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for the Family  
Caregiver™

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## A Family Caregiver's Guide to

# RESPITE

Paula Sanders McCarron

**R**espite: It's a simple concept. Respite means a break from something trying or distressing, an interval of relief. For those who provide care for a loved one, respite offers an opportunity to relax and re-energize. While this idea may seem simple enough, however, family caregivers know better than anyone how challenging it can be to obtain the help of others in order to take a break from their caregiving responsibilities.

The term "respite" is all-encompassing, describing any type of service that relieves a family caregiver. Respite can take a variety of forms depending on an individual's needs, resources, and preferences. No matter what form it takes, the idea is to provide family caregivers a short or extended period of "time out" to spend as they wish for their own rest, relaxation, and renewal.

### The Benefits of Respite

Few would argue how beneficial respite can be, both for the family caregiver and the care recipient. According to ARCH National Respite Network, "respite has been shown to provide family caregivers with the relief necessary to maintain their own health, bolster family stability, keep marriages intact, and avoid or delay more costly nursing home or foster care placement."

A sampling of study findings published by the National Respite Coalition provides further evidence of the benefits of respite:

- Children with complex medical needs whose parents use respite services are hospitalized less often, make fewer doctor visits, and use fewer antibiotics.
- Chronically ill elders whose families used respite services are hospitalized less often than chronically ill elders whose families don't use respite services.
- As the level of respite increases, the probability of a nursing home admission decreases significantly.
- In families where a loved one with dementia uses adult day services, caregivers experience lower levels of caregiving-related stress and better psychological well-

being than their peers whose loved ones don't use adult day services.

Family caregivers will find that most respite services can be categorized into one of the following areas:

1. Respite provided by supportive friends, co-workers, family members, faith communities, and volunteers.
2. Respite care provided by an agency, paid for with private funds, long-term care insurance, or, in some situations, covered under Medicaid.
3. Adult day programs that provide care recipients with services and socialization.
4. Respite services on a 24-hour-a-day, seven-day-a-week basis such as those found in some care facilities and other settings.

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## Respite

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### Finding What Will Work for You

Even when respite care is desired or necessary, it's not always easy to access services. Respite care is rarely covered by insurance, although it is included in most long-term care plans. Medicare does not cover respite care, although Medicaid may cover it, especially if a care recipient is at risk for abuse or neglect.

Respite is most often an "out-of-pocket" expense for a caregiver. But some free or sliding scale fee services may be available from non-profit agencies, and more states are offering either direct compensation or vouchers that can be used to obtain respite services of the family's choosing.

### Family, Friends, and Other Helpers

Caregivers who rely on the help of relatives, friends, and other volunteers know that one of the biggest challenges when trying to take advantage of respite opportunities involves keeping track of who is

available and what service they can offer. There are ways to coordinate the efforts of these well-meaning groups of people.

Lotsa Helping Hands offers a free, private, and easy-to-use calendar system. One person serves as a designated "coordinator" to track the offers of help and availability of friends, neighbors, and other volunteers. *Share the Care* (Fireside, 2004) is a "how to" book that helps those looking to coordinate the efforts of a "support team" for the family caregiver. The *Share the Care* model promotes a collaborative approach to caregiving to provide both the care recipient and the family the help they need.

## Words of Wisdom From Family Caregivers

**W**hen it comes to making use of respite services, family caregiver Liz de Nesnera knows that you have to be comfortable accepting help, and you have to be flexible. She cares for her mother, who had a massive stroke in 1994, and she also provided care for her father, who suffered from Alzheimer's. While her father eventually was admitted to an assisted living facility, where he died, de Nesnera continues to care for her mother in her home. She has hired private help on occasion and her mother attends adult day programs one to two days per week. "Even with help, it's not easy," says de Nesnera. "Every night, every weekend, it's up to me. I want my mother here with me and I just wouldn't be able to do it without help."

Although she is committed to home care, de Nesnera says, "Respite has not removed the possibility of placing my mom in a care facility. I want to have her at home but if it becomes necessary, then this is an option."

Pam Alesescu is another family caregiver who utilized respite services when caring for her husband. At first, Alesescu was reluctant to ask for help due to her feelings of guilt. She says, "I felt that this was my job, my duty, my responsibility. But in the end, I had to get rid of the guilt. I wanted my husband to be home. And having respite care made that possible."

Alesescu also had to come to terms with the costs involved with hiring private helpers. "Although it is less expensive to pay someone directly than to go through an agency, it's still expensive to have this kind of help," she says. "But if caregivers can't find respite help in any other way, then I strongly suggest they do what they can to budget themselves to the point where at least some paid help can be brought into the home."

Both de Nesnera and Alesescu will tell you that finding respite care often requires both patience and persistence. "You need to accept the help in whatever form it comes and you have to accept the fact that it won't be perfect," says Alesescu, who advises caregivers to look in "every nook and cranny and to chip away at every option." Adds de Nesnera, "I say I take it one day at a time and have a glass of wine with dinner."

### In-Home Respite Services

Across the country, many businesses exist to provide various levels of respite care for individuals in their own homes or those residing in a care facility. The businesses serve as an employer by screening, recruiting, and training employees who are then hired on a fee basis for a certain number of hours each week. Fees vary depending upon the type of care provided and there may or may not be a minimum number of hours required in a service contract.

Some family caregivers make the decision to hire their own private helpers. Some may pursue this option out of preference while others do so out of sheer necessity. When hiring privately, caregivers should be careful about screening potential employees and should also be informed about the legal and financial obligations that go along with becoming an employer.

Sometimes, free respite care is available from non-profit organizations, faith groups, or service programs. One example is the Senior Companion Program, which offers respite for family caregivers by matching volunteers age 60 and over with seniors who are socially isolated, ill, or disabled. Another is Faith in Action, an interfaith net-

work of volunteers nationwide who provide non-medical help and respite care for persons with long-term care needs.

### Adult Day Services

At present, over 3,000 adult day centers nationwide are providing socialization and recreational opportunities to both younger and older adults who live with physical or cognitive impairment. Some people participate two to three days per week while others may attend as often as five or six days. On average, the cost of adult day services runs a little more than \$50 per day. Many adult day programs offer sliding scale fees and some offer free care. Medicaid often provides coverage for adult day services.

### Assisted Living, Nursing Home Respite, and Respite Care Facilities

Admission to an assisted living home, a nursing home, or a respite facility may be an option when caregivers need an extended period of respite. Some people choose this option when a family caregiver plans a vacation or simply needs a longer period of rest.

Sometimes this type of respite is chosen because of a crisis that prevents the care recipient from remaining at home (e.g., if a caregiver becomes ill). Sometimes a respite stay at a care facility may help families learn about that facility firsthand in the event that long-term residence is ever needed or desired. Facilities vary in terms of what type of respite stays they offer (e.g., week-end stays, one- or two-week stays, or month-long stays).

Most often, the cost of assisted living care is met through private funds or long-term care insurance. In some situations, Medicaid may allow for facility-based respite if the care recipient is at risk for abuse or neglect. It's best to learn about a facility's admission criteria in advance of the need, including applicable fees and the level of service provided.

## Steps to Building Your Respite Plan

- Analyze what type of help is needed and how often it is needed.
- Learn if your loved one's health plan or long-term care policy covers respite care, including in-home, adult day or facility-based care. If your loved one is on Medicaid, contact the Medicaid office in your area.
- Determine what amount, if any, of your funds or those of the care recipient can be dedicated toward paying for respite.
- Contact your local Area Agency on Aging to see if respite services are available through the National Family Caregiver Support Program.
- Ask a friend to investigate respite options in your area. (Tip: When searching online, use specific search terms such as "Respite+Ohio" or "Respite+Cancer+New Hampshire" to get better search results.)
- Keep an ongoing file of information about respite providers.
- Identify what respite programs, if any, offer emergency respite care.
- Talk with other family caregivers and learn from your peers. They often have the best advice and referrals.

### Vacation Style Respite

In addition to the more traditional forms of respite, there are options for what might best be described as "vacation" respite. Some vacation-style respite programs offer services for care recipients while others focus solely on caregivers. There are also services aimed at the entire family.

Want to take a cruise? Royal Caribbean is one example of how cruise lines gear services to meet the needs of families whose loved ones have specialized needs. The cruise line offers packages for persons who are on dialysis as well as for individuals with autism. Services include specialized medical care, on-board activities, support groups, and educational forums for care recipients and their families.

Weekend, summer, and year-round camp programs are also available. Camp Sunshine in Sebago, Maine, offers a recreational opportunity for children with life-threatening illnesses while Friendship Ventures operates camps in Minnesota for children, teens, and adults who have a variety of health concerns. Many of these camps extend their services to include the entire family. Some camps offer sliding scale fees or

"scholarships" while others are entirely free.

### State-Funded Respite Care

Some states are finding that offering family caregivers funding toward respite care helps to avoid more costly nursing home stays. By helping to underwrite the cost of respite care, states are finding that care recipients can delay nursing home placement, which is most often paid for out of the state-funded Medicaid program.

Other states are finding that helping to deliver or arrange for respite care services can help care recipients in rural areas stay in their homes while keeping family caregivers employed, thereby helping to maintain the economic health of families. For example, Arizona offers assistance to families who need short-term or intermittent respite services. Adult day is one of the services included in the Arizona program.

North Carolina offers what is known as "Caregiver Day Out," a service where volunteer caregivers are provided with training and then scheduled to provide respite in situations where the care recipient is a

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physically or cognitively impaired older adult.

In New Hampshire as well as other states, the Administration on Aging's National Family Caregiver Support Program provides limited funds for respite services to caregivers of frail elders who are 60 years of age or older. A state-by-state listing of respite and other services for family caregivers can be found at the Family Caregiver Alliance Web site at [www.caregiver.org](http://www.caregiver.org).

### The Future of Respite Care

In December 2006, Congress passed the Lifespan Respite Care Act, which was created to increase the availability of both planned and emergency respite services regardless of the age of the care recipient. Although the bill promises to bring relief to family caregivers, it will be some time before caregivers find an improvement in local services since the act requires an allocation of \$289 million over a five-year period. At press time, Congress was being urged to provide the necessary funding to support this critical legislation.

Oregon, Nebraska, and Wisconsin have already passed and implemented their own Lifespan Respite legislation. These states are serving as models for how respite care will be organized and delivered throughout the country in the future.

What Lifespan Respite legislation promises is a coordinated statewide respite service with a single point of access. Lifespan Respite programs are designed to be extremely flexible, as seen in Nebraska, where caregivers may be eligible to receive vouchers that can then be used for traditional respite services such as adult day or private hire services. These vouchers can also fund more creative respite options, such as when one family was

## Respite Resources and Tools

### ARCH National Respite Network

Respite referral and information.  
800/773-5433  
[www.archrespite.org](http://www.archrespite.org)  
[www.respitelocator.org](http://www.respitelocator.org)

### Association of Jewish Family & Children's Agencies

Elder care, including respite services.  
800/634-7346  
[www.ajfca.org](http://www.ajfca.org)

### Catholic Charities USA

Respite services.  
703/549-1390  
[www.catholiccharitiesusa.org](http://www.catholiccharitiesusa.org)

### Eldercare Locator

**U.S. Administration on Aging**  
Referral service for elder services.  
800/677-1116  
[www.eldercare.gov](http://www.eldercare.gov)

### Faith in Action

Volunteers offering non-medical assistance.  
877/324-8411  
[www.fiavolunteers.org](http://www.fiavolunteers.org)

### Family Caregiver Alliance

A state-by-state listing of respite and other services for family caregivers.  
[www.caregiver.org](http://www.caregiver.org)

### Family Friends

**National Council on Aging**  
Older adult volunteers matched with families of special needs children.  
202/479-6672  
[www.family-friends.org](http://www.family-friends.org)

### Lotsa Helping Hands

Group calendar for organizing helpers.  
[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

### National Adult Day Services Association

Adult day health services locator.  
800/558-5301  
[www.nadsa.org](http://www.nadsa.org)

### National Center for Assisted Living

Consumer information and directory.  
202/842-4444  
[www.ncal.org](http://www.ncal.org)

### National Easter Seal Society

Serving children and adults with disabilities with home services, camps, and adult day programs.  
800/221-6827  
[www.easter-seals.org](http://www.easter-seals.org)

### Senior Corps, Senior Companions Corporation of National and Community Service

Older volunteers offering non-medical help and companionship.  
[www.seniorcorps.gov](http://www.seniorcorps.gov)

### Share the Care

Guide to creating a caregiving team.  
[www.sharethecare.org](http://www.sharethecare.org)

### Additional resources

A number of national associations provide respite services and/or financial assistance to obtain respite care. Some of these organizations include the American Diabetes Association, National Hospice and Palliative Care Organization, Alzheimer's Association, and the American Cancer Society. Check with the voluntary health agency that deals with your loved one's condition to find out if it offers caregiver respite services.

able to hire a golfing companion for the care recipient. The caregiver received a much-needed break while the care recipient benefited from both a social and recreational outing.

Whether respite services are ultimately provided at the state or national level, the encouraging news is that the importance of respite for

family caregivers and their loved ones is finally receiving the recognition it deserves. ■

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