



VA
Caregiver
Support



HEALTHY
CAREGIVING



INTRODUCTION

Being a Family Caregiver to a spouse, parent, child or loved one takes time, effort and work. Caregiving can challenge you intellectually and emotionally, teach you flexibility and strengthen your problem-solving abilities.

Caregiving may be one of the most important roles you will ever take on in your life. It is not an easy role, and most of us are never prepared for it.

In fact, Caregiver burnout is a real problem. Taking the time to stay fully charged is one of the most important things you can do for the Veteran you care for.

This guide is tailored to help you successfully navigate through the caregiving experience. On the following pages, you will find:

- Tips and suggestions to help with activities of daily living (ADLs)
- Available resources for you and your care recipient
- Steps you can take to make sure you are both living the best lives possible.

Family members, friends and future Caregivers can also benefit by taking the opportunity to understand the dimensions of caregiving to better prepare for the challenges that lie ahead.

In time, some care recipients recover and/or improve, which can be extremely satisfying. But even when those being cared for are not able to improve, know that every day your efforts are enhancing the quality of someone's life.

YOU ARE NOT ALONE

You Are Not Alone

- 17% of all Caregivers in the American population are caring for Veterans.
- 70% are women caring for their spouse or partner; while 1 in 4 provide care for their Veteran son or daughter.
- 41% are caring for Veterans 18-54 years old.

Are You a Caregiver?

One of the biggest obstacles in caregiving is recognizing that you **are** caregiving. Many family members feel that what they are doing for their spouse, child, other relative or friend is nothing more than what family does for each other when there is a need. And that is true.

Running errands, picking up medications, driving to the doctor, arranging home care, helping to get dressed... regardless of the task, it is all caregiving. If you are helping someone with some of his or her activities of daily living (ADLs), you are a Caregiver.

What Does a Caregiver Do?

Caregivers typically provide any of the following types of assistance:

- Help with paying bills
- Help with household chores such as shopping, cooking, laundry and/or home maintenance
- Help with personal care (dressing, bathing, feeding, toileting, etc.)
- Help moving around the house or outside the house (transportation)
- Help with taking medications
- Help with making or receiving telephone calls
- Help arranging or coordinating services outside the home
- Companionship through personal visits or by phone

TAKING CARE OF SOMEONE ELSE

Keeping or restoring your care recipient's health requires determination and effort. Plans to maximize their independence and health may include:

- **A healthy diet.** If the Veteran you care for has medical problems, you can ask his or her doctor if changes in diet should be made and whether you should consult a registered dietitian for additional information.
- **Vitamin and mineral supplements,** if advised by a doctor or dietitian. Remember that more is not always better; nothing replaces a healthy diet, and some vitamins/herbs can be dangerous if taken in excess or with certain medical conditions. It is important to consult with the Veteran's health care team.
- **Exercise.** If your care recipient is reasonably healthy, he or she can begin a regular program of exercise including stretching, weight training and low-impact aerobics. Make sure to discuss it with his or her doctor first.
- **Medication monitoring** in consultation with your care recipient's doctor and pharmacist (both over-the-counter and prescription) to ensure that there are no adverse drug reactions or bad reactions between drugs. Make sure that all medications are appropriate for the Veteran's individual needs and that the rules for safely taking drugs are followed.
- **Staying involved with family and friends.**
- **Taking part in community activities,** such as going to a recreation center.
- **Keeping an active mind** with activities ranging from reading to playing cards, board games and using a computer.
- **Learning about assistive devices** that can enhance independence and safety.
- **Ensuring home safety** with modifications such as ramps and low thresholds, better lighting and nonskid rugs.

Going to the Doctor

You may want to accompany the Veteran you care for at doctor's appointments to take notes. This helps to ensure that you both understand the recommended medical course of action and gives you the chance to observe the interaction between the two.

Following are some tips for improving communication with your care recipient's doctor(s):

1. Write down any symptoms or side effects that your care recipient may be experiencing, along with other pertinent information (time of day, what he or she ate, etc.).
2. Also write down any questions that you may want to ask, or any concerns that you have. Regardless of how insignificant you feel the doctor may think it is, *ask!*
3. Ask about any possible side effects your care recipient may experience while taking prescribed medications.
4. Ask if any new medication will interact negatively with current medications.
5. Make sure you know the correct spelling of each medication your care recipient is taking, the dosage and how many times a day he or she takes it.
6. Ask for recommendations regarding taking a medication, i.e., should it be taken with food, at what times and what to do if a dose is missed.
7. Ask for storage instructions for each medication, i.e., in the refrigerator, in a medicine cabinet, etc.

If your care recipient is limited in his or her physical abilities, ask the doctor about the possibility of having physical, speech or occupational therapy. You should also ask about assistive devices that are available. ☺

DAY-TO-DAY LIFE

Caregivers sometimes become so involved in their efforts to keep things going that they tend to forget that each day can present the opportunity to try new approaches and activities that will make a positive difference in their lives and the lives of those they care for.

Some things that can bring about positive changes include:

- Standing back and taking a look at your situation – what is working well and what is not – and finding ways to make changes for the better
- Establishing routines that effectively meet your needs as well as the needs of the Veteran you care for
- Improving your physical surroundings
- Physical, speech and occupational therapy and/or exercise
- Assistive devices that increase independence and safety, ranging from special eating utensils to specially equipped telephones
- Improved nutrition
- Carefully monitoring medications and their interactions
- Intellectual stimulation
- Social interaction
- Spiritual renewal
- Employing home and/or health care personnel who demonstrate that they really do care and who will work to foster independence
- Finding ways to economize on your workload
- Filling each day with activities you can both look forward to

Meals

For people who are homebound, mealtimes can be pleasant social events. If your care recipient is confined to bed, you can sit and talk while he or she eats or bring a tray in for yourself and eat together.

Practical Caregiving

If your loved one needs considerable help, a well-planned routine can make the more demanding parts of your day go more smoothly, take less time and help ensure that the Veteran you care for does not develop problems that could have been prevented.

1. Make a list of all the items you need for morning and bedtime routines, buy several, and keep them close at hand (e.g., bathing items, medications and clothing). If you use them in different rooms, have duplicates. This saves time and keeps you from having to search for items.
2. Since getting up and going to bed are often the most challenging times of day, have someone help you with the morning and bedtime routines.
3. Practice good oral hygiene that includes toothbrushing, preferably after every meal. Good oral hygiene helps to prevent tooth decay, tooth loss, gum diseases and secondary infections that can result from poor dental care.
4. If your care recipient is disabled, has poor eyesight or cognitive impairments, you may need to remind him or her about personal hygiene and/or provide assistance. If your care recipient is incontinent, it is important to ensure that he or she is clean at all times, to use protective (barrier) creams, and to change incontinence aids and clothing as often as needed.
5. Persons with limited movement should be turned in bed on a regular basis to prevent pressure sores. Consult with your medical team. Correct bedding, such as sheepskin or egg carton bed coverings and/or an air mattress, helps to prevent pressure sores.

It is important to move persons with disabilities at least once an hour, even if it's just to reposition them, to do range-of-motion exercises and to have them sit in various chairs that offer sufficient support. ♻️

Make Lists of:

- Emergency contacts (e.g. doctors, therapists, etc.)
- Morning and bedtime routines
- Medical personnel with their areas of expertise, addresses and telephone numbers
- Home health agencies
- Other people who can help or fill in, if needed
- Lawyers and financial advisors
- Where needed items are kept, such as thermometers and blood pressure monitors
- Medications, when they are to be taken and where they are stored (both prescribed and over-the-counter, as well as any vitamin, mineral or herbal supplements)
- Exercise schedules and directions

These lists and other needed information can be put into a clearly marked notebook and kept where others can easily find them. This book should be complete enough so that someone filling in for you will know exactly what is needed and what to do.

Safety Tips

Quick, easy and readily available ways to communicate with others who can help in an emergency are a must. You can get:

- A cordless speaker phone with memory so that you can simply hit one button in an emergency to get help.
- A cellular phone, if you and your care recipient travel.
- A signal system that will summon help with the push of a button, if you leave your care recipient alone at times.
- A specially equipped telephone with speed dialing, a large digital display for easy reading, and ring and voice enhancer, if your care recipient has hearing problems.
- An intercom that will alert you if your care recipient is having problems when you are in another room.
- Smoke detectors on each floor, which should be periodically checked to ensure that they are operating properly.

If your care recipient has a disability, ensure that he or she:

- Has a clear path through each room, that there is nothing to trip over and no slippery floors. You can carpet the bathroom with all-weather carpeting to help prevent falls.
- Uses a cane or walker, if needed.
- Is secure in his or her wheelchair. If your care recipient is weak, a tray that attaches to the wheelchair can prevent falls and give him or her a place for drinks, magazines, etc. It is important to ensure that the wheels are securely locked when doing transfers or if the chair is on an incline.
- Discuss with the Veteran's medical team safe ways to ensure the Veteran does not fall out of bed.

Exercise

Plan an exercise routine with your care recipient's doctor and physical therapist. Encourage him or her to do a little more physical activity each week, if appropriate. Exercise with them.

Clothing

Regardless of our age or physical condition, we all want to look and feel our best. Today's clothing options make that a much easier goal to reach. When buying clothing, consider the following:

- Clothing that is washable and wrinkle-free saves on dry-cleaning bills and ironing time.
- Pants and skirts that have elastic or tie waistbands are easier to get on/off and are more comfortable.
- Clothing with snaps or zippers and some that button down the front are easier to manipulate than pullovers.
- Shoes that will not easily slip off with a nonskid tread.
- Interchangeable and color-coordinated clothing, e.g., pants and tops that match several others make choosing clothing easier.
- Discuss other options with the Veteran's treatment team.

Home Environment

- Use a plastic tablecloth or place mats that are easy to clean and a towel, apron or other covering for your care recipient's clothes if there is a tendency to spill food. Be sure that it is large and long enough to cover his or her lap. Fold it inward before taking it off to avoid spillage on the floor.
- Brighten things up. Consider having a vase of flowers (even artificial) on the table or next to the bed if your care recipient is confined to bed, and open the curtains to let the sunshine in.
- Use lightweight, plastic, easy-grip glasses or cups with handles. If there is a lot of spillage, try a drink holder with a lid and plastic straw insert.
- If clothes are wrinkled, you can put them in the dryer with a wet towel or sponge on a warm setting. This often saves a lot of time ironing.

If your care recipient is incontinent, you can:

- Use washable or disposable pads on the bed above the sheet.
- Use rubberized sheets underneath the bedsheet.
- Use a stain- and water-resistant mattress pad.
- You can use water-resistant pads or heavy towels on the wheelchair or furniture that your care recipient uses. If you travel, keep pads in the car for use on the car seat and when visiting other places.

If a mattress does become soiled, it must be thoroughly cleaned and aired after being sprayed with a safe antibacterial cleaning agent. Ask your doctor or pharmacist for recommendations. ☺

- When buying towel sets, you may want to purchase extra washcloths since these are used more frequently and wear out faster.
- Thermal blankets also are useful because they are warm, lightweight and easy to wash.
- Discuss other options with the Veteran's treatment team.

Fun Activities

Boredom can sap our intellect and spirit, but you can change this by creating activities that you and the Veteran you care for look forward to.

- Choose your favorite programs to watch each day instead of keeping the TV on nonstop.
- Get books from the library and read together (you can try large print or talking books).
- Play cards and board games to stimulate mental activity.
- Plan day trips. Check for special events that are low-cost or free. Invite a friend or family member to join you, preferably one who can drive or help you if your care recipient has a physical disability.
- Go out to lunch.
- Visit an art or hobby store and find arts and crafts projects that you can both enjoy.
- Invite family or friends over for a meal, snack or coffee.
- Go on vacation if you can afford it. Make sure that the destination can accommodate your needs, especially if your care recipient has a disability.
- If you have room, invite friends or family members to come and stay with you for a while in your home.
- Check colleges, religious organizations and community centers for free courses and other activities.
- Visit museums, galleries, botanical and zoological parks or a petting zoo.
- If appropriate, get a pet. Your local shelter or humane society has many pets available for adoption.
- Get a computer with Internet access.
- Ask community-based organizations about friendly visitor, volunteer and telephone-reassurance programs.
- Ask VA CSC about other activities that may be available in your area. This can be a great way to extend your circle of friends and supportive network.

TAKING CARE OF YOURSELF

At times, you might find yourself so concerned about the Veteran you care for that you completely forget about your own needs. If you're "burning the candle at both ends," you may become exhausted, emotionally stressed or ill – compromising your own quality of life and your ability to care for another person.

What Is Caregiver Stress?

Caregiver stress is the emotional strain of caregiving.

- Studies show that caregiving takes a toll on physical and emotional health.
- Caregivers are more likely to suffer from depression than their peers.

Burnout

The term "burnout" has been applied across all of the helping professions and refers to the cumulative psychological strain of working with many different stressors. It often manifests as a gradual wearing down over time.

Research shows that providing care to a Veteran with a service-related condition has widespread impacts on the Caregiver's health:

- 88% report increased stress and anxiety
- 77% report sleep deprivation
- Healthy behaviors, such as exercising, eating well, visiting their own doctors or dentists, decline for roughly 6 out of 10 Caregivers of Veterans

Women Caregivers are particularly prone to feeling stressed and overwhelmed:

- Studies show that female Caregivers have more emotional and physical health problems, employment-related problems, and financial strain than male Caregivers.
- Other research shows that people who care for their spouses are more prone to caregiving-related stress than those who care for other family members.

Is Caregiving Too Stressful?

If you have any of the following symptoms, caregiving may be putting too much strain on you:

- Sleeping problems (sleeping too much or too little)
- Change in eating habits resulting in weight gain or loss
- Feeling tired or without energy most of the time
- Loss of interest in activities you used to enjoy, such as going out with friends, walking or reading
- Being easily irritated, angered or saddened
- Frequent headaches, stomach aches or other physical problems

How to Prevent & Relieve Stress

You owe it to yourself and to your family to maintain your own physical and emotional well-being. Take the following steps to make **your** health a priority:

- Try to get enough sleep and rest.
- Eat a healthy diet rich in fruits, vegetables and whole grains, and low in saturated fats.
- Find time to exercise and stay physically fit.
- Have periodic health checkups. Talk to your doctor about any symptoms of depression or sickness you may be having.
- Do not abuse alcohol and/or drugs.
- Spend time with family and friends. Social activities can help you feel connected and/or may reduce stress.
- Pursue your own interests.
- Seek support from family, friends, professionals or your religious advisor – or join a support group for caregivers in your situation.
- Ask for and accept help. Use appropriate in-home and community-based services.
- Prioritize, make lists and establish a daily routine.
- Take one day at a time.
- Talk to your Caregiver Support Coordinator (CSC) about resources that are available.

Pay Attention to Your Emotions

Just as hunger lets you know that you need food, emotions can let you know when you need assistance or support.

Keep in mind that it is okay to feel angry, frustrated, sad or inadequate from time to time. Having these feelings is completely normal, and almost every Caregiver experiences them at some point.

If you feel stressed, angry or depressed:

- Remove yourself from the situation by walking away, even if it is just around the house.
- Talk to someone you feel close to or call a hotline.
- Talk with your doctor or other health professional.
- Write your feelings down in a journal.

Caring for another person can also create positive emotional change. Aside from feeling stress, many Caregivers say their role has had many positive effects on their lives, such as giving them a sense of purpose.

If you find that you are often angry or depressed, or that your emotions are getting out of control, you may benefit from counseling, and/or find relief in respite care, Caregiver support groups and other supportive in-home services. Talk to your CSC about what is available at your local Department of Veterans Affairs (VA). ☺

A Note About Grief

Most people associate grief with the feelings you have when a loved one dies. As a Caregiver, you may experience many losses, including the loss of the relationship you had with the person you are caring for, and the progressive loss of independence that your loved one is going through.

To cope, talk about your feelings. Be as patient with yourself through this process as you would be with others.

Ways to Make Caregiving Easier

Set realistic goals.

Providing care is likely just one of the many conflicting demands on you. It is important to recognize what you can and cannot manage.

Explore work options.

Flextime, telecommuting, job sharing or rearranging your schedule can help to minimize stress. Companies are increasingly offering resource materials, counseling and training programs to help Caregivers.

Involve older children.

Older children living at home may be able to assist you and/or your care recipient. Such responsibility, provided it is not overly burdensome, can help young people become more empathic, responsible and self-confident, and give you some needed support.

Ask other family members to help.

A family meeting from time to time may help others understand what is involved in the caregiving and the kind of help you may need. If possible, develop a "care schedule" to share the responsibilities.

Friends and neighbors also may be willing to provide transportation, respite care and help with shopping, household chores, etc.

Did You Know...?

If you are feeling overwhelmed, taking a break from your job may help you get back on track. Under the Federal Family and Medical Leave Act (FMLA):

- Eligible employees may be able to take up to 12 weeks of unpaid leave per year to care for relatives.
- Eligible Family Caregivers of injured active-duty Servicemembers can take up to 26 weeks of unpaid leave per year to care for a loved one undergoing medical treatment, recuperation or therapy for a serious injury or illness. Check with your Human Resources Department for information.

CARING FOR A VETERAN WITH TBI

Traumatic brain injury (TBI) is defined as a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain. Not all blows or jolts to the head result in TBI.

The severity of a TBI may range from “mild,” i.e., a brief change in mental status or consciousness, to “severe,” i.e., an extended period of unconsciousness or amnesia after the injury. A TBI can result in short- or long-term problems with independent function.

Who Is at Risk?

Males are about 1.5 times more likely than females to sustain a TBI. Certain military duties increase the risk.

- Falls are the leading cause of TBI; rates are highest for children ages 0-4 and adults 75 years and older.
- Blasts are a leading cause of TBI for active-duty military personnel in war zones.

The Centers for Disease Control and Prevention (CDC) estimates that at least 5.3 million Americans currently have a long-term or lifelong need for help to perform ADLs as a result of a TBI.

TBI can cause a wide range of functional changes affecting thinking, sensation, language or emotion:

Thinking	Sensation
Memory and reasoning	Touch, taste and smell
Language	Emotion
Communication, expression and understanding	Depression, anxiety, personality changes, aggression, acting out and social inappropriateness

Remember, there is no single correct way to deal with the changes in your spouse, relative or friend following a TBI. 🌀

If the Veteran You Care for Is Diagnosed with a TBI:

- Be patient. They may be disoriented for some time.
- Help them become more independent. Provide opportunities for them to do things for themselves, even though they might not succeed.
- Be supportive. Your care recipient may need help to re-learn skills that were lost. Adjust the level of support to accommodate their current abilities and skills.
- Get counseling for your other family members. This can help everyone accept the new situation.
- Take care of yourself.

Make sure the Veteran you care for:

- Gets lots of rest and does not rush back to daily activities. Rest helps the brain to heal.
- Avoids doing anything that could cause another blow or jolt to the head.
- Asks the doctor when it's safe to drive a car, etc., because his or her ability to react may be slower.
- Takes only doctor-approved drugs, and doesn't drink alcohol until the doctor says it's okay.
- Writes things down if he or she has trouble remembering.
- Tries to do one thing at a time if he or she is easily distracted, e.g., turns off the TV while making something to eat.
- Consults with family members or close friends when making important decisions.

How long will it take to get better?

Healing takes time. How fast people recover from brain injury varies from person to person and depends on many factors, including:

- Severity and part of brain injured
- Age and level of health at time of injury
- How long it took to receive the right medical treatment

CARING FOR TRAUMA SURVIVORS

The new generation of Veterans being cared for by the Department of Veterans Affairs are returning combat Servicemembers who served in Operations Enduring Freedom, Iraqi Freedom and New Dawn (OEF/OIF/OND). The most common combination of diagnoses found is post-traumatic stress disorder (PTSD) and depression.

- It is important for Caregivers working with trauma survivors to know about traumatic stress because trauma survivors are in an ongoing process of healing and recovery.
- Pressing someone into talking about a traumatic event soon after exposure may have a detrimental effect on some traumatized individuals.

Many Servicemembers who have experienced combat, and their families, are familiar with the term "combat stress." The effects of combat, however, aren't limited to those directly connected to the experience.

Those who work with survivors may begin to show signs of stress disorders, ranging from difficulty sleeping to PTSD symptoms. Family Caregivers of wounded Veterans are also at risk.

Secondary Traumatic Stress

"Secondary Traumatic Stress" describes professional workers' signs and symptoms of PTSD that mirror those experienced by trauma clients, friends or family members.

While it is not recognized by current psychiatric standards as a clinical disorder, many clinicians note that those who witness traumatic stress in others may develop symptoms similar to or associated with PTSD, including:

- Hyper-arousal (heightened reactivity)
- Intrusive symptoms
- Avoidance or emotional "numbing"
- Anxiety
- Depression

Take steps toward self-care and lifestyle balance if you start to experience symptoms of secondary stress.

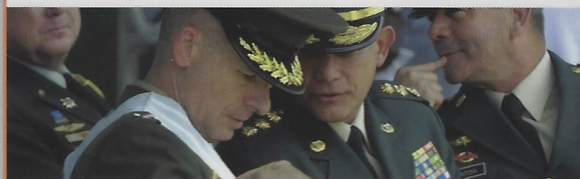
Individuals who have worked with trauma survivors over time may experience negative effects during times of heavier workloads, heightened personal stress, and overwhelming exposure to terrorist events and their aftereffects.

However, a large majority of individuals who work with trauma survivors indicate that it has:

- Brought great meaning into their lives,
- Increased their sense of purpose and strength, and
- Heightened their sense of connection with others.

Often these individuals took breaks, sought assistance or mentoring, or increased self-care when they began to see signs of negative effects.

People have their own pace for processing trauma, and it is important to let survivors know that they should listen to and honor their own inner pace.



For more information about stress-related disorders and resources for Veterans and their families, visit the National Center for PTSD at www.ptsd.va.gov.

Did You Know...?

An event, or series of events, that causes moderate to severe stress reactions is called a traumatic event. Traumatic events are characterized by a sense of horror, helplessness, serious injury, or the threat of serious injury or death. PTSD is an intense physical and emotional response to thoughts and reminders of the event that lasts for many weeks or months after the traumatic event.

LIVING ARRANGEMENTS

There are many times when it is not possible for a Caregiver and care recipient to live together.

- The level of care that the care recipient needs may require highly skilled health care personnel on a regular basis.
- The care recipient may live in another town and may not want to move.
- There may not be room in your home, or those involved may not want to live together.

Whatever the reasons, living in different housing does not mean that you cannot be a good Caregiver.

Choosing Housing & Living Arrangements

The type of housing and living arrangements you choose for persons with limited mobility and multiple needs is critical in assuring they get the care they need. Discuss options with your Caregiver Support Coordinator.

There are many options available and they often overlap in the types of care and services they provide. Before making a choice, you and your care recipient should assess present needs and envision how these needs may change in the future.

- What options will be open to you if the need for more supportive housing and living arrangements arises?
- Will your care recipient need to move to another care arrangement?
- Are these facilities available in the community and how much will they cost?
- How are you going to pay for housing and services now and in the future?
- What guarantees do you have that the facility is financially secure?

Even if you are not thinking about housing options now, it is smart to have several in mind in case an emergency arises and you need to secure temporary care. ☺

Types of Housing & Living Arrangements

Listed below are a few types of housing and living arrangements and what they generally offer. Added to these considerations are those of costs.

Accessory Apartments

Accessory apartments are self-contained apartments in your home or the care recipient's home. Designed for individuals who are largely self-sufficient or need help with housekeeping, cooking and personal care.

Medical Foster Home

Adult foster care is usually provided in private homes, often by the owner. The home usually provides meals, housekeeping and sometimes personal care and assistance with activities of daily living (ADLs).

Assisted Living

Some assisted living provides a full range of services, including skilled nursing care. Others provide only personal care, assistance with ADLs and/or social activities. These may also be called "retirement homes" or "residential care facilities."

Nursing Homes

Nursing homes provide many services, including 24-hour skilled medical care for total care patients; custodial care; therapy for convalescing patients; and personal care and help with ADLs for persons with dementia, chronic health and/or mobility problems.

Retirement & Continuing Care Communities

Both may include everything from housing for independent living to assisted living and skilled nursing home care. These communities are usually designed for older persons with substantial financial resources.

Shared Housing

Shared housing can be in the care recipient's or someone else's home. Common areas, such as the kitchen, are shared. It may offer companionship and the possibility of having someone else around to help with chores or in case of emergencies, depending on the situation.

When Your Care Recipient Lives with You

Will it work in your home? VA can assist with resources.

1. Is your home large enough so that everyone can have privacy when they want it?
2. Is there a separate bedroom and bath, or can you create an accessory apartment?
3. Are these rooms on the first floor? If not, can your care recipient climb stairs safely?
4. Can you add to or remodel your home to provide a first-floor bedroom and bath?
5. Do you need to add safety features?
6. Does the bathroom have a shower, is it large enough to accommodate a wheelchair (if needed), and can safety features be installed to prevent falls?
7. Are door openings wide enough for a wheelchair?

Share time together.

If you do want your care recipient to live with you, make it a point to spend time together that does not solely revolve around care.

- Set aside times to talk.
- Involve your care recipient in family outings and social events (if possible).
- Invite other family and friends to your home, and let them know that you are available to come to their house as well.
- Even errands, such as shopping, can be something of a social event and give your care recipient a chance to participate in decision-making.

At the same time, you want to ensure that other family members do not feel that they have been "displaced" and that they are as important to you as ever.

If you decide to live together, you might want to try it on a trial basis. Consider renting/subletting your care recipient's home on a short-term basis so that he or she can return home if the new arrangement does not work out. 🔄

LIVING TOGETHER

What are the pros and cons?

Every family's situation is unique. It is important for you, your loved one, and other family members to weigh the pros and cons of living together **before** you enter into an arrangement.

On the plus side:	On the down side:
If your care recipient needs considerable care, you will save the cost of a long-term care facility or, at least, some in-home services.	You may have less time for yourself and/or other family members, and if you work, you may find conflicts.
You know that your care recipient is getting the best possible care because you are either providing it yourself or directly overseeing the care.	You may find that you and/or your care recipient resent changes in your relationship that may take place.
You will be able to make major decisions that can give you a sense of empowerment.	You will lose at least some of your privacy.
You will have more time to spend together.	Other family members may resent the new arrangement.
Your children will learn about compassion and responsibility.	There may be less space for everyone in the family.
If your care recipient is fairly healthy, he or she may help with household tasks, and/or with the children.	You may find that hands-on caregiving is too physically and/or emotionally demanding.



LIVING TOGETHER

LIVING ARRANGEMENTS

SERVICES THAT CAN HELP

If you are a Caregiver, you are not alone in the challenge of keeping your life in balance. There are services available that can help lighten the load.

If you need help, you can find it right in your own community. There are many different government and privately funded services that may be available.

VA can provide many services and your Caregiver Support Coordinator can assist you in finding community resources.

Personal & In-Home Care

Personal and in-home care assistants help with bathing, dressing, preparing meals, house cleaning, laundry, toileting and other personal activities of daily living (ADLs).

Respite Care

Respite care can be a voluntary or paid service. It can be provided in your home, in an extended care facility, or at an adult day or senior center. Respite care can extend for a few hours or for several weeks. It provides the caregiver with the opportunity to take care of personal affairs, to get some rest or to take a vacation. Make sure you schedule respite care regularly. This gives you time to take care of your other responsibilities, or just to recharge your batteries.

Transportation

Transportation services are vitally important to persons with limited mobility. Many public mass transit systems are fitting buses and other vehicles with hydraulic lifts and other aids to assist persons with physical disabilities.

Transportation options may be available through private companies and nonprofit organizations. These include public fixed-route, demand-response, ride sharing, volunteer drivers, limousines, buses, vans, and regular and special-purpose taxis.

Home Health Care

Home health care includes such care activities as changing wound dressings, checking vital signs, cleaning catheters and providing tube feedings. Home health care staff also may provide some personal care services and light housekeeping.

Some home care can be given only by licensed health workers, such as skilled nursing care for the treatment of an illness or injury.

Skilled nursing care includes services and care that can only be performed safely and correctly by a licensed nurse (either a registered nurse or a licensed practical nurse) or a licensed therapist.

Home-Delivered Meals

Services provide meals to the elderly and persons with disabilities either in their own homes (e.g., Meals on Wheels) or in senior centers and other community locations (i.e., congregate meal programs).

- Persons who are 60 years and older may be able to receive government-subsidized home-delivered meals.

There are also local and national franchised meal delivery services, listed in the Yellow Pages™ or on the Internet.

Also, see if your grocery store prepares orders for pickup or provides delivery. Plus, many local restaurants deliver meals without additional charge and some even offer senior discounts.



Did You Know...?

Caregiver Support Coordinators (CSC), located at every VA Medical Center across the country, are licensed professionals devoted to informing you about the services and support available to you. As an advocate, your local CSC is there to help you, in the way you need. Call the Caregiver Support Line for a CSC referral, at 1-855-260-3274.

Adult Day Services

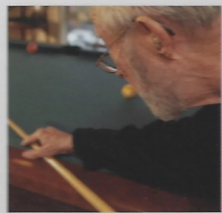
Adult day services provide activities and assistance for people with physical and/or mental impairments. This service is for people who cannot be left alone for long periods of time. For example, a person may use adult day services while his or her Caregiver is at work.

Adult day services can provide relief to working Caregivers and respite for full-time Caregivers. Some programs offer services in the evenings and on weekends, in addition to standard business hours. Programs may provide services for individuals with specific impairments such as Alzheimer's disease or mental illness.

Most adult day centers, like senior centers, are supported through public and nonprofit organizations. Fees may range from a few dollars a day to close to \$200, depending on the services provided.

Senior Centers

Senior centers are located in many communities to provide a wide range of services. The Administration on Aging (AoA) estimates that there are from 10,000 to 16,000 senior centers located throughout the U.S.



Senior centers offer older persons a safe environment where they can take part in a range of activities that promote healthy lifestyles and where they can develop a network of friends.

Most services are provided free or at low cost and can include:

- Nutrition
- Recreation
- Social and educational services
- Wellness and fitness activities
- Information and program referral services
- Internet training

Cleaning & Yard Work Services

An Area Agency on Aging (AAA) or other community-based service organization may be able to arrange for chore and yard maintenance services or put you in touch with religious, scout or other volunteer groups that provide one-time or occasional services to persons who need help.

Home Modification, Improvement & Weatherization Programs

Home modification and repair programs can make homes safer and more energy efficient. Home adaptations can result in greater independence for persons with disabilities, helping them perform daily activities such as bathing, cooking and climbing stairs.

Possible adaptations include:

- Installing grab bars, shower seals or transfer benches
- Placing nonskid strips or decals in the tub or shower
- Adding lever handles on doors, loop handles on cupboards and paddle electrical switches
- Installing ramps, elevators or stair lifts
- Installing insulation, storm windows and air-conditioning
- Installing handrails for support
- Widening doorways to accommodate walkers, crutches and wheelchairs

Veterans who have specific service-connected disabilities may be entitled to a grant from the VA for the purpose of constructing an adapted home or modifying an existing home to meet their adaptive needs. Flip to "Servicemember Benefits."

Did You Know...?

Adaptive home modifications can ease the burden on the Caregiver as much as they can improve the care recipient's quality of life.

SERVICEMEMBER BENEFITS & ASSISTANCE

The VA offers a range of benefits to Servicemembers, Veterans and their families.

- Over 3.7 million Veterans and beneficiaries receive compensation or pension benefits from the VA.
- Average annual amounts paid to Veterans or survivors under various benefits programs: disability compensation, \$9,811; pension, \$8,509; Dependency and Indemnity Compensation, \$13,612; and death pension, \$3,829.

The following persons may be eligible for VA benefits:

- Veterans and their dependents
- Surviving spouses, children or parents
- Active-duty Servicemembers
- Members of the Reserve or National Guard
- Family Caregivers of Veterans injured post 9/11

VA Benefit & Assistance Programs Include:

VA Pension

If your care recipient is a wartime Veteran with limited income, and is permanently and totally disabled or at least 65 years old, they may be entitled to receive a monthly pension.

VA Disability Compensation

Disability compensation is a benefit paid to a Veteran because of injuries or diseases that happened while on active duty, or were made worse by active military service. The benefits are tax-free.

Your care recipient may be eligible if he or she has a service-related disability and was discharged under other than dishonorable conditions. The amount of basic benefits paid ranges from \$117 to more than \$3,000 per month, depending on the disability.

VA BENEFITS & ASSISTANCE

Related Benefits:


- ▶ Priority Medical Care
- ▶ Vocational Rehabilitation
- ▶ Clothing Allowance
- ▶ Automobile Grant & Adaptive Equipment
- ▶ Service-Disabled Veterans Insurance
- ▶ Federal Employment Preference
- ▶ State/Local Veterans Benefits
- ▶ Military Exchange & Commissary Privileges

VA Special Monthly Compensation for Serious Disabilities

The VA can pay additional compensation to a Veteran who, as a result of military service, incurred the loss or loss of use of specific organs or extremities.

If a Veteran's disability is service-connected at the 100% rate and the Veteran is housebound, bedridden or so helpless as to need the aid and attendance of another person, then consideration of payment of additional special monthly compensation (SMC) can be considered.

Disability benefits, education, health care, rehabilitation services, residential care, compensated work therapy and life insurance are among the many services offered to eligible Veterans.

Call toll-free 1-800-827-1000 or visit www.va.gov for more information on these and other available programs. 

Did You Know...?

The Department of Defense (DoD) also offers a number of compensatory programs for wounded Servicemembers, including Disability Retired Pay and Combat-Related Special Compensation. Eligibility is determined by your care recipient's branch of service.

Comprehensive Assistance for Caregivers

Family Caregivers in a home environment can enhance the health and well-being of Veterans under VA care. They provide crucial support to their care recipients by allowing them to stay in the homes and communities they defended, surrounded by the loved ones they fought for. Additional VA services are now available to those Family Caregivers of Post 9/11 Servicemembers and Veterans through the Program for Comprehensive Assistance for Family Caregivers.

The additional Caregiver services for eligible Servicemembers and Veterans include:

- Monthly stipend paid directly to the primary Family Caregiver
- Health care coverage for Caregivers who are not insured already
- Mental health services: individual and group therapy
- Comprehensive Caregiver training
- Travel, lodging and daily meal allowance during training and, if accompanying a Veteran, for appointments
- A minimum of 30 days of respite care per year

Who is eligible?

- Veterans who sustained a serious injury – including traumatic brain injury, psychological trauma and other mental disorder – incurred or aggravated in the line of duty, on or after September 11, 2001; and,
- Who are in need of personal care services because of an inability to perform one or more activities of daily living (ADLs) and/or need supervision and protection due to neurological impairment or injury; and,
- Veterans must be enrolled for VA health services

You can start the Caregiver Program application process:

1. **By telephone:** 1-877-222-VETS
2. **In person:** at your local VA Medical Center
3. **By mail:** download a copy of the form (VA CG 10-10) at www.caregiver.va.gov.
4. **Online:** Live chat assistance is available to help you fill out the form at www.caregiver.va.gov.

VA Home Modification Programs

The VA has three main grant programs to assist veterans who have disabilities with necessary home modifications.

1. Specially Adapted Housing (SAH) Grant

Veterans who have specific service-connected disabilities may be entitled to a grant for the purpose of constructing an adapted home or modifying an existing home to meet their adaptive needs. The SAH grant is generally used to create a wheelchair-accessible home and is currently limited to \$63,780.

2. Special Housing Adaptation (SHA) Grant

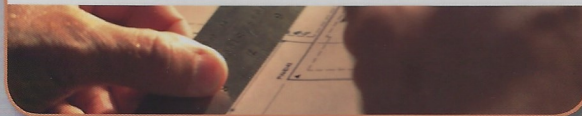
Veterans who have specific service-connected disabilities may be entitled to a grant for the purpose of modifying an existing home to meet their adaptive needs. The SHA grant is generally used to assist Veterans with mobility throughout their homes. This grant is currently limited to \$12,756.

3. Home Improvements and Structural Alterations (HISA) Grant

Veterans with service-connected or nonservice-connected disabilities may receive assistance for any home improvement necessary for the continuation of treatment or for disability access to the home, and essential lavatory and sanitary facilities. A HISA grant is available to Veterans who have received a medical determination indicating that improvements and structural alterations are necessary or appropriate for the effective and economical treatment of his or her disability. Veterans with:

- Service-connected disabilities may receive up to \$4,100.
- Nonservice-connected disabilities may receive up to \$1,200.

A Veteran may receive both a HISA grant and either a SHA or SAH grant.



ADDITIONAL GOVERNMENT BENEFITS & ASSISTANCE

Some persons with limited income and assets are eligible to participate in a number of benefit and assistance programs. Others have adequate assets to cover their regular living expenses, but cannot afford long-term care for an extended period.

Benefit Programs

In addition to Social Security, the Supplemental Security Income program provides benefits to persons with limited incomes and assets who are blind, disabled or 65 and older.

Health Benefits

- Medicare is the national health insurance program for people age 65 and older and for some younger persons with disabilities.
- Medicaid is a program that provides health care insurance for low-income older adults and adults with disabilities.

You may want look into Federal Centers for Medicare and Medicaid Services programs that assist low-income Medicare beneficiaries.

Medicaid covers many of the medical expenses not covered by Medicare. Each state sets its own income and asset eligibility requirements for Medicaid benefits.

You may also want to explore the possibility of purchasing Medigap and/or long-term care insurance.

- Medigap is private insurance that usually covers health care costs not covered by Medicare and Medicare deductibles.
- Long-term care insurance generally pays a set amount or percentage of long-term care costs both at home and in long-term care facilities. However, it may be quite expensive or unavailable, dependent on a person's age.

www.benefits.gov is the official benefits site of the U.S. Government, with information on over 1,000 benefit and assistance programs. ☘

Housing Programs

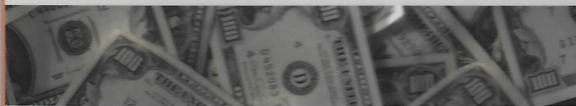
There are housing programs for persons with limited income who do not own their own homes, including public housing and rental certificates that are available regardless of age. These are U.S. Department of Housing and Urban Development programs, but you can contact your local housing authority for information.

There are also a number of U.S. Department of Agriculture Rural and Community Development housing assistance programs for persons living in rural areas, ranging from loans to buy homes to home-improvement and rent subsidy programs.

Tax Deductions & Credits

Some out-of-pocket expenses associated with long-term care are tax-deductible as medical expenses, including: transportation to medical appointments, long-term care insurance premiums, prescription drugs, privately hired in-home health care employees, and changes to a dwelling or car for medical reasons.

- The expenses must be for the care of a chronically ill individual who needs help with at least two ADLs or requires "substantial supervision to protect against threats to health and safety due to severe cognitive impairment."
- Tax credits generally benefit low-income taxpayers and usually require the Caregiver to live with the care recipient and work outside the home.



Did You Know...?

Most states now have programs that pay Family Caregivers to provide home-maker, chore and personal care services. Most use state funds to compensate families, while other states use Medicaid waiver funds. Contact your Area Agency on Aging (AAA) or Department of Social Services for more information.

ALTERNATIVE CARE PLANS

Family Caregivers cannot assume that they will always be able to provide care. It is important to establish both emergency and long-term alternative care plans, and to make sure that the necessary legal documents are in place.

Legal Documents & Care Plans

Every adult should have at least a power of attorney (POA), a living will or medical directive, and a will or trust in place so that his or her wishes can be followed. If your care recipient does not, you both should consult an attorney.

- It will be easier to make long-term plans with a POA.
- If your care recipient cannot make informed choices, it may be necessary to seek appointment as a conservator and/or guardian.

Discuss alternate plans with your care recipient, other family members, and the designated Caregiver to help avoid opposition in the future.

If you are the only possible Family Caregiver, you and/or your Veteran can appoint a trusted friend or committee of friends to oversee the care, or have a lawyer act as your care recipient's representative. (Make sure that they, too, have the legal power to make decisions when needed.)



Contact your VA social worker for assistance with advanced directives and health care POAs. 🔄

ALTERNATIVE CARE PLANS

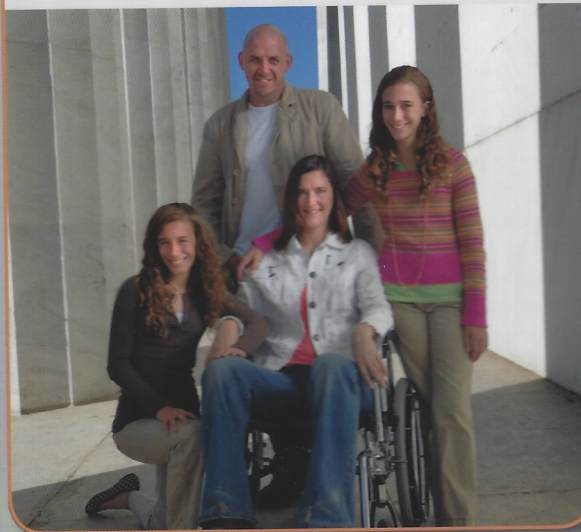
Short-Term Care

Short-term emergencies do not require the same amount of legal planning, but must be considered. If you are unable to look after your care recipient, make arrangements with:

- A relative or friend (and have a backup in place)
- A facility that provides short-term respite care
- A home care agency or geriatric care manager

Remember that home care agencies often cannot provide services on short notice.

With the Program for Comprehensive Assistance for Family Caregivers of Post 9/11 Servicemembers and Veterans, there is provision for Veterans to designate two secondary Family Caregivers. Your Caregiver Support Coordinator (CSC) and VA clinical team can assist in identifying short-term care in an emergency.



ALTERNATIVE CARE PLANS

ALTERNATIVE CARE PLANS

THE VA IS THERE TO SERVE YOU

The Role of Your Caregiver Support Coordinator (CSC)

As a Family Caregiver, it can be difficult to wade through all the programs and services available to you and the Veteran you care for. It may be impossible to even find the time to try. Your local CSC is there to step into the breach. Acting as an advocate for you, your CSC will:

- Offer support and assistance to you as a Family Caregiver
- Organize Caregiver support activities and services
- Inform you of other services available to you and your care recipient in your community
- Assist you with the application for new benefits
- Listen to you and ensure VA staff are sensitive to your concerns

There are CSCs stationed at every VA Medical Center across the nation. Get connected with your CSC at your local VA Medical Center, or you can sign up online at www.caregiver.va.gov or call the Caregiver Support Line at 1-855-260-3274.

There are all kinds of services you and your care recipient may be eligible for. Your CSC can explain these services:

- Adult Day Health Care (ADHC) Centers
- Home-Based Primary Care
- Skilled Home Care
- Homemaker and Home Health Aide Program
- Home Telehealth
- Respite Care
- Home Hospice Care ☼

ROLE OF YOUR CSC

Caregiver Support Is on the Line, Toll-Free

VA wants to help you stay strong and stay informed with strategies for maintaining balance, caring for yourself, and speaking up for you and your Veteran. The toll-free National Caregiver Support Line serves as a primary resource center for you. Your calls will be answered by licensed social workers who understand your needs.

The goals of the Caregiver Support Line are to provide you with:

- Emotional support
- Information on VA Caregiver support resources
- Information about community programs
- Answers to questions about benefits application

Just one number to dial to get the tools you need to be a positive and effective Caregiver.

1-855-260-3274

Monday–Friday, 8 a.m.–11 p.m. ET

Saturday, 10:30 a.m.–6 p.m. ET

...Or Online

Are you new to caregiving? The VA Caregiver Support website is your first stop to learn all the things you need to know. You will find the information you need to help you help your Veteran:

Check out the **Caregiver Tool Box**, which is full of useful tips such as 50 Things Every Caregiver Should Know. You'll find printable medication log sheets, a comprehensive list of questions to ask your Veteran's health care providers, and more.

Caring for the Veteran you love is often your primary focus for the day. But sometimes, caregiving for the Veteran and your family can feel exhausting, and leave you without much time for yourself. Click on the **Staying Strong** tab for helpful hints to maintain balance and take care of yourself.

Don't miss the **Caregiver Connections** section. All across the country, Family Caregivers like you are taking care of the Veterans they love. Here they share their stories and offer advice. Visit VA Caregiver Support at www.caregiver.va.gov.

CAREGIVER SUPPORT

ADDITIONAL RESOURCES

For Servicemembers

Our Military

www.ourmilitary.mil

Our Military is a DoD program that connects individuals, organizations and companies to hundreds of home-front groups offering a variety of support to the military community. The program also connects military Servicemembers and their families to groups that provide assistance.

VA Caregiver Support

www.caregiver.va.gov

Government Sites

Centers for Medicare and Medicaid Services

www.cms.hhs.gov

Social Security Administration

www.ssa.gov

U.S. Department of Housing and Urban Development

www.hud.gov

USDA Rural Development

www.rurdev.usda.gov

More Info, Please!

National Alliance for Caregiving

www.caregiving.org

Family Caregiver Alliance National

Center on Caregiving

www.caregiver.org

National Family Caregivers Association

www.thefamilycaregiver.org

Defense and Veterans Brain Injury Center

www.dvbic.org

Brain Injury Association of America

www.biausa.org

Caring Connections

www.caringinfo.org

BenefitsCheckUp

www.benefitscheckup.org

RESOURCES

National Alliance on Mental Illness: www.nami.org

Or call their information and referral helpline at 1-800-950-NAMI (6264) weekdays, 10 a.m. to 6 p.m. (ET).

NAMI is dedicated to the eradication of mental illnesses and to the improvement of the quality of life for persons of all ages affected by mental illnesses by providing support, education and advocacy.

Alzheimer's Association: www.alz.org

Or call toll-free 1-800-272-3900, day or night.

The Alzheimer's Association 24/7 Helpline provides reliable information and support to all those who need assistance.

Eldercare Locator: www.eldercare.gov

Or call toll-free 1-800-677-1116 weekdays, 9:00 a.m. to 8:00 p.m. (ET).

Eldercare Locator is the first step to finding resources for older adults in any U.S. community. It is a free national service of the AoA. Support services for caregivers are also available.

Did You Know...?

The National Family Caregiver Support Program administered by the AoA, calls for all states, working with AAAs and community-based service providers, to offer five basic services for Family Caregivers:

1. Information
2. Assistance
3. Individual counseling, organization of support groups and caregiver training
4. Respite care
5. Limited supplemental services

Eligible Caregivers: Family Caregivers of adults (60 or older) and persons with Alzheimer's disease or a related disorder (regardless of age); grandparents and relative Caregivers of children (18 and under) and relative Caregivers of an adult child (19-59) with a disability (not including parents).

RESOURCES

RESOURCES



HEALTHY CAREGIVING



Caregiving may be the most challenging and significant role you ever take on. Take the steps to make sure you and your care recipient are both living the best lives possible.

- Tips for day-to-day life
- Preventing Caregiver stress
- Living arrangements
- Caring for trauma survivors
- Services that can help
- Benefits and assistance



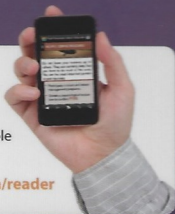
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