
CAREGIVER GUIDE

ARE YOU A CAREGIVER?

If you provide any of the following for another person you are probably a caregiver:

- ▲ Help with paying bills
- ▲ Help with household chores such as shopping, cooking, laundry, and/or home maintenance
- ▲ Help with personal care (dressing, bathing, feeding, toileting)
- ▲ Help moving around the house
- ▲ Help with transportation
- ▲ Help with taking medications
- ▲ Help with making or receiving telephone calls
- ▲ Help arranging/coordinating outside services
- ▲ Companionship by personal visits or telephone

Nationwide, one out of every four persons is providing care for a relative or friend, age 50 or older. You're part of a very important and diverse group. Caregivers can live with their relative or provide long-distance caregiving. Some family caregivers are employed and might also be juggling the care of a parent and children. Caregiving demands time, resources, love and energy. While there may be no one place that can meet all of your needs, there are valuable resources who can help. Roanoke's LOA—Area Agency on Aging (see Resource Information on page 5) and SeniorNavigator (www.SeniorNavigator.org) are two great places to start.

The Partnership for Employed Caregivers is a network of employers and others in the Roanoke Valley who have designed this Toolkit to help you navigate the caregiving maze.

CAREGIVER SUPPORT HISTORY

Caregiver Initiatives

While Virginia has offered services to caregivers for a number of years, nationally there was no comprehensive program to assist family caregivers. However, in 2000 the National Family Caregiver Support Act helped fill this gap. This act authorized a variety of services to support the important work of family caregivers.

Through this federal legislation, Virginia has started a new effort to assist family members and friends in their caregiving roles.

Through the Virginia Caregiver Support Program and SeniorNavigator, public and private organizations are partnering to provide information and services to family caregivers and to educate and train the professionals who work with them.

A 1997 survey, Family Caregiving in the United States, sponsored by the National Alliance for Caregiving and AARP, found that some 14.4 million workers are caring for elderly relatives, with one in five reporting that balancing work and family life is their greatest difficulty.

AREA AGENCIES ON AGING (AAAs)

AAAs provide a link to in-home services, or services that provide temporary relief for persons caring for an individual who is ill, injured or frail (also know as respite services). These services can be provided at home, in an adult day care center or other setting.

Other services include:

- ▲ home-delivered meals
- ▲ congregate meals
- ▲ adult day programs
- ▲ care management
- ▲ in-home aide service
- ▲ information and assistance
- ▲ transportation to vital appointments
- ▲ health promotion
- ▲ home-improvement
- ▲ ombudsman services
- ▲ abuse, neglect and exploitation education and awareness.

The availability of these services varies in each AAA. Contact Roanoke's LOA Area Agency on Aging at 540-345-0451 or SeniorNavigator at 866-393-0957 or visit www.SeniorNavigator.org.

SUPPORT GROUPS

Support groups can be found across the region. Many are designed for caregivers of people with specific diseases. *The Neighbors section of The Roanoke Times*, www.councilofcommunityservices.org and www.SeniorNavigator.org have listings of support groups. (See Resources page for more information.)

Support Groups allow caregivers to:

- ▲ discuss their concerns and frustrations
- ▲ receive and offer emotional encouragement
- ▲ share practical solutions to caregiving situations

Individual instruction in caregiving is available through the American Red Cross for qualified individuals.

THE FOLLOWING CHART CAN HELP YOU DEVELOP A CAREGIVING PLAN:

My Relative	What They Need	Refer To <i>Senior Quick Guide</i>
...really needs to get out and socialize	Socialization / Volunteering Programs	Life Enhancement, p. 4
...is grieving over the death of a loved one	Bereavement Support – Dealing with the normal grieving process	Hospices & Grief / Loss Support, p. 2
...cannot drive or use public transportation and taxicabs are too expensive	Transportation for older persons	Transportation, p. 5
...is unable to remain in his/her present housing	Special housing options are available for the elderly	General Caregiving Resources, p. 1 Housing, p. 2-3
...needs help with food preparation and/or housekeeping and/or laundry	Homemaker Services – Non-medical service to help an older person remain in the home	Home Care Needs, p. 2
...needs help with personal care (bathing, dressing, grooming and toileting)	Home Health or Personal Care Aide – Personal and basic health care provided by a specialist	Home Care Needs, p. 2
...needs skilled nursing, occupational, speech or physical therapy	Skilled nurse or therapist	Medical Care, p. 4-5 Nursing Homes, p. 3
...really needs 24-hour supervision even though he/she fights it	Private Home Care, Nursing Home Care – 24-hour medical supervision	Mental Health Resources, p. 5 Legal Services, p. 3 Medical Care, p. 4-5 General Caregiving Resources, p. 1
...cannot be left alone during the day	Monitoring / Safety – Volunteers who visit with the elderly or a facility which provides constant supervision	Respite & Day Care, p. 5 General Caregiving Resources, p. 1
...has health care costs which are overwhelming	Reducing cost of quality health care	Miscellaneous, p. 5-6 General Caregiving Resources, p. 1
...is depressed / suspicious / angry all the time, just sits	Talk with primary care physician. A mental health evaluation may be necessary to assess psychological stability	Mental Health Resources, p. 5
...has a terminal illness and wants to die at home	Hospice – Medical and social services designed for terminally ill patients	Hospice & Grief / Loss Support, p. 2

FINANCIAL / LEGAL RESOURCES

Legal Services:

Many older people experience problems that threaten their autonomy, dignity, health, income, rights, and security. Many of these problems can be avoided or remedied by legal intervention. See Resource Information, page 7.

Advance Medical Directives:

Advance care planning includes deciding about the kind of health care you want at the end of life. Advance health care directives are legal documents that you share with your health care providers and appropriate family members to make sure you get the kind of treatment you want if you can't speak for yourself. End-of-Life Care Partnership of the Roanoke Valley provides a step-by-step guide to advance care planning. The workbook, Tool Kit for Health Care Advance Planning, is designed to help individuals and families plan for the care they want at the end of life.

According to AARP, 20-30% of all adults are estimated to have advance directives, yet in nearly 35% of those cases, the directives cannot be found when needed.

While numerous forms and resources for advance medical planning are available at libraries and on-line, many attorneys and medical providers prefer utilization of an attorney experienced in these areas. Forms which may be specific to other states may not be interpreted by a Virginia provider or court in the way you intend. An attorney can help ensure that your wishes are properly stated, and that the persons you designate to make your decisions are appropriate for your situation.

Other valuable resources can be found at:

www.agingwithdignity.org: information on ordering *Five Wishes*, an advance medical directive form that gives persons the opportunity to elaborate on how they want to be treated at the end of life. *Five Wishes* is accepted in Virginia.

www.partnershipforcaring.org: provides access to advance medical forms specific to each State and related end of life care planning information.

HEALTH INSURANCE INFORMATION

Medicare:

Most adults age 65 and older and certain disabled adults under age 65 receive Medicare health insurance. It is divided into three parts: Hospital Insurance (Part A), Medical Insurance (Part B) and beginning January 1, 2006, Prescription Drug Plan (Part D).

Medicare, Part A:

Helps pay for care in a hospital or skilled nursing home, limited home health services and hospice care. There are usually no premiums for Medicare Part A, but there is a significant deductible per benefit period (for a hospital stay of 1-60 days) with additional significant co-pays for each day in the hospital for 61-90 days or 91-150 days.

Medicare, Part B:

Helps pay for doctor's services, outpatient hospital care and other medical services that Part A doesn't cover. There is a monthly premium for Medicare Part B, an annual deductible and a 20% coinsurance payment after the yearly deductible for all Medicare Part B approved services.

Medicare, Part D (begins January, 1, 2006):

Helps pay for prescription medication. There is a monthly premium, an annual deductible and coinsurance payment for all medicine covered by a plan selected by the Medicare beneficiary. For some low income individuals there is "help" available.

Many people still think that Medicare pays for long-term Nursing Home care. The reality is that there is no long-term non-medical care coverage under Medicare. Medicare does provide limited short-term care after a hospital stay and home health care services only under certain conditions. Coverage is not available for long-term chronic care. Medicare does provide a hospice benefit for persons with a terminal diagnosis. The benefit covers all non-curative services and medications administered under hospice.

Medicare also provides a hospice benefit for persons with limited life expectancy. Hospice covers medications related to the life-limiting diagnosis, nursing, home health aides, medical equipment, social work and chaplain services. For more information on Medicare coverage and benefits, call LOA Area Agency on Aging, or visit www.medicare.gov.

Medicaid:

Medicaid is a program that provides health care insurance for low-income older and disabled adults. It also covers nursing home care for eligible individuals. Contact an Elder Law attorney or Department of Social Services for eligibility information.

Private Insurance:

Since Medicare does not cover all health care costs, most Medicare beneficiaries have additional private coverage either through their former employers or with a Medicare Supplement policy. Additional long-term care insurance can be purchased to cover some of the costs of home care and nursing facility care. There are limits on both of these types of insurance, as well as state laws to protect the consumer. For insurance counseling and assistance, call the LOA Area Agency on Aging's Virginia Insurance Counseling and Assistance Program (VICAP).

Federal Tax Benefits:

In some circumstances, you may be able to claim a tax credit if you pay someone to care for your spouse or dependent who is not able to care for him/herself. The credit can be up to 30% of your expenses. For further information, contact the Internal Revenue Service online at www.irs.gov.

Assistance in Filing Tax Benefits:

AARP-Tax-Aid and Volunteer Income Tax Assistance (VITA) programs offer free assistance in preparing tax returns. In the Roanoke Valley, these services are currently arranged by LOA Area Agency on Aging in cooperation with AARP.

Family Medical Leave Act – FMLA

To qualify for eligibility, an employee must have worked at least 12 months, and during that 12 months have worked at least 1,250 hours, and your employer must employ at least 50 employees. Eligible employees are entitled to a total of 12 weeks of leave during a 12-month period for one or more of the following:

- ▲ Serious health condition of the employee
- ▲ Birth of a child
- ▲ Placement of a child for adoption or foster care
- ▲ Caring for a spouse, child, or parent with a serious health condition

AREA AGENCIES ON AGING

Regional Area Agencies on Aging

LOA Area Agency on Aging

Central office in Roanoke

540-345-0451

Serves 5th Planning District

Cities of Roanoke, Salem and Covington

Counties of Alleghany, Botetourt, Craig and Roanoke

New River Valley AAA

Central office in Pulaski

540-980-7720

Serves 4th Planning District

City of Radford

Counties of Floyd, Giles, Montgomery and Pulaski

Valley Program for Aging Services

Central office in Waynesboro

540-949-7141

Serves 6th Planning District

Cities of Buena Vista, Harrisonburg, Lexington, Staunton and Waynesboro

Counties of Augusta, Bath, Highland, Rockbridge and Rockingham

Central Virginia AAA

Central office in Lynchburg

434-385-9070

Serves 11th Planning District

Cities of Bedford and Lynchburg

Counties of Amherst, Appomattox, Bedford and Campbell

Southern Area Agency on Aging

Central office in Martinsville

276-632-6442

Serves 12th Planning District

Cities of Danville and Martinsville

Counties of Franklin, Henry, Patrick and Pittsylvania

RESOURCE INFORMATION

AARP, 866-296-2549 (Customer Service)

A membership organization for people 50 and over that provides information, education and advocacy on legislative, consumer and legal issues.

Visit: www.aarp.org/life

Adult Protective Services, Roanoke City 540-853-2591, Roanoke County/City of Salem 540-387-6087
Investigators are located throughout the state and work with agencies and family members to stop abuse, neglect and exploitation of older adults. Any person who has reason to suspect such abuse is mandated by law to report his/her concerns.

Alzheimer's Association, Roanoke Region, 540-345-7600 or 800-272-3900

Provides education and support for people diagnosed with Alzheimer's disease and other dementias and to their families and caregivers.

Visit: www.alzcvva.org

American Cancer Society, 540-344-8699, 800-227-2345

Dedicated to eliminating and preventing cancer through research, education, advocacy and service.

Visit: www.cancer.org

Blue Ridge Independent Living Center, 540-342-1231

Advocates for and supports persons with disabilities.

Visit: www.brilc.org

Carilion Center for Healthy Aging, 540-981-7653

Provides specialized geriatric expertise in assessment, medicine, psychiatry, nursing and nutrition. Serves as a resource for the region's aging population and their caregivers, as well as health care providers.

Visit: www.carilion.com and link to Center for Healthy Aging.

End of Life Care Partnership, c/o Good Samaritan Hospice, 540-776-0198, 888-466-7809

Provides education and resources on preparation for end of life.

Visit: www.roanokeendoflifecare.org

Health Insurance Information Program

Virginia Insurance Counseling and Assistance Program (VICAP), 540-345-0451

Provides assistance with questions on health insurance, Medicare, Medigap, and long-term care insurance.

Visit: www.loaa.org

Information and Referral Center, 211 or 540-982-2345 or 800-230-6977

Provides resource information and referral over the telephone, much like 411.

Visit: www.councilofcommunityservices.org

Legal Services - Blue Ridge, 540-344-2080

Legal Aid Society of Roanoke Valley, 540-344-2088

Free legal services for low-income persons and those 60 years of age and older.

Visit: www.brls.org

MyZiva.net

MyZiva is a free, objective and easy-to-use nursing home resource for prospective residents, caregivers and healthcare professionals.

Visit: www.myziva.net

National Academy of Elder Law Attorneys

Visit: www.naela.org

National Eldercare Locator, 800-677-1116

Helps older adults and their caregivers identify local support resources.

Visit: www.eldercare.gov

Nursing Home Quality Initiative, 866-708-1944, ext. 625

Provides detailed information on past performance of every Medicare and Medicaid certified nursing home in the state.

Visit: www.medicare.gov/NHCompare/home.asp or www.vhca.org (Virginia Health Care Association)

SeniorNavigator, 866-393-0957

Online directory listing over 18,500 resources that helps seniors remain independent and offers vital support to families and caregivers.

Visit: www.seniornavigator.org

Social Security Administration, 800-772-1213

Handles applications for retirement, disability, survivor's benefits, Medicare and Supplemental Security Income (SSI)

Visit: www.socialsecurity.gov

GLOSSARY

Activities of Daily Living (ADL) – routine activities that we all do on a daily basis – feeding, dressing, bathing, moving from a bed to a chair (also called transferring), toileting and walking.

Advance Medical Directives (Advance Care Planning) – documents that outline your wishes regarding healthcare at the end of life or in the event of a catastrophic illness. In Virginia, these documents can include a Living Will and Healthcare Power of Attorney.

Assisted Living Facilities – facilities that provide assistance with ADLs and IADLs, but do not provide 24-hour skilled nursing care. Housing for those who may need help living independently, but do not need skilled nursing care. The level of assistance varies among facilities and may include help with bathing, dressing, meals and housekeeping.

Case Management – a service offered by organizations to help coordinate community services for persons living at home, in assisted living facilities, or in nursing homes.

Co-Payment – a shared cost that a person must pay when using his/her health insurance.

Durable Power of Attorney – a legal document that grants legal authority to make financial/legal decisions on your behalf and remains effective if you become incapacitated.

Geriatrician or Geriatric Specialist – a medical doctor who specializes in the treatment of older people.

Home Health Care – rehabilitative and/or restorative care that is received in the home or assisted living setting. It may be paid for by Medicare, Medicaid, other insurance or private funds. Does not include hospice care.

Hospice – specialized care and support for persons with life-limiting illness, and their families.

Instrumental Activities of Daily Living (IADL) – common activities that require higher physical and mental skills – housework, preparing meals, managing finances, getting to appointments, taking medications, etc.

Long-Term Care – refers to a broad range of services needed by persons with physical or mental impairments who do not have the ability to function independently. Care can be provided in the home, assisted living facility, nursing home or other institutional setting.

Personal Care – assistance with bathing, dressing, toileting and other ADLs (See ADLs).

Support Group – formal or informal groups that meet to discuss issues of common interest/concern, such as caring for a person with Alzheimer’s disease, stroke or diabetes.

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