



Caregiver Support Line Telephone Education Group

Series: Care for the Caregiver

Topic: Dual Caregivers: Surviving and Conquering the Challenges

We all have a number of natural roles or relationships that we manage and balance roles such as wife, husband, sibling, parent, grandparent, employee, neighbor, and church or community member. When you become a caregiver in one of those relationships it may challenge your ability to fulfill your responsibility in other roles. That is what we will be discussing today. There are a staggering number of people managing dual caregiving roles, being a caregiver for two or more loved ones. The National Alliance for Caregiving reports that about 66 million Americans take care of a parent, spouse, relative or other loved one and about one third of them are also raising children.

This is challenging work and we will discuss some of the strategies and resources to help you successfully juggle dual caregiving roles while also attending to the other responsibilities in your life. We will examine how the roles you engage in may be affected when you also become a caregiver.

The role of spouse is a primary social relationship, with many other relationships springing from this one. Spouses normally share the responsibilities of providing for one another and the family, dividing up who takes the lead in certain tasks depending on their individual strengths and preferences. If you have children, you are partners in parenting your children. As parents, you are models for your children, nurturing, and educating them. Some of you are grandparents, wanting to love and spoil your grandkids, and spend extra time with them as you retire or near the end of your career. As adult children with aging parents, you are now fellow adults with your parents. You are on the same team so to speak, and you may have perspective to understand the roles they have played.

Let's discuss what can happen to your roles when you become a caregiver in one or more of these relationships. Due to injury or illness, their needs change your relationship with them, and this also changes your roles with others, just as dropping a stone in water causes ripples that gradually affect the whole pond. Caregiving for a family member can result in your whole family being challenged to adjust schedules and priorities. When you can adapt and work together as a family, your resilience becomes stronger. The most successful families tend to



be ones that are able to move forward from seeing the illness or injury as a catastrophe, to working as a team in tackling the new responsibilities. Resilient people build on their strengths to cope with changing demands.

As a caregiver you may find yourself struggling with how to cope with unpredictable or new behaviors. Illness and physical weakness may mean you will be helping with bathing, toileting, and transporting. You may also have to assume all the household responsibilities. If your spouse has PTSD, dementia or a mental illness, their perceptions or anxieties may limit what they can do for themselves and require a lot of your time and attention. They may have emotional needs that require your daily reassurance, support and protection. You may feel more like a single parent than a partner at times! You may feel lonely and long for the romantic relationship you once had. You may be grieving the loss of what you imagined your marriage would be like and feel robbed of enjoying your role as a partner to your spouse.

If you are caring for a spouse while raising children, your normal routine may be in turmoil. You may find your house getting messy, see chores piling up, and find yourself cooking sporadically. Personal interests frequently get set aside as you try to satisfy the needs of those you care for. Having a spouse with physical limitations or PTSD may require that you have a “plan B” if you need to make a quick exit from family outings, or you may have to plan some activities without your spouse.

You may struggle to give your children the individual attention they want and need. Your child may feel left out or resent having to do extra chores. They may feel guilty about having bad feelings toward their ill parent. This balancing act can leave you feeling inadequate as a parent and helpless to meet everyone’s needs. It is essential that you get help and that you carve out time for your children and yourself.

You may find there is limited time to keep up with friendships or enjoy social activities. You might find you no longer have the time or energy to actively participate and contribute to your clubs or faith community.

As a grandparent and caregiver, your “golden years” may not be what you expected. You may be strapped to home because of the physical limitations or dementia of the person you care for, feeling that you should protect your precious grandchildren from a grandpa or grandma who does not recognize them or who becomes agitated if they get too playful.



Having a young child with a disability, mental illness, or chronic medical condition affects the whole family. Everyone is challenged to work together, be flexible, and make sacrifices. In addition to requiring extra assistance and attention from you, your child may require counseling, tutoring, or frequent medical tests and treatment. You may find yourself grieving the loss of what you imagined and hoped your child's life would be without their condition. The child's needs can monopolize your time, and put a strain on finances and family relationships. It is important that you find ways to periodically spend individual time alone with your other children so siblings don't feel left out or guilty about having bad feelings toward the sick or disabled child.

Some of you may be caring for an adult child, possibly a Veteran, with a disabling injury, condition or illness. The disability may demand that you assist your child in the same way you did when they were young. You may feel resentful that you are forever a parent. You may grieve the fact that you may never see your child fulfill the dreams you had for them such as getting married, becoming a parent or having a career. You may feel robbed of enjoying your role as fellow adult with your child.

If you are caring for an aging parent, there may be a role reversal as you now find yourself helping them with bathing, dressing, eating and toileting, just like they once did for you. You may have to manage their finances, health care decisions, and take care of two homes. If your parent has to move into your home, you may feel a loss of privacy.

Where there is the dual responsibility of caring for children and aging or ailing parents, this has been called the "Sandwich Generation." If you are a member of this Sandwich Generation, you balance caring for your parents while also attending your children's school and social events. It is impossible to be in two places at once. Later on, we will suggest ideas to help you manage this juggling act.

Caring for a disabled parent can be a strain on your marriage, so it's important to keep the lines of communication open and make time alone with your spouse to nurture your relationship. Caring for an ill or aging parent can stir up a variety of feelings toward your parent or their feelings toward you. Your parent may see this caregiving shift as a loss of control of his or her life, and may be frustrated at what they can no longer do, targeting and blaming you. Resentment may also develop if you are caring for a parent that was absent or abusive to you as a child. You may be grieving the loss of the parent you once knew. If they have Dementia or Alzheimer's disease they may not even recognize you.



Have you ever felt embarrassed or angry when your parent with dementia behaves oddly in public? One caregiver managed these situations by having small business cards printed that read *“My husband suffers from Alzheimer’s disease. I appreciate your understanding and patience.”* She would discretely slip the card to people as needed without causing her husband embarrassment and relieving her of feeling pressure to control his behavior.

Do you feel overwhelmed and squeezed to the max by the added responsibilities you’ve taken on? Feelings of resentment can build when there isn’t enough time to enjoy your children and spouse. When you feel pressured to juggle competing demands for your time, it may leave you feeling like you are not doing anything well. You may feel guilty that you are not providing all you can to your parent, children and spouse. You may miss having a partner to help with parenting struggles and financial strains. It is understandable that you may end up feeling tired and depressed.

Depression is one of the most common feelings identified by caregivers struggling with the sense that their lives seem out of their control. The loss of normalcy and the added responsibilities may cause resentment. Do you find yourself saying *“This isn’t what I bargained for, where’s the exit?”* and then feel guilty for having these feelings? Whether you are struggling with grief, anger, resentment or guilt, be kind to yourself. Your feelings are not right or wrong, they are simply your feelings. Acknowledging them is the first step in getting past them and moving forward to find the support you need and develop new ways to renew your strength.

The stress and demands of being a dual caregiver can lead to caregiver discouragement and burnout. But there are also rewards and resources to help. We will now turn our focus to some strategies to help you manage your responsibilities while also taking care of yourself.

Dual caregivers have the difficult challenge of juggling the needs of their Veteran, all the others you are caring for, and your own needs. Caregivers need to practice self-care in order to meet these tasks and stay healthy. It is so important to caregiver self-care to learn to ask for and accept help. This also means that you will need to build on your list of resources that you can turn to for help. We strongly encourage you to write down on paper all the possible sources of support available to you; family, friends, neighbors, VA providers, community agencies, and religious or spiritual communities. Keep adding to the list and go to it when you are in need as often when stressed, you may forget who you may reach out to for support.



Self-care also requires that you relinquish unreasonable expectations of perfection and be forgiving and gentle with yourself. Sometimes the stress you are feeling is created from this pressure for perfection that could be relieved with slowing down, getting some perspective and accepting that you are doing the best you can and your best is good enough.

Self-care also means taking the time and attention to caring for your body as you care for others. Eating healthy, getting some needed stretching or exercise, drinking plenty of water, and keeping your medical appointments is keeping you strong and is an act of loving kindness for you. So, make the time for a few minutes of morning stretches, an evening walk, a healthy meal enjoyed slowly as these efforts will support your wellbeing.

Regularly give yourself a break and schedule “me” time. Finding the time to care for your self is a great challenge. The goal is to stay in tune with your own needs while you are also attending to others. Even routine mini breaks and some “alone time” throughout the day can renew you. Scheduling 15 minutes or so of “me” time will allow you the opportunity to unplug from your role as a caregiver so that you can recharge and begin again. Speak up and let others in the home know that for the next 15 minutes you will not be available. Set a timer if you need to. This is not selfish. It is self-care. Think ahead to how you will use those few precious minutes and just go for it. Perhaps you could enjoy coffee with the morning newspaper, take a walk, play music, chat with a friend, check your email, or do a crossword puzzle to recharge your battery.

With limited time and money, you might develop new resourcefulness and creativity to meet your needs. You have heard it said, *“Necessity is the mother of invention.”* Maybe you can’t take an actual walk in a forest or go to the beach, but you can use your imagination or guided imagery to transform a short break into a trip to a beautiful and comforting place. One caregiver shared that, *“Since I can’t travel, I’ll get travel magazines and look at them and say maybe I can start picking and choosing some of the places I can go someday, when this chapter of my life is over... I try to make plans for my future.”*

Another caregiver said, *“I keep a standing hair appointment at my favorite beauty salon.”* She relates, *“When you look good, it makes you feel better. That’s something I refuse to give up”.* Another caregiver related, *“I love reading so on a weekend sometimes I’ll go to Barnes and Noble.”* Other caregivers get self-care by going to the gym regularly. The important point is, make that time for you!



An important step you can take to improve your self-care is recognizing that you need help. The next step is asking for it. When people you trust ask, “How can I help?” be ready to let them know you would really appreciate them just sitting with your Veteran or parent, to allow you a much-needed break.

Support that either frees up your time or infuses you with positive energy is the most beneficial. Be strategic in using your formal supports at the VA and in the community, such as home care, respite care, or an adult day healthcare program. Informal supports might include family members, friends and members of faith communities and civic groups.

Are there others that may be going through similar experiences? Perhaps other caregivers can share resources or talk with you about what has worked for them. Some Veterans and caregivers living in rural areas may find distance is a barrier to connecting with supports. Consider using social media, connecting online with Skype or Facetime, or attending telephone support groups like this one. Maybe someone in your faith community, or even your child’s School Social Worker, Nurse, Counselor or Principal could be a support or a listening ear by phone. Think outside the box about who is there to support you and how you can add to your list of supports.

Education and flexibility are a crucial source of support for caregivers. The more you know about what drives behavior and mood changes, the better you are able to negotiate any abrupt changes. The National Alliance for Mental Illness (NAMI) and VA Mental Health Web sites are great resources to educate yourself and others about mental illnesses and how these impact your loved ones, or yourself. The Alzheimer’s Association is another great resource to help you understand the behavior of a person with dementia.

Frustration and fatigue may cause caregivers to lash out or react, which can make matters worse for everyone. Notice your tendency to be reactive as a warning sign to get you to slow down, calm down and think through how you want and need to act. Sometimes using your sense of humor can help you to lighten up and realize that feelings are temporary.

One caregiver with young children shared their family motto, “It’s not a crisis; it’s an adventure.” Whenever possible, have a plan B ready, so that you aren’t caught off guard when things don’t go as planned. We’ve probably all heard that change is constant, so allow yourself to be spontaneous. Talk with other family members or friends about the possibility of having a way out if needed, and weave flexibility into your plans.



Remember, it's important to have realistic expectations. No one has all the answers. Give yourself a pat on the back every day. Take pride in all you accomplished today, some things can wait until tomorrow. Remember, forget perfection, and accept what is good enough. Try to appreciate the little things, the "everyday wonders." Watch the sun rise, hang out in your pajamas and simply find comfort in each other's good company. Sharing joy and feeling connected can help you make it through hard times.

We've talked about how natural roles can change when you become a caregiver. It may seem like nothing is normal anymore. It is helpful to look for the new normal.

One woman describes her experience this way: *"Having aging parents with Alzheimer's disease simultaneously orphaned me, saddled me with two strangers, and shoved every nightmare about my own future right into my face."*

The emotional pain suffered by caregivers can be intense and caregivers often feel they are expected to just deal with it. This is the grief process and may include bargaining, anger, sadness and acceptance.

If you had a troubled relationship with a parent and are now caring for him or her, you may be spending time in the anger stage. Consider using this time as an opportunity to clean out your emotional closet. Explore the anger with a therapist or journal about it, process it with friends, or call the Caregiver Support Line.

On the other hand, if your declining parent was your main source of emotional support, you may find yourself spending lots of time in sadness. Acknowledge and process these feelings and try to accept this new chapter of life. Try to embrace the special moments and cherish the gift of laughter some of those moments can bring.

When it comes to dealing with aging, no one wants to acknowledge that a family member is in permanent decline. When your loved one's care needs escalate, pay attention. The sooner you acknowledge the truth that needs have escalated, the sooner you can begin exploring care options. Your notes and advice from all your supports: doctors, nurses, family, friends, minister, pharmacists, neighbors, should be written down, with their contact information. These people are your village. Not everyone in your village will provide direct care for your loved one in a crisis, but a long list gives you multiple possibilities for support on short notice. Remember: You are not alone, and you don't have to reinvent the wheel.

Now let's turn our attention to getting organized. This will help you be more successful and there can be several tools of the trade that may help you stay organized, especially as a dual caregiver. First, a calendar system is vital to track appointments and outings. Write in time



for yourself as well, even short breaks and activities such as “take a 15 minute walk, call a friend, or have coffee on the deck as the sun comes up.”

Next, have your phone list of supports ready at hand for when you are feeling overwhelmed. Make note of the days and specific times they are available.

Many caregivers play an important role in managing the prescriptions and over-the-counter medications of those in your care. Medication logs can be instrumental in keeping track of the name, dosage and side effects of medications, and are especially helpful when you are speaking to the doctor or pharmacist. There are two examples of medication logs available to you on the VA Caregiver Web site, in the Caregiver Toolbox. A pill box is also very useful; maybe even one for daytime medications and one for evening pills if necessary. These are filled weekly to lessen the time it takes to daily dispense medications, especially if you are responsible for more than one person’s prescriptions. A notebook with your loved one’s ongoing medical history is also helpful. A summary of medical appointments can help you follow your Veteran’s or other patient’s recovery.

Keeping a notepad and pen by the door is a good tool especially if your loved one has difficulty remembering. If you are not home when treatment providers or visitors come, they can simply sign in with their name, date and time, with a brief note for you and you can check this when you return home. Keeping a similar log by the telephone can prompt the Veteran or other family members to write down the name and number of the person calling, the reason for the call.

Notes and reminders around the house are also helpful with loved ones that have memory issues. Examples include putting notes such as the word “Stop” on the stove if they are not safe with cooking, or a note on the clock with the time you will return if you are running a short errand. Memory aids posted, such as instructions about how to wash hands or do laundry, can foster independence. Visual aids for morning activities on a board may include: toileting, getting dressed, brushing teeth, eating breakfast, taking pills, etc. Be creative and tailor these tools to your specific needs to help you stay organized.

Dual caregivers should try to multi-task whenever possible. For example, while laundry is washing, make your to-do list or check your calendar for “Me” time and take a mini break. While the home health aide is there tending to the Veteran, you can tend to your children, other loved ones, or yourself. When making dinner, cook extra and freeze portions or use leftovers for lunches. Try to arrange your errands by location for efficiency. Remember to



schedule a short stop for yourself maybe for an ice cream cone, a brief walk or a stop at the library.

Dual caregivers may need to strategically plan outings for maximum success. For example, if you are caring for a Veteran and children, maybe a full day at a noisy amusement park is too much for your Veteran. Or, if dealing with a family member who has a progressive illness such as Multiple Sclerosis or Parkinson's disease that limit mobility, plan special events that this loved one can handle or gain access to easily.

Now let's look some of the hidden gems of being a dual caregiver. There are health benefits of caregiving. You may be saying "What? Did I hear you right?" Most of us know firsthand that the stress of caregiving can negatively affect your health. The idea that caregiving could actually benefit your health seems to go against our common sense. A study done by Dr. Lisa Fredman from Boston University, found that although caregivers are more stressed than non-caregivers, they also tend to have lower mortality rates on average. She reports, "high-intensity caregivers (meaning those who help with the majority of daily activities) were found to be more physically fit than non-caregivers, performing better on tests like walking pace and grip strength. In addition, caregivers performed significantly better on memory tests." Many of the tasks of caregiving require a lot of movement. Exercise has been documented to have physical and cognitive benefits. So, a day of caregiving may equal a day at the gym. When you stop to think about it, caregiving requires complex thought too. You have to manage medications, finances and appointments and that keeps your brain stimulated.

Being a caregiver can bring personal growth and self-awareness. You may not have been prepared for your role as caregiver, but day by day you are figuring it out. You may discover new strength and qualities you never knew you had or thought you could ever develop. One caregiver expressed it beautifully, "Caregiving tested my mettle but it made me a stronger, more resilient man. I evolved into a much more responsible person." He went on to say "Caregiving also exposed my innermost flaws enough for me to see them. Every day I wanted to be a better man, a better person, and a better human being."

You may be developing new levels of patience, perseverance, flexibility and determination. You are becoming the manager you never knew you could be, developing new skills in financial and time management, organization, and negotiation. You may even be learning home repair and gardening skills. You are a new person after caring for someone you love; it can transform you and your life forever. Caregiving is a real accomplishment!



You may find that being a caregiver for someone brings new dimensions to your relationship and you discover new ways to express your love. Although caregiving can strain relationships, it can also deepen them, as you experience precious moments with your loved one. As one writer put it, when those moments happen, they make your heart sing. The time alone with your loved one presents an opportunity to ask them to share life stories you may otherwise have never known. Sharing life stories can impact quality of care and life for your loved one. The understanding gained from composing and sharing life stories nourishes the soul, defines identity, and strengthens care relationships.

Being a caregiver is not a job for the lone ranger. Caregiving can create new friendships and deepen old ones. In order to stay healthy and meet everyone's needs, it's best to accept help. You may develop new friendships with other caregivers through a support group focused on the conditions of the loved ones you are caring for. You may develop a sense of kinship with those who share your experience because they understand firsthand what you are going through and what you need. These Caregivers can help you to feel validated and not so alone. Many groups have social and fundraising activities that bring you together to have some much-needed fun and work together to accomplish a goal. These friendships can last years beyond your time as a caregiver.

The bottom line to caregiving is that you are making a difference! You may not get all the recognition you deserve, for all you are doing, but you are making a real impact in someone's life and in turn, caregiving is making an impact on you!

It's important to remember to celebrate your successes! Be a curious observer. Stop and notice your accomplishments and see yourself as a success story, and maybe even write that story. Give yourself the credit you deserve. See if you can identify with this Caregiver who shared the following in an online post: "When I first posted on this site, I was scared, overwhelmed, and had no direction. I can proudly say that I've become a professional on so many levels. I've been a nurse, home health aide, a companion, a financial advisor, a lawyer, and a social worker for my father. ...The crazy part of this story is that I've just turned 30, but my soul and heart is that of an old and wise one. ...It took hard work to get to where I'm at today. One of my main goals and purposes in life is to help others; it's what brings me the most happiness..."

We hope you will celebrate you and share your successes too. Even the smallest discovery can help someone else. Perhaps you could share with other caregivers how you became organized, resourceful, strong, flexible, or were able to prioritize and reprioritize. Remember



that others can learn a lot from your example and experience. We hope that you take the time to take care of you as you engage in your role as caregiver by recognizing and reaching out to your supports and that you continue to build on your supports. We hope that you keep yourself healthy and strong by taking time for yourself and attend to your physical and mental wellbeing. We hope that you try to be gentle on yourself with your expectations. We especially hope that you take a moment right now with us to recognize and appreciate the profound and life affirming gift of care that you generously give to your Veteran loved one and all those in your life who are better off because of you! Thank you.

This brings us to the end of our presentation. We would like you each to know how much you are appreciated for all you do as a caregiver. The support you give so freely to your loved ones does not go unnoticed. We hope this presentation has helped you in your caregiving journey and has encouraged you to care for you as you move forward.