. The rules are different for nursing home Medicaid

applications, which review all transfers of assets and can impose penalty periods.

What rules apply to a spouse of a home care Medicaid applicant?

The couple's resources determine financial eligibility for home care Medicaid, if the couple is married and living in one household. A spouse will be asked to disclose all financial resources as part of the application.

A community spouse may refuse to use his assets for his spouse's medical care; this is called the right of "spousal refusal." If a spouse refuses, Medicaid looks solely at the Medicaid applicant's income and resources to determine if she is Medicaid-eligible. If she is, she will receive Medicaid, but her spouse may be sued for support.

APPLYING FOR MEDICAID HOME CARE

What must my relative do to apply for Medicaid home care?

Beginning in New York City in 2012, and applying to the rest of the State by 2013, New York Medicaid recipients must now enroll in a Managed Long-Term Care (MLTC) Plan in order to receive Medicaid community-based long-term care services. Medicaid community-based long-term care services include:

- Personal care services (PCA/home attendant)
- Certified home health aide (CHHA) services
- Adult day care services
- Long-Term home health care services
- Skilled nursing services
- Consumer-Directed personal assistance program (CDPAP) services

For more information about managed long-term care, visit [NYS DOH MLTC](#).

If you need help finding MLTC plans in your area, visit the New York State Department of Health's MLTC directory ([DOH MLTC plan Directory](#)).

For New York City residents, the Department of Health has provided a consumer guide rating New York City MLTC plans by plan performance ([NYC MLTC Guide](#)).

For more information and help in choosing a MLTC plan for your relative, read the New York State Department of Health's booklet on choosing a MLTC plan ([DOH Guide to Choosing a Medicaid MLTC plan](#)) and visit the Medicaid Choice website ([Medicaid Choice MLTC plans](#)).

Is my relative required to enroll in a MLTC plan in order to receive Medicaid home care services?

Your relative must enroll in a managed care plan if:

- She is eligible for both Medicaid and Medicare ("dual eligible");
- She needs home care or other long-term care for more than 120 days; and
- She is age 21 or older.

My relative is already receiving Medicaid home care services, does she still have to enroll in a MLTC plan?

Yes, your relative is required to enroll in a MLTC plan if she received a letter from New York Medicaid Choice (New York State's enrollment broker for Medicaid MLTC plans) telling her to join a MLTC plan by a certain date. The MLTC plan you select will now manage your relative's care and will approve her home care services. If you do not select a MLTC plan for your relative, Medicaid Choice will assign her to one.

What types of MLTC plans are available in New York?

There are three different types of MLTC plans available in New York:

- The MLTC Medicaid Plan;
- The Medicaid Advantage Plus Plan; and
- The Program for All-Inclusive Care for the Elderly (PACE) Plan.

What is the MLTC Medicaid Plan, how does the plan work, and what home care services might my relative receive under the plan?

The MLTC Medicaid Plan is a stand-alone plan for long-term care services. This means that members of this plan continue to receive *Medicare* coverage for doctor visits and in-patient hospital stays and members carry two benefit cards—a Medicare card and a Medicaid card. The MLTC *Medicaid* Plan covers home health

care services, including skilled nursing services, physical therapy, and personal care services. Additionally, the MLTC Medicaid plan provides certain specialty medical services such as optometry and dental care and arranges for other services such as delivery of meals to the home.

What is the Medicaid Advantage Plus Plan, how does the plan work, and what home care services might my relative receive under the plan?

The Medicaid Advantage Plus Plan is a combined plan that manages both Medicaid and Medicare services. In order to enroll in this plan, your relative must also enroll in the plan's *Medicare* product and must choose a plan doctor to provide your relative with all of her Medicare health services. In addition to the Medicare services provided, the Medicaid Advantage Plus Plan also covers *Medicaid* home health care services, including skilled nursing services, physical therapy, and personal care services. Additionally, the plan provides certain specialty medical services such as optometry and dental care and arranges for other services such as delivery of meals to the home.

What is the PACE Plan, how does the plan work, and what home care services might my relative receive under the plan?

Like the Medicaid Advantage Plus Plan, the PACE Plan is a combined plan providing Medicaid and Medicare benefits. If she enrolls in this plan, your relative is required to use PACE Plan doctors for all covered services. Under the PACE Plan, your relative will receive her *Medicare* benefits (such as doctor visits) at an adult day care center. Your relative may also go to the center to participate in social activities with other plan members. In addition to the Medicare services provided, the PACE Plan also covers *Medicaid* home health care services, including skilled nursing services, physical therapy, and personal care services. Additionally, the plan provides certain specialty medical services such as optometry and dental care and arranges for other services such as delivery of meals to the home.

How do I enroll my relative in a Medicaid MLTC plan?

Additional MLTC enrollment guidance is available from the [DOH Guide to Choosing a Medicaid MLTC plan](#) and [Medicaid Choice MLTC plans](#).

In order to enroll your relative in a Medicaid MLTC plan, you can directly contact a MLTC plan in your area. You can also call New York Medicaid Choice (the New York State enrollment broker for the MLTC program) at (888) 401-MLTC (6582). Medicaid Choice can help you connect with a MLTC plan in your area. The MLTC plan will then contact your relative to schedule an assessment to evaluate her medical condition, her cognitive ability, and her living arrangements. A plan representative will also visit your relative to:

- Explain the rules and responsibilities of plan membership;
- Give her a copy of the member handbook and the plan's provider network;
- Assist her in completing the plan's enrollment application and agreement;
- Assist her in completing a Medicaid application, if needed;
- Help her to choose providers from the network of providers associated with the plan; and
- Answer any questions she may have.

You should ensure that the MLTC plan discusses your relative's home care needs with her before it sets up her home care plan.

APPEALING A DENIAL, REDUCTION, OR TERMINATION OF MEDICAID-FUNDED SERVICES

The New York State Department of Health lists Managed Long-Term Care Enrollee Rights at [MLTC Plan Enrollee Rights](#).

What can I do if I do not agree with the home care services the MLTC plan approves for my relative or if the MLTC plan does not approve enough hours of home care for my relative?

If the MLTC plan does not approve the home care services that you feel your relative needs, or if services are denied outright, she must file a grievance or an

appeal with the MLTC plan. A grievance is a procedure that allows a plan member to communicate to the plan her dissatisfaction regarding care and treatment she has received from the plan. If the member is not satisfied with the decision the plan makes concerning her grievance, she may request a second review of her issue by filing an appeal. Refer to the MLTC plan member handbook if you are considering filing a grievance or appeal regarding your relative's home care. The handbook will contain detailed information about whom you must contact and what steps you must follow in order to file a grievance or an appeal.

What if I am still unhappy after I have completed the MLTC plan's grievance and appeals process?

If your relative has completed the MLTC plan's appeals process, and the plan did not decide in her favor, then your relative can request a "fair hearing" before an administrative law judge. You can request a fair hearing using this [online request form](#) or you can mail or fax this [printable request form](#) to:

NYS Office of Temporary and Disability Assistance
Office of Administrative Hearings
Managed Care Hearing Unit
P.O. Box 22023
Albany, New York 12201-2023
Fax: (518) 473-6735

Does my relative need a lawyer?

No, but it is much better to have a professional who is familiar with the Medicaid and managed long-term care regulations to help you to present her case, if at all possible. Contact a private elder law attorney, a legal services attorney, or an experienced social worker.

Is it worth appealing?

In the current climate, it's almost always worth it. At the fair hearing, the administrative law judge will take a fresh look at your relative's case and may agree that she needs the amount of home care you requested. It is best to have a lawyer, but if you do not, ask to see

the MLTC plan's records ahead of time and read how they assessed your relative's care. If you have something new to support your relative's case, bring a copy with you to the fair hearing.

Can my relative keep getting home care services while appealing?

Yes. If your relative's appeal involves the plan's reduction, suspension, or termination of home care services, you can request to continue these services while you wait for the Fair Hearing decision. In order to do this, you must check the box on the Fair Hearing request form to indicate that you want your relative's home care services to continue. **Your request to continue the services must be made within 10 days of the date the appeal decision was sent by the MLTC plan.** Your relative's services will then continue until you withdraw the appeal, the original authorization period for your relative's services ends, or the Fair Hearing Officer issues a hearing decision that is not in your favor, whichever occurs first.

SPECIALIZED PROGRAMS OFFERING HOME CARE

HOSPICE AND PALLIATIVE CARE

What is hospice care, who provides it, and how is it paid for?

Hospice care is provided to terminally ill people who decide not to continue active medical treatment for their illnesses. It aims to make the dying person as comfortable as possible, to provide services and counseling to the patient and family, and to enable the patient to stay at home or close to home. Hospice professionals are particularly skilled in pain management.

Hospice care is given primarily in the home, but can also be provided to residents in their nursing homes and in hospice institutions. It includes doctors' visits, nursing care, social work, nutrition, physical and

To locate a hospice in your area, consult your local Area Agency on Aging ([AAA Agencies](#)), the New York State Department of Health ([DOH Agency Locator](#)), local hospitals, the Yellow Pages, or websites as the Hospice & Palliative Care Association of New York State ([HPCANYS Locator](#)) or the National Association for Home Care & Hospice Locator ([NAHC Locator](#)).

occupational therapy, home attendant care, and pastoral services. An interdisciplinary team of professionals, volunteers, relatives, and friends participate in a comprehensive care program that manages the patient's physical symptoms while addressing the psychological and emotional aspects of dying.

Visit [Caring Connections](#) for detailed information about hospice or call the Caring Connections HelpLine -at (800) 658-8898 for support and more information on end-of-life issues. Counselors on the HelpLine can also provide you with a variety of free consumer brochures, state-specific advance directives, and contact information for hospice-related community services.

When should my relative consider hospice?

Although many doctors refer patients to hospice only in the last few weeks of life, hospice can be considered months earlier when treatment options to cure an illness are exhausted or a patient decides to forgo additional treatment aimed at a cure.

Do Medicare and Medicaid pay for hospice care?

Medicare and Medicaid both cover hospice care, but Medicare pays for nearly all hospice programs for elderly people. To be eligible for coverage, a doctor must determine that your relative has less than six months to live if her disease follows its normal course, your relative (or her legal surrogate) must choose hospice care, and a Medicare-certified hospice program must provide all medical care for her terminal illness through the hospice program. Hospice coverage includes physician and intermittent nursing services, drugs, including outpatient drugs for pain relief, physical and occupational therapy, home care aide services, short-term inpatient care, including respite care, counseling, pastoral care and more.

Can someone leave hospice?

Hospice patients always have the right to reinstate traditional care at any time, for any reason. If your relative's condition improves or her disease goes into remission, she can be discharged from hospice care and returned to aggressive, curative measures, if she desires. Thereafter, if your relative changes her mind again and wants to return to hospice care, Medicare, Medicaid, and most private insurance companies and HMOs will allow readmission.

What happens if at the end of six months my relative still needs hospice care?

After six months, your relative's hospice care benefits can be extended for an unlimited number of additional 60-day periods, as long as her disease continues its normal course and her doctor renews the doctor's certification.

What is palliative care?

For more information about palliative care and for help finding a palliative care provider, visit the websites of the Center to Advance Palliative Care ([CAPC](#)) and the Hospice & Palliative Care Association of New York State ([HPCANYS](#)).

Palliative care is hospice-type care that can be offered to persons with chronic, life-limiting conditions even if they are not terminally ill. It differs from hospice in that it can be provided together with curative care, if desired by the patient.

Because the thrust of palliative care is symptom relief, patients receiving palliative care who also want to continue some treatments aimed at cure may have to be assertive to make that known. Good palliative care will include the patient in the care planning process.

How is palliative care paid for?

Palliative care is not covered as a separate Medicaid or Medicare benefit. Hospitals, nursing homes, home care agencies, and hospices that offer palliative care will be paid through the same Medicaid, Medicare, private insurance, and private payments that cover conventional care. You may have to pay privately for some elements of hospice and palliative care, such as acupuncture, massage, or respite for caregivers.

How do I find a hospice or palliative care provider?

Hospital discharge planners should be knowledgeable about hospice and palliative care services in your area. Additional information should also be available from an Area Agency on Aging and from the Hospice and Palliative Care Association of New York State.

These are a few important questions to consider in

choosing a hospice or palliative care provider:

- What and where are services offered?
- Is the program Medicare-certified? If not, does the program accept Medicaid or have a sliding scale?
- Who handles paperwork for Medicare, insurance, and hospital billing?
- What role does the family physician play?
- How are families involved in care?
- How are professional staff and volunteers chosen and trained?

LONG-TERM HOME HEALTH CARE/ LOMBARDI PROGRAMS

What is a Lombardi or LTHHC Program?

To locate a LTHHC program in your area, consult your local Area Agency on Aging ([AAA Agencies](#)), the New York State Department of Health ([DOH Agency Locator](#)), local hospitals, or the Yellow Pages.

This New York State program provides health care services at home for people who are medically eligible for placement in a nursing home but who have chronic or acute needs that can be met safely at home. It is known formally as the Long-Term Home Health Care (LTHHC) program and is also called the Lombardi program or the “nursing homes without walls” program. The LTHHC program can be paid for privately or through Medicaid (if special qualifications are met).

If my relative qualifies for Medicaid coverage, is she required to enroll in a MLTC plan in order to receive LTHHC services?

Probably. New York State has asked the federal government for permission to require Medicaid LTHHC program participants to in enroll in a MLTC plan. Assuming New York is granted the necessary federal permission, your relative will be required to enroll in a MLTC in order to receive LTHHC program services if:

- She is eligible for both Medicaid and Medicare (“dual eligible”);
- She needs home care or other long-term care for more than 120 days; and
- She is age 21 or older.

How does my relative qualify for Medicaid coverage for LTHHC program care?

In order to receive Medicaid LTHHC program services, your relative must meet all of the following requirements:

- She must be medically eligible for placement in a nursing facility as determined by the level of care form required by the New York State Department of Health;
- She must express a preference to remain at home and she must confirm that she has freely chosen the LTHHC waiver over other available long-term care options;
- She must have an assessment to confirm that her needs can be met safely at home;
- She must have physician verification that she is able to remain safely at home;
- She must require the case management services provided by the LTHHC program;
- She must require at least one LTHHC program service every 30 days in addition to case management; and
- The cost of her LTHHC plan of care cannot exceed 75% of what nursing home care would cost.

What services will my relative be able to get through a LTHHC program?

In addition to case management, the LTHHC program will furnish the following services for your relative:

- Medical Supplies and Equipment,
- Nursing,
- Homemaking/Housekeeping,
- Physical Therapy,
- Home Health Aide,
- Personal Care Aide,
- Occupational Therapy,
- Speech Therapy,
- Audiology,
- Medical Social Services,
- Nutritional Counseling/Education, and

- Respiratory Therapy.

Because the cost of the LTHHC program cannot exceed 75% of nursing home fees in the area where your relative lives, few people receive the maximum hours of care allowed. Therefore, this program works best for people whose health needs require fewer hours of aide services, who have a strong wish to stay at home, and who also have a helpful relative or other support system in place.

How can I find a LTHHC program in my area and how does my relative apply for LTHHC program care?

To find your local Department of Social Services, visit [LDSS Locator](#).

You can find out more about the LTHHC program from a hospital discharge planner, your local Department of Social Services (LDSS), or a Long-Term Home Health Care Provider. Until Medicaid LTHHC enrollees are required to enroll in MLTC plans, your local LDSS will authorize all LTHHC services that are provided. Once MLTC enrollment becomes mandatory, you should coordinate LTHHC services with your relative's MLTC plan.

ADDITIONAL COMMUNITY-BASED SERVICES

In most communities there are many services available which are not directly health-related but can make all the difference in keeping an elderly relative safely at home. Discussed in this section are services most commonly used to supplement home health care, including adult day care and respite care.

The services offered by the Mount Sinai Caregivers and Professionals Partnership Resource Center are free and confidential. Call (212) 241-2277 or visit [Mount Sinai](#).

For many families, these community-based services are all that are needed; home health care is not required. If you need a more detailed discussion than we can provide here, explore these and other options at your local Area Agency on Aging, senior citizen centers, or on the internet. In addition, some hospitals maintain caregiver resource rooms, such as the Mount Sinai Caregiver Resource Center in New York, with trained staff to help consumers access information and locate resources and programs.

What other things, beyond health care services, might my relative need?

While putting home health care services in place may be the first step, you and your relative may have other needs that can be met from resources in the community. You may have to make private arrangements for other kinds of support services, such as home-delivered meals, help with heavy or special cleaning (floor-scrubbing, window-washing, etc.), home maintenance tasks and repairs, yard work, driving, pet care, bill paying, and bookkeeping.

PERSONAL EMERGENCY RESPONSE SYSTEM

What is a personal emergency response system (PERS)?

For more information on a PERS and how to find a PERS provider, visit the Federal Trade Commission website ([FTC PERS](#)). You can also consult your local Area Agency on Aging ([AAA Agencies](#)) for more information on PERS providers in your area.

For added safety, your relative might benefit from a personal emergency response system (PERS). A PERS is an in-home alarm system that connects by telephone to employees of the PERS company. The trained employees are available 24 hours a day throughout the year and have access to clients' medical histories and a record of local emergency rooms, family, friends, and neighbors to use for responding to a client in crisis. Several different organizations and companies provide similar services. Monthly charges vary (\$35 for some; others have a sliding scale) and plans may or may not charge for installation, demand a security deposit, or insist on an annual contract. Your relative's doctor, nurse, or hospital social worker may be able to help you arrange for Medicaid reimbursement of the PERS monthly charges.

SAFE RETURN

How does Safe Return protect my relative with dementia?

If you want to find out more about Safe Return or enroll your relative in the Safe Return program, call (888) 572-8566 or visit [Safe Return](#).

Safe Return is designed only for people with Alzheimer's disease or dementia and is intended to return wandering and lost persons to where they live. Safe Return is a national program which works with local law enforcement throughout the country. The

\$55.00 registration fee (with an annual renewal fee of \$35.00) covers the cost of an engraved bracelet or necklace and a service available 24 hours a day to help relay key medical information to emergency responders if your relative wanders.

NEW YORK STATE'S MISSING ADULT ALERT PROGRAM

What is the Adult Alert Program and how will it help to protect my relative?

In 2011, New York State launched a new program to help safely bring home cognitively-impaired individuals who have wandered from their homes. If your relative has a cognitive impairment (a mental disability or brain disorder) and she has gone missing, contact your local law enforcement agency (police department or sheriff's office) and request the officer to trigger the Missing Adult Alert process. When you call you need only tell the officer that your relative has a cognitive impairment—it is not necessary to have medical confirmation of your relative's condition. To trigger the alert, your local law enforcement agency will enter your relative's name and photo into national and state-wide databases and, for the first eight hours following the trigger, highway message signs will be activated.

ADULT DAY CARE

What is adult day care?

As of 2013, New York State will require mandatory enrollment into a MLTC plan in order to receive Medicaid Adult Day Care services.

Adult day care, or adult day services, offers a structured, active environment with social and recreational activities for people who need more medical attention or supervision than can be offered at a senior center. Adult day care programs generally have flexible schedules for the benefit of participants and caregivers. Depending on the program, participants can attend between 3 to 12 hours a day up to 7 days a week. Some centers also offer nighttime hours.

What services do adult day care programs provide?

To locate an adult day care center program in your area, consult your local Area Agency on Aging ([AAA Agencies](#)), the New York State Adult Day Service Directory ([NYSADS Directory](#)) or the Adult Day Care Organization Directory ([ADC Directory](#)), local hospitals, or the Yellow Pages.

There are two types of adult day care programs: the social model and the medical model. For both social and medical models, transportation to the program is usually provided by the facility.

Designed to engage mentally or physically frail older adults, social model programs offer exercise, art and music therapy, meals, and transportation. Social day programs do not administer medication.

Medical model programs are similar but can supervise medication and offer other kinds of medical services in addition to social stimulation. The staff at medical model programs includes many different health care professionals, including physical therapists, occupational therapists, skilled nurses, pharmacists, speech therapists, dentists, and podiatrists.

Are adult day care programs connected to nursing homes?

Some medical and social model day care programs designed to accommodate people with Alzheimer's disease are offered by and in nursing homes. For many participants, these programs serve as transitions to eventual long-term placement in the nursing home.

Will Medicare or Medicaid cover adult day programs?

In most cases, Medicare will *not* cover adult day care services. Social and medical model programs are, however, covered by Medicaid and are available through your relative's MLTC plan if the MLTC determines that your relative is eligible for this level of care. You can also pay for these programs privately (costs range from \$25 to \$100 per day).

Who qualifies for adult day care and how is an application made?

To be eligible for adult day care, your relative must require assistance with at least two activities of daily

living (ADL), such as walking or using the bathroom. Applications may be made with your relative's MLTC plan or directly to the adult day care program if you intend to pay privately for services.

RESPITE CARE

What is respite care?

To locate a respite care provider in your area, consult your local Area Agency on Aging ([AAA Agencies](#)) or visit the [ARCH National Respite Network Locator](#) for New York or the New York State Caregiving & Respite Coalition listings of support services for caregivers [NYSCRC Locator](#). Respite care is also available through the EISEP program ([EISEP](#)).

Respite care provides short-term and infrequent care to an elderly person either at home, at a nursing home, or at another facility. Its purpose is to give family caregivers some relief from the responsibilities of taking care of sick or frail relatives. It can also provide substitute care when a usual caregiver is temporarily unavailable because of illness or other circumstance.

Different respite programs are designed for either day or overnight care. Respite care is often offered within adult day care programs. Long-term care institutions, such as nursing homes, may also provide overnight care.

How do I find a respite program?

Finding a respite care program may be difficult. Despite their benefits to the elderly and their caregivers, there are very few overnight respite programs. If your relative has dementia, ask the local chapter of the Alzheimer's Association for information about specialized respite programs. You may also want to call the nursing homes in your area and ask if they have an available respite bed.

Does Medicare or Medicaid cover respite care?

Medicare will cover respite care but only for hospice patients and only for five consecutive days at a time. Medicaid may also cover some respite care but you will have to arrange care through your relative's MLTC plan. If you pay privately for respite care, social day care and other community-based respite care providers typically charge about \$40 a day. Some respite providers charge on a sliding scale.

HOME CARE RESOURCES

Alzheimer's Association

225 North Michigan Avenue, Suite 1700, Chicago, IL 60601; (800) 272-3900. Provides training and support to those providing care to people with Alzheimer's disease and dementia. Call or visit the website to find a chapter in your area.

www.alz.org

Eldercare Locator

(800) 677-1116

The Eldercare Locator, a public service of the Administration on Aging, U.S. Department of Health and Human Services, is a nationwide service that connects older Americans and their caregivers with information on home care and other senior services:

http://eldercare.gov/Public/Resources/Factsheets/Home_Health_Care.aspx

There is also a search tool to locate agencies and services in your area:

<http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>

Long Term Care Community Coalition (LTCCC)

242 West 30th Street, Suite 306, New York, NY 10001; (212)-385-0355

An advocacy and watchdog group formed to protect the rights of nursing home residents.

<http://www.ltccc.org/>

Publishes a guide that contains extensive information and resources to help individuals understand and navigate the long-term care system in New York State:

<http://ltccc.org/publications/documents/NY-LTC-Consumer-Guide-finalcolor.pdf>

Medicare Rights Center, Inc.

520 Eighth Avenue, North Wing, 3rd Floor, New York, NY 10018; National Helpline: (800) 333-4114.

Call the helpline to speak to counselors about Medicare home care services, payment denials and appeals, complaints about care or treatment, and Medicare bills.

www.medicarerights.org.

MedlinePlus/Home Care

This service of the Department of Health and Human Services features in-depth information regarding home care for seniors, including a subscription service to receive the latest home care updates by email.

<http://www.nlm.nih.gov/medlineplus/homecareservices.html>

Mount Sinai Caregiver Resource Center

19 East 98th Street, 9th Floor, New York, NY 10029; (212) 241-2277.

Provides information about local home care services. Social workers are available to help strategize solutions caregiving problems. All services are confidential and free.

<http://www.mountsinai.org/patient-care/support-services/capp-caregiver-resource-center>.

National Association for Home Care & Hospice

Provides general information about home care including consumer guides to topics such as: *How to Choose a Home Care Provider*, *What is Home Care?*, *Who Provides Home Care?*, *What if A Problem Develops?*, *What Types of Services do Providers Deliver?*, *Who Pays for Home Care Services?*, and *How do I find Home Care Services?*. Also provides electronic access to *Caring* magazine.

<http://www.nahc.org/Consumer/>

New York City Department for the Aging

2 Lafayette Street, New York, NY 10007; call 311.

This is the New York City local Area Agency on Aging. Offers programs and services to help seniors live independently at home. Programs include informative seminars, senior centers, case management, in-home services, transportation, and legal help.

<http://www.nyc.gov/html/dfta/html/home/home.shtml>

New York State Department for the Aging

2 Empire State Plaza, Albany, New York 12223; Senior Citizens Hotline (800) 342-9871.

Provides information about home care and other long-term care options and will help you find your local Area Agency on Aging.

<http://www.aging.ny.gov/Index.cfm>

New York State Department of Financial Services

One State Street, New York, NY 10004.

<http://www.dfs.ny.gov/index.htm>

Responds to complaints against insurance companies regarding their failure to pay home health care benefits. Call (800) 342-3736 (New York City – (212) 480-6400) or file a complaint online:

<http://www.dfs.ny.gov/consumer/fileacomplaint.htm>

New York State Department of Health (DOH)

Corning Tower, Empire State Plaza, Albany, NY 12237

The DOH provides excellent consumer information on any issue relating to home care, home care providers, or reimbursement for services.

<http://www.health.ny.gov/>

Visit <http://www.health.ny.gov/contact/doh800.htm> for a directory of Department of Health Toll-Free Helplines, including a home health care hotline, (800) 628-5972, which includes information about Certified Home Health Care Agencies.

THIS CHAPTER WILL PROVIDE YOU WITH AN OVERVIEW OF ADULT HOMES, ASSISTED LIVING, AND SOME LESS COMMON HOUSING OPTIONS. IT INCLUDES THE FOLLOWING:

How to choose an adult home and apply for admission

Enriched housing programs, what they are, and how to find a good program

How to pay for an adult care facility through SSI (Supplemental Security Income) and other government programs

Residents' rights and complaint procedures in adult care facilities

Assisted living residences (ALRs), including choosing and paying for them

The New York State Assisted Living Program (ALP)

Adult foster care and Continuing Care Retirement Communities (CCRC)



ADULT HOMES, ASSISTED LIVING, AND OTHER OPTIONS

If home care isn't the right option for your relative, but she needs some assistance or supervision on a regular basis, there are some alternatives available. Each of the different housing possibilities discussed in this chapter offers a different combination of services, including meals, housekeeping, and supportive services that range from personal care services (help with dressing or eating) to skilled nursing services.

ADULT HOMES, ASSISTED LIVING, AND OTHER OPTIONS

If home care isn't the right option for your relative, she may want to consider some type of supported senior housing facility. There are a number of different senior housing options available, called "adult care facilities" in New York, and each of these options is described in this chapter. Most adult care facilities offer meals, housekeeping, and supportive services ranging from personal care services (help with dressing or eating) to skilled nursing services.

The State of New York licenses three different types of adult care facilities: 1) adult homes; 2) enriched housing programs; and 3) assisted living residences (ALRs) (an ALR must be licensed first as either an adult home or an enriched housing program before it can obtain an ALR license). Medicaid assisted living programs (ALPs), which enable Medicaid enrollees to receive Medicaid-funded health care services in an adult care facility, may be located in an adult home, an enriched housing program, or an ALR. In addition, ALRs may apply for special certification from the state to provide care to special populations such as residents with dementia or residents who hope to "age in place" rather than entering a nursing home.

Your relative might consider any of these housing possibilities if she can no longer live independently but isn't sick enough to be placed in a nursing home. Other housing options, like Continuing Care Retirement Communities (CCRCs) and adult foster care are also discussed in this chapter.

Are any of these housing alternatives a good choice for your relative? The answer, in part, depends upon the state of her health, her finances, and on the kinds of adult care facilities available in your area.

ADULT HOMES

THE BASICS

What is an adult home?

To find an adult home in your area, visit the New York State Department of Health's online directory ([NYS DOH ACF DIRECTORY](#)).

In New York, adult homes provide temporary or long-term residential care and services to adults who, though not requiring continual medical or nursing care, are unable or substantially unable to live independently without support. Adult homes must offer, at a minimum, room and board, case management services, and personal care services such as assistance with bathing, eating, dressing, grooming, and walking. They must also offer three congregate meals a day (nutritionally balanced meals served in a group setting) and an evening snack, housekeeping, social and recreational programs, and 24 hours of non-medical supervision. Adult homes can be operated on either a proprietary (for profit) or voluntary (not-for-profit) basis.

What New York State agency oversees adult homes?

To view Department of Health Adult Home inspection reports, visit [DOH AH INSPECTION REPORTS](#).

The New York State Department of Health (DOH) is the government agency that licenses, regulates, and inspects adult homes. The DOH makes routine inspections of each adult home in New York and responds to complaints made to the DOH about any facility. In some areas of the state, additional local laws may apply to adult homes as well.

What kind of caregiving staff is available at adult homes?

Adult homes are required to have staff on duty 24 hours a day, every day, to supervise residents. During daytime hours, a full resident-services staff should include: an administrator approved by the DOH, a case manager or social worker, an activities director, and a personal care director. The law says that “sufficient staff” must be available to provide all required services.

What is the minimum required ratio of staff to residents in adult homes?

It depends on the number of residents living in the home. New York law sets the following minimum staff to resident ratios for adult homes:

NUMBER OF RESDIENTS LIVING IN THE HOME	MINIMMUM NUMBER OF STAFF MEMBERS
1-40	1
41-80	2
81-150	3
151-200	4

For adult homes with more than 200 residents, an additional staff member is required for each additional 60 residents. In homes with fewer than 50 residents, the administrator may also serve as the case manager and/or activities director.

Are the required staff-to-resident ratios sufficient to provide good care?

Not really, especially in the larger homes where the minimum number of required staff is too small to serve residents properly. A facility that has the minimum ratio of staff to residents may not be suitable for people who need a lot of personal care.

How many adult homes are there in New York?

As of 2013, there are approximately 450 adult homes operating in New York State, including approximately 50 in New York City.

What's the average size of an adult home in New York?

That varies. Some have fewer than 10 residents, others as many as 350. Most of the small, less institutional homes that cater primarily to the elderly are outside New York City.

Do adult homes provide medical services?

See the detailed discussion of ALPs later in this chapter.

By law, adult homes may not provide medical services, unless they are affiliated with a New York State Assisted Living Program (ALP). However, adult home residents can keep their Medicaid cards, have personal doctors, and can receive medical services from visiting nurses, mental health teams, and home health care agencies.

What services are adult homes required to provide?

MFY has an Adult Home Advocacy Project. To learn more visit [MFY AH ADVOCACY](#).

Adult home operators must provide: room, board, supervision, housekeeping (including linen and laundry service), personal care items (such as toilet paper, soap, towels, and shampoo), medication management, recreational and social activities, and case management services. The cost of these services and supplies must be included in the home's basic monthly rate. Residents are entitled to receive help from staff to meet their personal needs, such as grooming, dressing, bathing, and toileting. In many homes, the amount of care available to each resident is limited, due to the small number of staff in proportion to the number of residents.

If at least 25% of a home's residents (or 25 residents, whichever is less) have a psychiatric disability, the home is also responsible for assessing residents' mental health needs, for supervising their general

mental health care, and for arranging visits from a social worker. Usually, the home arranges for these services through the outpatient or after-care department of the nearest state psychiatric or developmental facility, the local community mental health service, or a state-funded community support service provider.

SUPERVISION SERVICES

What type of supervision is provided in an adult home?

Adult home operators are required to supervise residents by:

- keeping track of the whereabouts of each resident;
- taking a daily census (count) of residents;
- monitoring residents for sudden changes in behavior or appearance;
- monitoring and, when necessary, assisting residents in performing basic daily activities, including meal attendance, personal hygiene and grooming, participation in facility and community-based programs, and basic money management; and
- maintaining the safety and security of the home and its residents.

The home may not confine residents to their rooms or beds (unless it is necessary for the treatment of a short-term illness), permit residents to use bedpans or in-room tray services (unless necessary for treatment of a short-term illness or as a night-time safety measure), or place residents in physical restraints.

What exactly is case management in an adult home?

New York adult homes must provide residents with case management services to support the residents in maintaining their independence of function and personal choice. These case management services include: helping residents adjust to the home, assisting residents in securing government benefits, linking

residents with medical and other service providers, and making discharge and transfer plans for residents. A member of the administrative staff, including the chief administrator, might handle case management. Adult homes are not required to have social workers on staff but homes must provide, without charge, a space for residents to meet in privacy with their medical and other service providers.

MEDICATION MANAGEMENT

Can the staff of an adult home give medicine to a resident?

Staff can assist with medication. Any staff person at the adult home is allowed to measure and prepare doses of medication for residents to take. You should be aware, however, that state regulations allow unlicensed staff to handle medication in ways that would be more highly regulated in another facility, such as a hospital or nursing home. There are a few homes that hire qualified personnel, even registered nurses, to supervise medication management. Other homes try to make sure that regular and properly trained staff members give out medications rather than untrained or temporary, per diem, workers.

Why is the administration of drugs an important issue?

Residents who have mental illness may be prescribed anti-psychotic drugs. Allowing untrained adult home staff to administer these drugs could be dangerous. New York regulations specify that adult home staff are not authorized to judge, on the basis of their observations, when to give medication to a resident. For this reason, it is illegal for adult homes to admit residents who need continual skilled observation and attention.

If your relative is already living in an adult home, keep informed about the way she is given her medicine by the staff. Find out if the worker who gives the medication is trained to do so. If possible, request that the same worker always administers your relative's

medication.

Can my relative take her own medicine?

Yes. If your relative is capable of keeping and taking her own medicines, she may do so. Your relative must first have a letter from her doctor, though, saying that she is able to self-administer her medication, and she must keep the home informed about the names and dosages of any medications she is taking.

Can residents be forced to take medication?

No. Residents have the right to refuse medication. If your relative decides not to take her medication, she should first talk to her doctor, case manager, or mental health professional.

FOOD

What food services do adult homes offer?

Adult homes must serve residents three meals a day and an evening snack. Meals must be served at regularly scheduled times. The evening meal can be no earlier than 4:30 p.m. and breakfast must be served within 15 hours of the evening meal. Menus must be posted in advance where residents and visitors can easily see them. Homes cannot use disposable plates and utensils on a regular basis.

What kind of food can the resident expect?

State regulations say only that meals must be balanced, nutritious, and adequate in amount and content to meet daily dietary needs. There must be a hot main course at either lunch or dinner; in other words, the home may not serve cold cuts at both meals. Water, milk, coffee, tea, and a hot decaffeinated drink must be available at every meal, although this does not always happen.

What about people with special dietary needs?

If a doctor has ordered a special diet for a particular resident, the home must provide it. If your relative's

doctor has prescribed a certain diet, ask the doctor to write a letter describing the diet in detail.

Residents on restricted diets—for example, vegetarians, diabetics, people with food allergies, and those who keep kosher (that is, observe Jewish dietary laws)—should notify the home before moving in. Adult homes do not necessarily have to serve special foods that residents prefer. It should be possible to arrange for packaged, frozen kosher meals to be brought in for residents who require them.

Do residents always have to eat at the adult home?

Residents are free to buy their own food or eat out in a restaurant if they wish. However, they will not get a refund for the uneaten meal at the home since food is included in the basic monthly rate.

ACTIVITIES

What kinds of activities must adult homes provide?

State regulations require that adult homes provide an activities program for all residents. Activities must be available to each resident for at least ten hours a week and be offered during evenings and weekends, as well as weekdays. The home is required to post the activity schedule every month. Homes are also required to provide transportation for residents who wish to participate in community activities.

Unfortunately, the regulations do not spell out clearly the kinds of activities that adult homes must provide. Ideally, an activities program should include physical exercise, social interaction, and intellectual stimulation. The program should also offer both individual and group events at the facility and in the community. Some adult homes offer a well-rounded schedule of activities for residents. At others, however, television and board games provide the main entertainment.

To read more about issues to consider when selecting an adult home, read the Coalition for the Institutionalized Disabled (CIAD) Guidebook ([CIAD GUIDE](#)).

CHOOSING AN ADULT HOME

What should I consider when helping my relative choose an adult home?

First, think about the location. If possible, go with your relative to visit several homes. Take a good look around and talk to the residents. Ask them what they like and don't like about the place. Their answers can be helpful in making a selection. Take notes on what you see and compare several different homes before making a decision. Use the following as a guide when you visit each home:

- Would my relative want to live in this area?
- Would people come to visit her here?
- Is the home clean and well kept-up?
- Are essential features of the home in good condition (for example, stairways and railings, elevators, floors, doors, and windows)?
- Is there a comfortable lounge?
- Is there air conditioning in summer and sufficient heat in winter?
- Would my relative feel safe taking a walk in the neighborhood?
- Are there stores, senior citizen centers, recreational facilities, places of worship, and cultural institutions nearby that meet my relative's needs?
- Is public transportation easy to arrange?
- Ask to see some residents' rooms.
- Find out whether residents are required to share rooms.

- Find out how the home manages medication.
- Ask about the ratio of staff members to residents.
- Ask to see the Department of Health (DOH) report on the home.
- Determine whether your relative is comfortable living in a place that houses only the elderly or if she would prefer a mixed-age population.

What about sharing bathroom facilities?

In addition to sharing bedrooms, residents may be required to share bathrooms. Under New York regulations, up to six people may share a single bathroom, although this rarely happens.

What about smoking in the home?

State regulations prohibit smoking in public areas or residents' rooms. There must be an indoor or outdoor area designated for smoking.

How do we find out if the food is good at a home we are considering?

Try to visit while a meal is being served and arrange to eat with the residents. This will help you and your relative evaluate the food's nutritional quality, taste, and the availability of second portions. Also, if this is important to your relative, ask staff if the home accommodates special or restricted diets (homes are required to accommodate medically restricted diets).

To view Department of Health Adult Home inspection reports, visit [DOH AH INSPECTION REPORTS](#).

Should I consider the Department of Health (DOH) inspection report?

Yes. Each adult home keeps copies of its DOH inspection reports and should post a copy of the most recent inspection report in a public place within the home. If you are considering a particular adult home and want to see its DOH inspection reports, make sure you ask for the full reports, which are more comprehensive, and not the partial (or "follow-up")

reports.

Although viewing the DOH inspection reports is a helpful tool, it is also important that you take the time to visit the home and make a decision that best meets your relative's needs and preferences.

What else should we consider when choosing an adult home?

Security. Ask about security guard and alarm arrangements so that you can gauge how easy it is for strangers to enter the home. The home is responsible for maintaining security and must install an alarm system, including an alarm system for the doors. A well-managed home should not have an open-door policy and should have established procedures to screen for strangers.

Protecting valuables. Find out how the home protects residents' possessions and valuables. Ask if all storage units have the same lock. If "one key fits all" is the policy, it might be better to store valuables with the home's management, if that can be arranged.

Emergency call systems. Ask how staff, other residents, or visitors contact residents. The home must be able to contact residents in their rooms with a bell, buzzer, or phone (a phone is best, even if it allows only incoming calls).

Privacy. Look for the public phone and see if it is located in an area where residents can speak with privacy. Also, adult homes must provide space for residents to meet privately outside their rooms with case managers and other service providers.

Access to mail. Ask about the procedure for residents to receive mail. The home should ensure that residents' incoming and outgoing mail is handled promptly and without tampering.

APPLYING TO AN ADULT HOME

How does my relative get admitted to an adult home?

Your relative can apply directly to an adult home for admission. She must have a medical evaluation, or check-up, by a private doctor or by a doctor at a clinic or hospital. Any major health problems and prescribed treatments must be noted.

If your relative has a history of mental illness, a social worker or a psychiatrist must also evaluate her. This is required even if your relative has been referred to the adult home by a mental health facility, a hospital, or a nursing home. Medical and mental health evaluations are necessary to help the home plan an adequate level of care.

Your relative must also have an admissions interview at the home. The interview has two purposes: to help your relative decide whether she wants to live at the home and to help the home's administration decide whether to accept your relative.

What happens at the admissions interview?

For more information about resident rights in adult homes, read *MFY's Rights of Adult Home Residents* ([RESIDENTS' RIGHTS](#)) and CIAD's manual on resident's rights ([CIAD MANUAL](#)).

Your relative should be given a copy of the admissions agreement, a contract between your relative and the home stating the home's basic daily rate and the services that the home agrees to provide to your relative.

Your relative must also be given a copy of the home's statement of resident rights, the home's rules, the personal allowance protections available to Supplemental Security Income (SSI) recipients, and the most recent DOH inspection report. All of these documents must also be posted in a public area of the home.

Can an adult home refuse to admit my relative?

Yes. Adult homes may refuse to admit anyone who:

- needs continual medical or nursing care (unless the applicant is participating in or qualifies for a New York State Assisted Living Program);
- needs health or mental health services that cannot be provided by local agencies or service providers;
- causes, or is likely to cause, danger to himself or to others;
- repeatedly behaves in a manner that directly impairs the well-being, care or safety of the resident or other residents, or which substantially interferes with the orderly operation of the home;
- has a medical condition which is unstable and which requires continual skilled observation of symptoms and reactions or accurate recording of such skilled observations for the purposes of reporting to the resident's physician;
- refuses to, or is unable to, comply with a prescribed treatment program;
- needs more than occasional help with activities of daily living (walking, toileting, transferring from bed to wheelchair, etc.);
- has chronic and uncontrolled bowel or urinary incontinence;
- engages in drug or alcohol abuse resulting in aggressive or destructive behavior; or
- is dependent on medical equipment (unless the equipment is safe, using the equipment does not interfere with life in the home, and the resident is able to maintain the equipment herself).

What if my relative is accepted at a home she doesn't like?

Even if your relative qualifies for and is accepted at a particular adult home, she doesn't have to accept the placement. If she is hospitalized, hospital discharge planners or other referral sources may try to pressure her to move to a particular place, but she has the right to refuse. In practice, though, it may be difficult for people who are frail, elderly, or have severe mental

illness to insist on their right to informed choice. Relatives, friends, or other advocates should get involved with the placement process and make sure the applicant's rights are not being violated.

PAYING FOR AN ADULT HOME

How do residents pay for care in an adult home?

Assisted Living Programs are discussed in greater detail later in this chapter.

Some adult home residents pay the home privately (that is, out of their own pockets). Others pay through Supplemental Security Income (SSI) or the other government benefit programs described below. Medicare and Medicaid do not cover the cost of adult homes, since adult homes do not provide medical care. However, Medicaid will pay the health care costs of a New York State Assisted Living Program (ALP) in an adult home.

What do adult homes cost?

In 2013, SSI will pay \$1,404 a month to adult homes for the benefit of residents qualified to receive SSI. From this amount, residents are entitled to a monthly personal needs allowance of \$187.

Private pay rates vary depending upon the size of the room and whether the resident must share her room with another resident. The average monthly cost for private pay homes is about \$1,500 - \$2,000. A single room can cost more, up to about \$3,000. Keep in mind that prices can vary widely from these averages and that the average monthly cost of a private pay home is typically higher than the average monthly cost of a home that accepts SSI.

Do adult homes require a security deposit?

Typically, an adult home will require one month's rent in advance as security if the resident is private pay. Before admission, be sure to ask whether the home requires a deposit and how much it is. If admitted, your relative should receive a written receipt showing the amount she paid for her security deposit.

How does my relative pay for an adult home through a government benefits program?

Even if your relative can afford to pay privately when she is first admitted to an adult home, it is **important to find out whether her home accepts SSI payments!** If your relative's home accepts only private payments, she might be evicted from the home if her funds run out. Here are some government benefit programs that might help your relative to pay for her adult home:

For more information about SSI, visit [**SOCIAL SECURITY**](#).

To apply for SSI in person, call (800) 772-1213 and ask for an appointment with a Social Security representative. Visit [**SSI APP**](#) to apply for SSI online.

For more information about SSD, visit [**SOCIAL SECURITY**](#).

To apply for SSD in person, call (800) 772-1213 and ask for an appointment with a Social Security representative. Visit [**SSD APP**](#) to apply for SSD online.

SUPPLEMENTAL SECURITY INCOME (SSI)

This is the government program that ensures a minimum income level to people who are 65 or older and to people who are blind or disabled and:

- Are United States citizens or are non-citizens who began receiving SSI before August 22, 1996. (Some non-citizens who did not begin receiving SSI before August 22, 1996 may still be eligible for SSI).
- Do not have more income or assets than the minimum allowed.

This cash benefit usually supplements other sources of income such as Social Security and pensions. In adult homes, it pays for rent, food, and related services like laundry. It does not pay for health care. In New York, SSI recipients are automatically entitled to receive Medicaid benefits.

SOCIAL SECURITY DISABILITY (SSD)

This is the government program providing benefits to people under 65 who are disabled. Like Social Security Retirement, it depends on work history and credits earned through Social Security taxes paid. People who have received SSD for 24 months are eligible for Medicare, but are not necessarily eligible for Medicaid.

COMBINED SSD AND SSI BENEFITS

If someone's SSD benefits are lower than the minimum income level guaranteed by SSI, she will qualify for SSI and receive a cash benefit that brings her income up to the SSI level. Once someone in New York receives SSI, even if it supplements SSD, she is entitled to Medicaid.

For more information about SNA, visit [SNA](#). To apply for SNA in New York City, contact your local job center at [NYC HRA](#) or call the New York State Temporary Assistance Hotline at (800) 342-3009. In other areas of the State, call the hotline or contact your local Department for Social Services ([LDSS](#)).

Immigrants needing SSI, SSD, or SNA information can call the New York Immigration Hotline at (800) 566-7636.

SAFETY NET ASSISTANCE (SNA)

Safety Net Assistance is a state public assistance program that provides financial assistance to individuals or households with no other form of support. In New York State, people who are not eligible for SSI may receive assistance through the Safety Net program. The program has a two-year time limit on cash assistance for most participants. After that period, assistance is non-cash.

How much will government programs pay for an adult home?

Government benefits programs each determine the rates they will pay to adult homes. The principal programs paying for adult homes in New York are SSI and SNA.

Recipients of SSD benefits whose private income or benefits are higher than SSI income levels must pay for adult homes as private payers and have no guarantee of a personal allowance. If SSD benefits are below SSI income levels, SSI adds enough to bring the benefit total up to SSI level.

What are the financial requirements for SSI?

There is a limit to the amount of income and to the amount of savings or other assets an applicant can have. The rules are complex and the eligibility levels may vary with individual circumstances.

How does somebody apply for SSI benefits?

If possible, applications should be made in person at the Social Security Administration (SSA) district office. If you or your relative are relatively computer literate,

you can start the application online.

To apply for SSI in person, call (800) 772-1213 and ask for an appointment with a Social Security representative. To find your Social Security district office, use this locator tool [SSA Locator](#).

Visit [SSI APP](#) to apply online.

When applying, gather as much documentation as possible to show eligibility for SSI benefits, including a Social Security card (or a record of a Social Security number) and a birth certificate (or other proof of age). Also, gather documents that show what your relative's income and resources are and how she has been managing without benefits.

If your relative is younger than 65 and applies for SSI because she is disabled, the SSA will determine whether she is eligible based on her medical records, reports from her doctors, and results of examinations by the SSA's doctors.

Even if your relative doesn't have all the right documents, she should apply anyway. The SSA is required to help any applicant obtain the documents or advise her how to establish certain facts if the documents are unavailable.

To find your relative's local LDSS, visit [LDSS](#).

While waiting to receive SSI benefits, your relative may qualify for Safety Net (public assistance or welfare) through a local Department of Social Services.

What if the SSA rejects my relative's application?

Visit [SS PROCESS](#) and [SS APPEAL](#) to learn more about the SSI appeals process and to get the necessary forms to file an appeal.

If your relative's application for SSI benefits is turned down, it is almost always worth it to appeal. The letter denying benefits will explain how to appeal the denial. Your relative can also appeal if benefits have been reduced or stopped, or if she believes that the benefit level is too low. For legal help with an appeal, contact the local Legal Aid or Legal Services office. [LawHelp.org](#) can help you locate free legal services for people who have low incomes.

How do SSI benefits get paid to the adult home?

Unless a resident has appointed a representative payee to manage her money, she has the right to receive and cash her own SSI checks, and then pay the home herself. She may prefer to sign her check over to the home. The home should give her a receipt, deduct the

rent from the check, and give her the money that remains. This leftover amount is called the “personal allowance.”

What happens to my relative’s SSI check if she is hospitalized?

Adult home residents who are hospitalized for 90 days or less are entitled to receive their full SSI benefits without interruption.

PERSONAL ALLOWANCES

How does the resident get her personal allowance?

In 2013, the minimum personal allowance for a SSI recipient residing in a New York adult home is \$187 per month.

As we explained, the personal allowance is the money left over from an SSI or Safety Net check after the adult home’s rent has been deducted. If the resident gives her check to the home, she is entitled to receive the personal allowance within two banking days. In practice, however, the state allows homes up to five days.

The personal allowance belongs to the resident and she can spend it on whatever she wishes. The home may not make a resident use personal allowance funds to pay for items or services that the adult home admissions agreement requires the home to provide, such as soap, towels, or toilet paper.

Residents may, however, ask a home to hold their allowances for them. In that case, the home arranges for residents to deposit the money in an account maintained by the home. This account does not have to be interest-bearing, but if it is, the resident keeps the interest.

When can the resident get access to her personal allowance account?

The home must make sure that residents have access to their money at least four hours a day, Monday through Friday, and the schedule must be posted. In addition, the home must show residents a statement of all deposits and withdrawals and their current balance

once every three months or whenever the resident asks to see it.

What if a home misuses my relative's money or violates the personal allowance rules?

You or your relative should notify the New York State Department of Health (DOH), which will investigate any suspected misuse or withholding of personal allowance funds. The DOH may or may not decide to take action on behalf of a single resident.

RESIDENT RIGHTS AND COMPLAINTS

For more information about resident rights in adult homes, read *MFY's Rights of Adult Home Residents* ([RESIDENTS' RIGHTS](#)) and CIAD's manual on resident's rights ([CIAD MANUAL](#)).

RESIDENT RIGHTS

Do residents have basic rights the adult home must respect?

Definitely. State regulations require that adult homes treat residents in accordance with a statement of resident rights. This statement of resident rights must be given to each resident and should be posted in a public area of the home.

Among the rights guaranteed to residents of adult homes are: civil and religious rights, a range of privacy rights, the right to present grievances to the adult home staff without fear of reprisal, the right to join with other residents to work toward improving care at the home, the right to be free from restraints, the right to come and go from the home at reasonable hours, and many others. The right to receive courteous, fair, and respectful care and treatment at all times is especially important. A resident who has not received her personal allowance or who has not been permitted to control her allowance can take legal action against the home.

If you need help forming a resident council, contact CIAD at (212) 481-7572 and read the [CIAD RESIDENT COUNCIL MANUAL](#).

RESIDENT COUNCILS

What are resident councils and how do they work?

People who live in adult homes have the right to organize and run their own groups, called resident councils, to confront and attempt to solve any problems that arise at the home.

Adult homes are required to encourage and assist residents in organizing and maintaining resident councils. Homes must also:

- make sure the residents run the council;
- appoint a staff member to serve as liaison to receive complaints from the council;
- send a staff supervisor to attend council meetings when the council requests it;
- reply in writing to complaints raised by the council; and
- permit the council to meet as often as the residents wish.

The Coalition for the Institutionalized and Disabled (CIAD) has a helpful guide to help your relative decide if her home is meeting her needs ([CIAD GUIDE](#)).

GRIEVANCE PROCEDURES

What should my relative do if she has a complaint about the adult home?

Adult home operators are required to set up a system to receive and respond confidentially to grievances by residents concerning problems with services or staff. The home must clearly identify, and post in a public area, the names of the staff member or members responsible for receiving grievances and suggestions for changes from any of the residents. However, state regulations do not specify a time limit within which the home must respond to grievances.

Your relative should start by taking her complaint to the home's resident council. If that doesn't work, she should speak to the director of the home. If she doesn't get results, there are several outside organizations that can help:

MFY Legal Services, Inc. – (877) 417-2427
Coalition of Institutionalized Aged and

Disabled (CIAD) - (212) 481-7572
New York State Long-Term Care Ombudsman
Program - (800) 342-9871
New York State Department of Health (DOH) - (866)
893-6772

To file a complaint regarding an adult home with the New York State Department of Health, call the Adult Home Complaint Hotline at (866) 893-6772. In you live in New York City, you can get help with your complaint by calling MFY at (877) 417-2427 or the Coalition for Institutionalized Aged and Disabled (CIAD) at (212) 481-7572. On Long Island, call the Nassau/Suffolk Law Services Committee, Inc. at (516) 292-8100.

You can also visit these organizations on the web: [MFY](#), [CIAD](#), and, to find your county long-term care ombudsman, [OMBUDSMAN](#).

FILING COMPLAINTS WITH THE STATE

Does New York State regulate adult homes?

Although New York State has adult home regulations that are more protective than those of most states, the rules are not always strictly enforced. Just like any other landlord, adult home operators are subject to the *warranty of habitability*, which requires that their building is fit to live in.

Although it rarely occurs, case managers who file a complaint on behalf of a resident are protected from being fired. Residents are also protected from retaliatory or arbitrary eviction. If physical conditions in a home are very bad, get legal help and advice from a lawyer who is familiar with landlord-tenant law.

How often are homes inspected by the Department of Health (DOH) and what is involved?

The DOH must make a full inspection of an adult home every 18 months, although in practice the time may be longer. Homes that have received poor ratings in the past should be visited every 12 months. The DOH also performs inspections in response to consumer complaints. Most adult homes, including those with serious problems, are forewarned that inspectors are coming. They sometimes make quick changes in order to meet state standards.

How well does the DOH do its job?

Unfortunately, there are too few DOH inspectors to cover the territory. As a result, the DOH inspection and enforcement systems can be slow. Even when an adult home has been cited for violations, it might be anywhere from 6 to 18 months before the state takes action against the home. And even if a penalty is

imposed, it may be reduced later through negotiations between the DOH and the home.

If you are interested in finding more out about the DOH inspection process, read the [DOH GUIDE on adult home inspections](#).

Can my relative or my family complain directly to the DOH?

Yes. Adult home residents and their relatives and friends should complain to the DOH when there are problems with care and services in an adult home. Even if the DOH does not respond promptly or adequately, consumer complaints reveal the most widespread problems and help keep state regulators focused on those problems.

How should complaints to the DOH be filed?

To find the address of your local DOH office, visit [DOH LOCATOR](#).

MFY recommends that you or your relative make the complaint by phone to the DOH state-wide adult home complaint hotline number—(866) 893-6772—as well as in writing, including all the following information: a description of the problem or incident, the date and time it occurred, the staff members involved, and the response of the home when told of the problem. The complaint should be mailed to your relative's local DOH office and a copy should be kept for your file.

TRANSFER, EVICTION, AND VOLUNTARY DISCHARGE FROM AN ADULT HOME

TRANSFER	EVICTION
This is usually a temporary move from an adult home to another facility, such as a hospital. A resident may be transferred if she requires immediate medical care that cannot be provided in the adult home or if she is a danger to herself or others	This is permanent and does not imply a transfer to another facility. A resident might be evicted if: <ul style="list-style-type: none">• her behavior is repeatedly disruptive;• she fails to pay her rent; or• the home closes

TRANSFERS

How do transfers work?

First, the home must get a doctor to evaluate a sick resident and determine whether she needs to be hospitalized or whether she is a danger to herself or others. If the doctor decides the resident needs hospital care, the home will arrange the transfer. If the resident poses a risk of serious physical harm to herself or others, a well-run home will ask for help from social service providers, such as mental health teams, on a crisis-intervention basis. As a last resort, the home may call the police, who will take the resident to a psychiatric emergency room for evaluation and possible involuntary commitment to the hospital.

What happens to the resident's bed at the adult home if she's transferred?

To learn more about SSI during a temporary hospital stay, visit [SSI 90 DAY](#).

Residents can continue to receive full, uninterrupted SSI benefits if they enter a public or Medicaid-approved hospital for a stay of 90 days or less. This allows the resident to continue to pay rent and hold her room at the adult home while she is hospitalized; however, the adult home has the right to decide what to do with the bed during that time. During the 90 days, SSI money will still be paid to the home and the personal allowance will still be set aside for the resident. It is important to remember that this benefit is available only for the first three months of a continuous but temporary stay in a hospital or other medical facility, and only if Medicaid is funding more than 50% of the cost of hospital care.

What happens if the resident's health or mental state improves?

When the reason for the temporary transfer no longer exists (that is, the resident recovers and is discharged from the hospital), the resident has the right to return to the adult home if she wishes.

If you or your relative is facing eviction from an adult home, call MFY at (877) 417-2427. On Long Island, call the Nassau/Suffolk Law Services Committee, Inc. at (516) 292-8100.

EVICTIIONS

How does the eviction process work?

An adult home cannot evict someone without going to court to cancel the admissions agreement. The resident has the right to fight the eviction.

The eviction process is as follows:

- The home must give the resident a written notice stating the reasons for the eviction and the intended date of termination of the admissions agreement. This notice must be received 30 days before the termination date and must also state that the resident has the right to contest it. **The resident, however, does not have to leave the home when she receives this notice.**
- If the resident does not wish to leave the home, she should get legal assistance immediately. (The home must also give the resident a list of free local legal service organizations and advocacy resources.)
- After 30 days, the home must serve the resident with a petition, which is the legal paper that begins a housing court case. **The resident, however, does not have to leave the home when she receives the petition.** If she submits an answer to the court, she has the right to go to trial.
- At the trial, the home must prove its right to evict. Of course, the resident can present evidence that disproves the home's claims and establishes her right to stay in the home. The resident must leave the home only if the judge decides that she must.

VOLUNTARY DISCHARGE

Can a resident move out of a home if she wants to?

Yes, any time a resident wants to move out of an adult home she may do so. To receive a rent refund, though, she should give the home 30 days notice of her intention to leave.

To find an enriched housing program in your area, visit the New York State Department of Health's online directory ([NYS DOH ACF DIRECTORY](#)).

ENRICHED HOUSING PROGRAMS

What is an Enriched Housing Program?

Like adult homes, enriched housing programs are long-term adult care facilities licensed by the New York State Department of Health. As of 2013, there are approximately 100 licensed enriched housing programs operating in New York.

The primary difference between adult homes and enriched housing programs is that enriched housing residents live in apartments rather than single rooms. Enriched housing program apartments usually contain a bedroom, a bath, a living room, and a kitchen. Under New York law, residents in enriched housing programs are entitled to services and protections similar to those provided to adult home residents including at least one meal, housekeeping, laundry, some supervision, assistance with self-administered medication, personal care assistance, case management services, and structured activity programs.

Although enriched housing programs are required to provide only one communal meal a day, most choose to serve three meals a day. Similarly, although enriched housing programs are only required to provide some supervision, most programs elect to provide 24 hour supervision like their adult home counterparts.

Who is eligible for enriched housing?

To qualify, residents must be 65 or older and need assistance with activities of daily living. Like adult home residents, they cannot be so sick that they cannot self-transfer (move from a wheelchair to a bed or toilet, for example) and they cannot require continuous medical, nursing, or personal care.

How much does an Enriched Housing Program cost?

Enriched Housing Program residents who pay housing and services on a private pay basis will pay between \$2,500 and \$4,000 a month, depending on the

apartment and services selected. Like adult homes, in 2013, Supplemental Security Income (SSI) will pay \$1,404 a month to enriched housing programs for the benefit of residents qualified to receive SSI. From this amount, residents are entitled to a monthly personal needs allowance of \$187.

Who operates enriched housing programs?

Most programs in subsidized buildings are operated by public or not-for-profit agencies. For-profit corporations also operate private-pay enriched housing programs. All are licensed by the New York State Department of Health.

To find an ALR, EALR, or SNALR in your area, see the New York State Department of Health's Directory ([DOH ALR DIRECTORY](#)).

The New York Department of Health has published a very helpful consumer guide to ALRs ([DOH ALR GUIDE](#)).

ASSISTED LIVING RESIDENCES

In 2004, New York passed the Assisted Living Reform Act to define "assisted living" and to require any facility calling itself an Assisted Living Residence (ALR) to be licensed by the New York State Department of Health as an adult care facility. In order to be licensed as an ALR, New York Law requires the facility to first be certified as either an adult home or an enriched housing program, as described earlier in this chapter.

What is an assisted living residence?

New York law defines an "assisted living residence" as an adult care facility that provides or arranges for housing, on-site monitoring and personal care services, and/or home care services (either directly or indirectly) in a home-like setting to five or more adult residents unrelated to the assisted living provider. ALRs also provide daily food service, 24-hour on-site monitoring, and case management services.

In addition to the services provided by adult homes and enriched housing programs, ALRs are required to develop individualized service plans (ISPs) for each resident. The ISP describes what services the ALR will provide to the resident and identifies the provider or staff responsible for the services. The ISP must be reviewed and updated every six months as well as whenever a resident has a significant change in needs.

Can my relative “age in place” in an ALR?

Yes, if she chooses an ALR with enhanced certification (EALR) from the New York Department of Health. An EALR certification authorizes the EALR to retain residents who desire to continue to remain in the EALR as they become more frail, including those who: (i) are chronically chairfast and unable to transfer or chronically require the physical assistance of one or more persons to transfer; (ii) chronically require the physical assistance of one or more persons in order to walk; (iii) chronically require the physical assistance of one or more persons to climb or descend stairs; (iv) are dependent on medical equipment and require more than intermittent or occasional assistance from medical personnel; or (v) have chronic unmanaged urinary or bowel incontinence. While EALR certification allows EALRs to admit and retain residents who exceed the retention standards of adult homes, enriched housing programs, and “basic” ALRs, EALRs still cannot admit residents in need of 24-hour skilled nursing care or medical care, unless certain conditions are met. These conditions are:

- the resident must hire appropriate nursing, medical, or hospice staff to care for her increased needs;
- the resident’s physician must determine that, with the provision of additional nursing, medical and/or hospice care, the resident’s health and safety will not be at risk, and the resident will not need to be discharged to another setting;
- the EALR must agree to retain the resident and to coordinate the care provided by either the EALR or another provider; and
- the resident must be otherwise eligible to reside in the EALR.

One of the advantages of living in an EALR is that the EALR is permitted to directly employ a registered professional or licensed practical nurse to provide nursing services for residents and to supervise the provision of care for residents. EALRs are not required to have a nurse on staff, however, and may choose to provide skilled services by contracting with a home care services agency.

If my relative has dementia or Alzheimer's disease, can she still live in an ALR?

Yes, if she chooses an ALR that the Department of Health has certified as a Special Needs Assisted Living Residence (SNALR). A SNALR is authorized to serve residents with special needs (such as Alzheimer's disease or dementia) in accordance with a special needs plan approved by the Department of Health.

What services are offered by SNALRs?

The services offered by the SNALR depend on the unique needs or type of resident the SNALR is certified to serve. For example, in a SNALR certified to serve residents with dementia, the SNALR will provide a secured environment and highly specialized health and personal care services meant to address the needs of each individual resident. Often SNALR residents are provided medical, social, and behavioral care and management.

PAYING FOR AN ASSISTED LIVING RESIDENCE

How much does an assisted living residence cost?

Costs vary but range from about \$3,000 to more than \$6,000 a month. Costs will depend on the particular residence, room size, and type of services provided. There are a few programs with sliding fee scales but they have long waiting lists.

Does insurance cover assisted living residences?

Medicare and long-term care insurance policies may cover some of the home health care services provided in ALRs. If your relative has long-term care insurance, check to see if assisted living is covered as an alternate care benefit.

Medicaid pays for very little of the health care provided in an ALR. Medicaid does, however, pay for health care in the New York State Assisted Living Program (ALP). Details about New York State ALP come later in this chapter.

What happens when my relative's money runs out?

Most ALRs are strictly private pay. Supplemental Security Income (SSI) does pay for ALRs but most ALRs will not accept SSI as payment in full, because the monthly amount SSI will pay is insufficient to meet the costs of providing the housing and services ALRs are required to provide to residents. As a result, when your relative's money runs out, she will probably have to move to an adult home or to a nursing home. Keep in mind that your relative may be more likely to be accepted at her first nursing home choice if she moves while she can still pay privately for a few months of nursing home care.

CHOOSING AN ASSISTED LIVING RESIDENCE

How should my relative choose an assisted living residence?

To find an ALR, EALR, or SNALR in your area, see the New York State Department of Health's Directory ([DOH ALR DIRECTORY](#)).

Be certain about what health care and other services your relative currently needs, and anticipate future needs as well. Find out how much health care services cost even if your relative doesn't need them now. Visit several ALRs to get a sense of what daily life is like and how well your relative will fit in. When you visit a facility, ask lots of questions. Ask both staff and residents the questions most important to you.

For additional information on how to select an ALR, Assisted Living Facilities.org, which is an ALR industry group, has some helpful information ([ALF](#)).

Review a copy of the ALR's standard residency agreement. Your relative will sign this Agreement before she moves into the ALR. The residency agreement should include: a description of the resident's living space (number of rooms, etc.); a description of the furniture supplied by the ALR and fees for the furniture; and a detailed description of services provided by the ALR and the fees for such services. Make sure you and your relative understand everything in the residency agreement before she signs. Don't rely on promotional material or on what staff say during a tour. If you face a problem later, only the residency agreement will count.

Make sure you understand the ALR's discharge policies. Most ALRs will not keep residents whose care needs are too great but, unfortunately, ALR staff answers to questions about discharge can often be misleading. "Of course, we can handle incontinent residents" sometimes means "We will keep incontinent residents able to handle diaper changes and extra laundry themselves." Ask how much notice your relative will be given if she is asked to leave because her care needs have grown too great.

What should we look for when visiting?

- Observe how staff relates to residents.
- Look at the staffing levels on each floor, particularly the floors where people have greater medical needs. Alzheimer's floors may require additional staff to insure adequate supervision.
- Look at menus to see if the food served is varied and if it will appeal to your relative.
- Find out if residents can choose when to eat meals, whether they can eat in their own units, and whether they can invite guests for meals.

What other questions should we ask?

- How much will the ALR cost?
- What type of license/certification does the ALR have ("basic" ALR, EALR, SNALR)? Will that certification enable the facility to meet your relative's current and future needs?
- What health services are available on-site and do doctors and nurses come to the facility? Are residents able to keep their own medical providers if they wish?
- What other services are available? What services need prior arrangement? Do any care services (bathing, for example) need an appointment? How far in advance?

- Is the ALR close to family and friends?
- What other costs or charges, such as dry cleaning, cable television, etc., might be additional? Will these costs change?
- What medical emergency procedures are in place? What hospital does the ALR send residents to if needed?
- Is there a residents' complaint system in place? Which ALR staff member should residents contact to make sure their complaints are handled promptly and efficiently?
- What transportation is available from the ALR? What choices are there for residents to schedule outings? What is within safe walking distance (shopping, park, library, bank, etc.)?
- Are there religious services available at the ALR? Is the ALR near places of worship?
- Is the ALR near civic or social organizations so that active participation is possible?
- Are there grocery stores or shopping centers nearby?
- What kinds of social activities are available at the ALR? Are there planned outings of interest to your relative? Is participation ever mandatory?
- Does the ALR have a policy for taking suggestions and making improvements for the residents?
- Think about the assistance your relative currently requires as well as the assistance she will need in a few years. Will the ALR help coordinate the needed services from other agencies or are the services available on site?

- During your visit, eat a meal. This will address the quality and type of food available. If, for cultural or medical reasons, a special diet is required, can the ALR prepare these types of meals?
- If English is not your relative's first language, is staff available to communicate in your relative's language? If your relative has difficulty hearing, will ALR staff assist her in communicating with others?
- Are overnight visits by guests allowed? Does the ALR have any rules about these visits? Can a visitor dine and pay for a meal? Is there a separate area for private meals or gatherings to celebrate a special occasion with relatives?

THE NEW YORK STATE ASSISTED LIVING PROGRAM (ALP)

To find an ALP in your area, use the New York State Department of Health's online directory ([NYS DOH ACF DIRECTORY](#)).

What is the New York State Assisted Living Program?

The New York State Assisted Living Program (ALP) is a program available in some adult homes, enriched housing programs, and ALRs, which combines residential and home care services. ALP operators must provide or arrange for resident services, including room, board, housekeeping, supervision, personal care, and case management. ALPs must also provide home health services, which they can arrange through a Certified Home Health Agency (CHHA), a Licensed Home Care Service Agency (LHCSA), or a Lombardi (Long-Term Home Health Care) program. CHHAs, LHCSAs, and Lombardi programs are all discussed in greater detail in [Chapter One](#).

Can my relative "age in place" in an ALP?

Yes, adult home, enriched housing program, and ALR residents can "age in place" through the ALP, receiving needed health care services without moving to a nursing home.

Who runs Assisted Living Programs?

To run an ALP, operators must first be licensed by the New York Department of Health as either an adult home or an enriched housing program and then must obtain an additional license as an ALP.

In 2013, there are about 100 ALPs licensed in New York, with approximately 25 located in New York City. Most are adult homes, but some are enriched housing programs or ALRs.

How does the New York State Assisted Living Program work?

The ALP allows people to move into or remain in adult homes, enriched housing programs, or ALRs by receiving additional support services under the same roof, such as:

- nursing services;
- personal care services;
- home health aide services;
- physical therapy;
- occupational therapy;
- speech therapy;
- medical supplies and equipment that do not require prior approval by Medicaid;
- Personal Emergency Response Systems (PERS); and
- adult day care.

Who can benefit from an ALP?

To be eligible for an ALP, your relative's medical needs must be great enough to qualify for acceptance in a nursing home but not so great that a nursing home environment is required. She must be medically stable and able, with direction, to take "sufficient action to assure self-preservation in an emergency."

An adult home, enriched housing program, or ALR that offers an ALP could be right for your relative if she:

- already lives in an adult home/enriched housing

- program/ALR but needs additional services to remain there; or
- is being discharged from a hospital and cannot return home due to insufficient supervision and services.

Who pays for the ALP services?

If your relative is eligible for Medicaid, she can enter the program as soon as Medicaid has approved the care services. If your relative is also eligible for Supplemental Security Income (SSI), SSI will pay for the residential costs, which are the charges for living at the adult home, enriched housing program, or ALR. In any case, the option to pay privately is available.

How does somebody apply for an ALP?

If your relative is already in an adult home, enriched housing program, or ALR, the staff will arrange for an assessment of her medical needs and take care of the Medicaid application needed to get approval for ALP services.

To find your relative's local LDSS, visit [LDSS](#).

If your relative still lives in her own home, you must first find an ALP willing to accept her and the ALP will arrange for an assessment of your relative including a physician order, nursing assessment, social assessment, and an interview with your relative. You can contact your relative's local department of social services (LDSS) to apply for the ALP after she has been accepted into the adult home, enriched housing program, or ALR.

How will we know what medical services will be provided?

Once your relative is accepted into the ALP, the ALP will draw up a plan of care and do a follow-up assessment within 45 days after her admission to the program. Additional follow-up assessments are then done every six months or as needed to respond to changes in your relative's condition. You and your relative should participate in the assessment and care planning.

After the service plan and budget are set, the ALP must deliver the specified services at the specified price. Services in the plan cannot be reduced or discontinued, even if they end up costing more than the Medicaid payment.

What if my relative applies to be part of an Assisted Living Program and is turned down?

If you disagree with the ALP and you think your relative should have qualified for the ALP, you can call the New York State Department of Health's Adult Home Complaint Hotline at (866) 893-6772.

You can get help with your complaint about an ALP by calling MFY at (877) 417-2427 or the Coalition for Institutionalized Aged and Disabled (CIAD) at (212) 481-7572. On Long Island, call the Nassau/Suffolk Law Services Committee, Inc. at (516) 292-8100.

What if problems arise with an ALP?

If the problem is related to the non-medical services in the ALP, it should be taken up with the administrator in the adult home, enriched housing program, or ALR. If you do not get satisfaction, then the complaint can be filed with the Department of Health's Adult Home Complaint Hotline at (866) 893-6772. Don't let problems go unsolved or unanswered. Sometimes even serious problems fall through the cracks. If this happens, call the Coalition of Institutionalized Aged and Disabled (CIAD) or MFY.

OTHER OPTIONS

ADULT FOSTER CARE

What is adult foster care?

Adult foster care places elderly people in private homes with families who provide rooms, meals, laundry service, personal care, and supervision. The program is administered by the New York State Department of Social Services. It is more commonly used and available in areas outside of New York City.

To qualify for adult foster care, your relative must: be able to use the bathroom without help; be able to walk without help; not be a danger to herself or others; not be bedridden; and not be in need of skilled nursing care.

To find your relative's local LDSS, visit [LDSS](#).

For more information about adult foster care, contact your relative's local Department of Social Services (LDSS).

CONTINUING CARE RETIREMENT COMMUNITIES

To learn more about CCRCs, read the helpful guides from the New York Department of Health ([DOH CCRC](#)) and the Department of Financial Services ([DFS CCRC](#)).

What are Continuing Care Retirement Communities?

Continuing care retirement communities (CCRCs) are residential complexes that offer elderly residents, under one contract, an independent living unit, food, residential amenities, and access to a continuum of long-term care services, as residents' health and social needs change over time. These communities provide not only housing but also organized social events, dining facilities, sports facilities, special interest clubs, outings, and vacation opportunities. They also provide home care services, nursing home services, adult home services, and access to physicians and other professional services.

CCRC residential and health care services include:

- independent housing, meals, social activities, scheduled transportation, housekeeping and maintenance;
- access to physician, prescription drug, and rehabilitation services;
- supportive housing and services provided in an adult home, an enriched housing setting, or an assisted living residence (not all CCRCs are required to provide this intermediate level of care, check before your relative moves to the CCRC); and
- skilled nursing facility (nursing home) care for residents who become temporarily ill or who require long-term care. Nursing home care may be provided in an on-site or off-site nursing home affiliated with the CCRC. Life-care communities, a type of CCRC, provide unlimited nursing home care for life. Other CCRCs provide more limited nursing home care but all CCRCs must provide at least sixty days of nursing home coverage.

Typically, CCRCs include small homes or apartments for independent living and an intermediate care facility, but no home health care. Intermediate care residences, such as adult homes, are not legally required and may not be included in some CCRCs.

A CCRC should offer a progression of living arrangements through which residents can move as their need for support services increases, allowing residents to age in place within the community.

To find out if there is a CCRC in your area, visit the Department of Health directory ([DOH CRCC DIRECTORY](#)).

How widespread is this option?

CCRCs are not a readily available option in New York. As of 2013, there are only 12 certified CCRCs in the state of New York and none of them are located in New York City.

Do CCRCs guarantee long-term health care for life?

Most CCRCs in New York are life-care communities that provide residents with housing, supportive services, and needed nursing home care for the remainder of their lives. These communities offer life-care contracts, which must include unlimited stays in an on-site or off-site nursing home. Life-care contracts are called “Type A” contracts.

CCRCs may also offer modified, or “Type B” contracts, which include only limited nursing home care (but all CCRCs must provide at least 60 days of nursing home care).

Before your relative moves into any CCRC, make sure you understand whether the CCRC offers a Type A unlimited contract or a Type B limited contract.

Is my relative a good candidate for a CCRC?

Typically, CCRCs appeal to independent seniors who are in reasonably good health, financially well-off, and willing to invest in the community in return for residential and health care services and a permanent place to live. Residents must be living independently when they apply to enter the community. The CCRCs

operating today are expensive and require a substantial financial investment.

How is care in a CCRC financed?

Residents pay for CCRCs with entrance fees and monthly fees that cover the costs of housing, services, and health care. Costs will vary, depending on the size, location, and luxury level of the housing but, as of 2013, CCRC entrance fees range in price from approximately \$200,000 to \$1 million and monthly fees range from \$2,000 to \$5,000. Some initial fees include the purchase of the housing unit as a coop or condominium.

Do residents need health insurance?

CCRC residents must have Medicare Parts A and B. Long-term care insurance is not required. Medicare and private insurance benefits are used to cover health care costs when they are needed.

How are CCRCs regulated?

To file a complaint regarding a CCRC with the New York State Department of Health, call the Adult Home Complaint Hotline at (866) 893-6772.

Certified CCRCs are subject to relatively strict oversight. The Department of Health and the Department of Financial Services share oversight responsibility. If housing units are coops or condominiums, review by the Attorney General is also needed. The Continuing Care Retirement Community Council gives final approval of applications to establish New York State CCRCs.

Promotional materials and contracts must meet disclosure requirements. Operators are required to maintain reserve funds and to make financial and other information available to residents.

Are all CCRCs certified?

If a community in New York State calls itself a life-care community or a continuing care retirement community, it must be certified by the New York State Department of Health. Some uncertified retirement communities resemble CCRCs but include no contractually

guaranteed health care services. Residents in uncertified communities must separately arrange and contract for any services that they may require now or in the future. These communities are sometimes called Multi-level Retirement Communities and are often are operated by providers with corporate or informal connections to health care providers.

As a practical matter, these “look-alikes” may offer easy access to long-term health care but, as a legal matter, the care cannot be pre-paid or guaranteed. The consumer protections imposed on certified CCRC providers do not apply and, as a result, residents must rely only on the provisions of their contract with the community.

ADULT CARE FACILITY RESOURCES

Coalition of Institutionalized Aged and Disabled (CIAD)

425 East 25th Street, New York, NY 10010; (212) 481-5149

CIAD is an advocacy organization that helps adult home residents organize resident councils. It also helps councils address problems with care and other services in adult homes. CIAD can assist prospective adult home residents, their families, friends, and other advocates in evaluating homes.

<http://www.ciadny.org/>

HealthAdvocates for Older People, Inc.

at Grace Institute, 1233 Second Avenue, New York, NY 10065; (212) 980-1700

This community-based organization publishes a web-based comprehensive resource guide for finding senior housing in New York City. The guide also has excellent descriptions of the various types of adult care facilities available in New York and a directory to find each in New York City.

http://hafop.org/pdf/HAFOP_SeniorHousingOps2012.pdf

LawHelp.org

This organization provides high-quality online information about free legal services and about legal rights in a broad range of substantive areas, including adult care facilities.

<http://www.lawhelp.org>

New York City Department for the Aging (DFTA)

2 Lafayette Street, New York, NY 10007; call 311

This is the New York City local Area Agency on Aging. DFTA publishes web-based borough-specific guides on alternatives in senior housing. Guides include explanations of the different housing types available to seniors. DFTA also lists appropriate borough contact information for adult homes, enriched housing programs, ALRs, ALPs, Mitchell-Lama housing designated for the elderly, public housing built for the elderly, and Section 202, Section 8, and SROs for the elderly.

<http://www.nyc.gov/html/dfta/html/benefits/housing.shtml>

http://www.nyc.gov/html/dfta/downloads/pdf/publications/housing_manh_010313.pdf

New York State Department of Health (DOH)

Corning Tower, Empire State Plaza, Albany, NY 12237; Adult Care Facility
Complaint Hotline (866) 893-6772

The DOH publishes excellent consumer information on issues relating to adult care facilities, including adult homes, enriched housing programs, assisted living residences, and continuing care retirement communities.

<http://www.health.ny.gov/>

Visit http://www.health.ny.gov/facilities/adult_care/ for a directory of adult care facilities and general information about adult care facilities operating in New York State.

New York State Office for the Aging (NYSOA)

New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12223;
Senior Citizens Help Line (800) 342-9871

The NYSOA administers programs and services that help older adults maintain their independence with programs such as senior housing, personal care, home and congregate meals, transportation assistance, caregiver assistance, and health promotion and prevention programs. NYSOA has a guide on licensed adult care facilities in New York State.

<http://www.aging.ny.gov/Housing/Options/Index.cfm>

New York State Office of Long-Term Care Ombudsman Program (LTCOP)

New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12223;
Senior Citizens Help Line (800) 342-9871

The LTCOP assists residents of adult homes and nursing homes in most parts of the state. To find your local ombudsman, use the LTCOP Directory:

<http://www.ltcombudsman.ny.gov/whois/directory.cfm>

Social Security Administration

(800) 772-1213

To find your local office: [SSA Locator](#).

For information about Supplemental Security Income (SSI):

<http://www.ssa.gov/pubs/11000.html>

For information about Social Security Disability:

<http://www.ssa.gov/pgm/disability.htm>

**THIS CHAPTER
INCLUDES THE
FOLLOWING:**

**A general
introduction to
nursing homes**

**Information on how
to place your
relative in a
nursing home,
whether from a
hospital, from
home, or from out-
of-state**

**Information about
veterans and long-
term care**

**Medicaid
applications and
appeals**

**NOTE: This chapter
should be read
together with
[Chapter Four](#), which
covers the cost of
long-term care and
how to pay for it,
and [Chapter Five](#),
which gives
detailed
suggestions on how
to evaluate nursing
homes. We hope
that these three
chapters will help
you make an
informed,
satisfactory choice.**



HARD CHOICES: WHEN A NURSING HOME BECOMES NECESSARY

For many of us, the thought of someone we love living in a nursing home is difficult to accept. But you may discover that the kind of medical care your relative needs, day in and day out, just can't be given at home or would make impossible demands on your own life. Also, for any number of reasons, the alternative forms of care discussed in Chapters One and Two — like home care, supportive housing, or assisted living — may not work for your family. Even if you are starting to accept nursing home placement as inevitable, you may run out of time to think about the best choice: many nursing home placements are made under pressure, directly from a hospital after a health crisis. This chapter will help you to plan for care in advance, so you can hopefully avoid this kind of rushed decision about your relative moving into a nursing home.

When to consider nursing home care for your relative depends on her health, her living situation, and the people needed to provide her care. Has she just been admitted to the hospital — due to a fall, a stroke, or other sudden and serious illness? Does she need around-the-clock skilled nursing care that can't be provided at home? If she lives alone, would she benefit from a more protective and sociable setting? Has a family caregiver gotten sick herself or is she facing new burdens caring for a child or husband?

The decision is difficult and so is the work of finding a home that meets your relative's needs and is convenient for you to visit. Unfortunately, when an emergency arises, most families aren't prepared to make informed choices. Keep in mind that the need

The topic of how to select a nursing home is discussed in greater detail in [Chapter Five](#), but, if you want to compare nursing homes in your area, consider the user-friendly tool provided by the Center for Medicare & Medicaid Services ([CMS NH COMPARE TOOL](#)). This tool contains comparative quality of care information on over 15,000 Medicare- and Medicaid-certified nursing homes nationwide. Also consider the New York State Department of Health's comparison tool ([NYS DOH NH COMPARE TOOL](#)). This tool contains comparative quality of care information on New York nursing homes.

See [Chapter Seven](#) for a more detailed discussion of how you can be an effective advocate for your relative.

for your relative to move into a nursing home may be sudden and unexpected. The more you can find out in advance about nursing homes, financial planning for eldercare, and programs that serve the frail elderly, the better chance you will have of your relative ending up in a facility well-suited to her needs.

This decision takes an emotional toll on everyone involved. Family members may feel guilty about not doing enough to keep their relative at home, even when that is not a realistic option. They may feel criticized by others in their community who know very little about the family's actual situation.

If your relative cannot be cared for safely at home, allowing fear and guilt to avoid or delay nursing home placement could jeopardize her health. Most elderly people are frightened by the idea of losing their independence; many feel depressed or angry that family and friends are “getting rid” of them. Reassure your relative that you will continue to love her and be involved in her care.

If you have been your relative's primary caregiver, be prepared to change roles when she moves from her home or a hospital to a nursing home. More than ever, you will be her contact with the outside world. If she values the intimacy of your personal caregiving, you will have to find new ways to continue that emotional tie. From now on, you will be monitoring her nursing home care. This means staying informed about her care needs, the home's services, and the grievance mechanisms available at the home. You may want to join (or start) a group or organization with other families of residents at the nursing home — called a family council — and work to make the facility better for all residents.

Remember to involve your relative in the decision-making process as much as possible. She may be depressed by the idea of going into a nursing home, but it could be worse to keep the plans a secret until the last moment. If you think you need help dealing with the emotional and psychological aspects of these issues, talk to the hospital or nursing home social

worker.

NURSING HOME PLACEMENT: AN OVERVIEW

What is a nursing home?

Nursing homes are *skilled nursing facilities*, which must provide around-the-clock registered nursing, social services, recreational activities, and physical, speech, and occupational therapies. They can be for-profit, not-for-profit, or publicly owned. In New York, they are licensed and inspected by the New York State Department of Health every 9 to 15 months.

See [Chapter Five](#) for a more detailed discussion on the issues you should consider when selecting a nursing home.

What should I look for when choosing a home?

While we consider this question in detail in Chapter Five, bear in mind that the home you choose should have the services your relative needs, a style she finds comfortable, and a location that makes it easy for you, other relatives, and friends to visit.

How does my relative get into a home?

Your relative must demonstrate a medical need, or medical eligibility, for nursing home care. She must apply for admission to a particular home and the home must accept her.

Who establishes medical eligibility for my relative?

If your relative is hospitalized, her doctor should discuss the best options for caring for her, which may include placement in a nursing home after discharge. The hospital staff will then evaluate your relative's medical needs. The evaluation can be paid for privately or through Medicaid. If your relative is still at home, you will have to arrange for qualified professionals to do the evaluation.

For more information about transfer and discharge, visit [DOH TRANSFER & DISCHARGE](#).

If you want to appeal a discharge or transfer from a New York Nursing Home, contact the New York State Department of Health's Nursing Home Complaint Hotline at (888) 201-4563. You can also file a nursing home complaint using this online form, [NURSING HOME COMPLAINT FORM](#), or you can print the form and mail it to: New York State Department of Health, DRS/SNHCP, Mailstop: CA/LTC, Empire State Plaza, Albany, NY 12237

The Alzheimer's Association publishes a guide on selecting a nursing home ([ALZ GUIDE](#)). See [Chapter Five](#) for a discussion on how to evaluate nursing home services for people with dementia.

Can someone go into a nursing home for just a short-term stay?

Yes. Many people need to spend a short period of time in a nursing home to recover from a stroke, an operation, or an acute illness. This is called sub-acute care and is often for rehabilitation. Most short-term rehabilitation care and sub-acute care is provided on separate floors or separate units of nursing homes and is covered by Medicare.

What if my relative is admitted to a home for short-term care but needs to stay longer than anticipated?

New York regulations treat admission for rehabilitation or sub-acute care the same way as other nursing home admissions. This means that the home cannot discharge your relative, as long as: 1) the home can provide her with the proper care, 2) the home has been paid for her care, and 3) she continues to need long-term nursing home care, even if her stay was originally intended to be short-term. **Although some facilities may tell you that your relative is only being accepted for short-term care and will have to move to another nursing home for a long-term stay, they cannot make her leave. You can appeal an attempt to force your relative to move but a formal appeal is rarely necessary. Letting the home know you are aware that your relative can stay is usually enough.**

If my relative has Alzheimer's disease, is a nursing home appropriate?

In most nursing homes, at least half of the residents have some type of cognitive impairment due to Alzheimer's disease, other dementias, or stroke. While some New York nursing homes have developed special services or special units for these residents, there are no state regulations that specify the kinds of services and staff the homes must have. Also, a special unit, by itself, is no guarantee that the right services are available. If your relative has Alzheimer's disease but doesn't have any additional medical needs, it may be difficult to find a nursing home willing to take her.

See [Chapter Two](#) for information on less institutional housing options, some of which offer only supervision and daily living assistance and some of which also offer medical care.

Once my relative is medically eligible, can she get into any home she wants?

In practice, it may be difficult to place your relative in the nursing home of her choice. Most well-run facilities have more applicants than they have beds. Because they can pick and choose, home administrators usually prefer to admit private-pay applicants and those with higher care needs, which, in turn, earn them higher Medicaid-reimbursement rates.

Sometimes, homes turn down applicants while holding beds open for more desirable applicants. For example, the home may be reluctant to admit your physically healthy relative who needs constant, relatively low-skilled care because of Alzheimer's disease or a similar condition. A bed-bound patient who needs round-the-clock physical assistance is more financially appealing to a nursing home and would likely be chosen first for the bed.

Are nursing homes free to accept or reject applicants on any grounds?

Federal law prohibits discrimination by nursing homes on the basis of race, color, national origin, sex, disability, and religion. A limited exemption to the prohibition against discrimination based on religion may apply to voluntary or non-profit nursing homes that are sponsored by a religious organization. State and local laws in some states, including New York, provide additional protections. Nursing homes should also accommodate the language, cultural, social, and dietary habits of all of their residents as part of the individualized care that the law requires.

Visit [VA INCOME THRESHOLDS](#) to learn more about VA income thresholds. You can also call (877) 222-VETS with enrollment and eligibility questions.

If my relative is a veteran, does the Department of Veterans Affairs provide long-term care services?

Maybe. The Department of Veterans Affairs (VA) health system will provide long-term care services for veterans who are financially eligible based on a priority ranking system, with highest priority given to those with severe service-related disabilities. Some veterans are not permitted to enroll into the VA health care

system because their income exceeds VA thresholds.

What are the long-term care options for veterans?

For more information about Community Living Centers, Community Nursing Homes, and State Homes, and to find VA facilities in your area, visit [VA LONG-TERM INFORMATION](#) and call (877) 222-VETS.

More information about New York's five VA State Homes can be found here: [NYS VA STATE HOMES](#).

There are three types of long-term care settings:

- Community Living Centers (formerly known as VA Nursing Home Care Units) are nursing home facilities located on or close to the campus of a VA medical center. There are often waiting lists for admission to Community Living Centers.
- Community Nursing Homes (CHNs) are public or private nursing homes that admit veterans whose care is paid for by the VA.
- State Homes are care facilities administered by the state and subsidized by the VA. At a State Home, a veteran may have to pay a percentage of the cost. In 2013, there are five New York State VA State Homes, including a New York City home located in Jamaica, Queens and a Long Island home located in Stony Brook.

MEDICAL ELIGIBILITY: THE PRI, THE SCREEN, MDS, AND RUGS III

What is the "Patient Review Instrument" (PRI) and how does it help establish my relative's medical eligibility for placement in a nursing home?

You can see the New York State PRI form here: [NYS PRI FORM](#).

Any individual applying to enter a New York State nursing home must have two assessments completed *before* admission to the nursing home. These assessments are known as the Patient Review Instrument (PRI) and the SCREEN (SCREEN).

The PRI is completed first, because a valid PRI is necessary to complete the SCREEN. The PRI is a more comprehensive assessment than the SCREEN. The PRI is used to assess selected physical, medical, and cognitive characteristics of the future nursing home resident in order to determine the level of care and the type of services the patient will require in the nursing home. The PRI includes assessment items in each of

the following general areas:

- **Administrative Data**, used to identify and track both the patient being assessed (name, Social Security number, date of birth, etc.) and the facility in which the assessment takes place;
- **Medical Conditions and Treatments**, whether or not the patient has any of eleven conditions (for example, whether or not the patient has diabetes or a urinary tract infection), and whether or not the patient is receiving any of thirteen medical treatments (for example, wound care, transfusions, etc.);
- **Activities of Daily Living (ADL)**, the degree to which the patient is independent in each of four areas: eating, mobility, ability to transfer between positions (for example, move from bed to chair), and toileting;
- **Selected Behaviors**, the frequency with which the patient has exhibited any of the following behaviors: verbally disruptive, physically aggressive, disruptive or socially inappropriate behavior, or has had hallucinations;
- **Specialized Services**, the frequency and level of any physical or occupational therapies and the frequency of physician visits during the past month;
- **Diagnosis**, the medical condition that requires the largest amount of nursing time; and
- **Plan of Care Summary**, any additional clinical information that may be needed for the pre-admission review of the patient, including the prognosis for each diagnosis, rehabilitation potential, medications, and treatments.

What is the scoring process for the activities of daily living (ADL)?

As part of the ADL assessment, the assessor will generate a numerical score, which reflects the patient's relative level of independence and how much assistance or supervision she needs with the four ADLs: eating, mobility, ability to transfer between positions (for example, move from bed to chair), and toileting. Your relative will be given a score for each of the four ADLs based on whether she was able to perform the ADL in 60% or more of her attempts during the past week (since ADL status may fluctuate over time).

Who can complete the PRI?

The PRI may be completed only by assessors who have qualified through the New York State Department of Health's PRI Training Program. Usually, hospital discharge planners, certified home health care agency registered nurses, nursing home registered nurses, county public health nurses, and other utilization review personnel are qualified to seek PRI training and to conduct PRI assessments.

What is the "SCREEN" (SCREEN) and how does it help establish my relative's medical eligibility for placement in a nursing home?

You can see the New York State SCREEN form here: [NYS SCREEN FORM](#).

The SCREEN is completed after the PRI and is required before any admission into a New York nursing home, for any length of stay. The SCREEN currently serves two purposes. The first purpose of the SCREEN is to determine if a person is able to be appropriately cared for in a setting other than a nursing home. The second purpose of the SCREEN is to perform an evaluation process known as the Level I Preadmission Screening and Resident Review (PASRR). The PASRR screens the potential resident for possible mental illness and/or mental retardation or developmental disabilities. If any of these conditions are found, a more comprehensive Level II PASRR evaluation is performed to determine the patient's needs to manage these conditions.

In order to complete the SCREEN, the person completing the SCREEN must review a current PRI (one that has been completed within the last 90 days and reflects the patient's current status). The person completing the SCREEN may also use as many additional sources of data as are relevant and available. This might include observation, documentation, or verbal communication with the patient, her health care providers, and/or her relatives.

There are four sections to the SCREEN. The first section of the SCREEN is identifying information for the patient being evaluated. The second section is used to determine the patient's potential for placement in a community setting rather than a nursing home. The third section is the Level I PASRR review for mental illness and/or mental retardation or developmental disabilities. The fourth section makes recommendations for placing the patient (i.e., care in the community or placement in a nursing home) based on the results of the first three sections of the SCREEN.

Who can complete the SCREEN?

The SCREEN can be completed only by health care professionals who have completed the New York State Department of Health SCREEN Certification Course and who have been issued a ten digit SCREENER identification numbers.

What is the "Minimum Data Set" (MDS) and how does it help assess my relative's suitability for nursing home care?

For more information about the MDS assessment and RUGS-III categories, visit the website of the Center for Medicare & Medicaid Services ([CMS MDS INFO](#)).

The Minimum Data Set (MDS) is an assessment tool that Medicare/Medicaid-certified nursing homes are required to use both upon the admission of a new resident and periodically thereafter. In fact, if a nursing home is Medicare/Medicaid-certified, the facility must complete MDS assessment forms for all of its residents and not just for Medicare/Medicaid patients. The MDS provides a comprehensive assessment of each resident's functional capabilities and helps nursing home staff identify health problems.

As part of the MDS, nursing homes develop Resident Assessment Protocols (RAPs) for each resident, and these RAPs are used to formulate each resident's individualized plan of care.

The MDS assessment covers the following areas:

- resident demographics;
- customary routine;
- cognitive patterns;
- communication/hearing/vision patterns;
- psychosocial well-being;
- physical functioning and structural problems;
- continence;
- disease diagnoses and health conditions;
- oral/dental/nutritional status;
- skin condition;
- activity pursuit patterns;
- medications;
- special treatments and procedures;
- discharge potential; and
- influenza and pneumococcal vaccine immunization status.

What is the “Resource Utilization Group” Classification System (RUGS-III) and how does it help assess my relative’s suitability for nursing home care?

The RUG-III classification system uses MDS assessment data on health, functional status, cognition, and service use to classify nursing home residents into mutually exclusive groups. Each of these groups then receives a score to represent how much direct care that group is expected to require as compared to the other groups.

As part of completing the MDS assessment, the nursing home will use the information collected on your relative's health, functional status, and cognition to sort her into one of 53 RUGS-III groups. It is important to realize that the nursing home receives a higher or lower reimbursement from Medicaid depending on which RUGS-III group your relative is

placed. In sorting your relative into her RUGS-III group, the nursing home will consider information regarding your relative's nursing needs, her need for help with the activities of daily living (ADL), her cognitive status, her behavioral problems, and her medical diagnoses.

RUGS-III groups are organized in a hierarchy so that residents with more specialized nursing requirements, licensed therapy requirements, or greater ADL dependency are assigned to the higher groups in the RUG-III hierarchy than residents who have fewer needs.

The RUG-III classification system has eight major classification groups, with the categories arranged from highest to lowest needs:

EIGHT MAJOR RUG-III CLASSIFICATION GROUPS	
MAJOR RUG-III GROUP	CHARACTERISTICS ASSOCIATED WITH MAJOR RUG-III GROUP
Rehabilitation Plus Extensive Services	Residents receiving physical, speech, or occupational therapy AND receiving IV-feeding or medications, suctioning, tracheostomy care, or ventilator/respirator care
Rehabilitation	Residents receiving physical, speech, or occupational therapy
Extensive Services	Residents receiving complex clinical care or with complex clinical needs such as IV feeding or medications, suctioning, tracheostomy care, ventilator/respirator care and comorbidities that make the resident eligible for other RUG categories

Special Care	Residents receiving complex clinical care or with serious medical conditions such as multiple sclerosis, quadriplegia, cerebral palsy, respiratory therapy, ulcers, stage III or IV pressure ulcers, radiation, surgical wounds or open lesions, tube feeding and aphasia, fever with dehydration, pneumonia, vomiting, weight loss or tube feeding
Clinically Complex	Residents receiving complex clinical care or with conditions requiring skilled nursing management and interventions for conditions and treatments such as burns, coma, septicemia, pneumonia, foot infections or wounds, internal bleeding, dehydration, tube feeding, oxygen, transfusions, hemiplegia, chemotherapy, dialysis, physician visits/order changes
Impaired Cognition	Residents having cognitive impairment in decision-making, recall and short-term memory.
Behavior Problems	Residents who: wander; engage in verbally abusive, physically abusive, or socially inappropriate behavior; or experience hallucinations or delusions
Reduced Physical Function	Residents whose needs are primarily for activities of daily living and general supervision

These eight major RUGS-III categories are further broken down into 53 individual groups based on resident ability to complete ADLs as well as other factors like signs of depression or infection.

Why are RUGS-III categories important?

Your relative's RUGS-III category helps determine how much money the nursing home will receive from Medicaid. Nursing homes are paid a daily dollar amount depending on the resources (the time of physicians, therapists, and staff, as well as medical equipment and supplies required) that a resident is expected to use. This means that if a nursing home has many residents assigned to high RUGS-III categories, it will receive more Medicaid money than if most of its residents are assigned to low RUGS-III categories. Nursing homes use RUGS-III categories to help make admission decisions. For example, if the admissions director at the nursing home calls your relative a "PA1," this means that she is in the "Reduced Physical Functioning" category with a low ADL score. (This is a common score for an Alzheimer's patient who doesn't require a lot of medical care.) A "PD2" is someone in that category who has a higher ADL score because of more significant medical needs. Because of the higher Medicaid reimbursement, your relative will be a more attractive applicant to a nursing home if she is a "PD2" and a relatively less attractive applicant if she is a "PA1."

Should the family take part in completing the PRI, the SCREEN, and the other assessments?

Yes. It helps to provide as much information as possible to the person completing the forms because she may be seeing your relative for the first time. The greater your relative's care needs, the easier nursing home placement will be. So make sure the person evaluating your relative has a true picture of her physical and mental health and, especially, of her ability to function. If the evaluator sees your relative when she is having a particularly good day, explain what her condition is most of the time. If your relative's primary diagnosis is dementia and she is relatively healthy physically, it would be advisable to have the assessments completed by a nurse familiar with the special needs of patients with dementia.

What can be done if you disagree with the assessments?

Sometimes assessment forms prepared by a hospital or nursing home (for transfer to another home, for example) will not accurately reflect your relative's condition. A discussion with the professional who did the assessment may bring a better understanding. You may also pay privately for a PRI and SCREEN by a certified evaluator that you hire.

Next Step in Care, a service of the United Hospital Fund, has information, consumer guides, and checklists for caregivers of people are transitioning from a hospital to a nursing home ([NEXT STEP](#)).

PLACEMENT FROM THE HOSPITAL

What does discharge planning involve?

If your relative is hospitalized, as her health improves the hospital will begin to make plans for a safe discharge that will provide your relative with proper health care after she leaves the hospital. Throughout this process, hospital staff must inform your family about the discharge plans and respect your preferences about nursing home care. You and your family have the right to help the discharge planners make decisions about your relative's post-hospital care. If you don't know much about nursing homes, though, you will have to work quickly. You also may have limited choices.

If your relative requires nursing home placement, hospital staff will fill out pre-admission medical evaluation forms (like the SCREEN and PRI) and make all other necessary arrangements, if you haven't already done so. The hospital is also responsible for sending your relative's PRI to several nursing homes or for finding a nursing home that will accept your relative upon her release from the hospital.

Who is usually responsible for the discharge planning?

A hospital staff member, usually a social worker or nurse, is responsible for the discharge planning. The discharge planner's role is to make sure that there is a plan for adequate care in place (whether at home, in an adult home, or in a nursing home) when your relative

is ready to leave the hospital.

Do hospital discharge planners help with Medicaid applications?

See [Chapter Four](#) for a detailed discussion of the transfer of assets and the Medicaid look-back period.

The discharge planner will submit an application for Medicaid, if necessary. If your relative received Medicaid in the community, the hospital must apply to convert that form of Medicaid (community Medicaid) to institutional Medicaid. If your relative is already on Medicaid and anticipates a short-term placement in the nursing home, she can apply for up to a maximum of 29 consecutive days of nursing home care to be funded by Medicaid without being subject to the penalty or “look-back” period that usually applies for Medicaid nursing home care.

What happens if my relative is hospitalized before we’ve even thought about a nursing home?

Unfortunately, this is what happens to most families. Their relative has a sudden illness or accident, goes into the hospital, and then requires nursing home care immediately after discharge. Insurance reimbursement rules, which are designed to save money, encourage hospitals to limit the number of days a patient can stay in the hospital. Because hospitals want to discharge patients quickly, families will find it especially difficult to arrange for a hospitalized relative to be placed in a home that is everybody’s first choice.

How can our family be involved in the placement decision?

Although it’s difficult to think about discharge plans when your relative is seriously ill and has just been admitted to the hospital, you will have more choices if you do. As soon as possible, assign one family member to work closely with the hospital discharge planner and stay informed about the plans being made.

Why is it important for the family to be involved?

Although good discharge planners try to meet individual needs and respect patient preferences, they are under pressure to find a placement quickly. Without your involvement, the discharge planner may place your relative in a home that is not to your family's liking or even convenient for visiting.

How do we get started?

Find out who is responsible for discharge planning. Talk to the social worker assigned to your relative, if there is one. Also, talk to your relative's doctor, who is responsible for setting the discharge date. If nursing home care is anticipated, discuss what types of medical services will be required, such as rehabilitation, and what special needs or conditions must be considered.

Read [Chapters One](#) and [Two](#) for more detailed information about alternatives to nursing home care.

Are there alternatives to nursing home care after discharge?

Perhaps your relative's needs can be met through home health care or other non-institutional services. If she qualifies for home care, the discharge planner can help set up a home care plan.

How much power does the patient's family have over the placement decision?

You and your relative have the right to notify the hospital of the nursing homes you prefer and the hospital must try to place your relative in these homes before all others. Your relative may not get her first choice, but you can have a strong influence on your relative's placement if you work at it. As soon as possible, begin to:

- Develop a good working relationship with the hospital discharge planner;
- Investigate homes on your own;
- Develop a good relationship with the admission staff at nursing homes that interest you; and

The New York State Department of Health has an informative consumer guide to selecting a nursing home in New York State ([NYS DOH SELECT NH](#)).

- Give the names of acceptable homes to the discharge planner.

To compare nursing homes in your area, use the comparison tool provided by the Center for Medicare & Medicaid Services ([CMS NH COMPARE TOOL](#)). This tool contains comparative quality of care information on over 15,000 Medicare and Medicaid-certified nursing homes nationwide.

Also use the tool provided by the New York State Department of Health ([NYS DOH NH COMPARE TOOL](#)). This tool contains comparative quality of care information on New York nursing homes.

Ask the doctor to delay the discharge date if your relative can benefit from continued hospital care. This gives you more time to search for the home best suited to your relative's needs and to make all the necessary arrangements. Keep in mind that the doctor must be able to medically justify delaying the discharge.

How much time will we have to decide on preferred nursing homes?

Not much — possibly only a few days. In some cases, relatives are told that placement will be made in a particular home the following day. If that happens to you, insist that the hospital give you more time to select homes. However, most discharge planners will try to alert you to the placement plan early on and suggest you begin making a list of homes right away.

What happens if time runs out?

When a patient no longer needs hospital-level medical care, Medicare, Medicaid, and private insurance will not pay the hospital bills unless the patient is waiting for covered medical services in a nursing home or for other follow-up care. At that point, the hospital will be paid at a lower rate for a reduced patient status called "alternate level of care" or ALOC.

Because of the lower reimbursement rate, hospitals work hard to find placements promptly. In addition, Medicaid requires that a patient ready for discharge be placed in the first available nursing home bed within 50 miles of her home. Once a week, the hospital should send your relative's application to the nursing homes she prefers and should follow up with calls to these homes. If no beds are available, you can give the discharge planner the names of additional homes. As soon as an available bed is located, the hospital must place the patient in it or else lose Medicaid reimbursement.

To initiate a complaint about a hospital, call the New York State Department of Health's toll-free complaint line at (800) 804-5447. You can also print this [COMPLAINT FORM](#) and send it to:
New York State
Department of
Health, Centralized
Hospital Intake
Program, Mailstop:
CA/DCS, Empire
State Plaza, Albany,
NY 12237

Visit the IPRO website, [IPRO APPEALS](#), for more information about discharge appeals. Also, hospitals must provide a booklet explaining patients' rights, including discharge appeals. You can see this booklet [here](#). Finally, StateWide, a New York advocacy group, has a Patient's Rights Hotline where you can receive help with hospital discharge problems. Call (800) 333-4374 or visit StateWide on the web [STATEWIDE](#).

If a Medicaid recipient has been waiting for a bed for over 60 days, the Local Department of Social Services can direct that she be placed in a nursing home over 50 miles away. Throughout this process, Medicaid will continue to pay for the hospital care of a patient waiting to go to a nursing home if the hospital has written proof that it is actively looking for an appropriate bed.

APPEALING THE DISCHARGE DATE

What can I do if we are given a discharge date but my relative isn't ready to leave the hospital or we have not arranged an acceptable placement or care plan?

All patients should receive a written notice informing them of their discharge date. If your relative does not receive one, she should request it. When your relative gets her notice, you and your family should protest if the discharge date is too early or if there is no adequate care plan in place. Express your concerns to your relative's doctor and social worker. At the same time, consider filing a formal appeal (see next question). If a lack of an appropriate discharge plan is the issue, you can complain to the New York State Department of Health.

How can I challenge the discharge date?

To discharge a patient, the treating doctor must decide that hospitalization is no longer necessary. You have the right to contest a discharge date or discharge plan. To do this, you must appeal to a peer review organization (PRO) through the hospital. Medicare patients can initiate an appeal by calling IPRO at (888) 880-9976. IPRO also works with the New York State Department of Health to conduct reviews of hospital care provided to Medicaid patients. If your relative is a Medicaid patient, contact IPRO at (800) 648-4776 to initiate a discharge appeal. For all patients, follow the directions on the written discharge notice your relative received setting the discharge date. The PRO will handle the appeal very quickly but you can use that time to work on an acceptable nursing home

placement. If the discharge is approved, your relative will be informed either by telephone or in writing. If your relative remains in the hospital past the official discharge date, her health insurance probably won't cover the stay. If the PRO finds that your relative still needs medical care, however, her hospital stay will be extended.

For help in determining if your relative qualifies for Medicaid, visit the New York State Public Health Insurance Screening Tool ([SCREENING TOOL](#)).

What happens if my relative is ready for discharge before her Medicaid application has been approved?

This happens frequently. Although nursing homes may be reluctant to admit residents not yet approved for Medicaid, they can often be persuaded to accept a patient whose eligibility is clear. If there are difficult issues on the Medicaid application, some families choose to have an attorney file the application. A letter from the attorney showing the evidence to support the application often reassures the nursing home.

If you need help filling out a Medicaid application, visit the New York State Department of Health's help page, [DOH MEDICAID](#), or contact your local Department for Social Services ([LDSS](#)), or call New York Options (Medicaid Enrollment Broker) at (800) 541-2831.

PLACEMENT FROM THE COMMUNITY

How does my relative get into a nursing home if she's not in the hospital?

It's far more difficult, and takes more time, to arrange a nursing home placement from a private home than from a hospital. This is true because hospitals seek to discharge patients as quickly as possible. Because of this, they pressure nursing homes to give hospitalized patients priority over patients who are entering nursing homes from the community.

If your relative is still at home, and her condition is deteriorating, start the nursing home placement process early. You'll have the advantage of being able to wait for an available bed in a preferred home. Keep in mind that the job will be easier and your choices greater if your relative can pay privately for at least several months rather than applying when she is on Medicaid or is Medicaid-eligible. Meanwhile, you'll have to make all the arrangements on your own because there is limited help available in the community. If your relative is already receiving home care or other community-based services, the agencies

To find a geriatric care manager in your area, use the New York Association of Professional Geriatric Care Managers ([LOCATOR TOOL](#)).

involved might help (some adult day care programs housed in nursing homes are bridges to placement in those facilities). Private geriatric care managers can do much of the work for you, but they charge for their time, typically between \$60 and \$150 an hour.

Once we've made a list of acceptable prospective homes, what do we do?

Phone each home to find out their application procedure. Ask the home:

- What application forms are required other than the SCREEN and PRI?
- How often must applications be updated to remain active?
- Is an interview with the prospective resident or family required?

Remember that applications have a way of getting lost, so keep in close touch with the nursing homes to which you have applied. Call each home regularly to find out if there is an opening for your relative and to let the admissions staff know that you are still interested. A new SCREEN and PRI must be completed *every 90 days* until placement.

What do we do next?

What you do next depends on your relative's financial situation. The application process is dependent on whether your relative is:

- receiving Medicaid currently;
- paying privately; or
- eligible for Medicaid once admitted to the nursing home.

To locate a CHHA in your area, consult your local Area Agency on Aging ([AAA Agencies](#)), the New York State Department of Health website, [DOH AGENCY LOCATOR](#), local hospitals, or websites such as the Health Care Association of New York State ([HCA-NYS LOCATOR](#)) or the National Association for Home Care and Hospice Locator ([NAHC LOCATOR](#)).

For help determining if your relative qualifies for Medicaid, visit the New York State Public Health Insurance Screening Tool ([SCREENING TOOL](#)).

If you need help filling out a Medicaid application, visit the Department of Health's help page ([DOH MEDICAID](#)), contact your local Department for Social Services ([LDSS](#)), or call New York Options (Medicaid Enrollment Broker) at (800) 541-2831.

What will the application process be like if my relative is currently receiving Medicaid or will pay privately?

If your relative has a current Medicaid card or is paying privately, have a certified assessor complete the SCREEN and PRI. You can contact a Certified Home Health Agency (CHHA) to find a certified assessor. After completing the SCREEN and the PRI, the assessor will tell you if your relative qualifies for nursing home care. Make several copies of your relative's Medicaid card, SCREEN, and PRI to send along with the nursing home's application form. **If your relative has been receiving home care on Medicaid, check to see if Medicaid approval was for community care only. If that is the case, she will have to apply again to be approved for Medicaid institutional care services.**

How do I proceed if my relative will be eligible for Medicaid once admitted to the home?

You may apply for Medicaid at the same time you are establishing your relative's medical eligibility to enter the home. You can contact a CHHA to arrange for a certified assessor to complete the SCREEN and PRI. After completing the assessments, she will tell you if your relative qualifies for nursing home care. Send several copies of the SCREEN and PRI, along with the nursing home application form, to the homes you are applying to. Then send the completed Medicaid application, supporting documents, the SCREEN, and the PRI to your local Department of Social Services (LDSS). Your relative no longer needs to have a personal interview at LDSS in order to apply for Medicaid but, if you have questions or need help with the Medicaid application, you can call or visit your LDSS. If Medicaid is granted, you will get an acceptance letter with your relative's Medicaid number.

How long does the Medicaid application process last?

Generally, the LDSS should send you a letter notifying you if your relative's Medicaid application has been accepted or denied within 45 days of the date of her

See [Chapter 4](#) for a detailed discussion of the transfer of assets and the Medicaid look-back period.

You can request a fair hearing using an online request form, [FAIR HEARING REQUEST FORM](#), or you can mail or fax the request form to: NYS Office of Temporary and Disability Assistance
P.O. Box 1930
Albany, New York 12201
Fax: (518) 473-6735

application. Unfortunately, this process can be delayed because of backlogs in the LDSS offices. Approval can be delayed even longer if your relative has transferred assets within the period that Medicaid reviews.

What happens if Medicaid is denied?

You will get a letter giving the reasons for the denial. If you believe that Medicaid was wrongly denied or if your relative's financial or medical circumstances have changed, you may appeal by asking for a "fair hearing." In a fair hearing, an administrative law judge will review the LDSS decision to deny your relative Medicaid. The Medicaid denial notice that your relative receives from her LDSS will give you more specific information about how to pursue a fair hearing appeal. A lawyer is not required for a fair hearing but it is wise to get advice from a professional familiar with Medicaid regulations if at all possible.

PLACEMENT FROM OUT-OF-STATE

Can a resident of another state be placed in a New York nursing home?

That depends on the person's finances and medical condition and on the willingness of the nursing home to cooperate. Not all homes are interested in admitting patients from out-of-state but, if you have the paperwork in order, it's worth trying.

What documents will my out-of-state relative need to submit to the home?

You'll need medical records that clearly describe your relative's current functioning level or a New York State PRI form filled out by a medical professional that knows your relative well. Your relative will also need documentation to show that she is no longer a resident of the other state.

Are there any other tips for bringing in a relative from out-of-state?

Don't forget to keep transportation costs in mind. Transportation usually has to be arranged quickly when a bed at a nursing home becomes available. If your relative is too ill to travel by car or plane, the cost of medical air transport may be prohibitive.

If possible, you might first consider having your relative move to your home for a brief period, until nursing home placement has been arranged. If your relative is in transit, you might also offer to pay the nursing home to hold the bed for a brief period of time.

Can my out-of-state relative get Medicaid to pay her nursing home bill in New York?

Your relative cannot apply for New York Medicaid until she is physically in the state. If the Medicaid application is straightforward, you may be able to find a home willing to take her while her application is pending.

NURSING HOME RESOURCES

Alzheimer's Association

225 North Michigan Avenue, Suite 1700, Chicago, IL 60601; (800) 272-3900
Provides training and support to those providing care for people with Alzheimer's disease and dementia. Call or visit the website to find a chapter in your area.

www.alz.org

Publishes an informative guide on selecting a nursing home:

http://www.alz.org/nyc/in_my_community_17490.asp

Also publishes a comprehensive resource list containing sources and strategies for finding, evaluating, and selecting nursing homes:

http://www.alz.org/library/downloads/search_nursinghomedecisions.pdf

Centers for Medicare & Medicaid Services

7500 Security Boulevard, Baltimore, Maryland 21244-1850; (800) MEDICARE
Provides comprehensive information relating to Medicaid and Medicare-certified nursing homes throughout the United States. Also gives detailed information on payment and patient rights and a nursing home checklist to use when visiting nursing homes.

<http://www.medicare.gov/nursing/overview.asp>

Also, visit the CMS Nursing Home Compare tool which provides quality of care information on over 15,000 nursing homes nationwide. Includes: nursing home characteristics such as number of beds, type of ownership and whether or not the nursing home participates in Medicare, Medicaid or both; resident characteristics including percent of residents with pressure sores; summary information about nursing homes during their last State inspection; and Information on the number of registered nurses, licensed practical or vocational nurses, and nursing assistants in each nursing home.

<http://www.medicare.gov/NursingHomeCompare/search.aspx?bhcp=1>

I PRO

1979 Marcus Avenue, Lake Success, NY 11042; (516) 326-7767

Conducts appeals for New York residents covered by Medicare or Medicaid.

Contract I PRO for an appeal if you feel you are being discharged from the hospital too soon. Call (888) 880-9976 for a Medicare appeal. Call (800) 648-4776 for a Medicaid appeal.

<http://www.ipro.org/>

Nassau County Office for the Aging

60 Charles Lindbergh Boulevard, Uniondale, NY 11553; (516) 227-8900

Provides excellent information on the process of selecting and being admitted to a nursing home (including the PRI and the SCREEN).

<http://www.nassaucountyny.gov/agencies/seniors/medical/snf.html>

National Alliance for Caregiving (NAC)

4720 Montgomery Lane, Fifth Floor, Bethesda, MD 20814; 301-718-8444
Conducts research, formulates policy, and provides consumer information regarding family caretakers.

www.caregiving.org

NAC has published *A Family Caregiver's Guide to Hospital Discharge Planning*, a booklet that provides family members with detailed information about discharge planning:

<http://www.caregiving.org/pdf/resources/familydischargeplanning.pdf>

National Association of Professional Geriatric Care Managers (NAPGCM)

3275 West Ina Road, Suite 130, Tucson, AZ 85741; (520) 881-8008

Provides general consumer information regarding nursing homes and other long-term care options. Also provides specific information regarding selecting and working with a geriatric care manager.

<http://www.caremanager.org/>

NAPGCM also has a locator tool that you can use to find a geriatric care manager in your area:

<http://memberfinder.caremanager.org/>

National Transitions of Care Coalition

750 First Street NE, Suite 700, Washington DC 20002; (888) 562-9267

Provides web-based information and tools to guide elders and their caretakers through transitions in care from one health care setting to another (for example, from a hospital to a nursing home).

<http://www.ntocc.org/WhoWeServe/Consumers.aspx>

New York State Department of Health (DOH)

Corning Tower, Empire State Plaza, Albany, NY 12237; Nursing Home Complaint Hotline (888) 201-4563; Hospital Complaint Line (800) 804-5447.

The DOH publishes excellent consumer information on issues relating to patient rights, hospital discharges, transitional care, and evaluating and selecting a nursing home.

<http://www.health.ny.gov/>

Visit <http://nursinghomes.nyhealth.gov/> to use the DOH's tool to find nursing homes in your area and to compare quality of care data for nursing homes operating in New York State.

Visit http://www.health.ny.gov/facilities/nursing/select_nh/docs/select_nh.pdf to read the DOH's consumer guide on selecting a nursing home.

New York State Office of Long-Term Care Ombudsman Program (LTCOP)

New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12223;
Senior Citizens Help Line (800) 342-9871

The LTCOP assists residents of nursing homes in most parts of the state. To find your local ombudsman, use the LTCOP Directory:

<http://www.ltcombudsman.ny.gov/whois/directory.cfm>

New York StateWide Senior Action Council

275 State Street, Albany, NY 12210

Patient Right's Hotline: (800) 333-4374

StateWide is a New York advocacy organization that assists consumers in enforcing their rights in accessing care in hospitals, nursing homes, or through home care. Call the hotline if you or your relative has been: denied emergency treatment, transferred unsafely, denied admission, discharged too soon, or not provided with an adequate hospital discharge plan.

<http://www.nysenior.org/>

United States Department of Veteran Affairs (VA)

810 Vermont Avenue, NW Washington DC 20420; (877)222-8387

The VA provides information about benefits for veterans of the United States armed forces. VA has a general information page about eligibility for the VA nursing home care benefit for veterans.

https://gibill.custhelp.com/app/answers/detail/a_id/1232

VA also has an information page on VA long-term care options.

http://www.va.gov/GERIATRICS/Guide/LongTermCare/Nursing_Home_and_Residential_Services.asp

NO MATTER HOW MUCH TIME YOUR RELATIVE WILL NEED TO STAY IN A NURSING HOME, YOU SHOULD KNOW WHAT OPTIONS THERE ARE FOR PAYING FOR HER CARE. THIS CHAPTER WILL ANSWER IMPORTANT QUESTIONS ABOUT THE FOLLOWING:

Medicare and Medicaid coverage of nursing homes and the differences between them

How to become eligible for Medicaid, including rules about transferring assets and protecting a non-institutionalized spouse's resources

Paying privately for nursing home care

Long-term care insurance policies and what kinds of coverage to expect from them

4

COPING WITH COSTS: PAYING FOR LONG-TERM NURSING HOME CARE

Your relative may have to go into a nursing home when her medical needs can't be met at home or in other health care settings — but given the high cost of nursing home care, paying for it can be a serious problem. Very few people can afford to pay privately for more than a few months. Keep in mind that information in this chapter is based on New York State rules; rules may differ in other states. You should contact your local Area Agency on Aging to find your state's current rules.

Neither ordinary private insurance nor Medicare will cover long-term care in nursing homes. Medicare will pay for short-term rehabilitation and other sub-acute care for up to 100 days in a nursing home, but not for permanent placement. Private health insurance will also often cover a limited short-term rehabilitation. None of these plans, however, cover certain types of custodial care, such as help with eating, bathing, using the toilet, dressing, and walking. These are the most common services provided by nursing homes and home care programs. Long-term care insurance, a growing part of the health insurance industry, may cover some (but not all) nursing home costs. Most people don't have long-term care insurance, because they can't afford the premiums or because they have chronic or pre-existing health conditions and cannot get it. A more complete discussion of insurance issues appears later in this chapter.

Without the means to pay for nursing home care over the long term, most residents apply for Medicaid, the government program that pays for health care when an individual's income and resources cannot cover the costs. Medicaid covers most long-term care in nursing homes. The majority of nursing home residents who

are in a facility for more than a short stay qualify for Medicaid either because they have spent all of their savings on care or because they have planned in advance and have legally protected their assets.

MEDICARE: AN OVERVIEW

Use the Medicare eligibility tool to find out more about Medicare eligibility ([MEDICARE ELIGIBILITY TOOL](#)).

Medicare is the government health insurance program covering most Americans over 65 and many people with disabilities. Part A is free and pays for hospital bills and some home care, hospice, and nursing home services. Part B requires a monthly payment, usually as an automatic deduction from Social Security payments. It covers doctor visits, laboratory charges, and other outpatient hospital services. Anyone eligible for Medicare can choose not to enroll in Part B. Older people not automatically eligible for Medicare can purchase Part A for a monthly fee. Part C is Medicare's managed care plan and Part D is Medicare's prescription drug plan. Medigap policies are offered by insurance companies and provide additional benefits to supplement Medicare.

MEDICARE PROGRAMS	
Medicare Part A	Offered by the government - covers inpatient hospital care and partially covers nursing home care
Medicare Part B	Offered by the government - partial coverage for out-patient care like doctor's visits, medical equipment, and supplies
Medicare Part C	Offered by private companies - managed care alternative to original Medicare; provides Part A and Part B coverage and most plans cover prescription drugs
Medicare Part D	Offered by private companies - optional stand-alone plan (with additional monthly premiums) providing prescription drug coverage
Medigap Policies	Offered by private companies - optional policy (with additional monthly premiums) covering hospital charges and other fees not fully covered by Medicare

Who qualifies for Medicare?

Medicare is available to American citizens and qualified immigrants who are: 65 and older and who receive Social Security benefits; or who are under 65, have a disability, and for two years have been receiving Social Security disability benefits or have kidney failure.

Most documented residents who have lived continually in the United States since August 22, 1996 and some others with special immigrant status are qualified to receive Medicare. The eligibility rules are complex. If your relative is not a citizen, you can get additional information about eligibility for Medicare and other government benefits from the New York Immigration Hotline at (800) 566-7636.

How does Medicare work?

To learn more about your costs as a Medicare beneficiary visit “Medicare Costs at a Glance” [HERE](#).

Medicare works like ordinary health insurance. It pays most medically necessary hospital costs after a deductible has been met. However, Medicare pays only part of the costs of doctor visits and other medical services. The Medicare recipient must pay the rest — through deductibles (a fixed amount that must be paid by the insured person, usually each year, before insurance payments begin), and co-payments (the portion of a bill that the patient is responsible for). The following table shows current amounts of Medicare premiums, deductibles and co-payments:

****For 2013, if your income exceeds \$85,000 (single) or \$170,000 (married), you will pay additional Part B premiums. Visit [HERE](#) to determine your Part B premium.**

The New York State Department of Financial Services publishes detailed information on the Medigap policies available in New York ([NY MEDIGAP](#)).

PART A		2013 RATES
HOSPITALS		
Deductible:		\$1,184/year
Co-Payments:		
Days 1 - 60		\$0
Days 61 - 90		\$296/day
Days 91 - 150		\$592/day
Days 151+		All costs
NURSING HOMES		
Co-Payments:		
Days 1 - 20		\$0
Days 21 - 100		\$148/day
Days 100+		All costs
PART B		2013 RATES
Premium		\$104.90/month (depending on income)**
Deductible		\$147/year
Co-Payment		20% of approved charges

Deductibles and co-payments may be covered in whole or in part by “Medigap” policies sold by private insurance companies.

What is Medigap Insurance?

Medigap, or Medicare Supplement Insurance, is optional, privately purchased insurance. Since Medicare pays for only part of typical health care services, there is a “gap” between Medicare coverage and what you must pay out of pocket to meet your total health care bill. Medigap insurance bridges that gap. It ensures that any medically necessary hospital charges or doctors’ fees not fully covered by Medicare are paid.

In New York State, Medigap policies have been approved to offer 10 different standardized “core packages” of benefits (plans A, B, C, D, F, G, K, L, M, and N – plans E, H, I, and J are no longer available).

The federal government’s Medicare website provides comprehensive information on Medigap policies, including a search tool to find Medigap policies offered in your area ([U.S. MEDIGAP](#)).

Each of these Medigap plans provides some basic core benefits such as covering the cost of some Medicare copayments and deductibles. Some of the plans also provide additional benefits, such as covering additional hospital days when the Medicare benefit is exhausted and/or nursing home coinsurance amounts.

New York requires insurers offering Medigap policies to accept a Medicare beneficiary’s application for Medigap coverage at any time throughout the year. Insurers also may not deny coverage or charge more premiums based on a beneficiary’s health status but may impose up to a six-month waiting period before pre-existing conditions are covered.

Enrolling in a Medicare Advantage Plan (Part C), which is like a HMO or PPO, eliminates the need for Medigap insurance. You will be limited, however, to receiving care from plan healthcare providers.

What is a Medicare Advantage Plan (Part C)?

To learn more about Medicare Advantage Plans, visit [MEDICARE ADVANTAGE](#).

If your Medicare Advantage Plan does not offer drug coverage, consider enrolling in a Part D plan.

A Medicare Advantage Plan is a type of health plan offered by a private company that contracts with Medicare to provide you with all of your Part A and Part B benefits. Medicare Advantage Plans include Health Maintenance Organizations, Preferred Provider Organizations, Private Fee-for-Service Plans, Special Needs Plans, and Medicare Medical Savings Account Plans. If you're enrolled in a Medicare Advantage Plan, Medicare services are covered through the plan and are not paid for under Original Medicare. Most Medicare Advantage Plans offer prescription drug coverage but, if yours doesn't, you can purchase a Part D plan. Every year, during special enrollment periods designated by Medicare, you can switch from either original Medicare to a Medicare Advantage Plan or from a Medicare Advantage Plan to original Medicare.

To find and compare Medicare Advantage Plans in your area, use Medicare's locator tool ([ADVANTAGE PLAN LOCATOR](#)).

Medicare Advantage Plans have grievance and appeal procedures, provide coverage for emergency room care if a "prudent layperson" would consider the situation an emergency, and require doctors to provide patients with complete information about available services and treatments. Medicare PPOs may offer a wider choice of health care providers than Medicare HMOs.

What is Medicare Part D (Prescription Drug Coverage)?

If you have limited income and assets, you can qualify for "Extra Help" from the federal government. The Extra Help program will pay for some or all of your Medicare Part D costs. Visit [EXTRA HELP](#) to learn more and to apply for Extra Help.

Beginning in 2006, anybody enrolled in Medicare (Part A or Part B) is also entitled to enroll in a Medicare prescription drug plan (Medicare Part D). Enrolling in a Part D plan is voluntary, unless you receive prescription drug coverage through Medicaid. If you have enrolled in a Medicare Advantage Plan (Part C), your drug coverage may be included in that plan, and, if so, you should not enroll in a Part D plan.

How do I choose a Part D plan?

To find a Part D plan in your area, use Medicare's locator tool ([PART D LOCATOR](#)). This tool allows you to compare costs of Part D plans based on the prescription medication you take.

Part D plans are offered by insurance companies approved by Medicare. You will pay an additional monthly premium for Part D coverage. If you do not already have prescription drug coverage through another plan, and you want prescription drug coverage, you should enroll in a Medicare Part D plan *as soon as you are eligible for Medicare* or your monthly premiums will be higher if you enroll in a Part D plan later. Because Part D plans are offered by private insurance companies, the plans vary in monthly premiums and in the list of drugs covered. Also, because Part D plans can make changes to their list of covered drugs, there is no guarantee that a particular Part D plan will cover all of the drugs you are taking.

What is the Part D plan coverage gap (the "donut hole")?

In 2013, there were 20 Part D plans offered in New York.

Some of the Part D plans offered in New York have a coverage gap, which is more commonly referred to as the "donut hole." After you (and your Part D plan) have spent a certain amount of money for drugs in a year

Under the Affordable Care Act, the “donut hole” is currently scheduled to shrink every year until it totally disappears in 2020.

(\$2,970 in 2013), *you will have to pay 100% of the costs of your drugs* until you have reached an out-of-pocket threshold (\$4,750 in 2013). At that point, Part D catastrophic coverage will become available. Some New York Part D plans offer some coverage during the coverage gap, so make sure to consider this issue when choosing your Part D plan.

To learn more and to enroll in the EPIC program, visit [EPIC](#).

New York State offers a program, the Elderly Pharmaceutical Insurance Coverage Program (EPIC), to New York seniors with limited income. The purpose of the EPIC program is to provide supplemental coverage for Medicare Part D covered drugs during the coverage gap or donut hole.

MEDICARE COVERAGE OF NURSING HOME CARE

When will Medicare cover nursing home care?

Visit [MEDICARE NH](#) to read Medicare’s official guide to Medicare coverage of nursing home care.

Medicare pays for short-term, post-hospital stays that involve high-level skilled nursing and rehabilitative therapy. If your relative qualifies for skilled rehabilitative therapy or other sub-acute care services, Medicare will cover a percentage of the cost for her first 100 days in a nursing home. Sub-acute care falls between acute hospital care and traditional long-term nursing home services. It includes services like short-term ventilator care, short-term physical rehabilitation, cardiac rehabilitation, IV therapy, and wound management.

Don’t rely on Medicare to pay for long-term nursing home care. Medicare pays nothing for long-term custodial care in a nursing home.

What criteria must be satisfied for Medicare to cover a nursing home stay?

Your relative must have been in a hospital at least three days in a row before going to a Medicare-certified nursing home. She must require additional care for the same condition that she was treated for in the hospital. She must be admitted to the nursing home within 30 days of her discharge from the hospital. A doctor must

certify that your relative needs skilled nursing or skilled rehabilitation services on a daily basis.

If all these conditions are met, will Medicare pay for nursing home care?

Yes. Part A will pay the entire cost of care in a Medicare-certified nursing home, except for doctors' bills, for the first 20 days.

In 2013, for days 21 to 100, Medicare will pay approximately 80% of the cost of care, or all but \$148 a day, the required co-payment. If your relative has private or Medigap insurance, it will pay her co-payment for as long as Medicare continues to cover her nursing home stay. If your relative also receives Medicaid benefits, Medicaid will cover her co-payment.

MEDICARE CO-PAYMENTS FOR NURSING HOME CARE	
Co-Payments:	
Days 1 - 20	\$0
Days 21 - 100	\$148/day
Days 100+	All costs

Who determines whether Medicare will cover a nursing home stay?

The nursing home staff will ask for Medicare coverage by submitting your relative's bill to Medicare. The nursing home may send your relative a warning if it believes that Medicare will not cover her stay. You have the right to insist that the home submit the bill to Medicare anyway, although your relative will have to pay privately if Medicare does not cover her bill.

If Medicare accepts your relative's claim, she will get coverage for up to 100 days, as long as she continues to benefit from the care. Medicare will end its coverage before the 100 days are up if your relative no longer needs skilled care at the level that Medicare approved.

To find out more about Medicare appeals, visit [MEDICARE APPEALS](#) and the Medicare Rights website ([MRC](#)).

What if Medicare denies coverage for nursing home care?

If Medicare denies your relative's claim, she should appeal the decision if you think she meets Medicare's requirements. Follow the instructions on the back of the Medicare denial notice. Call the Medicare Rights Center at 800-333-4114 if you need help.

How does Medicare cover doctors' costs?

Through Part B. After your relative meets her annual deductible, Medicare will cover 80% of the approved charge for almost all Part B services. These include doctor visits, physical therapy, medical equipment and supplies.

What if my relative is covered by a Medicare Advantage managed care plan?

Like regular Medicare coverage, a Medicare Advantage plan will also cover a short-term stay in a nursing home. Like managed care plans in general, this type of plan is more likely to restrict your relative's choice in nursing homes.

What about other managed care plans or traditional health insurance?

Traditional health insurance plans and managed care plans usually cover short-term skilled nursing care in a nursing home. But again, the managed care plans may restrict the choice of homes.

How do I make sure my relative gets the nursing home care Medicare is paying for?

Make sure that the doctor orders the skilled care she needs and find out exactly what medical services have been ordered. Confirm that the care is being provided by the home. If any problems arise, follow up with the doctor and nursing home staff.

The New York State Department of Health has comprehensive information about New York Medicaid ([NYS MEDICAID](#)).

MEDICAID: AN OVERVIEW

Medicaid is the government program that pays for long-term care services for most people who have no other way to pay for them. In New York State, Medicaid covers all nursing home-related costs for those whose incomes are less than the cost of nursing home care, whose other financial assets are under Medicaid's allowance levels, and who meet Medicaid's other eligibility requirements.

How does my relative qualify for Medicaid in a nursing home?

To qualify for Medicaid a person must:

- be a citizen of the United States, a legal resident, or a qualified immigrant residing in the United States under color of law;
- have evidence that she resides in New York State (such as a driver's license, voter registration card, mail received at a New York address, or bank statements);
- demonstrate that her income, savings, and other assets are low enough to qualify; and
- show all financial records covering a period of five years that explain what happened to savings and other assets she owned in the recent past.

If your relative's financial situation is not complicated, the nursing home that accepts her will take care of the Medicaid application for your family. If her financial situation is complicated or there are questions about her eligibility, it is important to talk with an elder law attorney.

PROGRAM	FAMILY SIZE	INCOME LIMITS	RESOURCE LIMITS
Community Medicaid	1	\$800/month + \$20/month	\$14,400 + \$1,500 burial fund + home + car
	2	\$1,175/month + \$20/month	\$21,150 + \$1,500 burial fund (each person) + home + car
Institutional Medicaid			\$14,400 + \$1,500 burial fund
Community Spouse Income and Resource Allowance		\$2,898/month	the greater of \$74,820 and ½ of the couple's total combined assets up to \$115,920

MEDICAID COVERAGE OF NURSING HOME CARE

How does Medicaid pay the nursing home?

If your relative becomes Medicaid-eligible, she pays the nursing home any income she has — minus allowable deductions. Medicaid then pays the home the difference between your relative's income and the Medicaid-approved nursing home rate.

Nursing homes will create a budget called Net Available Monthly Income (NAMI) showing all income and allowable deductions, including personal allowance money (\$50 per month for Medicaid residents) and Medicare, Medigap, or private insurance premiums. There are special rules for married couples that allow a spouse to keep some income and assets for his or her support.

What if my relative has no income at all?

If she has no income, she will receive a personal allowance from SSI (Supplemental Security Income), and Medicaid will pay the full costs to the home.

Can my out-of-state relative apply for Medicaid in New York?

If you want to move your relative to New York but need Medicaid to pay for her care, you can't apply until she is actually in New York State — and even then, it may take a while to process her claim. You can submit documents, like a postal change of address, that demonstrate she has severed ties to her previous state. If your relative is mentally-confused and a doctor or a legal procedure documents her condition, she is considered a resident of the state in which she is physically present.

See [Chapter One](#) for a more detailed discussion about community Medicaid.

If my relative is already on community Medicaid, does she automatically qualify for nursing home care through Medicaid?

No. If she has qualified only for community Medicaid, she must re-apply for institutional Medicaid by submitting information for the 60 months prior to her nursing home application.

What if my relative needs to go into a nursing home but hasn't yet been approved by Medicaid?

A nursing home may accept someone “pending Medicaid approval” and may ask the family to guarantee payment if Medicaid refuses. Medicaid will pay for the care your relative receives for up to three months before she makes her Medicaid application, as long as she was Medicaid eligible during that time.

Medicaid appeals are discussed in greater detail later in this chapter.

Will Medicaid allow my relative to continue to pay rent or to keep her home if she needs a short nursing home stay?

If the doctor expects your relative to return home within six months, and you provide Medicaid with “adequate medical evidence” that your relative will return home, Medicaid allows your relative to continue to keep her home or to continue making rent payments. Under this situation, your relative is allowed to keep the community Medicaid maximum monthly income (\$800 in 2013) and to keep her home or to pay the rent on her apartment for six months.

How do we show Medicaid that my relative will return home?

If your relative goes into a nursing home for rehabilitation or a short stay and is on Medicaid or is eligible for Medicaid, make sure the social worker or discharge planner files a signed statement from your relative that she intends to return to her home along with her Medicaid application. Also include a letter from your relative’s doctor stating that she is expected to return home within six months. These letters should be sufficient to allow your relative to overcome the presumption that she is entering the nursing home for a permanent stay. Because some discharge planners are not familiar with this rule, you should bring it to their attention and remind them that these letters need to be submitted with the Medicaid application.

If Medicaid rejects your relative’s application to remain on community Medicaid while in a nursing home for a short-term stay, you have the right to appeal the denial. Also, if the application is approved, at the end of six months you can apply for an extension if your relative’s doctor says she is not yet ready to leave the nursing home.

INCOME AND ASSETS RULES FOR MEDICAID

INCOME

Income is the total amount received by the individual or generated by her assets. Examples are earnings, pensions, Social Security, money from annuities, net gains from rents, interest on loans and mortgages, dividends or interest from stocks, bonds, bank accounts, and CDs, cash disbursements from capital gains, or any other kind of recurring money. Medicaid calculates total income per month.

Assets

Assets are items with monetary value or a marketable price — anything that can be converted into money. Assets include money that has been transferred into investments. Assets are separate from income; they include such things as checking and savings accounts, real estate, CDs, stocks, bonds, mutual funds, money market accounts, and life insurance policies.

How much income and other assets can my relative keep if she gets Medicaid for nursing home care?

Your relative will be expected to contribute ALL of her income towards her nursing home care, except for a \$50 per month personal needs allowance. In 2013, your relative may keep \$14,440 in assets but this figure changes annually.

Will my relative's home also be considered an asset?

Your relative's home will be exempt — that is, not considered an asset — as long as it's maintained for her and she says she intends to return home. Medicaid does not allow a resident to keep part of her monthly income to maintain her home indefinitely, except for the six-month exception discussed earlier. If your relative has not indicated an intention to return home from the nursing home, Medicaid can place a lien on her home to recover the money it spends on her nursing home costs. However, Medicaid *cannot* place a

lien on your relative's home as long as it's occupied by:

- her spouse;
- her child under the age of 21, or a child of any age who is blind or disabled; or
- your relative's brother or sister who has lived there for at least one year and who owns part of the home or has contributed to its upkeep.

Even If Medicaid places a valid lien on your relative's home, it cannot force a sale of her home as long as it is occupied by: 1) your relative's brother or sister if they lived in the home for at least one year immediately prior to your relative's nursing home admission or 2) your relative's adult child as long as they lived in the home and participated in the care of your relative for at least two years prior to her admission to the nursing home.

Can my relative set aside money for her burial?

Yes. Medicaid does not count a burial fund as an asset. Up to \$1,500 is exempt. Each Medicaid recipient may establish a burial fund, as long as it is in a separate bank account, which is exempt even if it bears interest.

In addition, your relative can prepay *all* of her funeral expenses provided she places the funds in an irrevocable (unchangeable) burial trust arranged by a funeral director. Funeral homes are familiar with this Medicaid rule and can assist your relative in setting up the trust. It is important to realize, however, that if any money remains in the trust after your relative's funeral expenses have been paid, that money will go to Medicaid to partially reimburse it for benefits it paid for your relative's nursing home care.

What if my relative has no burial fund?

The cash payment of any life insurance policy of up to \$1,500 can be counted as a burial fund.

Will my relative's estate have to repay the government for the Medicaid benefit after she dies?

Medicaid can recover funds from your relative's estate:

- if she received Medicaid benefits after the age of 55 and within 10 years before her death; or
- if a lien was placed on her property, unless there is a surviving spouse, a child under 21, or child who is blind or totally disabled. Medicaid cannot recover funds from the sale of your relative's house if her spouse or her minor, blind, or disabled child is still alive. For this reason, it is important not to distribute the estate to surviving members until Medicaid says it has no claims.

There are a variety of rules and exceptions that complicate Medicaid recovery. Consult an elder law attorney to best understand your situation.

Call the New York State Bar Association's Lawyer Referral and Information Service at (800) 342-3661 for help finding an elder care attorney in your area.

TRANSFER OF ASSETS

You should consult an experienced elder care lawyer about transferring assets or for other advice on financial support of your relative.

If my relative gives her money or property to someone else or places it in a trust, can she qualify for Medicaid?

She might not be able to qualify for Medicaid immediately if she or her spouse has transferred assets for less than their market value. The answer depends on how much money or property was transferred and on the date of the transfer. This will be explained in detail later in this chapter together with a discussion of the "penalty periods" that can result from asset transfers.

"Transfer of assets" rules and "penalty periods" apply only for nursing home care but *not* the Lombardi program and not for home care.

Are there exceptions for assets given to family members?

If your relative transfers assets to her spouse, the transfer will be exempt so long her spouse does not re-transfer the assets to someone else for less than market value before your relative's Medicaid application is approved. Your relative may also transfer assets to her minor, disabled, or legally-blind child and be exempt from the penalty. Finally, your relative may make a penalty-free transfer of her home to: 1) her sibling, if the sibling already partially owned the home and lived in the home for at least one year before your relative entered the nursing home; or 2) her adult child if that child lived in the home for at least two years before your relative entered the nursing home and that child provided care to your relative that allowed her to reside at home rather than in a nursing home.

Are there other exceptions to the transfer of assets rules?

Yes. A transfer will not affect Medicaid eligibility if the asset is transferred for a purpose other than to qualify for Medicaid or if denying Medicaid would create "undue hardship" — that is, if the person would be eligible for Medicaid except for the transfers, she cannot obtain medical care without Medicaid and, despite her best efforts, she cannot obtain return of the money.

If your relative is affected by any of these exceptions, she should consult an elder care lawyer.

How do transfer of assets rules affect someone's ability to get Medicaid for nursing home care?

All transfers of assets and large expenditures made within 60 months prior to the month your relative files her application for Medicaid coverage will be examined. The 60-month period is called the "look-back period." Medicaid reviews your relative's records to see whether she gave away income or assets that she could have used for medical expenses or whether she transferred property for less than fair market value during the look-

back period. If she did either, she will be ineligible to receive Medicaid for a specified period of time after the transfer. The amount of time she is ineligible is called the penalty period. The length of the penalty period depends on how much was transferred, when the transfer was made, and where your relative lives.

If your relative transfers her assets to a trust rather than to another person, Medicaid will still “look back” at the assets transferred within the 60 months before your relative made her Medicaid application.

If my relative has transferred assets, how long will she be ineligible for Medicaid?

Medicaid will determine the number of months that it will deny benefits by doing the following arithmetic. First, Medicaid looks at the amount of any assets transferred for less than market value during the 60 month “look-back period.” Then, it divides that amount by the average monthly cost of nursing home care in your area. The result is the length of the penalty period in months.

For example, if your relative lives in New York City and has transferred \$50,000 to an adult child, Medicaid will divide the \$50,000 by the average monthly cost of nursing home care for New York City, which in 2013 is \$11,350. The penalty period is 4.4 months. During this penalty period your relative will be ineligible to receive any Medicaid coverage of her nursing home care.

When does the penalty period start?

Due to a change in federal and New York law, the penalty period now does not begin to run until the *later* of: (i) the date your relative transferred the assets, and (ii) the date on which your relative is living in a nursing home, has applied for Medicaid, and would have qualified financially for Medicaid if she had not transferred the assets. In other words, if your relative made a transfer within the five-year look-back period, she will face the penalty period once she has exhausted all of her non-transferred funds.

This means that if your relative transferred assets during the look-back period, she will likely have to make two separate Medicaid applications. The first, which will be denied because she is in the penalty period, is nonetheless necessary because it will cause the penalty period to start running and will determine how long the penalty period will last. Once the penalty period expires, your relative should file the second application. She should then be eligible to receive Medicaid coverage as long as she did not make any additional transfers.

The best way to avoid the imposition of the penalty is to plan early! Try to make sure your relative makes transfers of her assets more than five years before she will need to enter a nursing home – there is no penalty imposed for a transfer made before the five-year look-back period.

How do I find out the average monthly cost of nursing home care in my area?

To see the regional rate for each of New York’s counties, visit [DOH NH RATES](#).

New York State determines the average regional cost. New figures are calculated annually based on the average private-pay nursing home rates in each of the following seven regions in New York State. For 2013, these regional rates are:

\$11,350	New York City
\$12,034	Nassau and Suffolk
\$10,737	Northern Metropolitan
\$ 8,432	Central
\$ 8,950	Northeastern
\$ 8,682	Western
\$ 9,782	Rochester

See [Chapter Eight](#) for a detailed discussion about powers of attorney and guardians.

Does anyone have the authority to transfer money for a person who is mentally incapacitated?

In certain circumstances, a guardian or someone holding a power of attorney can make transfers. The power of attorney must explicitly give the power to do this. A guardian must obtain permission from the court before making gifts. Transfers from the funds of a

person who is incapacitated should be made only after consulting an elder law attorney.

How do the rules differ for transfers to trusts?

The rules are basically the same and a transfer of assets to a trust is treated exactly like an outright transfer to another person. The look-back period is still five years and the penalty period is calculated in the same way as with outright transfers.

For more information about permitted asset and resource levels for the community spouse, visit the New York State Department of Health's website [HERE](#).

FINANCIAL RESPONSIBILITY OF THE SPOUSE

If the Medicaid applicant is married, is the applicant's spouse financially responsible for the costs of nursing home care?

Yes. Under New York State Domestic Relations Law, spouses are financially responsible for each other. But a couple does not have to spend all of their resources and income on the care of the spouse in the nursing home. When one spouse needs nursing home care, Medicaid permits the spouse in the community to retain a significant portion of the couple's assets and income.

What financial resources can a married nursing home resident keep in her own name?

The spouse in the nursing home is permitted to have the same assets as an unmarried nursing home resident: \$14,400 (in 2013) plus a \$1,500 burial fund and a prepaid funeral contract. Before applying for Medicaid, or within 90 days of the date of Medicaid acceptance, the nursing home spouse can transfer other assets to her spouse in the community, without penalty.

What happens to the nursing home spouse's monthly income?

First, the nursing home resident gets a monthly personal allowance (\$50) and her health insurance premiums are paid. Depending on the financial situation of the spouse in the community, some or all of the nursing home resident's income may be given to

the community spouse. Any income not given to the community spouse is paid to the nursing home.

What resources can the spouse in the community keep?

In 2013, the law allows the community spouse to keep \$74,820 or half of the couple's assets up to a maximum of \$115,920, whichever is more. This amount, called the Community Spouse Resource Allowance, changes annually. Assets that are held jointly or by the nursing home spouse alone must be transferred into the community spouse's name no later than 90 days after the nursing home spouse's Medicaid application is approved.

Medicaid Fair Hearings can be requested by: Telephone at (800)-342-3334; Fax at (518) 473-6735; On-Line by completing and sending an online request form ([FH REQUEST](#)); or in writing to the Fair Hearing Section, New York State Office of Temporary and Disability Assistance, P.O. Box 1930, Albany, New York 12201.

What income can the spouse in the community keep?

The spouse in the community may keep \$2,898 (in 2013) of the couple's combined monthly income from whatever sources — Social Security, pensions, interest from bank accounts, etc. If the joint monthly income of both spouses is less than \$2,898, the community spouse may keep additional assets (above the \$115,920 level), if any, to generate the allowed income level. The institutionalized spouse can insist that her income from Social Security be used for her care rather than her spouse's income. In this case, the community spouse may keep more assets in order to generate the allowed income level.

If this income isn't enough to live on, the community spouse can request a fair hearing from the state to have the amount increased. He must demonstrate that he suffers *excessive hardship* from circumstances beyond his control. The excessive hardship standard is difficult to meet. Obtaining the assistance of an experienced elder law attorney is essential.

What if the community spouse's monthly income is more than \$2,898?

Unless there is a court order or a fair hearing decision allowing him to keep additional income, he will be asked to contribute 25% of the excess of his income to

the nursing home.

What if the couple has a minor child or other dependents?

There is an additional family allowance available if the couple has minor children, disabled children or siblings, or dependent parents. In 2013, the family allowance was \$631 for each dependent.

What happens if a community spouse refuses to contribute to the nursing home care?

Medicaid cannot deny coverage to a nursing home resident when her community spouse feels he cannot or will not contribute to the nursing home costs from his income or resources. This non-payment is called “spousal refusal.” The community spouse is required, however, to disclose all of his financial information to Medicaid. The institutionalized spouse, when she applies for Medicaid, must give (“assign”) to Medicaid her right to sue the community spouse for support.

Is it likely that the community spouse will get sued?

Given the difficult fiscal situation that New York State is currently facing, it is increasingly common for local governments to pursue community spouses demanding full contribution and threatening a lawsuit. The first step is a letter asking the spouse to meet with social services officials. A community spouse should consult a lawyer before responding. With legal help, it is likely that a compromise will be reached.

PAYING PRIVATELY

What if my relative needs nursing home care and has enough money — at least at first — to pay for it?

If your relative has sufficient income and resources, she will be admitted to the nursing home as a private-pay resident. Private-pay rates vary from home to home, ranging from \$120,000 to over \$150,000 per year in New York City. Nursing home bills use a basic rate for room and board, plus additional charges for doctors’

services, laboratory tests, physical, occupational and speech therapies, and prescription drugs.

Are private-pay rates regulated?

No. Nursing homes may charge private-pay residents whatever they wish. In addition, various extra charges may be added to the basic rate. A private room costs more than a semi-private room. Private-pay rates can be expected to go up at least once a year. Residents are entitled to a written notice 30 days before rates are raised.

See [Chapter Six](#) for more on bed hold policies.

If your relative is paying privately for nursing home care, be sure to read and understand the admissions agreement before she is admitted. The admissions contract should detail all charges above a basic daily rate. Clarify the home's financial policies and the resident's responsibilities toward meeting them. Find out about the home's "bed hold policy" and what is charged to keep a nursing home bed for a resident who is hospitalized.

Can I be required to pay the home if my relative cannot or will not?

The only people who are financially responsible for your relative's care are her and her spouse. Even if they sign a contract promising to pay, the children of a nursing home resident are not financially responsible if their relative is on Medicaid or if the promise was a condition of admission to the nursing home. If, however, you control your relative's finances through, for example, a power of attorney, you must use her money for nursing home costs.

Can nursing homes ask for money as pre-payment or security?

Most homes will ask, **but three months payment is the most they are permitted to collect as security** from private-pay residents. Pre-payment cannot be required of residents who are eligible for Medicare coverage.

Pre-payment used as security must be deposited by the home in an interest-bearing account. If the resident leaves the home or dies, the home must refund any amount paid over the cost of services already provided.

Can a home require a resident to pay private-pay rates for a certain period of time even though she qualifies for Medicaid sooner?

No. If the home accepts Medicaid, it must take the Medicaid rate of payment for the entire period that the resident is eligible for Medicaid.

FINANCIAL DISCLOSURE AND CONTROL

What kind of financial information do nursing homes require of privately paying residents?

Most homes ask for full financial disclosure from residents who will be paying privately. Applicants may be asked to provide savings bank books, checking statements, pay stubs showing earnings, and stock and bond information. This is because many people who enter nursing homes paying privately eventually use up their funds and go on Medicaid. The homes want to know how long residents will be able to pay out of their own pockets.

If I'm asked to, should I make a donation to the home in order to help get my relative admitted quickly?

To find your local Medicaid Fraud Control Unit, visit [AG MEDICAID FRAUD DIRECTORY](#).

It is illegal for nursing home personnel to demand or accept donations from family members to assure placement of a relative, or to secure certain privileges, but the practice persists. We urge you *not* to contribute, even if you can afford to. If a donation is asked for or suggested, report the solicitation to the Office of the Attorney General Medicaid Fraud Control Unit.

Does someone paying privately have the right to control her money?

The law guarantees residents the right to control their financial affairs as long as they are willing and able to do so. If residents prefer, they can assign financial control over their money to a trusted friend or family member.

Should my relative allow the nursing home to hold her money in trust?

Although nursing home administrators sometimes suggest it, it is probably not in your relative's best interests to allow the home to control her finances.

WHEN PRIVATE MONEY RUNS OUT

If my relative is already at a nursing home, can she still apply for Medicaid?

Yes. The nursing home staff, in cooperation with you and your relative, will submit a Medicaid application at your relative's request. Because of delays in processing Medicaid applications, you should ask the nursing home to begin the application process when your relative has only enough funds left to cover two or three months of nursing home care.

Remember: transfer of assets rules will apply to the 60-month look-back period that begins with the month your relative's Medicaid application is submitted.

What if the home's staff refuses to process my relative's Medicaid application?

Insist that they do, even if they claim your relative is ineligible. It is Medicaid's responsibility, not the nursing home's, to determine eligibility. If necessary, however, you or your relative can submit a Medicaid application independently. In fact, it's often best to submit complicated applications in consultation with an elder law attorney without the nursing home's assistance.

If you need help obtaining a Medicaid application or help in completing the application, call New York Health Options at (855) 693-6765.

Mail your completed Medicaid application to your Local Department of Social Services ([LDSS](#)). Residents of New York City can mail applications to the Human Resources Administration ([HRA](#)) at: Initial Eligibility Unit, HRA/Medical Assistance Program P.O. Box 2798 New York, NY 10117

What if my relative's money runs out before Medicaid benefits are granted?

A nursing home may not discharge a resident for nonpayment if her Medicaid application is pending or even if Medicaid has been denied and an appeal is pending. If your relative is financially eligible for Medicaid at the time she applies, Medicaid will pay for medical care provided after the application was submitted but before it was approved. Medicaid can also pay for up to three months of care before the application was submitted, if your relative was Medicaid eligible at that time.

Where can I get an application form for nursing home Medicaid?

You can get a Medicaid application to print and fill out by hand at the website of the New State Department of Health here: [APPLICATION](#). You can also get a Medicaid application by phone, by mail, or in person through your Local Department of Social Services ([LDSS](#)). In New York City, applications can be obtained by contacting the New York City Human Resources Administration at (718) 557-1399. Finally, you can use the "Fill and Print" Medicaid application on the DOH website ([FILL AND PRINT MEDICAID APPLICATION](#)). In any case, make sure you complete the special questions and "Supplement A" to the application, which are specifically directed toward applicants applying for Medicaid coverage of nursing home care.

LONG-TERM CARE INSURANCE

A full explanation of long-term care insurance is beyond the scope of this book. You should seek additional information from the Resources listed at the end of the chapter or from your own financial advisor.

Visit the website of the New York State Department of Financial Services to learn more about long-term care insurance policies ([NYS DFS LTCP](#)).

What is long-term care insurance?

Long-term care insurance, a growing part of the health insurance industry, is a type of insurance specifically designed to cover the costs of long-term care, including the costs of long-term nursing home care. Plans are available to individuals and, through employers and associations, to groups.

The New York State Department of Financial Services (DFS) establishes minimum standards for long-term care insurance policies. DFS has established four different classifications for the long-term care insurance policies that are offered for sale in New York State:

Long-Term Care Insurance	Nursing Home and Home Care Insurance
Provides the broadest coverage of long-term care policies. Policies must cover at least 24 consecutive months of: 1) nursing home care at a benefit level of at least \$100 per day for policies sold in the New York City metropolitan area and \$70 per day for all other parts of the state; and 2) home care at a benefit level of at least 50% of the daily amount provided for nursing home care	Combines the benefit of Nursing Home Insurance Only and Home Care Insurance Only. Best for those who want some coverage for nursing home and home care services but who cannot afford a Long-Term Care Insurance policy. Policies must cover at least 12 consecutive months of: 1) custodial care at a benefit level of at least \$50 a day while confined in a nursing home; and custodial care at a benefit level of at least \$25 per day in a private home

Nursing Home Insurance Only	Home Care Insurance Only
<p>Best for those who:</p> <p>1) have no desire or intention to receive long-term home care services; or</p> <p>2) have the financial resources to self-pay for home care services but desire financial protection against the costs of nursing home care.</p> <p>Not recommended if there is any chance that home care services will be required in the future.</p> <p>Policies must cover at least 12 consecutive months of custodial care at a benefit level of at least \$50 a day while confined in a nursing home</p>	<p>This is a very limited policy. Best for those who either:</p> <p>1) have no desire or intention of entering a nursing home and would be able to obtain long-term care services in their home; or</p> <p>2) already have nursing home coverage and wish to add a home care benefit.</p> <p>Not recommended if there is any chance that nursing home coverage will be required in the future.</p> <p>Policies must cover at least 12 consecutive months of custodial care at a benefit level of at least \$25 per day in a private home</p>

Are there any drawbacks to long-term care insurance?

Yes. Policies set benefits at a specific dollar amount at the time of purchase. For example, a policy purchased in 2013 may have a benefit of \$100 per day. That amount, however, will in all likelihood not cover the costs of care five or ten years from the date of purchase. Even if you pay extra for inflation protection, you cannot be sure it will be enough. In contrast, traditional health insurance benefits are calculated to cover the cost of the services at the time they are used — not when the policy is purchased.

In addition, long-term care insurance benefits are based on today's health care system and may not cover future unanticipated types of assisted living or health care facilities.

Who should consider long-term care insurance?

Most financial planners think long-term care insurance makes sense for people who want to protect sizable

assets, generally at least \$500,000. Policies are expensive, particularly for those that include recommended features, such as inflation protection, and that have realistic benefit levels for all types of care.

People without family or other informal caregivers may find long-term care policies attractive, because they are more likely to use nursing homes rather than home care for long-term health management. This kind of insurance may be less appealing to someone who is willing to “spend down” assets in order to qualify for Medicaid. As a practical matter, an older person with significant health problems may be able to buy long-term care insurance only through a group.

Family members, a financial planner, an attorney, an insurance agent, an accountant, or a tax specialist may help your relative to decide whether long-term care insurance is the right choice, given her needs, goals, and circumstances.

The New York State Department of Financial Services publishes a Consumer Guide on long-term care policies ([LTCP GUIDE](#)).

For a list of insurance companies currently offering long-term care policies in New York State, and the type of long-term care policies offered, see [NYS LTCPs](#).

What should my relative look for when buying a long-term policy?

As with any insurance purchase, she should choose carefully. She should not be pressured into buying before she knows enough to choose wisely. She should start by evaluating her income and resources. She should think about her future needs. Then, she should compare several policies, read the fine print, and ask a lot of questions. The following questions will help start the evaluation process:

- How much will the policy pay for each day of nursing home care and of home health care? If costs in your relative’s area are higher, can she afford to pay the difference?
- Does the policy include benefits for assisted living, adult day care, respite care, an alternative level of care in a hospital, and hospice care?
- Is there a waiting or elimination period before benefits begin? (Since your relative must pay out of

pocket for care during a waiting period, a shorter waiting period is desirable, but will cost more.) Are there separate waiting periods for nursing home care and home care? (A single waiting period is usually best.)

- Is there a maximum benefit period or maximum number of days of coverage for each type of care? Is there a maximum benefit amount?
- Are there limits on the types of providers that can be used? Will the policy pay for a health care worker the family wants to hire who is not from an approved agency? Who determines what is covered and when coverage begins? How do you appeal coverage decisions?

New York State requires that plans offer specified options, but companies may charge for additional benefits. You should ask the insurance salesperson the following questions:

- Is there an inflation-protection benefit (preferably one that is computed by compounding) that regularly raises the original benefit amount?
- Is there a non-forfeiture benefit that lets an insured person recover some of the premiums from a policy she has had for a long time, even after it lapses, if claims have not been made on the policy?
- Are there any illnesses or conditions, such as alcoholism or mental disorders, that are excluded?
- Is the policy qualified for favorable tax treatment, with all the consumer protections that are required for qualified policies?

Can my relative change her mind after she's signed a contract for long-term insurance?

Yes. Under New York State law, the purchaser of a long-term care policy is given a 30 day free-look option. Your relative should take this time to review the contract. If the policy is not satisfactory, she can return

it within the free-look period for a full refund.

The New York Partnership for Long-Term Care has an informative website providing detailed information about Partnership plans: [NYSPLTC](#). Also, visit [PARTNERSHIP PLANS](#) to see a benefit comparison table for Partnership plans and [NYSPLTC BROCHURE](#) to see a Partnership consumer brochure describing the features of Partnership plans.

What is New York Partnership for Long-Term Care insurance?

New York State Partnership for Long-Term Care insurance allows people to purchase a special Partnership-approved long-term care insurance policy that, once the policy is held for the specified period, allows the policy holder to apply for a special Medicaid program called “Medicaid Extended Coverage.”

All partnership plans offer nursing home care, home care, and assisted living care services. All plans also offer inflation protection and are guaranteed renewable (the insured can renew regardless of health status).

The type of Partnership insurance policy your relative should select depends on how much of her assets she wants to protect when she applies for the Medicaid Extended Coverage. There are two types of asset protection available under Partnership plans: Total Asset Protection and Dollar for Dollar Asset Protection:

- Total Asset Protection plans protect all of your relative’s assets. There is no limit to the assets she may keep and still receive Medicaid Extended Coverage. Total asset protection is offered with Partnership long-term care insurance policies that provide three or more years of nursing home coverage. **Premiums on these plans are higher than for Dollar for Dollar Asset plans.**
- Dollar for Dollar Asset Protection plans protect your relative’s assets in an amount equal to the benefits paid out from the Partnership policy. Unprotected assets remain subject to regular Medicaid rules. Dollar for Dollar Asset Protection is available with Partnership long-term care insurance policies offering less than three years of nursing home coverage. **Benefits in these plans are lower than in Total Asset Protection plans.**

MEDICARE AND MEDICAID RESOURCES

Medicaid

Regional Office: Jacob K. Javits Federal Building, 26 Federal Plaza - Room 3835, New York, New York 10278; (212) 616-2400

Provides general information about Medicaid eligibility and plan benefits and exclusions.

<http://medicaid.gov/>

Also provides detailed information about Medicaid long-term care services and support, including institutional care and community-based care:

<http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Long-Term-Services-and-Support.html>

Medicare

7500 Security Boulevard, Baltimore, Maryland 21244; (800) MEDICARE

Provides comprehensive and authoritative information relating to Medicare plan enrollment, benefits, and costs.

www.medicare.gov

Publishes "Medicare & You," the official U.S. government handbook on Medicare:

<http://www.medicare.gov/Publications/Pubs/pdf/10050.pdf>

Use the eligibility tool to determine eligibility for Medicare benefits:

<http://www.medicare.gov/MedicareEligibility>

To find a Medicare plan in your area, use the locator tool:

<http://www.medicare.gov/find-a-plan/questions/home.aspx>

Medicare Rights Center, Inc.

520 Eighth Avenue, North Wing, 3rd Floor, New York, New York 10018; National Helpline: (800) 333-4114

This advocacy organization provides a helpline that you can call to speak to counselors about Medicare plan options, rights and benefits, and advice on getting required care and medications. The Medicare Rights Center also helps Medicare enrollees with payment denials and appeals, complaints about care or treatment, and Medicare bills.

www.medicarerights.org

National Association for Insurance Commissioners (NAIC)

444 North Capitol Street NW, Suite 701, Washington, DC 20001; (816) 783-8300

Offers excellent information to consumers considering the purchase of a long-term care insurance policy. Includes a frequently asked questions section, a buyer's guide, and a quiz to determine if you really need long-term care insurance:

http://www.naic.org/index_ltc_section.htm

National Clearinghouse for Long-Term Care Information

A service of the U.S. Department of Health and Human Services, this website provides excellent consumer information and resources on long-term care. Includes general and state-specific information to help you understand long-term care, plan for long-term care, pay for long-term care, and find long-term care services in your area. Generally, a good place to start when you have any questions relating to long-term care.

http://www.longtermcare.gov/LTC/Main_Site/Index.aspx

New York State Department of Financial Services

One State Street, New York, New York 10004; (800) 342-3736

Provides consumer-friendly information regarding the Medigap and long-term care insurance policies available for sale in New York State.

<http://www.dfs.ny.gov/>

Visit http://www.dfs.ny.gov/consumer/caremain.htm#sub_gen for information on New York Medigap policies.

Visit http://www.dfs.ny.gov/consumer/ltc/ltc_index.htm for basic long-term care insurance information.

Visit http://www.dfs.ny.gov/consumer/ltc/ltc_guide.pdf to see a consumer guide to buying long-term care insurance in New York State.

Visit http://www.dfs.ny.gov/consumer/ltc/ltc_companies.pdf to see a list of insurance companies currently offering long-term care policies in New York State together information about the benefits offered by each company.

New York State Department of Health (DOH)

Corning Tower, Empire State Plaza, Albany, New York 12237; Nursing Home

Complaint Hotline (888) 201-4563; Hospital Complaint Line (800) 804-5447

The DOH publishes excellent consumer information on issues relating to long-term care, including quality of care and reimbursement options.

<http://www.health.ny.gov/>

Visit http://www.health.ny.gov/health_care/medicaid/ for comprehensive information regarding New York Medicaid, including eligibility, asset and resource limitations, application procedure, long-term care coverage, look-back and penalty periods, and community-spouse and spousal-refusal rules.

New York State Office for the Aging (NYSOFA)

2 Empire State Plaza, Albany, New York 12223; Senior Citizens Help Line (800) 342-9871

<http://www.aging.ny.gov/>

NYSOFA administers programs and services that help older adults maintain their independence.

Through its Health Insurance Information, Counseling and Assistance Program (HIICAP), NYSOFA provides free, accurate, and objective information, counseling, assistance and advocacy on Medicare, private health insurance, and related health coverage plans. HIICAP helps people who have Medicare, their representatives, or people who will soon be eligible for Medicare.

<http://www.aging.ny.gov/HealthBenefits/Index.cfm>

New York State Partnership for Long-Term Care

Department of Health, OHIP, ESP, Corning Tower, Room 1970, Albany, New York 12237; (888) NYS-PLTC (697-7582)

<http://www.nyspltc.org/>

Publishes a consumer booklet:

http://www.nyspltc.org/docs/brochure_12_19_12.pdf

Also provides a benefit comparison table for Partnership plans:

<http://www.nyspltc.org/docs/policysummaryhandout.pdf>

**THIS CHAPTER
INCLUDES THE
FOLLOWING:**



INFORMED CHOICES: HOW TO SELECT A NURSING HOME

**General information
about different
types of nursing
homes**

**A four-step plan on
how to evaluate and
choose a nursing
home**

**The best place to
find free and
reliable information
on almost any
nursing home**

**A comprehensive
list of specific
things to look for
when visiting a
nursing home**

Many people enter a nursing home directly from the hospital after a sudden illness or accident. If that is what happens to your relative, your family may face the necessity of finding a nursing home quickly. In this situation, it may be difficult for your relative to get accepted by the home of her choice.

Don't wait until there is a crisis! Learn as much as you can about nursing homes now — before your relative gets sick. There are important differences between facilities that you should be aware of — from the range and quality of medical services available, to the ease of finding a parking place when you visit, to the different types of food served at meals. You should find out which homes offer any special medical therapies or treatments that your relative may need. If she has limited English proficiency, you'll want to make sure there are residents and staff members who speak her language. If short-term rehabilitation care is called for, you must make sure that the facility is able to provide it.

Keep in mind that going into a nursing home doesn't have to mean a total loss of independence. While your relative may not be able to manage aspects of her life, she may still be able to make significant personal choices every day — for example, the kind of food she wants to eat and when, the time she wants to bathe, the activities in which she wants to participate, and the holidays she wants to celebrate. Help preserve her power to make those choices.

You may want to consider visiting some of the nursing homes that are dedicated to “culture change” or to providing “person-centered care.” Person-centered care means that nursing home residents are permitted to

For more information on how to find a nursing home dedicated to culture change, read the Pioneer Network's suggested questions (and the answers to listen for) [HERE](#).

make their own choices, continue familiar routines, and maintain their dignity after moving into the nursing home. A nursing home engaged in the culture-change movement should be dedicated to transforming the home into a place where residents' individual needs and preferences are the core value of operating the home.

As much as possible, you should try to include your relative in the process of selecting the nursing home where she will live. The facility could be her home for many years to come.

This chapter will help you identify the nursing home that's best for your relative — even when the possibilities are limited. It offers tips on what features and services to look for and what questions to ask when you visit prospective facilities. Consider the following important factors throughout your search for a nursing home:

- Does the home provide services that meet your relative's medical needs?
- Is the home the best fit for your relative's personality and preferences?
- Will the home's location encourage frequent visits by friends and family?

See [Chapter Six](#) for information about what to expect of the nursing home once your relative has been admitted. See [Chapter Seven](#) for information on how to resolve problems as they arise and on how to become an effective advocate for your relative.

TYPES OF NURSING HOMES

The care your relative receives in a nursing home depends on many factors — including your involvement. If time permits, and you do your homework, you should be able to avoid homes that are below par and those that are not a good match for your relative. **However, there is no sure way of knowing in advance whether a home will provide the individualized care your relative needs.** You will need to stay informed and involved in your relative's care. You may also need to advocate for her to make sure she receives the care and special services she needs and deserves.

Types of Nursing Homes
<p>Who operates nursing homes?</p> <p>There are three different types of nursing homes, classified by ownership:</p>
<p>Proprietary homes are for-profit enterprises that operate like small businesses. While New York does not allow publicly traded national nursing home chains or corporations, a single owner may control many homes.</p>
<p>Voluntary homes are non-profit organizations sponsored by religious, fraternal, or community organizations. Any profit made at this type of home is put back into the operation of the facility.</p>
<p>Municipal or public homes are owned and operated by a county or municipal agency. There are far fewer municipal homes than proprietary or voluntary homes in New York.</p>

A facility's ownership doesn't indicate the quality of care it provides. Although there is some evidence that non-profit homes generally have slightly higher staffing levels, each home must be evaluated individually.

To find a nursing home in New York by geographic area, or by special services offered, use the New York State Department of Health's directory ([DOH NH DIRECTORY](#)).

What is the typical size of a nursing home in New York?

In 2013, there are approximately 550 nursing homes licensed in New York State ranging in size from under 50 to over 1,000 residents. In New York City, nursing homes considered to be of moderate size have approximately 200-300 beds. Size alone doesn't indicate whether the home will be bureaucratic and impersonal, whether it will focus on individual needs, or if it will provide high-quality care.

U.S. News & World Report has published a detailed guide to choosing a nursing home ([U.S. NEWS GUIDE](#)).

Although large homes may look and feel more "institutional" and can seem intimidating, they may have more professionals on staff and on-site services, such as dentistry and psychiatry. Some smaller homes may rely on part-time consultants and hospital clinics for such services. On the other hand, a smaller staff can allow personal relationships between workers and residents to develop more easily. It bears repeating: each home must be evaluated individually.

To find a nursing home with ventilator beds, visit the New York State Department of Health's directory, [DOH NH DIRECTORY](#), choose your geographical area, and under "Search for Special Services," select "Ventilator Dependent" from the drop-down box.

How do I decide which size home is best?

Consider her care needs and preferences. If she is very ill, she may be better off in a big home. Typically, large homes are more likely to offer special sub-acute units offering a level of treatment between hospital care and nursing home care. For example, intravenous (IV) treatments or ventilator units are more likely to be available at larger facilities.

Your relative may feel more comfortable in one size facility than another. Some residents find smaller facilities to be more home-like, while others like the expansive space and diversity of residents and staff available in bigger nursing homes.

Is the age of a nursing home important?

New homes are usually better designed for the purpose of long-term care, although many lack large rooms for performances or community use. Some older facilities have rooms that hold three or four residents, but homes built more recently usually do not house more than two people in each room. Just because a nursing home has a beautiful new building doesn't mean the care will be good. Most important is the quality of care — whether individual resident needs are met and how quickly the staff responds if problems arise.

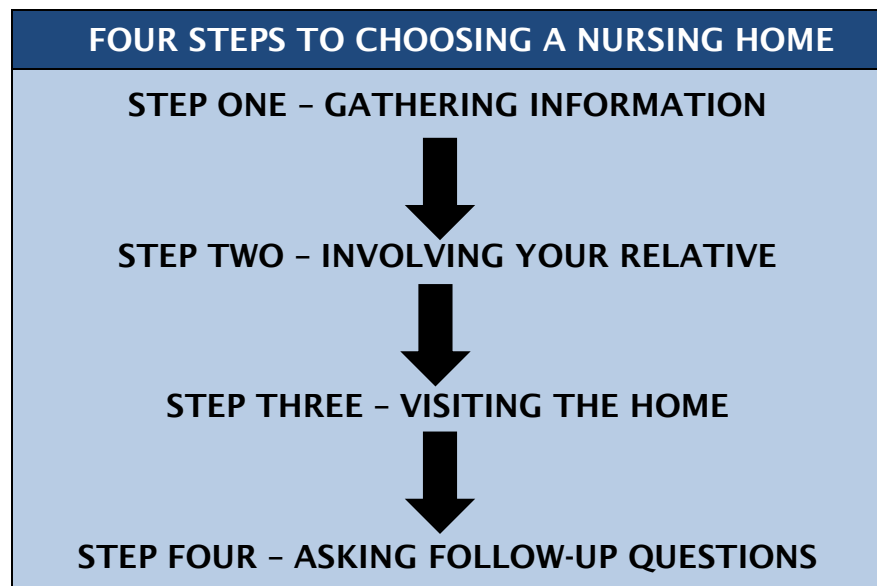
Are nursing homes with rehabilitation units different from long-term nursing homes?

See [Chapter Six](#) for more information on rehabilitation and sub-acute services.

All nursing homes are required to provide physical, occupational, and speech therapy to all residents who require these services. Some nursing homes have created separate floors, or units, for residents in short-term rehabilitation programs. These units, which are becoming more common, often have more staff and amenities than regular long-term care floors or units. Legally, however, these units are not considered exclusive "short-term rehab" units, but are simply part of the larger nursing home.

The Centers for Medicare & Medicaid Services publishes a helpful consumer guide to choosing a nursing home ([CMS CONSUMER GUIDE](#)).

HOW TO EVALUATE NURSING HOMES



STEP ONE – GATHERING INFORMATION

There is a lot of information available about nursing homes and how to choose them. Nonetheless, your relative's final choice of a home is more often determined by factors beyond your control — such as availability of beds, specific medical needs that can only be met at certain facilities, your relative's financial situation, how much time you have to look around before placement is necessary, and so on. That said, you should still learn as much as you can about the nursing homes in your area. This familiarity could help you if you decide to transfer your relative to a different home later.

Visit Nursing Home Compare ([CMS NH COMPARE](#)).

The Department of Health also provides a nursing home comparison tool ([NYS DOH NH COMPARE](#)).

Find out as much as you can about the nursing homes in your area by using online data and nursing home surveys provided by, for example, the New York Department of Health. On the internet, the best place to start gathering information is Nursing Home Compare. Nursing Home Compare, an interactive tool provided by the Centers for Medicare & Medicaid Services, contains comparative information on over 15,000 Medicare and Medicaid nursing homes nationwide. Nursing Home Compare allows you to search for nursing homes in your area by zip code or

nursing home name and to compare the nursing homes you are interested in by considering the following:

- The Five-Star Quality Rating - Nursing Home Compare gives each nursing home a rating from one star (low) to five stars (high) on the basis of each of the following: 1) the results of the nursing home's health inspections, 2) the nursing home's staffing (hours of care provided per resident by staff performing nursing care tasks), and 3) the nursing home's quality measures. A star rating is provided for each of these three measures, because different people find different areas more important than others. Then, these three individual ratings are combined to calculate an overall star rating (again, one to five stars) for the nursing home. Reviewing health inspection results, staffing data, and quality measure data are three important ways to measure nursing home quality. As a result, the star ratings in these areas, and the overall star rating, will give you a "snap shot" of the quality of the care that a particular home provides;
- Inspections and Complaints Data - For each nursing home, Nursing Home Compare gives detailed and summary information about the deficiencies found during the nursing home's three most recent state inspections and during recent complaint investigations. This includes information on health inspections (for example, information on proper management of medications, protecting residents from physical and mental abuse, and storage and preparation of food), fire safety inspections (including construction, protection, and operational features designed to provide safety from fire and smoke), and complaint investigations (inspections about a complaint that result in a health-deficiency citation are reported by Nursing Home Compare);
- Nursing Home Staffing Information - For each nursing home, Nursing Home Compare gives staffing hours per resident per day. This is the total number of hours worked by nursing home staff divided by the total number of residents. Staff included in this measure are: registered nurses, licensed practical or

vocational nurses, physical therapists, and certified nursing assistants;

- **Quality Measures** – Nursing Home Compare posts each nursing home's scores for certain quality measures. These quality measures include resident health, physical functioning, mental status, and general well-being. This includes the measurement of the quality of certain aspects of nursing home care, like whether residents have gotten their flu shots, are in pain, or are losing weight; and
- **Penalties** – Nursing Home Compare lists the penalties that have been imposed against each nursing home. Penalties may be imposed against a nursing home when a state inspector cites a nursing home for a serious deficiency or when the nursing home fails to correct a deficiency for a long period of time. Nursing Home Compare lists the two most common penalties: fines and payment denials.

You can also find nursing home evaluations and comparisons on commercial websites but these websites often charge a fee and the information they provide is based primarily on the information found on the government websites.

Can I rely on the information I find on the government websites to choose a nursing home?

The New York State Department of Health has an informative consumer guide on selecting a nursing home in New York State ([NYS DOH SELECT NH](#)).

You should start the *gathering information* process by visiting government websites, such as the CMS and DOH websites, **but this is not where you should end the process!** Although these websites are useful tools, they should not be your only basis for comparing homes or choosing a home. Instead, you should use the information you find on these websites to help you to recognize what to look for and what to ask about when you visit a home. You should personally visit every home you are considering and should talk to residents in the home, families of residents, and to knowledgeable, local advocates and professionals. Ask family and friends who have relatives living in the home about their experiences and their opinions of the care provided.

A home with a five-star rating in the various measures is worth looking into. A home with a two-star rating in some or all of the measures merits serious questioning about care in those areas. The quality measures also point to likely areas for improvement and care areas worth studying and monitoring. Note that all the quality measures involve physical health care. They tell you nothing about the quality of life experienced by residents in the home, which may be a more important factor for your relative.

What does the Department of Health survey report tell me?

To view summary information on the last three Certification Surveys and the last three years of Complaint Surveys, use the DOH Nursing Home Profiles tool, [NYS DOH NH](#). Using the search function, find the nursing home you are interested in and select the “Inspection” and the “Complaints” tabs. To view information about penalties imposed against the nursing home, view the “Enforcement” tab.

The Department of Health (DOH) inspects, or surveys, each nursing home licensed in New York every 12-15 months to determine if the home has complied with the Medicare/Medicaid quality standards (a Certification Survey). The DOH also conducts surveys in response to complaints reported to the DOH about the home, in which case the survey focuses on the specifics of the complaint (a Complaint Survey).

If, during a Certification or Complaint Survey, the DOH finds that the home did not meet federal or state standards, it will note the violation in the Survey as a deficiency and it will rate how severe the deficiency is in terms of endangering resident health. Depending on the seriousness of a deficiency, the DOH may impose penalties against the nursing home including fines, denial of payment for new admissions, or DOH-mandated staff training or other corrections. In cases where the violations are particularly egregious, and the home fails to correct the violations, the home may be terminated from the Medicare/Medicaid program or the home may be closed.

You can review DOH surveys for the nursing homes you are interested in by using the DOH’s Nursing Home Profiles tool. Also, nursing homes must post their most recent DOH Certification Survey in a prominent location in the nursing home where it is easily visible to residents, families, and visitors. If the report is not visible in the lobby, ask a staff person to find it for you.

If you have difficulty locating and viewing the most recent survey report, this may be a sign the home has something to hide. In addition to the report itself, the home must also post a summary of any deficiencies found by the DOH during the survey, any plan of correction in effect, and any DOH-enforcement actions taken against the home.

Can I rely on the CMS and DOH databases and the DOH survey reports to indicate whether or not a particular nursing home will provide good care?

Yes, but you should use these sources as only one piece of information to help you to form your own conclusions about a home. If the information in the database is based on a survey that was done many months ago, conditions in the home may have changed. Also, how strictly the DOH notes deficiencies or imposes penalties may vary with individual surveyors and over time. If a survey report lists many problem areas at a particular home, however, especially as it relates to medical and nursing care, you should consider it a bad sign.

STEP TWO – INVOLVING YOUR RELATIVE

Care Conversations, an industry advocacy group, provides information on how to ease your relative's transition to nursing home care ([NH TRANSITION](#)).

Your relative should be involved in the search for a nursing home. Even if she is opposed to a nursing home, including her in the selection process may help to lessen everyone's feelings of fear and guilt. While your relative may be resistant, the more she understands her alternatives and feels that her wishes were considered, the more easily she may adjust to nursing home life. Once you have gathered some basic information, invite your relative to visit the most promising homes, if at all possible, and to participate in making the decision.

If your relative cannot or will not take an active role in choosing a home, find out what her priorities are: for example, location, languages spoken in the home, availability of special services, and so forth. Keep her up to date about the search, describing what you've seen and what you've learned. If she has a severe cognitive impairment and can't make choices, focus on

You may want to print and take this checklist provided by the Centers for Medicare & Medicaid Services, [CMS CHECKLIST](#), when you visit nursing homes. The checklist will help you to rate the different nursing homes you visit based upon resident quality of life, quality of care, nutrition and hydration, and safety. The checklist also elaborates on how you can use the information you discovered through Nursing Home Compare when visiting a nursing home.

See [Chapter Seven](#) for more information on family councils.

the things that you know are important to her.

STEP THREE – VISITING THE HOMES

When and how often should I visit a home we are considering?

For comparison's sake, you should visit several homes, not just the first home that's on your list. If possible, take along a friend who can take notes or be a second pair of eyes. You may find that many nursing homes will allow prospective residents and families to visit the facility only at pre-set times during arranged tours. Try to avoid this. The idea is to see the home on a typical day, not when it has been spruced up for guests.

If you are not limited by time, visit each home more than once, in the evening as well as during the day, or on the weekend as well as during the week. Keep in mind that nobody can find out everything in one visit. Try to arrange one or more visits during a mealtime so you can see first-hand the quality of food, how the facility handles residents at a busy time, and how the staff handles residents who cannot feed themselves.

What should I do when I visit?

During your tour, don't be afraid to ask lots of questions; if you don't get satisfactory answers from the admissions representative, find out which staff person might be able to help you. Check the posted Department of Health inspection survey. Try to talk to residents and visiting families. Ask to speak to a representative of the family council, if there is one.

What kinds of features or qualities should I look for when I visit a home?

First, remember that no home will be perfect in every way. As you tour the home, focus on the aspects of care that are most important to your relative.

- Ask to see different areas of the home.
- Ask to see a specific floor you are told about, but

not shown.

- Ask whether all residents, or just those in selected programs, use special facilities and programs.
- Ask lots of questions and persist if you don't get a satisfactory answer.

The following pages list specific things to look for and ask about. This list is comprehensive. You will probably not be able to ask about everything. After reading through this chapter, print the [CMS CHECKLIST](#) and bring it along on your nursing home visits. Be sure to add questions to the checklist that are pertinent and important to your relative.

What is the location of the home?

The home's location and neighborhood could affect your relative's adjustment to nursing home life. Try to find a place that's easy to reach or close to the residences of family and friends who are likely to visit. As a rule, the nearer they live to the nursing home, the more often they will stop by. Frequent visits definitely help to ease your relative's feelings of isolation.

See [Chapter Seven](#) for more information on how to become an effective advocate.

Furthermore, nursing homes are more apt to pay attention to residents with regular visitors who are keeping an eye on the resident's care. Even more importantly, a family member who visits regularly will be in a better position to participate in decisions affecting the resident, to monitor care, or to serve as an advocate when problems arise.

- How convenient is public transportation to the home?
- Is parking available?
- What does the neighborhood look like?
- Will visitors feel comfortable coming to the home?
- Are there convenient shops and restaurants near the home where families can take residents?

Visit the AARP website for its "Ten Tips for Choosing a Nursing Home" ([AARP TEN TIPS](#)).

What does the home look, smell, and feel like?

The physical layout, condition, and maintenance of a home can often give a clear indication of how the home's residents are cared for. Keep your eyes open for details as you walk around. Try not to let the administrator restrict you to pre-selected floors or rooms. Insist on visiting other areas as well, such as the laundry, bathrooms, resident rooms, and shower rooms. You can also try picking a floor not on the general tour and asking to see it.

Remember, your relative may change rooms or floors during her stay in the facility, so quality on all the floors is important.

- Is the place home-like or institutional?
- Do unanswered call bells, overhead paging, and blaring televisions create a distracting and loud environment for residents?
- Is the home well maintained, clean, well lit, and free of unpleasant odors — including strong disinfectants that may be masking some other smell? Are the rooms and public areas free of hazards?
- What kind of security system is in place? Are there guards at each entrance to keep uninvited people out and to keep residents who are disoriented from wandering into the street?
- Do residents have personal belongings decorating their rooms, such as pictures, books, plants, and bedspreads?
- How are residents' personal belongings kept safe?
- How many beds are there in a room? Are single rooms available? Who gets them?
- Is the home respectful of differences in culture, religion, and sexual orientation?

- Does the home offer private meeting areas for residents who have visitors?
- Is there a comfortable outdoor area accessible throughout the year where residents can sit, and is it being used? Do staff members escort residents to this area or is the area in use only when visitors can escort them?
- Can residents smoke or is the home smoke free?

How are the residents treated?

Whenever possible, speak to the residents away from the staff. Also, seek out family visitors and ask them how they feel about the home. You can expect some complaints, but you can also learn a lot about the positive and negative qualities of the facility.

- Are residents clean, dressed, and well-groomed? Is their hair combed? Are their nails clean and trimmed?
- Are most people lying in bed or moving around freely?
- Are any residents in restraints or do any appear heavily sedated?
- Are many residents engaged in interesting activities or are most just staring at a TV set or a blank wall?
- Are residents talking with each other and the staff, or do they appear isolated from each other?

See [Chapter Six](#) for more details about physical and chemical restraints.

Note the mental alertness of the residents on the floor where your relative may live. Some nursing homes use a “case mix” model where residents of varying degrees of alertness or cognitive awareness are on the same unit, allowing for the less alert residents to benefit from being with people who are more alert than they are. Other homes choose a model where residents live on units with residents of similar capacity for awareness. When you visit, be sure to inquire about the home’s model or philosophy.

How well does the staff do its job?

The numbers, stability, and experience of the home's staff strongly affect the quality of the care that the home delivers — although all of this may be hard to determine during a single visit.

- Do you see staff members actively assisting residents?
- Is there a sufficient ratio of aides to residents on each unit, especially at night and on weekends?
- Are “temps” from agencies used on a typical day, particularly on weekends? If “temps” are used, will you be told when they are on duty?
- On average, how long have current workers been on staff?
- Does the same nurse or aide care for the resident during each shift?
- Are workers abrupt or rude when asked a question?
- Do staff members, including doctors, social workers, and others, speak respectfully to the residents?
- Do workers hand out food trays with a smile or friendly greeting?
- Are call bells and requests for assistance answered promptly?
- Do staff members speak your relative's language?
- How are language needs met for medical care, social needs, in emergencies, etc.?
- If bilingual staff is limited, what happens when they are sick, on vacation, or off-duty?

What's the quality of the food?

Meals become important events in the lives of nursing home residents. If you can, visit the nursing home while a meal is being served and actually eat a meal that the residents are being served.

- Does the food look and taste appetizing?
- Is it served at the proper temperature?
- Do residents who need help with eating get prompt attention?
- Do most of the home's residents eat in the dining room?
- Is the menu posted and does it reflect what's actually being served?
- Are substitutes for the main dish readily available?
- Does the menu accommodate residents with specific dietary needs (e.g., diabetics)?
- If the home serves kosher food only, is there an area in the home where non-kosher eaters can have meals brought in from the outside?
- Can residents request alcoholic beverages — such as wine — with dinner?

See [Chapter Six](#) for more information on kosher meals and kosher homes.

What activities are available to residents?

Regular activities, whether social, recreational, or cultural, are an important part of every nursing home. Activities help to keep residents alert and encourage them to socialize with one another. Not only should a home have many different kinds of activities planned throughout the week, including weekends, it should also make every effort to encourage residents to participate in community events and to continue to be active. When you visit, arrange to speak with the home's director of activities and ask to see the home's monthly activities schedule. Watch activities that are

taking place during your visit to see if the activities schedule accurately reflects what's happening at the home.

- How large is the activities room? Is it well-equipped and staffed? Are residents using it?
- If there isn't a specific activities room, where are activities held?
- If someone is bedbound, will the home bring activities to her room? How often and what activities?
- Is a list of activities posted? Are there activities planned for the entire week, including evenings and weekends? Does the list seem varied and does it include activities your relative would enjoy?
- Are outside volunteers involved in any programs at the home? For example, are there visits by entertainers or children from nearby schools?
- Are there religious services, recreational activities, memorial services, and language, cultural, or social clubs that meet your relative's needs?
- What holidays are celebrated and how are they celebrated? Are there special events like Black History Month or Gay Pride Day?
- Are any community resources being tapped to meet the language and social needs of an underserved group?

What kinds of services are available for residents with dementia or Alzheimer's disease?

The Alzheimer's Association has a helpful guide on selecting a nursing home ([ALZ GUIDE](#)).

In facilities that offer good care for residents with dementia, staff members have a real understanding of the illness and how it affects residents. Staff can recognize the underlying causes of dementia and related symptoms like confusion, agitation, aggression, and wandering, and can create the right physical, social, and emotional environment to make residents

feel comfortable.

Visit the website of the New York City chapter of the Alzheimer's Association for additional resources and training on issues relating to Alzheimer's and dementia ([NYC ALZ](#)).

While it is estimated that 70% of New York nursing home residents may have some form of dementia, many nursing homes have not trained their staff on how to understand this condition or on how to best serve these residents. The Alzheimer's Association's New York City Chapter, like many other local chapters, offers aides in nursing homes additional training on how to care for residents who have dementia. An Alzheimer's Association's training certificate is usually a good sign if the staff members involved in the training are still working with the residents.

Some nursing facilities offer good individualized care to residents with dementia, without establishing special programs. Still others promote dementia programs or units, but, on closer inspection, you may find only a single floor where all dementia patients are housed, without special activities or trained staff.

A good dementia program will be administered by staff with additional training in understanding Alzheimer's disease and dementia. These programs often include day programs where residents can spend much of the day with the same staff in a safe, supervised, and less institutional setting. Activities are designed specifically to involve individual residents, with attention on minimizing agitation and anxiety. If your relative has dementia, here are some additional questions to ask:

- If the home has an Alzheimer's unit, is it a separate area with skilled staff or is it simply a floor in the home where all the residents who have dementia live?
- Has the staff (including custodial, certified nursing assistants (CNAs), and dietary personnel) all received special training to work with residents who have dementia?
- Will my relative be able to take advantage of the activities offered in any special unit? Is my relative's functional level higher or lower than that of most residents served in the special unit?

- How does the staff handle disruptive behavior caused by residents who have dementia?
- If my relative wakes often at night, how will this be addressed?
- What safety measures are in place to protect confused residents who may try to leave the home?

What kinds of services are available for sub-acute patients?

Choosing a nursing home for temporary rehabilitation or sub-acute care is different from choosing a home for long-term care. The availability and quality of medical services should be your top priority; atmosphere and location may be less important.

- Does the home offer the therapies and medical services necessary for your relative's rehabilitation program?
- Does the home have the proper equipment?
- Is the regular staff trained to work with rehabilitation patients?
- If your relative may need long-term care at the end of the short-term rehabilitation period, look at both types of care, which may be provided in different areas of the building.

See [Chapter Six](#) for more information on nursing home discharge.

The New York State Department of Health provides detailed information about nursing home discharge [HERE](#).

In New York, nursing homes cannot discharge your relative involuntarily, as long as the home can provide the proper care for your relative, the home has been paid for your relative's care, and your relative continues to need long-term nursing home care, even if her stay was originally intended to be short-term.

If you want to appeal a discharge or transfer from a New York Nursing Home, contact the New York State Department of Health's Nursing Home Complaint Hotline at (888) 201-4563. You can also file a nursing home complaint online ([NURSING HOME COMPLAINT FORM](#)).

STEP FOUR – ASKING FOLLOW-UP QUESTIONS

After I've seen the home, what other kind of information should I get?

For any nursing home you are interested in, you should speak to the person in charge of admissions. Depending on the home, this may be a social worker, an administrator, or someone whose job it is to take applications. Now is the time to ask follow-up questions about what you've seen on the tour. It's also a good time to ask about the medical services the home offers and the policies that will affect your relative. For example, ask about the home's dedication to the culture-change movement and whether the home has a policy that prohibits discrimination based on, for example, gender, race, sexual orientation, or gender identity.

What is the home's admissions policy?

Ask for a copy of the home's admissions policy and get copies of all forms required for admission (although these may not be available until you are ready to apply for admission). When a relative is being admitted to a nursing home with little advance notice, ask to take the forms and admissions package home to review – try not to sign any documents on the spot.

- When will a bed be available for your relative?
- Does the wording of admissions and assessment forms allow for identification of partners and members of a family of choice?
- How long are applications kept on file? When do they need to be updated to remain active?

What are the home's financial policies?

Get a fee schedule and a copy of the admissions contract you will be asked to sign and keep it in your personal files. You may need to refer to them in the future.

See [Chapter Six](#) for more information on the fee schedule and the admissions contract.

See [Chapter Six](#) for more information on visiting hours.

Find out what services are included in the basic rate and what services cost extra. **Be sure you have this in writing, especially if you are paying privately.**

What is the home's visiting policy?

In New York, residents have the right to visit privately with a spouse, partner, or relative.

- Does the facility openly indicate support of this right?
- Does the facility respect the right of immediate family members to visit at all times?
- Does the facility allow residents to share meals with visitors in the dining room or other eating areas?

What medical services does the home offer?

Nursing homes may have doctors on staff or may contract with doctors in the community on a fee-for-service basis. Homes may also arrange for specialists, such as ophthalmologists or podiatrists, to come to the home when their services are needed.

- Are there physicians on staff? How many and how often are they on the premises?
- Are specialists (for example, psychiatrists, optometrists, dentists, etc.) available? How are specialists arranged for if needed? How long does it take for a resident to be seen?
- If a resident has a mental illness, what services does the home provide? Will these services meet all of the resident's needs?
- How can a resident get a second opinion?

- How will medical emergencies be handled? What arrangements are made for emergency treatment if the physician assigned to the resident is not available?
- What hospitals are used if a resident becomes acutely ill? Is the family notified before a resident is transferred to a hospital?
- Can you request that your relative be sent to a specific hospital other than those mentioned by the nursing home?
- Does the home have a comprehensive therapy department that includes occupational, physical, and speech therapy? If your relative needs extensive therapy, how often does the therapist come to the nursing home?
- How does a resident qualify for therapy?
- Does the home offer alternative medicine and complementary therapies?

See [Chapter Eight](#) for a detailed discussion about end-of-life decision-making.

What are the home's policies about end-of-life treatments?

Many homes, especially those with a religious affiliation, have policies that allow them, for religious or moral reasons, to refuse to honor a resident's wishes about end-of-life treatment decisions – such as a resident's wish to refuse artificial nutrition and hydration (feeding tubes). Homes must explain such policies before admitting new residents and, if a home refuses to honor a resident's end-of-life decisions, it must cooperate in transferring the resident to another home that is reasonably accessible and that is willing to honor the patient's end-of-life treatment decisions.

See [Chapter Eight](#) for a detailed discussion on DNR orders.

Will the home resuscitate my relative if she has cardiac arrest?

Nursing homes are required to have staff and equipment available and to provide CPR (Cardiopulmonary Resuscitation) if a resident needs it. CPR will not be provided if a resident chooses a Do Not Resuscitate (DNR) order.

See [Chapter Six](#) for more information on hospice and palliative care in nursing homes.

Does the home offer a hospice program?

Many nursing homes now offer hospice or palliative care services on site to nursing home residents who are terminally ill.

PLACEMENT DECISION

Is my relative likely to be admitted to her preferred home?

This depends on a number of factors. Highly regarded homes are able to be selective, preferring applicants whose condition warrants a more favorable reimbursement rate or who will be able to pay privately. Some medical conditions, such as a mental illness, might make an applicant more difficult to place. The intense pressure on hospitals for prompt discharge motivates hospitals to push patients toward nursing homes more likely to accept applicants because of the home's financial or business relationships with the discharging hospital.

If placement in a preferred home is not possible, can my relative transfer there later?

A transfer is possible, but very difficult. Your relative has the right to move from one home to any other that will admit her. Some families hesitate to consider a transfer because they fear a move might negatively impact their relative – especially if she has dementia. To succeed, it will be easiest if you have the cooperation of the social workers in the present home, as well as the preferred one. Stay in contact with the preferred home so that the admissions department is aware of your family's continued interest.

See [Chapter Four](#) for a detailed discussion on the PRI and how to hire a private nurse to prepare a PRI for your relative.

Sometimes, there is resistance by the transferring home. Staff may delay sending the PRI (Patient Review Instrument) and other necessary paperwork or may send a misleading account of your relative's condition. For this reason, it is a good idea to ask for a copy of the PRI before it is sent and to talk to the preferred home once it arrives. If necessary, you can hire a private nurse to prepare a PRI for you.□□□

SELECTING A NURSING HOME RESOURCES

Alzheimer's Association

225 North Michigan Avenue, Suite 1700, Chicago, IL 60601; (800) 272-3900.

Provides training and support to those providing care for people with Alzheimer's disease and dementia. Call or visit the website to find a chapter in your area.

www.alz.org

Publishes an informative guide on selecting a nursing home:

http://www.alz.org/nyc/in_my_community_17490.asp

Also publishes a comprehensive resource list containing sources and strategies for finding, evaluating, and selecting nursing homes:

http://www.alz.org/library/downloads/search_nursinghomedecisions.pdf

Care Conversations

1201 L Street, N.W., Washington, DC 20005; Phone: (202) 842-4444.

Trade group providing information aimed at empowering elderly patients to have conversations allowing them to form their own opinions about their care and to select the plan of care that's right for them.

<http://careconversations.org/home.aspx>

Provides guidance on finding and evaluating care, including nursing home care:

http://careconversations.org/Choosing/Finding_Evaluating_Care.aspx

Also offers advice on how to ease your relative's transition to nursing home care:

http://careconversations.org/Planning_Preparing/Helping_With_The_Transition.aspx

Centers for Medicare & Medicaid Services

7500 Security Boulevard, Baltimore, Maryland 21244-1850; (800) MEDICARE.

Provides comprehensive information relating to Medicaid and Medicare-certified nursing homes throughout the United States.

<http://www.medicare.gov/nursing/overview.asp>

Also, print and take the CMS nursing home checklist along with you when visiting nursing homes:

<http://www.medicare.gov/files/nursing-home-checklist.pdf>

Visit the CMS Nursing Home Compare tool, which has comparative quality of care information on over 15,000 nursing homes nationwide. Also gives each nursing home a rating from one (low) to five stars (high) on the basis of each of the following sources: 1) the results of the nursing home's health inspections, 2) the nursing home's staffing (hours of care provided per resident by staff performing nursing care tasks), and 3) the nursing home's quality measures.

<http://www.medicare.gov/NursingHomeCompare/search.aspx?bhcp=1>

Eldercare Locator

(800) 677-1116

The Eldercare Locator, a public service of the Administration on Aging, U.S. Department of Health and Human Services, is a nationwide service that connects older Americans and their caregivers with information on nursing homes and other senior services.

http://www.eldercare.gov/Eldercare.NET/Public/Resources/Topic/Nursing_Home.aspx

Provides a search tool to locate nursing homes and other services in your area:

<http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>

New York State Department of Health (DOH)

Corning Tower, Empire State Plaza, Albany, NY 12237; Nursing Home Complaint Hotline (888) 201-4563.

The DOH publishes excellent consumer information on issues relating to quality of care, nursing home resident complaints, and evaluating and selecting a nursing home.

<http://www.health.ny.gov/>

Visit <http://nursinghomes.nyhealth.gov/> to use the DOH's tool to find nursing homes in your area and to compare quality of care data for nursing homes operating in New York State.

Visit http://www.health.ny.gov/facilities/nursing/select_nh/docs/select_nh.pdf to read the DOH's consumer guide on selecting a nursing home.

New York State Office of Long-Term Care Ombudsman Program (LTCOP)

New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12223; Senior Citizens Help Line (800) 342-9871.

The LTCOP assists residents of nursing homes in most parts of the state. To find your local ombudsman, use the LTCOP Directory:

<http://www.ltcombudsman.ny.gov/whois/directory.cfm>

Pioneer Network in Culture Change (Pioneer Network)

35 East Wacker Drive, Suite 850, Chicago, IL 60601; (312) 224-2574.

An organization that promotes the culture-change movement. Pioneer Network advocates for a transition away from institutional provider-driven nursing home care toward a more humane resident-driven model that embraces flexibility and self-determination.

<http://www.pioneernetwork.org/>

**THIS CHAPTER
INCLUDES
INFORMATION
ABOUT THE
FOLLOWING:**

**New York State
Department of
Health regulations
governing nursing
homes**

**Residents' rights,
including visiting
hours and personal
allowances**

**Needs assessment
and comprehensive
care planning**

**Services nursing
homes are required
to provide by law
and who is
responsible for
providing them**

**Chemical and
physical restraints**

**Saving your
relative's nursing
home bed during a
therapeutic leave or
hospitalization**

**Discharge and
transfer**

**What happens when
a resident dies in a
nursing home**



EXPECTATIONS: REGULATIONS, RIGHTS, AND REQUIRED SERVICES

What is quality of care? Most homes, profit or non-profit, promise to provide it. But a home's standard of care may not be as high as you and your relative anticipate.

You have the right to expect that your relative will be treated respectfully and that she'll get the particular help and medical attention she needs. Unfortunately, many facilities fall far short of these expectations. Like other medical institutions functioning 24 hours a day, nursing homes have problems with staff, equipment, and financing, which in turn can cause problems for residents. So, even after the difficult placement process we described in Chapters Three and Five, your job isn't over. Your relative will still need help advocating to ensure that the care she receives addresses her needs. Ultimately, it's up to your relative, you, other family members, or friends of your relative to make a nursing home live up to its promises and abide by government regulations.

You will be in the best position to help your relative if you are familiar with the routines and staff at your relative's nursing home. While you help your relative to settle in during her first weeks, get to know the staff caring for her and get to know the routines of the home.

In the third week, there should be a comprehensive care planning meeting. Make time to attend. At this meeting you will learn the specifics of the care planned for your relative and you will have the chance to let staff know the personal things about your relative that will help the home to give her the best possible care.

Although it's a busy time, you will also want to become familiar with the basics of good care that we set out in this chapter. **Professional standards for nursing homes describe the necessity for individualized**

The Long Term Care Community Coalition provides an easy-to-read consumer guide on the rules and regulations governing New York nursing homes ([LTCCC BOOK](#)).

See [Chapter Seven](#) for tips on becoming an effective advocate for your relative.

care. That means good quality care is tailored to each resident's specific needs, allows each resident to have the greatest possible independence, and is respectful of each resident's dignity. These standards are embodied in the New York State Department of Health regulations that govern nursing homes and protect residents' rights and independence.

In this chapter, we let you know what New York rules, regulations, and professional standards require of New York nursing homes. Armed with this information, you will have a better idea of what is acceptable and what isn't, what you have the power to change or improve, and where to turn when you need help.

Families of nursing home residents who have high expectations and strong advocacy skills are most effective in getting quality care for their relatives.

FEDERAL AND STATE REGULATION OF NURSING HOMES

Federal and state laws and regulations largely determine the character of nursing homes. To be licensed, and to receive Medicare or Medicaid reimbursement, all nursing homes must meet minimum federal standards and provide certain services. New York adds additional protections and, unlike some other states, does not allow Medicaid enrollees to be segregated into Medicaid-only homes.

Who regulates New York State nursing homes?

The New York State Department of Health (DOH) is responsible for licensing and regulating New York nursing homes. State regulations are based on the federal Nursing Home Reform Act (NHRA) of 1987 (also called OBRA 1987). The NHRA sets standards of care for Medicare- and Medicaid-funded nursing homes and outlines protections of residents' basic rights. Remember, these are minimum standards that nursing homes are legally required to meet. The best homes surpass them.

How effective are New York's regulations?

Although the regulations describe basic standards of care and establish the rights of residents, they do not cover every situation and are not enforced consistently. It is rare to find facilities that follow all of them or that provide truly individualized, sensitive care.

ADMISSIONS AGREEMENTS

What services will be provided at the nursing home?

Before admission to a nursing home, residents (or their family members) will receive a contract known as the "admissions agreement." This contract itemizes all services to be included in the home's daily rate, all services that are not included and are subject to an extra charge, and the charges for those extra services.

What services must be included in a New York nursing home's basic or daily rate?

In New York State, all facilities must include the following in their daily rates:

- lodging, including a private bed and closet space;
- board, including therapeutic or modified diets as prescribed by a physician;
- 24-hour skilled nursing and other staff concerned with patient care;
- the use of all equipment and medical supplies, including but not limited to catheters, hypodermic syringes and needles, irrigation outfits, dressings, pads, diapers, etc.;
- the use of customarily stocked equipment including, but not limited to, wheelchairs, crutches, and walkers, including training in their use as necessary;
- fresh bed linen changed at least twice a week or as often as required for incontinent residents;
- hospital gowns or pajamas, unless the resident or family chooses to provide them;
- laundry services for washable clothing;
- general household medicine cabinet supplies,

including, but not limited to, non-prescription medication, materials for routine skin care, oral hygiene, hair care, etc.;

- assistance and supervision, when required, with activities of daily living, including, but not limited to, use of toilet, bathing, feeding, and walking;
- recreational, social, and motivational activities with necessary equipment and supplies; and
- social services.

What are examples of extra services and how are they paid for?

The home must also agree to supply or arrange for the following services, which are covered by Medicare or Medicaid:

- dental services;
- physical therapy;
- occupational therapy;
- speech pathology services; and
- audiology services.

Are all admission agreements the same?

See [Chapter Four](#) for more details about nursing home coverage through Medicaid and Medicare.

There is no standard nursing home admission agreement required in New York. However, homes that are paid through Medicaid and Medicare are required to include certain services in the basic rate. **Some nursing homes might try to include illegal clauses** asking family members to guarantee their relative's payment. Some nursing homes may also try to include special language for short-term rehabilitation or sub-acute care that attempts to limit the stay to the needed treatment time. Nursing homes are not permitted to include such clauses in their admission contracts — and, even if they do, the clauses cannot be enforced. A contract cannot require someone to enter into a discharge plan at admission and cannot require someone who is not legally responsible for a resident's support to agree to pay nursing home bills. A resident's spouse is considered legally responsible, but a resident's children, siblings, and parents are not.

What if the nursing home asks me to hire a private aide?

While the basic rate is supposed to cover all the staff help a resident needs, sometimes residents or their families are encouraged to hire private health care aides. A home cannot legally require you to have a private aide as a condition of admission to the home or of staying in the home. Residents or families can hire a “companion” for social interaction (such as reading to the resident or writing letters) and care monitoring. Hiring private nurse assistants to do what staff must do is trickier. Some homes do allow this if rules are met. A private companion or aide is likely to give more individualized attention to your relative, but the presence of this person may result in nursing home staff overlooking your relative’s needs.

The National Long-Term Care Ombudsman Resource Center provides a nursing home “bill of rights” ([RESIDENT RIGHTS](#)).

The New York State Department of Health publishes a Consumer Guide, “Your Rights as a Nursing Home Resident in New York State and Nursing Home Responsibilities” ([NYS DOH RESIDENT RIGHTS](#)).

RESIDENT RIGHTS

New York law guarantees each nursing home resident the following rights:

- The right to be encouraged and assisted to exercise her rights as a citizen, to voice grievances, pursue legal remedies, and recommend changes in policy and services to facility, staff, and outside representatives of her choice, free from restraint, interference, coercion, discrimination, or reprisal;
- The right to participate in the facility’s resident council;
- The right to communicate privately with anyone she chooses;
- The right to send and receive personal mail unopened;
- The right to join with other residents or persons within or outside the facility for improvements in patient care;
- The right to meet with social, religious, and community groups and to participate in their activities;
- The right to privacy for visits by a spouse, partner, or relative and to share a room with a partner or relative if both are residents of the facility;
- The right to exercise civil and religious liberties; and

- The right to make independent personal decisions and to be informed about available choices.

Will entering a nursing home limit my relative's personal or civil rights?

Absolutely not. New York regulations guarantee fundamental rights for nursing home residents. Residents have the same personal rights as any other citizen — and the staff must respect them. By law, each home is required to inform newcomers and their families about these rights and to post them in a prominent place in the facility.

Nursing home staff and even some family members need to be reminded that many residents are fully capable of making decisions for themselves. They have the right and should be encouraged to do so. Unfortunately, some nursing homes abuse these rights in the interest of institutional efficiency.

How can family members help protect their relatives' rights?

When a person is admitted to a nursing home, she is asked to appoint a family member or friend to be her designated representative. The home must keep the representative informed about the resident's condition and care.

If your relative can't make her own decisions, your family can choose a designated representative after discussing the matter with the nursing home staff. It helps if everyone in the family agrees on the choice of representative. It's best if that representative is the family's only spokesperson in all dealings with the home and with your relative's doctor.

See [Chapter Eight](#) for information on guardians, health care proxies, and surrogate decision-making under the Family Health Care Decisions Act.

The designated representative does not have the right to make treatment decisions. Only the patient, a legally appointed guardian, a health care agent (through a health care proxy), or a surrogate under New York's Family Health Care Decisions Act can make these decisions.

Read more about health care proxies and get the New York State health care proxy form here: [NYS DOH PROXY](#).

Why is a health care proxy important?

In New York, a health care proxy allows each person to appoint somebody that they trust — for example, a family member or close friend — to make health care decisions on their behalf if they lose the ability to make decisions for themselves. By appointing a health care agent, you can make sure that health care providers follow your wishes, even if you have lost the capacity to direct your own health care. In nursing homes, health care proxies may be particularly important because they are necessary to obtain hospice care for a resident who lacks capacity and to ensure that end-of-life care is delivered in accordance with the resident's wishes.

VISITING HOURS

When and how often can I visit my relative?

By law, the home must have at least 10 hours of visiting time a day, spanning at least two meal times. Residents and their visitors have the right to be informed about the home's official visiting hours and policies and the home must provide residents with a private area to meet with visitors.

State regulations give residents the right to see their families, a federal or state representative of the Department of Health, their doctors, or any certified ombudsman at any time. In other words, if a resident has an urgent need to see a family member outside official visiting hours, she must be allowed to do so.

Call MFY at (855) 444-6477 if you are having problems getting access to the home to visit your relative.

Do I have a right to see my relative?

In New York, no one, not even a family member, has a legal right to visit a resident of a nursing home. Rather, the law says that residents have the right to receive visitors. Only those visitors a resident wants to see can visit the nursing home.

PERSONAL ALLOWANCE AND FINANCIAL ACCOUNTS

How does my relative pay for personal expenses at the home?

If your relative is on Medicaid, she is entitled to receive an allowance of \$50 a month to cover her personal expenses. In New York, a resident with no income gets a personal allowance of \$50 a month from Supplemental Security Income (SSI). Residents with some income (Social Security, pension, etc.) keep their allowance from their income. Private-pay residents may deposit money with the home to use for personal expenses.

The resident can use the allowance any way she wishes: for postage, transportation, newspapers, clothing, or other personal items. It should not be used to pay for items covered in the home's basic rate (such as soap and tissues) or for items covered by Medicaid.

How does my relative get access to her money?

The home must have a system for keeping an account of each resident's personal allowance. In effect, the facility acts like a bank, providing access to the account for a certain period of time during the day. Residents are not, however, required to deposit their funds with the facility. Instead, the resident may prefer to open a bank account of her own, give the monthly allowance to a friend or relative, or instruct the nursing home to give the allowance to someone else she names to handle purchases on her behalf.

If the resident decides to "bank" at the home, the facility must keep a separate accounting of her funds. The home must also keep funds over \$50 in an interest-bearing account. The resident must sign for each withdrawal or deposit made. Each quarter, the home must give the resident a written record of the account.

See [Chapter Four](#) for more information about Medicaid income and resource limits.

If my relative is a Medicaid enrollee, should I be concerned if her money accumulates?

If your relative does not spend her personal allowance, the balance in her account will grow and one day it may exceed the limits that Medicaid puts on personal resources (\$14,400 in 2013). At that point, your relative may become ineligible for Medicaid and will have to pay privately for her nursing home care. Thereafter, after your relative again “spends down” her resources, she will be required to reapply for Medicaid benefits. The home must inform the resident and her designated representative when the personal allowance account is within \$200 of the Medicaid resource limit.

What if my relative is too confused to manage her own allowance?

Your family may be able to use the allowance on her behalf. By making arrangements with the home, you can be reimbursed for any purchases you make that are used by your relative. Once you’ve turned in receipts for these items, the home will pay you back from your relative’s personal allowance account.

What happens to the money in the personal account if my relative dies?

In that event, within 30 days of your relative’s death, the home must give a final statement of the account to the individual handling your relative’s estate. Be sure you receive this account of your relative’s funds, as well as anything else belonging to your relative. Any balance in the account goes to your relative’s estate. A limited amount of money can be drawn upon to pay for burial expenses.

NEEDS ASSESSMENT AND COMPREHENSIVE CARE PLANNING

How and when will my relative's care needs first be assessed?

See [Chapter Three](#) for a detailed discussion of the MDS assessment.

The first needs assessment must be completed within 14 days after your relative is admitted to the home. An interdisciplinary care team at the nursing home will conduct a comprehensive study of your relative's care needs ("needs assessment") through an assessment tool called the Minimum Data Set (MDS). Using the MDS, the care team will determine your relative's medical, physical, and mental status, her rehabilitation potential, current medications, nutritional status and requirements, and any necessary treatments and procedures. The MDS will provide a comprehensive assessment of your relative's functional capabilities and will help nursing home staff to identify health problems.

The care team should be made up of those in charge of your relative's care in the nursing home, including her physician, social worker, and therapists. It should also include staff from dietary, activity, and other service areas. Good care planning requires the aides to be part of the care planning team.

What is a comprehensive care plan?

New York regulations require that the nursing home develop a comprehensive care plan for each resident. The plan sets clear goals for the resident's care and assigns responsibility for meeting those goals. Specific recommendations for treatment therapies and programs that will most benefit each resident are included in the plan. Care plans are normally approved at a meeting of the care team to which the resident and her designated representative are invited.

What happens at the first comprehensive care plan meeting?

The first comprehensive care plan meeting should be held within the first 21 days after admission. This is an especially important meeting to attend. It gives the resident, family, and friends an opportunity to meet with nursing home staff and to discuss the resident's plan of care.

Your input is important. You and your relative will be able to make contributions to the care plan. If your relative is unable to speak for herself, you should share your intimate knowledge of her history, habits, likes, and dislikes at the meeting, especially the activities that will stimulate her interest and participation. You can provide the staff with vital information about your relative's past medical conditions, telling which treatments and medications worked and which didn't. Without this information, it will be hard for the staff to provide the appropriate and individualized care that is legally required or to fill out the MDS form's questions about your relative's customary routines and needs.

You, your relative, and her designated representative should attend and participate in the comprehensive care plan process. Residents and family members who do so are more likely to develop good communication with the staff who attend the meeting and to get a clear understanding of the services that will be provided. Residents may also have an easier time adjusting to the nursing home if they actively participate in formulating their care plan.

Are all care plan meetings the same?

Different facilities have different types of care planning meetings. At some homes, everyone involved in the resident's care, from doctors and nurses to therapists and social workers, will attend the meeting. In other homes, only a few professionals may participate in the meeting, although they all help create the plan.

What if the comprehensive care plan meeting is confusing?

Some families find it hard to take in everything that's discussed. They may not understand the medical jargon used by professionals, or they may not speak English well enough to keep up, especially if the meetings are rushed (which they often are). For these reasons, many families do not fully contribute to their relative's care plan. To avoid missing out, ask a friend or interpreter to come with you. Above all, take notes. You may want to ask questions later.

At the end of the meeting, summarize your understanding of what is going to be done for your relative and who is going to be responsible for each task or service. Keep your notes as a record. Later on, they might serve as a reminder if the staff fails to do what it promised to do for your relative.

Call MFY at (855) 444-6477 or visit us on the web ([MFY](#)).

To find your local ombudsman, visit [OMBUDSMAN](#).

Some homes try to discourage the family from asking questions or making suggestions at the care planning meeting. Insist on being heard. If the initial meeting is brief or the staff unfriendly, ask the home's social worker to help you prepare your questions ahead of time for future meetings. If you do not find help or would like assistance, call MFY or your local ombudsman program.

How often can we meet with the care planning committee?

The total plan must be reviewed every year or whenever there is a major change in the resident's condition. The staff must also review aspects of the care plan every three months. Families must be invited to participate with the care team at least once a year. The nursing home is supposed to send you an advance notice of each meeting. If the time is inconvenient, ask for it to be rescheduled. Additional meetings may be called if health care workers, you, or other family members notice a significant change in your relative's health and care needs.

Can families ask for a care planning meeting to be held?

Yes, you should do so if you are concerned about a change in your relative's condition or care. In fact, meetings called in response to family concerns are often more helpful in solving problems than the regularly scheduled meetings.

What if I can't attend the meetings?

The home is always obliged to inform you of what was discussed and decided by the care team. In most cases, it will be your relative's social worker that will provide you with a summary. However, if you want first-hand information, you can ask the home to reschedule the meeting or arrange to participate through a speakerphone.

NURSING HOME STAFF AND SERVICES

ADMINISTRATIVE STAFF

Who runs the nursing home?

The operator is an individual or corporation licensed by the New York State Department of Health (DOH) to run the nursing home. The operator is ultimately responsible for all that goes on in the nursing home. In New York State, people convicted of serious felonies and nursing home-related felonies are barred from operating nursing homes.

The administrator is a full-time employee of the nursing home, accountable to the operator and responsible for the day-to-day operation of the home. The DOH also licenses the administrator. In order to maintain an active license, the administrator must complete 48 hours of approved continuing education every two years.

MEDICAL STAFF

Who's in charge of medical care?

The medical director, who must be a doctor licensed by the State of New York, coordinates medical care for the entire facility. Depending on the size of the home, this person may be a part-time or full-time employee, and he may coordinate the medical care of more than one nursing home. Medical directors may be part of the facility's staff or may be in private practice and under contract to fulfill this role.

The medical director's duties include developing sound medical policies and insuring that each resident gets appropriate care from a personal primary care physician. He must assure backup care when the resident's doctor is not available and arrange for emergency care through agreements with local hospitals. Usually, the medical director himself provides medical care to residents only in an emergency, when the personal physician and alternate are not available.

Who is directly responsible for my relative's medical care?

There must be a primary care doctor assigned to each resident. Most doctors provide services on a contract basis, although some homes — mostly large, non-profit facilities — have doctors on staff. Your relative has a right to know the name, address, and telephone number of her assigned doctor. She also has the right to speak with the doctor if she has any questions about treatment, to participate in planning treatment, and to refuse treatment.

How often do residents see the primary care doctor?

Doctors do not play a major role in the everyday care of nursing home residents. However, state regulations require that residents see their doctor once every 30 days for the first 90 days after admission, at least once

every 60 days thereafter, and whenever medical care is required between visits.

Can my relative choose to be treated by an outside doctor (that is, one who is not affiliated with the home)?

Yes, if the doctor is approved for a staff appointment or granted courtesy privileges at the nursing home. The right to see an outside doctor is sometimes difficult to exercise. Most private doctors, discouraged by low Medicaid and Medicare reimbursement rates, are not willing to treat patients in nursing homes. A resident can also arrange for an outside doctor to come to the home or can go outside the home to a doctor's office for a second opinion. But doctors are sometimes reluctant to come, because they hesitate to contradict their peers in an institutional setting.

How is an outside doctor paid?

If doctors on contract serve the home, you should be able to make similar payment arrangements with any personal physician willing to accept the Medicaid or Medicare Part B reimbursement. If your relative is a private-pay patient and does not have Medicare Part B, or if the physician won't accept the Medicare rate, your relative or your family will have to pay the fee. If the home employs staff doctors and includes physician services in its basic rate, you will not be able to deduct the private doctor's fee from the basic rate.

Always make sure that the nursing staff is carrying out the doctor's orders. Speak to the doctor if you feel that your relative isn't getting the proper medical care.

Who runs the nursing staff?

The Director of Nursing Services (DNS), who must be a registered nurse with training and experience in geriatrics, supervises the nursing home's registered nurses (RNs), licensed practical nurses (LPNs), and nurse aides (NAs or CNAs). The DNS must insure that there is adequate nursing staff at all times. There

must be a DNS on duty during the day seven days a week.

Who will be most involved in my relative's care?

Nurse aides (also known as nursing attendants or certified nursing assistants) provide most direct patient care. These are the workers responsible for waking residents, helping them wash, dress, and getting them to the dining room. If necessary, nurse aides help residents eat or go to the toilet; they also change and clean residents who are incontinent. It is a demanding job, both physically and emotionally, for which they receive little training and relatively low pay.

What qualifications or training do nurse aides have?

All nurse aides working in New York nursing homes must earn a certificate through an approved training program and be registered by the state. Nurse aides must be recertified every two years. They work under the direction of the registered nurses (RNs) who supervise nursing care on a given floor or unit of the home.

DIETARY STAFF AND SERVICES

Who is responsible for planning meals at the nursing home?

All meals served by the home must be prepared under the supervision of a licensed dietitian. In some homes, the dietitian is only a part-time consultant. Nonetheless, she should be available to meet with residents to discuss their food likes and dislikes and make an attempt to accommodate them. The dietitian must also make sure that special diets prescribed by a resident's physician are followed.

What are the state's requirements for meals?

Regulations require that residents get at least three substantial meals a day. The food must be nutritionally balanced, tasty, and served at the right

temperature. There should be a hot substitute (not just cottage cheese, for example) for each main dish. Second portions should be available for those who request them. Breakfast should be served no more than 14 hours after the last meal; snacks must be provided at bedtime. Menus should be posted in advance.

What if my relative doesn't eat enough?

The home must have a system for identifying residents who are not eating and must provide staff to help residents eat if they need assistance. **Weight loss in elderly people can quickly lead to serious health problems.** It's important that staff evaluate why a resident is losing weight or refusing to eat. Some common reasons why residents refuse to eat include mouth or throat pain, poor positioning when being fed, inadequate feeding assistance, depression, unfamiliar food, and poor-tasting food. Failure to deal early with eating problems may lead to unnecessary tube feeding.

What if my relative isn't eating enough because the food is so unlike what she is used to?

If a resident refuses the food that is served, the nursing home must provide a substitute of similar nutritional value, keeping in mind the resident's cultural background and dietary habits.

What about kosher dietary requirements?

Kosher meals must be made available in non-kosher nursing homes to those requesting them for religious reasons. These meals might be pre-packaged.

What does "kosher" mean?

Many families do not know what to expect in a home that offers only kosher food. In these homes, residents will not be served any pork or shellfish products. They will not be served milk or any dairy products with a meal that includes meat. A non-dairy cream product will usually be served with coffee or tea.

During Passover, no leavened bread or bakery products are used; matzoh is served instead. In addition, all meats served will be slaughtered and otherwise prepared according to Jewish law. This does not affect how the food appears or tastes.

In a kosher home, food preparation will not necessarily follow all Jewish dietary laws, but it is likely that the prohibition on pork and shellfish will be followed and dairy products will not be served with meat.

What does it mean if my relative chooses a home that is kosher?

Many kosher nursing homes in New York today serve a non-Jewish and non-kosher-observing population. Some have rules banning any non-kosher food from the facility, including traditional gifts of Christmas cookies and Easter candy. Other kosher homes set aside a room away from the kitchen where non-kosher food may be consumed. A kosher home must explain its rules to families at admission.

SOCIAL WORK AND SERVICES

What kinds of social work services are available in nursing homes and who provides them?

Nursing homes provide social work services for residents as needed, under the supervision of a staff person with a graduate degree in social work. When a new client enters the home, a social worker must interview her and her family and then inform the nursing staff of her individual needs and how her care was managed in the past. Afterwards, the social worker should be available to deal with any problems the resident or the family has in adjusting to the home. For example, a resident might tell her social worker that she would like to be moved to a different room or that she'd like help getting to activities programs. In many facilities, the social worker also handles applications both for admission to the home and for Medicaid, as well as discharge planning.

ACTIVITIES STAFF AND SERVICES

What are the state regulations about activities and who organizes them?

The state requires nursing homes to provide an activities program for all residents. A rich activities program helps keep residents alert, gives them a chance to socialize, and enhances their quality of life.

A director of activities with experience in planning programs in a health care setting must be on staff at the home. Ideally, this person should organize a full schedule of events, including art, music, dance, discussion groups, cooking sessions, holiday celebrations, and more. For each activity, there should be adequate staff and equipment available.

Offering activities that appeal to residents helps motivate them to participate. The home's director of activities should interview residents to find out what interests them and should choose activities that reflect the cultural and language backgrounds of residents. If this doesn't occur, residents or their families should tell the director what activities they would like.

Does my relative have to participate in activities if she doesn't want to?

No. The home should encourage residents to take part, but it may not force anyone to participate in an activity.

What if my relative is confined to her bed?

Your relative's activities plan must consider any of her special needs, including bed restrictions. Activities such as music, singing, and reading can be carried out at her bedside.

What if my relative wants to take part in activities in the neighborhood?

If she is able, the home should make arrangements for her to do so.

What can I do if my relative's home doesn't offer enough activities?

See [Chapter Seven](#) for problem solving tips.

If you find that your relative's nursing home offers too few activities (which may be a problem especially on weekends), discuss the problem with the activities director. If that doesn't work, file a complaint with the director or the administrator of the nursing home.

MEDICAL SERVICES

REHABILITATIVE SERVICES

What rehabilitation services do nursing homes provide?

Nursing homes must provide rehabilitative, or "rehab," services for all residents who require them. These include physical and occupational therapy, as well as therapies relating to speech, language, and hearing. The resident's physician must order all specialized rehabilitation services. If a nursing home does not have trained therapists on staff, it must obtain these services from an outside resource at no additional cost to the resident.

How do I find out what kind of therapy my relative needs?

Medicare coverage of restorative therapy is explained in the Sub-Acute Care Services section of this chapter.

If you think your relative could benefit from one or more of these rehabilitative services, talk to her doctor. Keep in mind that there are two basic kinds of rehabilitation. Restorative rehabilitation is intended to restore a function that a person has lost — such as loss of speech or mobility following a stroke. Maintenance therapy is used to prevent further functional loss or to maintain and strengthen a current level of functioning. A nursing home should offer both restorative and maintenance rehabilitation. Most restorative therapy is needed after a hospitalization because of a stroke, cardiac problems, or fractures.

Why is maintenance rehabilitation important?

Immobility weakens muscles and can lead to incontinence, bedsores, and depression. If your relative doesn't get around on her own, she should be prompted daily to move about as much as possible or helped with daily "range of motion" exercises that promote muscle function. Many facilities state that they provide range of motion exercise, but in reality fall short of providing what residents need to strengthen their muscles. Inadequate range of motion exercises can easily lead to contractures — contracted and atrophied muscles.

How do I make sure my relative is getting the rehabilitation services she needs?

Speak with your relative's doctor. Ask about the type and extent of rehabilitation he recommends. Review your relative's care plan, and, if necessary, discuss adding the rehabilitation services she needs with the planning team.

Visit the website of the New York City chapter of the Alzheimer's Association for additional resources and family support and training on issues relating to Alzheimer's and dementia ([NYC ALZ](#)).

ALZHEIMER'S DISEASE OR DEMENTIA SERVICES

Do nursing homes provide special services for people with Alzheimer's disease or dementia?

Many nursing home residents have some form of dementia and all nursing home staff should be trained to specifically care for people with dementia. Trained staff understand the different effects of dementia, from memory loss and confusion to agitation, aggression, and wandering. As a result, they can structure activities and daily life in ways that are most appropriate for these residents. Some nursing homes have day programs for residents who have dementia where they are put in a group setting, with a lot of one-on-one attention to keep them stimulated.

Many facilities that claim to have a "dementia unit" merely have a floor or unit where all the residents with dementia live. If your relative's nursing home is not adequately providing care for residents with dementia, contact MFY for suggestions and assistance in

improving your relative's situation. The New York City Chapter of the Alzheimer's Association offers consultation and training to nursing homes.

DRUGS AND MEDICAL SUPPLIES

How will my relative get the medications or supplies she needs?

The nursing staff must make arrangements to obtain prescription drugs and medical supplies (such as diapers, lotions, or powders) ordered by the resident's doctor. A consulting pharmacist must review each resident's prescription drug plan every 30 days. The purpose of the review is to alert the physician to incorrect dosages and potential conflicts between drugs.

Can my relative take medicines herself?

Your relative has the right to self-administer drugs unless the care team decides this would be unsafe. In that case, the nursing staff will administer the medications.

Should the family help to monitor a resident's drugs?

Family members should always be aware of what drugs their relative is prescribed and what the side effects are. Talk to the doctor if you have any concerns about your relative's medication. Over-medication or wrongly prescribed medication is a persistent problem in nursing homes. Make sure you provide information to the doctor about your relative's medication history. Tell the doctor about any medications that worked well or that caused negative side effects in the past.

How are drugs paid for?

If your relative is on Medicaid, Medicaid will pay for the cost of drugs and supplies. Medicaid will also pay for over-the-counter medicines and such items as powders and creams that the nursing home does not stock, if the resident's physician prescribes them. There is no

**To find your local
ombudsman, visit
[OMBUDSMAN](#).**

need for residents to spend their personal allowance on such items. If Medicare Part A covers your relative's stay, Medicare pays for medications.

If your relative is paying privately, insist on an itemized bill including medication expenses and check it closely. If the costs of medications are excessive, compare prices on the internet, ask the home to reduce the price, and as a next step, contact your local Ombudsman for help in resolving the issue.

DENTAL SERVICES

Is the nursing home required to provide dental care?

Nursing homes must provide oral hygiene care, as well as routine and emergency dental care. Within a week after your relative is admitted, and every year she spends at the home thereafter, she must have a complete oral exam by a dentist or oral hygienist.

However, not all homes provide dental care on site. If your relative's home does not have a dentist and hygienist on staff, she will have to get dental services outside, and the home will have to provide her transportation.

Are dental services included in the basic rate?

Not always. If your relative's home charges extra for dentistry and your relative is on Medicaid, a dentist who accepts Medicaid should serve her. If your relative is paying privately and dental services are not included in the basic rate, she may prefer to go to a dentist she knows.

If your relative's dentures are lost, insist that they be replaced promptly; it is the home's responsibility. Without them, she may not get enough nourishment and may develop health problems associated with weight loss. Medicaid will reimburse for the replacement of one set of dentures.

MENTAL HEALTH SERVICES

What mental health services do nursing homes provide?

See [Chapter Five](#) for detailed information on how to evaluate and select a nursing home.

Most homes make psychiatrists and other mental health professionals available onsite when they determine a resident needs these services. However, research shows that mental illness, especially depression, often goes untreated in nursing homes. Your relative's need for mental health services should be assessed in the comprehensive care planning process. It is helpful to know as much as possible about your relative's illness and the services that she may need before going into the home, so you are able to ask for specific services and better advocate for her.

Applicants for nursing homes who have mental illness histories often have difficulty getting into the most desirable facilities. Unfortunately, this can result in large numbers of residents with special mental health-related needs clustered in homes least able or inclined to create the specialized services needed.

Visit [Caring Connections](#) for detailed information about hospice or call the Caring Connections HelpLine at (800) 658-8898 for support and more information on end-of-life issues. Counselors on the HelpLine can also provide you with a variety of free consumer brochures, state-specific advance directives, and contact information for hospice-related services.

HOSPICE AND PALLIATIVE CARE SERVICES

Do nursing homes provide hospice care?

Many nursing homes provide hospice services through a contract with a hospice provider in the community. Hospice programs are for terminally ill nursing home residents with six months or less to live who choose palliative or comfort care instead of care to cure the illness or disease. Hospice care emphasizes the quality of life, instead of the length of life.

How is hospice care different from traditional nursing home care?

Hospice care is provided by an interdisciplinary care team of physicians, social workers, therapists, aides, and clergy who address the emotional, physical, spiritual, and psychological needs of both the resident and the family. There is an emphasis on making the patient as comfortable as possible in her last months

See [Chapter One](#) for more information on hospice and palliative care.

of life, so pain and symptom management is central to hospice care. Residents receiving hospice services usually get more individualized attention and have activities that are matched to their personal needs.

How is hospice care paid for?

Medicare pays for hospice care. In a nursing home, private payment or Medicaid continues to pay for housing, food, and personal needs.

For more information about palliative care, and for help in finding palliative care providers, visit the websites of the Center to Advance Palliative Care ([CAPC](#)) and the Hospice & Palliative Care Association of New York State ([HPCANYS](#)).

Can my relative get palliative care in a nursing home?

Palliative care is becoming more common in nursing homes. Similar to hospice, these programs emphasize symptom relief for residents who are terminally ill and for those who have chronic, life-limiting illnesses. Nursing homes offer palliative care using an interdisciplinary team approach.

Aggressive treatment aimed at cure can be included in a palliative care program. As a practical matter, if your relative wants to include curative treatment, you should help her raise the issue and see that the care plan reflects her wishes. Good palliative care will have a strong care-planning component and staff skilled in facilitating discussions about the kind of care desired as the patient's illness progresses.

Does Medicare pay for palliative care?

No, palliative care in a nursing home is paid for in the same way as other care and most often by Medicaid. This may mean that some of the individualized attention and extras made possible in hospice programs by Medicare reimbursement and volunteer staff will not be included in palliative care. You may have to pay extra for complementary medicine components, such as acupuncture or massage.

SPECIALIZED MEDICAL SERVICES

SUB-ACUTE CARE SERVICES

What sub-acute care services do nursing homes provide?

Sub-acute care falls between acute hospital care and traditional skilled nursing home care. It is needed immediately after, or instead of, hospitalization and includes medical services such as short-term rehabilitation, ventilator/respirator care, intravenous therapy, wound management, and cardiac rehabilitation.

See [Chapter Four](#) for more information on Medicare's coverage of nursing home care.

Sub-acute care is most often short term, 15-100 days, and is covered by Medicare for the length of time that a patient continues to benefit. Medicare will pay 100% of the cost for the first 20 days, and approximately 80% for up to 80 more days. Sub-acute care is usually provided in a separate area of the nursing home with additional staff assigned.

Some sub-acute care is long-term and is paid for privately or through Medicaid. Ventilator-dependent or brain trauma units are examples. These units must be certified and meet standards set and enforced by the Department of Health.

How often does the nursing home staff assess the sub-acute residents?

It is recommended that nursing home staff assess sub-acute residents within the first week of the resident's stay and on a frequent basis thereafter. Long-term nursing home residents are initially assessed within the first two weeks of their admission, and then on a quarterly basis. A resident is also evaluated after any significant change in her medical condition.

For more information about transfer and discharge, visit:

[DOH TRANSFER & DISCHARGE](#).

If you want to appeal a discharge or transfer from a New York Nursing Home, contact the New York State Department of Health's Nursing Home Complaint Hotline at (888) 201-4563. You can also file a nursing home complaint online using this form: [NURSING HOME COMPLAINT FORM](#)

or you can print the form and mail it to:
New York State
Department of
Health
DRS/SNHCP
Mailstop: CA/LTC
Empire State Plaza
Albany, NY 12237

Can my relative stay in a nursing home after short-term care ends, if she now needs long-term care?

In New York, a nursing home cannot discharge your relative against her wishes as long as the nursing home can provide your relative with the proper care, the home has been paid for her care, and your relative continues to need long-term nursing home care, even if the stay was originally intended to be short-term. Discharge regulations for sub-acute units are no different from those governing the rest of the nursing home, although nursing homes sometimes act as if they are. **Even if the nursing home tells you that your relative is being accepted only for short-term care and will have to move to another nursing home for a long-term stay, they cannot make her leave.** You can appeal an attempt to force your relative to move but a formal appeal is rarely necessary. Letting the home know you are aware that your relative can stay is usually enough.

What do I do if I am told my relative will be admitted for short-term care only?

Nursing homes would prefer to reserve some beds for short-term sub-acute care because they receive higher Medicare reimbursement rates for sub-acute care. They may try to mislead you into believing your relative must transfer to a new "long-term care" nursing home.

Don't agree to a short-term-only placement. Even if you do, agreements to stay for only a short-term are not binding. If your relative's doctor thinks that her need for care will end in less than 30 days, you may receive a 30-day notice of discharge at the time you enter the facility.

If you receive a 30-day notice of discharge, and you believe your relative may not be ready to go home that soon, or may need to stay indefinitely for long-term care, follow the instructions for appealing the notice of discharge, which are located on the back of the notice. If the nursing home insists on the discharge, file a complaint with the Department of Health.

Your relative has the right to appeal within 15 days of receiving the notice. Don't wait until you are sure that she needs additional care; appeal within the 15 days. If your relative is ready to go home as scheduled, you can cancel the appeal.

OTHER SPECIALIZED UNITS

Do nursing homes admit residents who are dependent on ventilators or have other specialized needs?

To find a nursing home with specialized ventilator, TBI, AIDS, or behavioral units, visit the New York State Department of Health's directory, [DOH NH DIRECTORY](#), choose your geographical area, and under "Search for Special Services," select "Ventilator Dependent," "Traumatic Brain Injury," "AIDS," or "Behavioral Intervention" from the drop-down box.

Some nursing homes have specialized units for ventilator-dependent residents, for residents with traumatic brain injury (TBI units), with AIDS, with severe behavioral problems (neurobehavioral units) or with other specific medical needs. A few nursing homes in New York City serve only residents with AIDS. Regulations require additional and specially trained staff for these units. Also required are more extensive assessments and review of the condition and care needs of residents in these specialized units.

If my relative has been living in a nursing home, can she get sub-acute care there if her condition changes so that she needs it?

Sometimes. Nursing homes without specially certified units for ventilator-dependent residents, for example, may have the required equipment and may provide the specialized medical services for a resident who comes to need them.

If you are offered this kind of specialized care in a facility without a certified unit, make sure that the home is following the same regulations for the single resident as they would for an entire unit. For example, the law requires that a nursing home provide a pulmonologist (a respiratory specialist) for ventilator patients whether they are in a vent unit or in a single vent bed.

ADDITIONAL REGULATIONS AND RIGHTS

PHYSICAL AND CHEMICAL RESTRAINTS

When and why do nursing homes use restraints?

The Long Term Care Community Coalition publishes a consumer guide summarizing and explaining the rules governing the use of restraints in New York State nursing homes ([LTCCC RESTRAINTS](#)).

Federal and State regulations prohibit restraints except in very limited circumstances. **Physical restraints** — devices or appliances that restrict movement, such as bedrails, lapboards, seat belts, and vests — may be used to control residents with disruptive or self-destructive behavior under certain circumstances. Examples include residents with violent seizures or those who repeatedly pull out an I.V. or stomach tube. People who exhibit disruptive, paranoid, or delusional behavior may be given psychoactive medications, which are considered **chemical restraints**.

Aren't restraints necessary for some residents?

Very rarely. Not only are physical restraints dangerous; they also undermine a person's dignity and independence. They can increase anxiety and cause depression, distress, and even death. Restraints are often used for the wrong reasons — and are sometimes merely substitutes for proper care. While restraints may seem like they make life easier for staff, in the long run their use can create greater demands on staff time because of the severe physical and psychological consequences for residents.

Restraints should be avoided whenever possible, and nursing homes must seek alternatives to their use. Most nursing homes are trying to comply with these regulations, but few homes offer truly restraint-free environments. Some nursing homes still use physical and chemical restraints inappropriately, for example, to control residents whose behavior is troublesome.

How can physical restraints harm a resident?

If too tightly applied, physical restraints can cause brush burns, bruises, blisters and poor circulation. If they are too loosely applied, the patient may slip

through and become entangled in them. Leaving a resident in a physical restraint for too long may cause stiffening of the muscles and increase the risk of breathing, urinary, and skin problems.

Are there alternatives to physical restraints?

Call MFY at (855) 444-6477 if you are concerned about the use of restraints on your relative.

Yes — depending on the reason for their use. For example, supporting someone in a wheelchair by wedging a specially shaped pillow under her knees might work better to prevent falls than tying her into the chair. There have been many studies of alternatives to restraints. Ask the nursing home staff about safer ways of restricting movement or safeguarding a resident. Or call MFY for suggestions.

But do some restraints, like bedrails, make my relative safer?

That depends. Bedrails can sometimes cause accidents with far more serious consequences than falling out of bed. Active residents with dementia trying to get out of a bed with bedrails are at a greater risk. They can easily get caught on the bedrail, making a fall more dangerous. Facilities can avoid most bedrail use if they take the time to figure out why a resident is likely to fall out of bed and then try alternative preventive measures, like prompt help with toileting or lowering the bed and putting mattresses on the floor to cushion a fall. Newer beds allow for partial bedrails, which are safer than full-length ones.

Department of Health guidelines allow residents and their representatives some leeway in choosing bedrails. Those who decide that the risk of a fall out of bed outweighs the risk of accidents involving bedrails can usually get bedrails. Make sure you have enough information to make the safest choice.

What are chemical restraints?

Sometimes psychoactive drugs are prescribed for nursing home residents to alleviate anxiety, angry behavior, screaming, delusions, and paranoia. If carefully prescribed and vigorously monitored, drugs

can be effective in alleviating these symptoms. However, these drugs are very powerful and may have adverse side effects.

Furthermore, such medications should be used only for psychiatric purposes — not to control difficult behavior. Use of these medications to deal with an agitated or aggressive resident can be a way for the home to avoid examining the underlying causes of her behavior.

But what can I do if my relative acts in a disruptive manner?

Work with the home to analyze her behavior. Try all non-drug interventions before medications are prescribed. Usually, residents get agitated or aggressive when they are afraid, anxious, bored, thirsty, or hungry but unable to communicate with those around them. For residents who have dementia, agitation can indicate pain or infection, such as a urinary tract infection (UTI). Suggest changing your relative's routine or encourage staff to engage her on a more one-on-one basis to keep her calm and involved in an activity. If these changes don't work, a medical evaluation may be useful to identify any physical pain. If staff members address the underlying problems, they can reduce or avoid the use of psychoactive drugs.

What are the side effects of these drugs?

In the short-term, chemical restraints can cause drowsiness and confusion. Other side effects can include sleeplessness, constipation, blurry vision, or unsteady gait. What's more, side effects can lead to other problems. For example, if your relative's vision is blurry or her gait unsteady, she may fall and suffer a fracture. To prevent such accidents, make sure the home takes the necessary steps to keep her safe until the drug has worn off.

Long-term use may bring on a neurological disorder called tardive dyskinesia, which causes involuntary twitching of the hands, arms, legs, mouth, and facial

muscles. And there can be other serious effects, such as incontinence, pneumonia, and psychological and emotional reactions.

If you are worried about the use of restraints on your relative, and you are unable to resolve your concerns with the nursing home directly, contact your local ombudsman [OMBUDSMAN](#).

How do state regulations limit the use of restraints?

Each facility must have written policies describing the kinds of restraints it uses and the reasons for their use. Except in an emergency, a doctor must prescribe restraints and restraints may be used for a limited and specific period of time only. The reason for the restraint must be recorded in the resident's medical record. **Restraint orders must be reviewed and rewritten by the resident's doctor at each regular visit; the resident or her designated representative also has the right to request that the orders be reviewed.**

**If you want to file a complaint about nursing home restraints, contact the New York State Department of Health's Nursing Home Complaint Hotline at (888) 201-4563. You can also file a nursing home complaint form online ([NURSING HOME COMPLAINT FORM](#)), or you can print the form and mail it to: New York State Department of Health
DRS/SNHCP
Mailstop: CA/LTC
Empire State Plaza
Albany, NY 12237**

In an emergency, physical restraints may be applied at the discretion of the medical director, director of nursing or, in their absence, a registered nurse. The circumstances requiring the emergency use of restraints must be fully documented in the resident's medical records and the resident's personal physician must be consulted within 24 hours. Chemical restraints can be ordered only by a physician.

Is there a limit to the length of time a resident can be held in physical restraints?

Yes. Residents in physical restraints must be released every two hours and helped to walk or change position. They must be examined, when being dressed and un-dressed, for problems such as skin abrasions and loss of circulation.

Can a resident refuse the use of restraints?

Yes. Nursing home residents have the right to refuse either physical or chemical restraints after being informed of the risks of doing so. A health care agent can also refuse on a resident's behalf. A designated representative, while not empowered to refuse, should nonetheless try to advocate for the resident.

If the home is planning to use restraints on my relative, will I be informed?

State regulations require that families be told in advance of a home's decision to use or remove restraints. Staff should explain the risks and benefits of the plan so that the family understands the medical reasons for this decision. **You have the right to bring in an outside medical consultant if you are not satisfied with the advice of the home's physician.**

HOLDING A NURSING HOME BED

THERAPEUTIC LEAVE – OVERNIGHT VISITS OR SHORT TRIPS

Can a resident leave the nursing home for an overnight visit or a short trip without losing her bed?

Yes, if the resident's care plan permits overnight stays outside the facility and her physician orders the leave. If a resident is on Medicaid, Medicaid will pay the nursing home a portion of the regular Medicaid rate to keep the resident's bed during these overnight trips if: 1) she has been in the home for more than 30 days; and 2) 5% or less of the home's beds will be vacant during the resident's leave days. If the purpose of the leave is to visit a health care professional to improve the patient's physical condition or quality of life consistent with the resident's plan of care (a "therapeutic leave"), Medicaid will pay to hold the bed for a maximum of 14 days during any 12-month period. Keep in mind that this 14-day maximum includes any hospital leave days (see below) taken during the 12-month period. If the resident takes a leave for reasons other than a therapeutic leave, Medicaid will pay to hold the patient's bed for another 10 days during the 12-month period.

If you are planning a personal leave for your relative, let the home know well in advance so that they can do the necessary paperwork and assemble any medications or supplies needed during the time she will be away.

HOSPITALIZATION

What happens if my relative needs to be hospitalized during a nursing home stay?

After a short hospital stay, your relative should be able to return to her same bed at the nursing home. However, this privilege varies. It depends on how long she needs to be in the hospital, how long she has lived at the home, and how she is paying for nursing home care. A guarantee to hold the bed is important. Sometimes residents refuse to go into a hospital because they are afraid they will lose their place at the home.

If your relative is on Medicaid, Medicaid will pay the nursing home a portion of the regular Medicaid rate to keep your relative's bed during her hospitalization if: 1) she has been in the home for more than 30 days; 2) she has been hospitalized no more than 14 days in any 12-month period (combined with her therapeutic leave days, as described above); and 3) 5% or less of the home's beds are vacant during the days she is hospitalized. Under these circumstances, Medicaid will pay the nursing home to hold her place while she is in the hospital so that she can return to the same room and the same bed in the same nursing home after discharge.

What if my relative does not meet the criteria for a Medicaid bed hold?

Medicaid will not pay the home to keep the bed open if she exceeds the allowed days during any 12-month period, as described above, or if more than 5% of the home's beds are vacant during her hospitalization or leave. However, a resident who loses a "bed hold," but has been in the home more than 30 days, has the right to return to the first-available bed in that facility.

There is no time limit on the right to return. If the patient is waiting for the first-available bed in the home she came from, the hospital discharge planner typically will not try to find another nursing home bed

for her as long as there are other hospital patients who can fill available nursing home beds in other homes.

If my relative is in and out of the hospital a lot, is there a limit to the amount of time the home must hold her bed for her?

Yes. A nursing home is not required to hold a bed for any resident who has been hospitalized for more than 14 days in any 12-month period.

Does the same policy apply to residents who are on Medicare?

No. Medicare does not pay to keep a bed open while a nursing home patient is in the hospital. If your relative is paying privately or is on Medicare, ask about the home's bed-reservation policy. Many homes ask for payment from the resident or family to reserve the bed.

What about private-pay residents?

Families of a private-pay resident who agree to pay to hold a bed if the resident is hospitalized should remember to tell the home if the situation changes and they no longer want the bed held. Otherwise, they may continue to be charged.

What if the nursing home refuses to take my relative back from the hospital?

In rare cases, a resident's health condition changes significantly while in the hospital so that the nursing home is no longer able to provide adequate care. Sometimes the refusal is simply a way to get rid of a resident considered undesirable. A refusal to take a resident back is a discharge. You can appeal a discharge made while the resident is in a hospital.

Although nursing homes are required to give a hospitalized resident a discharge notice, if they refuse to take her back this may not always happen. You should ask the nursing home for a discharge notice at the same time you let the Department of Health know

The Department of Health and Human Services, National Legal Resource Center, provides information about locating free or low-cost legal services for the elderly ([LEGAL SERVICES PROVIDERS](#)).

Call MFY at (855) 444-6477 if you need advice or legal representation on issues relating to nursing home resident abuse and neglect, civil rights violations, improper discharge planning, or unfair consumer practices.

you want to appeal. If possible, a lawyer in this kind of appeal should represent your relative. Free legal services lawyers may be available for residents on Medicaid.

DISCHARGE OR TRANSFER FROM THE NURSING HOME AND APPEAL RIGHTS

Does a resident have the right to move out of a home of her own accord?

Yes, a resident can voluntarily transfer out of the facility. In that event, the home is responsible for helping her find appropriate housing with necessary support systems.

Can a resident leave a home even if the nursing home thinks it's not in her best interests?

The resident has the right to do this, but the facility must warn her of the potential risks if proper support services cannot be secured elsewhere. If the resident leaves, she will be asked to sign a form acknowledging that she is leaving "against medical advice," sometimes referred to as AMA. If the resident is not able to understand the consequences of leaving, the nursing home must go to court to have a guardian appointed.

Can my relative's room in the nursing home be changed without her consent?

Yes. However, guidelines issued by the Department of Health suggest that the decision to change a resident's room should be made only after a consultation between the resident, the family, and the home. When a resident objects to the move, the home should conduct an evaluation to determine if the reasons for the move outweigh the resident's objection.

Moving from familiar surroundings can be traumatic. A well-run nursing home will make sure that residents, especially those with dementia, are given some preparation and emotional support before they are moved, and will make room changes only if there are no alternatives.

Can the nursing home discharge or transfer my relative from the home involuntarily?

According to state regulations, nursing home residents may be discharged or transferred to another facility only when the nursing home's interdisciplinary care team determines that one of the following applies:

- the transfer or discharge is necessary for the resident's welfare, and the resident's needs cannot be met at the facility;
- the resident's health has improved sufficiently so the resident no longer needs the services provided by the facility; or
- the resident endangers the health or safety of others at the facility.

Can a resident be discharged for not paying the nursing home fees?

Yes. A resident may be discharged for failing to pay for her stay. However, she may not be discharged while she is disputing a charge, if she is appealing a denial of benefits by Medicaid or Medicare, or if she has funds that are not accessible to her.

Does the home have to notify anyone of its decision to discharge or transfer a resident?

Yes. The resident and her designated representative must receive a written notice at least 30 days in advance explaining the reasons for the transfer. Meanwhile, the home must make appropriate discharge plans in consultation with the resident and designated representative.

The home does not have to give a 30-day notice if:

- the resident's urgent medical needs require transfer or discharge sooner;
- the resident endangers the safety or health of other residents;
- the resident's health has improved sufficiently to allow a more immediate discharge or transfer; or

- the resident has requested the discharge.

Under these circumstances, however, the home should give the resident as much advance notice as possible.

To appeal a discharge or transfer from a New York Nursing Home, contact the New York State Department of Health's Nursing Home Complaint Hotline at (888) 201-4563. You can also file an appeal or discharge complaint online ([NURSING HOME COMPLAINT FORM](#)) or you can print the form and mail it to: New York State Department of Health DRS/SNHCP Mailstop: CA/LTC Empire State Plaza Albany, NY 12237

Can my relative or her representative contest the home's decision to discharge or transfer her?

Yes. Unless your relative is a danger to other people at the home, she has the right to demand an appeal from the Department of Health (DOH) within 15 days after receiving the discharge notice. The home's written discharge notice must include information on how to appeal the home's decision. This hearing is conducted at the nursing home, and the DOH requires that it be held before an impartial party, as fair hearings usually are. If the request for a hearing has been made in a timely way, your relative may not be discharged until there is a decision on the appeal.

What happens if we don't file the appeal on time?

If you don't file the appeal until after the 15-day limit, the home can discharge or transfer your relative against her will. However, a hearing must still be held within 30 days of her discharge or transfer. If the state decides the home's action was inappropriate, the home must readmit her before it can take in another resident.

What if my relative's behavior is dangerous to other residents?

In cases involving immediate danger to others, the home can transfer your relative against her will. However, if she appeals the transfer, the home must hold her bed until the hearing decision is handed down. Keep in mind, though, that if the home's action is upheld, and your relative is a private-pay patient, she will be charged for the days the bed was held.

To find contact information for your local Mental Hygiene Legal Services office, visit [MHLS](#).

Can the home transfer my relative to a mental hospital?

If two psychiatrists certify that your relative represents a danger to herself or others, she can be committed to a state psychiatric facility for 30 days. But, even then, she has the right to a hearing and free legal representation, which is provided by Mental Hygiene Legal Services.

The New York City Department of Consumer Affairs publishes a helpful booklet on what to do when a loved one dies ([NYC DCA WHAT TO DO](#)). Also, the National Institutes on Aging publishes a consumer guide on end-of-life issues, including the steps that must be taken after a death ([NIA END OF LIFE ISSUES](#)).

WHEN A RESIDENT DIES IN A NURSING HOME

What will happen if my relative dies while she is in a nursing home?

The nursing home must notify your relative's designated representative of her death. If there are personal belongings you want to retrieve, try to make the arrangements promptly as things may be discarded very quickly.

Good social services staff will tell the residents who knew your relative. They might arrange a memorial service within the home or help arrange transportation for residents to a funeral or service outside. If this is not done, you may want to take the initiative yourself to speak to residents who were close to your relative.

NURSING HOME REGULATIONS & RIGHTS RESOURCES

Alzheimer's Association

225 North Michigan Avenue, Suite 1700, Chicago, IL 60601; (800) 272-3900. Provides training and support to those providing care for people with Alzheimer's disease and dementia. Call or visit the website to find a chapter in your area.

www.alz.org

Publishes a resource list on making nursing home decisions, including finding care providers and transforming nursing home environments to benefit the home's residents:

http://www.alz.org/library/downloads/search_nursinghomedecisions.pdf

Also publishes a comprehensive resource list containing sources and strategies for finding, evaluating, and selecting nursing homes:

http://www.alz.org/library/downloads/search_nursinghomedecisions.pdf

Caring Connections

HelpLine: (800) 658-8898

A consumer engagement initiative of the National Hospice and Palliative Care Organization. Provides state-specific advance directives and other resources and information to help people make decisions about end-of-life care and services before a crisis. Call the HelpLine for a compassionate ear and for answers to questions on hospice and palliative care services, end-of-life issues, and to obtain a variety of free consumer brochures and contact information for community services.

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>

Provides information on palliative and hospice care in a question and answer format:

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3355>

Long Term Care Community Coalition (LTCCC)

242 West 30th Street, Suite 306, New York, NY 10001; (212)-385-0355

An advocacy and watchdog group formed to protect the rights of nursing home residents.

<http://www.ltccc.org/>

Publishes a guide that contains extensive information and resources to help individuals understand and navigate the long-term care system in New York State:

<http://ltccc.org/publications/documents/NY-LTC-Consumer-Guide-finalcolor.pdf>

Publishes a comprehensive and easy-to-read guide on the rules and regulations governing New York nursing homes:

http://www.ltccc.org/publications/documents/RulesRegulationsGoverningNYSNH_000.pdf

Visit <http://www.ltccc.org/ConsumersGuideTheUseofRestraintsinNYS.pdf> to read LTCCC's consumer guide on the use of restraints in nursing homes. LTCCC also publishes a consumer guide on how the law can be used to help protect the rights of nursing home residents: http://nursinghome411.org/documents/NHLegalRightsBriefing2007_000.pdf

Mental Hygiene Legal Services (MHLS)

MHLS, an agency of the New York courts, provides free legal services and advice and assistance to patients in New York psychiatric hospitals. Visit http://www.omh.ny.gov/omhweb/consumer_affairs/resources/docs/Contact_MHLS.html to get contact information for the MHLS office in your area or call the statewide help line at (800) 597-8481.

National Long-Term Care Ombudsman Resource Center (NORC)

1001 Connecticut Avenue, NW, Suite 425, Washington, DC 20036; (202) 332-2275

NORC provides support, technical assistance, and training to state and regional ombudsman programs.

<http://www.ltcombudsman.org>

Provides a bill of rights for nursing home residents:

<http://www.ltcombudsman.org/sites/default/files/norc/Module-2.pdf>

New York State Department of Health (DOH)

Corning Tower, Empire State Plaza, Albany, NY 12237; Nursing Home Complaint Hotline (888) 201-4563.

The DOH publishes excellent consumer information on issues relating to quality of care, nursing home resident rights, and nursing home complaints, transfers and discharges.

<http://www.health.ny.gov/>

Visit this page if you want to make a complaint about a New York nursing home with the DOH:

https://apps.nyhealth.gov/nursing_homes/complaint_form/complain.action

Read the DOH's guide "Your Rights as a Nursing Home Resident in New York State":

http://www.health.ny.gov/facilities/nursing/rights/docs/your_rights_as_a_nursing_home_resident.pdf.

Visit http://www.health.ny.gov/professionals/patients/health_care_proxy/ to learn more about New York health care proxies.

New York State Office of Long-Term Care Ombudsman Program (LTCOP)

New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12223; Senior Citizens Help Line (800) 342-9871.

The LTCOP assists residents of nursing homes in most parts of the state. To find your local ombudsman, use the LTCOP Directory:

<http://www.ltcombudsman.ny.gov/whois/directory.cfm>

**THIS CHAPTER
INCLUDES THE
FOLLOWING:**

**An overview of
problems that occur
in nursing homes
and how to solve
them**

**Specific strategies
to help you become
an advocate for
your relative**

**Information on
government
agencies and other
organizations that
can help you fight
for your relative's
right to quality
nursing home care**



**SOLVING PROBLEMS:
BECOMING AN
ADVOCATE FOR
YOUR RELATIVE**

Even in the best of nursing homes, problems arise. Many problems are minor and can be easily resolved when called to the attention of responsive nursing home staff. Some residents never experience serious problems, but it is wise to be aware of what can happen and what you can do about it. Inadequate staffing levels or poorly trained workers may result in neglect of residents' personal-care needs. Neglect, in turn, can compromise the health of frail, elderly people. For example, too little time spent feeding a resident who can't eat by herself can lead to weight loss and other physical complications. Failure to make sure a resident walks often and performs daily range-of-motion exercises can lead to loss of mobility and confinement to a wheelchair.

A poor attitude on the part of a nursing home's top administrators can also create problems. If administrators fail to show interest and respect for residents and their families, the staff has no incentive to act in a caring and supportive manner. To ensure residents' health and comfort, staff members must visit with them and be alert to changes in their conditions. However, management may pressure health care workers to spend more time on paperwork or measurable tasks (such as making beds and cleaning rooms) than on personal exchanges with the residents in their care. The extent to which physical or chemical restraints are used in the home also reveals the prevailing attitude about residents' autonomy and quality of life.

See [Chapter Six](#) for more information about regulations and resident rights.

New York State regulations lay out minimum standards for good health care in nursing homes, define many resident rights, and obligate nursing homes to maintain a high quality of life for their residents. They require “sufficient staffing” to provide the level of care described, but understaffing is widespread in New York nursing homes. Many consumers support state and national proposals to require minimum-staffing levels.

There is more information about complaints to the DOH later on in this chapter.

The regulations themselves are not enough to ensure that adequate care is provided every day in every home for every resident. Sometimes serious forms of neglect and outright abuse can occur in nursing homes. If violations occur, regulations require that such incidents be reported immediately to the Department of Health (DOH). However, because the DOH is not always effective, you should actively participate in your relative’s care. Visit the home often. Learn about your relative’s care plan — enough to monitor her treatment effectively and to become a good advocate for her when problems arise.

The U.S. Department of Health & Human Services Administration on Aging publishes a number of helpful publications on identifying and preventing elder abuse ([AOA ELDER ABUSE](#)).

Many friends and families hesitate to complain or fight for change for fear that the nursing home staff will retaliate against their relatives. But residents who have someone to advocate for them tend to receive better care than residents without an advocate. If other residents are having the same problem as your relative, you can join forces with their families, or with the home’s family or resident council, to address the problem and improve care.

Nursing homes can be intimidating. But keep in mind that your role in monitoring care is crucial in improving care for your relative and future residents. If there are problems, it’s likely that without your involvement, your relative’s care won’t improve. If the problems are serious, other residents are probably suffering, too.

MFY’s Nursing Home Residents helpline is (855) 444-6477.

MFY can help, with our tips in this chapter and through our Nursing Home Residents Project helpline. The first part of this chapter discusses the advocacy skills and strategies you’ll need to solve problems at your

relative's facility. Then we'll talk about formal complaints to the Department of Health, specifically about abuse, neglect, and serious mistreatment. As you read, keep in mind that no single method works in every situation. Sometimes a combination of approaches is necessary.

PROBLEM SOLVING

What are typical problems that arise in nursing homes?

The National Consumer Voice for Quality Long-Term Care (Consumer Voice) publishes a handy fact sheet on problem solving in nursing homes: [PROBLEM SOLVING](#).

Problems that arise in nursing homes vary widely from the occasional to the chronic, and from the irritating to the life-threatening. A common problem is that family members may discover that certain aspects of their relative's comprehensive care plan (also called a plan of care) are being neglected. For example, a common complaint from family members is that nursing homes do not provide regular range-of-motion exercises to maintain their relative's level of mobility. Family members might also notice that their relative is unusually drowsy or unresponsive because of too much or inappropriate medication. Overworked attendants may ignore residents' requests to go to the toilet, or may leave them to sit all day without taking them for a walk, or even changing their position. In some homes, signs of illness may be overlooked. For example, the failure of nursing home staff to realize that a resident is having difficulty swallowing could lead to medical complications resulting in hospitalization due to dehydration and rapid weight loss.

Can my family really get problems solved at our relative's nursing home?

That depends on the type of problem and the home's responsiveness to your family's concerns. The kind of action that you will need to take depends on the answers to these questions:

- **Is this a problem being experienced only by your relative?** Individual care problems are the easiest ones for individual family members to solve. You

may be able to correct problems with a simple conversation with a worker or supervisor at the nursing home. It's best to make an appointment to have this conversation. Staff might be less responsive if you interrupt at a bad time.

See later in this chapter for more information on making DOH complaints.

- **Is this a case of abuse by a staff member or by another resident?** When there is a situation of abuse or any serious incident, you should immediately report the incident directly to the nursing home's administrator and to the New York State Department of Health (DOH).

More information on family councils appears later in this chapter.

- **Is this problem the result of larger, systemic issues at the home, such as insufficient staff assigned to do the necessary tasks?** This kind of problem is the hardest for a single family to solve. It helps to join together with other relatives or urge an existing family council to address the problem.

Can anybody else help?

Yes, help is available and it is important to remember that you are not alone. Family councils and resident councils at the nursing home may lend support to any complaints you need to file. MFY can give New York City nursing home residents and their families information and advice about how to identify problems and work with the home to solve them. Most counties have Long-Term Care Ombudsman programs that help resolve complaints. The New York State Department of Health (DOH) investigates complaints. The Medicaid Fraud Unit of the State Attorney General's Office investigates criminal cases of abuse, neglect, or mistreatment in a nursing home. The police are also an option in cases of criminal behavior.

To find your local ombudsman, visit [**OMBUDSMAN**](#).

To find your local Medicaid Fraud Control Unit, visit [**MFCU MEDICAID FRAUD DIRECTORY**](#).

If I complain, will the nursing home take it out on my relative?

As mentioned earlier, many families are afraid to speak out about problems for fear of retaliation against their relative. Retaliation can occur, and some staff members may treat you less pleasantly than before. However, if you don't complain, the problem isn't

going to go away, and it could get even worse.

Good administrators and supervisors want to be informed about problem areas or negligent workers in their facilities. In fact, your complaints can help them take action against incompetent or abusive employees. Most importantly, New York State regulatory agencies can do nothing at all if you don't bring the problem to their attention.

BECOMING A GOOD ADVOCATE

FIVE STEPS TO BECOMING A GOOD ADVOCATE:

1. PLAN AHEAD,
2. KEEP A DIARY OR LOG,
3. IDENTIFY THE PROBLEMS,
4. WORK OUT A SOLUTION, &
5. GET SUPPORT

PLAN AHEAD

Are there things I can do before a problem occurs?

Yes. Keep your eyes open when you visit your relative. Get to know the home's routine, your relative's care plan, and the staff members most involved in providing her care.

How do I find out what I need to know?

See [Chapter Six](#) for complete information about the comprehensive care plan.

- Attend the comprehensive care plan meeting to find out about the home's plan of care for your relative and to provide staff with information about your relative's medical and personal history. Tell the doctor, the care team, and the social worker that you are concerned about care and want to be consulted if problems or changes occur. It's extremely important for you to attend this meeting, which is held within the first 21 days after your relative enters the nursing home. Make sure you get a copy of the care plan, even if you weren't able to attend the care plan meeting.
- Get to know your relative's daily schedule. The

care plan includes your relative's daily schedule, her medications, the activities or therapy sessions she is supposed to attend, and so forth. It also indicates treatment goals — for example, what outcomes the staff expects from physical therapy. **The more you know about your relative's routine, the quicker you'll notice if something goes wrong.**

- Get to know the staff. Make a list of the names and telephone numbers (or extensions) of all the people who have primary responsibility for your relative's care: her doctor on both the day and the night shifts, the supervising floor nurse, her social worker, the director of nursing, the medical director, and the nursing home administrator (all staff must wear nametags). If possible, call staff during the shifts when you can't visit the home and ask about your relative's status.
- Try to develop good relationships with all of the staff you encounter, especially with the nurse aides (CNAs or NAs) directly involved in your relative's day-to-day care. In most well-run homes, the nurse aides caring for your relative will stay the same. However, some nursing homes rotate staff or rely heavily on per diem or substitute nurse aides. By visiting frequently and on different shifts, you increase the chance of meeting all the staff caring for your relative. The aides' willingness to know and support your relative is an essential piece of your relative receiving good quality care from the home. Let the aides caring for your relative know that you support and appreciate them. Remember, they are trained, skilled professionals and should be treated as such.
- Find out about the home's complaint procedure. All homes are required to have one, although it's sometimes a well-kept secret. Nursing homes must respond to complaints within 21 days of receiving them. It is a good idea to put complaints in writing, noting the date, time, and other details.

See the **Family Councils** section later in this chapter.

See [Chapter Eight](#) for more information on health care agents and surrogate decision-making under the Family Health Care Decisions Act.

- Join the nursing home's family council, if there is one. Councils sometimes have a complaint process and may be able to help you solve problems.
- Review your relative's medical records on a regular basis. Your relative can give you permission to read them. However, if your relative is mentally incapacitated, you must be the designated health care agent or a surrogate under the Family Health Care Decisions Act to see the medical chart. Doctors should inform close family members about your relative's condition and care. Ask questions about what the records mean if you don't understand them. This will put you in a good position to monitor changes and irregularities that appear in the chart.

KEEP A DIARY OR LOG

What should be in a diary or log?

It's a good idea to take notes of what you observe every time you visit the home, especially if the problem is a chronic one, such as failure to provide clean sheets or to change your relative when needed. You don't have to write volumes — just a few words to remind you what happened, when, etc. For example, if feeding seems rushed, note why and when you first decided to keep track of your relative's mealtimes. Then, each day note what you observed during meals and how long the staff spent assisting with feeding.

IDENTIFY THE PROBLEMS

How do I identify a problem?

Trust your instincts. If something seems wrong to you, it probably is — even if you can't put your finger on it. You may notice changes in your relative that staff have overlooked. Note any changes you see. Discuss your observations with family and friends who visit your relative in the home. If you suspect a medication error, look at your relative's medical chart for new or changed prescriptions. Ask to see the chart even if the staff insists there's been no change. Often,

aides and nurses will not have been informed about changes in your relative's medication.

Tell the supervisor. It's always best to tell supervisors about a problem sooner rather than later. The situation may be relatively easy to solve once you've reached the person able to make the change you need.

Be concrete and specific. Get the facts and write them down. Make sure you know specific answers to the following questions:

- What exactly is the problem?
- Is the problem a one-time incident or has it occurred gradually over time (weight loss, for example)?
- Where in the home did the problem occur? Be specific about the location.
- What day did the problem occur? What time? What work shift?
- Which staff members were on duty at the time the problem occurred?
- Were there any witnesses — such as residents or visitors?
- What can nursing home staff tell you about what happened?

Sticking to concrete facts and a reasonable conversational tone can be very difficult when you are extremely angry or frustrated. But if you raise a problem and then mix facts with an outpouring of emotion, you give staff the opportunity to focus on the emotion — to try to calm you down — while ignoring the problem itself. Even if it means a slight delay, approach staff only when you can keep the discussion focused on the problem.

Take photos. If you can't get staff attention but see that a problem is getting worse, like a spreading rash or a pressure sore that isn't healing, photos can help you document the problem. Confronting a charge nurse or director of nursing with photos of bruises, wounds, or rashes could force them to look into a problem that has been ignored. Remember to respect other residents' privacy and avoid taking their picture without consent.

WORK OUT A SOLUTION

Once I've identified the problem, then what?

Find the right person. Very few health care problems are simple and straightforward enough to resolve directly by speaking with floor staff. Most administrative staff work from 9 to 5, Monday through Friday. However, State law requires that there be a nurse supervisor on duty at all times. If the home has an effective complaint system or a responsive social work department, begin there. If you don't get a prompt response, go to the appropriate supervisory staff. For example, if your relative is having problems with her nutritional intake, you should speak to the dietary director. Most care problems, however, should be taken to the director of nursing services.

Be a good negotiator. Be clear about what you want and ask for it in a neutral, straightforward way. Stick to the facts and stay focused on your goals. In real life, this is hard — especially if you are afraid for your relative or angry at how she was treated. But remember: the idea is to fix the problem as quickly as you can. Usually, the best way to do that is to stay calm, focused, factual, and persistent.

Set a timetable for change. In your diary or log, keep track of the names of the staff members you spoke to, what you told them, and what they told you. Ask them to specify what they plan to do and how much time it will take to do it. If you are told that the problem can't be solved immediately, set up a reasonable timetable. Write up your notes, with a summary of what has been agreed to, and give a copy of them to the staff

member.

Follow through. If the problem isn't solved by the date you've agreed upon, find out why. Keep notes on any changes — positive or negative — that result from your complaints and suggestions. Stay in touch with the department head and the staff. This may not be easy: key staff people generally work weekdays and are not available to speak to you in the evening or on weekends, the times when you are most likely to visit your relative.

What are other suggestions for addressing problems?

There is more information filing complaints with the DOH later on in this chapter.

If you don't seem to be getting anywhere, speak to the top administrator of the nursing home. Also consider making a complaint to the Department of Health (DOH). Make sure you put the problem in writing to the DOH and send copies of your letter or report to the administrator and the supervisory staff you've been dealing with. Many families also send copies to the home's family council. Often, problems are solved more quickly when the home realizes that others outside the nursing home are aware of them.

What if I'm doing everything possible to solve the problem but I'm getting nowhere?

If the nursing home staff is unresponsive to your calls or complaints, you may need to get help from outside sources. But first, try to clarify why the problem has not been solved:

- Is the problem due to a nursing home policy or practice that the staff has no power to change?
- Is the administrator unwilling to change the policy or is the problem the failure of the staff to carry out a home's policy?
- Is the policy not being carried out because of a lack of supplies or insufficient staff assigned to do the tasks needed?

GET SUPPORT

FAMILY COUNCILS

What are family councils?

Visit the Consumer Voice for Quality Long-Term Care's online family council center to obtain factsheets and other materials related to family council creation, maintenance, rights under federal law, and advocacy tips: [CONSUMER VOICE FAMILY COUNCIL CENTER](#).

As the name suggests, family councils are organizations made up of the family and other regular visitors of residents in a particular nursing home. Some organizations are called “family and friends councils” or “friends and relatives councils” to make sure partners, neighbors, and all regular visitors are included.

The functions of councils vary from home to home. Most provide a forum for their members to talk about concerns over the quality of the care delivered by the nursing home for its residents. Many councils meet regularly with the home's administration to discuss complaints brought by relatives and friends. Some groups focus on social, educational, or fundraising activities; they may also welcome and support new families and find ways to help residents who have no regular visitors.

How can family councils help resolve problems?

When families attend council meetings, they share information about the care that their relatives are receiving at the facility. You may learn that your relative isn't the only one with a particular problem. Other residents may be having the same difficulty and their families or friends might be willing to join forces with you. Discussing the problem with other concerned families could help you redefine the problem and figure out a new way to solve it.

Just to take one example, a doctor in a nursing home might delay treating one resident's foot infection, causing her condition to worsen and putting her at risk of amputation. If the resident's condition is shared with the family council, and members of the family council realize that other complaints about delayed medical treatment involve the same doctor, the doctor's negligence can be dealt with more promptly.

In this case, all the families involved can communicate with each other and can approach the nursing home's administrative staff as a group.

Who organizes family councils?

In many homes, independent councils are organized and sustained by family members themselves, often with some help from the social services staff. In other places, groups of families are organized and supervised by the home's social worker. Some homes welcome family leadership for these groups; others resist it.

Are there advantages to independent family-led councils?

Yes. Independent, family-led councils may find it easier to challenge the home's administration than councils run by the facility itself. Family-led councils set their own agendas, decide what they most want to work on, and raise and control their own money. They also serve as a strong voice for families regarding what the home is doing right, about problems, and about possible future changes.

What if the nursing home administration doesn't want an independent, family-led council?

State regulations give family members the right to meet privately at the facility and to have staff assigned to assist them, if they wish. It's harder to organize a council if administrators are resistant — but they can't prevent you from doing it. Initially, you may want to meet outside the home.

What's the advantage of joining or organizing a family council?

Even though it takes a lot of time and energy to participate in a family council, it can be well worth it. When families work together as a group to solve problems, they don't have to fear retaliation against an individual resident or family member. Also, a strong

group can bring about change more quickly and effectively than a single voice.

Keep in mind, Department of Health officials will meet with a family organization during an inspection survey if they request it.

How can I organize a family council?

First, check to see if the home already has a council and if it's already dealing with the problem that concerns you. If council members aren't aware of the problem, bring it to their attention — and urge other affected families to speak up as well.

If there is no family council at the home, consider organizing one. Try to find a core group of relatives of other residents (at least two) willing to work with you. Among other things, you'll need to meet regularly (typically monthly), keep records and minutes, make phone calls, and recruit more members. It's best to select one person or a small group to negotiate with the administrative staff. It helps to divide up the work — ask each member to volunteer to do what comes easiest for her.

In some homes, administration may be willing to print and mail notices and flyers and may include information about the council in admissions packets and quarterly mailings.

How does MFY help family councils?

MFY can provide a training for your family council. Call us at (855) 444-6477.

MFY provides assistance and trainings for new and existing councils on a variety of topics. Contact MFY for support, training, and resources on the workings of an effective and independent family-led council.

RESIDENT COUNCILS

How do resident councils work?

Every nursing home is required to organize a resident council, which is an independent group of residents who report problems or express concerns to nursing

The Coalition of the Institutionalized and Disabled (CIAD) publishes a manual on organizing resident councils in adult homes and nursing homes ([CIAD RESIDENT COUNCILS](#)).

home administration. Resident councils are not controlled by the home; it's up to council members to decide whether to permit staff members to attend. In reality, however, many nursing homes do not have independent resident councils. Family councils and resident councils can work together to improve conditions and quality of life in the home. Many councils accomplish this by sending a representative from the resident council to family council meetings.

LODGING COMPLAINTS

MFY'S NURSING HOME RESIDENTS PROJECT

How can MFY help?

MFY's Nursing Home Residents Project helpline has trained, knowledgeable counselors to help residents, families, and friends solve problems in New York City area nursing homes. Call us at 855-444-NHRP (6477).

MFY can tell you what New York State regulations require of nursing homes and can help identify problems, determine which staff to approach, and develop advocacy strategies.

Because MFY talks with so many families, our counselors may have some insight into how best to approach problems in your home. Sometimes, at the caller's request, MFY will intervene directly with the administration or, together with the caller, make a complaint to the Department of Health. All calls are confidential.

Outside New York City, it is difficult to find an organization precisely like MFY. Ombudsman programs are often the best bet. Other resources, such as elected officials' constituent-services staff or the National Consumer Voice for Quality Long-Term Care may also be helpful.

Visit Consumer Voice on the web: [CONSUMER VOICE](#).

LONG-TERM CARE OMBUDSMAN PROGRAM

To read helpful information about the Ombudsman program, visit [OMBUDSMAN INFORMATION](#).

To find your local ombudsman, visit [OMBUDSMAN](#).

What is the Ombudsman Program?

This program, funded principally by the New York State Office for the Aging, places trained volunteers in nursing homes and adult homes in most areas of the state. The volunteers visit with residents, have a right to examine records, initiate complaints, and address complaints lodged by individual residents or their families. Staff members in each county's Ombudsman Program office are knowledgeable about nursing homes and may be able to help resolve problems.

THE DEPARTMENT OF HEALTH

When should I bring a complaint to the Department of Health (DOH)?

Call the DOH immediately if you know of abuse, neglect, or serious mistreatment of a nursing home resident.

Most people try to solve everyday problems by working with the home's administration first. If, however, administrators are unresponsive or do not follow through on plans to correct a problem, you should make a complaint to the DOH. Priority is given to charges of patient abuse and other emergencies. Complaints that involve systemic but less serious problems may be referred to DOH inspectors to check on during their next routine survey of the facility, which takes place approximately once a year. New York State law has specific definitions for the most serious types of problems that arise in nursing homes.

If you want to file a complaint with the DOH about abuse, mistreatment, neglect, or misappropriation involving a nursing home resident, call the DOH's Nursing Home Complaint Hotline at (888) 201-4563. You can also file a nursing home complaint with the DOH online ([NURSING HOME COMPLAINT FORM](#)) or you can print the form and mail it to: New York State Department of Health
DRS/SNHCP
Mailstop: CA/LTC
Empire State Plaza
Albany, NY 12237

USE THE APPROPRIATE TERMS WHEN YOU FILE A COMPLAINT:

Abuse: inappropriate physical contact that harms or is likely to harm the resident. Inappropriate physical contact includes, but is not limited to striking, pinching, kicking, shoving, bumping, and sexual molestation.

Mistreatment: inappropriate use of medications, inappropriate isolation, or inappropriate use of chemical or physical restraints.

Neglect: failure to provide timely, consistent, safe, adequate and appropriate services, treatment and care, including but not limited to nutrition, medication, therapies, sanitary clothing and surroundings, and activities of daily living.

Misappropriation: The theft, unauthorized use or removal, embezzlement, or intentional destruction of the resident's personal property, including but not limited to money, clothing, furniture, appliances, jewelry, works of art, and such other possessions and articles belonging to the resident regardless of monetary value.

How do I make a complaint?

New York State's Nursing Home Patient Abuse Reporting law requires all licensed nursing home employees, as well as hospital and other healthcare workers, to report to the Department of Health any instances of abuse, mistreatment, or neglect of a nursing home resident. Such reports should be made immediately as soon as the home learns of the incident, but in no event should the report be made more than 24 hours after the incident occurred. Other interested persons, such as relatives and advocates, are encouraged to file complaints as well. After making the report, the home must immediately investigate the allegations and report the results of the investigation to the DOH within five days of the incident.

You can make a complaint to the DOH by phone, in writing, or by using the on-line form. Although you can make an anonymous complaint, it is best to include your name, address, and phone number. In

the complaint, give as much specific information as possible: for example, names of people involved, dates, times, and the place that the incident occurred. If you saw someone doing something abusive, the DOH investigator should interview you. If you named witnesses, they should also be interviewed.

If it is a case of neglect that occurred over time, give a chronology of events. For example, if your relative developed a rash, describe how you saw the rash getting worse during your visits over several weeks, including dates and time. If you repeatedly brought it to the staff's attention, include the names of the staff members as well.

What happens next?

It often takes months, but you will receive a letter telling you whether the DOH found evidence to support your complaint. Specific information in complaint files is confidential. You will only be able to find out what stage your case has reached in the investigative process. You will be told by letter when the case is closed.

Families are often frustrated by the way the DOH works. Investigations take a long time. Witnesses may not be interviewed. Administrative policies that contribute to neglect and mistreatment may not be fully examined.

Most often, complaints are not substantiated, which means the investigators did not find enough evidence to take action against the home. If a complaint about abuse or serious neglect is substantiated — that is, if there is enough evidence of wrongdoing — the staff person and the nursing home can be held accountable and may be fined. If the wrongdoing is a criminal act, the case will be referred to the Attorney General. If nurse aides are involved, the names of those who are found guilty are recorded in the state registry. These nurse aides will not be permitted to work in a New York State nursing home again. Professional workers who have been found guilty may lose their licenses.

Should I bother making a complaint to the Department of Health?

Even if the Department of Health (DOH) doesn't sustain your complaint, the charge could help the nursing home administrator establish grounds to fire an abusive or incompetent employee or take steps to correct the problem. DOH inspectors are also informed about complaints that alert them to the kinds of problems to look for when they conduct surveys of nursing homes.

Get more information on OPMC complaints and when to file them here: [OPMC COMPLAINTS](#).

When you file a complaint, you keep the DOH on its toes. Whenever a DOH spokesperson claims that the numbers of complaints are decreasing, this could really mean the DOH has made it too hard to file complaints. MFY is working to make the DOH improve its response to complaints.

To file a complaint with OPMC, fill out this form ([OPMC COMPLAINT FORM](#)) and mail it to:
NYS Department of Health, Office of Professional Medical Conduct, Riverview Center 150 Broadway, Suite 355 Albany, New York 12204-2719.
Call OPMC at (800) 663-6114 with any questions.

THE OFFICE OF PROFESSIONAL MEDICAL CONDUCT (OPMC)

What complaints does this office handle?

The Office of Professional Medical Conduct (OPMC) in the New York State Department of Health is responsible for the professional discipline of physicians, physician assistants, and specialist assistants. All complaints of misconduct made to the OPMC are investigated and can lead to charges being issued and a hearing convened.

**NEW YORK STATE OFFICE OF THE ATTORNEY
GENERAL MEDICAID FRAUD CONTROL UNIT**

What kind of complaints does this office handle?

The Medicaid Fraud Control Unit investigates and prosecutes criminal conduct on the part of nursing home operators and employees. Investigators and attorneys in this office have specialized experience and expertise in nursing home cases. Cases of assault, gross negligence, suspicious death, suicide, life-threatening conditions, misuse of personal allowance

To find your local Medicaid Fraud Control Unit (MFCU), visit [MFCU MEDICAID FRAUD DIRECTORY](#).

To file an online complaint with MFCU, visit [MFCU ONLINE COMPLAINT](#).

monies, discriminatory admissions practices, and Medicaid fraud should be reported to this office. Note that the unit is not required to investigate all cases referred to it. Some complaints may be referred to the DOH Patient Care Investigations.

POLICE

Should I call the police?

In cases of criminal acts against residents, some families choose to call 911 to involve the police. Police are likely to be interested only in the most serious cases. Once local police are involved, the Attorney General's Office will not investigate. The Department of Health (DOH) will investigate a complaint even if the police are handling the same case but the police are not required to notify the DOH. If you choose to call the police, you should also notify the DOH.

PRIVATE LAWSUITS

Do I have the right to sue the nursing home?

Yes, but to succeed you need a strong case proving your relative suffered because of something the nursing home did or failed to do. Because our law does not place a high monetary value on losses suffered by people who are sick or elderly, the damages awarded even in a successful lawsuit may be low. You may have trouble finding a lawyer willing to take your case on a contingent fee basis (which means the lawyer's fee is paid only if the suit is successful).

In addition to traditional negligence and medical malpractice cases, the New York State Public Health Law, Section 2801-d, creates a special category of cases allowing residents to sue when homes fail to comply with New York State nursing home regulations.

WHEN NOTHING SEEMS TO WORK

What if nothing works to resolve a problem?

See [Chapter Six](#) for more information on transfers.

MFY's Nursing Home Residents helpline is (855) 444-6477.

Families get frustrated after they have tried advocating for better care with little or no success. Sometimes, no matter how hard you try to improve a nursing home's treatment of your relative, things just don't get better. Some residents in this situation will consider transferring to another facility. Keep in mind, however, that new problems or even some of the same ones may come up at a different facility. Also consider the stress that a move might cause your relative. On the other hand, a new facility may offer an easier path to resolving problems or be better suited to your relative's needs. Call MFY at (855) 444-6477 to discuss these issues and to get help in formulating a plan to advocate for your relative's needs at her nursing home.

NURSING HOME ADVOCACY RESOURCES

Coalition of Institutionalized Aged and Disabled (CIAD)

425 East 25th Street, New York, NY 10010; (212) 481-5149

CIAD is an advocacy organization that helps adult home and nursing home residents organize resident councils. CIAD can assist nursing home residents, their families, friends, and other interested parties in advocating for nursing home resident rights.

<http://www.ciadny.org/>

CIAD publishes a manual on organizing resident councils in adult homes and nursing homes:

<http://www.ciadny.org/documents/OrganizingManual7.pdf>

The National Consumer Voice for Quality Long-Term Care (Consumer Voice)

1001 Connecticut Avenue, NW, Suite 425, Washington, DC 20036; (202) 332-2275

Consumer Voice is an advocacy group formed to represent consumers with problems related to long-term care. Consumer Voice aims to help ensure that consumers are empowered to advocate for themselves. The Consumer Voice website is an excellent source of information and tools for consumers, families, caregivers, advocates, and ombudsmen to help ensure quality care for the individual.

<http://www.theconsumervoice.org>

Visit the Consumer Voice online family council center to obtain factsheets and other materials related to family council creation, maintenance, rights under federal law, and advocacy tips:

<http://www.theconsumervoice.org/familymember/family-council-center>

National Long-Term Care Ombudsman Resource Center (NORC)

1001 Connecticut Avenue, NW, Suite 425, Washington, DC 20036; (202) 332-2275

NORC provides support, technical assistance, and training to state and regional ombudsman programs and informational resources for the families of nursing home residents.

<http://www.ltombudsman.org>

New York State Department of Health (DOH)

Corning Tower, Empire State Plaza, Albany, NY 12237; Nursing Home Complaint Hotline (888) 201-4563.

The DOH publishes excellent consumer information on issues relating to quality of care, nursing home resident rights, and nursing home complaints, transfers and discharges.

<http://www.health.ny.gov/>

Visit this page if you want to make a complaint about a New York nursing home with the DOH:

https://apps.nyhealth.gov/nursing_homes/complaint_form/complain.action

New York State Office of Long-Term Care Ombudsman Program (LTCOP)

New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12223; Senior Citizens Help Line (800) 342-9871.

The LTCOP assists residents of nursing homes in most parts of the state. To find your local ombudsman, use the LTCOP Directory:

<http://www.ltcombudsman.ny.gov/whois/directory.cfm>

New York State Office of Professional Medical Conduct (OPMC)

Central Intake Unit, Riverview Center, 150 Broadway, Suite 355, Albany, NY 12204; (800) 663-6114.

Publishes “How to Choose the Right Physician – How to Tell us if You Don’t”:

<http://www.health.ny.gov/publications/1444/>

To file a complaint with OPMC regarding the misconduct of a physician, physician assistant, or specialist assistant, visit:

<http://www.health.ny.gov/forms/doh-3867.pdf>.

New York State Office of the Attorney General Medicaid Fraud Control Unit (MFCU)

New York City Regional Office – 120 Broadway, 13th Floor, New York, New York 10271; (212) 417-5300; New York State Attorney General’s Medicaid Fraud Control Unit Hotline: (800) 771-7755.

Investigates and prosecutes health care providers and Medicaid administrators who defraud the Medicaid program and investigates and prosecutes those who abuse, neglect, or mistreat nursing home residents.

<http://www.ag.ny.gov/bureau/medicaid-fraud-control-unit>

File an online complaint with MFCU:

<http://www.ag.ny.gov/comments-mfcu>.

**THIS CHAPTER
INCLUDES THE
FOLLOWING:**

Powers of Attorney

Guardianships

**Health Care Agents
and Proxies**

Living Wills

**New York State's
Family Health Care
Decisions Act**

**The New York State
MOLST (Medical
Orders for Life-
Sustaining
Treatment) Form**



WHEN MY RELATIVE CANNOT ACT FOR HERSELF: LEGAL ARRANGEMENTS

Many people remain able to take care of their own affairs as long as they live. Others, however, become unable to make informed decisions. When this happens, who is allowed to make decisions? What most New Yorkers don't realize is that in our state, we do not have an automatic right to make all medical, financial, or other critical decisions for a relative who is incapacitated. To obtain that right, certain legal arrangements must be made.

Of course, it is always best to make these arrangements before there is a crisis. Planning ahead allows family members and potential caregivers to discuss and make decisions together. It also increases the likelihood that the patient's wishes are known and will be followed.

If your relative is still able to make decisions, help her plan ahead by sharing the information in this chapter; or encourage her to ask a lawyer for advice. We also hope that you will make plans for someone to act on your behalf should that become necessary.

ANTICIPATING INCAPACITY

What is incapacity?

We say that someone does not have mental capacity when they cannot make informed decisions because they cannot understand and appreciate the nature and consequences of their decisions. An individual can lose capacity to make some decisions and still be able to make others. For example, your relative might be able to name her spouse as the person to handle her finances, although she may not be able to understand and give informed consent to experimental drug

therapy.

Decision-making capacity fluctuates for those with dementia. Professionals describe this as “fluidity.” Your relative may be able to make medical decisions at one point in the day when she is lucid, secure in familiar surroundings, or with people she knows and trusts. At a different time the same day, or if she is in unfamiliar surroundings, she may feel confused or afraid, and may not be able to think rationally. Your relative’s capacity can also be affected by medication, an agitated emotional state, or distractions in the environment. Some people, unfortunately, lose all decision-making capacity.

Who determines incapacity?

Psychiatrists are the most skilled in evaluating and determining mental capacity, though other doctors often make this assessment. As a practical matter, the decision is usually made medically, but if the determination is disputed and brought to court, a judge will decide. Under the Family Health Care Decisions Act (FHCDA), the attending physician makes the initial determination that a person “lacks decision-making capacity to a reasonable degree of medical certainty.”

See the detailed discussion of the FHCDA later in this chapter.

Who has the legal right to make decisions for a relative who is incapacitated?

If your relative has made arrangements for incapacity by signing advance directives, such as a power of attorney (for financial matters) or a health care proxy (for medical matters), the individuals appointed in these documents have the right to make decisions for her. If no arrangements have been made in advance, a guardian may be appointed to make certain financial decisions and a surrogate under the Family Health Care Decisions Act may make certain medical decisions.

See the section on guardians later in this chapter for more information.

Can more than one person be given responsibility for making decisions for a friend or relative who is incapacitated?

Yes. Certain decision-making powers can be divided up. For example, one person may manage financial and property matters, while another determines medical treatment. However, only one person can be appointed health care agent for medical decisions.

If our family wants to plan ahead for a relative's incapacity, what kinds of things should we discuss?

Visit Compassion and Support's family resource center, including how to complete New York advance directives in "five easy steps" ([COMPASSION AND SUPPORT](#)).

In New York, everyone should have advance directives for medical and financial decisions. The family, including the older relative, should plan together. Use this list of questions as a guide:

- Who will have the power to make important medical and/or financial decisions?
- At what point should others start making decisions on behalf of the person?
- Who will decide when that point is reached?
- What kinds of medical treatments are acceptable?
- What kinds of medical treatments are unacceptable?
- What kind of care and surroundings would be wanted, if death were imminent?
- What kind of financial decisions need to be made?
- What advance directives (power of attorney, health care proxy, living will) are important to each of us?

Having clear and specific answers to the above questions can minimize confusion and disputes among family and friends when a crisis arises. Make sure that everyone involved understands the decisions and agrees on what is to be done.

Visit [GROWTH HOUSE](#) for free access to educational materials about end-of-life care, palliative medicine, and hospice care, including the full text of several books.

How should the family approach this conversation?

Talking personally with loved ones about incapacity and death can be emotionally trying. Many people begin a conversation about medical decisions by discussing a friend's experience or an end-of-life situation they've read about or seen on television. Even though a conversation like this can be hard to begin, your relative may find comfort and relief in an open conversation. Also, if you are called upon to make decisions for your relative later, you will feel better and more confident if you know what your relative's wishes are. Asking your relative to name the person she most trusts to handle financial matters may also be a touchy subject. It may help to explain to your relative that this is one way to ensure that her money will be used the way she wants it to be used.

PLANNING AHEAD FOR FINANCIAL DECISIONS

What should my family do to plan ahead for financial decisions?

Giving a power of attorney to a trusted person is the best way to ensure that someone can handle your relative's finances if she becomes incapacitated.

If an aging relative has substantial property, a lawyer should be consulted!

A joint bank account insures that another person can assist with money management. However, it is important to remember that Medicaid will assume that all the money in such an account belongs to the Medicaid applicant, and large withdrawals will have to be explained at the time of the Medicaid application. Moreover, at the time of the death of one of the owners, the funds remaining will belong to the survivor, no matter what the person's will says.

What is power of attorney?

A person can legally give responsibility to a representative to handle financial transactions for her or make decisions about her property or finances. This is known as giving power of attorney. The person giving the power of attorney is called the principal.

The person given the power to act on the principal's behalf is called the attorney-in-fact or agent.

A durable power of attorney is the most flexible. It is effective and continues to be available even after your relative loses the ability to act on her own. However, as long as your relative has full mental capacity, she can always revoke the power of attorney. To revoke a power of attorney, your relative should give written notice of the revocation to her agent and to any third party (such as a bank) who may have acted or relied on the power. The authority granted by a durable power of attorney ends when the principal dies.

How should my relative choose someone for a power of attorney?

Powers of attorney are powerful documents. It is extremely important that your relative pick an agent she trusts completely to act only in her best interest.

The New York State Bar Association makes the New York State durable power of attorney form available online: [NYS DURABLE POA](#).

Where can I get power of attorney forms?

You can get power of attorney forms on the internet or at banks and other financial institutions. Make sure the form is current. Elder law attorneys usually prepare these documents for clients.

How is a power of attorney put into effect?

Your relative must initial the boxes next to the powers that she is giving to the agent. Then your relative and her agent must sign the form in the presence of a notary public. If there is any doubt about your relative's ability to understand what she is signing, it is a good idea to have her evaluated by a doctor beforehand in case the power of attorney is challenged.

The New York State Department of Health publishes a guide on surrogate healthcare decision-making ([DOH SURROGATE DECISIONS](#)).

PLANNING AHEAD FOR MEDICAL DECISIONS

Why is it important to plan for future medical care?

In New York, every adult patient has the right to decide to consent to or refuse any medical treatment, including life-saving treatment, as long as the patient has the mental capacity to make such a decision. New York's health care proxy law gives every adult the right to appoint a person, a health care agent, to make medical decisions for her if she becomes incapacitated.

What is the difference between a health care proxy and a health care agent?

A health care *proxy* is a legal document that you use to name a health care *agent*. If your relative becomes incapacitated, her health care agent is given the power to make decisions regarding her medical treatment.

If your relative signs a health care proxy, it goes into effect only when she becomes incapacitated. Even after your relative signs the proxy, she has the right to make her own health care decisions as long as she is capable of doing so. Without your relative's permission, medical treatment cannot be given or withdrawn. She has the right to change the proxy, name a new health care agent, or cancel the proxy altogether.

The New York State Department of Health publishes a guidebook on the New York health proxy law ([HEALTH CARE PROXY GUIDEBOOK](#)).

Who can be a health care agent?

The health care agent can be a family member, a friend, or even a doctor, as long as the doctor is not providing your relative's medical care at the same time. If your relative is a patient or resident of a hospital, nursing home, or mental health facility, she may not name an employee of the facility as her health care agent unless she is related to the employee.

Can my relative choose more than one agent?

No. Only one person at a time can serve as health care agent. However, your relative should name alternate agents who will act if the first agent is not available.

When should my relative appoint a health care agent?

As always, it's best to make decisions about appointing a health care agent before there is an emergency that leads to hospitalization or admission to a nursing home. Hospitals and nursing homes often suggest signing a proxy at admission.

If my relative has a mental impairment, can she still appoint an agent?

Even people with dementia who do not have the capacity to make decisions about their health care or to handle their finances may have the capacity to appoint a health care agent. In New York, every adult is presumed to be competent to appoint a health care agent unless the person has been adjudged to lack capacity. While it is clearly better to have appointed an agent in advance of any incapacity, a person with a mental impairment may still understand enough to appoint an agent.

How much power does an agent have?

That's up to the individual naming the agent. For example, your relative may authorize her agent to make decisions about all aspects of health care — or only about certain types of treatments. **If your relative wants her agent to be able to make decisions about artificial nutrition and hydration, your relative must make some reference to this on the health care proxy form.** For example, she may write in section 4 of the form, "My agent knows my wishes concerning artificial nutrition and hydration."

It is a good idea for your relative to talk to her agent ahead of time about the things she knows she wants done or not done. This makes it much easier for the health care agent to know your relative's wishes when asked to make decisions. It also makes it more likely that your relative's wishes will be respected if she is seriously ill and incapacitated.

Where can my family get a health care proxy form?

The New York State Department of Health provides the health care proxy form, and detailed instructions for filling out the form, here: [NYS HEALTH CARE PROXY FORM](#).

The New York State Department of Health has the most up-to-date information available about the New York health care proxy form and the health care proxy law. Nursing homes, hospitals, and some doctor's offices also have health care proxy forms. Lawyers can also provide proxies and help clients fill them out. However, if you read the instructions on the form and consider the issues raised in this chapter, a lawyer should not be necessary to fill out a proxy.

How is a health care proxy put into effect?

The form must be signed before two witnesses, neither of whom can be the designated agent. The form does not have to be notarized. Copies of the health care proxy form should be given to the individual's doctor, lawyer, health care agent, and other family members or close friends. If your relative is hospitalized or enters a nursing home, the proxy should be given to the facility when she is admitted.

If I am the health care agent, how do I know what decisions to make?

You should make decisions according to what you know your relative would want. In some cases, because of conversations with her in the past, you may know exactly what she would decide herself if she were able. At other times, you may have to decide what her decision would most likely be, based on everything you know about her. If you have no way of knowing what your relative would decide about a certain treatment, you should make decisions based on what you think are her best interests.

There are special considerations for decisions about end-of-life care and withholding life-sustaining treatments. They are discussed later in this chapter.

WHEN THERE IS NO ADVANCE PLANNING

FINANCIAL DECISIONS

What can my family do if my relative is already incapacitated, but we have no power of attorney and all of her property is still in her name?

If your relative's funds are in accounts in her name only and she is unable to give someone power of attorney, there is only one way to get access to those funds — through a guardian. If the guardianship is needed to submit an application for Medicaid, the nursing home or other health care provider may be willing to bring the court proceeding. An exception for Social Security benefits is discussed at the end of this section.

The New York State Office of Children and Family Services publishes a comprehensive guide on adult guardianship proceedings ([NYS OCFS GUARDIAN GUIDE](#)).

What is a guardian? How does guardianship work?

In New York State, a guardian is a person appointed by a court who has the power to take care of someone else's personal needs and property. The court can appoint a guardian for a person who agrees to the appointment, but most often a guardian is named for a person who is both unable to take care of herself or her property and who cannot understand the consequences of her inability to function. A guardian will usually not be appointed if the person signed a health care proxy and power of attorney when she had capacity to do so and those agents are acting appropriately.

The court proceeding to appoint a guardian is expensive, and costs are generally paid from the funds of the person who allegedly lacks capacity. If relatives are available, they are usually appointed guardians. However, the judge may appoint someone other than a family member, usually an attorney. In some localities, guardians can be appointed for poor people without relatives through an Adult Protective Services Agency.

What are guardians permitted to do by law?

Each guardian is given specific powers tailored to the needs of the person who is incapacitated. These powers are designed to promote the independence and self-determination of the individual who is incapacitated as much as possible. Guardians can be given power to make both financial and personal decisions, including the power to make most medical decisions.

See later in this chapter for a detailed discussion of the Family Health Care Decisions Act.

Unless there is also a health care agent, a guardian has the power to act as a surrogate decision maker under the Family Health Care Decisions Act if the patient is hospitalized or in a nursing home. If not, the guardian can still consent to or refuse most routine and major medical and dental treatment on behalf of the patient.

A guardian may not place a person in a nursing home over her objections without special permission from a judge. The guardian must show that alternatives to nursing home care have been seriously considered.

The guardian must make annual reports to the court that explain what decisions the guardian has made and how the person's money has been used.

How does Social Security allow me to use my relative's benefits for her needs?

Visit [SS PAYEE](#) to find out more about becoming your relative's representative payee.

If your relative is receiving Social Security payments or Supplemental Security Income (SSI) and becomes incapacitated, you can apply to the Social Security Administration (SSA) to become her representative payee. This means that your relative's Social Security or SSI checks will be issued to you to use on her behalf. To apply to become your relative's payee, call the SSA at (800) 772-1213. You must fill out a form and have a face-to-face interview. You must keep records of how you spend the money and make a report to the SSA once a year.

MEDICAL DECISIONS

The New York State Assembly publishes an informative guide explaining and comparing the New York State Proxy law and the Family Health Care Decisions Act ([NYS ASSEMBLY GUIDE](#)).

THE FAMILY HEALTH CARE DECISIONS ACT

If a person who is incapacitated has no health care agent, who makes decisions about routine medical treatment?

Even after New York passed the health care proxy law, most New Yorkers still failed to sign a health care proxy. This routinely led to the unfortunate circumstance where even family members could not make important health care decisions on behalf of a patient who had lost the ability to make their own decisions. As a result, New York passed the Family Health Care Decisions Act (FHCDA) in 2010. Under the FHCDA, New York joins most other states in allowing family, friends, and other surrogates to make health care decisions on behalf of patients who are incapacitated and have not signed a health care proxy. This decision-making authority includes the surrogate's ability to terminate life support when the standards in the FHCDA are satisfied.

Now that the FHCDA is law, should I still encourage my relative to sign a health care proxy?

Visit the New York State Bar Association's Family Health Care Decisions Act online information center for a wealth of information about the FHCDA ([NYS BAR FHCDA INFORMATION CENTER](#)).

Yes. It is important to realize, even with the FHCDA, that it is still best to sign a health care proxy because:

- the FHCDA applies only to patients who are in hospitals or nursing homes;
- surrogates under the FHCDA have more limits placed on their decision-making authority than agents appointed under a health care proxy; and
- with a health care proxy, the patient chooses the person making medical decisions on her behalf while, under the FHCDA, the surrogate is selected from the list set forth in the FHCDA.

Under what situations does the FHCDA apply?

Surrogate decision-making under the FHCDA is

authorized when:

- the patient has not signed a health care proxy; and
- the patient is an adult, is in a hospital or nursing home, and is determined by an attending physician to lack capacity by reason of her illness to make health care decisions on her own behalf. For nursing home patients, a second health care professional must confirm the attending physician's determination of incapacity.

If the patient objects to a determination of incapacity, then the patient's objection prevails, and no surrogate decision-making occurs, unless a court decides the patient lacks capacity or another legal basis exists to override the patient's decision.

The New York State Bar Association publishes an easy to understand summary of the key provisions of the FHCDA ([FHCDA SUMMARY](#)).

Who can be a surrogate under the FHCDA?

The FHCDA lists the order of who may serve as a surrogate for the patient in the following order of priority:

- the patient's court appointed guardian,
- the patient's spouse or domestic partner,
- the patient's adult child,
- the patient's parent,
- the patient's adult sibling, or
- the patient's close friend or relative (other than spouse, adult child, parent, brother, or sister) who has maintained such regular contact with the patient as to be familiar with the patient's activities, health, and religious or moral beliefs, and who presents a signed statement to that effect to the attending physician.

The highest-ranking surrogate who accepts the position will have the authority to make all health care decisions, including whether or not to initiate, withdraw, or withhold life-sustaining treatment. In order to make these decisions, nursing homes and hospitals must give surrogates full access to the patient's medical information and medical records.

What standard must a surrogate use when making decisions on behalf of an incapacitated patient under the FHCDA?

The FHCDA requires surrogates to base decisions on the patient's wishes, including her religious and moral beliefs. If the surrogate does not know the patient's wishes, then the surrogate is required to make decisions according to the patient's "best interests."

When does surrogate decision-making under the FHCDA not apply?

The surrogate does not have authority to make a decision on behalf of the patient when the patient has already made a decision about the proposed health care, expressed orally or in writing. If the patient previously made a decision to withdraw or withhold life-sustaining treatment, she must have expressed her decision:

- in writing; or
- orally, while in a hospital or nursing home, in the presence of two adult witnesses, at least one of whom is a health or social services practitioner affiliated with the hospital or nursing home.

Are there any limits on a surrogate's decision-making ability under the FHCDA?

Yes, and this is one of the primary reasons why you should still urge your relative to sign a health care proxy while she still has capacity. Under the FHCDA, a surrogate's decision to withhold or withdraw life-sustaining treatment will be honored **only if one of the following two conditions are satisfied:**

- the surrogate determines that treatment would be an extraordinary burden to the patient and the patient's attending physician and another physician agree that (A) the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or (B) the patient is permanently

- unconscious; or
- the surrogate determines that treatment would cause the patient such pain, suffering, or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances, and the patient's physician and another physician agree that the patient has an irreversible or incurable condition.

Can a FHCDCA surrogate consent to a Do-Not-Resuscitate (DNR) Order? Can a surrogate refuse artificial nutrition and hydration?

Under the FHCDCA, a DNR order is considered a decision to withhold life-sustaining treatment, so a surrogate may consent to a DNR order only if one of the conditions listed in the preceding question are satisfied. The same standard applies to decisions regarding artificial nutrition and hydration (nutrition or hydration through a tube inserted in the nose, stomach, or vein). Decisions regarding providing regular food and drink are not considered health care decisions and are outside the scope of the FHCDCA.

What happens when no surrogate can be found or if none of the listed surrogates are willing to act?

If a patient has no surrogate, the FHCDCA requires the hospital or nursing home to make health care decisions on behalf of the patient under the same guidelines as required for surrogates. The facility may not make medical decisions based on financial considerations.

Are hospitals and nursing homes required to honor a surrogate's decisions under the FHCDCA?

Yes, but a facility may refuse to act on a surrogate's decision to withhold or withdraw life-sustaining treatment if the decision contradicts the facility's religious or moral principles. A facility choosing not to honor the surrogate's decision must promptly transfer the patient to another hospital or nursing home where the surrogate's decision will be carried out.

MedlinePlus offers excellent resources to help patients and family members understand and cope with end-of-life issues:
[MEDLINEPLUS END-OF-LIFE ISSUES.](#)

SOME SPECIAL CONSIDERATIONS FOR END-OF-LIFE CARE

What is end-of-life care?

Most medical care is aimed at curing disease. Patients endure painful treatments, uncomfortable side effects, and unpleasant hospitalizations because they expect to get well soon. Medical care for someone who is dying may need a special approach.

When an illness is incurable, patients may not want painful tests or treatments that offer little help. Care may focus on treating symptoms, like pain. Being with family, receiving spiritual comfort, or pleasures like music may be more important than any medical treatment. While some people want everything done to keep them alive for as long as possible, others may feel strongly that they do not want to be kept alive by artificial or extraordinary means.

A person facing an incurable illness should discuss options with her doctor to make sure her doctor understands exactly what end-of-life care she wants. It is more common now for doctors to raise this subject, but the patient may still have to begin the conversation herself.

What are life-sustaining treatments?

Life-sustaining treatments are treatments that are necessary to keep someone alive. For example, for a patient who relies on a ventilator to breathe, use of the ventilator would be called a life-sustaining treatment. As with all medical treatments, a patient has the right to consent to or refuse life-sustaining treatments.

Is “tube-feeding” — artificial nutrition and hydration — a life-sustaining treatment?

Yes. Some people feel that if they are close to death and unable to eat, they do not want to be kept alive through nutrients administered by tube. Others object on religious grounds to withholding or withdrawing tube-feeding under any circumstances. Religious

beliefs about end-of-life issues have made decisions about artificial nutrition and hydration especially controversial.

Is there a difference between withholding and withdrawing treatment?

When carrying out a patient's known wishes, there is no legal difference between not starting treatment and stopping treatment. Patients can discontinue any medical treatment they no longer find beneficial.

If a person's desire to refuse life-sustaining treatment is clear, must a hospital or nursing home respect that wish?

New York State law allows some nursing homes and other health providers to disregard, for religious or moral reasons, a person's desire to refuse medical treatment, including feeding tubes, when the individual is close to death. In that case, the home must help the resident transfer to another nursing home willing to respect the patient's wishes.

Homes with a policy requiring tube-feeding and other life sustaining treatments must inform prospective residents of that policy at the time of admission. In practice, this is often not done. If this is an important issue for your family, ask about the nursing home's policy before admission.

Is a health care proxy a good way to make sure my relative's end-of-life treatment decisions are followed?

It is the best way in New York State. A proxy allows the person named as agent to make all health decisions for your relative if she cannot make them herself. This includes end-of-life decisions, although you will have to take an additional step to make sure your relative's wishes about artificial hydration and nutrition are respected.

If your relative does not want feeding tubes when she is dying, she must include some reference to artificial

nutrition and hydration (“tube feeding”) when signing her health care proxy. For example, **“My agent knows my wishes about artificial nutrition and hydration.”** Otherwise, your relative’s agent may not be able to refuse, or to later withdraw, artificial nutrition or hydration even if the agent has determined this is the right thing to do.

What is a living will?

A living will documents the individual’s wishes regarding medical treatment when she can no longer make decisions regarding routine medical care and life-sustaining treatments at the end of life. A living will can let doctors know what the patient’s wishes are, but it only holds for the situations it addresses. If the decision that needs to be made is not spelled out, the living will is useless for that decision.

Some practitioners warn that is it unwise to sign a living will if the patient has already signed a health care proxy. With a health care proxy, the agent’s authority is clear; if the patient also signs an imprecisely worded living will, the agent’s authority may be unclear or limited under particular circumstances. If the individual wishes to provide specific instructions, or to limit her agent’s authority, these additions can be made directly on the health care proxy form.

The New York Department of Health publishes questions and answers about the MOLST form: [DOH MOLST Q&A](#).

You can see a MOLST from here: [NYS MOLST FORM](#). The form is usually printed on bright pink paper.

What is the Medical Orders for Life-Sustaining Treatment (MOLST) form?

The MOLST form is one way of documenting your relative’s preferences concerning cardiopulmonary resuscitation (CPR) and other life-sustaining treatments. Completion of the MOLST form begins with a conversation between your relative, her family, and her physician to define your relative’s goals for her care and to review the possible treatment options, as described on the MOLST form. The MOLST form, which is easily recognizable because it is printed on bright pink paper, is a medical order that must be signed by your relative’s physician. All health care professionals, including EMS and other emergency

personnel, are trained to recognize MOLST forms and are required to follow the orders given in the MOLST form even as a patient moves from one facility to another.

Does my relative need a MOLST form?

The MOLST form is generally for patients with serious health conditions (advanced chronic or terminal illness) or for others who are interested in further defining their end-of-life care wishes. You or your relative should consider asking her doctor to fill out a MOLST form if she:

- wants to avoid or receive any or all life-sustaining treatment;
- wants to allow her natural death and avoid any efforts to attempt cardiopulmonary resuscitation (CPR) if her heart or breathing stops;
- lives in a nursing home or requires long-term care services; or
- might die within the next year.

What exactly might be included in my relative's MOLST form?

Your relative's MOLST form will contain medical orders concerning your relative's goals and preferences regarding one or more of the following:

- Resuscitation instructions for when your relative has no pulse and/or is not breathing;
- Instructions for intubation and mechanical ventilation when your relative has a pulse and is breathing;
- Treatment guidelines for your relative;
- Future hospitalization and transfer plans for your relative;
- Artificially administered fluids and nutrition authorized for your relative;
- Antibiotics ordered for your relative; and
- Other instructions about treatments for your relative.

What is the difference between a health care proxy and the MOLST form? Does my relative really need both?

A health care proxy is an advance directive, completed ahead of time, which applies only if your relative loses her decision-making capabilities. The proxy form allows your relative's agent to make decisions on her behalf as her medical condition evolves in the future.

A MOLST form, on the other hand, is a medical order that applies right now and is not conditional on your relative losing her ability to make medical decisions.

Both a health care proxy and a MOLST form are important documents to help your relative carry out her end-of-life wishes but neither one is a substitute for the other. Encourage your relative to sign a proxy *and* to speak to her doctor about signing a MOLST form on her behalf.

ADVANCE DIRECTIVES RESOURCES

Compassion and Support

(877) 718-6709.

An advocacy group striving to increase the acceptance of advance directives in New York State. Advocates for facilitated discussions on planning for end-of-life care.

<https://www.compassionandsupport.org/>

Visit Compassion and Support's Family Resource Center:

https://www.compassionandsupport.org/index.php/for_patients_families

Growth House, Inc. (Growth House)

2261 Market Street, #199A, San Francisco, California, 94114; (415) 863-3045.

The Growth House website provides access to over 4,000 pages delivering education about life-threatening illness and end-of-life care. The Growth House search engine provides access to the internet's most comprehensive collection of reviewed resources for end-of-life care.

<http://www.growthhouse.org/>

Read *A Handbook for Mortals*, Growth House's comprehensive consumer guide to end-of-life issues and care:

<http://www.growthhouse.org/mortals/mor0.html>

New York State Department of Health (DOH)

Corning Tower, Empire State Plaza, Albany, NY 12237.

The DOH publishes excellent consumer information on issues relating to quality of care, New York State Health Care Proxies, and the New York State MOLST form.

<http://www.health.ny.gov/>

Get the New York State Health Care Proxy form here:

<http://www.health.ny.gov/forms/doh-1430.pdf>

Read the DOH guidebook on Health Care Proxies here:

http://www.health.ny.gov/regulations/task_force/health_care_proxy/guidebook

See the New York State MOLST form here:

<http://www.health.ny.gov/forms/doh-5003.pdf>

MedlinePlus

National Library of Medicine, 8600 Rockville Pike, Bethesda, MD 20894; (800) 663-6114.

MedlinePlus is the National Institutes of Health's Web site for patients and their families and friends. Produced by the National Library of Medicine, MedlinePlus provides easy to understand information about diseases, conditions, and wellness issues.

<http://www.nlm.nih.gov/medlineplus/>

Visit the MedlinePlus end-of-life resource center here:

<http://www.nlm.nih.gov/medlineplus/endoflifeissues.html>

New York State Bar Association (NYSBA)

1 Elk Street, Albany, NY 12207; (518) 463-3200.

The NYSBA provides a wide variety of helpful publications for lawyers and for the general public.

<http://www.nysba.org>

Get a copy of the New York Durable Power of Attorney:

<http://www.nysba.org/AM/Template.cfm?Section=Home&CONTENTID=41935&TEMPLATE=/CM/HTMLDisplay.cfm>.

Visit NYSBA's Family Healthcare Decisions Act online family information center:

<http://www.nysba.org/AM/Template.cfm?Section=Home&CONTENTID=41935&TEMPLATE=/CM/HTMLDisplay.cfm>

New York State Office of Children and Family Services (OCFS)

52 Washington Street, Rensselaer, New York 12144; (518) 473-7793.

Through its Adult Protective Services Division, OCFS provides services to adults who have impairments and investigates allegations of elder abuse.

<https://www.ocfs.state.ny.us/main/default.asp>

Read the OCFS guidebook on adult guardians:

<http://www.ocfs.state.ny.us/ohrd/materials/151670.pdf>

Social Security Administration

(800) 772-1213.

To find your local office: [SSA Locator](#).

For information about becoming your relative's representative payee:

<http://www.ssa.gov/payee/>

GLOSSARY

ACTIVITIES DIRECTOR (RECREATION DIRECTOR)

Plans programs seven days a week to help keep residents alert and socializing with others.

ACTIVITIES OF DAILY LIVING (ADL)

Tasks performed routinely to maintain bodily functions (e.g. personal hygiene, walking, eating, dressing, bathing, transferring).

ADULT DAY CARE

Day programs that provide social, recreational, and some medical services in a community setting for adults who are mentally or physically frail. There are both medical model and social model day care programs.

ADULT FOSTER CARE

The service provided to people who are elderly living with unrelated families who provide room, meals, laundry service, personal care, and supervision.

ADULT HOME

A long-term residential facility that provides room, board, housekeeping, personal care and supervision for five or more adults who are not related to the proprietor.

ADVANCE DIRECTIVES

Verbal or written instructions expressing someone's wishes about medical treatment in case of a future illness or injury causing mental incapacity. Examples are: health care proxies, medical orders for life-sustaining treatment (MOLST) orders, and living wills.

ALTERNATIVE LEVEL OF CARE (ALOC)

The intermediate level of care at a reduced reimbursement rate given to a hospital patient after acute care is no longer necessary, but an appropriate discharge is not yet available to a nursing home or other facility.

ALZHEIMER'S DISEASE

A degenerative disease affecting the brain that results in impaired memory and thought processes.

APHASIA

A partial or complete loss of the ability to speak, read or understand written and spoken language.

ARTIFICIAL NUTRITION AND HYDRATION

Provision of nutrients and liquids through tubes. An NG (Naso-Gastric) tube is a tube inserted into the stomach via the nose. A PEG (percutaneous endoscopic gastrostomy), or G-Tube (Gastro Tube) is a tube placed directly into the stomach through which liquid nourishment is delivered.

ASSISTED LIVING PROGRAM (ALP)

A New York State program providing home health care services for adult home residents who qualify for nursing home care.

ASSISTED LIVING RESIDENCE (ALR)

A New York State licensed residence for the elderly, combining housing, home care services, food, and social support.

AUDIOLOGY

Evaluation and rehabilitative treatment for residents who have impaired hearing.

BURIAL FUND

A sum of money (or life insurance policy of equivalent value) that is not counted as a financial resource for the purpose of qualifying for Medicaid and other government benefits programs.

CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS)

The federal agency responsible for administering Medicare and Medicaid.

CENTRAL COMPLAINT INTAKE PROGRAM (CCIP)

The unit of the New York State Department of Health that investigates all formal complaints about nursing home care.

CERTIFIED HOME HEALTH AGENCY (CHHA)

An agency certified by Medicare to provide medical home care services, including nursing, home health aide services, and skilled therapy services.

CHEMICAL RESTRAINTS

Psychoactive or mind-altering drugs, including anti-psychotics, sedatives, and antidepressants used to control behavioral symptoms, when less aggressive alternatives could be used.

COMFORT CARE

See palliative care.

COMPREHENSIVE CARE PLAN (CCP)

A total plan of care designed for a nursing home resident, based on an assessment of a resident's physical, mental, emotional, rehabilitative, and dietary status and needs, by an interdisciplinary team made up of staff, family, and the resident.

CONTINUING CARE RETIREMENT COMMUNITY (CCRC)

Residential complexes that offer elderly residents, under one contract, an independent living unit, food, residential amenities, and access to a continuum of long-term care services, as residents' health and social needs change over time. For a set fee, residents receive whatever services they need during a contract period, often the remainder of the resident's lifetime. *(Also called a Life Care Community).*

CONTRACTURE

A restriction of movement of any joint, or shortening of muscles, which can affect fingers, wrists, elbows, shoulders, hips, knees and ankles. If left untreated, it can cause a person's body to curl up.

COPAYMENT

A portion of a medical bill that is not covered by an insurance company (government or private) and that the patient must pay directly.

CPR (CARDIOPULMONARY RESUSCITATION)

The emergency procedure administered when the heart or breathing stops. CPR includes mouth-to-mouth breathing, closed heart massage, starting the heart with an electrical current, and using a mechanical ventilator.

CULTURE CHANGE

A nursing home reform movement that is dedicated to transforming nursing homes into places where residents' individual needs and preferences are the core value of operating the home.

CUSTODIAL CARE

Also called "personal care," services provided by a home care attendant to help a person to bathe, get dressed, eat, walk, use the bathroom, or move from a bed or chair to a wheelchair.

DECUBITI

Pressure sores or bedsores are lesions or ulcerations caused by unrelieved pressure on the skin.

DEDUCTIBLE

The amount a policyholder must pay before an insurance policy will begin to cover costs.

DEMENTIA

Impairment and deterioration of cognitive functions (such as thinking, Remembering, and reasoning) sufficient to interfere with an individual's daily living.

DESIGNATED REPRESENTATIVE

A family member or friend chosen by a nursing home resident to be her contact with the home.

DFTA (NEW YORK CITY DEPARTMENT FOR THE AGING)

The local government agency that provides community social services for older New Yorkers, including senior centers, information and referral for obtaining benefits and entitlements, residential and nursing home information, advocacy, and employment opportunities.

DIRECTOR OF NURSING SERVICES (DNS)

A registered nurse with training and experience in geriatrics who supervises professional and semi-professional nursing services in a nursing home.

DISCHARGE PLANNING

Planning and making arrangements for someone's care after discharge from a hospital or nursing home. This is done by the staff of the medical facility in cooperation with the patient and family.

DIVISION OF QUALITY AND SURVEILLANCE (DQS) FOR NURSING HOMES

The New York State agency that licenses, regulates and inspects adult homes. DQS is one division within the New York State Department of Health.

DNH (DO NOT HOSPITALIZE ORDER)

A doctor's order, authorized by a patient, or a health care agent or a family member (in cases of the patient's mental incapacity) stating that the patient should not be transferred to a hospital for care.

DNR (DO NOT RESUSCITATE ORDER)

A doctor's order, authorized by a patient, or a health care agent or a family member (in cases of the patient's mental incapacity) stating that the patient should not receive CPR if his breathing or heart stop.

DOH (NEW YORK STATE DEPARTMENT OF HEALTH)

The state agency that regulates all medical facilities, including hospitals and nursing homes.

DSS (DEPARTMENT OF SOCIAL SERVICES)

State-funded county agencies that provide public assistance, human services, and other welfare services. In New York City, the Human Resource Administration (HRA) is the local Department of Social Services.

ENRICHED HOUSING

A residence providing a supervised apartment with supportive services, usually for elderly residents.

ETHICS COMMITTEE

An interdisciplinary group in a health-care facility that evaluates medical decisions that pose ethical conflicts.

EVICTION

A forced removal of an individual, family or business from housing, land, or other real property and the legal process permitting it.

EXPANDED IN-HOME SERVICES FOR THE ELDERLY PROGRAM (EISEP)

A state-funded program providing, on a sliding fee basis, housekeeping chores, homemaker services, case management and other services for elderly, low-income people in the community needing home care but not eligible for Medicaid.

EXPEDITED DISCHARGE PROGRAM

See rent retention rule.

FAIR HEARING

An informal independent legal proceeding to review a decision by an administrative agency.

FAMILY COUNCIL

An independent organization made up of family members and friends of residents in a particular nursing home, to support each other and work on mutual concerns regarding resident care and life.

FAMILY HEALTH CARE DECISIONS ACT

The New York State law that allows family members and close friends to make health care decisions, under certain circumstances, for a person who is incapacitated.

FEEDING TUBES

See Artificial Nutrition and Hydration.

GUARDIAN

An individual appointed by a court to manage personal and financial affairs of a person judged not able to act for himself.

HEALTH CARE AGENT

A person appointed by a patient to make health care decisions on the patient's behalf in case she is mentally incapacitated in the future.

HEALTH CARE PROXY

The legal document an individual signs to appoint someone to act as her health care agent in case she becomes mentally incapacitated.

HEALTH MAINTENANCE ORGANIZATION (HMO)

A managed care provider that serves as both a health insurance company and a system of health care delivery for its members. An HMO serves members through its network of health care professionals.

HOME ATTENDANT

A person providing personal care services, including help with the activities of daily living, to someone in her own home. Also called a "personal care attendant."

HOMEBOUND

Unable to leave the house because of illness or injury without the help of a person or device and without a considerable and taxing effort.

HOME CARE SERVICES/IN-HOME SERVICES

Medically prescribed care provided in a patient's home or residence that includes medical home health services and personal care services.

HOME HEALTH AIDE

A person providing both personal care assistance and health-related services such as simple dressing changes, assistance with medications, and routine care of prosthetic and orthotic devices.

HOME RELIEF

See Safety Net.

HOSPICE CARE

Care for terminally-ill patients that emphasizes comfort and not cure, and that combines home care with needed in-patient care.

HRA (HUMAN RESOURCES ADMINISTRATION)

See DSS.

IMMUNOSUPPRESSIVE DRUGS

Drugs that suppress the body's immune system, risking exposure to infections that the body normally resists.

INCAPACITY

A mental state in which an individual is unable to make reasoned decisions or judgments.

INSTITUTIONALIZATION

Admission of an individual to an institution, such as a nursing home, for an extended stay or permanent residence.

LHCSA (LICENSED HOME CARE SERVICES AGENCY)

An agency licensed by the Department of Health that, directly or through a contract, provides nursing, home health aides or personal care services in a patient's home.

LIFE CARE COMMUNITIES

See Continuing Care Retirement Communities.

LIFE-SUSTAINING TREATMENT

A treatment or procedure that either supports or replaces a specific bodily function necessary to keep a person alive.

LIVING WILL

A document that states someone's wishes regarding medical treatment if she becomes terminally or irreversibly ill and is mentally incapacitated.

LOMBARDI PROGRAM

See Long-Term Home Health Care Program (LTHHCP).

LONG-TERM CARE INSURANCE

Policies that cover a part of the cost of nursing home care and/or home care.

LONG-TERM CARE OMBUDSMAN PROGRAM OF NEW YORK STATE

A program of the New York State Office for the Aging that places trained volunteers in nursing homes and adult homes to assist residents in resolving problems.

LONG-TERM HOME HEALTH CARE PROGRAM (LTHHCP) (LOMBARDI PROGRAM/"NURSING HOME WITHOUT WALLS")

A program that provides home health care services for people who are medically eligible for nursing home care and Medicaid, but who can be cared for at home at a cost that is less than 75% of nursing home care.

LOOK-BACK PERIOD

The period prior to a Medicaid application that Medicaid examines for financial transactions, including transfer of assets, that affect Medicaid eligibility.

LPN (LICENSED PRACTICAL NURSE)

Member of a nursing home staff with formal training to perform some skilled tasks. LPNs are supervised by registered nurses and assisted by nurse's aides.

MAINTENANCE REHABILITATION

The type of rehabilitation intended to maintain and strengthen a person's current level of functioning or to prevent further functional loss.

MANAGED CARE

A way to provide health care services through an insurance plan that, in exchange for a pre-paid premium, offers comprehensive coverage within the plan's own network of doctors, hospitals and other providers.

MDS (MINIMUM DATA SET)

The comprehensive assessment form used by a nursing home to measure the level of functioning and strengths and weaknesses of a resident in order to develop an appropriate individual care plan.

MEDICAID

The joint federal-state program that pays for health care for low-income people.

MEDICAL DIRECTOR

The doctor responsible for formulating and coordinating the medical care policies and procedures within a nursing home.

MEDICAL HOME HEALTH SERVICES

The type of home care service that includes skilled services, such as: intravenous drug therapy; artificial feeding and hydration; kidney dialysis and oxygen therapy; nursing visits for wound care; injections; catheter and colostomy care; administration of medication; speech, occupation and physical rehabilitation therapy; and services of home health aides.

MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT (MOLST) FORM

A bright pink form containing medical orders written by a physician to document a patient's preferences concerning cardiopulmonary resuscitation (CPR), do-not-resuscitate (DNR) orders, and other life-sustaining treatments.

MEDICARE

The government health insurance program tied to Social Security that is available to certain people with disabilities and most Americans over 65.

MEDICARE ADVANTAGE

A Medicaid managed care plan that restricts access to certain providers and hospitals in order to limit costs.

MEDIGAP INSURANCE

Optional, privately-purchased insurance that bridges the gap between what Medicare covers and what a patient must pay out of pocket for Medicare-covered services. Also called Medicare Supplement Insurance.

MUNICIPAL NURSING HOME

A nursing home owned and operated by a county or city.

NAMI (NET AVAILABLE MONTHLY INCOME)

The amount of a Medicaid recipient's income that must be paid to a nursing home.

NEEDS ASSESSMENT

A formal process that social workers and medical personnel use to determine what care or services someone should receive.

NURSE AIDE (NA OR CNA)

The person who provides hands-on non-nursing care under the supervision of nurses. Also called nursing attendants or nursing assistants.

NURSE PRACTITIONER (NP)

A nurse with advanced training who can order lab tests, diagnose, prescribe some medications, and perform other tasks traditionally done only by physicians.

NURSING HOME

A residential facility that provides room and board, around-the-clock skilled nursing care, rehabilitation services, personal care services, social services and recreation.

“NURSING HOME WITHOUT WALLS”

See Long-Term Home Health Care Program (LTHHCP).

OCCUPATIONAL THERAPY

Rehabilitation treatment that teaches people who have physical or mental impairments a specific skill, using purposeful and practical exercises to help them return to their everyday life.

OMBUDSMAN PROGRAM

See Long-Term Care Ombudsman program.

PALLIATIVE CARE

Care given to a terminally-ill or chronically-ill patient, often through a hospice program, that eases suffering and emphasizes physical and emotional comfort without trying to cure illness or prolong life.

PARTNERSHIP FOR LONG-TERM CARE INSURANCE

A type of long-term care insurance, jointly sponsored by New York State and private insurance companies, that allows people to protect assets and qualify for Medicaid when the insurance benefits run out.

PASTORAL CARE

Services provided by a clergyman or other spiritual advisor.

PATIENT REVIEW INSTRUMENT (PRI)

A form used to determine the level of medical care and services a person needs before placement in a nursing home. The form is also a key element in determining Medicaid reimbursement levels for nursing homes.

PATIENT SCREENING INSTRUMENT (SCREEN)

A form used to determine whether a person is appropriate for placement in a nursing home, or could be cared for in a less institutionalized setting or needs specialized care because of a history of mental illness.

PEER REVIEW ORGANIZATION

Independent agencies that have contracts with the government to handle patients' appeals of hospital discharges.

PENALTY PERIOD

The number of months that a person is ineligible for institutional Medicaid, due to transferring assets.

PERSONAL CARE ATTENDANT

See Home Attendant.

PERSONAL CARE SERVICES

A type of home care service where home attendants provide assistance with bathing, dressing, eating, walking, toileting, transferring from a bed or chair to a wheelchair, and housekeeping services such as cooking, shopping, cleaning and laundry.

PERSONAL EMERGENCY RESPONSE SYSTEM (PERS)

A mechanical alarm system that connects a person in distress to someone who can get emergency assistance.

PHYSICAL RESTRAINTS

Devices that restrict movement such as bedrails, lapboards, seat belts and vests.

PHYSICAL THERAPY

Rehabilitation treatment to improve or maintain a resident's physical functioning (e.g. walking, lifting).

POWER OF ATTORNEY

A legal document that allows a person to legally give responsibility to a representative to handle financial transactions for him or make decisions about his property or finances.

PROPRIETARY NURSING HOMES

Nursing homes that are privately owned and operated on a for-profit basis.

PSYCHIATRIC DRUGS

Drugs that alter a patient's perception, cognitive ability, and mood (e.g. antidepressants). Also called psychotropic or psychoactive drugs.

RANGE OF MOTION (MAINTENANCE THERAPY)

Rehabilitation to prevent further functional loss or to maintain and strengthen a current level of functioning.

REHABILITATION (REHAB)

The combination of therapy, exercise and other activities designed to restore people who have become impaired through injury, disease, or dysfunction to a higher level of functioning.

RENT RETENTION RULE (EXPEDITED DISCHARGE)

The Medicaid provision that allows a nursing home resident to pay rent or other costs to maintain a residence for up to six months of a nursing home stay, with income that would otherwise have to be used for medical costs.

REPRESENTATIVE PAYEE

Someone authorized to receive and spend another person's Social Security or SSI check on that person's behalf.

RESIDENT COUNCIL

An organization of residents in a nursing home working together on mutual concerns about resident care.

RESOURCE UTILIZATION GROUPS (RUGs)

The categories that are the basis of the New York State Medicaid reimbursement system that pays nursing homes for the care of Medicaid residents.

RESPITE CARE

Short-term and infrequent care for a person who is elderly or incapacitated at home or at a nursing home or other facility. It is intended to give family members some relief from the responsibilities of care giving.

RESTORATIVE REHABILITATION

The type of rehabilitation intended to restore a function that a person has lost, such as the loss of speech or mobility following a stroke.

REGISTERED NURSE (RN)

The most highly skilled member of the nursing home's nursing team, who supervises licensed practical nurses and nurse aides.

SAFE RETURN PROGRAM

A national program of the Alzheimer's Association that helps identify and return lost "wanderers" who have memory-impairments due to Alzheimer's disease or a related disorder.

SAFETY NET PROGRAM (FORMERLY CALLED HOME RELIEF)

The New York State public assistance (welfare) program that provides financial assistance to individuals or households with no other form of support.

SCREEN

See Patient Screening Instrument.

SOFA (NEW YORK STATE OFFICE FOR THE AGING)

The state agency that oversees and coordinates state programs for the aged.

SPEECH THERAPY

Evaluation and rehabilitation treatment to help restore an impaired ability to speak or swallow.

SPENDING DOWN

Depleting personal income and resources sufficiently to meet the eligibility requirements for Medicaid.

SSD (SOCIAL SECURITY DISABILITY)

A federal benefits program for individuals who are disabled. Eligibility and the amount of benefits depends on the person's work history and the amount paid in Social Security payroll taxes.

SSI (SUPPLEMENTAL SECURITY INCOME)

The federal public assistance program that provides a minimum level of income to people over the age of 65, or under 65 and disabled or blind, who do not have enough income or resources to provide for themselves.

SUB-ACUTE CARE

A level of care that falls between acute care (usually provided in a hospital) and skilled nursing care (usually provided in a nursing home). It is generally short term — 15-100 days — and is covered by Medicare.

SURVEY REPORT

The findings of a Department of Health inspection of a nursing home, stating problems found and the home's plan to correct them.

TARDIVE DYSKINESIA

A neurological disorder that causes involuntary twitching of the hands, arms, legs, mouth and facial muscles and may lead to other serious effects, such as incontinence, pneumonia, and psychological or emotional reactions.

THERAPEUTIC LEAVE

Time spent by a nursing home resident away from the facility as part of the treatment plan, usually visiting a physician or other health care professional.

TRANSFER OF ASSETS

Giving away or otherwise disposing of property for less than its fair market value.

TRAUMATIC BRAIN INJURY (TBI)

A brain disorder that can result from a flaring of nerve fibers, bruising of the brain tissue against the skull, brain stem injuries, or edema.

TUBE FEEDING

See artificial feeding.

VOLUNTARY NURSING HOME

A nursing home sponsored by a religious, fraternal, community or other non-profit organization.