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## **A Variety of Respite Programs Available**

### **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 if possible 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 can be beneficial, meaningful, and enjoyable to both the caregiver and the care recipient.

- 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 that provide a sense of belonging with others, but 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 [\*Time for Living and Caring: Making Respite Services Work for You!\*](#) (English version updated 2014) prepared by Dr. Dale Lund and others.

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 harms 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. Since 2009, the US Administration on Aging has funded 37 states and the District of Columbia to implement State Lifespan Respite Programs, which were designed to help families find respite providers and to help them access respite payment resources. Many, but not all, of the originally funded state programs still are available to assist families in navigating the maze of respite programs and funding streams. Your first stop for information should be to your state's [Lifespan Respite Program](#) if it has one. [State respite or caregiving coalitions](#) may have this information as well.

If your state does not have a State Lifespan Respite program or a State Respite Coalition, first check the [ARCH National Respite Locator](#) to find emergency or planned respite providers. You can also check with an Area Agency on Aging (AAA), or an Aging and Disability Resource Center (ADRC). To find an AAA or ADRC near you, visit the [Eldercare Locator Service](#)

Private organizations such as Easterseals, the Alzheimer's Association, Family Voices or Family to Family Health Information Centers, the National Multiple Sclerosis Society, The ALS Association, University Centers on Disabilities (UCEDDs), or United Cerebral Palsy may also be able to refer you to respite services in your community.

If you are a veteran or the family caregiver of a veteran, call the VA Caregiver Support Line at 1-833-260-3274 or visit the online [VA Caregiver Support Center](#)

To find additional family caregiver support and assistance, visit the Family Caregiver Alliance's [Services by State](#).

## **Types of Respite**

Formal and informal, in-home, and out-of-home respite options may exist in your locality. 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 (e.g., volunteer or faith-based initiatives, 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 *How do I pay for respite?* below).

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 you hire and train your own provider).
- Transportation barriers for the care recipient are eliminated.

Sometimes in-home care is coordinated by an agency that agrees to recruit, provides basic training, and keeps a database of all respite providers. Families can be matched with a provider by calling the agency and are usually responsible for training, payment, and repeat scheduling. If you have a Lifespan Respite Program or a State Respite Coalition in your state, they will be able to assist you in finding providers, payment resources, and training options. Online services, such as Care.com, Rewarding Work, or state online direct care worker registries, can help you find an independent respite provider that you hire and train yourself.

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

#### **Model 1: Home-Based Services**

In addition to respite providers you may find and train yourself, 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), which 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 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. This approach may also be available for in-home or out-of-home respite.

The state or agency offering the vouchers may employ a fiscal management agency to help with payment and necessary payroll taxes for respite providers. The sponsoring agency may also utilize a list of possible agencies or respite providers to provide respite and families may select from this list of approved 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 because it gives them an opportunity 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 or group home used 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. 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 older adults on a regular, daily, or intermittent basis (e.g., one weekend day a month).

Certain service organizations, such as Easterseals, human service agencies, community-based private independent respite providers, or faith-based organizations 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 Foster or Group Homes**

In some states, foster care regulations and licensing accommodate the development and operation of foster care or group "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 trained, rotating staff. These foster or group 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.

Increasingly, group home settings for older individuals are offering long-term residential care, and may also offer respite services. You can check with an Area Agency on Aging (AAA) or an Aging and Disability Resource Center (ADRC) to see if these exist in your community. Contact the [Eldercare Locator](#) to find the AAA or ADRC near you.

#### **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 or nursing homes for older adults are offering respite for overnight, weekend, or extended stays.

#### **Model 8: Parent / Family Caregiver Cooperative Model**

Parent or Family Caregiver 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 or family caregiver cooperatives, fees are not assessed. This model has proven to be especially effective for families whose children or other family members have similar disabilities.

#### **Model 9: Respitality Model**

Respitivity is an innovative concept for providing respite. It provides a cost-effective partnership between the private sector and respite agencies. During Respitivity, participating hotels provided 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 Respitivity 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. Veterans (VA) Medical Centers often provide respite for eligible veterans.

#### **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 adapted camp can be life-expanding. Many places around the country offer such experiences, either as day or overnight camps. Such models are sometimes available for adults with disabilities as well through agencies such as Easterseals or United Cerebral Palsy.

#### **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 decades. Such services have expanded dramatically in the last twenty years 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 dementia, including Alzheimer's disease, 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 adult respite, both group and in-home care, and adult day care is that adult day centers not only provide respite to family caregivers but also therapeutic care for older adults with cognitive or physical disabilities.

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 services, although a few may offer half-day services on Saturdays.

## **How to Choose a Respite Provider**

### **Hiring on Your Own**

Some states require training and 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 and you are hiring the individual on your own. 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. Conduct a telephone screening
2. Follow up with an in-person Interview
3. Ask for references and documentation of training or credentials
4. Assess whether the provider is trained and capable of administering medications, assisting with medical tasks or daily living needs, if necessary. Are they experienced and comfortable in handling the unique needs of your loved one?
5. Ask if they are willing to engage in or offer activities or companion services requested by the person in care.
6. If the provider will be driving the care recipient, do they have a valid driver's license?
7. Check references and do a criminal background check or make sure that a background check was performed recently.
8. Evaluate costs and financing
9. 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 and when difficulties arise later.

### **Using an Agency**

If you are selecting a home health or other agency that will send a respite provider into your home or if you are using a center-based program, you should ask these additional questions:

1. How are the workers selected and trained?
2. Are background checks performed?
3. Are respite workers licensed and bonded, if required?
4. What tasks can be performed by the respite worker?
5. Can the respite worker administer medications, assist with medical tasks or daily living needs, if necessary?
6. Will the respite provider engage in or offer activities or companion services requested by the person in care?
7. What hours and days are services available?
8. If the provider will be driving the care recipient, do they have a valid driver's license?
9. What is the eligibility process?
10. What are the fees and how are they paid?
11. How are emergencies and problems handled?
12. Are references available?

If you are considering respite services outside the home, request a tour for you and your loved one. When possible, visit the facility or program more than once and observe the engagement between participants and staff. Observe for cleanliness and the types of activities available. Are there opportunities for social engagement or other activities desired by the care recipient?

For more information on respite for specific ages or conditions, see free downloadable [\*Nine Steps to Respite Fact Sheets\*](#). ARCH also provides [\*National Respite Guidelines\*](#) that may help you learn what to look for in a high quality respite setting.

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 so you can train the respite provider yourself:

### **Help for Choosing Children's Respite**

- A [\*Practical Guide to Respite for Your Family\*](#) by Molly Dellinger-Wray and Monica Uhl with the Partnership for People with Disabilities (formerly the Virginia Institute for Developmental Disabilities), a university affiliated program at Virginia Commonwealth University
- [\*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.
- [\*Finding Caregivers and Respite Providers\*](#) compiled by the SC Respite Coalition and Family Connection
- [\*The Respite Notebook\*](#) developed by the Child Neurology Foundation (updated 2017)

### **Help for Choosing Respite for Adults and Aging**

- [\*Respite Care Guide\*](#) - The Alzheimer's Association
- National Adult Day Services Association (NADSA) guidelines and [\*checklist\*](#) for adult day service programs to help in [\*choosing a center\*](#).

### **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.

Contact the National Adult Day Services Association (NADSA) for a [\*set of guidelines\*](#) for helping to select adult day service programs. They also have a [\*directory of adult day programs\*](#).

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 Find and Pay for Respite?**

The first place to look for respite providers or programs is your [\*State Lifespan Respite Program\*](#) or [\*State Respite Coalition\*](#). Some states maintain their own state respite registries. If your state does not have these resources, the [\*ARCH National Respite Locator Service\*](#) (NRLS) can provide you with a list of respite programs in your geographic area. You can search the NRLS by the age of the person you are providing care for and by zip code.

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 other available state funding possibilities, including state-specific Medicaid waiver funding or other available funding possibilities, you can also visit the [\*ARCH National Respite Locator Service \(NRLS\)\*](#) funding and resources map and click on your state for program eligibility and funding information.

The following list of possible federal funding sources to help pay for respite is by no means exhaustive. For additional possible federal respite funding sources and how

to connect to them, see [Federal Funding and Support Opportunities for Respite](#). Information on federal programs that support respite is presented in a [summary table](#).

A few funding possibilities include:

**Medicaid Waivers:** Generally, every state offers some respite assistance through various home and community-based Medicaid Waivers. Each state's eligibility criteria and funding for waivers are different and you should check with your state's Medicaid office. To find out which waivers are available in your state and information about eligibility, see ARCH's [Medicaid Waivers for Respite Support](#).

**Medicaid State Plan:** If you live in a state that adopted the **Section 1915(i) Medicaid State Plan Option for Home and Community-Based Services** and the person you care for qualifies for Medicaid under income guidelines, respite may be covered under your state's Medicaid plan without the need for a waiver.

**Medicare Hospice Benefit:** If someone is eligible for Medicare and is in hospice, their caregivers are eligible for the Medicare respite benefit under Hospice Care. See more about the [Medicare Hospice Benefit](#).

**Medicare Advantage Plans:** Medicare Advantage plans may now cover non-medical supplemental benefits such as adult day care services and respite. Other optional covered services that benefit the plan holder, as well as their family caregivers, may include home care, transportation to appointments, meal delivery, and home modifications.

**National Family Caregiver Support Program:** Funding may be available through the National Family Caregiver Support Program, which is administered through your local Area Agency on Aging (AAA) if you are caring for someone over the age of 60 or someone of any age with Alzheimer's or other dementias. Funding for respite may also be available if you are a grandparent or other relative age 55 or older caring for a child or if you are a parent or other relative age 55 or older caring for an adult child with disabilities. Visit the [Eldercare locator service](#) to contact your AAA about respite funding options.

**State Family Caregiver Support Programs:** If your state has a state-funded family caregiver support program, you may have respite funding available. Visit

[Services by State](#) from the Family Caregiver Alliance for more information.

**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. A program administered by the Department of Veterans Affairs, the *Program of Comprehensive Assistance to Family Caregivers* is available to eligible Veterans who elect to receive their care in a home setting from a primary family caregiver. For more information, visit the [VA Caregiver Support Program](#) or call the VA Caregiver Support Line at 1-855-260-3274. See ARCH's [Nine Steps to Respite for Military and Veteran Caregivers](#) for more information and additional resources.

**Military Families:** Military families should also look to TRICARE's Extended Care Health Option (ECHO) or the Military Exceptional Family Member Program (EFMP), which offers respite to anyone in the military who is enrolled in the EFMP and meets the criteria. See summary [table of federal programs](#) that may be available to military families for respite.

**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. See also Medicare Advantage above.

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The mission of the [ARCH National Respite Network and Resource Center](https://archrespite.org) is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

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