

# Why Is Respite Important for Caregivers?

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## You already know...

- More people with chronic disease are living in the community than ever before.
- The number of persons living longer is increasing.
- The number of persons living longer with chronic disease is increasing.
- People prefer to live in their community rather than in institutions.
- Home and Community-Based Long term services and supports are essential because...

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■ **It's a matter of love and money:**

- Institutionalizing all of the people with chronic disease is expensive. Medicaid cannot be sustained.
- Families want to help care for their loved ones.

## Definitions

- **Caregiving** - Caregiving is based on a relationship, but caregiving is an additional role that requires preparation, acceptance, support, and resources to assist a person with a chronic disease or condition remain in the community.

Source: The Challenges of Family Caregiving: What Experts Say Needs to Be Done Susan C. Reinhard, Lynn Feinberg, and Rita Choula AARP Public Policy Institute

- **Care receiver** - person with a chronic disease or condition(s) in need of assistance in order to remain living in the community
- **Caregiver**
  - Informal – not hired (further defined next slide)
  - Formal – hired

## Definitions - Caregivers

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Caregivers are mainly wives and adult daughters or daughters-in-law, but increasingly men are becoming caregivers too. Most caregivers are related by blood or marriage, but partners, friends, and neighbors are also caregivers.

Source: The Challenges of Family Caregiving: What Experts Say Needs to Be Done Susan C. Reinhard, Lynn Feinberg, and Rita Choula AARP Public Policy Institute

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## Why do Caregivers provide care?

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Adult sons and daughters caring for their parents often experience their new roles as intensely personal, profoundly meaningful and rewarding, and a way to give back to a parent the love and care they were given as children.

Yet, despite its rewards, the caregiving role is also complicated, bewildering, and frustrating. It is also stressful to many American families because of the range of situations they face and the high costs of care. Most caregivers are employed at a paying job in addition to their caregiving responsibilities.

Source: The Challenges of Family Caregiving: What Experts Say Needs to Be Done Susan C. Reinhard, Lynn Feinberg, and Rita Choula AARP Public Policy Institute

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*“We care because we love.”*  
*Donna and Mike*



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## **Definitions – ADL**

### **Activities of Daily Living**

**Basic ADLs consist of self-care tasks, including:**

- **Personal hygiene and grooming**
- **Dressing and undressing**
- **Self feeding**
- **Functional transfers** (getting into and out of bed or wheelchair, getting onto or off toilet, etc.)
- **Bowel and bladder management**
- **Ambulation** (walking with or without use of an assistive device such as a walker, cane, or crutches and/or using a wheelchair)

Source: McDowell, I., and Newell, C. (1996). *Measuring Health: A Guide to Rating Scales and Questionnaires*, 2nd edition. New York: Oxford University Press

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## Definitions – IADL

### Instrumental Activities of Daily Living

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Instrumental activities of daily living (IADLs) are not necessary for fundamental functioning, but they let an individual live independently in a community:

- Housework
- Taking medications as prescribed
- Managing money
- Shopping for groceries or clothing
- Use of telephone or other form of communication
- Using technology (as applicable)
- Transportation within the community

Source: Bookman, A., Harrington, M., Pass, L., & Reisner, E. (2007). *Family Caregiver Handbook*. Cambridge, MA: Massachusetts Institute of Technology.

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## Why is Caregiving difficult?

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- Socially isolating
- Expensive
  - Annual Adult Day Care = \$17,767
  - Annual Home Care = \$49,640
- Help with ADLs and IADLs
  - Need training
  - Embarrassing
- Takes Time
  - From work
  - From other family

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## An inspiration!

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## From Crystal:

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**“Caring for my Grandmother Carrie and Aunt Henrene is the most rewarding, and at the same time, the most stressful thing that I have ever encountered in my life.”**

**“Caregiving is stressful. It is such a big responsibility and at times I feel like I’m in over my head.”**

**“I feel like I should be doing so much more. There is always something that needs to be done – as if it is never enough.”**

Photography: Adult Care Center of Central Virginia  
Elizabeth Sumpter, Photographer

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## Respite is one way to support Caregivers – What is respite?

- relieve, let-up, relief, breathing space, break (Microsoft Word synonyms)
- Service in which trained professionals or volunteers come *into the home* to provide short-term care (from a few hours to a few days) for an older person to allow caregivers some time away from their caregiving role. (Webster's Online Dictionary – Aging domain)
- The provision of short-term relief (respite) to families caring for their frail elders offers tremendous potential for maintaining dependent persons in the least restrictive environment. *Respite services encompass traditional home-based care, as well as adult day health, skilled nursing, home health aide and short term institutional care.* Respite can vary in time from part of a day to several weeks. (Webster's Online Dictionary – Aging domain)
- Patient care provided in the home or institution intermittently in order to provide temporary relief to the family home care giver. (Webster's Online Dictionary – Health domain)
- I want to be alone (Greta Garbo)

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## What are examples of Respite Care?

- Adult Day Health Care
- Personal Care Providers
- Companion Service
- Transportation
- Institutional Respite
- Direct Payments

*Someone else to provide care while the caregiver gets a break.*

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## Is Respite Care Readily Available?

- **NOVA:** Adult Day Care, Personal Care, Companion Service, Transportation waiting lists or limited service; no adult Institutional and Direct Payment Respite
- **Greater Richmond:** Adult Day Care not available in rural or outside of the City; Personal Care and Companion Service inadequate; Transportation need ten times greater than available
- **Tidewater:** Adult Day Care, Personal Care and Companion Service limited one reason is not enough providers; Institutional and Direct Payment Respite
- **Greater Charlottesville Area:** Adult Day Care limited; Personal Care, Companion Service, Transportation, Institutional and Direct Payment Respite needed especially in rural areas
- **Greater Roanoke:** Adult Day Care limited; other services rare; Personal Care waiting list (2 years)
- **Western Area:** No Adult Day Care in Lee County; Companion Services inadequate in all areas; Transportation waiting lists; Institutional Respite not available in Scott County; no direct payment respite

*This is why we believe a survey is not necessary, we know we have an inadequate service network.*

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## Why is Respite Care needed?

### Caregivers' health conditions suffer

- **US Caregivers of individuals with ALZ and other dementias had \$8.7 billion in additional health care costs in 2011** (Alzheimer's Association's 2012: Alzheimer's Disease Fact and Figures [www.alz.org](http://www.alz.org))
- **23% of family caregivers caring for loved ones for more than five years report their health is fair or poor** (Caregiving in the United States; National Alliance for Caregiver in Collaboration with AARP; November 2009)
- **40% to 70% of family caregiver have clinically significant symptoms of depression with approximately a quarter to half of these caregivers meeting the diagnostic criteria for major depression** (Zarit, S. (2006). Assessment of Family Caregivers: A Research perspective)

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## Why is Respite Care needed?

- **20% of employed female caregivers over 50 years old report symptoms of depression compared to 8% of their non-caregiving peers.**

(MetLife Study of Working Caregiving and Employer Health Costs; National Alliance for Caregiving and MetLife Mature Market Institute. February 2010)

- **Family caregivers experiencing extreme stress have been shown to age prematurely. This level of stress can take as much as 10 years off a family caregiver's life.**

(Elissa E. Epel, Dept of Psychiatry, Univ of Calif, SF, et al, From the Proceedings of the National Academy of Sciences, Dec 7, 2004, Vol 101, No. 49)

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## Caregiving is a tough job.

- **“A worn-out caregiver cannot give very good care. The FAA makes pilots take rest periods to refresh themselves to prevent plane crashes. Caregivers need to prevent care crashes.”**

Robert L. Kane, MD, with Jeannine Ouellette, *The Good Caregiver: A One-of-a-Kind Compassionate Resource for Anyone Caring for an Aging Loved One* (New York, NY: Penquin Group, 2011)

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## Even in Virginia?



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## Number of Caregivers and the Economic Value of Caregiving, Virginia, 2009

<b>Total State Population</b>	<b>7,880,000</b>
<b>Number of Caregivers</b>	
At any given time	1,180,000
At any given time during the year	1,720,000
<b>Total Hours of Care (millions)</b>	<b>1,130</b>
<b>Economic Value/Hour</b>	<b>\$10.37</b>
<b>Total Value (millions)</b>	<b>\$11,700*</b>

***\*Savings to Public Funds***

Source: Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving*, Insight on the Issues #51 (Washington, DC: AARP Public Policy Institute, June 2011).

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## What's the problem?

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**“The problem is not that public policy looks first to families but that it generally looks only to families and fails to support those who accept responsibility.”**

Carol Levine, editor,  
*Always on Call: When Illness Turns Families into Caregivers* (Nashville, TN: Vanderbilt University Press, 2004)

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## What can we do about it?

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### ***Increase funding for Respite Care Initiative***

- Established by the 1988 General Assembly to provide respite for elderly (60 and older), and persons with Alzheimer's disease or related dementias
- Clients must have a twenty-four hour caregiver
- Respite care limited to 35 hours per month per client

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## How many were served by AAAs and how much did it cost?

### *Respite Care Initiative*

SFY12:

- 290 Caregivers were provided respite through the Respite Care Initiative costing \$456,209 of state general fund
- \$1,573.13 per year per client

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## How many were served by AAAs and how much did it cost?

### *Older Americans Act National Family Caregiver Support Program (OAA NFCSP)*

FFY11

- 4,044 Caregivers with Counseling, Support Groups, Training, Respite, Supplemental, or Access Assistance (unduplicated)
- 7,330 with Information Services
- \$5,435,531 (plus \$214,425 in program income)
  - \$3,107,091 (57%) OAA NFCSP
  - \$2,328,440 (43%) SGF, LGF, AAA fundraising
  - \$1,032 per year per client

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## Resources

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- DARS – Virginia Caregiver Coalition
- Dementia State Plan
- Biennial progress Report on Virginia’s Four-Year Plan for Aging Services #417, 2011
- Virginia’s Blueprint for Livable Communities
- AARP
- MetLife
- Rosalynn Carter Institute
- [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)
- [www.caregiving.org](http://www.caregiving.org)
- [www.caregiver.org](http://www.caregiver.org)

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## It’s about Love and Money

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- You don’t need to worry about the love.
- Funding is crucial to support Family Caregivers with Respite Care.
  - Double the Respite Care Initiative funds
  - $\$456,209 \times 2 = \$912,418$  – round to \$1M
  - A million dollars for respite will save state general fund by
    - Reducing premature institutionalization
    - Delaying institutionalization
    - Avoiding institutionalization all together
    - Supporting families

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# *You Can't Live Without Aging!*



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