

ABCs of Respite:

A Consumer Guide for Family Caregivers



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Caregiver Programs & Lifespan Respite: Technical Assistance Centers

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Table of Contents

BEFORE YOU GET STARTED	3
TYPES OF RESPITE	3
IN-HOME MODELS	4
<i>Model 1: Home-Based Services</i>	5
<i>Model 2: Sitter-Companion Services</i>	5
<i>Model 3: Consumer-Directed Respite</i>	5
OUT-OF-HOME MODELS.....	5
<i>Model 4: Family Care Homes or Host Family Model.</i>	5
<i>Model 5: Respite Center-based Model</i>	6
<i>Model 6: Respite in Corporate Foster Home Settings for Children and Teens</i>	6
<i>Model 7: Residential Facilities</i>	6
<i>Model 8: Parent Cooperative Model.</i>	6
<i>Model 9: Respitality Model</i>	7
<i>Model 10: Hospital-Based</i>	7
<i>Model 11: Camps</i>	7
<i>Model 12: Adult Day Care Centers</i>	7
HOW TO CHOOSE A RESPITE PROVIDER.....	7
HOW DO I CHOOSE AN ADULT DAY CARE CENTER?	8
HOW DO I PAY FOR RESPITE?.....	9
REFERENCES.....	10
RESOURCE LINKS.....	10

The ABCs of Respite: A Consumer Guide for Family Caregivers

- **Types of Respite**
- **How do I choose a respite program or provider?**
- **How do I choose an Adult Day Care Program?**
- **How do I pay for Respite?**

Before You Get Started: Respite is a service that provides a temporary break between the family caregiver and the care recipient. It is most important for caregivers to plan ahead when they begin their caregiving activities to access intermittent breaks from caregiving. To be most effective you should consider respite services much earlier than you think you will need them. Respite will be most helpful if you use it before you become exhausted, isolated, and overwhelmed by your responsibilities. Respite services should be beneficial, meaningful, and enjoyable to both the caregiver and the care receiver.

- Family caregivers need to have sufficient and regular amounts of respite time. Give careful thought to how you want to spend your respite time. Respite needs to be meaningful and purposeful for caregivers to fulfill their needs and plans, as well as safe and enjoyable for the care receiver.
- Respite is most effective when combined with other services and assistance, but don't wait to take your break. You may also benefit from additional financial support, education, emotional and social support and a sense of belonging with others. Before you can seek out those services, respite will give you a chance to step back and recharge.

To assess your own need for respite and to ensure that you are making the most of your respite time, please utilize [RESPITE SERVICES: Enhancing the Quality of Daily Life for Caregivers and Care Receivers](#)¹ prepared by Dr. Dale Lund with California State University at San Bernardino. This important guidebook is also available [in Spanish](#).

Sometimes you may need respite in emergencies to deal with a personal health crisis, housing or job loss or other immediate situation that might put the care recipient in harm's way. For children this type of respite may be called a "Crisis Nursery". Emergency or crisis respite may be more difficult to find so familiarizing yourself with providers who might offer emergency respite or even registering in advance with such providers, is important. Both emergency and planned respites are critical resources for caregivers who are caring for an individual with special needs at any age across the lifespan.

In 1997, the first Lifespan Respite Program was established in Oregon. By 2000, similar programs were implemented in Nebraska, Oklahoma, and Wisconsin. In 2009, the US Administration on Aging funded twelve states² to implement State Lifespan Respite Programs, which are designed to help families find respite providers and to help them access respite payment resources. An additional twelve states were funded to establish such systems in 2010³. Many of the state programs are still in their early

¹ For URL addresses of links in blue, see Resource Links at the end of the document.

² Alabama, Arizona, Connecticut, District of Columbia, Illinois, Nevada, New Hampshire, North Carolina, Rhode Island, South Carolina, Tennessee, and Texas.

³ Delaware, Kansas, Louisiana, Nebraska, Massachusetts, Minnesota, New York, Oklahoma, Pennsylvania, Utah, Washington, Wisconsin

implementation phase, but are available to assist families in navigating the maze of respite programs and funding streams by offering a single point of entry for respite. Your first stop for information about respite providers and ways to pay for the service should be to your state's [Lifespan Respite Program](#), if it has one.

If your state does not have a State Lifespan Respite program, first check the [ARCH National Respite Locator](#) to find emergency or planned respite. You can also check with your [State Respite Coalition](#), your state's [Children's Trust Fund](#) or child welfare agency, an [Aging and Disability Resource Center](#), or the [Eldercare Locator Service](#). Private organizations such as Easter Seals, the Alzheimer's Association, National Multiple Sclerosis Society, The ALS Association, University Centers on Disabilities, The Arc of the US, or United Cerebral Palsy may also be able to refer you to respite services in your community.

Types of Respite

Respite programs may utilize an available bed in a health care facility for families who require extended respite options and whose family member or friend requires skilled care; whereas other respite programs may only offer time-limited (a few hours) services in the family's home. In addition, respite services may be available to families through formal programs that hire and train their staff or may be available to families through informal networks such as parent cooperatives or cash subsidies from states to purchase respite through relatives and friends.

Respite services are usually offered on a sliding fee schedule or there may be a combination of family fees, state and federal funding, including Medicaid waivers, and/or private insurance. Providers may be paid or unpaid in many of the following models (See Funding Sources).

The following descriptions are examples of local respite program models.

In-home Models

Many families prefer respite that is provided in the home. There are several advantages to in-home respite:

- The care recipient may be most comfortable in the home setting and does not have to adjust to a different environment.
- The parents/caregivers may be more comfortable if the care recipient does not have to leave the home.
- The home is already equipped for any special needs the child/adult may have.
- The cost is relatively economical (especially if voucher systems are used to pay for services).

Sometimes in-home care is coordinated by a broker, an individual or agency who agrees to recruit, provide basic training and keep a database of all respite providers. Families can be matched with a provider by calling the broker or agency, and they are usually responsible for training, payment and repeat scheduling. If you have a Lifespan Respite Program in your state, they will be able to assist you in finding providers, payment resources and training options.

Listed here are some of the typical models used in in-home respite.

Model 1: Home-Based Services

Home-based respite services may be provided through a public health nursing agency, a social service department, a volunteer association, a private nonprofit agency and/or a private homemaker service or home health agency. A trained and perhaps licensed employee of the agency is available to come into the home and offer respite. Ideally, services should be available twenty-four hours a day, 365 days per year.

Model 2: Sitter-Companion Services

Sitter services may be provided by individuals who are trained in caring for children or adults with special needs. Often this type of service can be a project of a service organization or specialized agency (Camp Fire, Jaycees, Junior League, local ARC or United Cerebral Palsy Associations) that is willing to sponsor training and/or maintain a register of trained providers to link to families in need.

Model 3: Consumer-Directed Respite

This model is similar to having a friend or relative volunteer to care for a child or adult with special needs. The primary difference is that the person providing care is identified or selected by the family and trained by a respite program or by the families themselves. Providers may be paid or unpaid. If they are paid, it is often through a voucher program offered directly to family caregivers to allow them to locate, hire, train and pay their own providers.

Out-of-Home Models

Out-of-home respite provides an opportunity for the care recipients to be outside the home. This may be a particularly attractive option for adolescents who are preparing to leave the family home for a more independent living arrangement, for young adults with disabilities who prefer to be with people their own age, or even aging populations with mild to moderate memory loss. Such settings provide an opportunity for them to experience new surroundings, different expectations, peer relationships and even cognitive and emotional stimulation. Families are free to enjoy time in their own home without the constraints of constant care and they can devote more attention to siblings and other family members.

Listed below are some special considerations regarding out-of-home models.

- Transportation may be required and special equipment may need to be moved.
- The individual receiving care may not like the unfamiliar environment or may have difficulty adjusting to the changes.
- The services may be offered in a variety of settings more restrictive than the care recipient's home, such as special medical centers or nursing homes.

Model 4: Family Care Homes or Host Family Model

In this model, respite is offered in the provider's home. This could be the home of a staff person from a respite program, a family day care home, a trained volunteer's family home or a licensed foster home

used only for respite stays. Offering respite in a provider's home enables an individual to receive services in a more familiar setting. It is recommended that homes used under this model be licensed under state regulations governing foster homes or similar homes used for group care.

Model 5: Respite Center-based Model

Some respite programs contract with existing day care centers to provide respite to children with special needs. This is an effective model in rural areas because it allows children to be in a supervised environment in a facility that may be relatively close to home. Children may be placed in these settings on a short-term "drop in" basis as well. Day care centers may be housed in churches, community centers and after school programs. Not all centers are licensed by the state to provide services. Respite centers utilizing church, mosque or synagogue social halls, community centers or senior service centers offer similar services for the aging population on a regular, daily or intermittent basis (e.g., one weekend day a month).

Certain service organizations, such as Easter Seals, human service agencies or community-based private independent respite providers may offer respite in a center-based setting, employing trained staff and/or volunteers. These settings are usually regulated by the state.

Model 6: Respite in Corporate Foster Home Settings for Children and Teens

In some states, foster care regulations and licensing accommodate the development and operation of foster care "homes" which are managed by a non-profit or for-profit corporation. In this situation, several children or adolescents who have disabilities are placed outside their family homes and live together in a homelike environment with the help of a trained, rotating staff. These corporation operated foster homes may provide respite care, either as vacancies occur in the homes or as the sole purpose for which the "home" exists. Some adolescents adapt especially well to this situation, enjoying a setting that is like semi-independent living.

Model 7: Residential Facilities

Some long-term residential facilities, particularly those serving persons with developmental disabilities, have a specified number of beds set aside for short-term respite. Some examples of such facilities are community residences such as group homes and supervised apartments, nursing homes and state-owned facilities. Increasingly assisted living programs for the aging population are offering respite for overnight, weekend or extended stays.

Model 8: Parent/Family Cooperative Model

Parent cooperatives have been developed in communities, especially rural areas, where respite services are very limited. In this type of model, families of children with disabilities and/or chronic illnesses develop an informal association and "trade" respite services with each other. This model has been used successfully for young veterans with traumatic brain injury or other conditions who are living at home. This exchange program allows families to receive respite on scheduled dates. In most parent cooperatives, fees are not assessed. This model has proven to be especially effective for families whose children or family members have similar disabilities.

Model 9: Respitality Model

Respitality is an innovative concept for providing respite. It provides a cost-effective partnership between the private sector and respite agencies. During Respitality, participating hotels provide the family with a room, a pleasant dining experience and perhaps entertainment while a local respite program provides respite either in the family's home or in an out-of-home respite situation. The Respitality concept was developed by United Cerebral Palsy of America.

Model 10: Hospital-Based

Facility-based respite occurs primarily in hospitals. It provides a safe setting for children and adults with high care needs. It can be a good alternative for a small community that has a hospital with a typically low census or a hospital with low weekend occupancy. Individuals can receive high quality care while remaining in a familiar setting with familiar people. In larger communities, a hospital provides the sense of security parents and caregivers need when considering respite.

Model 11: Camps

Camp has been a form of respite for many families for many years. Whether or not a child has a disability, camp can be a positive experience for any child as well as a break for parents/caregivers. For children with disabilities, chronic or terminal illnesses, the chance to participate in either an integrated or an adapted camp can be life-expanding. Many places around the country offer such experiences as either day or overnight camps.

Model 12: Adult day care centers

Adult day care centers, also known as adult day services, have been providing a form of respite for caregivers for more than twenty years. Such services have expanded dramatically in the last decade as demand has increased but also as new funding sources, such as Medicaid waivers, became available. Adult day care centers provide a break (respite) to the caregiver while providing health services, therapeutic services and social activities for people with Alzheimer's disease and related dementia, chronic illnesses, traumatic brain injuries, developmental disabilities and other problems that increase their care needs. Some adult day care centers are dementia specific, providing services exclusively to that population. Other centers serve the broader population.

One difference between traditional group and in-home adult respite and adult day care is that adult day centers not only provide respite to family caregivers but also therapeutic care for cognitively and physically impaired older adults.

Generally, although programs vary, participants attend the program for several hours a day to a full day (eight hours) up to five days a week. Most programs do not offer weekend or overnight services although a few may offer half-day services on Saturdays.

How to Choose a Respite Provider

Some states require licensing for respite providers. If your state does not it is even more important to do a thorough background and qualifications check, especially if you are dealing with individuals who are not associated with companies or agencies. Most company and agency providers will have done background and reference checks for their employees but do not assume, ask instead. Here is a quick checklist to use when considering a provider:

1. Telephone screening and interview
2. Ask for references
3. Check references, criminal background
4. Personal interview
5. Evaluate costs and financing
6. Write a contract that provides specific details

The idea is to get to know the prospective provider as well as possible before committing to the relationship. Then you must communicate your expectations in very specific terms. Finally, these expectations should be in writing to help assure that both parties understand them and will not need to rely on memory if difficulties arise later. For more information on respite for specific ages or conditions, see free downloadable [ARCH Fact Sheets](#). A variety of consumer guides, workbooks and checklists also are available to help you sort out the myriad of options you may have in your community and, in some instances, offer guidance on training the provider:

- [The Respite Care Workbook](#) from the Child Neurology Foundation
- [Get Creative About Respite-A Parent's Guide and Get Creative about Respite - What You Need To Know About Me](#) from the [Connecticut Lifespan Respite Coalition](#)
- [A Respite Guide for Caregivers and Providers](#): Developed by the Texas Dept. on Aging in Partnership with the Area Agency On Aging Caregiver Task Force
- [Finding Caregivers and Respite Providers](#) compiled by the SC Respite Coalition and Family Connection
- [Respite Care Guide: Finding What's Best For You](#) - The Alzheimer's Association
- [Relax. Take a Break: A Family Guide to Respite for Children in Michigan](#)
- [Guide To Caregivers](#) (February 2004) A result of the "Caregiver Project", a committee of the Saskatoon Council on Aging.
- [Family Guide to Respite \(August 2006\)](#). Prepared by Special Kid's Network's regional staff in collaboration with their community partners and the Pennsylvania Department of Health's Children with Special Health Care Needs Consultants

How Do I Choose an Adult Day Care Center?

Family members must do some research to determine whether the adult day care center is right for their loved ones. The components of a quality adult day care program should include the following:

- Conducts an individual needs assessment before admission to determine the person's range of abilities and needs;
- Provides an active program that meets the daily social, recreational and rehabilitative needs of the person in care;

- Develops an individualized treatment plan for participants and monitors it regularly, adjusting the plan as necessary;
- Provides referrals to other needed community services;
- Has clear criteria for service and guidelines for termination based on the functional status of the person in care;
- Provides a full range of in-house services which may include personal care, transportation, meals, health screening and monitoring, educational programs, counseling and rehabilitative services;
- Provides a safe, secure environment;
- Uses qualified and well-trained volunteers;
- Adheres to or exceeds existing state and national standards and guidelines.

A good place to begin searching for a program is the Yellow Pages, which will list possible options under "Day Care Centers-Adult". The Better Business Bureau may have information on for-profit adult day care centers. At the national level contact the National Council on Aging (NCOA) or the National Adult Day Services Association (NADSA) for a set of guidelines for adult day service programs <http://www.nadsa.org/knowledgebase/details.php?id=557>

Local Area Agencies on Aging (AAA) can also direct you to adult day care centers in your area. Contact the [Eldercare Locator](#) to find the AAA nearest you. Ultimately, word of mouth is often one of the best ways of finding quality adult day care.

How do I pay for Respite?

A range of possible state and federal funding sources may be available to help you pay for respite. If you have a [State Lifespan Respite Program](#) or [State Respite Coalition](#) they should be able to link you to existing funding sources or assist with possible funding sources that may be unique to your state. For state-by-state information on funding sources for adult respite, visit the [Family Caregiver Alliance Family Care Navigator Program](#). Check the [Funding Update](#) section of the ARCH website frequently for new ARCH information on state-by-state respite funding sources for all ages. A few possibilities include:

Medicaid Waivers: Generally, every state offers some respite assistance through various Medicaid Waivers. Each state's eligibility criteria and funding for waivers is different and you should check with your state's Medicaid office.

Medicaid State Plan: If you live in IA, CO, NV, and WA, and you qualify for Medicaid under income guidelines and other home and community-based services (HCBS) needs-based criteria, respite may be covered under your state's Medicaid plan without the need for a waiver.

Medicare Hospice Benefit: If someone you love is in hospice, their caregivers are eligible for respite funding under Medicare.

National Family Caregiver Support Program: Funding may be available if you are caring for someone over the age of 60 or someone of any age with Alzheimer's. Funding for respite may also be available through the National Family Caregiver Support Program, which is administered through your local Area Agency on Aging (AAA) if you are a grandparent age 55 or older caring for a grandchild or the relative of

an adult with certain disabilities. Visit the Elder Care locator service at www.eldercare.gov to contact your AAA about respite funding options.

State Family Caregiver Support Programs: If your state has a state-funded family caregiver support program (visit the [Family Caregiver Alliance Family Care Navigator Program](#)), you may have respite funding available.

Military Families and Veterans: Veterans eligible for outpatient medical services can also receive non-institutional respite, outpatient geriatric evaluation and management services and therapeutically oriented outpatient day care. Respite care may be provided in a home or other non-institutional setting, such as a community nursing home. Ordinarily respite is limited to no more than 30 days per year. The services can be contracted or provided directly by the staff of the Veterans Health Administration (VHA) or by another provider or payor. Military families should also look to TRICARE's Extended Care Health Option (ECHO) or the Military Exceptional Family Member Program (EFMP), which offers respite care to anyone in the military who is enrolled in the EFMP and meets the criteria. A new program administered by the Department of Veterans Affairs, the Family Caregiver Program of the Caregivers and Veterans Omnibus Health Services Act of 2010, will provide additional support to eligible post-9/11 Veterans who elect to receive their care in a home setting from a primary Family Caregiver. For more information, [click here](#).

Funding for Adult Day Care

Medicare does not cover day care costs but Medicaid can pay all the costs in a licensed day care center with a medical model or an Alzheimer's environment, if the senior qualifies financially. Some day care centers offer need-based scholarships. Others may use a sliding fee scale based on income. Private medical insurance policies sometimes cover a portion of day care costs when registered, licensed medical personnel are involved in the care. Long-term care insurance may also pay for adult day services, depending upon the policy. Dependent care tax credits may be available to the caregiver as well.

This list is by no means exhaustive. For a general fact sheet on additional possible federal respite funding sources, see [Building Blocks for Lifespan Respite: Federal Funding for Adult's and Children's Respite](#).

References

ARCH National Respite Resource Center (Rev. 1994). *Respite for Children with Disabilities and Chronic or Terminal Illnesses*. Chapel Hill: ARCH Factsheet Number 2, 1992.

ARCH National Respite Resource Center (2002). *Adult Day Care: One Form of Respite for Older Adults*. Chapel Hill: ARCH Factsheet Number 54, April 2002.

ARCH National Respite Resource Center (2002). *Respite for Persons with Alzheimer's Disease or Related Dementia*. Chapel Hill: ARCH Factsheet Number 55, April 2002.

ARCH National Respite Network and Resource Center (2011). *Building Blocks for Lifespan Respite: Federal-Funding for Adult and Children's Respite*. Chapel Hill: Lifespan Respite 101 Toolkit: Fact Sheet 2, 2011.

Resource Links

[Aging and Disability Resource Centers](#)

<http://www.adrc-tae.org/tiki-index.php?page=AboutStates>

[ARCH Fact Sheets](#)

<http://archrespite.org/productspublications/arch-fact-sheets>

[ARCH National Respite Locator](#)

<http://archrespite.org/respitelocator>

Building Blocks for Lifespan Respite: Federal Guide to Funding for Adult's and Children's Respite

http://www.archrespite.org/images/docs/Lifespan_Summit_Docs/Building_Blocks_for_Lifespan_Respite.pdf

[Children's Trust Fund](#)

<http://www.friendsnrc.org/state-lead-agency-contacts>

[Eldercare Locator Service](#)

[Family Caregiver Alliance Family Care Navigator Program](#)

http://caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083

[Lifespan Respite Program Contacts](#)

<http://www.archrespite.org/lifespan-programs>

Respite Guide Books

- [The Respite Care Workbook](#) the Child Neurology Foundation
http://www.childneurologyfoundation.org/main_advocacy_2.cfm
- [Get Creative About Respite-A Parent's Guide](#) and [Get Creative about Respite - What You Need To Know About Me](#) from the [Connecticut Lifespan Respite Coalition](#) <http://ctrespite.org/>
- [A Respite Guide for Caregivers and Providers](#): Developed by the Texas Dept. on Aging in Partnership with the Area Agency On Aging Caregiver Task Force
http://www.dads.state.tx.us/providers/AAA/Forms/voucher_program/RespiteGuide.doc
- [Finding Caregivers and Respite Providers](#) compiled by the SC Respite Coalition and Family Connection http://www.archrespite.org/docs/Faith-Based_Caregivers_SC.pdf
- [Respite Care Guide: Finding What's Best For You](#) - The Alzheimer's Association
http://www.alz.org/national/documents/brochure_respitecareguide.pdf
- [Relax. Take a Break: A Family Guide to Respite for Children in Michigan](#)
http://www.hcbs.org/files/116/5773/Family_Guide_To_Respite-FINAL.pdf

- [Guide To Caregivers](http://caregive.sasktelwebsite.net/caregiverguide/guide2005.pdf) (February 2004) A result of the “Caregiver Project”, a committee of the Saskatoon Council on Aging. <http://caregive.sasktelwebsite.net/caregiverguide/guide2005.pdf>
- [Family Guide to Respite \(August 2006\)](http://www.dsf.health.state.pa.us/health/lib/health/familyhealth/familyguidetorespitecare.pdf). Prepared by Special Kid’s Network’s regional staff in collaboration with their community partners and the Pennsylvania Department of Health’s Children with Special Health Care Needs Consultants <http://www.dsf.health.state.pa.us/health/lib/health/familyhealth/familyguidetorespitecare.pdf>

Respite Services: Enhancing the Quality of Daily Life for Caregivers and Care Receivers
<http://sociology.csusb.edu/docs/Respite%20Brochure%20%282010%29.pdf>

Spanish Version: Respite Services: Enhancing the Quality of Daily Life for Caregivers and Care Receivers
<http://sociology.csusb.edu/docs/Respite%20Brochure%20Final%20Spanish%20Version.pdf>

National Adult Day Services Association (NADSA) guidelines for adult day service programs
<http://www.nadsa.org/knowledgebase/details.php?id=557>

[State Respite Coalition](http://archrespite.org/state-respite-coalitions) Contacts
<http://archrespite.org/state-respite-coalitions>