

Dementia-Specific Respite: The Key to Effective Caregiver Support

Karisa Durrence, MA

Value of Informal Dementia Care

Most older adults, including those with dementia, prefer to remain at home and in the community for as long as possible. More than 70% of the 4.5 million Americans currently diagnosed with Alzheimer's disease live at home and are cared for by family and friends.¹ In order to ensure that individuals with dementia receive quality care in the environment of their choice, the support of informal caregiving is critical.⁺ Extending the duration of home care is also an important health and quality of life issue. Adjusting to a new environment is particularly difficult for a person with Alzheimer's disease. The comfort and security of familiar surroundings and a stable routine can help alleviate the fear and anxiety often associated with progressive memory loss.

The value of informal caregiving extends beyond ensuring quality of life and freedom of choice. It has become "an essential element of our health and long-term care system."² The national cost of caring for people with Alzheimer's disease has reached at least \$100 billion.³ Unless an intervention or cure is found soon, Alzheimer's could bankrupt Medicare and Medicaid.³ Even a one-month delay in nursing home placement is estimated to save the healthcare system \$1 billion a year.⁴ The contributions of family caregivers, worth \$257 billion in unpaid services and support, are more than double the annual cost of home care (\$32 billion) and nursing home care (\$92 billion)

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combined.¹ This level of assistance simply cannot be replaced. The need to support and sustain family care at home will only intensify as our population ages.

Burden of Dementia Caregiving

The progressive and unpredictable nature of Alzheimer's disease poses enormous challenges to caregivers. People with Alzheimer's disease live an average of eight years after diagnosis but may survive for up to 20 years. They need help with most activities of daily living such as bathing, dressing, eating, and dealing with incontinence. Their level of care and ability to communicate can fluctuate from one day to the next and they may be resistant to personal care assistance. Behaviors such as wandering, hoarding, and perseveration further complicate care needs and create serious safety issues. Eventually, most individuals with Alzheimer's disease will need full-time care and continuous supervision.

A recent survey reported that among all caregivers, those caring for people with dementia experience a disproportionately heavy burden.⁵ They spend more hours providing care over longer periods of time. More than half feel as if they are "on call" 24 hours a day and have to reduce or end employment to fulfill the demands of caregiving.^{6,8} Dementia caregivers encounter more family conflict, personal stress, serious health problems, and a shorter life expectancy.^{6,8,9} Many of these caregivers cope with immense grief and feelings of guilt, anxiety, and anger. Nearly half (43%) are clinically depressed.¹⁰ The unique behavioral and communication challenges associated with dementia require specialized skills and make it even more difficult for the caregiver to get rest or help providing care.

Dementia caregivers are particularly vulnerable to severe burnout. Reaching this level of stress and fatigue places both the caregiver and the person with dementia at risk and is one of the most cited reasons for early institution-

+ In this commentary, the term "informal caregiver" is used interchangeably with "family caregiver" to include all types of unpaid primary caregivers: family members, friends, and/or neighbors. The term "Alzheimer's" is used interchangeably with "dementia" to include all types of progressive memory impairment or mental confusion.

Karisa Durrence, MA, is the Alzheimer's Specialist at the Division of Aging and Adult Services, NC Department of Health and Human Services. She is also the Director for the NC Alzheimer's Demonstration Grant Program (Project CARE). She can be reached at karisa.durrence@ncmail.net or 2101 Mail Service Center, Raleigh, NC 27699. Telephone: 919-733-0440.

alization.¹¹ Caregivers need to adequately manage stress and have effective ways to relieve the tremendous burden of providing constant care. In doing so, family caregivers strengthen their ability to provide quality long-term care at home.

Respite* Options

Family caregivers identify respite care as one of their greatest needs.¹² Respite care offers relief for family, friends, and other informal caregivers so they can take a much needed break from their daily responsibilities while knowing their loved ones are in good care. Respite represents a continuum of services based on the individual needs of the caregiver and the person with dementia. There are many different ways respite can be provided (see Table 1):*

- In a home, community organization, or residential facility;
- For part of the day, evening, or overnight;
- By paid staff, volunteers, family, or friends;
- Occasionally or on a regular basis.

Dementia caregivers desperately need sufficient and regular amounts of respite, more than just temporary or short-term intervals. Respite support should be ongoing and is most helpful before the caregiver becomes exhausted, isolated, and overwhelmed. Families need to consider respite care before reaching a point of crisis. The unique circumstances of each family will help determine what type of support is most appropriate. The most successful and effective respite programs promote flexibility and consumer control, allowing caregivers to direct their own care.

Benefits of Respite Care

Respite care benefits both the primary caregiver and the individual with dementia. The person with dementia is provided with social stimulation and the opportunity to live in the community longer. Respite enhances quality of life, promotes better psychological health, and preserves family and caregiving relationships.

Respite care also mitigates the distress of caregiving and delays costly out-of-home placement.¹² Caregivers receive the kind of help that reduces the burden of dementia care and the likelihood of abuse and neglect. Without adequate support and timely respite, families often suffer economically and emotionally, and caregivers themselves face serious health and social consequences.

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Comprehensive Interventions

Respite care is most effective when enhanced with other caregiver-focused services such as individualized counseling, education, and ongoing support. Though essential, these services should not be used in isolation.¹³ Flexible and comprehensive support programs maximize the benefits of caregiver interventions by effectively relieving caregiver depression and care-related stress over a long period of time.^{10,13,14}

For many caregivers, respite is a gateway to more comprehensive care including training and emotional support.^{15,16} Respite relief helps caregivers gain further perspective and make better decisions. Caregivers begin to take steps toward maintaining personal health and are often more willing to connect with peers and explore additional resource opportunities.

A Model Program

The North Carolina Alzheimer's Demonstration Program, Project CARE (Caregiver Alternatives to Running on Empty), uses a consumer-directed, family consultant model to provide comprehensive respite support to dementia caregivers. The goal of the program is to increase access, choice, use, and quality of respite care to underserved rural and minority communities. Through the integration of dementia-specific services, Project CARE intends to create a seamless, coordinated delivery system that is responsive to the needs, values, and preferences of Alzheimer's families.

Project CARE is funded through the federal Administration on Aging Alzheimer's Disease Demonstration Grants to States Program (ADDGS). The program is administered by the North Carolina Division of Aging and Adult Services and receives technical assistance from the Duke Aging Center Family Support Program. Operating within the community-based contexts of the Western Carolina Alzheimer's Association and the Mecklenburg County Department of Social Services, Project CARE Family Consultants visit the homes of referred Alzheimer's caregivers in crises. The consultants offer timely, individualized guidance, counseling, support, advocacy, and education for family caregivers. Their aim is to match families with the most appropriate and preferred local respite and community services tailored to the unique context of care and family needs. Families are able to choose among a full continuum of consumer-directed care options, including adult day services, group respite, private or agency in-home care, and overnight residential respite. There are three pilot sites set up to serve the following ten counties: Winston-Salem (Forsyth, Surry, and Stokes Counties); Asheville (Polk, Henderson, Transylvania, Rutherford, Madison, and McDowell Counties); and Charlotte (Mecklenburg County).

Project CARE Family Consultants employ a family-centered, home-based intervention. The North Carolina demonstration program emphasizes the use of home visits to accommodate caregiver time and energy limits. During home visits, the consultant:

* Respite (res' pit) n. 1. a delay or postponement 2. an interval of temporary relief or rest.

Table 1.
Respite Options

Types	Provider	Services	Benefits/Cost
In-home Care	Employed privately, through a home health agency, or as part of a government program	1 Companion: help with supervision, recreational activities, and visiting. 2 Personal Care: assistance with bathing, dressing, incontinence care, and other activities of daily living. 3 Homemaker: help with housekeeping, shopping, and meal preparation. 4 Skilled nursing care: help with medication and other medical needs.	Person with dementia receives one-on-one attention within the comfort of their own home. Caregiver does not have to provide or arrange for transportation. Variety of service options and types of assistance. Moderate cost—dependent on level of care.
Adult Day Programs (or “community-based service”)	State Certified Adult Day Care or Day Health Centers; Group Respite Programs	Daily activities may include music, exercise, social stimulation, and peer support. Staff are often highly interactive and, in some centers, consist of a social worker and recreation therapist. Adult Day Health Centers offer medical services administered by a registered or licensed nurse. Some centers have specialized Alzheimer’s programs.	Participants have the opportunity to interact with others while being part of a structured environment. Most programs provide a meal and/or snacks. State certified centers are open a minimum of six hours per day for at least five days a week. Group respite programs are open a maximum of five hours per day, four days a week. Allows caregivers to continue working outside the home. More respite time available at a lower annual cost.
Residential Respite (or “institutional respite”)	Nursing Homes, Residential Care Facilities, and Assisted Living Facilities	Provides overnight or short-term respite stays ranging from a few days to several weeks. Services include personal care assistance, meals, laundry, and therapeutic activities. Some facilities have special care units or programs for people with dementia.	Allows caregivers to take an extended break or vacation while the person with dementia stays in a safe, secure environment. Option for emergency situations such as an accident, illness, surgery, or long-distance trip. May be needed for crisis situations where there is a risk of abuse or neglect. High cost. Person with dementia may have difficulty adjusting to the new environment.
Informal Respite	Involves the help of family, friends, neighbors, church groups, or other volunteers who can share the responsibility of caregiving.	Range from companion services to personal care or household assistance. Some communities have organizations or support team networks that provide a stable source of volunteer caregiving services (e.g., Center for Volunteer Caregiving: www.volunteercaregiving.org ; The Support Team Network: www.supportteam.org)	Provides emotional support for the caregiver and helps the person with dementia maintain a healthy level of social and recreational activity. Receive same benefits as non-medical in-home care at no cost. Not available in all communities. May not be as dependable as professional care. Some families feel they have less quality control when services are free. Can also be used to supplement formal care.

For more information, see the Respite Care Guide: How to Find What’s Right for You (National Alzheimer’s Association: www.alz.org), Community Care Options (Family Caregiver Alliance: www.caregiver.org) or Respite for Persons with Alzheimer’s Disease or Related Disorders (ARCH National Respite Network and Resource Center: www.archrespite.com)

- assesses the family care environment,
- identifies the needs of both the caregiver and the person with dementia,
- facilitates discussion and mutual understanding among family members,
- connects the family with community resources, and
- ensures the provision of quality services.

The personalized approach of the Family Consultant fosters family trust, instills a variety of skills, and promotes self-care. Project CARE families learn the value of respite and are empowered to make self-directed, informed decisions about care.

Project CARE builds upon, enhances, and sustains existing home and community-based services. The Family Consultant uses local providers to deliver respite care and serves as a direct link to the expertise and resources of the Alzheimer's Association. Project CARE also opens doors to the Family Caregiver Support Program and other caregiver-focused initiatives creating a strong network of community support for Alzheimer's families. This comprehensive system builds the family's capacity to manage all the challenges inherent in caring for individuals with dementia.

Future Direction

Within the next ten years, as the first wave of baby boomers reach the age of greatest risk, the numbers of people affected by Alzheimer's disease will increase dramatically. In 2000, an estimated 132,329 older adults in North Carolina had mild, moderate, or severe Alzheimer's disease. This number is projected to rise to 253,176 by 2025—an increase of 91%.¹⁷ It is critical that we prepare for this upcoming healthcare crisis by creating a sustainable, dementia-capable system of respite support for Alzheimer's families across the entire state.

The future of respite care in North Carolina is at a crossroads. The state Family Caregiver Support Program (FCSP) has insufficient funds to adequately serve all types of caregivers, and it does not contain a dementia-specific component. As we look to the future, federal and state policy makers would be well advised to build on the success of the FCSP and the Alzheimer's Disease Demonstration Project. North Carolina must integrate and fund dementia-specific respite as part of all future caregiver support programs. **NCMJ**

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North Carolina Alzheimer's and Dementia Web Resources

Diagnostic and Treatment Centers:

- Duke University Center for the Study of Aging and Human Development - Geriatric Evaluation and Treatment Clinic, Durham: www.geri.duke.edu/service/get.html 919-620-4070
- Duke University Joseph & Kathleen Bryan Alzheimer's Disease Research Center - Memory Disorders Clinic, Durham: <http://adrc.mc.duke.edu/mdcfront.htm> 919-668-7600 or 866-444-2373
- East Carolina University Brody School of Medicine - Geriatric Center, Greenville: www.ecu.edu/ecuphysicians/fpc/geriatric_center.htm 252-744-2045
- Memory Assessment Clinic and Eldercare Resource Center, Asheville: www.memorycare.org 828-771-2219
- Neurology Consultants of the Carolinas, Charlotte: www.neurology-consultants.com 704-927-7300
- University of North Carolina Memory and Cognitive Disorders Clinic - Department of Neurology, Chapel Hill: <http://neuron.med.unc.edu/neurology/memcog.htm> 919-966-5549
- University of North Carolina Program on Aging - Geriatric Evaluation Clinic, Chapel Hill: www.med.unc.edu/aging/clinical_services_patient.htm 919-966-5945
- Wake Forest University Baptist Medical Center - J. Paul Sticht Center on Aging and Rehabilitation: Geriatric Consultation Clinic, Winston-Salem: <http://www.wfubmc.edu/sticht/services/geriatric-asses.html> 336-713-8543
- Veterans Health Administration Medical Center - Geriatric Research, Education and Clinical Center (GRECC), Durham: www1.va.gov/geriatricsshg/docs/GRECC.doc 919-286-0411 ext. 6900

Alzheimer's and Dementia Support Services:

- Eastern North Carolina Alzheimer's Association Chapter: www.alznc.org 919-832-3732 24-HOUR HELPLINE 800-228-8738
- Western Carolina Alzheimer's Association Chapter: www.alz-nc.org 704-532-7392 24-HOUR HELPLINE 800-888-6671
- Duke Aging Center Family Support Program: www.dukefamilysupport.org 919-660-7510 or 800-672-4213

Family Caregiver Support and Community Education:

- AARP: www.aarp.org/states/nc
- Area Agencies on Aging: <http://www.dhhs.state.nc.us/aging/aaa.htm>
- North Carolina Division of Aging and Adult Services: www.dhhs.state.nc.us/aging
- North Carolina Family Caregiver Support Program: www.dhhs.state.nc.us/aging/fcaregr/fchome.htm
- North Carolina Caregiver Information: www.fullcirclecare.org
- North Carolina State Cooperative Extension: www.ces.ncsu.edu/depts/fcs/human/adult.html

Respite Care Information and Programs:

- ARCH National Respite Network and Resource Center: www.archrespite.org

- Easter Seals: www.easterseals.com
- Faith In Action: www.fiavolunteers.org
- North Carolina Information and Assistance Program: <http://www.dhhs.state.nc.us/aging/services/iassist.htm>
- North Carolina Adult Day Services Association: www.ncadsa.org
- Project Compassion: www.project-compassion.org
- Shepherd's Center of America: www.shepherdcenters.org
- The Brookdale Foundation: www.brookdalefoundation.org
- The Support Team Network: www.careteam.org

National Organizations, Programs, and Referral Sources:

- Alzheimer's Association (National Office): www.alz.org
- Alzheimer's Disease Education & Referral Center (ADEAR): www.alzheimers.org
- Alzheimer's Research Forum: www.alzforum.org/dis/abo
- American Association of Geriatric Psychiatry: www.aagppa.org
- American Health Assistance Foundation: www.ahaf.org
- Eldercare Locator: www.eldercare.gov
- eMedicine Consumer Health: www.emedicinehealth.com/articles/39500-1.asp
- Family Caregiver Alliance: www.caregiver.org
- Fisher Center for Alzheimer's Research Foundation: www.alzinfo.org
- Mayo Clinic's Alzheimer's Center: www.mayoclinic.com
- National Adult Day Services Association: www.nadsa.org
- National Association of Professional Geriatric Care Managers: www.caremanager.org
- National Family Caregivers Association: www.nfcacares.org
- National Institutes of Health:
 - Senior Health: <http://nihseniorhealth.gov/alzheimersdisease/toc.html>
 - National Institute on Aging: www.nia.nih.gov
 - National Institute on Neurological Disorders & Stroke: www.ninds.nih.gov
 - National Library of Medicine: Medline Plus - Alzheimer's Caregivers: www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html
 - Alzheimer's Disease: www.nlm.nih.gov/medlineplus/alzheimersdisease.html
- Neuropathology - Dementia: www.uvm.edu/~jkessler/NP/neudemmen.htm
- The Alzheimer's List Homepage: <http://alzheimer.wustl.edu/adrc2/alzheimerlist>
- United States Administration on Aging Alzheimer's Resource Room: www.aoa.gov/alz