#### **FAMILY CAREGIVING**

# Respite Care: What it is and Where to Find it

Caregiving for an elderly, ill, or disabled family member is a demanding job and no one is equipped to do it alone. Finding respite care services can provide a vital break.

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# What is respite care?

Respite care provides temporary relief for a primary caregiver, enabling you to take a much-needed break from the demands of caregiving a sick, aging, or disabled family member.

Respite care can take place in your own home, at day-care centers, or at residential or nursing facilities that offer overnight stays. Whether it's for just a few hours a week or an extended vacation, seeking respite care can help ease the burden of family caregiving and help to relieve stress, restore your energy, and promote balance in your life. It can also prevent you from becoming exhausted, isolated, or even burned out.

Respite care can benefit the person you're caring for, too, providing them with variety, stimulation, and a welcome change of routine.

Seeking support and maintaining your own health are key to managing <u>your role as a caregiver</u>, so it's not selfish to need time to yourself. If you're overwhelmed by the daily grind of caregiving, your patience and compassion will wear thin, you'll find it harder to connect with the person you're caring for, and you'll probably both feel unfulfilled.

After a break to recharge your batteries, though, you'll feel more energetic, focused, and reinvigorated about your caregiving role. You may even be able to pick up tips on new ways to tackle common problems you face as a caregiver, helping to make the caregiving journey a more enjoyable and rewarding experience for both you and the loved one in your care.

# Types of respite services



Respite care can take many forms, but boils down to two basic ideas: sharing the responsibility for caregiving and getting support for yourself.

Respite could take the form of enlisting friends and family to watch your loved one so you can take a break to visit others, go to the gym, or handle chores, for example. Or respite care can mean finding volunteers or paid carers to provide in-home services for your loved one, either occasionally or on a regular basis.

Finally, respite care can mean using out-of-home programs such as adult day care centers, day camps, assisted living facilities, or <u>nursing homes</u> to provide you with a break and your loved one with the continued care that they need.

#### In-home respite care

<u>In-home services</u> can be provided by volunteer or paid help, either occasionally as needed or on a regular basis. Services may last from a few hours to overnight, and may be arranged directly or through an agency.

This popular respite choice enables your loved one to remain in their own home while they continue to receive care, and can be invaluable for you as the primary caregiver.

Volunteers may be available from faith-based, community, and other non-profit organizations.

Trained staff from home-care businesses are available to cover short periods of in-home care.

Personal care providers can assist with daily living skills such as bathing, dressing, or feeding.

Homemaker services support meal preparation, shopping, and housekeeping.

[Read: Home Care Services for Seniors]

Skilled health care, which requires more specialized training and expertise, can address your loved one's medical needs.

#### Out-of-home respite care

Whether you're caring for a child, an adult, or a senior, there are a range of private and non-profit respite programs available depending on your location. These can include:

Adult day care centers, designed for older adults who can no longer manage independently, or who are isolated and lonely. Planned activities promote well-being though social and health services. Adult day care centers operate during daytime hours, Monday through Friday, in a safe, supportive, and cheerful environment. Typically, meals and afternoon snacks, including those that accommodate special diets, are included.

[Read: Adult Day Care Services]



Residential programs offer temporary care for varying lengths of time. Group homes, hospitals, <u>nursing homes</u>, and other specialized facilities provide emergency and planned overnight services, allowing caregivers 24-hour relief. While medical insurance in the U.S. generally does not cover overnight respite, long-term care policies and veterans' programs may subsidize the cost of care.

Caregiver retreats and respite camps are available in some areas, combining respite with education and peer support.

### Engaging family members in respite care

Family members and friends may be able to help out while you run an errand, take a break, or even go on vacation. However, just as the burden of caregiving is often more than one person can handle, it can also be a tough process for families to share. Even the healthiest families can be severely stressed by ongoing care, and the division of labor is frequently lopsided.

You can encourage support and participation by employing the following strategies:

Talk openly and regularly. Keep your family up to date on your loved one's needs and condition. Family members who don't share the day-to-day caregiving experience may not fully appreciate the demands and stresses involved.

Encourage family members to evaluate what they can reasonably and honestly do. Changing roles and varying resource levels can impact family involvement. Welcome different viewpoints, accept limitations, and be willing to try different strategies. Share your list of needs and take advantage of all offers to help.

Recognize your own feelings and discuss disproportionate tasks. Harboring resentment when you need more help can impair your health and even lead to <u>burnout</u>. Ask family members directly for concrete support and specific time commitments. Consider establishing an online calendar to organize relief and confirm schedules.

**Use technology to bridge distances.** Try free video conferencing services to hold family meetings at times that work for everyone. Create a web-based community to share updates and explore options.

Look for peer support. Learning how other families cope can provide you with new options and ways of coping. Building relationships with other dependable, trustworthy caregivers can also offer an opportunity to trade respite services. And when siblings are unable or unwilling to share the load, peer support can be invaluable.

# Overcoming obstacles to respite care

While it may seem obvious to friends and family—and even yourself—that you desperately need a break from the physical and emotional demands of caregiving, actually seeking help is not always an easy step. When you're the primary, long-term caregiver for a close family member, handing over the responsibility for their care can seem a daunting prospect.

Perhaps you feel that your daily caregiving routine is too complex to explain to another person or that taking time off will only create more problems when you return; it's easier to just tough it out and do everything yourself. Or maybe you feel that it's wrong of you to ever feel tired of caring for someone you love, especially if



you're a parent caring for a child.

Perhaps you're simply worried that the person taking over will not do a good enough job caring for your loved one. Or conversely, maybe deep down you're worried that a respite carer will do a better job and you'll somehow feel inadequate or no longer needed.

These are all common reasons for declining respite care. However, it's important to remember that respite care is an integral part of the caregiving process, not just for you, but also the person you're caring for and the rest of your family.

Multiple relationships are vital. No matter how close you are to your loved one or how well you're coping as their caregiver, it's not healthy to spend every hour of every day and night with the same person, especially in an inevitably stressful caregiving environment. Everyone needs the stimulation of multiple relationships, including you as the carer and your loved one as the care recipient.

Accept that no one else will offer the same level of love as you—and find the best alternative. Even if you know that you're the best possible person to care for your loved one, that's no reason not to seek respite care. If nothing else, your loved one will appreciate you even more when you return from your break. Having time apart can help refresh and rejuvenate any relationship.

There's nothing abnormal about needing a break. Most of us work 40-hour weeks with a coffee break and lunch hour every day, and evenings and weekends off. Even people with tougher schedules don't work around the clock, day after day, without ever having a break or some time to themselves to look forward to. Taking time off is vital to your health and well-being.

#### [Read: Caregiver Stress and Burnout]

Respite care can provide a fresh pair of eyes. If, like most caregivers, you accepted the role as family caregiver without any formal training, it's unreasonable to expect that you'll be an expert and know everything about your new role. Seeking respite care from others, especially those who have previous experience or professional training, can bring a fresh pair of eyes to your daily routine and may offer tips on different ways to handle certain caregiving tasks.

Consider a respite swap. Trading respite services with other caregivers you know and trust can be an easy way to carve out some time for yourself. This could take the form of taking it in turns to host an occasional kids' sleepover, for example, or to care for each other's patients while the other has a weekend off.

Planning, selection, and choice are key to your respite care experience. Understanding your needs, selecting the right type of respite care, and choosing the right provider can ease the stress of handing over the reins of your loved one's care. Doing your homework, seeking references and referrals from providers or carefully planning for other family members to take over can help set your mind at rest.

Maintain or rekindle your hobbies and interests. It's not uncommon for long-time family caregivers to finally seek respite care and then find a void in their lives. Having devoted so much time to caregiving, they're suddenly lost once those caregiving responsibilities are no longer there, even for a short period. By seeking respite services early and often, you'll be better able to maintain interests outside of your loved one's care and preserve your own identity.



# Planning your relief

Planning for respite care starts with analyzing the needs of both you and your loved one. Establishing the type, skills, frequency, and location of respite services is critical to ensure you receive appropriate support and your loved one continues receiving the best care.

As a caregiver, is support what you need most? Or is it some regular free time? Or maybe help with transportation? Keeping a record of your daily activities will make it easier to hand over responsibility to a family member or respite care provider while you take a break. It can also help to identify the areas and times when you most need help.

Identifying your loved one's needs and preferences will also help you find the right match. Are social activities most important to your loved one? Do they require assistance with walking, eating, or medications? Do they need mental stimulation? Or exercise? Answering these types of questions can help you determine which respite options to pursue.

When you devote so much love and energy to caregiving, it can be difficult to entrust your family member's care to others, especially strangers. Whether you engage a care provider directly or work through an agency, you can allay your fears by conducting some basic research.

# Using independent respite services

Taking time to find the right person is essential for your peace of mind and your loved one's safety. Make sure you:

- **01.** Conduct an in-depth interview with each candidate. Screening applicants on the phone should always be followed with an in-person interview.
- 02. Be specific about all of the tasks, skills, and schedules involved in your loved one's care.
- 03. Discuss compensation and payment schedules. Do not pay for services in advance.
- **04.** Request several work and personal references, and check them carefully. Verify the information provided, and ask all references about reliability, trustworthiness, punctuality, and the care provider's ability to handle stress.
- **05.** Consider a background check. These can be done inexpensively through online agencies and alert you to potentially serious problems.

Always include the potential care recipient in the screening process if they're able to participate, to ensure that both parties are comfortable and that your loved one's needs are respected.

# Working with respite care agencies

While independent providers are generally less expensive, home care agencies and referral services can be easier to use.



An agency provides appropriate carers, handles payroll, and usually provides substitutes for sick or absent personnel. If problems occur, you also have specific avenues of recourse (complaints, mediation, or arbitration) that are not available when working with individuals.

Referral services work to match your needs with local respite programs.

## Choosing out-of-home respite programs

When you have identified potential <u>out-of-home programs</u>, plan to visit at least three. Observe the staff and how they interact with care participants. Try to picture your loved one there and ask plenty of questions.

- → How are care providers screened?
- → What is the training and level of experience of the care providers?
- → Will care providers need additional training to meet specific family needs?
- → How, and by whom, are the care providers supervised?
- → What procedures does the program have for emergencies?
- → Are families limited to a certain number of hours of services?
- → Does the program provide transportation and meals?
- → What is the cost of services? How is payment arranged?

If you can, spend a day at the center that seems best to you, so that you can get a feel for the people and environment. Bring a site checklist such as the one below. You may wish to return a few times to see whether your experience on different days confirms your initial impressions.

#### Adult day care center site visit checklist

- → Were you made to feel welcome at the center?
- → Did someone properly explain the services and activities offered by the center?
- → Were you offered clear information about staff, programming, and costs?
- → Was the center clean, well-maintained, and odor-free?
- → Was the center wheelchair accessible?
- → Was the furniture clean and comfortable?
- → Was there a quiet, comfortable place for relaxation?
- → Did the staff and participants seem cheerful and at ease when interacting?

## Paying for respite care



Respite care costs can vary significantly depending on your country or state. For example, in the United States, the average cost of adult daycare is about \$80 a day, according to 2021 figures. At assisted living facilities in the US, you can expect to pay about \$160 per day, while in-home care by a home health aide may cost about \$180 per day.

Because these are just daily averages, it's important to be aware how quickly respite care costs can mount up. If you're in the U.S., you can look to Medicare, Medicaid, or your health insurance to help with the coverage.

- → Medicare covers respite care if you qualify for the hospice care benefit .
- → Medicaid doesn't offer respite care coverage as a standard benefit, but some states' Medicaid offices offer waivers that may help.
- → Many insurance plans may not cover respite care costs, while others cover just a portion. Reach out to your insurance provider for the specifics of your coverage.

You can also try the following to help with paying for respite care:

Search for local organizations that might offer similar services for more affordable prices. For example, consider respite services from a church or nonprofit group. Some organizations may even use a sliding-scale payment approach (charging based on your ability to pay).

Reach out to government agencies or programs, such as your state health insurance assistance program, for advice. When it comes to caring for veterans, you might also find respite care support or aid through the Department of Veterans Affairs.

Talk to friends and family members who may be able to offer informal care. They might not be able to offer the same professional-level care, but they can still help lighten your caregiving load.

# Getting the most out of respite care

While finding and arranging respite care sounds like a lot of work, it's important to remember that respite is not just a service, it's an effect that comes from taking breaks from the stresses of caregiving.

Plan and schedule frequent breaks. Overlooking your own needs or trying to take on all of the responsibilities of caregiving without regular breaks will only lead to serious health problems such as burnout.

**Use checklists** to inform respite care providers about your loved one's schedules, likes and dislikes. Offer suggestions for handling any difficult behaviors.

Make back-up plans. Always keep a list of alternate respite care providers and resources. Unplanned emergencies should not prevent you from taking care of yourself.

**Evaluate respite care providers often**. Observe your care recipient before and after respite sessions. Ask for brief updates and more detailed reports regularly.

**Expect changes**. Respite care is a process that often requires fine-tuning. Anticipating and accepting changes in personnel or programs can keep you from becoming discouraged.



Attend a support group regularly. Both structured and informal groups allow you to meet others in situations much like your own. You can talk, vent, laugh, and exchange tips with people who understand what you're going through. If you can't easily leave home, online communities, message boards, and forums can also provide some much-needed support. Some online therapy platforms also offer support groups.

## Find respite care

In the U.S Eldercare Locator – Search directory of elder care services or call 1-800-677-1116.

(The U.S. Department on Aging)

Respite Locator – National respite care directory. (Arch National Respite Network

and Resource Center)

Respite Care - Find respite services for Alzheimer's and dementia caregivers or call

1-800-272-3900. (Alzheimer's Association)

In other <u>Carer's Breaks and Respite Care</u> – NHS services available to UK carers. (NHS)

Carer Gateway – Find respite care services in Australia. (Australian Government)

Carers New Zealand - In New Zealand, find help and advice or call 0800 777 797.

(Carers NZ)

## **More Information**

#### Helpful links

countries

- **01.** Respite: Time Out for Caregivers Types of respite and how to overcome obstacles. (Caregiver Action Network)
- **02.** Resources for Caregivers Government resources in the U.S. (U.S. Dept. Health and Human Services)
- **O3.** Lotsa Helping Hands Organize respite schedules and manage activities using an interactive calendar. (LotsaHelpingHands.com)

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