



# *Quality Long-Term Care: A Roadmap to Success*

## *Consumer Guide 2011 Virginia Edition*

*A Collaborative Effort of the ENDependence Center of Northern Virginia/Loudoun  
ENDependence and TLC 4 Long Term Care Residents*

**FUNDED BY**  
*The National Consumer Voice for Quality Long Term Care*

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To request additional copies of this manual, please write to:

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**1828 L. Street, NW, Suite 801**  
**Washington, DC 20036**

*Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.*

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## Introduction

### *A Message from the members of TLC 4 Long Term Care Residents and Loudoun ENDependence*

*Dear Consumer,*

*Navigating the United States' system of long-term services maze, locating services, finding the right supports and knowledgeable people to help you on your journey is filled with uncertainty, missteps, u-turns and is a completely daunting undertaking.*

*This guide is designed for the individual who is currently receiving or making preparations for long-term services and supports. While there are a number of different terms that can be used to describe you, such as "participant," the expressions we will use in this guide are "**consumer**" or "**individual**".*

*The purpose of this guide is to inform you about your options for long-term care services and supports. Its goal is also to empower you - through education - to effectively advocate on your own behalf. We want you to know that you can have **choice, dignity, quality of life and competent, compassionate care.***

*For some individuals who are currently living 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 in Chapter 16.*

*Although this guide is intended for long-term care consumers, we recognize the important role of family caregivers and that there are kind, compassionate direct service providers who go the extra mile. For that reason, much of the information in this guide can also be used by family caregivers and direct service providers as they work to assist and support you.*

*Knowledge is key.*

## What is Person Centered Care?

The philosophy of **person centered care** places the person being cared for in a partnership with the team of people who work together to provide care. In this partnership, honor is given to all who are involved. Nurturing elders is an extraordinary achievement that should be honored as much as we honor those who nurture the young.

An eldercare community should honor its elders by placing the maximum possible decision making authority in the hands the elders or in the hands of those closest to them. A plan of care of care is made according to the needs of the individual and care partners are chosen to help fulfill the plan. Care partners may be friends, family members, people that are hired or a combination of all three.

The person centered philosophy of care focuses on the fact that relationships provide a pathway to a life worth living. People who practice person centered care realize that loneliness, helplessness and boredom account for the bulk of suffering among our elders and that loving companionship is the antidote to loneliness. When it comes to creating a place where elders can develop, human warmth is found in smaller homes where care-partners and elders will know and be known by each other.

Care partners have a duty to protect elders and to understand what makes life worth living for elders with whom they work. See: *My Personal Directions for Quality Living* in Appendix 10.

*This section on Person Centered Care is derived from **The Eden Alternative**. For complete information about The Eden Alternative visit: [www.edenalt.org](http://www.edenalt.org)*

## Chapter One: How to Use This Guide

### Use this publication to:

- Establish a Long Term Care road map for yourself or for a loved one/family member who is facing long term care options or will be facing them in the near future
- Understand the numerous, potential options that may (or may not) be right for you
- Make informed decisions about your long term care desires and ensure that those you have appointed are legally able to carry out those decisions
- Use the proper terminology and language when discussing your needs with others
- Help you formulate and ask the right questions when calling other agencies and organizations seeking additional help, advice or services
- Direct you to the proper person/agency to further your knowledge
- Locate resources throughout Virginia and more localized to your address for information and referral

## ABOUT: TENDER LOVING CARE 4 LONG TERM CARE Residents (TLC4LTCR)



**TLC 4 Long Term Care Residents** is a grassroots organization of family members and friends of long term care residents. We are based in Northern Virginia with a chapter in Roanoke, Virginia. Our goals are to create public awareness about the need for improvement in nursing home care and to educate the public about alternative choices available for people who are in need of long term care.

We meet regularly with numerous related organizations such as the Northern Virginia Aging Network, the Virginia Culture Change Coalition and Loudoun Senior Interest Network. We also meet with state officials to discuss our mission and hold free educational meetings that are open to the public at various times and locations throughout the year. We maintain our organization's official website: [www.tlc4ltc.org](http://www.tlc4ltc.org).

**TLC4LTCR** is a member of the National Consumer Voice for Long Term Care and we attend their annual teaching conferences.

**TLC4LTCR** membership is open to any individual who adheres to the principles of **TLC 4 Long Term Care Residents** as delineated in our bylaws.

**TLC4LTCR** is made up of volunteers and is a 501c3 organization.

### **Roanoke Chapter**

TLC 4 LTC  
PO Box 8955  
Roanoke, VA 24014  
Tel. 540-338-7333  
Tel. 540-563-4813

### **Springfield Chapter**

TLC 4 LTC  
PO Box 523323  
Springfield, VA 22152  
703-451-8631  
[www.tlc4ltc.org](http://www.tlc4ltc.org)  
E-mail: [tlc4ltc@msn.com](mailto:tlc4ltc@msn.com)

## ABOUT: THE ENDePendence CENTER OF NORTHERN VIRGINIA/ LOUDOUN ENDePendence



Loudoun ENDePendence (LEND) is a Center for Independent Living (CIL) Satellite Program of the ENDePendence Center of Northern Virginia (ECNV). LEND provides peer counseling, mentoring, and other self-help services that are designed to increase the independence and self-sufficiency of Loudoun County residents who have disabilities and to promote those residents full participation in community life.

LEND is a program made possible by funding from the Virginia Department of Rehabilitative Services (VDRS) under the CIL Satellite Program, and through a Rehabilitative Services Incentive Fund (RSIF) grant from the Loudoun County Disability Services Board (LCDSB).

### *What services does LEND provide?*

All of LEND staff are persons who have disabilities and they provide a unique combination of peer-based, self-help services that include:

- **Peer Counseling** – LEND Peer Counselors assist individuals with disabilities to develop and work toward their own goals to achieve independence and self-reliance by providing peer mentoring, encouragement, and information about community resources and adaptive techniques as well as sharing insights and perspectives gained through their own experience of living with disability. Peer counseling can be provided on an individual basis and through support groups.
- **Independent Living Skills Training** – LEND staff can provide specific training in adaptive skills and techniques that enhance one’s capacity to face the challenges of living with a disability and become more self-reliant, e.g., acquiring and learning to use assistive technology, learning to use public transportation when you can’t drive, making your home environment more accessible and usable, budgeting and money management, or acquiring the skills needed for effective personal assistance management.
- **Information and Referral Services** – LEND staff can guide consumers and their families to information about community resources, public and private service providers and assistive technology vendors, disability rights laws and protections, and much more.
- **Advocacy Services** – LEND staff include advocates experienced in assisting consumers with individual complaints and concerns or to organize and address communal and societal barriers, both physical and attitudinal.
- **Personal Assistance Registry and Referral Services** – In cooperation with ECVN, LEND staff maintains a listing of individuals and organizations that provide assistance with activities of daily living, such as bathing, dressing and transferring, and with other tasks such as meal preparation, shopping and driving, to persons with disabilities who reside in, or work in Loudoun.

- **Monthly Support Group** – The LEND support group is for individuals with disabilities, their family members and caregivers who want to gather and talk about issues that relate to their lives, find support, resources and information for successful living. We may also have guest speakers that offer expansive knowledge on various subjects.

### ***Who operates LEND?***

LEND is a satellite program of the ENDependence Center of Northern Virginia (ECNV). ECVN is a community resource and advocacy center run by and for people with disabilities. ECVN provides peer-based, self-help services to persons of all ages who have all types of disabilities. Loudoun County is part of ECVN's service area, which also includes Alexandria, Arlington, Fairfax, and Falls Church.

ECNV is one of 16 Centers for Independent Living (CILs) in the Commonwealth of Virginia. A CIL is a community-based, non-residential, non-profit organization, which must be run by people with disabilities themselves and provide peer-based, self-help services on a cross-disability basis.

CILs are an outgrowth of the consumer self-help and disability rights movement. There are over 400 CILs nationwide.

### ***How did LEND start?***

Loudoun citizens who have disabilities expressed an interest in starting their own CIL in Loudoun County. That group worked with the ECVN Board of Directors to obtain the resources to start a CIL satellite, called LEND, which will operate as a satellite program of ECVN until it can secure sufficient funding to allow LEND to become a "freestanding CIL". A group of Loudoun County citizens has formed a LEND Advisory Board to provide policy direction and oversight of LEND operations.

### **Loudoun ENDependence (LEND)**

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Ashburn, VA 20147

Voice: 571-291-9550

Fax: 571-291-9552

### **ENDependence Center of Northern Virginia (ECNV)**

2300 Clarendon Blvd., Suite 305

Arlington, VA 22201

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Fax: 703-525-3585

## **Chapter Two – Understanding the Lingo and Gaining Support**

Whenever discussing subjects that are diverse and complex, it might seem like the people around you are speaking a foreign language. For an explanation of terms used throughout this guide, turn to the glossary in Appendix 1.

For additional assistance, you may choose to contact local agencies directly as they may be the best source of information for your particular situation.

Also you may wish to contact caregiver support groups or peers who have gone or are going through the issues you are facing as they are often very knowledgeable and willing to help. Your local senior centers are another valuable resource.

## Chapter Three: Options for Long-Term Services and Supports – Community (Home) Based Services and Supports

Long-term care options can be vastly different from state to state. Many states are realizing that long-term care is going to be a vital issue in years to come and as such are becoming the pioneers in addressing the need, while other states lag far behind in solving America's long-term care maze and the shortage of quality programs and assistance.

There are two important kinds of Long-term Services and Supports:

1. **HOME and COMMUNITY BASED SERVICES and SUPPORTS** are those provided to you in your own home or a home of your choosing within the community. Home and Community Based Services often provide the most ideal setting but may not be achievable if the prognosis and mobility of the individual is compromised or limited.

Being able to obtain these services to support you *in* your home can mean the difference between staying in your home or moving into an institution.

2. **RESIDENTIAL SERVICES and SUPPORTS** are those services and supports provided to you in a residential setting (e.g. nursing home, assisted living facility, etc.) These type of settings does not offer as great of an opportunity to exercise one's independence.

### **HOME and COMMUNITY BASED SERVICES and SUPPORTS**

Medicaid Waivers were developed to help people with disabilities and the elderly to access services in their homes and communities. Federally funded, Medicaid is a state program and the Medicaid Waivers provide funding to serve people eligible for long-term care in institutions such as hospitals, nursing facilities, and intermediate-care facilities.

There are seven different types of waivers currently available in the state of Virginia. The Virginia Department of Rehabilitative Services (DRS) **[www.vadrs.org](http://www.vadrs.org)** provides the bulk of the (home) community-based services and supports that allow people with disabilities to remain in their homes. There are seven different waivers that provide financial assistance to pay for some of these supports.

There are many eligibility requirements for the waivers and many have waiting lists but they remain a great option for living in “your” home within the community.

There are many eligibility requirements for the waivers and many have waiting lists but they remain an option for living in “your” home within the community. Here is the list of Virginia’s waivers:

- Alzheimer’s Assisted Living Waiver
- Day Support Waiver
- Elderly or Disabled with Consumer Direction Waiver
- HIV/ AIDS Waiver
- Individual and Family Developmental Disabilities Support Waiver
- Mental Retardation/Intellectual Disabilities Waiver
- Technology-Assisted Waiver

For a complete listing and overview of the seven different Medicaid Waivers, visit:

**[http://dmasva.dmas.virginia.gov/Content\\_atchs/ltc/ltc\\_md\\_waiver.pdf](http://dmasva.dmas.virginia.gov/Content_atchs/ltc/ltc_md_waiver.pdf)**

Below is a listing of many of the, home and community-based services and supports. The names of these services and supports may also be different and not ALL of them may be provided. A more detailed explanation of some of the terms can be found in the Glossary, Appendix 1.

- 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
- Behavior management
- 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
- Cognitive rehabilitation

- Congregate meals
- Case management
- Community resource utilization / Community Integration Training
- Crisis intervention
- Durable medical equipment
- Education
- Environmental modifications/Home Maintenance/Home Repair\*
- Financial and Legal Support
- Housing (locating suitable/affordable housing options)
- Independent Living Services
- Independent living skills training
- Individual and group counseling
- Information and Referral
- Medical Treatment/Services
- Personal Assistance Services/ Home Health Services
- Psychotherapy
- Social/Recreation/Leisure Opportunities
- Rehabilitation engineering
- Respite/Day Services
- 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 (medical) or Travel Training / Navigation
- Vehicle adaptation

## Chapter Four: Options for Long-Term Services and Supports – Residential Setting Services and Supports

Persons may opt to live in a residential type setting. This means that the consumer does not need 24-hour nursing care and supervision.

There are numerous classifications for “residential” settings. Residential places may also be known as adult care homes, adult foster care, adult family homes, board and care homes, assisted living facilities, housing with service establishments.

There is a burgeoning effort to provide supports and services to the elderly and people with disabilities so that they may remain in their homes and thus in their community but this is not always possible. Not only is in the home care better than a facility or institution, it is more cost effective to do what service providers can to help people remain at home.

### **Residential care facilities are needed when home care cannot be attained.**

Some examples of “residential” settings include:

- **Nursing Homes** – provide room and board, nursing care, dietary services, medication, social activities, physical and occupational therapy, dental, podiatry care, optometry and transportation access to medical appointments and doctors. Some nursing homes have more than one section in that people with differing needs, e.g. Alzheimer’s patients can be among others that have needs similar to theirs.
- *Note: Individuals with mental illness are not eligible for nursing home care due to their mental illness. They must go through a screening process called the Pre Admission Screening and Resident Review. People with Mental Illness must also need the services that a nursing home provides.*
- **Continuing Care Retirement Communities (CCRC)** – Housing communities that offer several different levels of care at one central location. CCRC may be made up of apartments for residents who can live on their own as well as another adjoining (or nearby) facility that houses those who need more assistance with daily care and those who require a “nursing home” setting. CCRC’s can charge a move-in fee, and other additional monthly fees based on the services required.
- **Therapeutic Communities** – Long term residential programs for people with mental illness. Clients and therapist live in the same community.

- **Long-term Recovery Residences** – Facilities for people with mental illness offering the support, structure and service needed with the goal to help the individuals reintegrate into the community.
- **Intermediate Care Facilities for People with Intellectual Disabilities (ICF-ID)** – A facility in which more than 16 people with developmental or intellectual disabilities reside. Residents receive 24-hour care, supervision and support that is not available in group homes. Training and support in life skills, employment, socialization and recreation is provided as well as skilled nursing services. ICF-ID's must follow federal regulations.
- **State-funded Institutions** – a facility, usually very large (more than 16 beds) that is similar to the ICF's in that they provide 24-hour care and supervision to individuals with developmental or intellectual disabilities. These state funded institutions are run by the state. Recently there has been an effort to eliminate these kinds of institutions in an order to move people back in the community because community based supports are far more favorable for individuals than living in institutions.

Note: Not all states have therapeutic or long-term recovery residences

*Also note: in the last few years, the word "retarded" is being removed from all documents, papers, and any written materials used to discuss about people with disabilities. "Retarded" is considered degrading and derogatory and should not be used in any setting. In the place of "MR", throughout this manual and in other areas of the disability realm, people will use or say "people with intellectual disabilities" or the "intellectually disabled". This includes anyone with a cognitive disability including but not limited to Down Syndrome or Autism.*

## Chapter Five: Housing

Housing options can be another daunting task especially if one's family does not live nearby or if special care is required. Additionally, limited financial resources or lack of home ownership can add stress to an already strained situation.

Many housing options exist that allow one to remain in control of his or her care and daily activities. These include:

- **Living with a family member or having a roommate** – in some circumstances, the services and supports that an individual requires to live their life can be offered by a family member or relative
- **“Live-in” personal care assistant or home health aide** – An aide or personal care assistant who agrees to live as a roommate at a reduced rent, exchanging personal care assistance for room and board
- **Subsidized Housing** – housing that is made available to those that fit certain income levels, including, but not restricted to the disabled and/or elderly due to income limits. Subsidized housing is sometimes called Public Housing
  - **Senior Housing** – private apartment or house in a community of adults where there is an age restriction, usually age 55 or older. Senior housing provides recreation and social opportunities but individuals have to provide for their own other services and supports
  - **Housing Choice Vouchers** – issued to individuals or families and used to pay for any housing that the owner has agreed to rent under the program – also may be called Section 8 Housing and Affordable Dwelling Unit Programs
  - **Supportive Housing** – rental housing with services for low-income persons with disabilities and older adults – Review more about supportive housing through the Housing and Urban Development Sections 202 – for initiatives for the Elderly and Section 811 for initiatives for Persons with Disabilities by visiting: [http://portal.hud.gov/hudportal/HUD?src=/program\\_offices/cfo/reports/2012/main\\_toc](http://portal.hud.gov/hudportal/HUD?src=/program_offices/cfo/reports/2012/main_toc) - Look Under “Housing”
  - **Group homes for people with developmental or intellectual disabilities or mental illness** – these types of living arrangements may house up to 15 people but usually house six or fewer. The home is usually owned and run by the provider (home owner). This person hires staff to provide care, services, daily activities and supervision 24-hours a day. The staff helps the residents learn various life skills such as money management, cooking, cleaning and medication management. Residents may work outside of the home in sheltered workshops and/or participate in day habilitation programs. Homes for people with intellectual disabilities may also be called small intermediate care facilities (ICF/ID). The goal for

those with mental illness is to assist individuals in reintegrating into the community and to develop skills that will enable them to understand and cope with their illness.

The waiting lists for these housing options can be very long so you may wish to apply for your preference as soon as possible.

*Choosing a place to live can be difficult, but to ensure that you are making the most informed decision about the type of housing that's right for you, understanding more about the Fair Housing Act and your rights will be helpful, see the **Informed Consumer's Guide to Accessible Housing** by visiting: [http://www.abledata.com/abledata\\_docs/icg-hous.htm](http://www.abledata.com/abledata_docs/icg-hous.htm)*

Many Area Agencies on Aging and Centers for Independent Living maintain a listing of accessible and affordable housing for the area they serve. You can usually obtain the list by calling or visiting their website. Find the nearest center by entering your zip code at the organization's website.

Virginia Association of Centers for Independent Living - <http://vacil.org/>

Virginia Area Agency on Aging - <http://vaaaa.org/>

## Chapter Six: Knowing Your Rights

One should never take his or her rights for granted but with so many civil laws and regulations, it can be very difficult to know when and if you are being discriminated against.

Discussion about each of the following laws is for information purposes only and further research should be conducted to ensure your understanding about each one. All four titles of the Americans with Disabilities Act (ADA) are reviewed in more detail in Appendix 3.

**OLMSTEAD DECISION** - Under Title II of the Americans with Disabilities Act, requires states to make efforts to place persons with intellectual disabilities in community settings rather than in institutions. This means that wherever possible, service providers and institution workers should evaluate and give residents of current facilities the option and the support to be integrated in a setting of their choosing within the community (home based supports and services). The 'integration mandate' of the Americans with Disabilities Act requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

This ruling stemmed from a Georgia court case on the behalf of two plaintiffs who were segregated because of their intellectual disabilities even when their own treatment professionals had recommended their transfer to community-based care.

**FAIR HOUSING ACT** - Under Title VIII of the Civil Rights Act of 1968 (Fair Housing Act), prohibits discrimination in the sale, rental, and financing of dwellings, and in other housing-related transactions, based on race, color, national origin, religion, sex, familial status (including children under the age of 18 living with parents or legal custodians, pregnant women, and people securing custody of children under the age of 18), and handicap (disability).

**AMERICANS with DISABILITIES ACT**- The following is a brief overview of the Americans with Disabilities Act (ADA). The titles pertain to your rights as an individual, however for very specific cases, please call the ADA General and Technical Assistance Center at 1-800

Signed into law on July 26 1990, the Americans with Disabilities Act is a wide-ranging legislation intended to make American Society more accessible to people with disabilities.

It is divided into five titles:

## **Title I. - Employment**

Business must provide reasonable accommodations to protect the rights of individuals with disabilities in all aspects of employment. Possible changes may include restructuring jobs, altering the layout of workstations, or modifying equipment. Employment aspects may include the application process, hiring, wages, benefits, and all other aspects of employment. Medical examinations are highly regulated.

## **Title II. - Public Services**

Public services, which include state and local government instrumentalities, the National Railroad Passenger Corporation, and other commuter authorities, cannot deny services to people with disabilities participation in programs or activities which are available to people without disabilities. In addition, public transportation systems, such as public transit buses, must be accessible to individuals with disabilities.

## **Title III. - Public Accommodations**

All new construction and modifications must be accessible to individuals with disabilities. For existing facilities, barriers to services must be removed if readily achievable. Public accommodations include facilities such as restaurants, hotels, grocery stores, retail stores, etc., as well as privately owned transportation systems.

## **Title IV. - Telecommunications (Title IV)**

Telecommunications companies offering telephone service to the general public must have telephone relay service to individuals who use telecommunication devices for the deaf (TTYs) or similar devices.

## **Title V. - Miscellaneous**

This includes a provision prohibiting either (a) coercing or threatening or (b) retaliating against the people with disabilities, or those attempting to aid people with disabilities in asserting their rights under the ADA.

The ADA's protection applies primarily, but not exclusively, to "disabled" individuals. An individual is "disabled" if he or she meets at least any one of the following tests:

1. He or she has a physical or mental impairment that substantially limits one or more of his/her major life activities;
2. He or she has a record of such an impairment; or
3. He or she is regarded as having such an impairment.

This short overview of the ADA and in no way encompasses all of the ADA. Each experience and individual is different and must be addressed on a case by case basis.

For more specific information on the Americans with Disabilities Act, please contact the **Mid-Atlantic ADA Center** at **1-800-949-4232** which serves Region 3 (Delaware, District of Columbia, Maryland, Pennsylvania, Virginia and West Virginia)

**Mid-Atlantic ADA Center**

TransCen, Inc.

451 Hungerford Drive, Suite 700

Rockville, Maryland 20850

Phone: (301) 217-0124 (V/TTY)

Fax: (301) 217-0754

Website: **[www.adata.org](http://www.adata.org)**

Region 3 Website: **[www.adainfo.org](http://www.adainfo.org)**

1-800-949-4232

**This information has been adapted from the:**

ADA General and Technical Assistance Center **[www.ada.gov](http://www.ada.gov)** and the

US Department of Justice (DOJ)

**<http://www.usdoj.gov/crt/ada/adahom1.htm>**

## Chapter Seven: 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/ID. 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 is 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 locate a hospice provider, visit:

**[www.hospicedirectory.org](http://www.hospicedirectory.org)**

or call the

Hospice Directory

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.

*This chapter on Hospice is taken from the National Consumer Guide produced by the National Consumer Voice for Quality Long Term Care © 2011.*

## Chapter Eight: Getting Started – What are my Needs?

Your own personal assessment can help you sort out the many options that are available to you. Answering the following questions may be a useful tool.

Age \_\_\_\_\_

Current Living Arrangement \_\_\_\_\_

Where would you like to live? \_\_\_\_\_

Are you a veteran? \_\_\_\_\_

Current income? \_\_\_\_\_

What is your diagnosed disability (if any)? \_\_\_\_\_

Do you need assistance with:

Bathing \_\_\_\_\_ Using the restroom \_\_\_\_\_ Eating \_\_\_\_\_ Dressing \_\_\_\_\_

Cooking \_\_\_\_\_ Taking medications \_\_\_\_\_ Cleaning \_\_\_\_\_

Transferring \_\_\_\_\_ Oral Hygiene \_\_\_\_\_ Ambulation \_\_\_\_\_

If you are unable to objectively fill out this survey, you may wish to contact a professional who can make an assessment with you. Following are some options.

Case manager and/or Care managers through centers for independent living, department of social services, department of medical assistance services, department of family services, the area agency on aging, community services boards, aging and disability resource center coordinators, etc.,

There are also private geriatric care/case managers who are available for a fee. However, if you have a long term care insurance plan or policy, this service may be included. To find a geriatric care manager, visit:

<http://www.caremanager.org>

Also be sure to ask family and friends. They may point out instances you may not have thought about.

If you would like financial assistance from the state or federal government, it is necessary to seek an assessment from your Area Agency on Aging. Go to [www.eldercare.gov](http://www.eldercare.gov) website or call 1- 800-677-1116.

## Chapter Nine: Finding Information and Obtaining Services

### Where do you find information and resources about long-term care?

Your first stop may be Easy Access:

<http://www.easyaccess.virginia.gov/financialhelp.shtml>

You may also want to **call 2-1-1** toll free, which is a special nationwide telephone number you can use to obtain quick and easy information and referrals to health and human service organizations throughout each state. People who are Deaf and Hard of Hearing can dial **7-1-1** for Virginia Relay then dial 2-1-1. Video phone users dial **1-800-230-6977**

### Other options:

#### 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](http://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 on Aging office closest to you by visiting:

[www.eldercare.gov](http://www.eldercare.gov). Or call (800) 677-1116

#### Virginia Department for the Aging

1610 Forest Avenue

Suite 100

Richmond, VA 23229

E-mail: [aging@vda.virginia.gov](mailto:aging@vda.virginia.gov)

Website: [www.vda.virginia.gov](http://www.vda.virginia.gov)

1-804-662-9333

#### 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 CILs core services is to provide disability-specific information and referral services. To locate a CIL near you, call

1-877-525-3400 or visit

<http://www.vacil.org>

### **Aging and Disability Resource Centers (ADRC)**

These centers provide easy access to free information about the full range of long-term care services and support options in a state or area to consumers and their families. To find the ADRC closest to you, go to:

<http://www.adrc-tae.org/tiki-index.php?page=CordaMaps&st=VA>

or call 1-800-677-1116.

### **Family and friends**

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](http://www.va.gov) (Click on “Veteran Services”).

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

“**Self-direction**”, (also called **Consumer-Direction**) gives you control over your own services and supports. This allows you flexibility as well as responsibility.

If you are eligible for Medicaid Waiver services, (see section Chapter 11, Payment Options for Long Term Care) you can choose to be part of the self-directed waiver program.

Under one type of self-direction you are the employer and responsible for assuming both payroll and tax responsibilities. You are in charge of finding, 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 locate, 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.

### **How do you access services?**

**Department of Rehabilitative Services:** DRS offers consumer-directed home care services through the Personal Assistance Services (PAS) Program. Recipients must have physical and/or sensory disabilities to qualify. For more information, call 1-800-662-7000 or 1-800-552-5019 or visit [www.vadrs.org](http://www.vadrs.org)

Here are some points to think about as you consider the option of self-direction<sup>1</sup>:

- You can pick the worker who is most compatible with you and your situation.
- You have more flexibility in scheduling.
- You are responsible for locating, 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 the worksheet in Appendix 4 to help you think through whether self-direction is right for you.

To find potential personal care assistants through the Personal Assistance Services (PAS) Registry you can obtain the PAS Registry from your local Center for Independent Living (CIL). The PAS Registry is a list maintained and compiled by many CILs listing local (some experienced, some not) home health aides, nurses and certified nursing assistant’s that are or have provided assistance services to area consumers. The Registry lists the types of services that the personal assistant may be willing to provide, the general location the personal assistant may reside, and the areas the personal assistant is willing to travel to for work. You can obtain a list of personal care assistants in your area by contacting your local CIL.

Note: While Centers for Independent Living (CIL) maintain a Personal Assistant Services Registry, the CILs do not conduct an in-depth screening of each individual on this list. The individuals complete a simple and often short orientation thus it is imperative that you do your

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<sup>1</sup> *Help at Home, published by the Ohio Department of Aging.*

homework to obtain vital details about each person.

First, check personal and employment references carefully. When placing an ad for a personal assistant, be sure to announce that interviewees will be required to undergo a background check. This is often (but not always) a deterrent to anyone with a questionable past.

To obtain a Virginia background check form and the instructions for its completion go to:

**[www.vsp.state.va.us/downloads/SP167.pdf](http://www.vsp.state.va.us/downloads/SP167.pdf)**

There is a cost (usually in the \$20-\$50 range) but it is imperative that this step in the hiring process be taken.

You can also e-mail questions about conducting background checks to:

**[background\\_checks@vsp.virginia.gov](mailto:background_checks@vsp.virginia.gov)**

## Chapter Ten: What Do Long Term Care Services and Supports Cost?

### 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.<sup>2</sup>

#### Home care

Home health aide (from licensed agencies) \$21 per hour

Homemaker/companion services (from an agency) \$19 per hour

Note: This is the amount you pay the agency. It is not the amount the home health aide or homemaker/companion receives.

Attendant \$8.91 - 11.99<sup>3</sup>

**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:

[http://www.longtermcare.gov/LTC/Main\\_Site/Paying\\_LTC/Costs\\_Of\\_Care/Costs\\_Of\\_Care.aspx](http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx) and clicking on your state

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*<http://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-2010-market-survey-long-term-care->*

## Chapter Eleven: Payment Options 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.

<http://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-2010-market-survey-long-term-care-costs.pdf>

### **Medicare**

Medicare is a federally-funded and administered program that provides 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.

### **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.

### **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 that 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.

3) Hospice care if you are eligible for Medicare Part A (hospital insurance); your physician certifies that 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 that 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.

### **1-800-MEDICARE**

To get general Medicare information.

1-800- 633-4227

TTY 1-877-486-2048

### **State Health Insurance Assistance Program (SHIP)**

To get free personalized health insurance counseling, including help making health care decisions, information on programs for people with limited income and resources, and help with claims, billing, and appeals.

1-800-552-3402

### **Social Security**

To get a replacement Medicare card, change your address or name, get information about Part A and/or Part B eligibility, entitlement, and enrollment, apply for “extra help” with Medicare prescription drug costs, and report a death.

(800) 772-1213  
TTY (800) 325-0778

### **Coordination of Benefits Contractor**

To get information on whether Medicare or your other insurance pays first.

1-(800) 999-1118  
TTY (800) 318-8782

Medicaid – Information from Virginia Easy Access-

**<http://easyaccess.virginia.gov/medicaidandstate.shtml>**

### **What is Medicaid?**

Medicaid is a federal and state-funded health insurance program that helps pay for health care. It is for low-income people who meet eligibility requirements.

Pregnant women, children, people with disabilities, and people age 65 and older may also qualify. The rules may be different for children, adults, and people in nursing facilities, but they all may get the same services.

### **What programs and services are available under Medicaid?**

The federal law allows the Virginia Medicaid program to cover a wide range of services. Services include:

- inpatient and outpatient hospital care
- doctor's services
- lab and x-ray services
- transportation
- skilled nursing care
- home health care, and
- prescription medications

### **What does Medicaid cost?**

Some Medicaid covered services have a co-payment that you must pay if you are an adult. There are some exceptions. For example, an adult in hospice care may not have to pay a co-pay. Co-payments range from \$1 for a clinic visit to \$100 for an inpatient hospital admission. You may also have to pay more toward your care (called a patient pay amount) if you use nursing home or other long-term care services.

### **How do I qualify for Medicaid services?**

You may be eligible if you are:

- a child in a low income family

- a pregnant woman
- elderly
- have a disability, or
- are a parent who meets specific income levels

You must also meet certain financial requirements. You will be asked to verify any financial resources you have. This includes your checking and savings accounts, stocks, and property depending on what you are applying for.

You will also be asked for your Social Security number, proof of Virginia residency, U.S. Citizenship, and identity or alien status. If you cannot work due to a disability, you will be asked whether you have applied for disability benefits. If you have not, you may be asked more information about your medical condition. If you are pregnant, you will be asked to provide proof of pregnancy from a medical provider.

### **Where do I apply for Medicaid services?**

If you are interested in applying for Medicaid, you can visit the Department of Social Services website by visiting the site listed and printing out a copy of the application. You must then send the application to your local **Department of Social Services**. Visit: <http://www.dss.virginia.gov/localagency/> or call:

- **The Virginia Department of Social Services (VDSS) General Information**  
800-552-3431 (toll-free)  
804-726-7000 (Richmond)

You may also file an application at some larger hospitals. If you cannot sign the application, your parent, legal guardian, conservator, attorney-in-fact, or authorized representative can sign on your behalf. An interview is not needed.

To obtain a Medicaid Application, visit here:

**[http://www.dss.virginia.gov/files/division/bp/fs/intro\\_page/forms/032-03-0824-24-eng.pdf](http://www.dss.virginia.gov/files/division/bp/fs/intro_page/forms/032-03-0824-24-eng.pdf)**

The application for Medicaid will have to be printed and filled in by hand. You may also call the toll free number to request that a copy be mailed to your home.

### **Other Medicaid Programs**

**MEDICAID WORKS** (also known as Medicaid Buy-In) is a work incentive program offered by Virginia Medicaid for people with disabilities who are employed or want to go to work. If you have Medicaid, this voluntary option

allows you to work, earn more money, and still keep Medicaid. For information about Medicaid Works visit the Medicaid Works section of the Department of Medical Assistance Services website, here:

**<http://www.dmas.virginia.gov/mb-home.htm>**

The **Health Insurance Premium Payment (HIPP) Program** is run by the Virginia Medicaid Program and offered to individuals enrolled in Medicaid. This program may pay some or a person's entire share of their private health insurance when it is cheaper for Medicaid to do so. For information about the Health Insurance Premium Payment Program visit the Department of Medical Assistance Services website, Health Insurance Premium Payment Program, here:

**<http://www.dmas.virginia.gov/rcp-HIPP.htm>**

Where can I find out more?

- The Virginia Department of Medical Assistance Services  
**[http://www.dss.virginia.gov/benefit/medical\\_assistance/](http://www.dss.virginia.gov/benefit/medical_assistance/)**
- The Centers for Medicare and Medicaid Services - **[www.cms.gov](http://www.cms.gov)**
- Medicare Service Center: 1-800-MEDICARE 1-800-633-4227

To apply for Medicaid: The Virginia Department of Social Services Medicaid is a health insurance program financed and run jointly by the federal and state government 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 that certain services be provided. 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:

**[http://www.nasmd.org/links/state\\_medicaid\\_links.asp](http://www.nasmd.org/links/state_medicaid_links.asp)**

Medicaid covers:

- 1) Nursing home services
- 2) Home and community-based services
- 3) Hospice care in most states

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 that are very 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.

In some states, a Medicaid personal care 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, 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.

Virginia has seven types of Medicaid Home and Community based waivers:

- Alzheimer’s Assisted Living Waiver
- Day Support Waiver
- Elderly or Disabled with Consumer Direction Waiver
- HIV/AIDS Waiver
- Individual and Family Developmental Disabilities Support Waiver
- Mental Retardation/Intellectual Disabilities Waiver
- Technology-Assisted Waiver

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.theconsumervoicework.org](http://www.theconsumervoicework.org)** (click on “Government Policy,” then “Health Care Reform”).

**The Older Americans Act (OAA)** – is a Federal program designed to organize, coordinate, and provide home and community-based services to older adults and their families to help elders remain in the community as independently as possible. The Older Americans Act provides funding, through state and local agencies known as the Aging Network, for a range of services that include nutrition programs in the community and for homebound elderly; programs for Native American elders; services for low-income minority elders; health promotion and disease prevention activities; in-home services for frail elders; services that protect the rights of older persons such as the long-term care ombudsman program; and services and supports for family caregivers. 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. Local agencies, called Area Agencies on Aging (AAAs), in collaboration with State Agencies on Aging, plan and develop service and support programs based on the needs of elders and families in their respective areas.

For a state to receive federal funds to implement to OAA, the Governor has to appoint a State Unit on Aging. State Units on Aging develop a statewide aging plan of how services and supports will be provided.

#### **Virginia State Unit on Aging Contact Information**

Dept for the Aging  
1600 Forest Avenue  
Suite 102  
Richmond, VA 23229  
<http://www.aging.state.va.us/>

Read about Virginia’s policy for cost sharing by visiting:

**<http://www.vda.virginia.gov/pdfdocs/Cost%20Sharing-Fee%20for%20Service%20State%20Policy.pdf>**

#### **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.va.gov**, 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.

### **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 (such as the Alzheimer's Association),**

These groups may be able to help in a more limited or targeted way.

**Private Pay** - Private long-term care financing options include long-term care insurance, trusts, annuities, and reverse mortgages. Which option is best for you depend on many factors including your age, your health status, your risk of

needing long-term care, and your personal financial situation. For a detailed and interactive chart outlining various options and considerations applicable to each one, visit:

**[http://www.longtermcare.gov/LTC/Main\\_Site/Paying\\_LTC/Private\\_Programs/Private%20Financing/index.aspx](http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Private_Programs/Private%20Financing/index.aspx)**

Some private payment options are good choices for older people; others make more sense for a younger person.

**The two resources listed below can help you figure out what programs may help you pay for your long-term care services.**

**Benefits Check-Up: [www.benefitscheckup.org](http://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):**

**<http://www.healthassistancepartnership.org/ship-locator/>  
1-800-MEDICARE (699-4887)**

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.

**Private Pay- Private long-term care** financing options include long-term care insurance, trusts, annuities, and reverse mortgages. Which option is best for you depend on many factors including your age, your health status, your risk of needing long-term care, and your personal financial situation. A more detailed chart outlining the various options can be found by visiting the Long Term Care portion of the Department of Health and Human Services website, here:

**[http://www.longtermcare.gov/LTC/Main\\_Site/Paying\\_LTC/Private\\_Programs/Private%20Financing/index.aspx](http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Private_Programs/Private%20Financing/index.aspx)**

## Chapter Twelve: Financial and Health Care Planning

By planning ahead you can express what care you would want and ensure that 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: 1) give direction about the type of care and treatment you would want if you can’t communicate your wishes and/or 2) 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.

Individuals with serious progressive or terminal conditions may want to ask their doctor about a POLST form (Physician's Order for Life Sustaining Treatment) 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:

Read more about a POLST here:

<http://www.ohsu.edu/polst/>

<http://dying.about.com/od/ethicsandchoices/f/POLST.htm>

Some states have specific requirements or language for advance directives. To get a copy of your state's advance directive forms, download the VIRGINIA ADVANCE MEDICAL DIRECTIVE here:

<http://www.vsb.org/sections/hl/add06/2005Form.pdf>

Or <http://www.caringinfo.org/stateadownload>

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!

*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 Thirteen: How to Advocate for Yourself

As you become more educated and empowered about the things you need to consider in long-term care planning, there may be those around you who feel that they know what's best for you, but in the end, only YOU know what is best for you.

After you gather all the important data, weigh what everyone has to say, and make a decision, friends and love ones should agree to support you.

Below, we outline ten tips to help you advocate for yourself:

1. **Keep an open mind** – Don't immediately discard ideas until you have fully considered and weighed whether or not they are right for you. Speak up and tell your care partners why you want things the way you do.
2. **Stay current** – Remember that information is changing daily and you will need to keep up to date. Consult with professionals and dig deeper to find the most accurate information about your condition.
3. **Develop an objective support system** – Find family or friends who want to help you to get the best possible care. Anyone that stands to gain financially, or through some other means, cannot be objective and won't always have your best interest in mind.
4. **Be a good listener** – Hear the pros and cons of a solution before saying yes or no. Listen to all the facts you need without "shutting down" another person. The other person helping you will then show you the same courtesy and listen to you when you speak up to present your thoughts and opinions.
5. **Trust but verify** – Know what care services and supports you are supposed to receive. Take notes during any phone calls or meetings. If you are not good at taking notes, ask a relative or friend. Take a friend with you when you have meetings with care providers so you can review or discuss what was said with them. Wherever possible, ask if you would be permitted to record calls/meetings or request information in writing.
6. **Keep good records** – Always keep a copy of the originals. Pack them up and ensure they are kept in a safe and dry place. Write down any questions or miscommunications that might come up so you can follow up for clarification.
7. **Know whom to contact** within the agency, facility or system when you have questions about your care or services.

8. **Know that there is an Ombudsman Service** in your community that will advocate for you. If something goes against your true desires, tell someone and keep telling them until you are heard.

9. **Know that you have residents' rights** if you are a hospital patient, living in a nursing home or in an assisted living community. *(See appendix 12)*

10. **Know that you can change providers** if you are not happy with the care you are receiving.

**Systems Advocacy** - Navigating through all of the options for long term care can be a long and arduous journey. Taking on additional responsibility at this time may seem impossible. However, sharing what we learn helps others who may not have voice in the process.

Becoming involved in organizations that are working to make changes is one way to improve long-term care. Getting involved in advocacy efforts helps to bring the issues to the forefront which may attract much needed media attention. Attention to the problems facing individuals in long-term care settings can influence legislators' views when it comes time to enact laws and regulations. Joining with others who are having similar problems will strengthen your influence.

To find out how you can become more involved and make a difference, contact your local Center for Independent Living or Agency on Aging

To find the legislators for your district visit: <http://legis.state.va.us/>

To find Virginia representatives to Congress visit:

[http://www.arcofva.org/advocacy/get\\_started/legislator.html](http://www.arcofva.org/advocacy/get_started/legislator.html)

The next portions of this guide will help you navigate your way to quality care, supports and services at home from an attendant/aide or in an assisted living, group home setting or in a nursing home.

## Chapter Fourteen: Caregiver Support

Your role as a caregiver is vital. You enable a loved one or your “client” to live their life to the fullest. This chapter is dedicated to that family member, friend, personal care assistant or other type of person primarily responsible for providing care.

Even though you (the caregiver) have taken on the responsibility to care for someone with a willing heart, this willingness to help does not mean that your role will always be easy. It’s important that you realize sometimes, you will get tired and that in helping others, you may have some days that are fought with tension. You too need a break and that means you will have to set up a network where you can feel comfortable venting those frustrations, talking with others that are experiencing similar issues and simply being yourself without performing your duties as a caregiver.

There are many networks, support groups that have been developed so that you can gain support, and receive the energy you need to continue providing the best possible care for the consumer.

Traditional outlets such as church support groups, supportive friends and families and even professional organizations are there for you to get involved in, while new nontraditional outlets allow caregivers the ability to participate in these groups from the comfort of their home through use of the internet and via telephone.

As a caregiver, there are also more specific groups you can join addressing the challenges unique to Alzheimer’s, aging parents, various kinds of cancer or those providing support for the terminally ill.

Never be afraid to reach out to these groups, the people involved will support you, nurture you, find opportunities for you to have a break and ultimately allow you to be the best possible caregiver you can be.

To find a support network near you begin with:

Local churches

Hospitals

Chapters of various organizations such the Alzheimer’s Association, Cancer Centers, and other diseases

Centers for Independent Living (a list of VA CILs can be found Appendix 9)

Local Area Agency on Aging

ElderCare Online's Caregiver Support Network

**<http://www.ec-online.net/community/Activists/can.htm>**

To Locate Caregiver Support Groups by State, visit:

**<http://www.caregiver.com/regionalresources/states/VA/support/index.htm>**

There is also a bimonthly magazine you can subscribe to called *Today's Caregiver* **[www.caregiver.com](http://www.caregiver.com)**

## Chapter Fifteen: Oversight

Government and state oversight is critical to protect vulnerable populations in long-term care facilities; however, it can be difficult to find sound, objective advice when choosing providers, facilities and overall making decisions based on the information you are able to gather through various sources. Information comes from everywhere, word of mouth, authoritative figures, experts, professionals and unfortunately anyone with a computer and some level of writing ability can make their thoughts and personal experiences and opinions seem, at first glance, like credible information.

When something goes wrong, however, who is responsible? Who can you and your family call to ensure the people served are protected?

### What is an Ombudsman?

An **ombudsman** is a person that advocates for older people receiving long term care services, whether the care is provided in a nursing home, assisted living facility, or through community-based services and supports. Ombudsmen also provide families and the public with information, advocacy, and assistance to help resolve conflicts and concerns surrounding an individual's care.

Ombudsmen are made up of both paid staff and volunteers.

The directory containing all Virginia State Ombudsmen can be found here:

**<http://www.elderrightsva.org/va-ombudsman.aspx>**

or by calling

804-565-1600

1-800-552-3402

The Office of Licensure and Certification, also referred to as OLC, licenses and surveys nursing homes, home health agencies, hospice programs and hospitals to determine whether they are in compliance with all applicable laws and regulations. OLC receives and investigates complaints about the quality of care provided.

### Office of Licensure and Certification

Virginia Department of Health

9960 Mayland Drive, Ste. 401

Richmond, Virginia 23233

Phone: 804-367-2100

Toll free complaint line: 1-800-955-1819

**<http://www.vdh.state.va.us/OLC/>**

The Virginia Department of Social Services Division of Licensing Programs oversees Assisted Living Facilities and Adult Day Care Programs.

**Virginia Department of Social Services Division of Licensing Programs**

7 North Eighth Street

Richmond, VA 23219-3301

Phone: 804-726-7165

To find your regions office, visit:

**<http://www.elderrightsva.org/regional-regulation.aspx>**

Note, before filing a complaint, it is very important that you familiarize yourself with the rights that apply to your state. Keep in mind that many states also have their own regulations and laws in place and that the federal regulations may overlap. Federal and state nursing home regulations are enforced through regular inspections, usually occurring every year.

The Virginia State regulations for each kind of facility can be found by visiting:

**<http://www.elderrightsva.org/ombudsman-regulatory-agencies.aspx>**

*This chapter on Oversight compiled from the Office of the State Long Term Care Ombudsman website and the **ElderRightsva.org** website.*

## Chapter Sixteen: Nursing Home Transition

### **What is “nursing home transition?”**

Nursing home transition refers to the process that helps individuals living in nursing homes move back into a home in the community.

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. Another principle stems from a person with disabilities’ right, under the Americans with Disabilities Act (ADA), to live in the “most integrated setting” possible. The Supreme Court issued a ruling called the Olmstead decision to address this right. *You can read a complete overview of the ADA and the Olmstead Decision in Chapter 6.*

### **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.

You can also 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 Center for Independent Living (CIL).

### **What does the nursing home transition process involve?**

**1) Determining your eligibility and conducting your assessment** – The first steps in nursing home transition involve making sure you are eligible for services. If you are told you are not eligible, ask 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. 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 wherever possible. This helps make sure that 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.

Participate as actively as you can in the assessment process. Remember that you are the best advocate for yourself. 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.

**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 some of the areas that should be included.

### **Housing**

The goal is to find affordable, accessible housing in the community. This can prove to be a lengthy process and require your name be placed on long waiting lists. Persistency and patience will play a large role and often, getting your name on several waiting lists increases your chances of locating housing. In your transition plan you will need to address where you will obtain household goods, furniture and other necessities to set up your new home and you will need to ensure that the utilities are on when you move in. In some cases the following agencies may be of assistance.

Both of the following organizations maintain a directory of affordable and/or accessible housing in Virginia.

Virginia Housing Development Authority-(VHDA) - **[www.vhda.com](http://www.vhda.com)** and the Virginia Department of Housing and Community Development-(DHCD) **[www.dhcd.virginia.gov](http://www.dhcd.virginia.gov)**

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

### **Personal Assistance**

You will need to describe what assistance you need to carry out your daily activities such as bathing, dressing, shopping for groceries, doing the laundry. Will you hire your own personal care assistant (PCA) or use one provided through an agency? Will you or someone else cook for you, or will you receive home-delivered meals?

If needing assistance, obtain approval for the number of hours of care/service that you will need. Like housing, there can be very long waiting lists for services and supports provided through a Medicaid Waiver or other program. In Virginia, Medicaid Waivers and the State Personal Assistance Service (PAS) are the primary personal assistance providers. Many Centers for Independent

Living maintain a Personal Assistance Services (PAS) Registry which lists area personal care assistants/caregivers that can provide in-home healthcare. (See chapter 9 for more information on screening potential PCA's).

**Transportation** - Accessible and affordable transportation is critical when you live in the community. Get to know what transportation services are available in your area. Many transportation providers are limited by service area, hours, days of operation and distance traveled.

**Healthcare** - Do you already have a primary doctor in the community or do you need to find one? Some agencies offer assistance in getting to medical appointments. For information on getting to and from appointments, contact your Department of Family Services (DFS). If traveling to a doctor's office will be difficult, you may be able find a doctor that makes 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 to come to your new location in advance.

**Medication** - Ensure that 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 prescription assistance programs to help cover the costs. In addition to paying for medications, how will you receive your medications? There are some pharmacies that will deliver and if they do, make the necessary arrangements.

**Home Modification, Assistive Technology (AT) and Durable Medical Equipment (DME)** - What do you need in order to live comfortably in your home and to function as independently as possible? In Virginia, some funding is available through the Virginia Department of Housing and Community Development (DHCD) at [www.dhcd.virginia.gov](http://www.dhcd.virginia.gov) if you qualify. There may also be various grants and low-interest loans available for purchasing equipment. Review Appendix 1 for information about AT and DME.

**Finances** - As you move back into the community, taking care of your finances will become very important. Consider the following:

- Applying for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). If you have SSI, notify the Social Security Administration to ensure they are aware of your living arrangements

- which may increase payments to you because you no longer live in a nursing home. **www.ssa.gov**
- Setting up a monthly budget
  - Applying for 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. **www.cms.gov**
  - Applying for food stamps, utility assistance or other supplemental benefits as needed.

Note: The Supplemental Security Income (SSI) program pays benefits to disabled adults who have limited income and resources. SSI benefits also are payable to people age 65 and older without disabilities who meet the financial requirements. Social Security Disability Insurance (SSDI) is a monthly benefit for people who have worked previously and paid taxes. SSDI benefits are paid to people who can no longer work due to their disability regardless of age. You can start your application on line at the Social Security Administration’s website. There are also online checklists to ensure you meet all the application requirements before starting, and to ensure you have all the personal documents they will require.

Visit **www.ssa.gov** for more information.

You will also need to fill out *change of address forms* to ensure important documents are not held up in the transitioning process. You can change your address online through the United States Post Office website (small fee involved) or by visiting your local post office to ensure your address is changed with all the appropriate agencies, visit:

**[http://www.usa.gov/Citizen/Services/Address\\_Changes.shtml](http://www.usa.gov/Citizen/Services/Address_Changes.shtml)**

**Roles of Family and Friends** - Gather your “circle of support” or form one to help support you once you are back in the community. A good support system with family, friends, neighbors or others you know can make your transition much 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 try to become active beforehand.

Participate actively in creating your transition plan! Take the lead if possible and refer to Chapter 13 which overviews *How to Advocate for Yourself*. Once the plan is completed, create a checklist and schedule. Also list which people are

responsible for various tasks and their numbers so everything you need is centrally located.

**Implementing Your Plan** - At this point in the nursing home transition process you, your transition coordinator, other agencies, and anyone else you have asked to join you will need to work together to make the move happen. Where possible, you should direct your plan as much as possible, making the calls, requesting the information and conducting research, following up, submitting applications, etc. Do not be afraid to ask for help, however, the more responsibility you can take in your transition process, the better self advocate you will become meeting future needs after the move.

While waiting for responses, put that time to good use, developing your support system, making follow-up phone calls, and connecting with the community. You may wish to learn more or brush up on independent living skills through your local Center on Independent Living (CIL). You can also learn more about locating, hiring, maintaining and firing personal care assistants through your local CIL.

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. A detailed plan of care is vitally important before leaving the facility. Success in transition is most probable when your independent living needs have been met.

**Types of Residences** - If possible, move to a “qualified residence.” A qualified residence is a home that you or your family member owns or leases; 2) an apartment with an individual lease, with lockable entrances and exits, that includes living, sleeping, bathing and cooking areas over which you or your family has control; or 3) a residence in a community-based residential setting in which no more than four (4) unrelated individuals reside.

### **Post transition**

You should always feel free to call your transition coordinator with any questions or concerns about follow-up supports. In Virginia your local ombudsman is available if you have any concerns even when living outside a nursing home. An Ombudsman provides advocacy, information, and assistance to persons in Virginia whether in nursing homes, assisted living facilities, and through community-services in their own homes. A full list of Ombudsmen in Virginia is available at [www.elderrightsva.org](http://www.elderrightsva.org)

### **Can Money Follows the Person (MFP) Demonstration Project help me?**

Virginia is one of 31 states taking part in the federal grant program entitled, “Money Follows the Person” (MFP). If you are eligible, MFP provides funding to assist residents moving from institutions to the community. This would assist with the security deposit; first month’s rent, setting up utilities, and other items such as furniture.

To participate in the MFP project, you must:

- Have lived in a nursing facility, an intermediate care facility for individuals with mental retardation/intellectual disabilities, or a long-stay hospital licensed in Virginia, for six (6) consecutive months. This time can include any periods of hospitalization;
- Be a resident of the Commonwealth of Virginia;
- Be Medicaid eligible for at least one month at the time of discharge;
- Be qualified for one of the following waiver programs:
  - Elderly or Disabled with Consumer-Direction (EDCD) Waiver,
  - Individual and Family Developmental Disabilities Support (DD) Waiver,
  - HIV/Aids (AIDS) Waiver
  - Mental Retardation (MR, no called the ID) Waiver, and
  - Technology Assisted (TECH) Wavier

Since October 1, 2010, the staff and personnel that work in Medicaid and/or Medicare certified Skilled Nursing Facilities/Nursing Facilities (SNFs/NFs) were required to begin asking residents the following question every six months: “Do you want to talk with someone about the possibility of returning to the community?” as part of the MDS 3.0 Section Q.

If the response is “yes,” the facility staff will contact the designated **Local Contact Agency (LCA)**. LCA’s assist the resident and the SNF/NF by talking to the resident (and/or resident representative) and providing information about home and community-based services (HCBS) and other long-term care supports available in the community.

A complete list of LCAs in Virginia is attached in Appendix 11. After the LCA is aware that the resident would like to reintegrate into the community setting, the LCA must then provide information on local Transition Coordination Providers (TCPs) to be a part of the transition planning process. A Complete list of TCPs in Virginia is also listed in Appendix 11. As part of their efforts to prepare for successful implementation of the MDS 3.0 Section Q, states have named a State level point of contact (POC) to be available to address questions and concerns of organizations, providers and other stakeholders. To find the current state level POC

call, 804-225-2984 or visit the Department of Medical Assistance Services website:  
**[www.dmas.virginia.gov](http://www.dmas.virginia.gov)**

Additional Information on Money Follows the Person (MFP), is available at these  
websites: **[www.olmsteadva.com/mfp](http://www.olmsteadva.com/mfp)** and  
**<http://easyaccess.virginia.gov>**

*This chapter on Nursing Home Transition derived from **The ABCs of Nursing Home Transition: An Orientation Manual for New Transition Facilitators** © 2006 by the IL Net National Training and Technical Assistance Program at Independent Living Research Utilization and the National Consumer Voice for Quality Long Term Care.*

## APPENDIX

### Resources

Appendix 1: Glossary

Appendix 2: National Organizations

Appendix 3: Sample letter requesting housing modification

Appendix 4: Self-Direction - Is it Right for You?

Appendix 5: Guidelines for Presenting a Problem, developed by PHI

Appendix 6: Coaching-based Communication, developed by PHI

Appendix 7: Additional agencies to contact for compliance issues

Appendix 8: Additional Sources, Websites and Publications

Appendix 9: Virginia Centers for Independent Living

Appendix 10: My Personal Directions for Quality Living

Appendix 11: Virginia Listing for Local Contact Agencies (LCA's)  
and Transition Coordination Planners (TCP's)

Appendix 12: Residents' Rights

## Appendix 1: Glossary

**Adult day services** - 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 such as medical monitoring, medication administration and, in some cases, skilled nursing services, are provided in addition to social, recreational and therapeutic activities.

**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 the additional structured activities of this level of care. This service includes diagnostic, medical, psychiatric and psychosocial methods of treatment.

**Day habilitation:** is 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 (AT):** (also referred to as Adaptive Technology) is the broad term used to describe any assistive, adaptive or rehabilitative devices for people with disabilities. AT helps individuals with disabilities complete tasks they might not have been able to prior to the technology being in place and overall promotes greater independence.

**Physical aids:** examples include canes, walkers, built-up utensils, computer keyboard aid, transfer bench, portable commode - *(also referred to as mobility aides, aides to daily living or assistive technology (AT))*

**Cognitive aids:** examples include cognitive software, personal digital assistants (PDA) with reminder alarms linked to calendars, pillbox reminders; electronic memory aids

**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

**Communication aids:** examples include communication boards, mouth sticks; text-to-speech devices *(could also be referred to as assistive technology (AT))*

**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. *(Also referred to as personal care assistance (PCA), personal assistant (PA), home health aide, or caregiver).*

**Behavior consultation services** - also referred to as behavior management/behavior program and counseling - Training, supervision or assistance in learning how to behave 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.

**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.

**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.

**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 (DME)** - Devices and appliances such as wheelchairs, walkers, hospital beds, quad cane/cane and transfer lifts that assist a person with a medical need or increase their mobility and independence.

**Hoyer, Hydraulic or Barrier Free Lift** – A mechanical aid that assists with transferring a person from a wheelchair to a bed, chair, toilet or any other place. Note: A “sling” is needed to utilize with the Hoyer lift.

**Sling** – A device used often in conjunction with a Hoyer Life (also called a hydraulic or barrier free lift). It is made of strong, durable mesh netting materials and is used for an individual with a mobility disability to sit in to be able to transfer the individual from one place to another. The sling has hooks usually at four corners which then hook on to the lift so that the person can be lifted and transferred. (*See where to obtain this kind of equipment, below.*)

### ***Where to borrow/obtain Durable Medical Equipment and Assistive Technology***

There is often an association, organization or agency for every type of disability. These organizations assist persons diagnosed with the disability they cater to and assist him/her with referrals, services, funding for equipment and have other information that is vital to the consumers they serve. Moreover, they often have **loan closets** where they store numerous donated items for use such wheelchairs, lifts, canes, walkers, portable ramps, and many other types of equipment. There are many agencies (as there are disabilities). The larger organizations have local-area chapters. If you are in need of equipment, visit the website and simply enter your zip code to locate the nearest local chapter.

**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 .

**Guardianship** – A person who is legally entrusted to manage someone else’s affairs

**Legal Guardian** – A person appointed by the Circuit court who is legally responsible for managing the legal affairs of another individual.

**Conservator** – A person appointed by the Circuit court who is legally responsible for managing the financial affairs of another individual.

**Attorney-in-Fact** - An agent or representatives with the authority to do some particular act as authorized by a power-of-attorney document.

**Authorized Representative** - A person age 18 or older who is authorized in writing to conduct business and make decisions on your behalf, for example, applying for services on your behalf.

**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 their 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.

**Legal assistance** - Advice and representation for certain legal matters such as government program benefits, tenant rights and consumer problems.\*

**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** - 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 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.

**Personal Care Assistance** - with activities of daily living often provided through an agency.

**Personal Emergency Response System** - An electronic device that allows a person to call for help in an emergency. This can be a small device worn around the individual's neck or as a bracelet on their arm.

**Recovery groups** - 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.

**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 brief 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.

**Supported living services** - Services to assist a person to live on their own in the community. Services may include helping a person to develop skills needed to take care of a home, take care of themselves, and get around in the community.

**Support groups** - 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.

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: <http://www.power2u.org/> or call 1-800-power2u

**Telephone reassurance** - Regular contact and safety checks by trained volunteers.

**Therapies** - physical, occupational, respiratory, speech/language, cognitive, behavioral, vocational, recreational, restorative therapies are outlined here

**Behavioral therapy** - a form of psychotherapy that uses learning techniques to change behavior.

**Cognitive therapy** - a form of psychotherapy used to change a person's way of thinking and behavior.

**Occupational therapy** - Assessment, treatment and training to increase a persons' ability to perform self-care and other activities in order to maximize independence and quality of life. May include adaptation of tasks or equipment.

**Physical therapy** - assessment, treatment and training to maintain or improve functioning such as strength, muscle tone and mobility.

**Respiratory therapy** - Assessment, treatment and management of breathing disorders.

**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).

**Speech/language therapy** - Assessment and treatment for speech and language communication disorders and swallowing problems.

**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.

**Universal Design** - is considered a way of ensuring that at the first stages of discussion, design, planning and building, environments, products and buildings are accessible for both able-bodied persons and persons with disabilities.

**Vocational training** - Training in the skills and knowledge needed to perform a particular job or trade.

*Glossary Terms are a compilation, excerpted from the National Consumer Guide (the National Consumer Voice for Quality Long Term Care) © 2010; Access Granted: Creating Access for Victims with disAbilities, a Guide for Service Providers © 2004; and the Center for Medicaid and Medicare Services Website.*

## Appendix 2: National Organizations

**National organizations – Remember most national organizations have area (local) chapters that may be located in your neighborhood or not from where you live.**

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: 1-866-403-3073

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 (232)-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 **http://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

Muscular Dystrophy Association - **www.mdausa.org**

1-800-572-1717

National Alliance on Mental Illness: advocates for people with mental illness

**www.nami.org**, 1-800-950-NAMI (6264)

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

The 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

National Multiple Sclerosis Society – **www.nationalmssociety.org**

1-800-344-4867

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

## 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 Approach<sup>SM</sup> to Supervision

Used with permission of the Paraprofessional Healthcare Institute, 2010.  
([www.PHInational.org](http://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 Paraprofessional Healthcare Institute, 2010.  
(www.PHInational.org)*



### **PHI Coaching Approach<sup>SM</sup> 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 compliance issues**

### **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:

**<http://www.theconsumervoice.org/ombudsman>** 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: <http://www.theconsumervoice.org/ombudsman> 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:

**<http://www.theconsumervoice.org/ombudsman>** 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 agencies 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 experienced by older adults, persons with disabilities, and their families.

To locate an elder law attorney in your area, go to:

**[www.naela.org/MemberDirectory/](http://www.naela.org/MemberDirectory/)**

### **Legal Services Corporation, Inc.**

Legal Services Corporation programs offer a wide range civil legal assistance to those who meet certain financial criteria. For more information, go to **<http://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: **<http://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. Use the Elder Care Locator, **[eldercare.gov](http://eldercare.gov)** or the Administration on Aging's website **[www.aoa.gov](http://www.aoa.gov)** to locate your local Area Agency on Aging office.

## **Appendix 8: Additional Sources, Websites and Publications**

### *Commonwealth Council on Aging Overview*

<http://vda.virginia.gov/pdfdocs/CCoA-Overview.pdf>

### *Virginia Department of Social Services*

<http://www.dss.virginia.gov/facility/search/alf.cgi->

### *Universal Design*

<http://www.arlingtonva.us/departments/HumanServices/AgingDisability/page70248.aspx->

### *A Guide for Long Term Care Services in Virginia*

[http://dmasva.dmas.virginia.gov/Content\\_atchs/ltc/ltc-guide\\_srvcs.pdf](http://dmasva.dmas.virginia.gov/Content_atchs/ltc/ltc-guide_srvcs.pdf) -

### *Department of Medical Assistance Services*

[http://dmasva.dmas.virginia.gov/Content\\_pgs/ltc-home.aspx](http://dmasva.dmas.virginia.gov/Content_pgs/ltc-home.aspx)

### *Senior Citizens Handbook ~ 2009 Edition*

<http://www.vsb.org/docs/conferences/senior-lawyers/SCHandbook09.pdf>

### *Virginia Association of Free Clinics*

<http://www.vafreeclinics.org/find-a-free-clinic.asp>

*Locate a free clinic*

<http://www.vafreeclinics.org/find-a-free-clinic.asp>

### *Prescription Drug Assistance Programs Available in Virginia*

<http://www.vda.virginia.gov/pdfdocs/PrescriptionDrugAssistanceProgramsInVA.pdf>

### *Easy Access Virginia*

[www.easyaccess.virginia.gov](http://www.easyaccess.virginia.gov)

### *Senior Navigator*

[www.seniornavigator.com](http://www.seniornavigator.com)

### *The National Clearinghouse for Long Term Care Information*

[http://www.longtermcare.gov/LTC/Main\\_Site/Paying\\_LTC/Costs\\_Of\\_Care/Costs\\_Of\\_Care.aspx](http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx)

### *Questions to Ask When Looking at Assisted Living Facilities Checklist*

[http://www.helpguide.org/elder/assisted\\_living\\_facilities.htm](http://www.helpguide.org/elder/assisted_living_facilities.htm)

***Housing and Long Term Care***

[www.seniornavigator.org](http://www.seniornavigator.org) – search under “Housing and Long Term Care”

***Virginia Department for the Aging***

<http://www.vda.virginia.gov>

***Virginia Policy on Cost Sharing for Public Programs***

<http://www.vda.virginia.gov/pdfdocs/Cost%20Sharing-Fee%20for%20Service%20State%20Policy.pdf>

***Virginia Department of Health - Laws, Regulations and guidelines***

<http://www.vdh.virginia.gov/OLC/Laws/index.htm>

***Caregiver Today magazine***

[www.caregiver.com](http://www.caregiver.com)

***Easy Access Virginia - Caregiver Support***

<http://www.easyaccess.virginia.gov/caregiversupport.shtml>

## **Appendix 9: Virginia Association of Centers for Independent Living**

### **Virginia Association of CILs (VACIL)**

1502B Williamson Rd. NE  
Roanoke, VA 24012-5100  
Phone: (540) 342-1231  
TTY: (540) 342-1231  
FAX: (540) 342-9505  
E-mail: [info@vacil.org](mailto:info@vacil.org)  
Website: <http://www.vacil.org>

### **Access Independence, Inc. (AI)**

324 Hope Dr.  
Winchester, Virginia 22601  
(540) 662-4452 V  
(540) 722-9693 TTY  
(540) 662-4474 FAX  
Center's e-mail: [askAI@accessindependence.org](mailto:askAI@accessindependence.org)  
<http://www.accessindependence.org>

### **Appalachian Independence Center (AIC)**

230 Charwood Dr.  
Abingdon, Virginia 24210  
(276) 628-2979 V  
(276) 676-0920 TTY  
(276) 628-4931 FAX  
Center's e-mail: [aicadmin@ntelos.net](mailto:aicadmin@ntelos.net)

### **Blue Ridge Independent Living Center (BRILC)**

1502B Williamson Road NE  
Roanoke, Virginia 24012  
(540) 342-1231 V/TTY  
(540) 342-9505 FAX  
Center's e-mail: [brilc@brilc.org](mailto:brilc@brilc.org)

### **Clinch Independent Living Services (CILS)**

1139C Plaza Drive  
Grundy, VA 24614  
(276) 935-6088 V  
(800) 597-2322 Toll Free  
(276) 935-4348 TTY  
(276) 935-6342 FAX

Center's e-mail: [cils@vmmicro.net](mailto:cils@vmmicro.net)

**Disability Resource Center (DRC)**

409 Progress Street  
Fredericksburg, Virginia 22401  
(540) 373-2559 V  
(540) 373-5890 TTY  
1 (800) 648-6324 Voice or Relay  
(540) 373-8126 FAX  
Center's e-mail: [drc@drccil.org](mailto:drc@drccil.org)

**Eastern Shore Center for Independent Living (ESCIL)**

4364 Lankford Highway, Suite A  
Exmore, VA 23350  
(757) 414-0100 V  
1(800) 324-2988  
(757) 414-0080 TTY  
(757) 414-0205 FAX

**Endeppendence Center, Inc. (ECI)**

6300 E. Virginia Beach Boulevard  
Norfolk, Virginia 23502  
(757) 461-8007 V  
(757) 461-7527 TTY  
(757) 455-8223 or (757) 461-5375 FAX  
Center's e-mail: [Ecinorf@endeppendence.org](mailto:Ecinorf@endeppendence.org)

**Endeppendence Center of Northern Virginia (ECNV)**

2300 Clarendon Blvd., Suite 305  
Arlington, Virginia 22201  
(703) 525-3268 V  
(703) 525-3553 TTY  
(703) 525-3585 FAX  
Center's e-mail: [info@ecnv.org](mailto:info@ecnv.org)

**Indeppendence Empowerment Center (IEC)**

9001 Diggs Rd., Ste. 103  
Manassas, VA 20110  
(703) 257-5400 V/TTY  
(703) 257-5043 FAX  
Center's e-mail: [Info@ieccil.org](mailto:Info@ieccil.org)

**Indeppendence Resource Center (IRC)**

815 Cherry Avenue  
Charlottesville, VA 22903  
(434) 971-9629 V/TTY  
(434) 971-8242 FAX

**Junction Center for Independent Living (JCIL)**

Mail: P.O. Box 1210, Norton, VA 24273  
Physical: 147 Plaza Rd SW,  
Wise Cnty Plaza Shopping Ctr #229 Wise, VA 24293  
(276) 679-5989 V/TTY or  
(276) 679-5988  
(276) 679-6569 FAX  
jcil1@junctioncenter.org

**Lynchburg Area Center for IL (LACIL)**

500 Alleghany Ave., Suite 520,  
Lynchburg, VA 24501  
(434) 528-4971 V  
(434) 528-4972 TTY  
(434) 528-4976 FAX

**Peninsula Center for Independent Living (PCIL)**

2021-A Cunningham Drive, Suite 2  
Hampton, VA 23666  
Ralph Shelman, Executive Director  
(757) 827-0275 V  
(757) 827-8800 TTY  
(757) 827-0655 FAX  
Center's e-mail: iepcil@hvacil.org

**Piedmont Independent Living Center (PILC)**

1045 Main St.  
Danville, VA 24541  
Clarence Dickerson, Executive Director  
(434) 797-2576 V  
(434) 797-2568 FAX  
Center's e-mail: pilc@gamewood.net

**Resources for Independent Living, Inc. (RIL)**

4009 Fitzhugh Ave.  
Richmond, VA 23230  
(804) 353-6503 V  
(804) 353-6583 TTY  
(804) 358-5606 FAX

**Valley Associates for Independent Living (VAIL)**

205 B S. Liberty St.  
Harrisonburg, VA 22801  
Marcia DuBois, Executive Director  
(540) 433-6513 V  
(540) 438-9265 TTY  
(540) 433-6313 FAX  
Center's e-mail: VAIL@govail.org

**Satellite/Branch/Associated Offices**

**AIC Branch Office - Bristol**

P.O. Box 16744  
Bristol, VA 24209  
(276) 466-4437 V/TTY/FAX  
E-mail: Aicbristol@bvunet.net

**AIC Branch Office - Wytheville**

P.O. Box 1073  
Wytheville, VA 24382  
(276) 228-8765 V/TTY  
(276) 228-0508 FAX

**AIC Branch Office - Galax**

104 Rex Lane  
Galax, VA 24333  
(276) 236-6055 V/TTY  
(276) 236-4700 FAX  
E-mail: Aic.galax@embarqmail.com

**BRILC - Alleghany Area Branch Office**

Alleghany Regional Hospital  
P.O. Box 7  
Low Moor, VA 24457  
540-862-0252 (v/tty/fax)

**BRILC - New River Valley Satellite**

210 S. Pepper St. Suite D  
Christiansburg, VA 24073  
540-381-8829, 540-381-9149 (v/tty)  
540-381-8833 FAX  
E-mail: rwright@brilc.org or sroberson@brilc.org

**CILS - Tazewell Branch Office**

559 W. Main St.  
Tazewell, VA 24651  
(276) 988-0503 V  
(276) 988-1883 TTY  
(276) 988-0603 FAX

**ECNV - Loudoun ENDependence (LEND)**

44121 Harry Byrd Hwy #240  
Ashburn, VA 20147-5668  
(571) 291-9550 PHONE/VOICE  
571-291-9552 FAX

## Appendix 10: My Personal Directions for Quality Living

I am recording my personal preferences and information about my self, in case I need long-term care services in my home or in a long-term care facility. I hope this information will be useful to those who assist me. Please always talk to me about my day-to-day life to see what it is that I want and enjoy.

The information below may provide some help in understanding me and in providing my care.

To my caregivers paid and unpaid:

**Name:** \_\_\_\_\_

**Completion Date:** \_\_\_\_\_

### My Personal Directions for Quality Living

I want my caregivers to know:

The way I like to awaken & begin my day:

The way I relax and prepare to sleep at night:

Activities I enjoy:

Things that I would like to have in my room:

Foods that I enjoy:

Things I do not like:

I become anxious when:

Things that calm or soothe me:

Things that make me laugh:

Religious Preferences:

Other:

At the end of my life, I would like:

For more information about me please talk to:

*My Personal Directions for Quality Living is taken from The National Consumer Voice for Quality Long Term Care's website formerly the National Citizens' Coalition for Nursing Home Reform (NCCNHR) © 2009.*

The National Consumer Voice for Quality Long-Term Care  
1001 Connecticut Avenue, NW  
Suite 425  
Washington, DC 20036  
**[www.nccnhr.org](http://www.nccnhr.org)**

*The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.*

## **Appendix 11: Virginia Listing for Local Contact Agencies (LCA's) and Transition Coordination Planners (TCP's)**

Agency contacts is constantly changing, thus in an effort to ensure this guide provides the most current information you can find your **Local Contact Agency's** (LCA's) Staff Information at the Virginia Department for the Aging's website [www.vda.virginia.gov](http://www.vda.virginia.gov) or

[www.vda.virginia.gov/localcontactagency.asp](http://www.vda.virginia.gov/localcontactagency.asp)

Click on "spreadsheet"

Your local **Transition Coordination Planners** (TCP's) can be found by visiting: [www.olmsteadva.com/mfp](http://www.olmsteadva.com/mfp)

On the right hand menu, click on "**Medicaid-Enrolled Providers for Transition Coordination**"

## Appendix 12: Residents' Rights

**Residents' Rights** are guaranteed by the federal 1987 Nursing Home Reform Law. The law requires nursing homes to "*promote and protect the rights of each resident*" and places a strong emphasis on individual dignity and self-determination. Nursing homes must meet federal residents' rights requirements if they participate in Medicare or Medicaid. Some states have residents' rights in state law or regulation for nursing homes, licensed assisted living, adult care homes, and other board and care facilities. A person living in a long-term care facility maintains the same rights as an individual in the larger community.

### **Residents' Rights Guarantee Quality of Life**

The 1987 Nursing Home Reform Law requires each nursing home to care for its residents in a manner that promotes and enhances the quality of life of each resident, ensuring *dignity, choice, and self-determination*.

All nursing homes are required "to provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care that... is initially prepared, with participation, to the extent practicable, of the resident, the resident's family, or legal representative." *This means a resident **should not decline in health or well-being as a result of the way a nursing facility provides care.***

The 1987 Nursing Home Reform Law protects the following rights of nursing home residents:

### **The Right to Be Fully Informed of**

- Available services and the charges for each service
- Facility rules and regulations, including a written copy of resident rights
- Address and telephone number of the State Ombudsman and state survey agency
- State survey reports and the nursing home's plan of correction
- Advance plans of a change in rooms or roommates
- Assistance if a sensory impairment exists
- Residents have a right to receive information in a language they understand  
(Spanish, Braille, etc.)

### **Right to Complain**

- Present grievances to staff or any other person, without fear of reprisal and with prompt efforts by the facility to resolve those grievances
- To complain to the ombudsman program
- To file a complaint with the state survey and certification agency

### **Right to Participate in One's Own Care**

- Receive adequate and appropriate care

- Be informed of all changes in medical condition
- Participate in their own assessment, care-planning, treatment, and discharge
- Refuse medication and treatment
- Refuse chemical and physical restraints
- Review one's medical record
- Be free from charge for services covered by Medicaid or Medicare

### **Right to Privacy and Confidentiality**

- Private and unrestricted communication with any person of their choice
- During treatment and care of one's personal needs
- Regarding medical, personal, or financial affairs

### **Rights During Transfers and Discharges**

- Remain in the nursing facility unless a transfer or discharge:
  - (a) is necessary to meet the resident's welfare;
  - (b) is appropriate because the resident's health has improved and s/he no longer requires nursing home care;
  - (c) is needed to protect the health and safety of other residents or staff;
  - (d) is required because the resident has failed, after reasonable notice, to pay the facility charge for an item or service provided at the resident's request
- Receive thirty-day notice of transfer or discharge which includes the reason, effective date, location to which the resident is transferred or discharged, the right to appeal, and the name, address, and telephone number of the state long-term care ombudsman
- Safe transfer or discharge through sufficient preparation by the nursing home

### **Right to Dignity, Respect, and Freedom**

- To be treated with consideration, respect, and dignity
- To be free from mental and physical abuse, corporal punishment, involuntary seclusion, and physical and chemical restraints
- To self-determination
- Security of possessions

### **Right to Visits**

- By a resident's personal physician and representatives from the state survey agency and ombudsman programs
- By relatives, friends, and others of the residents' choosing
- By organizations or individuals providing health, social, legal, or other services
- Residents have the right to refuse visitors

### *Advocates for Residents Rights*

Where do you go for help if you're concerned a facility is not guaranteeing the rights of residents? Contact your local or state long-term care ombudsman or your state's citizen advocacy group. The Long Term Care Ombudsman Program is required by federal law to promote and protect the rights of residents in licensed long-term care facilities. The national Consumer Voice for Quality Long Term Care can help you locate advocates and ombudsmen in your area. Visit our website: [www.nccnhr.org](http://www.nccnhr.org) to view a map listing ombudsmen and citizen advocacy groups nationwide.

#### **Right to Make Independent Choices**

- Make personal decisions, such as what to wear and how to spend free time
- Reasonable accommodation of one's needs and preferences
- Choose a physician
- Participate in community activities, both inside and outside the nursing home
- Organize and participate in a Resident Council
- Manage one's own financial affairs

More fact sheets and publications on how to get good care in nursing homes are available by calling NCCNHR at 202.332.2275 or visiting our website at **[www.nccnhr.org](http://www.nccnhr.org)**

**Nursing Homes: Getting Good Care There, \$11.95**

**Fact Sheets:**

*A Consumer Guide to Choosing a Nursing Home:  
Restraints Access and Visitation Involuntary Transfer and Discharge*

*Residents' Rights is taken from The National Consumer Voice for Quality Long Term Care's website formerly the National Citizens' Coalition for Nursing Home Reform (NCCNHR) © 2009.*

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*The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.*