



Respite Care Guide

Finding What's Best for You

alzheimer's  association®

Everyone needs a break. If you are a caregiver, you may need a break from caregiving tasks. If you have dementia, you may want a break from the daily routine and have the opportunity to meet others who share some of the same challenges. Respite care can help, by providing a new environment or time to relax. It can be for a few hours or several days or weeks depending on your particular needs and interests.

What is respite care?

Respite refers to a short time of rest or relief. It provides a break from the typical care routine – allowing the caregiver some down time while the person with dementia continues to receive care from qualified individuals and has the opportunity to have different experiences.

An individual can receive respite care:

- From paid staff, volunteers, family or friends
- At home, a community organization or a residential care center
- For part of the day, evening or overnight
- Occasionally or on a regular basis

Why use respite care services?

Some caregivers work or have other responsibilities in addition to providing care. Respite care can give a caregiver the time and assistance required to meet these personal needs.

Respite care can provide the caregiver with:

- A chance to spend time with other friends and family, or to just relax
- Time to take care of errands such as shopping, exercising, getting a haircut or going to the doctor
- Comfort or peace of mind knowing that the person with dementia is spending time with another caring individual

The person with dementia is experiencing many changes and challenges, too, and may also need variety in his or her routine and social interactions.

Respite care services can give the person with dementia an opportunity to:

- Interact with others having similar experiences
- Spend time in a safe, supportive environment
- Participate in enjoyable activities designed to match personal abilities and needs

What are the different kinds of respite care services?

There are a number of ways that respite care can be provided. Following are descriptions of five common types.

1

In-home respite care

These respite care services are provided in the home to assist the caregiver and the person with dementia. Services vary in type and can include:

Companion services

Help with supervision, recreational activities and visiting

Personal care services

Help with bathing, dressing, toileting, exercising and other daily activities

Homemaker services

Help with housekeeping, shopping and meal preparation

Skilled care services

Help with certain medical services or care

In-home aides can be employed privately, through an agency or as part of a government program. Be sure the aide and services are appropriate for your specific needs. Cost, level of training and specific services provided will vary among workers and agencies. Generally, Medicare does not pay for this type of help, but financial assistance may be available.

Some respite care aides have received training about Alzheimer's disease and the unique needs of a person with the disease. It is important that the in-home aide is knowledgeable – or at least willing to learn – about Alzheimer's disease and effective approaches to care.

2 Adult day centers

An adult day center provides care outside the home and is designed to meet individual needs while supporting strengths, abilities and independence. Participants have the opportunity to interact with others while being part of a structured environment.

Daily activities may include music, recreation, discussion and support groups. Staff may include a nurse, social worker and recreation or music therapist. However, staffing can vary across centers. If the person with Alzheimer's requires medical services (i.e., insulin shots, help with medication, etc.) be sure to ask if staff provides medical assistance.

Many caregivers who work during the day find this type of center very helpful as they try to balance a job with caregiving duties. Hours of service vary at each center, but some are open from seven to 10 hours per day, five days a week. Some may even offer weekend and evening hours, and most centers provide a meal or snacks.

3 Informal respite care

Many times, a family member, close friend, neighbor or volunteer is willing to occasionally help out, giving the caregiver time to run to the store or just take a break. Caregivers should keep in mind people who have offered to help.

Put together a schedule of times when others are available. It may be in the evenings, on the weekends or on special occasions. This can allow the caregiver some down time while the person with dementia is spending time with someone else you both trust.

4 Residential respite care

Another respite care option is a stay in a residential facility overnight, for a few days or a few weeks. Overnight care allows caregivers to take an extended break or vacation while the person with dementia stays in a supervised, safe environment designed to meet personal needs. The cost for these services varies and is usually not covered by insurance or Medicare. Be sure to make a reservation in advance, as some centers may not always have an available room.

Sometimes, a person with dementia may have difficulty adjusting to this new environment. Regular stays can allow the overall adjustment to become easier for everyone. Over time, the staff can become more familiar with the needs of the individual, and he or she will become more comfortable with the staff and the environment.

5 Respite care for emergency situations

Accidents, surgery or unexpected trips can create a need for emergency respite care. In case an emergency does come up, it's helpful to have done research and planning ahead of time. Call around to agencies to find out which ones offer services when the need arises. Try out a service in a non-emergency situation and see how it works. Also, talk with people you trust – including family, friends and neighbors – about the possibility of asking for help in case of an emergency.

How to choose a respite care service

Once you've assessed your needs for type of care, skills, location and frequency, you can:

- Select a service that best meets these needs
- Prepare the aide and the person with dementia
- Evaluate the service's effectiveness or usefulness

In some areas, respite care options may be limited. Contact your local Alzheimer's Association to find out about the respite care services that are available in your area, and talk with people in your community to gain additional information about respite care options. Then, you can call these services with specific questions or inquiries.

Describe your situation and explain what you would like from a respite care service. Ask questions over the telephone regarding qualifications, types of services offered, cost and hours of availability. The more information you receive over the phone, the easier it will be to identify which service is best for you. You will also be able to limit the number of services you interview or visit.

Selecting the respite care service

If you are selecting an [in-home aide](#), arrange a time to meet with the person in your home. Ask plenty of questions to gain an understanding of his or her skills.

Ask prospective aides about their availability, training, background, care philosophy and experience with dementia.

Be specific about the needs and the characteristics of the person with dementia. If possible, it is a good idea for both the person with dementia and the caregiver to participate in the interview process.

If necessary, interview several aides to find the right person for your particular situation; don't feel pressured to settle on someone who doesn't make you feel comfortable. Do be aware, however, that if the home care aide is coming from a government program, your choices may be limited.

If you are selecting an [adult day center](#), arrange a meeting with the staff and take time to look around. Assess your overall feeling about the environment. Look to see if individuals are involved in activities and if the center looks clean.

Get a better idea of the center by attending a function there or talking with staff. Ask if they provide personalized care, and find out about both the people who work there and those who attend the center. Be direct about the needs and characteristics of the person with dementia, and find a center that is able to meet your needs.

If you are selecting a [residential facility](#), you will be faced with additional considerations. Since you will not be around 24 hours a day to observe care, it's important to make sure that the environment and services will be a good fit for the person with dementia.

It is also important to see the care firsthand. Ask to take a look around and talk with the facility's staff, as well as residents and families who use service. Again, examine the environment yourself to see if it's clean, if residents seem content and engaged, to gauge your general sense of the facility.

Stop by one evening or weekend and see if the facility is any different than during the day. You may even want to make an unannounced visit.

For a complete guide of questions you may want to ask when selecting a respite care service, see [Things to consider when choosing respite care](#) on page 12.

Overcoming concerns about respite care

It's normal to be apprehensive about trying something new. Some concerns you may have about using respite services:

Cost

You may be concerned about how to pay for services.

Look into financial assistance such as scholarships, sliding scale fees or government programs. Contact your local Alzheimer's Association to learn what kind of financial assistance may be available.

Reliability

You may be concerned about the dependability of the aide or service.

Those who work for an agency or facility should be reliable and well trained, and are often certified. Ask each individual and facility about training and qualifications. If hiring someone independently, interview the person thoroughly and check references.

Guilt

You may believe that you should be able to "do it all."

Seeking help does not make you a failure. It's important to remember that respite services benefit the person with dementia as well as the caregiver.

Preparing the respite care provider

Whatever type or combination of respite care options you choose, you will want to familiarize the aide or staff to the needs and characteristics of the person with dementia. Be honest in your discussions. Establish a relationship and learn from each other. If necessary, define the specific tasks the respite caregiver should be responsible for.

Be sure the aide or staff gets to know the person with dementia. Provide a written history of the individual; show photographs; share stories and memories.

Use the “Personal Facts and Insights” form (in the Fact Sheets/Forms section on CareFinder at www.alz.org) to help the respite care provider get to know the person. Provide it as a quick reference for the aide when you are not available. When completed, it provides information about the individual, including:

Personality	Personal habits
Level of Cognition	Daily Routine
Communication Skills	Family
Mobility	Hobbies
Likes and Dislikes	Occupation

Preparing the person with dementia

The person with dementia will also need time to prepare for and adjust to an additional caregiver. Provide as much information as is appropriate. Some people with dementia may initially resist new situations; to help with a smooth transition to respite care, the caregiver may say someone is coming over to help around the house or refer to a day center as a social club or work. The service or aide may have valuable suggestions if the person with dementia is hesitant.

Evaluating the service

It is important to periodically evaluate the service you use. Many times, needs will change and a particular aide or facility may no longer be suitable. In addition, the service may suggest they can no longer meet your needs.

In either case, you will want to find a different service that can better meet your specific needs. If you do decide to change services, make a list of the limitations of the current service and compare it to other options.

When evaluating your current respite care service, consider:

- Is the service meeting your needs?
- What is working best?
- What can be improved?
- What do you need that your current service doesn't offer?
- Can you help the service recognize and address your needs?
- If not, where can you find what you need?

Contact the Alzheimer's Association 24/7 Helpline at 1.800.272.3900 for more information on respite care options and how to evaluate what's right for your situation.

Things to consider when choosing respite care

Use the following checklist when you are screening different respite care options to find out if the provider, service or care setting will meet your needs. If it's helpful, make copies of this list and use it to take notes about the different care options you explore.

This list is not comprehensive, but may serve as a starting point for you to think of additional ideas, preferences and priorities.

Checklist for help in the home or home care provider

- Offers the specific services you need
 - companionship: visiting, supervision and leisure activities
 - personal care: help with bathing, dressing, toileting and exercising
 - homemaking: housekeeping, shopping and cooking
 - skilled care: help with medication and other medical needs

- Provider is
 - able to communicate in the preferred language, if important
 - trained in first aid and CPR
 - trained in dementia care
 - experienced in working with someone with dementia
 - with an agency, if important
 - bonded (protects clients from potential losses caused by the employee), if important
 - able to provide references
 - available when you need them
 - able to provide a back-up if they are sick
 - able to manage your specific health and behavioral care needs (list below)

List the needs you are most concerned about

Additional concerns:

Checklist for adult day care center

- Able to provide respite care
- Convenient location
- Convenient hours
- Appropriate services and programming based on your specific health and behavioral care needs including:

- Staff trained in dementia care
- Affordable
- Transportation available if needed
- Meals and snacks provided
- Able to dispense/monitor medications
- Enrollment in Alzheimer's Association Safe Return® program strongly encouraged

Checklist for nursing home, assisted living or other type of residential care

Family Involvement

- Families are encouraged to participate in care planning
- Families are informed of changes in resident's condition and care needs
- Families are encouraged to communicate with staff

Staffing

- Medical care is provided to the extent that it is needed
- Personal care and assistance is provided to the extent that it is needed
- Staff recognize persons with dementia as unique individuals, and personalize care to meet specific needs, abilities and interests
- Staff trained in dementia care

Programs and Services

- Appropriate services and programming based on specific health and behavioral care needs, including:

- Planned activities (ask to see activity schedule; note if the activity listed at the time of your visit is occurring)
 - Activities on the weekends or during evenings
 - Activities designed to meet specific needs, interests and abilities
- Transportation available for:
 - Medical appointments
 - Shopping for personal items

Environment

- Indoor space that allows for freedom of movement and promotes independence
- Safe and secure indoor and outdoor areas
- Easy to navigate
- Designated family visiting area

Meals

- Regular meal and snack times
- Appetizing food (ask to see the weekly menu and come for a meal)
- Pleasant dining environment
- Family and friends able to join at mealtime
- Staff have a plan for monitoring adequate nutrition
- Staff are able to provide for any special dietary needs
- Staff provide appropriate assistance based on person's abilities (for example, allow the person to drink independently, if able)
- No environmental distractions during meal time (noisy TV etc.)

Policies and Procedures

- Family and friends able to participate in care
- Visiting hours
- Discharge policy (learn about any situation or condition that would lead to a discharge from the facility)
- Enrollment in Alzheimer's Association Safe Return® program strongly encouraged

State Inspection Results

If the facility is licensed, ask for recent state inspection survey results – administrators are required to provide this information if asked.

Several things to note:

- Report should be dated within the last 9–15 months.
- Compare the number of deficiencies cited to the state average.
- If a facility has received a citation in a particular service area, be sure to ask questions about this area when you visit the facility.
- Beware of choosing a facility with a very high number of deficiencies compared to other facilities in the area and the state average.

(Adapted from National Citizens' Coalition for Nursing Home Reform: Consumer Guide to Choosing a Nursing Home)

If the facility is a nursing home, go to the Nursing Home Compare Web site to learn how it compares to the national average at www.medicare.gov/NHCompare/Home.

When contacting provider or residential care setting, be prepared by having the following information available about the person seeking care:

- Name and Social Security number
- Physician's name and phone number
- Diagnoses, other health and behavioral care needs
- List of medications
- Insurance coverage including Medicare, Medicaid and long-term care insurance
- Special care equipment required

Questions to ask after evaluating:

- Does the service/program meet my needs? How?
- Does the provider appear to be adequately trained? How?
- Is it convenient?
- Is it affordable?

Quick Tips

- Good dementia care includes ensuring safety and meeting basic needs – but it also means involving the person with dementia as much as possible.
- Caregivers should aim to treat a whole person, not a patient.
- When you look for a care provider, ask about special training in dementia care.
- Find out how care providers are supervised and supported in their daily work.
- A good long-term care facility should feel comfortable and homelike.
- People with dementia may be unable to express their feelings in words and behaviors may speak for them. Care providers should try to understand a behavior's cause and consider the best solution.

The Alzheimer's Association, a world leader in Alzheimer research, care and support, is dedicated to finding prevention methods, treatments and an eventual cure for Alzheimer's.

For reliable information and support, contact the Alzheimer's Association:

alzheimer's  association®

the compassion to care, the leadership to conquer

1.800.272.3900 | www.alz.org

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