



archrespite.org

STEP
1

Understanding
Respite Care

STEP
2

Types of Respite
Care Available

STEP
3

Where Do
I Find Services?

STEP
4

How Will I Pay
for Respite?

STEP
5

How Do I Decide
What's Right for Me?

STEP
6

Preparing My Loved
One for Respite

STEP
7

Planning to Make the
Most of Respite

STEP
8

Orienting Respite
Providers

STEP
9

Find Out About Other
Helpful Resources

9 STEPS TO RESPITE CARE for Family Caregivers of Persons with Dementia, including Alzheimer's Disease

Are you a caregiver of a family member with dementia including Alzheimer's disease?

You are called a caregiver if you help or support another person in need due to medical, physical or mental conditions or functional limitations, whether you help full-time or as time permits. The person needing help may live in their own home, with you or in a residential setting.

Caregivers of family members with dementia including Alzheimer's disease (D/AD) may face special challenges. Sometimes, individuals with dementia or Alzheimer's disease have unique physical, emotional and behavioral conditions that require specialized care. For example, memory, decision-making abilities, and behavior associated with D/AD change over time. This results in changing roles within the family and the need for more intensive levels of care. Providing care can be complicated and challenging and will require careful planning.

▶▶▶ Tools are available to assess your own needs including the **Caregiver Self-Assessment Questionnaire** caregiverslibrary.org/Portals/0/CaringforYourself_CaregiverSelfAssessmentQuestionnaire.pdf from the American Medical Association.

Recent research has shown a growing incidence of early onset Alzheimer's for people with Down's Syndrome. There are additional resources available for this population and they are listed on page 10.

At times you and members of your family may feel overwhelmed and stressed while your family member may be confused or depressed. You may find that your health and well-being are impacted by all that caregiving entails. Therefore, identifying yourself as a "caregiver" is important for there are numerous resources available to help you.

▶▶▶ This factsheet is a guide for getting the respite care you deserve. By reading it, you will have a better understanding of the resources that are available, what you can expect and how to select a high-quality service that best meets the needs of your family.

9 STEPS TO RESPITE CARE for Family Caregivers of Persons with Dementia, including Alzheimer's Disease

STEP 1 Understanding Respite Care

It is important for you to be aware of a resource called respite care. Respite services can provide you with a much needed break away from your caregiving responsibilities. By taking a break, you will become less stressed, better rested and renewed. Sometimes feelings of guilt or anxiety about leaving your family member may keep you from seeking respite in a timely way. Families are encouraged to start using respite care at the beginning of their caregiving experience and on a regular basis to avoid feelings of guilt, exhaustion, isolation and burnout.

STEP 2 Types of Respite Care Available

Respite care is offered in a variety of ways. You can receive a break for a few hours, a few days or even several weeks. Services may take place in the home, or outside the home, in a community or faith-based agency or organization, at an adult day care program, in a hospital or healthcare facility, or in a residential setting such as a nursing home, an assisted living facility, or adult foster home. Other family members, friends or neighbors may also be available to provide informal respite opportunities.

Paid care may be provided by a home health agency or other community-based program, or it could be someone you hire on your own. Volunteer services are available in many communities. Churches, synagogues and other faith-based organizations are increasingly offering respite for people with memory loss and some forms of dementia, often utilizing volunteers from the congregation. Services may be free or offered on a sliding scale. Some respite service organizations support people within a specific age bracket or persons with specific conditions. In some cases, emergency respite services are available.

The [Alzheimer's Association – Respite Care, Alzheimer's and Dementia Caregiver Center](#) has information on using respite care, types of respite care, and overcoming concerns: alz.org/help-support/resources/helpline



▶▶▶ The National Institute on Aging's [Getting Help with Alzheimer's Caregiving](#) provides an overview of caregiver resources and strategies for taking care of yourself while caregiving at nia.nih.gov/health/getting-help-alzheimers-caregiving. You can also order the FREE resource [Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide](#) at order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide

STEP
3

Where Do I Find Services?

There are several ways to find respite. Some programs are for specific populations such as adults with disabilities or older adults with dementia, while others are provided to the general public. Below is an overview of places to contact regarding the respite services that are available in your community.

Respite Programs Serving Individuals with Dementia or Alzheimer's Disease

- **Local Alzheimer's Association chapters** provide support to caregivers and can help you find respite services and options in your community. Also, some chapters offer respite services. Follow this link to find your local Alzheimer's Association chapter: alz.org/local_resources/find_your_local_chapter
- The **Alzheimer's Foundation of America (AFA)** provides a search option to assist you in locating local services including respite and adult day services provided by their member agencies: alzfdn.org/membership-grants/find-an-afa-member-organization
- The **National Family Caregiver Support Program** provides respite and other caregiver support to caregivers assisting someone 60 and older, an Alzheimer's patient of any age, or to a grandparent or relative caregiver (age 55+) of a minor child, or to an older parent or relative caregiver (age 55+) of an adult with disabilities. You can access services through your local **Area Agency on Aging (AAA)**. To find the AAA nearest you, contact the **Eldercare Locator** at eldercare.acl.gov or call 1-800-677-1116.
- **Programs of All Inclusive Care for the Elderly (PACE)** provide a continuum of services that allow persons who are certified to need nursing home care to remain at home for as long as possible. Respite care and adult day services are provided in addition to medical and other services. To find a PACE program near you, visit and npaonline.org/

▶▶▶ These Alzheimer's helplines are available for information and referrals:

- The **Alzheimer's Association 24/7 Helpline** provides information and support to people with memory loss, caregivers, health care professionals, and the public at 1-800-272-3900. The helpline can also assist with referrals to community programs and services: alz.org/help-support/resources/helpline
- The **Alzheimer's Foundation National Toll-free Helpline** provides information and counseling by licensed social workers and can refer you to community resources. Call 1-866-232-8484 or go to alzfdn.org/contact-social-worker

pace-you/pacefinder-find-pace-program-your-neighborhood.

- **National Adult Day Services Association** has a checklist (nadsa.org/wp-content/uploads/2015/08/Site-Visit-Checklist-for-the-web.pdf) to help you select an adult day service program and a locator at nadsa.org/locator to find services near you.
- The **VA Caregiver Support Program** at the U.S. Veterans Health Administration offers up to 30 days of respite care per year for eligible Veterans. The care is provided in the home, at a VA facility or an adult day care center. Respite is a covered benefit for all Veterans enrolled in the VA health care system or who are eligible for VA health care without the need to enroll for such care. For more information, contact your local VA Caregiver Support Coordinator at caregiver.va.gov or call toll-free 1-855-260-3274.

Finding Respite in the General Population

These programs are available to help all caregivers. You will need to contact the organization listed for further details:

- **No Wrong Door (NWD) Systems** established jointly by the Administration for Community Living and the Centers for Medicare and Medicaid Services are working in every state to make it easier for all people needing long-term services, including respite, to get the support they need. To find a NWD system (also known as **Aging and Disability**

Resource Centers) near you, visit the **Eldercare Locator** eldercare.acl.gov or call 1-800-677-1116.

- The **Lifespan Respite Care Program** is available in some states to help caregivers of children and adults get respite services. Some states provide planned and emergency respite services to persons who are unserved by other programs. Lifespan Respite programs or their State Respite Coalition partners may help you find respite providers or funding resources to help you pay for respite. For Lifespan Respite state contacts, see archrespite.org/lifespan-programs. For State Respite Coalition Contacts, see archrespite.org/state-respite-coalitions. If your state does not have a State Lifespan Respite Program or a State Respite Coalition, you can visit the **ARCH National Respite Locator Service (NRLS)** at archrespite.org/respitelocator to find possible respite programs in your area.



- Community-based disability organizations, such as **Easterseals**, provide adult day and in-home services for people with disabilities, including those with dementia and Alzheimer's disease. Find services in your state at easterseals.com/our-programs/adult-services.
- **National Association for Home Care and Hospice** provides a National Agency Location Service. Visit agencylocator.nahc.org.

STEP
4

How Will I Pay for Respite?

In many cases, respite will be free. In some cases, however, you will be required to pay a co-payment based on the care recipient's medical or disability status and financial information. Similarly, Medicaid respite is for caregivers of older adults or persons with specific disabilities or conditions that meet income guidelines. Services are delivered without charge. In addition, some volunteer and public respite programs are free for caregivers.

Possible Public Funding Sources for Respite

- **Medicaid:** Generally, every state offers some respite assistance through various Medicaid Waivers. Contact your local Medicaid office by visiting medicaiddirectors.org/about/medicaid-directors for details about eligibility and providers under the Medicaid state plan. To find out more about specific Medicaid waivers that pay for respite in your state, click on your state on the **ARCH US Map for Medicaid Waivers** at archrespite.org/resource-library/medicaid-waivers.

- **State Funded Respite Programs:** Your state may provide respite through state-funded respite, caregiver or family support programs for children and/or adults with developmental and intellectual disabilities, special medical needs or for older family members with Alzheimer's. Check with your State Lifespan Respite program for more information or check with your state aging agency.

- **State Family Caregiver Support Programs:** If your state has a state-funded family caregiver support program, you may have respite funding available. Visit the **Family Caregiver Alliance** at caregiver.org/connecting-caregivers/services-by-state.
- **Consumer-Directed Respite:** Some Lifespan Respite Programs, state-funded respite programs, and Medicaid waivers, provide respite vouchers or a service budget that allow family caregivers to hire, train and pay your own respite providers. These programs are sometimes known as cash and counseling, or consumer or participant-directed services, but program names differ from state to state.
- **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. A similar benefit exists for Medicaid eligible individuals in some states: medicare.gov/Pubs/pdf/02154-Medicare-Hospice-Benefits.PDF
- **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. Visit the Eldercare Locator to contact your AAA about respite funding options: eldercare.acl.gov

Private Funding Sources for Respite

- **HFC Grant Program:** HFC and the **Home Instead Senior Care** network are working together to provide in-home respite care grants for those providing care for loved ones with Alzheimer's disease or other dementias: www.helpforalzheimersfamilies.com/get-help/hilarity-for-charity
- **Alzheimer's Association – Alzheimer's and Dementia Caregiver Center:** The *Paying for Care* program provides information on financial resources to assist in paying for care including insurance, government assistance, and community support services: alz.org/help-support/caregiving/

*financial-legal-planning/
paying-for-care*

- Some local member agencies of the **Alzheimer's Foundation of America** provide respite scholarships to family caregivers of individuals with Alzheimer's disease.

Other Funding Options

Private Pay: If none of the options listed above work for you, you may choose to pay for private respite services. In limited cases, there may be respite care coverage in some long-term care insurance policies. According to the 2020 Genworth Cost of Care Survey, the average hourly cost of a home health aide or homemaker aide is \$24 per hour, and adult day health averages \$80 per day. Rates vary by where you live.

▶▶▶ For additional information on federal funding sources to help you pay for respite, refer to **Federal Funding and Support Opportunities for Respite 2021:** archrespite.org/library/federal-funding-and-support-opportunities-for-respite

STEP 5

How Do I Decide What's Right for Me?

Once you have decided to use respite care, you want to make sure the service you are considering is right for your situation and family. Unfortunately, in some areas there may only be one option for respite care. If you do have a choice of services, however, use the following tips when selecting what's right for you.

Before You Contact Potential Providers

- If you have feelings of guilt or anxiety about leaving your loved one, speak to another family caregiver about their respite experiences. Respite for you will mean that you will be better prepared to continue providing care.
- Plan a time to sit down with your family members to discuss the possibility of using respite services. Be sure to include your loved one in the discussion if possible. To include family members living far away,

9 STEPS TO RESPITE CARE for Family Caregivers of Persons with Dementia, including Alzheimer's Disease



consider arranging a conference call or Skype session.

- Take time to explore respite options and decide what would work best; in-home or out-of-home care, adult day care, or care in a residential or medical setting.
- Discuss how often you would like to use the respite service.
- Confirm what each family member would need to make the most of respite care. Are there activities your loved one would like to do while you are getting respite? Are there important considerations that need to be addressed so that your family member is comfortable?
- Make a list of questions to ask potential providers (see ideas below).
- Create a checklist of important information you think the care provider needs to know about the

▶▶▶ The **Alzheimer's Association Respite Care Guide: Finding What's Best for You** can help you explore which respite options will work well for you, your family, and the care recipient: archrespite.org/library/respite-care-guide-finding-whats-best-for-you.

medical, behavioral, and daily living (toileting, feeding, and mobility) needs of the person who will receive care, including dietary, recreational and other preferences. (See **Step 8 Orienting Respite Providers** on page 8.) Lots of guidebooks and templates exist to help you put this information together. See the *ABCs of Respite* at archrespite.org/consumer-information and *Personal Facts and Insights* (Alzheimer's Association) at alz.org/care/downloads/personalfacts.pdf

- If respite is being provided in the home consider strategies to increase safety and avoid theft, such as placing all valuables and medication in a safe. Be sure to discuss whether the respite provider will be given a key or access to home security systems.

Contact Potential Providers

Once the family has had an initial discussion, and you have identified possible respite services or providers, ask each provider you are considering to send you a brochure and other pertinent information in advance so you can get familiar with their services. Contact the potential providers along with your loved one, when possible, and discuss your family's expectations and these questions:

- How are the respite providers selected and trained?
- Are background checks performed?
- Do the respite providers have training and/or experience with individuals with dementia including Alzheimer's?
- Are respite providers licensed and bonded, if required?
- What tasks can be performed by the respite provider?
- Are individuals with incontinence issues or behavioral issues able to attend?
- Can the respite provider administer medications, assist with medical tasks or daily living needs, including toileting, if necessary?

- Will the respite provider engage in or offer activities or companion services requested by the care recipient?
- What hours and days are services available?
- If the provider will be driving the care recipient, do they have a valid driver's license?
- What is the eligibility process for families?
- What are the fees and how are they paid?
- How are emergencies and problems handled?
- 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? Are therapeutic services provided?

If you decide to hire a private independent respite provider who is not an employee of an agency, then the questions listed above become essential. In addition, it is even more important to check references, use telephone interviews to screen providers, and conduct a background check for safety reasons. Although finding someone on your own is usually less expensive, it is more complicated. Remember, you may also be responsible for paying household employee taxes if you use one provider consistently. To find independent providers, start by asking family and friends, check with religious communities and online respite registries, and you may consider placing an ad in local newspapers or using vetted online resources.

STEP
6

Preparing My Loved One for Respite

Respite provides a much needed break for both the caregiver and the care recipient. Some care recipients, however, may be resistant because they are uncomfortable in an unfamiliar environment or being with people who are considered "strangers." This may be especially true for those with dementia including Alzheimer's disease. Allowing someone new to provide help may be outside of his or her comfort zone, and yours. Here are a few tips that may help:

- Introduce the idea of respite well in advance of when you might want to start using it. Planning is key! Set aside enough time to prepare your family member for the respite experience and enough time to plan for how it will occur.
- You, as the caregiver, have the primary responsibility for making the decision to access respite services. However, when it is possible, involving the care recipient in some aspects of respite service planning may help smooth the transition and assist in acceptance of respite care. Ways in which the care recipient might be involved could include choosing the location of service, activities, or time frames. Providing appealing respite options with desirable activities or social



9 STEPS TO RESPITE CARE for Family Caregivers of Persons with Dementia, including Alzheimer's Disease

opportunities may increase the care recipient's willingness to participate.

- When talking about the respite service, use positive language and show your excitement about the opportunity.
- Keep in mind that for someone with advanced Alzheimer's you may not be able to involve them in the decision to use respite.
- Have someone else who your loved one respects explain how helpful respite will be for the family.
- Try spending time with your family member in the respite setting or with the respite provider to help them feel more comfortable.
- Have the respite provider arrive early so that you can plan a smooth transition for your family member. This also provides an opportunity to share up-to-date information or any changes in the care recipients needs.
- Consider hiring your family member's daytime caregiver to provide overnight respite care.
- To make the respite situation more comfortable for your family member with dementia or Alzheimer's disease, be sure that familiar routines and activities will be included in the respite experience.

STEP 7 Planning to Make the Most of Respite

There are several ways you can make the most of your time away from caregiving.

Use Respite Early. First, when possible, try to take a break on a regular basis beginning as soon as possible in your caregiving experience. Avoid waiting until you are overwhelmed and stressed.

▶▶▶ **Time for Living and Caring: Making Respite Services Work for You** archrespite.org/library/time-for-living-and-caring-making-respite-services-work-for-you.

Use Respite as Frequently as Possible. By getting respite at least once a week, when possible, you can restore your balance and reduce stress.

Planning is Key. You want to make sure your respite time is enjoyable. Find ways to use your time to reconnect with friends, exercise, participate in a hobby or get some much needed rest. Plan what you will do during your respite time and resist waiting until the last minute to confirm your plans.

Focus on You. Some respite initiatives might focus on activities specifically for you – through weekend retreats for families caring for loved ones with dementia and Alzheimer's, respitality or get-aways, or caregiver education programs (see resource list on page 9). Remember, your goal with respite is to take care of yourself, while ensuring your loved one is safe and secure.

STEP 8 Orienting Respite Providers

As mentioned earlier, it will be helpful to create a checklist for the respite provider. Make it clear to the respite provider that you, as the caregiver, are the primary point of contact.

Checklist for the Respite Provider

- ✓ Your contact information
- ✓ The care recipient's preferences, likes and dislikes
- ✓ Information about special diets, medications, and daily living needs (e.g., the need for toileting assistance or use of incontinence products).
- ✓ Overview of a typical day in the life of the care recipient
- ✓ Tips for how to deal with any difficult behaviors exhibited by the care recipient

Summarize key information in a packet that the care provider can "grab and go" if they need to take the care recipient to the hospital. Include essential

information from the above checklist and put the packet by the door for easy retrieval.

If the respite provider is qualified to perform medical tasks, administer medication, or assist with more complex activities of daily living, make sure you dedicate sufficient time before you leave to demonstrate correct and preferred approaches. You know your family member best. By sharing your expectations for how care is to be provided, you will help ensure the safety and well being of your loved one.

▶▶▶ A useful tool is the *Alzheimer's Association Personal Facts and Insights* that helps you summarize personal history information and characteristics including level of functioning, communication, personality and temperament, daily routine, religion and spirituality, daily needs, walking/mobility, and others. alz.org/care/downloads/personalfacts.pdf

STEP
9

Find Out About Other Helpful Resources

Although being a caregiver is rewarding, it can also be challenging. Using respite services on a regular basis helps you be the best caregiver you can be. There are also a number of other types of services that can help. You will want to get all of the support and assistance that is available. Use the following resources to find the most desirable, safe and appropriate respite options and other useful services.

**General Respite Information:
What Is Respite, How to Find It,
Choose It and Pay for It**

ARCH National Respite Network and Resource Center's *The ABCs of Respite: A consumer guide for family caregivers* at archrespite.org/consumer-information

Caregiver Resources for the General Population

Caregiver Action Network (CAN) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge including a *Family Caregiver Toolbox* at caregiveraction.org/family-caregiver-toolbox.

Family Caregiver Alliance provides caregiver resources and care recipient benefits by state at caregiver.org/connecting-caregivers/services-by-state. FCA just developed a new resource *Caregiving at Home: A Guide to Community Resources, Family Caregiver Alliance* at caregiver.org/resource/caregiving-home-guide-community-resources.

Specific to Dementia and Alzheimer's disease

Alzheimer's Association – Respite Care, Alzheimer's and Dementia Caregiver Center has information on using respite care, types of respite care, and overcoming concerns: alz.org/help-support/caregiving/care-options/respites-care or call 24/7 helpline at 1-800-272-3900.

Alzheimer's Disease and Caregiving, Family Caregiver Alliance at caregiver.org/resource/alzheimers-disease-caregiving

Alzheimer's Disease: Helping Yourself Help A Loved One, Caregiver Workbook, Alliance for Aging Research at agingresearch.org/document/alzheimers-disease-helping-yourself-help-a-loved-one-caregiver-workbook

Alzheimers.gov is a free information resource about Alzheimer's disease and related dementias: alzheimers.gov. The website is also available in Spanish at alzheimers.gov/es?utm_source=partner-eblast&utm_medium=affiliate&utm_campaign=alzesp-202110&utm_term=NAPA

Alzheimer's Talk is a social network for families, friends, and medical professionals to chat, post messages, share favorite links and view forums, blogs, pictures, and videos: alzinfo.org/alztalk

9 STEPS TO RESPITE CARE for Family Caregivers of Persons with Dementia, including Alzheimer's Disease

ARCH National Respite Network and Resource Center Fact Sheet: *Respite for Family Caregivers of Persons with Dementia, including Alzheimer's Disease* at archrespite.org/library/respites-for-family-caregivers-of-persons-with-dementia-including-alzheimers-disease.

HBO The Alzheimer's Project provides 15 short films looking at cutting edge scientific research on AD and caregiving: hbo.com/documentaries/the-alzheimers-project-caregivers

NIH's Alzheimer's Disease Education and Referral (ADEAR) Center is a service of the National Institute

on Aging that provides information on diagnosing, treating, and caring for persons with AD: nia.nih.gov/health/alzheimers or call 1-800-438-4380 or email at adear@nia.nih.gov

Specific to Down Syndrome and Alzheimer's Disease

Alzheimer's Disease & Down Syndrome – An Introduction to Alzheimer's Disease at ndss.org/resources/alzheimers

Alzheimer's Disease in People with Down Syndrome at nia.nih.gov/health/alzheimers-disease-people-down-syndrome

A Caregiver's Guide to Down Syndrome & Alzheimer's Disease at ndss.org/about-down-syndrome/publications/caregiver-guide-order-form

Dementia Be Damned Blogspot at dementiabedamned.blogspot.com

Down Syndrome and Alzheimer's Disease at alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome

National Task Group on Intellectual Disabilities and Dementia Practices, Family Support Resources at the-ntg.org/family-caregivers



Author: Monica Uhl, M.A., Consultant

Layout: Norma McReynolds, Graphic Designer

This project was supported, in part by grant number 90LT0001, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

This information is in the public domain. Readers are encouraged to copy and share it, but please credit the ARCH National Respite Network and Resource Center.

