

Family Caregiving In North Carolina



*A Guide
for Family Caregivers*



Nationwide, it is estimated that one of every four persons is providing care for a relative or friend age 50 or older.

Although providing care to a family member can be a positive and rewarding experience, family care can be stressful. Some caregivers live with their relative while others are long-distance caregivers and must travel or coordinate care over the phone. Over one-half of all caregivers are employed full time and many have other family responsibilities. The physical, emotional and financial demands can be overwhelming. Although studies have shown that the use of formal services may reduce some of the burden associated with caregiving, many caregivers do not use outside or formal services.

A snapshot taken in a survey in the year 2000 showed that 17% of adult North Carolinians reported that they had cared for a family member or friend age 60 or older during the previous month. Many reports state that 80% of the care provided to older adults is done informally by family and friends. This care may involve running errands, cleaning the home, preparing meals, taking the person to the doctor, helping with bathing or dressing, or providing round-the-clock care and supervision. Caregivers often make it possible for frail and disabled adults to remain in their home setting rather than moving into a long-term care facility. Even when a move to a facility is necessary, many family members continue to be involved with their relative's care.

Caregiver Initiatives

North Carolina has recognized the importance of family care and has offered services to benefit caregivers for a number of years. However, there was no comprehensive program for family caregivers. The National Family Caregiver Support Act, a part of the Older Americans Act reauthorized by the US Congress in 2000, has helped fill this gap. This act authorizes a variety of services to support the important work of family caregivers.

Through this federal legislation, North Carolina has embarked on a new effort to assist family members and friends in their caregiving role.

The North Carolina Family Caregiver Support Program strives to “complete the care” by making information, supports, and services available as needed and desired by caregivers and to help caregivers know that they need not be alone. North Carolina’s Family Caregiver Support Program is administered by the Department of Health and Human Services,

Division of Aging (DOA), the Area Agencies on Aging (AAAs), and local counties.

With the implementation of the Family Caregiver Support Program, state-level public and private organizations are partnering to provide information and services to family caregivers and to educate and train professionals who work with them.



These partners along with the Division of Aging, include North Carolina-AARP, the North Carolina Cooperative Extension, The Carolinas Center for Hospice and End of Life Care, the Duke Family Support Program, and the University of North Carolina Jordan Institute for Families. Area Agencies on Aging across the state are forming similar partnerships locally to establish or expand services for caregivers.

Support Groups

Support groups are offered formally and informally across the state. Many are designed for caregivers of people with specific diseases and are often sponsored by national associations. The Alzheimer's Association sponsors Alzheimer's support groups and the American Parkinson Disease Association sponsors Parkinson Disease support groups (see Contact Information for phone numbers). There are also general caregiver support groups, many of which are sponsored by local aging service



providers or faith-based organizations. Support groups allow caregivers to discuss their concerns and frustrations and to receive and offer emotional encouragement and practical solutions to caregiving situations.

Training / Workshops

The statewide partners are collaborating to train professionals to offer workshops that help caregivers take better care of themselves and others. These include the Rosalynn Carter Institute for Human Development's *Caring for You, Caring for Me* (for both professional and family caregivers, focusing on what it means to be a caregiver); *Taking Care of You: Powerful Tools for Caregiving* (focused on self-care for family caregivers); and *Respecting Choices™* (a curriculum on advance care planning). For information contact the Family Caregiver Program Coordinator at the Division of Aging (919-733-3983) or check with the Family Caregiver Resource Specialist at your Area Agency on Aging (see Contact Information).

Other Resources

Home and Community Care

Block Grant Services

North Carolina administers the Older Americans Act programs through a Home and Community Care Block Grant. The block grant provides in-home and community-based services for older adults and their unpaid caregivers. Block Grant services specifically for caregivers include in-home, group and institutional *respite. Other caregiving benefits include home-delivered meals, congregate



*** Respite Care**

A service that provides temporary relief for persons caring for someone who is ill, injured, or frail. Services can be provided in an adult day care center, the home of the person being cared for, or other settings.

meals, adult day services, care management, in-home aide service, information and assistance, transportation, senior center, housing and home-improvement, health promotion, and medication management. The availability of these services varies in each county. Contact the Family Caregiver

Resource Specialist at your Area Agency on Aging or visit the Division of Aging on-line directory of local service providers at www.dhhs.state.nc.us/aging/services/svclist.htm

Advance Care Planning

Advance care planning is deciding about the kind of health care you want at the end of life. Advance health care directives are the legal documents in which you give written instructions about your health care if, in the future, you cannot speak for yourself.

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

The Carolinas Center for Hospice and End of Life Care provides a step-by-step guide to advance care planning. The 23-page workbook is designed to help individuals and families plan for the care they want at the end of life.



For more information, call 800-662-8859 or visit www.carolinasendoflifecare.org.

The North Carolina Cooperative Extension also provides information on advance care planning and forms for writing advance directives. For more information visit www.ces.ncsu.edu/depts/fcs/estates/registry.html

The North Carolina Secretary of State's office has established an online registry that allows residents to file up to four different advance directives. To learn more about the registry, visit the website at www.sosnc.com or www.nclifelinks.org and click on the heart-shaped icon or call 919-807-2162.





Health Insurance

Medicare: Most adults age 65 and older and certain disabled adults receive Medicare health insurance. Medicare covers a portion of costs such as hospitalizations, doctors' visits, and diagnostic testing. In some cases, it may cover limited care in a skilled nursing facility and limited home health care. Medicare-approved home health care may include the services of a nurse, physical therapist, speech therapist, medical social worker, occupational therapist and home health aide. Medicare also has a Hospice benefit for persons with limited life expectancy. Hospice covers medications related to the life-limiting diagnosis, nursing, home health aides, social work, and chaplain services. For information visit the US

Government's official Medicare website at www.medicare.gov

Medicaid is a federal-state program that provides health care insurance for low-income older and disabled adults. It also covers nursing home care for eligible individuals. Contact your county Department of Social Services for eligibility information. For general information on Medicaid or county specific contacts, call 919-733-3055 or visit www.dhhs.state.nc.us/dss/cty_cnr/dir.htm

Private Insurance: Since Medicare does not cover all health care costs most Medicare beneficiaries have additional private coverage either through their former employer 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 Seniors' Health Insurance Information Program (SHIIP) in the Department of Insurance at 800-443-9354.

Federal Tax Benefits

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 himself or herself. The credit can be up to 30% of your expenses. To qualify, you must pay these expenses so you can work or look for work. If you received any dependent care benefits from your employer during the year, you may be able to exclude



from your income all or part of these benefits. You must complete Part III of Form 2441 or Schedule 2 (Form 1040A) before you can figure the amount of your credit. For further information, contact the Internal Revenue Service online at www.irs.gov.

Other Tax Benefit Resources

AARP Tax-Aide and Volunteer Income Tax Assistance (VITA) programs offer free assistance in preparing tax returns. Low Income Taxpayer Clinics (LITC) offer free assistance to lower income taxpayers (earning less than \$42,625 for a family of four) regarding disputes with the IRS. For information contact AARP Tax-Aide at 888-AARPNOW; see the website: www.aarp.org/taxaide or for VITA and LITC, call 800-829-1040.

Estate Planning

For information on estate planning and estate and gift taxes visit the NC Cooperative Extension website, at www.ces.ncsu.edu/depts/fcs/estates/index.html (planning your estate) and www.ces.ncsu.edu/depts/fcs/estates/taxes.html (estate and gift taxes).

Family and Medical Leave

Under the Family and Medical Leave Act (FMLA) of 1993, many private, state and local government employees, and some federal employees meeting certain eligibility requirements can take up to 12 weeks of unpaid, job-protected leave in a 12-month period to care for an ill family member. Check with your employer for eligibility questions.

Contact Information

AARP (NC State Office), 919-755-9757.

AARP is a membership organization for people 50 and over providing information, education and advocacy on legislative, consumer, and legal issues. Visit: www.aarp.org/life or ncaarp@aarp.org

Alzheimer's Association,

Eastern NC Chapter, Raleigh, NC,
800-228-8738. www.alznc.org

Western NC Chapter, Charlotte, NC,
800-888-6671. www.perigee.net/~alz

This association provides education and support for people diagnosed with Alzheimer's Disease, their families and caregivers.

American Parkinson Disease Association,

800-223-2732. This association provides referrals and education materials on Parkinson Disease. www.apdaparkinson.com





The Arc of North Carolina, 800-662-8706. This organization works with persons with developmental disabilities. www.arcnc.org

Area Agency on Aging Family Caregiver Resource Specialist, (see listing at the end of this document, North Carolina Area Agency on Aging Family Caregiver Resource Specialists).

BenefitsCheckUp, an online service of The National Council on the Aging, This website helps find programs for seniors that may pay for some of their costs of prescription drugs, health care, utilities, and other essential items or services. www.benefitscheckup.org

The Carolinas Center for Hospice and End of Life Care, 800-662-8859. This association provides technical assistance, education and advocacy to improve advance care planning, palliative care, hospice and bereavement care. www.carolinasendoflifecare.org

Duke Family Support Program, 800-672-4213. This program provides an in-state hotline for crisis information and referrals for families and professionals caring for persons with dementia. A free newsletter with caregiving advice is available at www.dhhs.state.nc.us/aging/fcaregr/cgnwsltr.htm.

Visit the website at: <http://adrc.mc.duke.edu>

Easter Seal Society, 800-662-7119. This organization provides services to help children and adults with disabilities and/or special needs as well as support for their families. www.nc.easter-seal.org

Eldercare Locator, 800-677-1116. This is a service that offers local contact information for aging services nationwide. www.eldercare.gov



Geriatric Evaluation and Assessment Centers

Duke University

Geriatric Evaluation and Treatment Clinic,
4020 N. Roxboro Rd., Durham, NC 27710,
919-620-4070

Duke Memory Disorders Clinic,
932 Morreene Rd., Durham, NC 27705,
919-668-7600

East Carolina University

ECU School of Medicine, 1705 W. 6th St.,
Bldg. C, Greenville, NC 27858-4354,
252-816-2045

http://fed_med.ecu.edu/fam_med/geriatric_mfd.htm

Memory Assessment Clinic and Eldercare

Resource Center, 2360 Sweeten Creek Rd.,
Asheville, NC,
828-771-2219

www.memorycare.org

University of North Carolina

UNC Hospital Geriatric Clinic,
Program on Aging, 141 MacNider Bldg.,
Chapel Hill, NC 27599-7550,
919-966-5945

www.med.unc.edu/aging

Wake Forest University Baptist Medical Ctr.

J. Paul Sticht Center on Aging and
Rehabilitation, Medical Center Blvd.,
Winston-Salem, NC,
828-713-8250

(Memory Disorders Clinic 336-716-4551)

www.wfubmc.edu/sticht

North Carolina Division of Aging,

919-733-3983. This agency within the Department of Health and Human Services is responsible for planning, administering, coordinating, and evaluating the activities developed under the federal Older Americans Act and the programs for older adults funded by the General Assembly.

www.dhhs.state.nc.us/aging

North Carolina State University, NC Cooperative Extension,

Department of Family and Consumer Sciences 919-515-9132. This is a community-based outreach program of NC State University and NC A&T State University located in all 100 counties and the Cherokee Reservation.

Extension Agents provide educational programs to families and leadership for community initiatives. Contact your county Cooperative Extension Center,

www.ces.ncsu.edu/counties

Seniors' Health Insurance Information Program (SHIIP),

800-443-9354. SHIIP answers questions and counsels senior citizens about Medicare, Medicare supplements, Medicare+Choice, long-term care insurance and other health insurance concerns.

www.ncdoi.com/Consumer/Shiip/Shiip.asp

www.fullcirclecare.org is a website for family caregivers providing information on a variety of topics. (Sponsored by Triangle J Area Agency on Aging)



North Carolina Family Caregiver Support Program

Area Agency on Agency Family Caregiver Resource Specialists

Area &/or Region	COG Address	Contact / Family Caregiver Resource Specialist	Counties served
A	Southwestern Commission P.O. Box 850 Bryson City, NC 28713	828-488-9211 http://www.regiona.org <i>Tamara McGee</i> Ext 3030	Cherokee, Clay, Graham, Haywood, Jackson, Macon, Swain
B	Land-of-Sky Regional Council 25 Heritage Drive Asheville, NC 28806	828-251-6622 http://www.landofsky.org/aaa <i>Carol McLimans</i> Ext 115 Carol@landofsky.org	Buncombe, Henderson, Madison, Transylvania
C	Isothermal Planning & Development Commission P.O. Box 841 Rutherfordton, NC 28139	828-287-2281 http://www.regionc.org <i>Michelle Doty</i> Ext 1258 Mdoty1@regionc.org	Cleveland, McDowell, Polk, Rutherford
D	Region D Council of Governments P.O. Box 1820 Boone, NC 28607	828-265-5434 http://www.regiond.org <i>Heather Presley</i> Ext. 128 hpresley@regiond.org	Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes, Yancey
E	Western Piedmont Council of Governments P.O. Box 9026 Hickory, NC 28603	828-322-9191 http://www.wpcog.dst.nc.us <i>Virginia Parrish</i> Ext. 156 virginia.parrish@wpcog.dst.nc.us	Alexander, Burke, Caldwell, Catawba
F	Centralina Council of Governments 1300 Baxter Street, P.O. Box 35008 Charlotte, NC 28235	704-372-2416 (COG) http://www.centralina.org <i>Ronda Deitch</i> (704) 348-2738 rdeitch@centralina.org	Anson, Cabarrus, Gaston, Iredell, Lincoln, Mecklenburg, Rowan, Stanly, Union
G	Piedmont Triad Council of Governments Koger Center, Wilmington Bldg., 2216 W. Meadowview Road, Suite 201 Greensboro, NC 27407-3480	336-294-4950 www.ptcog.org/d_aging.htm <i>Blair Barton-Percival</i> bbpercival@ptcog.org	Alamance, Caswell, Davidson, Guilford, Montgomery, Randolph, Rockingham
I	Northwest Piedmont Council of Governments 400 W. Fourth Street, Ste. 400 Winston Salem, NC 27101	336-761-2111 www.nwpcog.dst.nc.us	Davie, Forsyth, Stokes, Surry, Yadkin



Area &/or Region	COG Address	Contact / Family Caregiver Resource Specialist	Counties served
J	Triangle J Council of Governments P.O. Box 12276 Research Triangle Park, NC 27709	919-558-9391 www.tjcog.dst.nc.us/ <i>Ellison Jones</i> ejones@tjcog.org	Chatham, Durham, Johnston, Lee, Moore, Orange, Wake
K	Kerr Tar Regional COG P.O. Box 709 Henderson, NC 27536	252-436-2040 <i>Michael Rood</i> Mrood@kerrtarcog.org	Granville, Franklin, Vance, Warren, Person
L	Upper Coastal Plain Council of Governments P.O. Drawer 2748 Rocky Mount, NC 27802	252-446-0411 www.ucpcog.org <i>Taryn Edwards</i> Tedwards@ucpcog.org	Edgecombe, Halifax, Nash, Northampton, Wilson
M	Mid-Carolina Council of Governments P.O. Drawer 1510 Fayetteville, NC 28302	910-323-4191 <i>Kristina Dice</i> kdice@fayetteville.net	Cumberland, Harnett, Sampson
N	Lumber River Council of Governments 4721 Fayetteville Road Lumberton, NC 28358	910-618-5533 <i>Anne Oglesby</i> Ext. 3008 aco@mail.lrcog.dst.nc.us	Bladen, Hoke, Richmond, Robeson, Scotland
O	Cape Fear Council of Governments 1480 Harbour Drive Wilmington, NC 28401	910-395-4553 www.capefearcog.org <i>Holly Henderson</i> Ext. 204 Hhenderson@capefearcog.org	Brunswick, Columbus, New Hanover, Pender
P	Eastern Carolina Council of Governments 233 Middle Street P.O. Box 1717 New Bern, NC 28563	252-638-3185 1-800-824-4648 www.eccog.org <i>Jody Riddle</i> Ext. 3015 Jriddle@eccog.org	Carteret, Craven, Duplin, Greene, Jones, Lenoir, Onslow, Pamlico, Wayne
Q	Mid-East Commission 1385 John Small Avenue, P. O. Box 1787 Washington, NC 27889	252-974-1800 www.mecaaa.org <i>Sallie Williamson</i> swilliamson@mideastcom.org <i>Marian Tabak</i> Mtabak@mideastcom.org	Beaufort, Bertie, Hertford, Martin, Pitt
R	Albemarle Commission P.O. Box 646 Hertford, NC 27944	252-426-5753 <i>Catherine Smith</i> cpmith@hotmail.com	Camden, Chowan, Dare, Currituck, Gates, Hyde, Pasquotank, Perquimans, Tyrrell, Washington





North Carolina Family Caregiver Support Program
Completing the Care

North Carolina
Cooperative
Extension

Duke Family
Support
Program

North Carolina
Association of
Area Agencies
on Aging

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