

Piecing Together Quality Long-Term Care: A Consumer's Guide to Choices and Advocacy



Produced by The National Consumer Voice for Quality Long-Term Care

Produced by



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Please send any corrections or updates you may have to this guide to info@theconsumervoice.org.

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TABLE OF CONTENTS

INTRODUCTION	2
CHAPTER 1: WHAT ARE "LONG-TERM SERVICES & SUPPORTS?"	4
CHAPTER 2: WHAT ARE YOUR OPTIONS FOR LONG-TERM SERVICES AND SUPPORTS?	5
CHAPTER 3: HOME AND COMMUNITY-BASED SERVICES AND SUPPORTS	6
CHAPTER 4: THE "HOME" IN HOME AND COMMUNITY-BASED SERVICES: HOUSING OPTIONS	7
CHAPTER 5: HOUSING RIGHTS	9
CHAPTER 6: LONG-TERM SERVICES AND SUPPORTS IN RESIDENTIAL SETTINGS: WHEN 24-HOUR NURSING SUPERVISION/CARE IS NOT NEEDED	11
CHAPTER 7: LONG-TERM SERVICES AND SUPPORTS IN RESIDENTIAL SETTINGS: WHEN 24-HOUR NURSING SUPERVISION/CARE IS NEEDED	13
CHAPTER 8: HOSPICE	15
CHAPTER 9: GETTING STARTED: FINDING INFORMATION, DETERMINING NEEDS AND OBTAINING SERVICES	16
CHAPTER 10: COSTS & PAYMENT	19
CHAPTER 11: FINANCIAL AND HEALTH CARE PLANNING	23
CHAPTER 12: ADVOCATING FOR QUALITY LONG-TERM SERVICES AND SUPPORTS: SELECTING YOUR PROVIDER	26
CHAPTER 13: ADVOCATING FOR QUALITY LONG-TERM SERVICES AND SUPPORTS: BEING PROACTIVE	33
CHAPTER 14: ADVOCATING FOR QUALITY LONG-TERM SERVICES AND SUPPORTS: ADDRESSING PROBLEMS	42
CHAPTER 15: NURSING HOME TRANSITION	50
CHAPTER 16: HELPING FAMILY AND OTHER CAREGIVERS	56
CHAPTER 17: ADVOCATING FOR QUALITY CARE: IMPROVING THE LONG-TERM SYSTEM	58
RESOURCES	60
APPENDIX 1: GLOSSARY	66
APPENDIX 2: DESCRIPTION OF LONG-TERM SERVICES AND SUPPORTS	67
APPENDIX 3: SAMPLE LETTER REQUESTING HOUSING MODIFICATION	72
APPENDIX 4: SELF-DIRECTION - IS IT RIGHT FOR YOU?	73
APPENDIX 5: GUIDELINES FOR PRESENTING A PROBLEM	74
APPENDIX 6: COACHING APPROACH TO COMMUNICATION	75
APPENDIX 7: ADDITIONAL AGENCIES TO CONTACT FOR COMPLAINT RESOLUTION	77



INTRODUCTION

Almost all of us will need some assistance with the tasks of every day life at some point in our lives. This type of assistance is referred to as "long-term services and supports" or "long-term care." If you are an older adult, you may need help due to the development of one or more chronic conditions, like arthritis, that make activities like dressing, bathing and getting around more difficult. Or you may require assistance because of a disability.

The United States' system of long-term services and supports is complicated and confusing. Sadly, figuring out how to get quality services that fit your needs, and even finding information, can be difficult.

This guide is designed for you, the individual who is currently receiving or who may in the future receive long-term services and supports. While there are a number of different terms that can be used to describe you, such as "participant," the expression we will use in this guide is "long-term care consumer." If you are in a group living setting such as assisted living, we will refer to you as a "resident."

The purpose of this guide is to inform you about your options for long-term services and supports. Its goal is also to empower you - through education - to effectively advocate on your own behalf.

The guide is intended to be a roadmap to assist you in getting to your destination - the right kind of long-term services and supports at the right time with the right provider so that you have independence, choice, dignity, quality of life and quality care and services. For some individuals in nursing homes, the right care/services at the right time may mean moving out of the nursing home and back into the community with services and supports. Information about these "nursing home transitions" is included. Because no one knows better about what you can do to receive the best services than long-term care consumers who have faced these challenges themselves, the guide presents tips from individuals around the country who have already traveled down the same road.

Although this guide is intended for long-term care consumers, we recognize the important role of family and other caregivers. For that reason, much of the information in this guide can also be used by caregivers. In addition, we have included resources to assist and support caregivers as they work to assist and support you.

It may seem to you that people are speaking in a foreign language when talking about long-term services and supports. In many ways they are! To help you "translate" the terms and expressions, we have created a glossary. Any time you come across a term with an asterisk (*) after it, just go to the glossary for an explanation. The glossary can be found in Appendix 1.

Legend	
	Web Link
	Key Points

The general web address for an organization's homepage is provided in this guide. Links to specific documents or sections were not listed because organizations frequently change or update their weblinks. To find a document or item referenced in this guide, visit the organization's general web address and then search for the item.

Finding the Right Road

To begin your journey, you need to figure out what road to take. This section of the guide gives you the lay of the land and provides you with a "large scale" map to help you in deciding what option is right for you.





CHAPTER 1: WHAT ARE "LONG-TERM SERVICES & SUPPORTS?"

Step #1: Educate yourself about options for long-term services and supports.

Long-term services and supports are the assistance people need to carry out the tasks of daily living and live as independently as possible. These tasks include "activities of daily living" or "ADLs." While the definition of activities of daily living varies, the activities are generally considered to be bathing; dressing; eating; toileting/maintaining continence (getting to/from and on/off the toilet, performing personal hygiene, and controlling bowel/bladder functions); getting around (sometimes referred to as "mobility") and getting in or out of bed or a chair/wheelchair (called "transferring").

Daily tasks may also include housework, preparing and cleaning up meals, running errands, taking medications, using the telephone and managing money. These tasks are called "instrumental activities of daily living" or "IADLs." Services and supports can be provided voluntarily by a person's family members/friends or by paid providers.

Another name for "long-term services and supports" is "long-term care." In this guide these two terms will be used interchangeably.

Person-directed or person-centered care/services

Long-term services and supports should be person-directed. This means you are the one directing or guiding the services you receive, when you receive them and how you receive them. Person-directed (sometimes called "person-centered") care and services focus on your strengths and preferences and put you in charge of determining the direction of your life. It gives you the opportunity to express choice and make decisions in meaningful ways at every level of daily life.¹

Person-directed care/services is a philosophy of how care and services should be provided. The idea has existed for quite some time in the disability community where "person-directed planning" is an important concept. Person-directed planning is the process of creating a plan that allows an individual to build or continue the kind of life he or she wants, with the supports he or she needs to do so. It emphasizes the person as the decision maker instead of having decisions made by professionals or family members. More recently, the concept of person-directed care has become the heart of "culture change," a movement to provide older adults services in a way that values choice, dignity, respect, self-determination and purposeful living.²

Summary:

Long-term services and supports are the assistance people need to carry out the tasks of daily living and live as independently as possible.

¹ www.pioneernetwork.net/CultureChange/

² www.pioneernetwork.net/CultureChange/Whats/



CHAPTER 2: WHAT ARE YOUR OPTIONS FOR LONG-TERM SERVICES AND SUPPORTS?

Your options will vary by state, so everyone's roadmap is a little different. Some states have a wide range of services and supports available, while others are more limited.

In general you can think about two major categories of long-term services and supports: those provided at home or in the community, which are usually called "home and community-based services" or "HCBS" and those provided in a residential setting.



One of the best steps you can take is to educate yourself about long-term services and supports BEFORE you need them! This will allow you to make more informed decisions and reduce stress when the time comes.





CHAPTER 3: HOME AND COMMUNITY-BASED SERVICES AND SUPPORTS

Below is a listing of many, but not all, home and community-based services (HCBS) provided across the country. You will find a description of these services in Appendix 2. Remember that not all of these services may be available in your state. The names of these services and supports may also be different.

- Adult day services
 - Social/therapeutic adult day services
 - Medical adult day services
 - Mental health day treatment
 - Day habilitation
- Assistive technology
 - Physical aids
 - Cognitive aids
 - Sensory aids
 - Communication aids
- Attendant care
- Behavior consultation services, also referred to as behavior management/behavior program and counseling
- Care management (also referred to as case management, service coordinator or supports coordinator)
- Chores
- Congregate meals
- Cognitive rehabilitation
- Community integration training
- Companion services
- Counseling
- Durable medical equipment
- Environmental modification/home modification
- Family or consumer training
- Financial assistance
- Habilitation
- Home-delivered meals
- Home health services
- Home maintenance /home repair
- Homemaker services
- Information and assistance
- Legal assistance
- Medical supplies
- Monitoring technology
- Nursing services
- Personal care
- Personal emergency response system
- Recovery groups
- Respite care
- Senior centers
- Supported living services
- Support groups
- Telephone reassurance
- Therapies: physical, occupational, respiratory, speech/language, cognitive, behavioral, vocational, recreational, restorative
- Transportation
- Vehicle adaptation



People with mental illness may face barriers in obtaining services. Even though the services we have listed may be available in your state, providers may believe they are not equipped to serve people with mental illness. They may deny service based on the mental illness instead of an assessment of need. If you believe this has happened, contact a legal services program for assistance.

Summary:

HCBS are services that you can receive at home, like assistance with personal care or home-delivered meals, and services you can receive or participate in out in the community, such as adult day services.



CHAPTER 4: THE "HOME" IN HOME AND COMMUNITY-BASED SERVICES: HOUSING OPTIONS

Ask people where they want to receive care and services and they will almost unanimously say "in my own home!" That "home" can vary greatly from one person to the next because there is a range of options.

One option is for you to remain exactly where you are and receive services and supports to help you continue living in your current residence.

Sometimes, however, you may need or choose to find a different housing option. Your current home may have become too difficult to maintain, not accessible* enough or you may want more company and activities.

Below are descriptions of some of the more common housing options:

Living with a family member

Many individuals have relatives who welcome them into their homes. Services may be brought into the home or accessed in the community, provided by family members, or both.

Subsidized housing

Subsidized housing is housing made available to older adults, persons with disabilities and families who are low-income. Federal subsidized housing is provided through the Department of Housing and Urban Development (HUD). It includes:

- **Public housing**, usually apartments that are available at a rate less than what is normally charged in the community. Apartments are often part of public housing projects. For more information, call (202) 708-1112, TTY (202) 798-1455 or go to: www.hud.gov. You can apply for public housing at a public housing agency. To find the public housing agency near you, go to: www.hud.gov or call the Public and Indian Housing (PIH) Customer Service Center at 1 (800) 955-2232 and request information.
- **Housing Choice Vouchers** that are issued to individuals or families and can be used to pay for any housing unit where the owner agrees to rent under the Housing Choice Voucher Program. This program is commonly referred to as "Section 8." The voucher will cover all or part of the rent. The application process is the same as it is with public housing.



- **Privately owned subsidized housing.** HUD helps apartment owners offer reduced rents. You can find additional information about this option by going to: www.hud.gov or calling the PIH Customer Service Center listed above.



If you are considering living in any type of subsidized housing, apply as soon as you possibly can. Be prepared to be put on a waiting list that is usually very long.

Supportive housing

Supportive housing is rental housing with services for low-income persons with disabilities and older adults. Services may include: nutrition services, health-related services, mental health services, services for non-medical counseling, meals, transportation, personal care, bathing, getting to and using the toilet, housekeeping, chore assistance, safety, socializing, help with medications and case management. The most common forms of supportive housing are HUD Section 202 Supportive Housing for the Elderly and Section 811 Supportive Housing for Persons with Disabilities.

A variation of supportive housing is supported living programs for persons with developmental disabilities, mental illness or brain injuries. In these programs, a very small number of persons share their own apartment or home and are supported by a range of services, depending on their disability. Services may include up to 24-hour attendant care.

Accessible housing

Accessible housing allows people to do what they want or need to do as independently as possible. Whether or not housing is accessible depends on the type of disability. For instance, access for wheelchair users may mean wider doorways, while it may mean a strobe light smoke alarm in an apartment for someone with a hearing impairment. It is often possible to adapt or modify housing to make it accessible.³

Senior housing

Senior housing is housing in a private apartment or house in a community of adults who are age 55 or older or sometimes 62 or older. Senior housing typically does not provide services onsite, but seniors can hire their own services or get their health care services outside of their home environment. Some communities provide a lot of recreational and social activities, while others offer few amenities. See subsidized housing above for information about low-income senior housing.

Senior housing has many different names such as senior apartments, independent living communities or apartments or retirement communities, to name just a few.

Affordable housing

Affordable housing is housing a person does not have to pay more than 30 percent of his or her monthly income for rent and utilities. Subsidized housing is considered to be affordable housing.

The best place to start when looking for any housing option is your local Area Agency on Aging, Center for Independent Living or Aging and Disability Resource Center (see section, "Where do you find information and resources about long-term care?" for definitions of these agencies and how to find them). Your local city government may also be able to give you some guidance.

Summary:

You can live in your own home or a family member's home. Your home can be a house or an apartment. Subsidized, accessible apartments are available. Senior housing is also available. You can have services and supports provided to you in your home.

When looking for housing, start by contacting your AAA or CIL.

³ Informed Consumer's Guide to Accessible Housing



CHAPTER 5: HOUSING RIGHTS

Your rights

Knowing your rights as a tenant is very important. Many of your rights come from the Fair Housing Act, which gives persons with disabilities significant protections. Since the federal law defines a disability broadly, many older adults qualify as persons with disabilities as well.

The Fair Housing Act applies to anywhere that someone considers "home." It does not apply to a hotel or hospital, but it does apply to nursing homes, assisted living facilities, senior communities and other places where people live. Under the law, a landlord cannot take any of the following actions based on disability:

- Refuse to rent or sell housing
- Refuse to negotiate for housing
- Make housing unavailable
- Deny a dwelling
- Set different terms, conditions or privileges for sale or rental of a dwelling
- Provide different housing services or facilities
- Falsely deny housing is available for inspection, sale or rental
- For profit, persuade owners to sell or rent (blockbusting)
- Deny anyone access to or membership in a facility or service (such as a multiple listing service) related to the sale or rental of housing

In addition, you have the right to:

- Make reasonable modifications to your dwelling or common use areas, at your expense, if it is necessary for you use the housing. (Where reasonable, the landlord may permit changes only if you agree to restore the property to its original condition when you move.)
- Make reasonable accommodations in rules, policies, practices or services if necessary to use the housing. ⁴

Overcoming barriers to obtaining affordable, accessible housing

Unfortunately, you may face some barriers in obtaining housing that is both accessible and affordable.

Here are some common barriers and what you can do to overcome those obstacles.

Barrier #1: Shortage of this type of housing. There are far too few housing units to meet the demand. You may be put on a long waiting list.

Solution: Apply for housing as soon as possible, even if you're not sure you will definitely need it. Apply for all types of housing available. For example, if you are applying for Section 8 and HUD subsidized housing, take the first one that comes up. You can always switch to the other one as it becomes available.

Join or support an organization that is advocating for more affordable, accessible housing. While this won't help you immediately, it could make a difference in the future.

⁴ www.hud.gov/offices/fheo/FHLaws/yourrights.cfm

Barrier #2: Lack of knowledge about the existence of affordable, accessible housing or how to find it.

Solution: Contact your closest Center for Independent Living, Area Agency on Aging or Aging and Disability Resource Center.

Barrier #3: Housing claiming to be accessible is not accessible to you. For example, you are a wheelchair user, and there is no roll-in shower in an apartment you are considering.

Solution: Request a "reasonable modification" of the current shower in the apartment (although you will most likely have to pay for it yourself unless you are in federally subsidized housing). It is best to make such a request in writing. See Appendix 3 for a sample letter you could use.

Barrier #4: Your request for a reasonable modification or accommodation is denied, or you have been trying to rent or buy an apartment or home and feel you have been discriminated against.

Solution: File a complaint with the Office of Fair Housing & Equal Opportunity.

Office of Fair Housing & Equal Opportunity
Department of Housing and Urban Development (HUD)
451 Seventh Street SW
Washington, DC 20410-2000
1 (800) 669-9777



To file a complaint online (simple form), go here: www.hud.gov.

You can file on your own or with help from a lawyer. Free legal assistance may be available from your local legal aid office/legal services provider (contact your Area Agency on Aging, Center for Disability or Aging and Disability Resource Center for information). To assist persons with disabilities in filing the complaint, HUD will provide a toll-free TTY phone for the hearing impaired (1 (800) 927-9275), interpreters, tapes and Braille materials and assistance in reading and completing forms.

In many states, there are also state agencies where you can file a complaint.

Summary:

As a tenant, you have rights that protect you against discrimination. One of these rights allows you to request a reasonable modification to your home if it's necessary for you to use the housing. If you feel that your rights have been violated, you can file a complaint with the Office of Fair Housing and Equal Opportunity.



CHAPTER 6: LONG-TERM SERVICES AND SUPPORTS IN RESIDENTIAL SETTINGS: WHEN 24-HOUR NURSING SUPERVISION/CARE IS NOT NEEDED

When round-the-clock care is not needed, there are a number of different group living arrangements. These group living options provide housing; care/services such as assistance with activities of daily living and medication management; and supports such as meals laundry, housekeeping and transportation. Recreational and social activities are usually provided as well. Individuals living in this type of home are generally more independent than nursing home residents but may need assistance with dressing, bathing, etc.

There are many types of group living options around the country. States describe, name and license them differently. They may be called adult care homes, adult foster care, adult foster homes, adult family homes, board and care homes, personal care homes, housing with services establishments, residential care facilities or assisted living facilities - to name just a few. To make matters even more confusing, the term used in one state to refer to a certain type of home may mean a completely different type of home in another state.

Because there are such a great variety of terms, we are providing you with general descriptions of some of the most common forms of group living options. You can use the description to ask if such a group living option exists in your state and if so, what it is called. Your local long-term care ombudsman* is a good person to ask.

Option #1

Individuals live in the home of an unrelated family or individual homeowner. The family/homeowner provides the care and services. These homes are small and usually house one to four people but no more than six.⁵

Option #2

Individuals live in a home that may be a converted/adapted family home. While they are not living with a family, the setting is family-like. The operator/manager of the home may be the homeowner and may provide the services him or herself or hire attendants/aides. These homes may care for more people than in option #1.

Option #3

Individuals live in a group residence where they share rooms with others. There is a group dining area and common areas for social and recreational activities. These homes are often larger than the homes in options #1 and #2. Staff is hired to provide care and services.

Option #4

Individuals live in their own apartment, which usually consists of a bedroom, bathroom, a scaled-down kitchen with a small refrigerator and microwave and a living area. Meals are provided in a communal dining room. Residents have a greater level of privacy and independence in this setting because each person has his or her own apartment. These facilities can be quite large and corporately-owned. In some facilities, personal care assistance and medication administration are provided through a home health agency.

⁵ www.housingpolicy.org/toolbox/strategy/policies/foster_care.html

Warning

The term "assisted living facility" is being used more and more, but it means something different in almost every state. In some states, it is more of a marketing term than a legal term. It may refer to the type of home described in option #4, or it may be a very broad term used for any home that provides housing and some support

In some cases a home may specialize in providing care/services for persons with developmental disabilities, brain injury or mental illnesses. These are sometimes referred to as group homes.

Group homes for persons with developmental disabilities house up to 15 people but generally house six or fewer. These homes are usually owned and run by one provider, who hires staff to provide care, services and supervision 24-hours a day. Staff helps residents learn self-care and daily living skills such as money management, cooking, cleaning and medication management. Residents often participate in day habilitation programs or sheltered workshops in the community. These homes may also be called small intermediate care facilities for the mentally retarded (ICF/MR).

Group homes for person with brain injury provide 24-supervision, support and training. Staff also helps individuals learn self-care and daily living skills.

Group homes for persons with mental illness offer structure and support and may have a goal of helping residents return to independence in the community. Staff works with residents to develop skills for self care and daily living and to understand and cope with their mental illness. Staff also typically offers medication management. However, in some states, group homes provide very little assistance with ADLs. Staff may help with reminders and cueing but may do little hands-on care.

Summary:

There are many different group living arrangements offering both housing and services. If you don't need 24-hour medical/nursing care, there are options such as living with a family or in a home that feels family-like. Or, you can live in a residence where you share a room or where you have your own apartment. A few of the terms used to describe these options are adult family homes, personal care homes and assisted living.



CHAPTER 7: LONG-TERM SERVICES AND SUPPORTS IN RESIDENTIAL SETTINGS: WHEN 24-HOUR NURSING SUPERVISION/CARE IS NEEDED

Nationally there is a movement to provide care and services to people at home or in a community-based setting. In fact, in the landmark *Olmstead* decision, the U.S. Supreme Court held that states could not unjustifiably segregate people in institutions if they could be served in the community. Moreover, both states and the federal government have recognized that home and community-based services are generally more cost-effective than institutional care. While efforts are being made to keep people at home or to transition individuals out of the larger, more institutional residential settings such as nursing homes and Intermediate Care Facilities for the Mentally Retarded (ICF/MRs), these facilities are currently still part of our system. Below are descriptions of these facilities.

Nursing homes

These facilities provide services and supports to people who need round-the-clock nursing care or supervision,

Nursing homes provide a standard set of core services that include: room and board, personal care, nursing services, dietary services, social services, activities, housekeeping and maintenance. Nursing homes must also provide or arrange for therapy, such as physical therapy, occupational therapy or speech/language therapy; dental care; podiatry services; optometry services and transportation to medical appointments. Some nursing homes provide skilled nursing care and rehabilitation therapy after an injury or hospital stay. Others may have a special unit for residents with Alzheimer's disease or another form of dementia. These units may be referred to as "memory care," dementia, "Alzheimer's" or "behavioral" units.

Individuals with mental illness are not eligible for nursing home care solely on the basis of their mental illness. They must also need the type of care provided by a nursing home – such as assistance with activities of daily living or care for a medical condition. A screening (PASRR – Pre-Admission Screening and Resident Review) is done to determine, among other things, if a person with a mental illness needs nursing home care. The purpose of the screening is to make sure someone is not admitted to or allowed to continue living in a nursing home when they could receive services and supports in the community.



Continuing Care Retirement Communities

Continuing Care Retirement Communities (CCRCs) are housing communities that offer several levels of care in one location. Where people live depends on the level of care they need. In the same community, there may be individual homes or apartments for residents who still live on their own, an assisted living facility for people who need some help with daily care and a nursing home for those who require higher levels of care. Residents move from one level of care to another based on their needs but still stay within the CCRC campus or location.

CCRCs generally charge a large payment before a person moves in (called an entry or entrance fee) and then charge monthly fees. The fees vary according to whether the resident owns or rents the living space; the size and location of the residence; the amenities chosen; whether the living space is for one or two individuals; the type of service contract chosen and the current risk for needing intensive, long-term care.

Therapeutic communities

Therapeutic communities are long-term residential programs for persons with mental illness in which clients and therapists live together in a community. The program provides daily structure and includes therapy opportunities and practical activities. The approach is based on the idea that the community is healing, and people can help themselves and each other.

Long-term recovery residences

These facilities for persons with mental illness offer support, structure and services. The goal of the facility is to help the individual return to the community.

Your state may not have therapeutic communities and/or long-term recovery residences.

Large Intermediate Care Facilities for the Mentally Retarded (ICF-MR)

An ICF/MR is a facility in which more than 16 people with developmental disabilities live and receive 24-hour supervision and care. Residents in these facilities require a level of medical care, support and supervision that is not available in group homes. These facilities provide developmental services including training and support in life skills such as mobility, socialization, employment and recreation as well as skilled nursing services. ICF/MRs can be large or small and must follow federal regulations. Each state currently has at least one ICF/MR.⁶

State-funded institutions

A facility, usually quite large, that provides 24-hour care and supervision to individuals with developmental disabilities or mental illness. These facilities are run by the state and staffed by state employees. Some states have completely eliminated these institutions.

Summary:

If you need round-the-clock care/services, the primary group living options include nursing homes and Intermediate Care Facilities for the Mentally Retarded (ICF-MRs). Therapeutic communities and long-term recovery residences for persons with mental illness exist in some states.

⁶ www.workworld.org/wwwwebhelp/intermediate_care_facility_for_people_with_mental_retardation_icf_mr_.htm



CHAPTER 8: HOSPICE

The goal of hospice is to improve a person's last days and to allow him or her to die pain-free and with dignity. Hospice is designed to care not just for a person's physical needs but for his or her emotional, social and spiritual needs as well. Hospice care can be provided in any setting – in your own home, a group home or assisted living, or in a nursing home or ICF/MR. There are also an increasing number of "free-standing" hospice facilities.

Who qualifies for hospice services?

To qualify for hospice care, your physician must certify you as being terminally ill. An individual is considered to be terminally ill if death is expected within six months or less. This does not mean that care will only be provided for six months. Hospice can be provided as long as the person's physician and hospice team certify the condition remains life-limiting.

What services does hospice provide?

A wide range of services are available through hospice. These include:

- Physician services
- Nursing care
- Physical therapy, occupational therapy and speech/language therapy services
- Medical social services
- Home health aide services
- Homemaker services
- Medical supplies, including drugs and medical appliances
- Counseling, including dietary counseling, counseling about care of the terminally ill patient and bereavement counseling for family that continues for at least 13 months following the death of the individual
- Short-term inpatient care for respite care, pain control and symptom management



To find a hospice provider, go to www.hospicedirectory.org or call the Hospice Directory at 1 (800) 854-3402. The Hospice Directory is a website on hospice and end-of-life care for consumers. It also provides information and resources.

Summary:

Hospice is end-of-life care designed to improve the quality of a person's last days by offering comfort and dignity. People are generally referred to hospice when they are terminally ill. To be eligible for services, a physician must certify a person is within six months of death. Support is provided to both the individual and his or her family. Hospice can be provided in any setting.



CHAPTER 9: GETTING STARTED: FINDING INFORMATION, DETERMINING NEEDS AND OBTAINING SERVICES

Step #2: Learn what options are available in your area and identify what you need.

Where do you find information and resources about long-term care? You can obtain information from a number of places.

Eldercare Locator



This is a free national service, providing written information about long-term support options in general and connecting you to resources in your own community. To contact the Eldercare Locator, call 1 (800) 677-1116 or go to: www.eldercare.gov.

Area Agencies on Aging (AAA)



An Area Agency on Aging is a non-profit organization that coordinates and often provides a range of services to assist older adults in a particular community or region. Many AAAs also serve younger persons with disabilities and may have some programs that are available to anyone age 18 or older. The AAA can connect you with the right information and available services for your particular situation. You can find the Area Agency closest to you by going to: www.aoa.gov or calling the Eldercare Locator number.

Centers for Independent Living (CIL)



CILs are grassroots, advocacy-driven organizations run by and for people with disabilities. CILs help promote the independence and productivity of persons with disabilities, and they often have expertise in assisting people with disabilities arrange for housing and supports in the community. One of the CIL's core services is to provide disability-specific information and referral services. To locate a CIL near you, go to: www.virtualcil.net or call 1 (877) 525-3400.

Aging and Disability Resource Centers (ADRC)



These centers provide easy access to free information about the full range of long-term service and support options in a state or area to consumers and their families. To find the ADRC closest to you, go to: www.adrc-tae.org or call 1 (800) 677-1116. Not all states have ADRCs statewide, and some states may only have them in a few areas.

Family and friends

The people you know may be able to tell you how to find information and resources about long-term care, services and supports.

The Department of Veterans Affairs (VA)



The VA offers a range of services to veterans who need long-term care. For information and resources, contact the social work department of any VA Medical Facility; call 1 (877) 222-8387, or visit www.va.gov (Click on "Veteran Services").

How do you figure out what care, services and supports you need?

In the world of long-term care, assessment generally means the process used to determine in what areas you do or don't need assistance and whether you are eligible for certain programs that provide services and supports. Different assessments may be required to obtain various services and supports.

A number of professionals conduct these assessments. They include:

1. Care managers* through an AAA or your state's agency for developmental disabilities services. (Care managers may also be referred to as case managers, service coordinators or supports coordinators.)
2. Care managers through social service organizations in the community (e.g. Catholic Social Services, Family Services Association, Jewish Family and Children Services)
3. Private geriatric care managers - "Private" means you must pay out of your own pocket, although some long-term care insurance policies may cover this service. Many geriatric care managers also work with younger persons with disabilities. To find out more about private care managers, visit: www.caremanager.org.
4. Aging and Disability Resource Center Coordinators



If you would like financial assistance from the state or federal governments for services, it is best to seek an assessment from your AAA.

If you can, participate actively in your own assessment. The more information you provide, the more thorough the assessment. You may find it helpful to look at some assessment tools to give you an idea of the type of information that is collected. Several tools are listed in the Resources section under "Assessment Tools."

You can also ask family and friends to assist you in the assessment process. They may be able to point out areas that you may not have considered.

What is self-direction, and how do you know if it is right for you?

As you are determining what options are best for you and what services you will receive, you should also consider whether you want to be responsible for and in charge of your own services and supports. This is called "self-direction." It gives you control and flexibility as well as responsibility and duties.

If you are eligible for Medicaid waiver services, (see section, "How do you pay for long-term services and supports?") you can choose to be part of the self-directed waiver program.

This waiver varies from state to state. Under one type of self-direction you are the employer and responsible for assuming both payroll and tax responsibilities. You are in charge of hiring, training, supervising and firing your attendants.* In general, these workers can include your friends or family members who are not considered to be "legally responsible" (for example, a spouse). Some states even permit you to hire any family member, including someone who is legally responsible.

Another type of self-direction gives you the authority to hire, fire, train and supervise your attendants, but responsibility for wages, payroll taxes, and worker's compensation insurance is assigned to a state agency or a third-party fiscal intermediary with whom the state contracts. In a few states the fiscal intermediary is a "public authority" that takes on the responsibility for duties such as issuing paychecks and withholding taxes. The public authority may also run a registry that screens workers and then provides a list of the screened workers to consumers. Consumers can use the list to identify workers to interview and possibly hire. Ask your state Medicaid office if your state has a public authority.

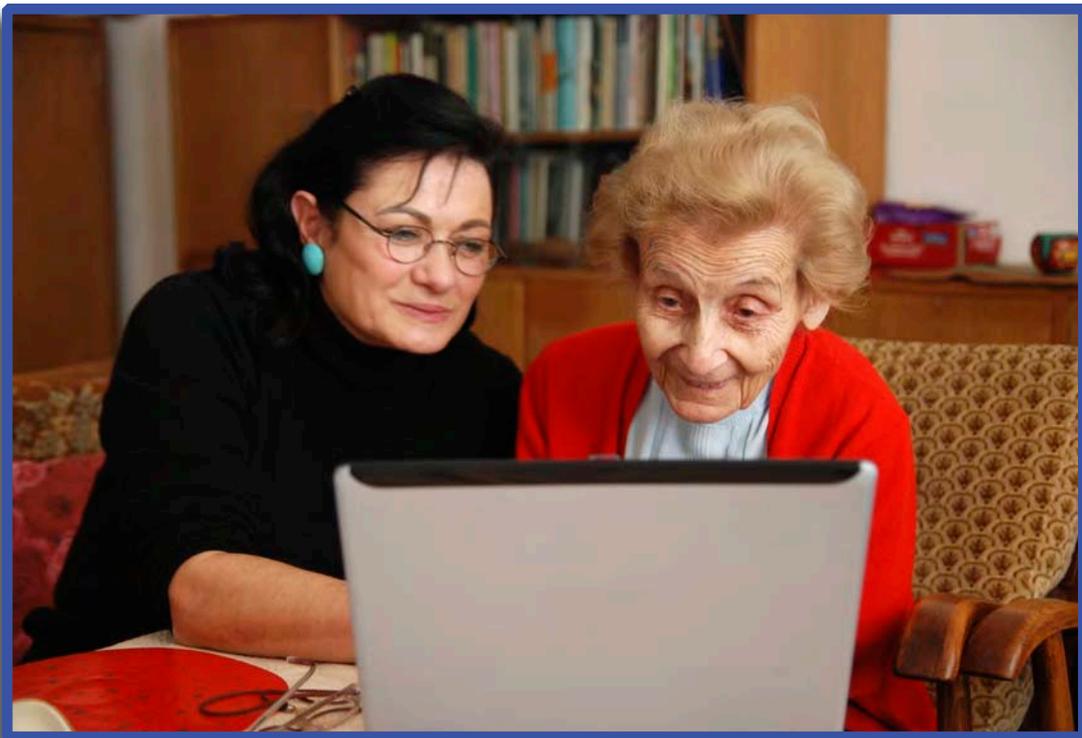
Here are some points to think about as you consider the option of self-direction ⁷:

- You can pick the worker who is most compatible with you and your situation.
- You have more flexibility in scheduling.
- You are responsible for hiring, training and scheduling workers and finding replacements to cover illness and other time off.
- You are responsible for paying workers (unless you use a fiscal intermediary or public authority).

You can use a worksheet in Appendix 4 to help you think through whether self-direction is right for you.

How do you access services?

In most states, you access services through an AAA and, in some states, through an ADRC.



Summary:

The best way to start is to contact the Eldercare Locator or your local Center for Independent Living. Both of them will provide you with information and resources, including who can assess your needs and how to obtain services.

⁷ Help At Home, published by the Ohio Department of Aging.

CHAPTER 10: COSTS & PAYMENT

Step #3: Figure out how you can pay for your long-term services and supports.

What do long-term services and supports cost?

The question of cost is very important because in many instances your options are determined by how much you can pay.

To give you some idea of cost, below are the national average costs in 2010 for home care services, adult day services, assisted living and nursing home care.⁸

Home care

Home health aide (from licensed agencies)	\$21 per hour
Homemaker/companion services (from an agency) (Note: This is the amount you pay the agency. It is not the amount the home health aide or homemaker/companion receives.)	\$19 per hour
Attendant	\$8.91 – 11.99 ⁹
Adult day services	\$67 per day

Assisted living facilities

\$3,293 per month

This is the monthly average base rate cost, which includes room and board, with usually at least two meals a day, housekeeping and personal care assistance for a one-bedroom apartment or private room with private bath.

Nursing homes

Private room	\$229 per day; \$83,585 per year
Semi-private room	\$205 per day; \$74,825 per year
Private room, Alzheimer's Unit	\$228 per day; \$83,220 per year
Semi-private room, Alzheimer's Unit	\$206 per day; \$75,190 per year



You can find out how much care/services cost where you live by going to: www.longtermcare.gov and clicking on your state.

How do I pay for long-term care?

There are a variety of ways to pay for long-term services and supports. Your options will depend upon your situation. Some payment options require you to meet certain physical and/or financial qualifications. Below is a brief description of the range of payment options.

Medicare

Medicare is a federally-funded and administered program providing health insurance for most people age 65 years and older, people under age 65 years with certain disabilities and people of all ages with end-stage renal failure. Since Medicare is a federal program, the eligibility guidelines and services are the same all over the country.

⁸ www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-2010-market-survey-long-term-care-costs.pdf

⁹ [www.payscale.com/research/US/Job=Personal_Care_Attendant_\(PCA\)/Hourly_Rate](http://www.payscale.com/research/US/Job=Personal_Care_Attendant_(PCA)/Hourly_Rate)

Medicare covers:

1) Home health care if your care is considered "medically necessary," and you need skilled nursing care (part-time or from time-to-time) and/or therapies (physical, occupational, speech/language therapy). Medicare home health care also includes home health aide services, medical supplies and durable medical equipment. Medicare will continue to pay for home health care as long as it is determined to be medically necessary; your doctor orders the care every 60 days; your care is provided by a Medicare-certified agency, and you are "homebound." Being homebound means that leaving home is a major effort, and you are unable to leave without personal assistance or the help of a wheelchair, crutches, etc. If you do leave home, it must be to get medical care, or for short, infrequent non-medical reasons such as a trip to get a haircut or to attend religious services.

Beware

Medicare will not pay for home health aide services if that is all you need. You must also require skilled nursing care and/or therapies to qualify for coverage.

2) Skilled nursing home care if you have had a hospital stay of at least three days; you receive care from a Medicare-certified nursing home and you need skilled nursing care and/or therapies. See the section "Problems with care/services being reduced, terminated or not paid for" to learn about important information relating to the three-day stay requirement.

Beware

Medicare covers very little nursing home care! Medicare will completely cover the cost of your skilled nursing facility stay for the first 20 days if you need skilled services throughout that period. From days 21-100, Medicare will pay a portion of the cost of your care if you continue to require skilled services. You must pay part of the cost (called the "co-pay") of your stay. Medicare does not pay at all after 100 days.

Medicare coverage ends when you no longer need skilled nursing care or therapy. Often a nursing home decides that in its opinion you don't qualify any longer and will notify you it is stopping services. This decision is frequently based on the incorrect belief that a person does not qualify if he or she is no longer making improvement. Don't fall for this. You have the right to appeal the nursing home's decision. Information about the appeal process can be found in section "Problems with care/services being reduced, terminated or not paid for."

3) Hospice care if you are eligible for Medicare Part A (hospital insurance); your physician certifies you are terminally ill (death is likely within six months or less); you sign a statement choosing hospice care instead of routine Medicare-covered benefits and you receive care from a Medicare-approved hospice program.

Beware

Hospice care under Medicare does not pay for room and board if you are in a nursing home! This means you will have to pay privately for that portion of your nursing home stay unless you are on Medicaid or have long-term care insurance or other insurance policy that includes hospice.

Medicare Part C, known as Medicare Advantage, is an option to original Medicare in which private insurance companies receive money from Medicare to provide coverage. Medicare Advantage is required to cover everything included in original Medicare Part A and Part B except hospice care. However, plans vary in terms of out-of-pocket costs, how you get services and extra benefits.

Medicaid

Medicaid is a health insurance program financed and run jointly by the federal and state governments for people who have limited income and resources (often called "assets") and who meet certain eligibility criteria such as being age 65 or older, blind or disabled. The federal government requires certain services be provided to beneficiaries. However, each state can decide if it wishes to provide additional services. States can also determine who is eligible. Because Medicaid is administered at the state level, you should contact your state Medicaid office for information. You can locate your state Medicaid office by calling the National Association of State Medicaid Directors at (202) 682-0100 or visiting: www.nasmd.org.



Medicaid covers:

1. Nursing home services
2. Home and community-based services

There are different ways Medicaid pays for services at home or in the community. Here are just a few examples of the various programs:

Medicaid home health services

State Medicaid programs provide home health services similar to the Medicare services described above. However, the federal government has made clear that Medicaid home health programs have less restrictive eligibility requirements than Medicare home health services. For example, Medicaid programs cannot require beneficiaries to be homebound to qualify for home health care.

The Medicaid personal care services benefit

In some states, a Medicaid personal care services program will pay to provide assistance with activities of daily living and instrumental activities of daily living to an individual. Individuals must need help with personal care as defined by the state and meet the Medicaid financial requirements.

Medicaid waiver

Federal law requires Medicaid to pay for long-term care services only when they are delivered in a nursing home, group home or other long-term care facility. However, states can receive a "waiver" of that requirement in order to provide long-term services and supports in the home and community. Under the waiver, states can provide a wide range of services such as homemaker services, respite, home-delivered meals and care management that traditional Medicaid does not cover.

To qualify for Medicaid waiver services, a person must meet:

a) Financial requirements.

The financial eligibility requirements for Medicaid waivers are different from the requirements for traditional Medicaid. Medicaid waiver allows you to have more money and still qualify. Individuals who would not financially qualify for traditional Medicaid may be eligible for Medicaid waivers. Often people who might qualify for Medicaid waivers do not apply because they believe that their income is too high. If you are unsure as to whether or not you would qualify, contact your local AAA.

b) Level of care requirements.

You must need the same level of care as those who qualify for Medicaid nursing home or group home care.

There are several different types of waivers. The names of the waivers vary from state to state. To learn what waivers exist in your state, contact your local AAA, CIL, ADRC or State Unit on Aging and Disabilities.*



The Health Care Reform Act that became law in March 2010 has several provisions that will help make home and community-based services paid for by Medicaid more readily available. To learn more about these provisions, go to: www.theconsumervoice.org.

3. Hospice care in most states

Older Americans Act

The Older Americans Act (OAA) is a federal law authorizing a wide range of services and programs to older adults and their families. The OAA provides funding through state and local agencies, such as the State Unit on Aging and the Area Agencies on Aging, for a number of home and community-based services. While there are no specific financial eligibility criteria for Older Americans Act services, they are generally targeted for low-income, frail seniors over age 60 and minority elders and seniors living in rural areas.¹⁰

¹⁰ www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Public_Programs/Public_Programs.aspx

Veterans Affairs (VA)

Federal law requires the Department of Veterans Affairs to provide long-term care to veterans who meet established disability criteria or to those who need care because of service-connected disabilities. Low-income veterans may qualify for the Housebound benefit for care at home or the Aid and Attendance benefit for care at home, in an assisted living facility or in a nursing home. In addition, the VA provides nursing home services to veterans through VA-owned and operated Community Living Centers (CLC) and the contract community nursing home program. Each program has admission and eligibility criteria specific to the program and the amount paid varies. There are also state-owned and operated veterans' homes.

 For more information, go to [eBenefits](#), a one-stop shop for benefits-related online tools and information. The website, run by the Veterans Administration and Department of Defense, is designed for wounded warriors, veterans, service members, their families and those who care for them. You can also get information from the National Hotline for VA benefits at 1 (800) 827-1000.

Long-term care insurance

Long-term care insurance pays for long-term services and supports, most of which are not covered by traditional health insurance. Policies pay for nursing home care and increasingly cover home care, adult day services and assisted living. The cost of your long-term care insurance policy is based on the type and amount of services you choose to have covered, how old you are when you buy the policy and any optional benefits you choose, such as Inflation Protection. Long-term care insurance is not for everyone, and it is very important that consumers carefully evaluate the pros and cons and their own financial situation.

CLASS Act

The CLASS (Community Living Assistance Services and Supports) Act creates a new national long-term care insurance program beginning in 2013. Full and part-time workers will be able to choose to have the premiums deducted from their paychecks. After you have participated in CLASS for at least five years and can no longer perform basic activities of daily living, or if you have Alzheimer's disease or other forms of dementia, you will be eligible to receive a daily cash benefit. You will be able to use this benefit to pay for anything that will help you stay at home.¹¹

State funding

Many states fund a state program that pays for one or more home and community-based services. Each state determines who is eligible for services.

Disease-based organizations, community agencies, local charities

Groups, such as the Alzheimer's Association or Catholic Charities, may be able to help in a more limited or targeted way.

Private pay

You pay for services out of your own pocket.

These resources can help you figure out what programs may help you pay for your long-term care services.



BenefitsCheckUp: www.benefitscheckup.org

This comprehensive online resource for locating financial assistance programs may help you pay for medications, health care, utilities, meals and other expenses. The website is developed and maintained by the National Council on Aging.



State Health Insurance Assistance Program (SHIP): www.healthassistancepartnership.org, 1 (800) MEDICARE

The State Health Insurance Assistance Program is a free counseling program. Trained counselors provide answers to questions related to Medicare, Medicare Supplement Insurance, Medicare Advantage, Medicaid, long-term care insurance, prescription coverage and low-income assistance. Each state has a SHIP program. You can find the SHIP program in your state by going to the website or calling the above phone number.

Summary:

There are several ways to pay for the services and supports you need, including Medicaid, Medicare, VA benefits and more. To figure out how what works best for you, begin by talking with someone at your AAA, CIL or ADRC, if you have one. You can also use BenefitsCheckUp at www.benefitscheckup.org or the SHIP program.

11 National Council on Aging. "Straight Talk for Seniors." www.ncoa.org/assets/files/pdf/Straight-Talk-for-Seniors.pdf



CHAPTER 11: FINANCIAL AND HEALTH CARE PLANNING

Step #4: Consider legal planning for the time when you might not be able to make your own decisions about your health care or handle your financial affairs.

While we don't like to think about a time when we can't make our own decisions, advance planning for such a time is one of the best things we can do. By planning ahead you can express what care you would want and ensure decisions about your finances and care will be made by someone you trust.

This section provides a very brief and general description of the ways you can express your wishes and give someone the legal authority to make decisions for you.

Financial decisions

Financial Durable Power of Attorney: This is a document in which you can give another person (the agent or attorney in fact) the authority to handle a part or all of your financial matters. To create such a document, a person must be considered to have "capacity" – that is, to be able to understand the nature of the document and to make the decision to have someone else take care of his or her finances. In many states, unless stated otherwise, the financial power of attorney is durable, meaning that it remains in effect if you are no longer able to make your own informed decisions. You can include instructions, guidelines or limitations as you wish. Be cautious: Even though your agent must follow certain legal rules as a "fiduciary," there is no formal oversight of the agent. If there is no one you trust fully to act as your agent, this is not a good tool for you.

Health care decisions

An advance directive is a legal document you can use to plan for your health care needs. In an advance directive, you can:

- Give direction about the type of care and treatment you would want if you can't communicate your wishes; and/or
- Appoint someone to make those decisions on your behalf. You must have decision-making capacity to create an advance directive.

What are the different types of advance directives?

While names vary by state, there are essentially two types of advance directives.

1) Durable power of attorney for healthcare (DPOA): a document in which you name another person - often called the health care proxy or health care agent - to make medical decisions when you are unable to do so. A DPOA can become active any time a person is unconscious or unable to make healthcare decisions. Other terms used for this type of advance directive include healthcare power of attorney and medical power of attorney. Choosing your agent is important. Be sure your agent knows your values and can be a good advocate.

2) Living will: a document in which you give instruction about medical treatment (usually about life support) if you are not able to speak for yourself. In some states a living will applies only to terminal illness or a permanent vegetative state. Living wills involve decisions about life-prolonging treatments such as ventilators, artificial nutrition and hydration, dialysis and antibiotics. Because a living will applies only in certain circumstances, it is best to appoint an agent under a health care power of attorney.



Some states have specific requirements or language for advance directives. To get a copy of your state's advance directive forms, go to: www.caringinfo.org.



Individuals with serious progressive or terminal conditions may want to ask their doctor about a Physician's Order for Life Sustaining Treatment (POLST) form that will be effective in any care setting. A POLST form is a brightly colored medical form used to write down orders indicating life-sustaining treatment wishes. Not all states recognize these forms. To find out about POLST in your state, go to the POLST website: dying.about.com.

The key to good advance planning is discussing your values, beliefs and wishes with your family, friends, doctor and other caregivers. Don't assume they know what you want!

Summary:

You can plan ahead by creating legal documents such as a power of attorney or a living will. These documents will allow you to tell others what you want and give someone you trust the authority to make decisions if you can't do so. Make sure to talk about your wishes with your family and health care providers.



Finding Your Way to Quality

Once you've decided what option is right for you, you need to choose your provider of services, learn how to partner with your provider to get quality care/services and resolve any problems that might arise.

You need a different map at this stage – one that focuses on the details and shows you how best to successfully go down the specific road you have chosen. This section of the guide gives you a roadmap for navigating your way to quality care and services at home from an attendant/aide, in an assisted living or group home setting or in a nursing home.





CHAPTER 12: ADVOCATING FOR QUALITY LONG-TERM SERVICES AND SUPPORTS: SELECTING YOUR PROVIDER

Step #5: Research your choice of providers carefully and then select the one that best fits your needs and preferences.

By choosing the best possible provider from the very beginning, you greatly increase your chances of getting good care and services. Here are some important points to consider or information to gather during the selection process.

Track record of provider

- Research the provider's history over time (a three-year period is helpful). See if the performance is consistently good, bad or up and down.
- Check with family or friends who have had experience with the provider and get their opinion. Another good approach is to talk to others who are currently using or have recently used the same provider. If you don't know anyone, you can ask a care manager, long-term care ombudsman or your doctor if they know someone whom they could ask to contact you. You can also talk with people you meet during an on-site visit (see below) or even ask the provider to give you the names of consumers to contact (noting that the provider will probably steer you to individuals who speak positively about their experiences).
- Check with the long-term care ombudsman program to find out if they have had complaints against any provider you are considering. Every state has a long-term care ombudsman program that can tell you about assisted living residences, nursing homes and, in some cases, home health agencies. To find out how to contact your local ombudsman, call the National Consumer Voice for Quality Long-Term Care (Consumer Voice) at (202) 332-2275 or go to: www.theconsumervoices.org, and click on "Locate an Ombudsman."



Some states also have ombudsman programs that serve people with mental illness or developmental disabilities. These programs may be able to share information with you about providers.

- Review data about the provider and compare it to other providers if possible. The federal government offers data about Medicare home health agencies and Medicare/Medicaid nursing homes on its website.



- **Home Health Compare**
www.medicare.gov



- **Nursing Home Compare**
www.medicare.gov

- Your state may offer additional information about home health agencies and nursing homes, such as "report cards." It may also rate assisted living facilities. Contact your state survey agency* to see if such information is available. To locate the survey agency, go to: www.theconsumervoices.org/ombudsman, choose your state and look for "Licensure and Certifications," or call the Consumer Voice at (202) 332-2275.



- Look at state survey (inspection) reports for the provider in your state. If the entity is licensed by the state or certified,* the state survey agency will inspect it on a regular basis. The survey reports provide detailed information about any violations that

have been found. You can access these reports through your state survey agency or from the facility or agency in many cases.

Background checks

- Ask the provider if they conduct a national criminal background check or a state background check on all their employees.
- If you are hiring your own attendant/aide, ask the individual to provide you with a national criminal background check or state background check (at your expense). If there are any arrests or convictions, you can evaluate the nature of those convictions and make your own decision.
- If your attendant is paid for by a Medicaid waiver, you may be able to select an individual who has already had a background check and is listed on a state registry.*

Who is served?

Don't assume the provider will serve anyone. Ask if there are any age or other limits on who can receive services.

What care/services are provided?

Ask for a list of exactly what services are included in the rate you are paying, and the cost of other services that are offered, but not included. Do the best you can to "drill down" and get details.

Disclosure forms: An increasing number of states are requiring assisted living facilities and any center/facility providing "dementia special care" to complete disclosure forms. These forms can be very helpful because they give more detailed information and a way to compare one facility to another. In some states, CCRCs must also provide disclosure forms that inform you about a facility's financial status. Ask your local long-term care ombudsman if your state requires such disclosure forms. If so, request these forms if they aren't given to you.

Contracts: Ask for a copy of the contract or agreement and review it before you sign. In some settings, such as assisted living, the contract is the only way to really know what is provided and the costs. In both assisted living facility and CCRCs, review contracts carefully to see under what circumstances you may be asked to move from your unit.

Expertise and experience

Ask providers about their expertise and experience with the services you are asking them to provide. How long have they provided this type of care/service?

Accommodation of your needs, preferences and routines

Discuss your needs and any particular preferences or routines that are important to you with the provider. Ask the provider if they will accommodate those needs and preferences and how. In addition, ask who determines when you need more services or when the services provided can no longer meet your needs – you or the facility.

Person-directed care

Ask how the provider practices person-directed care. Ask them to tell you how they will learn what is important to you and if/how they will honor your choices and decisions.

Memory care

If the provider claims to offer "memory care," ask what they mean by this term. What does "memory care" involve? What makes it different from other care? What training does the provider have in memory care or working with individuals with memory loss, confusion and/or behavioral symptoms?

Staffing levels

If you are considering a residential option, ask what the staff-to-resident ratio is. The fewer residents a nurse, aide or other staff person has to care for, the better!

Staff qualifications and training

Find out what education, training and experience the provider has with the services you want.

Regular staff assignments

Ask if the same attendant/aide will be assigned to you each time. This is called "consistent assignment" and has been shown to result in better care/services and increased satisfaction for both the person receiving and providing services.

Location

If you are receiving services at home, how far the provider lives from you can impact his or her ability to assist you when the weather is bad and transportation is difficult. In residential settings, such as an assisted living/group home or a nursing home, the facility's distance from your family and friends will affect their ability to visit you.

References

Request at least three references.

Checklists

There are many checklists you can use to assist you in evaluating a provider. These help you ask questions you may not otherwise have thought about and gather information. If you have online access, you can search for checklists by entering "assisted living facility checklist" or "home health agency checklist," etc. You can also contact your local Area Agency on Aging.

Visit the center or home if possible

Take any formal tour the provider may offer, but try to go back unannounced several times, including evenings and weekends. Observe and spend time getting a feel for the center or facility. If possible, speak to any current residents and any family or friends who may be visiting.

Summary:

There are many factors to consider when selecting a provider. Key points include the provider's track record, ability to meet your needs, willingness to accommodate your preferences and routines, experience in providing the type of care and services you need and location. Think about what factors are most important to you when making your decision.

The Consumer Voice: Tips from long-term care consumers for specific settings

This section and the corresponding sections in the next two chapters give you advice and recommendations from the experts – the people who are actually receiving care and services at home, in an assisted living/group home or a nursing home.

Each of the individuals quoted in these sections is a long-term care consumer who was interviewed and asked what suggestions they had about how to get good care/services.

Selecting Your Provider

At Home

When hiring your own attendant

If you're hiring your own attendants, try posting an ad through local colleges. Go to the Department of Nursing or the Occupational Therapy school. I've had good luck doing this.

- Kathy

Ask people you know if they know anyone who might want to work as your attendant. I mentioned to my neighbor who lives in the apartment above me that I was looking for someone. Turns out her daughter is an aide and was looking for work. It's worked out really well!

- Miss B

In Michigan, we have the Michigan Quality Community Care Council, which operates a registry to help people receiving in-home services through one of our Medicaid programs find someone to work for them. MQCCC does some initial screening and gives you a list of individuals you can consider. This is probably the best way to start your search. People should call their state unit on aging or Medicaid office to see if a similar service is offered in their state.

- Clark

When interviewing possible aides, be very clear about the help you need and whether the person is willing and able to do those tasks. I ask very specific questions, such as "Do you mind changing adult briefs?" "I'm a double amputee. Do you have a problem washing my stumps?" "How do you feel about bathing someone who is obese?" I don't hire anyone who has a problem doing any of those things.

- Miss B

After explaining what the duties will be, I tell potential providers approximately how much time they should take on their tasks. That way they know exactly what to expect.

- Carol (Note: Where Carol lives attendants are referred to as "providers.")

Try to get a sense of the candidate's reliability in the interview. I do this by asking things like, "Tell me a little bit about yourself." or "Tell me about your family." I also ask how many children they have, how far away they live and if they have a dependable form of transportation.

- Kathy

In the interview, I tell them right off the bat how important it is that they be on time.

- Miss B

If you are interviewing someone who has no connection to anyone you know or has not come from a registry, consider having your first interview somewhere other than your home if possible.

- Clark

Be very wary about who you hire. When I'm interviewing a possible attendant in my home, I watch to see if they're looking around my apartment a lot or asking a lot of really personal questions. You need to be able to read people really well.

- Barb



Ask for references and then call all of them.

- Clark

Sometimes you may be desperate to hire someone, particularly if your personal care assistant just quit. In those circumstances, you may want to hire the very first person who says they will take the job. That's a mistake. In Michigan, the state will pay for an agency to provide someone to assist you for a brief period of time in an emergency situation while you look for a personal care assistant. I recommend that people contact their state agencies to see if such assistance is available where they live.

- Clark

I would advise people not to hire their family or friends as their primary caregivers. This changes the role of your family member or friend and can be debilitating to your relationship. Instead, use family or friends as emergency back-up. My wife is my emergency back-up when all else fails.

- Marc

When working with an agency

Make a list of all the different ways you want help. List everything. Give the agency you are considering the list and ask if they have the capacity to provide the assistance you need.

- Linda

Ask the agency exactly what duties the attendant can provide – and make sure to be very specific. When I was interviewing one agency, they told me the attendants couldn't do any scrubbing. I thought that meant they couldn't do heavy cleaning – like scrubbing the walls and floors. I said ok because I didn't expect them to do heavy cleaning. When the attendants came, it turned out that “no scrubbing” also meant that they couldn't scrub the inside of a cooking pot or even the bathtub! I had to fire this agency and find another one.

- Julie

When possible, try to find an agency that allows you to communicate directly with your attendant. Here's why: When my regular attendant can't come, I want the agency to send me the person who usually subs for her. But the agency doesn't always do that. Sometimes I'd rather skip care at a certain time than have someone I don't know come in. I want to be the one who decides. I've worked things out so my attendant calls me and the agency when she can't make it. I then let the agency know what I would prefer that day. None of that is possible if I can't talk with my attendant myself.

- Linda

If you are considering an agency, find out who is responsible for arranging back-up when an attendant is sick, on vacation or not able to come for some unexpected reason, such as a transportation problem. Additionally, you may need assistance at an unexpected time such as becoming ill or acquiring a minor injury. Will the agency make arrangements for another person to assist you and how soon or is it your job to find the assistance?

- RoAnne

If you have a pet, find out if the agency allows attendants to take care of pets. The agencies I work with are not required to provide someone who will care for my dog, but it's alright if the attendant is willing to do so.

- Julie

Summary:

Hiring an attendant

- When looking for an attendant, ask people you know if they know someone.
- In the interview, be very clear and very detailed about exactly what you expect the attendant to do.
- Ask potential attendants about themselves, their work experience, how far away they live, and the reliability of their transportation.

Using an agency

- Give the potential agency a list of all the help you need and ask if they can do everything on your list.
- Ask the agency exactly what the attendants can and cannot do.
- Find out who is responsible for arranging backup when an attendant can't come.

Group Living Options: In Assisted Living/Group Homes

Look for a place where you can have your own room.

- Bill

Ask questions like, "Are there specific times for meals?" "Is there a specific time when you have to get up in the morning?" "How do you get the assistance you need in the morning when there are lots of residents who need to be helped at the same time?" "What happens if there is an emergency and your aide can't come when she's supposed to?" "Is transportation provided and is there a cost?"

- Fran

Find out what restrictions or policies they have. Ask for a copy of the policies. For instance, in one place I lived there was a policy that you couldn't stay if you couldn't give yourself your own insulin shot. Where I live now, the policies say the facility doesn't provide special diets. If you're on a diabetic diet, you need to know that beforehand.

- Jim

Find out if religious services are offered in the facility if that's important to you.

- Joe

Check out the activities program. This is very important because activities get you out of your room and mingling with others. Look at the activities calendar.

- Mary Jean

Choose a place that has an active resident council. Find out what kinds of things the council does. Does the council work on resident concerns or just do things like bake sales to raise money for curtains in the dining room?

- Jim

Get written materials about the places you are interested in. You can ask them to mail information to you. Read through the materials before you go visit. That way you can ask better questions.

- Fran

Make sure the staff communicates in a language you can understand. It makes a whole lot of difference.

- Jim

Find out who provides transportation and where exactly you can go. I had a doctor in another county I needed to see, but the para-transit service I used wouldn't go outside the county where the facility was located. This made it very difficult to get to appointments. You may want to choose a place where transportation isn't a problem.

- Jim

Summary:

- Find out how much flexibility there is. Ask if there are specific times for meals or if you have to get up at a specific time in the morning.
- Ask how you get the help you need if there are lots of others who need help at the same time or if there is an emergency and your aide can't come.
- Make sure to find out about any restrictions or policies. Get a copy of the policies. There may be a restriction or policy that wouldn't work for you.
- Check out the activities program.
- See if there is an active resident council.

In Nursing Homes

Look to see if residents and staff both appear to be happy. In order for residents to be happy, the staff has to be happy.

- Marilyn

Pick a nursing home that is as close to family and friends as possible.

- Brian

Check the beds for comfort! The bed I had was so uncomfortable that I had to bring in my own mattress.

- Marilyn

When considering a specific nursing home, ask people if they have heard anything good about it.

- Brian

Find out if there is an active activity department. That's really important.

- Marilyn

See if the kitchen tries to provide residents with food they like and will eat.

- Marilyn

Find out where the nursing home is with culture change.

- Howard

Are reading materials, like books and a computer available for residents?

- Marilyn

Observe whether wheelchairs are the right size for residents. There is one woman here in a wheelchair that is too big for her and it is very hard for her to get around.

- Marilyn

Ask if the nursing home is responsible for lost or stolen items. If something is missing and can't be found in this facility, they give you a check for \$10, no matter how much the item cost.

- Marilyn

Summary:

- **Look to see if both residents and staff seem happy.**
- **Check out the activities department.**
- **Find out if the kitchen serves foods the residents like and eat.**
- **Choose a place that is as close to family and friends as possible.**
- **Find out if the nursing home is responsible for lost or stolen items.**



CHAPTER 13: ADVOCATING FOR QUALITY LONG-TERM SERVICES AND SUPPORTS: BEING PROACTIVE

Step #6: Actively participate in and monitor your care and services.

The best way to achieve quality care and services is for you and your provider to come together as a team. Your provider brings skills, health care knowledge and expertise to the team, while your expertise is YOU. No one knows more about you than you, and no one cares more!

By actively participating in and monitoring your care and services, you can help ensure quality. Here are steps you can take.

Know the full range of care/services/supports for which you are eligible.

Ask for a written description of all the services you are entitled to. Far too often people don't receive all the services they need because they aren't aware that they have the right to receive those services.

Learn about your medical condition, if appropriate.

Educate yourself about the symptoms of your condition, its treatment or management and its progression over time if appropriate. The more you know, the better equipped you are to ask questions and shape your care.

Learn what you have the right to expect.

It is critical that you know your provider's responsibilities. You can find out a provider's obligations by:

- Reading the regulations if the provider is a center, agency, home or facility that is state licensed or Medicaid and/or Medicare-certified. In most states, the regulations are available online.
- Reviewing the contract or agreement you signed at the start of services or the time of admission. In cases, where the provider is not licensed or certified, the contract is the only place in which the provider's responsibilities will be stated.

Learn what your rights are.

You can't exercise your rights if you don't know what they are! Depending on your situation, you may have rights relating to several different aspects of your care and services. For instance, if you are living in an apartment and receiving services under a Medicaid waiver, your rights will include:

1. Rights regarding the type of services and number of hours of services you receive;
2. Rights pertaining to your housing under the Fair Housing Act and other anti-discrimination laws;
3. Rights regarding appeals, choice, confidentiality, consent, providers, records, planning, waiting lists and written notice;
4. Rights related to both Medicaid and the Medicaid waiver and more. Ask your provider for a copy of your rights.

Create a circle of support.

A circle of support is a group of family members, friends and/or other people you trust who provide assistance, guidance, relationships, safety and community to you. Members of your circle of support can assist you in advocating for the care and services you want, suggest steps you might take relating to your care, serve as a sounding board and provide encouragement.

Provide information about yourself to your providers.

The more your providers know about you, the better job they can do of giving you care and services in a way that meets your needs and respects what is important to you. Make sure to tell them how you like care to be done, when you want your care and services provided, your routines, preferences, likes and dislikes. Consider putting this information in writing, giving a copy to your provider and keeping a copy where you can access it easily.

Participate in developing your care/service/support plan.

With a few exceptions, you will have a care plan, service plan or support plan wherever and however you receive care and services. In general, such a plan outlines your goals; your abilities and needs; what care, services and supports will be provided to meet those needs and maintain or further develop those abilities in a way that supports your normal routines, choices and preferences; and who will provide the care and services.

If the development of a plan is not required by regulation, you should consider creating one with your provider anyway. It is always helpful to be clear about exactly what services will be provided to meet your needs and goals.

The plan will be reviewed on a regular basis or if there is a major change in your condition. Ask your provider how frequently the plan will be reconsidered.

Suggestions for developing your care/service/support plan: ¹²

- Inform your provider that you want to be involved in developing or reviewing your plan.
- If you have more than one aide/attendant, ask the person who is most familiar with you and whom you trust the most to participate as well.
- Prepare for the discussion by identifying any questions, comments or concerns you have. Make a list so you remember the points.
- Speak up at the meeting! Tell your provider what you want and need.
- Ask for a copy of the plan after it has been created or revised.
- Monitor that the plan is being followed.
- Request that the plan be changed if it is not working or if your condition changes.

Ask for the same aides/attendants every time you receive care and services (consistent assignment).

When the same people assist you on an ongoing basis, they become familiar with your needs, preferences and how you like things done. This results in better care and services for you. It also helps you and your aide/attendant develop a solid relationship, which makes both of you more satisfied.

Get to know your aides/attendants and treat them with respect and appreciation.

Just as your aides/attendants will try to get to know you, you should make an effort to get to know them as well. Show them that you are interested in and care about who they are as people and their lives.

- Be polite, respectful and considerate. Practice the "golden rule:" Do unto others as you would have them do unto you.
- Show appreciation. Caregiving can be a hard job and often pays very poorly. Saying "thank you" frequently can make a big difference in how a worker feels about his or her job – and in the quality of care and services you receive.

Know what care/services you are supposed to receive according to your care/service/support plan.

The only way to ensure you get all the care/services stated in your plan is to know exactly what your plan says. Getting a copy of your most recent plan allows you to do this.

In addition, know what medications you need to take and when, and what they look like. This helps prevent medication errors.

¹² Caregiver Digest: A Guide to Indiana Long-term Care Resources. United Senior Action Foundation.

Communicate effectively.

- Ask questions if something is unclear.
- State what you mean clearly, politely, respectfully and in language that is free of blame and judgment. Speak up nicely if something isn't done, or if it isn't done the right way. How you communicate is just as important as what you communicate.
- Show appreciation. Remember to thank staff when a problem has been addressed or when good care has been provided.

Monitor care/services.

Overseeing your own care and services is critical in ensuring you receive the right care and services in the right way at the right time.

Review records kept by the provider

Almost all providers are required to maintain records regarding your care and services. Most providers develop assessments and reports that include information about the services provided, adequacy of services, progress with goals and objectives, your satisfaction with services and other individual and personal information.¹³ Because written documentation can influence the quality, type and amount of services you receive, you should review these records periodically for accuracy.

Don't be surprised if your provider wants to know why you are asking to look at your records. Most consumers don't know they have the right to see their records, so providers don't receive many requests. When they do receive a request, it's a bit out of the norm. Simply tell your provider that you want to work with them as part of a team. Being an active participant in your care and services and reviewing your records is one of the ways you can do that.

Request your own copies of key records and keep any documents or paperwork you receive related to your care/services.

Trust, but verify.

If your provider tells you they can't do something because "state" or the "rules" won't let them, ask them to show you where it says in writing that something can't be done. Sometimes staff have misunderstood a regulation or mistakenly thought a rule existed when it didn't.

Keep notes.

You should keep your own records of your care and services. It is particularly important to document any incidents or problems that arise. Indicate the date and time of the incident or problem, what happened, where it happened, who was involved and their names and what the provider said they would do about the problem or incident. In the event that the problem is not solved or the incident occurs again, your documentation can help if you have to go up the chain of command or request outside assistance.

Know whom to contact within the agency, facility or system when you have questions/concerns about your care/services.

Find out from the very beginning the person to turn to if you have any questions and the best way to reach them. For example, you might talk to your care manager or service coordinator if you receive services in the community or the social worker in the nursing home.

Know what advocates are available to guide/counsel you.

There are a range of advocates who can give you advice and suggestions about your care and services and answer questions free of charge. These individuals don't work for the provider and can give you unbiased information and guidance. Below is a list of some of the key advocates. Not all of these may be available in your state.

¹³ Home and Community-based Services for People with Disabilities: Medicaid waiver Services Guide. Virginia Board for People with Disabilities.

- Available in every state:
 - Long-term care ombudsman ¹⁴
 - Centers for Independent Living
 - Protection & Advocacy Services. See section, "Addressing Problems," for information about this agency.

- Some states only:
 - Other ombudsman programs
 - Developmental disabilities ombudsman
 - Mental health ombudsman
 - Contact your state human services agency for information. To find contact information for the human services agency in your state, go to: www.aphsa.org, or call (202) 682-0100.

 - Citizen advocacy group

these are organizations at the local or state level that advocate for quality long-term care. To find out if there is a group in your state, go to: www.theconsumervoice.org.

Know that you can change providers if you are not happy with care/services.

You do not have to continue receiving services from the same provider if that provider is not meeting your needs. You have the right to change providers at any time. However, this may not be easy if there is a lack of providers in your area or if providers don't feel they can meet your needs. In those situations you may have to wait a while, or even consider a provider outside of your community.

Summary:

Getting involved in your own care is essential for receiving good care and services. Steps you can take include: learning what your rights are and exactly what care/services you are entitled to; sharing information about yourself with your provider; participating in developing your care or service/support plan; asking for the same aides/attendants; showing appreciation for their work; and communicating effectively.

¹⁴ In the following states, the long-term care ombudsman program has responsibility for home care: Alaska, Idaho, Indiana, Maine, Minnesota, Ohio, Pennsylvania, Rhode Island, Vermont, Virginia, Wisconsin, Wyoming.

The Consumer Voice:

Tips from long-term care consumers

for specific settings

Being Proactive

At Home

To get off to a good start, I respect my attendants as new to the skill set and the environment. I try to set them at ease by chit-chatting while they are doing personal care. I work to get to know them while maintaining some professional distance.

- Kathy

Not all workers in department of human services county offices know about all the programs. You need to know what you are entitled to so you can get all the services you qualify for. If you've educated yourself and workers tell you that you're not eligible for a program or that a program doesn't exist, just say, "I'll wait while you check."

- Clark

If it's important to you, tell the agency that you would like to have some say in the type of person they send out to care for you. When you are first talking to the agency make sure to let them know your preferences, and what personality traits or characteristics you are looking for in an aide/attendant.

- Clark

Ask for the same attendant to be assigned to you. Many people don't realize that the agency may have the capacity to give you continuity of services. Also, if you find an attendant you get along with, try to give that person as many hours as you can.

- Clark

I let my attendants know that I expect responsibility, reliability, respect and good communication from them – and I hold myself to the same standards. It's a two way street.

- Kathy

Unfortunately, I have had experiences in the past where providers have stolen from me and taken advantage of me. As a result this is what I say to my provider when he or she first starts the job:

"I've been abused before, so please don't take advantage of me. This includes abusing my trust. There is zero tolerance of abuse. If I feel that you have abused my trust and are not doing your duties right, I will have to let you go. I will be very fair with you and give you notice, but I will terminate you."

- Carol

Ask the agency to give you a number you can call if your attendant doesn't show up, leaves early or does something you're not comfortable with. I learned this the hard way when one of my attendants just didn't show up one day.

- Julie

You should ask for adjustments in your schedule if you find that would work better for you. I like to stay up late, so I asked that my attendants come later than had originally been arranged.

- Clark

Make sure you know the number of hours and the type of service you are supposed to receive and track these carefully. I get two hours a day provided by a combination of home health aides through Medicare and homemaker and attendant care services. My home health aides can't run errands, and the homemaker can't do personal care, but my attendant can do both these tasks. I track my hours and juggle them to get all the assistance I need.*

- Linda



Know what payor source is paying for your services and check that the paperwork your attendants or aides fill out is correct. For instance, most of my hours are paid through a state program. One time my attendant made a mistake and marked down the payor source as being Medicaid Waiver. If I hadn't caught this, it could have messed up my hours and my eligibility and created lots of problems.

- Linda

You may have to use several agencies to get the help you need. I have three agencies that work with me at one time.

- Marc

It is important to be very detailed. I write out a list of exactly what my provider needs to do every time she comes. I ask her to check each task off as she does it and then bring me the list at the end of her shift. That way I know everything has been taken care of.

- Carol

Your attendant may not be aware of your care or service plan. Ask the agency to give you something in writing that states exactly what your attendants are expected to do.

- Julie

When you first start working with an aide or attendant, try to get to know him or her. Look for some things the two of you have in common.

- Linda

The first time I have an attendant, I follow them around for a while to see if they're doing things right.

- Linda

Request to only have to work on scheduling with one agency person. This reduces confusion and improves follow-through.

- Linda

Help your attendant learn how to do things the way that works best for you. I have to wear compression stockings, and I need them put on me a certain way or it's painful. A new attendant may never have put compression stockings on someone or done it a different way. I say, "I put these on in a way that's a little bit different, and if it's ok, I'm going to walk you through it."

- Linda

I have color labels on my kitchen cabinets and drawers on which I have written what they contain. This helps the provider know exactly where everything should go and ensures that I can find things.

- Carol

When you have a substitute attendant, keep track of who the agency sends you and how that person worked out. Next time you need a sub, you can ask for one you've already had who worked well.

- Linda

Be very careful about the number of keys you give out to attendants. Unfortunately one of my attendants used one of the keys to get into my house when I was gone. My \$600 laptop was stolen. Now I keep a key in a lockbox, and you have to know the code to get into the box. I can check the box when someone leaves to make sure the key has been put back.

Also, be careful about your valuables. I keep mine in a lockbox that I have hidden in my apartment. It's also a good idea to put any narcotics that you use as painkillers in the box.

- Barb

I tell my attendants that if something comes up that makes them feel uncomfortable or that they don't understand, we need to talk about it right away.

- Kathy

Make sure to tell your attendants in a nice way when you would like them to do something in a different way. I explain what I would prefer and then ask, "Could you please do this instead?"

- Julie

The biggest thing you can do is to take care of your attendants. You've got to take care of those who take care of you. I make sure they feel appreciated. I say things like, "Thank you for hanging up my clothes that way," or "Thank you for putting my laundry where I wanted it."

- Marc

You need to be very involved in your care and very vocal.

- Julie

Summary:

- Know exactly what services you are entitled to and make sure you get them.
- Check the paperwork your attendants fill out to make sure it's correct.
- Let the agency know what type of person you prefer as an attendant and then ask that the same aide be assigned to you.
- In getting to know your attendants, try to find something you have in common.
- Help attendants learn how to do things the way you need and prefer.
- Give your attendant a list of duties to be performed.
- Be very careful about valuables.
- Say thank you, show appreciation.
- Get a number you can call if your attendant doesn't show up.

Group Living Options: In Assisted Living/Group Homes

Get to know your aides and talk with them. I learn about their families and their lives and how things are going for them. Sometimes I'm able to make suggestions about what they can do if they're having problems. That way I'm helping them and they're helping me.

- Fran

Join the resident council and any other council. We have a food council here that I participate in. Councils give us a chance to make improvements.

- Joe

Make yourself known to staff and tell staff what your needs are.

- Jim

Introduce yourself to the head person in charge so they know you.

- Joe

Communication is very important. If you can, have a one-on-one session with your aide. It can prevent or break down animosity that might arise.

- Joe

Know your rights. A lot of places make up their own rules, so you need to know what your rights really are.

- Jim

Be sure to do a really good job of marking your clothes with your name! This helps when things get lost.

- Mary Jean

Get to know the maintenance staff! This has helped me get extra help. One time my power chair wasn't working right and the maintenance person fixed it for me.

- Jim



Be aware of your own medical needs and take charge of your care. One time I had a foot ulcer that looked really bad. I was very concerned about it and asked the aides to look at it. Since it was night time, they just told me to show it to the Director of Nursing in the morning. I knew the condition of my ulcer was serious, so I called a friend to take me to the hospital. I ended up having a stent put in by a vascular surgeon. I would have lost my leg if I hadn't acted.

- Jim

Use good manners. Don't forget to say "please" and "thank you." If staff has done something extra special for me, I write a thank-you note.

- Fran

Speak up if you have suggestions for improvements. Everything I've suggested has been looked into and changes have been made. For instance, there wasn't enough time at lunch for residents to eat and enjoy their meals. Everything was hurried and rushed. I said something and now things have slowed down and are better.

- Mary Jean

Ask for things that you would like. For instance, bingo is a big part of activities here, but I wanted something that would make me use my brain. I asked the activities person if we could play something else. Now we play card games that make me think.

- Bee

*Ask for help in a nice way. Don't be demanding. When I need assistance, I ask staff **when** they can help me.*

- Bee

Get to know your ombudsman.

- Jim

Summary:

- **Get to know your aides and talk with them.**
- **Introduce yourself to the person in charge.**
- **Know your own medical needs and take charge of your care.**
- **Ask for help in a nice way.**
- **Show appreciation.**
- **Join the resident council.**
- **Speak up if you need something or if you have suggestions for improvement.**

In Nursing Homes

The first few days in the nursing home can be very important. People form attitudes quickly. Put forth your best self.

- James

Go to care plan meetings, especially if something is going on that you don't like. It helps if a family member can join you. If your care plan isn't scheduled for a while, talk with the Director of Nursing.

- Marilyn

Speak up about your care. My care plan called for me to get a certain treatment twice a day, with one treatment at night after 8:00 p.m. But evening is the time I really get into researching things on my computer, and the treatment took away from my computer time. I asked if we could do a shorter version of the treatment at night, and they agreed.

- Brian

Practice what you preach. Be very appreciative of staff. Thank them for what they do. A thank you goes a long way.

- James

Reach out to staff and ask them how they are doing.

- Brian

Get to know management, like the Administrator or Director of Nursing. This has really helped me. For instance, if I'm having a problem, the Director of Nursing will take care of it because I have good rapport with her.

- Brian

Know what medications you're on and what they look like. Make sure to look at the medications in the cup when staff is giving them to you. If the medications look different or don't look right, question it.

- Marilyn

If you have family, get them involved. I see a real difference in the experience that people with family have. If you don't have family, make sure to have outside connections.

- Howard

Get to know the names of your aides and nurses. Help them get to know your likes, dislikes and needs. I told them that my mother comes to visit three days a week at 12:30 p.m. so I need to have all my care done before that time. They have accommodated my needs.

- Brian

Be as kind and considerate to the aides as possible.

- Marilyn

Summary:

- Let staff know your preferences.
- Know your rights.
- Be tactful.
- Get to know administration and your nurses and aides.
- Go to care plan meetings and speak up about your care.
- Know what medications you are on.
- Show appreciation.





CHAPTER 14: ADVOCATING FOR QUALITY LONG-TERM SERVICES AND SUPPORTS: ADDRESSING PROBLEMS

Step #7: Speak up, and take action when there is a problem.

Problems with quality of care/services

Problems can arise in any setting because no provider is perfect – just as none of us is perfect. While you can't expect perfection, you can – and should – expect your provider to respond to and do whatever they can to address your concern.

This section discusses approaches you can take to resolve problems. The strategies are not listed in any order.

However, before you communicate your concern to anyone, start by gathering the details of the problem. The more information you have, the easier it will be for the provider to try to address the concern.

As appropriate, include the specifics, such as when and where the problem occurs and who is involved. If you have a major concern, particularly one that is ongoing, it can help to write up a description of the problem before you talk to someone. This makes it easier to communicate later. Describe the facts of the situation, using objective language. While you may be very angry about the problem, you will hurt, rather than help your efforts, if you describe the problem with blaming or threatening language.

In addition, before speaking up, evaluate how you talk to staff and managers about concerns. As mentioned earlier, how you communicate is just as important as what you communicate. Avoid blaming individuals. The way you express your concern can build a bridge – or a wall. Here are a few tips.¹⁵

- **Ask open-ended questions.** These questions can build rapport as well as provide you with information. Example: "Can you help me understand the delay in answering my call light?"
- **Use reflective listening.** Reflective listening or responding is the process of restating in our own words the content and/or feeling of what someone has said. It shows that you are truly listening and trying to understand the other person. Example: Your attendant has missed several days of work because her car keeps breaking down. She tells you she doesn't have enough money to fix the car right now, and the people who promise to give her a ride keep forgetting. She says she hopes you'll understand. You might say, "You're frustrated because you're having problems with your car. You feel that you're doing everything you can to get here and hope that I will be patient during this time."
- **Utilize the power of "we."** When you say "we" in your conversation, it creates a sense of team and partnership between you and your provider. This sends a message that you both are working together to ensure good care and services. Example: "Can we talk about what we can do to address this issue?"

Two very helpful handouts on communication by PHI are *Guidelines for Presenting the Problem* and *Coaching-based Communication*. These handouts discuss ways in which problems can be presented respectfully and effectively. They can be found in Appendix 5 and 6.

¹⁵ "Working for residents, by working with families." National Long-Term Care Ombudsman Resource Center.

Problem-solving approaches

- Speak to the attendant/staff person most directly involved. If the issue relates to something the attendant/staff person can control, it may be possible to resolve the matter at this level. Document your conversation.
- Talk to the staff person you were told to contact with any questions/concerns (see previous section). If you don't know who that person is, start by speaking with the agency/facility social worker or service coordinator, or ask whom the best person is to contact.
- Follow agency/facility policy for grievances. Find out if the agency or facility providing care/services to you has a grievance policy (it may be called something else) and what the policy is. Then follow the policy. The strength of this approach is that you are using the entity's own process. You can usually express your concern orally or in writing. If you voice your complaint verbally, it is a good idea to also submit it in writing. This way your concern is communicated as you described it and with all the detail. Make sure to keep a copy of your written concern.
- Ask a family member, friend or member of your circle of support to give you suggestions on how to proceed and to even be with you when you are voicing concerns. It's always helpful to get feedback and support from others.
- Ask for a special care/service plan meeting to discuss your concerns. Make sure someone with the authority to change things attends.
- Go up the chain of command. If speaking to the attendant/staff person most directly involved is not successful, work your way up.
 - Speak to:
 - the supervisor
 - the administrator/director/manager of the agency or facility
 - the person to whom the administrator/director/manager reports
- Document all conversations. Keep copies of any correspondence you receive.
- Unite with others who share the same concern.
 - Many nursing homes, assisted living facilities, group homes, continuing care retirement communities and public housing buildings have resident councils (these may be called self-governance councils in group homes that are small ICF/MRs).

A resident council is a group of residents who work together to improve the quality of care/services, conditions and quality of life of all residents living in the facility or building. To find out if your facility has a council, ask the social worker, service coordinator or manager. If there is a resident council, ask the council president to discuss the problem at the next meeting. If other residents are experiencing the same problem, the council can bring the issue to the attention of the administration. When there is "strength in numbers," the concern is more likely to be addressed.

If your facility does not have a council, consider starting one. The ombudsman can help you form a council in a nursing home or assisted living facility. You can obtain information on council development by calling the Consumer Voice at (202) 332-2275 or going to: www.theconsumervoice.org.



- Join with others who receive care and services from the same provider. If you are receiving services in your home, it is still possible, although more difficult, to connect with other consumers.
 - If a case manager is coordinating your services, you can ask him or her to give your name, contact information and request to call you to other clients being served by the same provider.
 - Be a "networker" and attend support group meetings or conferences held by groups such as the National Multiple Sclerosis Society or the Alzheimer's Association. This gives you the opportunity to meet people receiving similar services who might have the same provider.
 - In states where the long-term care ombudsman program serves in-home services clients or there is an ombudsman for Medicaid waiver services, you can see if the ombudsman will help connect individuals.

- Advocacy organizations might also be of assistance. See Chapter 17.

Other avenues to pursue

Many people successfully resolve their concerns using the above approaches. Sometimes, however, you may need to turn to outside organizations, agencies or programs to address the problem.

• Long-Term Care Ombudsman Program

Long-term care ombudsmen serve as advocates for residents of nursing homes and assisted living facilities. In a few states, the long-term care ombudsman program also serves individuals receiving in-home services.

Long-term care ombudsmen work to ensure the health, safety, welfare and rights of residents by:

- Investigating/working to resolve complaints, concerns or problems voiced by residents or their representatives
- Providing information about residents' rights and facility responsibilities
- Working for improvements in the long-term care system

Long-term care ombudsman services are free and confidential.

 To find contact information for your long-term care ombudsman, you can call the Consumer Voice at (202) 332-2275 or go to: www.theconsumervoices.org and click on "Locate an Ombudsman."

• Other ombudsman programs

In some states, there are other types of ombudsmen who can help to resolve problems. These may include mental health ombudsmen, managed care ombudsmen, Medicaid ombudsmen or developmental disabilities waiver ombudsmen. The best way to find out what, if any, other ombudsman programs exist in your state, is to contact your state's human services agency. To find out what that agency is and how to reach it, go to: www.aphsa.org, or call (202) 682-0100.



• Care managers

Care managers can also help to resolve problems. A private geriatric care manager will advocate on behalf of both older adults and persons with disabilities and brings knowledge and expertise to a problem. Private geriatric care managers charge a fee for their services and most will also bill for out-of-pocket expenses, such as mileage. To get a list of private geriatric care managers in your state, go to: www.caremanager.org, or call (520) 881-8008.



If your services are funded through the Medicaid waiver or a state-funded program, you will most likely have a case manager assigned to you. In many cases, the case manager will work with you and your provider to resolve a problem.

• Centers for Independent Living (CIL)

CILs are organizations that provide services to maximize the independence of individuals with disabilities. They offer individual advocacy that may help you in resolving a concern. To learn what CIL is closest to you, go to: www.virtualcil.net, or call 1 (877) 525-3400.



• Protection and Advocacy Services (P&A) /Client Assistance Programs (CAP)

This federally mandated agency works to address concerns about care/services, rights, access to services and more for people with disabilities both in residential or community settings. To contact your state's P&A/CAP, go to: www.napas.org, "Get help in your state," or call (202) 408-9514 or (202) 408-9520 TTY.



• State agency that oversees/regulates the provider

In every state there is an agency that monitors or regulates providers that are licensed or certified. For many providers, that agency is the state survey agency (also known as licensure and certification). In some cases, as with home and community-based services or entities such as adult foster homes, the state agency for human services may have oversight.

The responsible agency investigates complaints about care, services, rights and other issues.

You can work to get your problem corrected by filing a complaint. Make sure to provide the agency with detailed information in your complaint. Contact information for your state survey agency and human services agency has been provided in previous sections.

Additional agencies/entities you can contact for assistance include:

- Adult Protective Services
- Medicaid Fraud Control Unit
- Licensing boards
- Quality Improvement Organizations
- Law enforcement
- Legal assistance programs

Descriptions and contact information for these entities are provided in Appendix 6.

What do you do about problems if you hire your own attendant?

If you run into problems with an attendant whom you have hired and are paying completely out of your own pocket, there are fewer options to pursue. Nevertheless, the following approaches may help you address your concerns.

- Use good communication skills to review your expectations with your attendant. Follow the points discussed in the two handouts from PHI mentioned earlier, *Guidelines for Presenting the Problem and Coaching-based Communication*.
- Contact your local long-term care ombudsman and ask if the ombudsman program covers in-home services regardless of funding source. Most long-term care ombudsman programs don't cover in-home services, but it is worth checking. However, even if the program does not handle home care complaints, the ombudsmen may be able to give you suggestions or strategies to try.
- Remember if things really aren't working out, you can fire the attendant. While this is certainly not pleasant, it may be the best solution for both you and the attendant.

Fear of retaliation

No matter where people receive care and services, the fear of retaliation is very real. Individuals are often afraid to speak up about problems or concerns because they are afraid they will make an attendant/staff person/provider angry, and this anger will result in retaliation. Retaliation can often be very subtle – like making you wait to be taken to the bathroom. It is also hard to prove.

While retaliation can and does exist, here are some points to consider: ¹⁶

- The fear of retaliation is often greater than its actual occurrence. It's important to weigh your concern about what *might* happen with your concern about what *is* happening right now.
- There is certainly no guarantee that retaliation won't occur, but there is the guarantee that nothing will change or improve if you don't speak up.
- Speaking up often results in better care and services rather than in retaliation. Frequently the "squeaky wheel" really does get the "grease."
- Building positive relationships with staff can reduce the likelihood of retaliation.
- Connect with the long-term care ombudsman, the CIL, your local legal services program (www.lsc.gov; (202) 295-1500) or some other outside advocate. Retaliation may be prevented if the ombudsman or other advocate tells the provider they expect the problem will be resolved, and they will be monitoring the situation closely.



¹⁶ "Working for residents with families." National Long-Term Care Ombudsman Resource Center.

Problems with care/services being reduced, terminated or not paid for

Sometimes the problems consumers face relate to services being cut back, stopped or not covered.

You should always receive some type of written notice before there is a change in service. Examples of such changes include decisions to cut the number of hours of attendant care you receive weekly, stop physical therapy in a skilled nursing facility or not pay for a service you think should be covered. The notice will tell you how you can appeal if you disagree with the decision. Consumers often win these appeals. The local legal services program may provide help with these appeals. You can also check with the local long-term care ombudsman program or CIL.

One problem consumers sometimes encounter relates to Medicaid "recertification." This is the process in which the Medicaid program determines if you are still eligible for Medicaid. It requires you, or someone on your behalf, to submit required paperwork and may require the state to evaluate whether you continue to be medically eligible for the services you are receiving. If you fail to comply with the requests for documentation, you may be at risk of losing your services, at least for a little while.

You can avoid this problem by being proactive. Know when your paperwork is due and keep on top of it! Before the state terminates your services, it should send you a pre-termination notice and give you a chance to appeal. If you appeal promptly, you will generally be able to keep your benefits and services until the appeal is decided. This gives you more time to demonstrate that you continue to be eligible for Medicaid. If you need help with an appeal, your local legal services agency may be able to assist you.



For Medicare beneficiaries

Medicare beneficiaries are increasingly facing a problem with the requirement that they have a three-day hospital stay in order for Medicare to pay for rehabilitation in a skilled nursing facility. Instead of being admitted to a hospital, beneficiaries are being placed in "observation status." Their hospital stay is considered outpatient observation and therefore does not count toward the three days. Beneficiaries who go from the hospital to a skilled nursing facility are then informed that Medicare will not pay for their nursing home stay because the three-day requirement was not met.



For information about how to address this issue, and other Medicare coverage problems, like therapy services being terminated in a skilled nursing facility because you are not "improving," contact the Center for Medicare Advocacy at (860) 456-7790 or www.medicareadvocacy.org. The SHIP program may also be able to help.

Summary:

Begin by trying to work directly with your provider to solve the problem. Approaches include speaking with the individuals involved, going up the chain of command, following a grievance procedure, raising the concern at a care/service plan meeting, or uniting with others.

Turn to outside agencies for help if you cannot resolve the problem with your provider.

If you are receiving services at home, start by contacting your AAA care manager or your local CIL. If you are living in a group home or facility, contact your local long-term care ombudsman.

The Consumer Voice:

Tips from long-term care consumers for specific settings

Addressing Problems

At Home

I tell my attendants that if something comes up that makes them feel uncomfortable or that they don't understand, we need to talk about it right away.

- Kathy

Use open communication to resolve problems.

- Kathy

If my attendant is not doing the job the way it was explained at the very beginning, I start by repeating my explanation of my expectations. I am friendly but firm.

- Carol

If you are having problems with your aide/attendant, keep a record of what the problems are and when they're happening. That will help you later if you have to call the agency.

- Julie

If things are not working out with a particular attendant, you should absolutely call the agency and ask for a different person to be assigned. I didn't know at first that I could do that. All you have to do is call and say "I don't think we're a good match. Could we find someone else?" The agency has never said no. Don't be afraid to request a different attendant.

- Julie

If you've gone through the chain of command at your agency, you can ask your care manager. The care manager will ask you if you want to change agencies, give it more time or if you would like him or her to talk to the agency. This can be a big help.

- Linda

Summary:

- Tell your attendants to raise any concerns they have right away.
- Start by explaining your expectations again.
- Keep a record of any problems.
- Don't hesitate to ask the agency for a different attendant.
- Fire the attendant if necessary if you do the hiring yourself.

Group Living Options: In Assisted Living/Group Homes

I start by talking to the administrator. If the administrator won't listen, I call the state licensing agency or the ombudsman.

- Jim

It helps to have a suggestion you can make that would solve the problem.

- Fran

I try to be pleasant when I point out a problem.

- Fran

Know the right person to talk to when you have a problem. Otherwise you get nowhere.

- Jim

Speak up at the time something happens.

- Mary Jean

Be strong in saying what you need. There was one staff person who hurt me when she cared for me. I went to the Director and told her that I was not going to let this person care for me anymore and why. They assigned a different person to me.

- Bee

Take your concern to the resident council or other council, such as a food council. At the food council, we meet with the chef and point out problems and make suggestions about food we would like. As a result, we get the food we request. At one time the residents in my facility were really upset about the food, which was terrible. Because the council complained, the chef was fired, and a new person was hired. The new chef is much better.

- Joe

I start by discussing any problems with the aides. Then I go to the administrator if I can't get things worked out.

- Bill

Turn to the long-term care ombudsman for help. I was told that I couldn't use my power chair indoors and couldn't even use it to go down the hall. When I complained to management, I was told if I didn't like the situation, I should find some other place to live. I contacted the State Ombudsman, who contacted the program's lawyer. We filed a complaint, and the facility was cited for violating the Americans with Disabilities Act.

- Jim

Sometimes the problem isn't with the facility. I had problems with the transportation service I was using. I called my state senator and he was able to work things out for me.

Summary:

- Talk to the aides.
- Speak with the manager or administrator.
- Say something when it happens – don't wait.
- Have a suggested solution to the problem.
- Take your concern to the resident council.
- Turn to the long-term care ombudsman for help.

In Nursing Homes

Document the problem if you can. One time when I needed help and put my call light on, I documented that staff walked by my door 18 times without responding to my call light. I then took that information to the Director of Nursing.

- Brian

When I have a problem, I start by talking to the social concerns person. If that doesn't work, I go to the Director of Nursing, the ombudsman and finally the state.

- Marilyn

Start by talking with the staff person involved. For instance, you might tell an aide that you didn't like the way she treated you at a particular time. Then follow-up with the next person in the chain of command (charge nurse in this case). Tell the charge nurse that you had an issue with an aide. Explain what happened and ask the nurse if she would remind the aide not to treat you that way tomorrow.

- Brian

Act on a problem immediately if you can. That way the details are fresh. The longer you wait, the harder it is to remember things.

- Brian

Compromise is really important in solving a problem. For instance, if I'm being hurried during a meal, I might say, "I've noticed that I'm being hurried when I eat. I would appreciate it if I could have a few more minutes." I might like to have more than just a few minutes, but I realize that staff has schedules too.

- James

An order from your doctor can help solve certain problems. I take a particular medication for my nerves whenever I need it. One day I really needed it, but it was gone. It turned out that the medication had been mistakenly destroyed by the Director of Nursing. It upset me not to have this medication available. I talked to my doctor about this, and he wrote an order allowing me to keep this medication in my room. My doctor has also written an order on a couple of other occasions for different issues.

- Marilyn

I try to solve problems in the facility if I can. I'll talk first with the Director of Nursing. If that doesn't work, I fill out a complaint form. After that I go to the Administrator.

- James

When talking to staff, state your concern as nicely as you can. Explain why the problem is a concern. Do this without showing anger.

- Marilyn

It's very helpful to have a solution that you can propose. For example, there needs to be coffee available 24 hours a day in my facility. This wasn't happening. I proposed that we start by having coffee available for residents who get up early. The management agreed to this. Now the kitchen brings up coffee in the morning and places it at the nurses' station and dining room.

- James

Summary:

- Document the problem.
- Start by talking with the staff person involved or the social services staff person.
- State your concern as nicely as possible, then explain why the problem is a concern.
- Act on the problem quickly while it's fresh in your mind.
- Propose a possible solution or compromise.
- An order from your doctor may solve some problems.



CHAPTER 15: NURSING HOME TRANSITION

What is "nursing home transition?"

Nursing home transition refers to the process or sometimes a state program that helps individuals living in nursing homes who wish to move into a home in the community. During a nursing home transition, residents (often with assistance) arrange for the move and receive the services they need to be as independent as possible. The home may be an apartment where they live by themselves or with others, a group home, an assisted living facility or another residential setting.

The concept of nursing home transition is based on the idea that consumers have the right to make decisions about their own lives and well-being and the right to choose where they live and receive care and assistance. This includes the right to be in control of their lives and to encounter and manage risks. Nursing home transition is also based on a person with disabilities' right, under the Americans with Disabilities Act (ADA), to live in the "most integrated setting" possible.

Despite the ADA, states continued to provide care and services primarily in institutions such as nursing homes. Advocates challenged the states' failure to implement this part of the ADA. One of these challenges went all the way to the U.S. Supreme Court. The Court determined the state in that case was indeed violating the ADA by serving the plaintiffs in an institution instead of in the community. This ruling is called the Olmstead decision.

Across the country, states are working to transition people out of nursing homes. A federal grant program, called "Money Follows The Person" provides funding to participating states to move residents from institutions to the community.

Many, but not all, states have a formal "Nursing Home Transition" program. Even if a state doesn't have a program in place, it has some type of process for transitioning individuals.

Whom do you contact if you want to move out of your nursing home?

You can start by telling the social worker in your facility that you would like to move into a home in the community. The social worker should - but may not always - make a referral to your state's nursing home transition program or whomever is helping individuals move out of nursing homes in your state.

There are other ways to get help. You can contact your local long-term care ombudsman. The phone number for your local ombudsman must be posted in the nursing home. The ombudsman will talk with you about your wishes and make a referral. In addition, you can contact your local CIL. Your AAA, ADRC or Medicaid waiver program also may be able to connect you to your state's nursing home transition program.

What does the nursing home transition process involve? What should you expect?

While this process will vary from state to state, there are steps and procedures that all state processes have in common. These are outlined below, along with tips from consumers who have successfully transitioned out of a nursing home.

1) Determining your eligibility and conducting your assessment

The state transition program will decide if you are eligible. The eligibility requirements vary across the country.

If you are told you are not eligible, question why. Ask to see what program requirements you don't meet. You may be able to get help with eligibility issues from your local legal services office.

Next an assessment will be conducted by a member of the transition program, often called a nursing home transition coordinator (this individual may also be called a care manager or a service coordinator). The transition coordinator will meet with you in your nursing home and talk with you to learn your strengths, abilities, wishes and needs. He or she will probably meet with you several

times to gather this information. The transition coordinator will also review your medical records. Ask your transition coordinator to review your medical records with you if possible. This helps make sure the information obtained from the records is accurate and complete. If it is not possible for you to review your records with the transition coordinator, ask him or her to summarize the review for you.¹⁷

Participate as actively as you can in the assessment process. You can play an important role by providing your transition coordinator with information about what's important to you, your strengths, what assistance/supports you need, and your interests, preferences and priorities.

You can ask any one you like to also be involved in the assessment process such as family members, friends or the ombudsman.

2) **Developing your transition plan**

The information that was gathered during the assessment process is used in creating your transition plan. The plan needs to cover all aspects of your life. Here are just some of the areas that should be included.¹⁸

Housing

The goal is to find affordable, accessible housing in the community. This can be extremely difficult because the demand is great. Prepare to have your name placed on a long waiting list. You will also need to make sure you have or that the transition program helps you obtain household goods, furniture and other necessities to set up your new home and works with you to ensure the utilities are on when you move in. Make sure the location is close to the things you need and value.

Personal Assistance

You will need to think about who will assist you with activities such as bathing, dressing, positioning, shopping for groceries and other items you need, laundry and more. Will you hire your own attendant/aide or use one provided through an agency? Will your attendant/aide help you with meal preparation or do you want home-delivered meals?

It's also necessary to obtain approval for the number of hours of care/service you need. Like housing, there can be very long waiting lists for care/services provided through a Medicaid waiver or other programs. You want this assistance in place so you can begin receiving care/services as soon as you move out of the nursing home.

Transportation

Accessible and affordable transportation is critical when you live in the community. Research what options are available, costs and any limits on where you can go. Often transportation providers can only operate in one county.

Health care

Health care providers: Do you already have a doctor in the community or do you need to find one? If going to a doctor's office is difficult, you may need to see if you can find a doctor that comes to your home. An increasing number of physicians now make house calls.

If there are other health care professionals who provide care to you in your nursing home, such as podiatrists, dentists or psychiatrists, you will need to arrange to see them in their offices or find new providers. Any therapy you require or nursing care that must be given by a licensed nurse should also be arranged in advance.

Medication: Make sure you have a plan in place for getting your medications once you leave the nursing home. Consider how your medications will be paid for and whether you need to apply for programs to help cover co-pays. In addition, think about how you will receive your medications. You may want to research whether there is a pharmacy that will deliver and if so, make the necessary arrangements.

Don't forget to take your remaining medications with you from the nursing home when you leave!

¹⁷ "ABCs of Nursing Home Transition: An Orientation Manual for New Transition Facilitators." Judith Holt, Ph.D., Darrell L. Jones, M.A., Richard E. Petty, M.B.A., Helen Roth, M.A., Heather Christensen, M.S. A Publication of the IL Net National Training and Technical Assistance Program at Independent Living Research Utilization. 2006.

¹⁸ Ibid.

Home modification/assistive technology/durable medical equipment

What do you need in order to live comfortably in your home and to function as independently as possible in all aspects of your life? See the definitions of home modification, assistive technology and durable medical equipment to get an idea of what might be helpful to you.

Adult day services/programs

See the range of services listed in Appendix 2. Your transition coordinator can assist you in connecting to these services.

Finances

There are also financial matters that need to be addressed in order to move back into the community. Many individuals will have to take care of the following:

- Applying for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). If you have SSI, notify the Social Security Administration so your SSI will go up after you leave the nursing home.
- Setting up a monthly budget.
- Applying for community Medicaid. While you are in the nursing home, you have what is called "institutional" Medicaid. When you move out of the facility, however, your Medicaid doesn't automatically transfer to the community. You have to apply for the appropriate home and community-based Medicaid program, which changes your Medicaid from institutional to "community."
- Applying for food stamps, utility assistance or other benefits as needed.

You will also need to fill out change of address forms.

Roles of Family and Friends

Mobilize your "circle of support" or form one to support you once you are back in the community. Connecting with family, friends, neighbors or others you know can reduce the sense of isolation you may experience and make the adjustment process easier.

Community Connections

Being involved in the community is important to many people. This could include participating in a faith community, taking part in recreational activities, going to a senior center, volunteering, or being a member of a club or service organization. It is a good idea to think about how you would like to connect with the community prior to moving out and even become active beforehand.

You, your transition coordinator and anyone else you would like to join you will develop your plan.

Participate actively in creating your transition plan! Take the lead if possible. Once the plan is completed, create a master checklist and schedule with a section indicating who is responsible for each task and by what date.

Implementing the plan

During this part of the nursing home transition process, you, your transition coordinator and anyone else you have asked to join you will work to make the move happen.

Get as involved in carrying out the transition activities as you can such as making the calls, requesting information, asking for applications, conducting research, submitting applications, etc. The more responsibility you take on, the more practice you will get in handling the tasks and activities you will need to do for yourself after the move.

Many people are able to transition out of the nursing home in a short time. The services and supports they need are available, and they return to homes or apartments they had before, find a new apartment, move in with family or enter an assisted living facility.

In some situations, however, you may have to wait for services or housing, particularly if you need subsidized, accessible housing. Because there are often waiting lists, it may take a while to find housing that is both subsidized and accessible.



Some waiting lists are quite long. Try to put that time to good use. Start connecting with the community, perhaps by taking part in an activity you like. Go visit or talk to someone who has successfully transitioned out. You can also learn or brush up on independent living skills through your local Center on Independent Living. If you will be hiring your own attendant, you can learn more about hiring and supervising attendants through attendant care training manuals. You can find such a manual on the Center for Personal Assistance Services website, www.pascenter.org.

If you qualify, money may be available through the Money Follows the Person grant program to pay for the security deposit, first month's rent, setting up utilities, and other items such as furniture.

Your transition coordinator will help if necessary with obtaining furniture, moving your possessions into your new home, making sure you have food and necessary medications, and other aspects of the move.

Before you move out of the nursing home, there should be a discharge planning meeting. Use that meeting as an opportunity to make sure everything is in place.

Post transition

In many cases, your transition coordinator will work with you for a year after you leave the nursing home. His or her role is to provide you with follow-up support and to help make sure your needs are being met. At the beginning, your transition coordinator will be in touch with you quite frequently.

You should always feel free to call your coordinator with any questions or concerns. In some states, you can also contact your local ombudsman if you have any problems during this first year. Before moving, ask your ombudsman if he or she is available to people living outside a nursing home.

At some point, a care manager will replace the transition coordinator.

Summary:

If you want to leave your nursing home and return to the community, contact the home's social worker or your local long-term care ombudsman. You will be assigned a transition coordinator who will work with you to develop a plan for moving out. If you will need your own housing, place your name on a waiting list as soon as possible!

Your transition coordinator will assist you through the move and then check in with you for a period of time after you are in your new home.

The Consumer Voice:

Tips from long-term care consumers who have transitioned

You need to know that you can leave the nursing home. People don't know that. They think that once they're in the facility, they have to stay.

- Miss B

When the nursing home kept telling me there was no way I could live on my own, I called the ombudsman. She got the ball rolling. She was also the person I went to whenever I had a problem during the process.

- Barb

Request your medical records from all your health care providers right at the beginning of the process. By reviewing them I got an idea of the right "terms" to use in my applications. For instance, I learned to state that I have an "arthritis knee" instead of a "sore leg."

- Duane

I recommend that you go to the Social Security office if possible to get an application and have them help you out there. You get a personal touch that you can't get online.

- Duane

Get your name on a waiting list for housing as soon as you can. In my area the waiting list was three years! Once your name is on the list, call the apartment office every six months just to check where you are on the list.

- Duane

Keep pushing to get out.

- Barb

Make sure your credit ratings are ok and take care of any problems you have with outstanding bills for utilities or phone service. Apartment landlords are going to check you out. I had a utility bill that I had forgotten about that was going to prevent me from moving forward. My transition coordinator helped me and got the bill paid for me.

- Duane

I arranged for transportation from the nursing home so I could go look at the different housing options I was considering. This is very important!

- Julie

Your transition coordinator can help you go see apartments.

- Duane

Be adaptable. Track things. Be a bird dog.

- Gordon

While you're in the nursing home and waiting, get yourself to the best level of functioning that you can. This will help you be more independent after you move out.

- Duane

Figure out what you're going to do about medical care after you move. I was able to find a doctor who comes to my apartment. I also have my medications delivered.

- Julie

Make sure to really think through transportation before you move out. I had asked what I would do about transportation and was told that I could get transportation through the senior citizens' center. Only when I was out of the nursing home did I learn that the senior citizens' van will take me to the doctor's, but not to the grocery store. At that point I had a real problem. I got it worked out, but I wish I could have planned for this before I left the facility.

- Shirley

Find someone who has already moved out and have them map out the process with you.

- Gordon

Don't take no for an answer and be realistic. Those two may conflict. I am on a ventilator. I understood what it takes to be safe, and I knew there would be fewer people around to assist me. That added risk. But I knew I could minimize it by having a generator, batteries and so on.

- Jeff

I got into a bind because the landlord needed confirmation of the amount of Social Security I would receive in the community so my rent could be calculated. But the Social Security office said it wouldn't issue a letter with the amount until I moved out. It took a lot of pushing with help from my transition coordinator, but we got the letter. It can be done!
- Duane

Ask to have your application for housing time and date stamped. This will help if you ever get into a dispute about when your application was submitted.
- Gordon

When checking out apartments, look carefully at the bathroom. It can be a big problem if there isn't a roll-in shower.
- Julie

Make sure to think about what kind of bed you will need when you move. I just figured I'd have the same kind of bed I had in the nursing home – a fully electric bed – and nobody asked me if I needed a special bed. The first night in my apartment, I realized at bedtime that the bed was not fully electric and had big metal plates on the side. I couldn't even get into the bed. I slept in my wheelchair that first night.
- Julie

You may end up getting your apartment before you have your services lined up and approved. That happened to me. I learned that it can be a problem if you take possession of an apartment and don't move in for a while. This can be considered "abandonment." Read the housing contract carefully before you sign to see if there is an abandonment clause. Then you can discuss with the landlord and your transition coordinator what you will do if you can't move in right away.
- Gordon

You need support during the transition process.
- Jeff

Think about how you're going to get your food. It seems so simple, but it never occurred to me to figure that out before I moved out. My apartment was stocked with food to begin with, but after I ran out I didn't know what to do. I had no transportation, no power chair and I hadn't been in a grocery store for years.
- Julie

Insist on having a meeting before you leave the nursing home. Ask that everyone who is involved in your care be there. I didn't have a meeting and it would have helped a lot. It would have given me a chance to ask questions and express my concerns. It would have helped clarify things.
- Shirley

When I first moved out, I hired some of the aides from the nursing home to be my attendants. That got me started.
- Miss B

I bought a cart wagon that I take on the bus with me when I go grocery shopping and when I do laundry.
- Duane

I have a personal emergency response system that I wear around my neck. It makes me feel more secure.
- Barb

I have to make sure to plan ahead. I can't just do things at a drop of a hat because I have to make arrangements for transportation.
- Gordon

Speak up if you have a problem. I was so used to being in a nursing home where speaking up didn't do any good, that I didn't realize things could improve if I said something.
- Julie

Summary:

- If you need housing, apply right away.
- Check out housing options in person if possible. Assess accessibility.
- Get credit card problems or outstanding bills taken care of (there are funds available to help you with this).
- Think about how you will get food, prescriptions, medical care.
- Figure out how you will get around in the community and whether transportation is readily available.
- Create or turn to a support system.
- Keep pushing.
- Make sure to have a meeting at the nursing home to go over all the details before you move out.
- Speak up if you have a problem once you're in the community.



CHAPTER 16: HELPING FAMILY AND OTHER CAREGIVERS

While the focus of this guide is on you – the person receiving or planning to receive long-term services and supports - your family or friends may play an important role in your care. Their assistance may make it possible for you to remain at home, or they may help you in advocating for quality services – or both.

Caregiving can be rewarding as well as difficult and stressful at times. For that reason, your caregiver should know there is a wealth of resources available to support and assist him or her.

By contacting your local Area Agency on Aging, your caregiver can access the following services:

- Information to caregivers about available services
- Assistance to caregivers in gaining access to services
- Individual counseling
- Support groups
- Caregiver training
- Respite services
- Supplemental services on a limited basis, such as home-delivered meals

The majority of these services are free.

Area Agencies on Aging can also connect your caregiver to a great deal of written information for caregivers and community groups such as local chapters of the Alzheimer's Association or the Alzheimer's Foundation.

Here are some additional resources:



Family Caregiver Alliance (FCA)

www.caregiver.org, 1 (800) 445-8106

The Family Caregiver Alliance is a national organization that serves as a public voice for caregivers. FCA provides education and information to caregivers, and conducts research and advocacy. FCA houses the National Center on Caregiving (NCC) that is a great source of information on caregiving and other long-term care issues. The NCC in turn, offers the Family Care Navigator that allows caregivers to locate support services in their communities.



National Alliance for Caregiving

www.caregiving.org

The National Alliance for Caregiving (NAC) is a coalition of national organizations focusing on issues of family caregiving. The goal of the Alliance is to improve the quality of life of families and individuals receiving care and services. The Alliance has numerous brochures, booklets and other publications useful to family and other caregivers. In addition, NAC's Family Care Resource Clearinghouse finds reviews and ratings of hundreds of books, videos, websites, magazines, fact sheets and other resources addressing the range of issues and questions faced by family and other caregivers. To contact the Alliance, send an e-mail to info@caregiving.org or write to National Alliance for Caregiving, 4720 Montgomery Lane, 2nd Floor, Bethesda, MD 20814. No phone number listed.



MetLife Mature Market Institute in cooperation with the National Alliance for Caregiving

www.metlife.com

This guide is designed to help family and other caregivers learn how to be strong and effective advocates for someone they love in any setting. It includes tips on talking to doctors, communicating with insurance companies and getting good care at home, in assisted living or in a nursing home.



Next Step in Care

www.nextstepincare.org

Next Step in Care is a website filled with resources to help family and other caregivers work better with health care professionals to plan and carry out smoother, safer transitions of a loved one between health care settings (home to hospital, hospital to nursing home or home, etc). The website provides guides and checklists to help families ask questions to avoid miscommunication and errors and to ensure the best possible transition.

Summary:

There are many resources to help family or friends who may be assisting you with care and services. Contact your local Area Agency on Aging for information about educational materials, support groups, services and more.





CHAPTER 17: ADVOCATING FOR QUALITY LONG-TERM SERVICES AND SUPPORTS: IMPROVING THE SYSTEM

While progress has been made in developing and providing a range of readily available, affordable and quality long-term services and supports across the country, there is still a long way to go. Far too many individuals are still forced into nursing homes because there are no other affordable options in their communities, and quality of care and services at home or in a residential setting is uneven at best.

Current advocacy efforts at the national level include:

- Balancing the long-term care system so more home and community-based services are available to consumers. Currently Medicaid, which funds the majority of long-term services and supports, is mandated to pay for institutional or nursing home care in every state. Home and community-based services, however, are optional. As a result, many consumers cannot choose where, when and how services are provided.
- Moving people out of institutions and into the community so they can live in the most integrated setting possible.
- Preventing assisted living providers from evicting residents on Medicaid when providers withdraw from the Medicaid program or fail to renew their contract.
- Implementing new nursing home provisions under the Affordable Care Act (also known as the health reform law). These include providing better information to consumers about nursing home ownership, staffing, inspections and more; improving the complaint investigation process; and better protecting residents' families and legal representatives from retaliation.

There are numerous national and state organizations that advocate for the issues described above as well as other public policy concerns. Here is a listing of some of these groups:

National organizations:



AARP: advocates for older adults
www.aarp.org, 1 (888) 687-2277, TTY: 1 (877) 434-7589



The Alzheimer's Association: advocates on behalf of persons with Alzheimer's disease or other related dementias and their families
www.alz.org, 1 (800) 272-3900, TDD: (866) 403-3073



Alzheimer's Foundation: advocates on behalf of persons with Alzheimer's disease or other related dementias and their families
www.alzfdn.org, 1 (866) AFA-8484



The ARC: advocates for people with intellectual and developmental disabilities
www.thearc.org, 1 (800) 433-5255



The Association of University Centers on Disabilities (AUCD): advocates for persons with disabilities
www.aucd.org, (301) 588-8252



Bazelon Mental Health Law Center: advocates for people with mental illnesses
www.bazelon.org, (202) 467-5730



Brain Injury Association of America (BIA): advocates for persons with brain injuries and their families
www.biausa.org, (703) 761-0750



Disability Rights Network: advocates on behalf of people with disabilities
www.napas.org, (202) 408-9514, TTY: (202) 408-9521

 **Easter Seals:** advocates on behalf of people with disabilities
www.easterseals.com, 1 (800) 221-6827

 **National Alliance on Mental Illness:** advocates for people with mental illness
www.nami.org, 1 (800) 950-NAMI

 **National Association of Area Agencies on Aging (n4a):** advocates on behalf older adults
www.n4a.org, (202) 872-0888

 **National Association of States United for Aging and Disabilities:** advocates on behalf of older adults and persons with disabilities
www.nasuad.org, (202) 898-2578

 **National Consumer Voice for Quality Long-Term Care:** advocates on behalf of long-term care consumers in all settings
www.theconsumervoice.org, (202) 332-2275

 **National Council on Aging (NCOA):** advocates on behalf of older adults
www.ncoa.org, (202) 479-1200

 **National Empowerment Network:** advocates on behalf of people with mental illness
www.power2u.org, 1 (800) 769-3728

 **The National Senior Citizens Law Center:** advocates on behalf of older adults and people with disabilities
www.nsclc.org

 **United Cerebral Palsy:** advocates on behalf of people with disabilities
www.ucp.org, 1 (800) 872-5827

More information about most of these groups is provided in the Resources section under "Organizations."

Many of these organizations also have state chapters, affiliates or member groups that support the policy agenda of their national organization, while also advocating for state-specific issues. In addition, there are advocacy groups that operate only within a particular state.

In the previous sections of this guide, you learned ways to self-advocate to improve your care/services. You can also advocate for improvements in the care and services available to everyone in your state or across the country.

There are several ways you can advocate for changes in the long-term care system. You can do this on your own by contacting your state and federal policymakers and sharing any concerns or ideas for improvements you have about the system. Legislators pay attention when they hear from their own constituents!

You can also advocate by getting involved in an advocacy organization. These groups keep you informed about critical policy issues and how you can take action, often just by making a telephone call or sending an e-mail to policymakers.

If you care about the availability, affordability and quality of long-term services and supports in your state or in the country, you can do something about it. Becoming active and adding your voice to others can help advance and improve our system of care and services – not only for yourself but for others as well.

Summary:

In addition to advocating to improve your own care and services, you can advocate for improvements in the long-term care system. There are many state and national organizations that work to improve the availability, affordability and quality of long-term services and supports. Joining and becoming active in one or more of these groups helps make the system better not only for you but for others as well.



RESOURCES

The list of resources in this section is designed to direct you to more in-depth information about a number of the topics covered in this guide. The list is not intended to be complete and comprehensive. Instead its purpose is to take you farther down the road on your long-term care journey.

Assessment tools

The tools listed below can help you identify the type of long-term care assistance you may need now or in the future.



Medicare Chart

www.medicare.gov



New Mexico Person-Centered Planning Tool

www.nmresourcedirectory.org

(Note: Although this tool refers to some New Mexico state agencies, programs and services, the questions and the information it gathers apply in any state.)

Culture Change



The Pioneer Network

www.pioneernetwork.org, (312) 224-2574

The Pioneer Network is made up of consumers, providers, health care professionals, direct-care workers and others who want to promote culture change. The Pioneer Network website provides information and materials on culture change, including a consumer guide for finding a nursing home that has adopted culture change.

Culture Change in Nursing Homes



National Consumer Voice for Quality Long-Term Care (Consumer Voice)

www.theconsumervoicere.org or (202) 332-2275

This factsheet briefly discusses the principles of culture change, presents some person-directed practices and gives some examples of culture change.

Housing



n4a Senior Housing Locator

www.seniorhousinglocator.org

The National Association of Area Agencies on Aging (n4a)'s Senior Housing Locator is a tool for assisting seniors, their families and others to find appropriate senior housing options anywhere in the country. The website also provides information about the different housing options available, home care and hospice services, legal assistance, transition coordination and more.

Housing Options for Older Adults: A Guide for Making Housing Decisions

This booklet provides an overview of the many housing options available across the country. It also discusses key benefits and challenges to consider for each housing option and describes the primary legal considerations relevant for each option. To



receive a copy of the booklet, call the Eldercare Locator at 1 (800) 677-1116 or download it at: www.eldercare.gov.



Disability.gov

www.disability.gov, click on "Housing"

The "Housing" section of this website has information about housing rights, tax credits, making a home accessible, and supportive housing services that can help people with disabilities live independent, self-directed lives.

Financial and health care planning



American Bar Association (ABA)

www.abanet.org, 1 (800) 285-2221

The American Bar Association has written a number of publications for consumers about health and financial decision making. These include "Health & Financial Decisions: Legal Tools for Preserving Your Personal Autonomy," "Myths and Facts about Health Care Advance Directives," "Advance Planning Resources" and more. To access the list of publications, go to: new.abanet.org.

Paying for long-term care



BenefitsCheckUp

www.benefitscheckup.org

A comprehensive resource for locating financial assistance programs that may help pay for medications, health care, utilities, meals and other expenses. The website is developed and maintained by the National Council on Aging.



Medicaid Reference Desk

www.thedesk.info

The Medicaid Reference Desk is a resource for people with intellectual disabilities and their families to learn about Medicaid and other public benefits, services and supports. Information about Medicaid programs, eligibility and services is provided for every state. While this resource is intended for people with intellectual disabilities, it can be helpful to other consumers.



State Health Insurance Assistance Program (SHIP)

www.healthassistancepartnership.org or 800-MEDICARE

The State Health Insurance Assistance Program is a free counseling program. Trained counselors provide answers to questions related to Medicare, Medicare Supplement Insurance, Medicare Advantage, Medicaid, long-term care insurance, prescription coverage, and low-income assistance. Each state has a SHIP program.



National Clearinghouse for Long-term Care Information

www.longtermcare.gov

This section of a website developed by the U.S. Department of Health and Human Services discusses the cost of long-term care, what the costs are across the country, and who pays for long-term care. You can find out how much care costs in your state by clicking on an interactive map.



Center for Medicare Advocacy (CMA)

www.medicareadvocacy.org, (860) 456-7790

The Center for Medicare Advocacy, Inc. is a national organization that provides education, advocacy and legal assistance to help elders and people with disabilities obtain Medicare and necessary health care. There is a wealth of resources on CMA's website, including self-help packets for dealing with issues beneficiaries may face. You can also contact the Center with questions.



Medicare Rights Center (MRC)

www.medicarerights.org, 1 (800) 333-4114

The Medicare Rights Center offers many free resources to help people with Medicare and their caregivers understand their rights and options. In addition to written information and webinars, MRC provides a national phone hotline where individuals can consult with counselors about a wide range of Medicare-related issues. It also runs Medicare Interactive – a website that provides detailed information about the ins and outs of Medicare in an easy to understand manner.

Home care/services

Medicare and Home Health Care



www.medicare.gov

This booklet by the Centers for Medicare and Medicaid Services discusses what home health care is, Medicare coverage, how to choose an agency and how to monitor services.

The Personal Assistance Services (PAS) Center



www.pascenter.org

The Personal Assistance Services Center's website section for PAS users provides a wealth of information for consumers employing their own attendant. Its "Guide to Using PAS" covers a range of topics, including finding, interviewing and hiring an attendant, supervising and communicating with an attendant, and firing an attendant. The sections of the website provide helpful PAS-related information as well.

The MetLife Aging in Place Workbook: our Home as a Care Setting



www.metlife.com

The guide walks you through what to consider if you want to make your home into a care setting. It helps you evaluate your needs; determine whether your home needs modifications to permit you to age in place; identify care resources to assist you, including family and friends and paid services and assess the costs of remaining at home and receiving needed care.

Assisted living/group homes

Thinking of Moving to an Assisted Living Residence?



Written by the New York Long-term Care Community Coalition and the Coalition of the Institutionalized Aged & Disabled.

www.assisted-living411.org, (212) 385-0355

Designed for potential residents and their families, this guide helps individuals choose an assisted living community that is right for the resident.

Resident's Guide for Assisted Living.



Written by the New York Long-term Care community Coalition and the Coalition of the Institutionalized Aged & Disabled.

www.assisted-living411.org, (212) 385-0355

This book helps people currently in assisted living determine whether their residence meets their expectations and suggests ways to work with staff and other residents to make it better.

Assisted Living Consumer Alliance (ALCA)



www.assistedlivingconsumers.org

The Assisted Living Consumer Alliance (ALCA) is a national collaboration of groups and individuals working together to promote consumer safety, choice and rights in assisted living. ALCA provides information for both consumers and advocates, and works collaboratively with government officials and health care professionals to improve assisted living.

Where the Heart Is: Choosing a Group Home



www.ilresources.com/articles/Grouphomecriteria.html

This article discusses what to look for and questions to ask when selecting a group home for persons with developmental disabilities.

Nursing homes

National Consumer Voice for Quality Long-Term Care (Consumer Voice)



www.theconsumervoice.org, (202) 332-2275

The National Consumer Voice for Quality Long-Term Care is a national organization that represents the voice of long-term care consumers. The Consumer Voice advocates for public policies that support quality care and quality of life; empowers and educates consumers to advocate for themselves; trains and supports individuals and groups that empower and advocate for consumers; and promotes the critical role of direct-care workers and best practices in quality-care delivery. The Consumer Voice connects consumers to a wide range of resources including factsheets, guides, resident council materials and more.

Advancing Excellence in America's Nursing Homes



www.nhqualitycampaign.org

Advancing Excellence in America's Nursing Homes is a national campaign to improve quality of care and quality of life for the country's nursing home residents. It works to achieve this goal by helping nursing homes improve quality in eight key areas; supporting certified nursing assistants and promoting communication between residents, families and nursing home staff. Advancing Excellence provides consumer factsheets and other materials for consumers on its website.

Nursing Homes: Getting Good Care There

National Consumer Voice for Quality Long-Term Care

Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. 2nd edition. 2002.

This book discusses how to advocate for quality nursing home care. Available for purchase. To order, call (202) 332-2275.

A Baby Boomer's Guide to Nursing Home Care

National Senior Citizens Law Center

Eric M. Carlson, Katharine Bau Hsiao. 2006.

This guidebook takes a "nuts and bolts" approach to explaining the laws that protect nursing home residents and providing practical advice on how residents and their families can obtain the best nursing home care possible.



To order, go to: www.nsclc.org.

Nursing home transition

ABCs of Nursing Home Transition: An Orientation Manual for New Transition Facilitators

Judith Holt, Ph.D., Darrell L. Jones, M.A., Richard E. Petty, M.B.A., Helen Roth, M.A., Heather Christensen, M.S.

A Publication of the IL Net National Training and Technical Assistance Program at Independent Living Research Utilization. Developed in Collaboration with Utah State University Center for Persons with Disabilities. 2006

Although this book is for facilitators, its information can also help consumers who wish to transition out of a nursing home.

Hospice

Medicare Hospice Benefits

Centers for Medicare and Medicaid Services



www.medicare.gov

This guide describes hospice care, the Medicare hospice benefit and finding a hospice program.

Organizations

AARP



www.aarp.org, 1 (888) 687-2277, TTY 1 (877) 434-7589

AARP is a national organization representing individuals age 50 years or older. Among its many and varied activities and services, AARP advocates at both the state and national levels and provides information on a wide range of topics. Its Caregiver Resource Center provides educational materials on long-term care, including living at home, assisted living, nursing homes, and continuing care retirement communities and tools such as the Long-term Care Calculator.

The Alzheimer's Association



www.alz.org, 1 (800) 272-3900, TDD: (866) 403-3073

The Alzheimer's Association provides information, education, support and services to individuals with Alzheimer's and their families. One of the tools offered by the Association is CareFinder, an interactive online program that provides consumers with recommended long-term care options based on answers consumers provide about their needs, abilities and preferences. The Alzheimer's Association also conducts both state and federal advocacy.

Alzheimer's Foundation



www.alzfdn.org, (866) AFA-8484

The Alzheimer's Foundation provides education, such as written materials; conferences and workshops; social services, such as counseling, support groups, early stage stimulation programs, and social model adult day services; and advocacy at both the state and national level.

The Arc



www.thearc.org, 1 (800) 433-5255

The Arc is a national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. In addition to advocacy, many of The Arc's state and local chapters offer supports and services such as case management and community living opportunities. The Arc also provides information such as factsheets and publications.

Association of University Centers on Disabilities (AUCD)



www.aucd.org, (301) 588-8252

The Association of University Centers on Disabilities is a network of interdisciplinary centers that works to advance policy and practices for and with individuals with developmental and other disabilities, their families and communities. AUCD supports this network in a number of different ways, including advocacy with Congress and executive branch agencies that regulate and fund programs used by people with disabilities, leadership on major problems affecting all people living with developmental or other disabilities or special health needs and dissemination of best practices and new information. A listing of all network centers can be accessed on AUCD's website.

Brain Injury Association of America (BIA)



www.biausa.org, (703) 761-0750

The Brain Injury Association of America promotes awareness, understanding and prevention of brain injury through education, advocacy, research grants and community support services. BIA provides information about brain injury and services and also offers the Brain Injury Information Center at 1 (800) 444-6443.

Easter Seals



www.easterseals.com, 1 (800) 221-6827

Easter Seals is a national organization that helps people with disabilities. It provides direct services and supports through a network of sites across the country and conducts education, outreach and federal and state advocacy. Its website has information to help consumers better understand different disabilities and services such as physical and occupational therapies.



National Alliance on Mental Illness (NAMI)

www.nami.org, (703) 524-7600, Helpline: 1 (800) 950-6264

The National Alliance on Mental Illness is a national grassroots mental health advocacy organization dedicated to improving the lives of individuals affected by mental illness and their families. NAMI focuses on raising awareness, education and national and state advocacy. In addition NAMI provides services such as an information helpline, support groups and information about mental illnesses, mental health care, diagnosis, treatment and recovery.



National Association of Area Agencies on Aging (n4a)

www.n4a.org, (202) 872-0888

The National Association of Area Agencies on Aging represents Area Agencies on Aging and champions Title VI Native American aging programs. It supports the national network of Area Agencies on Aging and Title VI programs through advocacy, training and technical assistance. On its website, n4a has a consumer section with consumer publications and access to the n4a Senior Housing Locator (described above).



National Council on Aging (NCOA)

www.ncoa.org, (202) 479-1200

The National Council on Aging is a service and advocacy organization that is a voice for older adults in greatest need and the organizations that serve them. NCOA works to improve the health of older adults, enhance their economic security, promote their independence and dignity and strengthen the community organizations that serve them. NCOA advocates at the national level and educates and informs older adults about laws and policies that affect long-term care and other aspects of their lives. It also offers BenefitsCheckUp (see description under "Paying for Long-Term Care").



National Empowerment Network (NEC)

www.power2u.org, 1 (800) 769-3728

The goal of the National Empowerment Network is to assist people with mental illness with recovery and to empower them. NEC provides information and referral services; educational materials on advance directives, self-help techniques, legal services and other topics; and support groups. NEC also advocates at the local, state and national levels. As part of its advocacy, NEC organizes and develops consumer-run organizations and helps them and others gain the knowledge and skills to create a more recovery-oriented and consumer and family-driven mental health service system.



The National Senior Citizens Law Center (NSCLC)

www.nsclc.org

The National Senior Citizens Law Center is a national organization that works to promote the independence and well-being of low-income elderly and persons with disabilities through advocacy, litigation and the education and counseling of local advocates. NSCLC also provides consumer information and publications on home care, assisted living and nursing home care.



Self-Advocate Leadership Network

www2.hsri.org, (503) 924-3783

The Self-Advocate Leadership Network is a collaboration between self-advocates from across the country and the Human Services Research Institute (HSRI). Its purpose is to help people with developmental disabilities become strong self-advocates. The Network offers toolkits and training to provide self-advocates with the skills and tools to gather information about what is happening in a state's developmental disabilities system, conduct an analysis of the system and work for needed changes. Its "My Voice, My Choice" is a curriculum that teaches persons with developmental disabilities to be self-advocates and become active participants in local and statewide systems change and in planning their own services and supports.



United Cerebral Palsy (UCP)

www.ucp.org, (800) 872-5827

United Cerebral Palsy is a national organization that advocates for people with disabilities nationally and at the state level and provides direct services such as housing, therapy, and community living. UCP has developed a comprehensive set of state-based guides, called "One-Stop Resource Guides," that help locate assistance, information and resources for people with disabilities. To access the guide, go to www.ucp.org.



APPENDIX 1: GLOSSARY

Accessible	Easy to approach, enter or use.
Attendant	An individual who provides assistance with activities of daily living and daily tasks. These include help with bathing, oral hygiene, shaving, dressing, transferring, meal planning, meal preparation and cleanup, toileting assistance, running errands, housecleaning and other day-to-day activities. Also called a personal care attendant or personal attendant.
Care manager	A specialist who assesses your needs, helps develop a plan for care and services, and arranges, coordinates, manages and monitors those services. Care managers are often social workers or nurses. These specialists are also called case managers, service coordinators or supports coordinators.
Certified	A provider of services that receives funding from Medicare and/or Medicaid. To receive funding the provider must comply with Medicare or Medicaid regulations or standards.
Long-term care ombudsman	A representative of the long-term care ombudsman program who advocates on behalf of residents of long-term care facilities.
Sheltered workshop	Employment for persons with disabilities in a setting that provides training and supervision.
State registry	A listing of attendants available to work in a state under the Medicaid waiver program. Attendants on the registry have usually undergone some type of screening and background check.
State Unit on Aging and Disabilities	A state division or department that administers, manages, designs and advocates for benefits, programs and services for the elderly and their families and, in many states, for adults with physical disabilities. The term "state unit on aging" is a general term: the specific title and organization of the governmental unit will vary from state to state. To find your state unit on aging, call the National Association of States United for Aging and Disabilities at (202) 898-2578 or go to: www.nasuad.org .





APPENDIX 2: DESCRIPTION OF LONG-TERM SERVICES AND SUPPORTS

Type of care/ service/ support	Description
Adult day services	<ul style="list-style-type: none"> • Social/therapeutic adult day services: Social, recreational and therapeutic activities provided in a community-based program for adults with physical, mental or cognitive impairments. • Medical adult day services: Health and medical-related care provided in a community-based setting in addition to social, recreational and therapeutic activities. Examples of health and medical-related care include medical monitoring, medication administration and, in some cases, skilled nursing services. • Mental health day treatment: A community-based, coordinated set of individualized treatment services to individuals with mental illness who are not able to function full-time in a normal school, work and/or home environment and need additional structured activities. This service includes diagnostic, medical, psychiatric and psychosocial methods of treatment. • Day habilitation: Assistance to individuals with developmental disabilities or brain injury to develop or maintain socialization and self-help skills. Training in day habilitation programs may include such topics as money management, nutrition, household management, social skills and using community resources
Assistive technology	<p>Products, devices or equipment that enable people to maintain or improve their functional capabilities and achieve greater independence. There are different types of assistive technology.</p> <p>Physical aids: Examples include canes, walkers, built-up utensils, computer keyboard aid, transfer bench</p> <p>Cognitive aids: Examples include cognitive software, personal digital assistants (PDA) with reminder alarms linked to calendars, pillbox reminders, electronic memory aids</p> <p>Sensory aids: Examples include talking equipment such as clocks, closed circuit television for magnification, large button phones, hearing aids, TDDs/TYYs devices, vibrating bed alarms</p> <p>Communication aids: Examples include communication boards, mouth sticks, text-to-speech devices</p>

Attendant care	Assistance with activities of daily living and daily tasks. Can include help with bathing, oral hygiene, shaving, dressing, transferring, meal planning, meal preparation and cleanup, toileting assistance, running errands, housecleaning and other day-to-day activities.
Behavior consultation services, also referred to as behavior management/behavior program and counseling	Training, supervision or assistance in learning how to behave or express emotions in ways that are considered to be "socially appropriate."
Care management	Specialists who assess your needs, help create a plan for services and supports, and arrange, coordinate, manage and monitor those services. These specialists are also called case managers, service coordinators, or supports coordinators. They are often social workers or nurses.
Chores	Performance of tasks such as laundry, cleaning, shopping, yard work, lifting or moving heavy objects and packing/unpacking a household.
Cognitive rehabilitation	Therapy to achieve the most independent or highest level of functioning for a person with a brain injury. Goals of therapy might include substituting new skills for lost function and relearning social interaction skills.
Community integration training	Training that gives individuals with developmental disabilities or brain injury the opportunity to integrate into their community while practicing appropriate social skills, community safety and self-reliance.
Companion services	Visits to older adults or persons with disabilities who live on their own or while a caregiver takes a break.
Congregate meals	Meals that comply with national nutritional guidelines and that are served in senior centers, a nutrition site or other approved setting at a reduced cost to eligible participants.
Counseling	Services to help a person understand the causes of issues or problems he or she is facing and to resolve those issues.
Durable medical equipment	Devices and appliances such as wheelchairs, walkers, hospital beds and lifts that assist a person with a medical need or increase their mobility and independence.
Environmental modification/home modification	Adaptation of an existing home to make it more accessible and/or safer and to help make it easier to get around and do daily activities. Examples of modifications include adding ramps, hand rails, grab bars, lever handles on doors, lifts and wider doors.
Family or consumer training	Training to improve a family caregiver's or individual's ability to care for themselves or another. Includes training in use of equipment and treatment regimens.

Financial assistance	Counseling on financial management, prescription drug programs, Social Security benefits, food stamps, energy assistance and more. ("Home and Community-Based Services." National Association of Area Agencies on Aging-n4a).
Habilitation	Assistance in developing daily living skills and socialization skills with a goal of becoming as independent as possible.
Home-delivered meals	Nutritionally sound meals delivered to an individual's home.
Home health services	Skilled nursing care or therapies ordered by a doctor and provided or overseen by licensed health care professionals such as nurses or physical therapists. Under certain circumstances assistance with personal care, meal preparation and light housekeeping may also be included.
Home maintenance/repair	Home maintenance that allows a person to remain safely in his or her home. This includes repair of plumbing, heating, storm doors, windows and screens, etc.
Homemaker services	Assistance with household tasks such as dusting, vacuuming, making and cleaning up meals, doing dishes, grocery shopping and running errands.
Information and assistance	Assistance and connection to available services and resources. ("Home and Community-Based Services." National Association of Area Agencies on Aging-n4a).
Legal assistance	Advice and representation for certain legal matters such as government program benefits, tenant rights and consumer problems. ("Home and Community-Based Services." National Association of Area Agencies on Aging-n4a).
Medical supplies	Health care materials such as dressings, catheters and diabetic supplies.
Medication monitoring	Monitoring of medications taken by persons with mental illness. Monitoring is often done by a local community mental health center.
Monitoring technology	Technology that allows an individual or an individual's health to be monitored remotely. Remote patient monitoring can help in managing chronic diseases or prompt intervention when a person has fallen or is injured.

Nursing services	<p>Services provided for people with serious medical conditions and complex health care needs that require specific skilled nursing services that cannot be provided by non-nursing personnel. Skilled nursing may be provided in the person's home or other community setting on a regularly scheduled or intermittent (on and off) need basis. Nursing services are ordered by a physician and are provided by a registered professional nurse or licensed practical nurse under the supervision of a registered nurse.</p> <p>("Home and Community-Based Services." National Association of Area Agencies on Aging-n4A).</p>
Personal care	Assistance with activities of daily living provided by an agency, an attendant hired by the consumer, or family or friends.
Personal emergency response system	An electronic device that allows a person to call for help in an emergency.
Recovery groups	<p>A group in which persons with mental illness share ideas, experiences and coping strategies to assist them in living a life that is satisfying, hopeful and meaningful even with the challenges presented by the illness. WRAP (Wellness Recovery Action Plan) is an approach that helps with recovery by providing tools to assist people with mental illness to identify the things that they can do to stay well and to feel better when they are experiencing uncomfortable symptoms and feelings.</p>
Respite care	Short-term, temporary supervision or care of an individual when the primary caregiver cannot be there or needs a break or "time off" from caregiving responsibilities. Can include someone coming into your home, a stay in a nursing home or assisted living facility, or adult day services.
Senior centers	A center in the community that provides a variety of services including nutrition, recreation, health, social and educational services and comprehensive information and referral to help older adults find care/services.
Support groups	<p>Groups where a person can give and receive emotional and practical support and information about an issue or topic. There are support groups for many medical conditions and a wide range of issues such as grief and loss.</p> <p>For persons with mental illness, there are consumer support groups led by consumer-run state organizations focused on recovery and empowerment. (Contact the National Empowerment Center to find a listing of state organizations: www.power2u.org or 1 (800) power2u)</p>
Supported living services	Services to assist people to live on their own in the community, take care of a home, take care of themselves, and get around in the community.

Telephone reassurance	Regular contact and safety checks by trained volunteers. ("Home and Community-Based Services." National Association of Area Agencies on Aging-n4a).
Therapies: physical, occupational, respiratory, speech/language, cognitive, behavioral, vocational, recreational, restorative	<ul style="list-style-type: none"> • Physical therapy: Assessment, treatment and training to maintain or improve functioning such as strength, muscle tone and mobility. • Occupational therapy: Assessment, treatment and training to increase a person's ability to perform self-care and other activities in order to maximize independence and quality of life. May include adaptation of tasks or equipment. • Respiratory therapy: Assessment, treatment and management of breathing disorders. • Speech/language therapy: Assessment and treatment for speech and language communication disorders and swallowing problems. • Cognitive therapy: A form of psychotherapy used to change a person's way of thinking and behavior. • Behavioral therapy: A form of psychotherapy that uses learning techniques to change behavior. • Recreational therapy: Therapy that uses recreation and activities to improve a person's functioning, independence and quality of life. • Restorative therapy/care: Interventions that focus on maintaining or improving an individual's ability to function independently (e.g. perform activities of daily living on their own). • Vocational training: Training in the skills and knowledge needed to perform a particular job or trade.
Transportation	Services to get a person to medical appointments, shopping centers and community services or activities. Transportation may include curb-to-curb taxicab services, public buses or vans that are wheelchair accessible.
Vehicle adaptation	Modifications to a vehicle that allow a person to use it to access the community and remain independent.



APPENDIX 3: SAMPLE LETTER REQUESTING HOUSING MODIFICATION*

Date

Dear Ms. Housing/Facility Manager:

I am writing to request a reasonable accommodation/modification with regard to my disability [describe disability here] which substantially limits one or more of my major life activities.

Specifically, I am writing to request: [describe the specific change in rule, policy, practice or service, or physical premises, you are seeking].

I need this accommodation so that I can live here as easily and successfully as the other residents and fully use and enjoy the premises.

I have attached a letter from my doctor certifying that this request is necessary. (Attaching such a letter may or may not be necessary.)

As you probably know, because I have a disability, fair housing laws entitle me to reasonable accommodations/modifications.

Please respond to my request in writing within seven business days. Thank you for your assistance.

Sincerely,

Your Name

* From: National Long-Term Care Ombudsman Resource Center: The Fair Housing Law: Reasonable Accommodations and Modifications (Two-part teleconference; July 2008). Aisha Bierma (now Elmquist) and Holly Robinson.



APPENDIX 4: SELF-DIRECTION - IS IT RIGHT FOR YOU?

Adapted from "Mi Via: Is It Right For You,"
with permission from the New Mexico Aging & Long-Term Services Department

Pros and Cons

This worksheet can help you figure out if self-direction is right for you. In the column labeled "Pros," write out all the reasons self-direction would be right for you. In the column labeled "Cons," list all the reasons self-direction would not be right for you. After you have listed all the pros and cons, ask your family and friends what they think. They may have ideas that you didn't think of. List their suggestions in the pros and cons columns too. After you have listed all the pros and cons, decide how important each is to you and rank it according to:

Not important = 1 It matters = 2 Very important = 3

When you are done, every pro and every con should be ranked with a 1, 2 or 3.

Pros	Rank	Cons	Rank

After reviewing all this information, self-direction is:

- Right for me
- Not right for me
- Still not sure



APPENDIX 5: GUIDELINES FOR PRESENTING A PROBLEM

Adapted from The PHI Coaching ApproachSM to Supervision,
with permission of the PHI, 2010. (www.PHInational.org)



GUIDELINES FOR PRESENTING THE PROBLEM

1. Describe the behavior—don't pass judgment on it. For instance, rather than saying, "no one seems to be able to take the time to help," say, "The last two times I have visited I have found my mother's call bell going off and her needing to go to the bathroom. Can you tell me what is going on for this to be happening?"
2. Be specific rather than vague. For instance, rather than saying, "It has been like this all week," say, "The last two times I have visited."
3. Describe what you observed rather than what you assume to be the reason it happened. Focus on what happened rather than why you think it happened. For instance, don't assume understaffing. Offer an explanation only if you know for certain it is true.
4. Focus on a behavior rather than the person. For instance, rather than saying, "I am beginning to think no one really cares here," say, "Normally when I visit my Mom after work she is very comfortable and her needs are met. The last two times I visited her I have found her with the call bell going off and needing to go to the bathroom."
5. Don't avoid presenting the problem. Be sure to address the problem behavior or situation even if the immediate situation is resolved.

THREE RULES FOR PRESENTING THE PROBLEM

1. Be clear and direct about what the problem is.
2. Use objective language free from blame or judgment.
3. Indicate belief in the person's ability to resolve the problem.



APPENDIX 6: COACHING APPROACH TO COMMUNICATION

Used with permission of the
PHI, 2010. (www.PHInational.org)



PHI Coaching ApproachSM to Communication

Create a Relationship with the Other Person

- Identify any of your own personal emotional triggers or listening blocks; use a pull-back strategy that works for you
- Find a good time to raise the issue
 - Private setting
 - Careful timing
 - Distractions minimized
- Indicate interest and belief in the other person
 - Keep an open mind about the person
 - Keep an interest in the person, in understanding his or her reality
- Use an inviting and encouraging tone of voice

Present the Problem

- Be clear and direct about what the problem is
- Limit the statement to a single problem (not a litany)
- Use objective language free of blame or judgment
- Emphasize your wish to resolve the problem positively
- Indicate your belief in the person's abilities, including his or her ability to resolve problems
- Reinforce the positive by pointing out the person's specific accomplishments and successes

Listen for the Other Person's Perspective Put aside your own agenda while listening

- Listen actively to understand the person's perspective
- Acknowledge the person's perspective
- Paraphrase and use open-ended clarifying questions

Resolve the Problem with the Other Person

- Maintain a focus on issue-related behaviors
- Reach mutual agreement on the nature of the problem
- Develop strategies together to address the problem

Obtain Commitment to Action Steps

- Make mutual commitments for specific, measurable action steps
- Follow through on commitments



APPENDIX 7: ADDITIONAL AGENCIES TO CONTACT FOR COMPLAINT RESOLUTION

Adult Protective Services (APS)

Adult Protective Services investigators investigate reports of abuse, neglect or exploitation of endangered adults. Most APS programs serve both older and younger vulnerable adults. However, in some states, APS is responsible only for cases involving older adults, while a few APS programs serve only younger adults ages 18-59. In addition, APS does not conduct investigations in nursing homes in some states. To get contact information for your state's Adult Protective Services program, go to: www.theconsumervoiced.org or call (202) 332-2275.



Medicaid Fraud Control Unit

The duties of this unit include investigation of abuse and neglect of residents of long-term care facilities and theft of residents' personal funds. To get contact information for your state's Medicaid Fraud Control Unit, go to: www.theconsumervoiced.org or call (202) 332-2275.



Quality Improvement Organizations

Quality Improvement Organizations (QIO) work to improve the quality of health care for Medicare beneficiaries. As part of this job, the QIO is required to review care if a complaint is filed by a Medicare beneficiary regarding a Medicare-certified agency or facility. The QIO will review your medical records to determine if your care met professional standards. To get contact information for your state's QIO, go to: www.theconsumervoiced.org or call (202) 332-2275.



Licensing Boards

There are a variety of boards that license health professionals such as nurses, physical therapists, occupational therapists, nursing home administrators, doctors and other health care professionals. These boards also investigate complaints filed against these individuals. Search for state professional licensing agency for your state online or in the phonebook.

Law enforcement

Local law enforcement agencies are responsible for investigating crimes wherever they occur, including nursing homes or ICF/MRs.

Legal assistance programs

Elder Law Firms

Private attorneys can often help get a problem resolved, help with an appeal and assist you in seeking compensation and justice when you've been harmed or neglected by a provider. "Elder law" attorneys may be most helpful in this regard as they focus their practice on issues frequently confronted by older adults, persons with disabilities, and their families. To locate an elder law attorney in your area, go to: www.naela.org.



Legal Services Corporation, Inc.

Legal Services Corporation programs offer a wide range of civil legal assistance to those who meet certain financial criteria. For more information, go to: www.lsc.gov or call (202) 295-1500.



Senior Legal Hotlines

Free legal telephone advice is provided to people over 60 years of age in a number of states. Go to: www.legalhotlines.org to find out if your state has a senior legal hotline.



Area Agencies on Aging

Each Area Agency on Aging must arrange for legal assistance to be provided in its area. Call your local Area Agency on Aging to find out who the legal services providers are in your area.

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