

Caring for the **CAREGIVER**



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Practical Ways to Cope

1. **Get a diagnosis as soon as possible.** This will allow you and your loved one to know exactly what you're dealing with, to receive treatments/interventions as soon as possible, and to provide you the opportunity to plan.
2. **Have a family conference -** to discuss the situation and plan for the future, and have ongoing conferences, as the situation changes. Any major change warrants another conference.
3. **Set realistic expectations and limits.** No one can be the "perfect" caregiver, so be kind to yourself. Whether you are living with the person, next door, or thousands of miles away, it's important to recognize that you can't do it all. Setting limits is beneficial for both the caregiver AND the care recipient. Know your physical limits as well as your signs of stress.
4. **Identify available resources -** of both formal (community agencies/ services) and informal (family, friends, neighbors, church, etc.). Making a list of your needs will help you determine what resources are available to best meet those needs, both now and in the future.
5. **Learn as much about the disease as possible.** So that you can understand and respond to your loved one's changing needs and abilities. Be realistic about these changes and try to accept them. Knowledge will keep you from being "blind sighted" by changes and help you to know how to handle them when they occur.
6. **Seek professional financial and legal advice -** to avoid making rushed decisions in times of crisis and to ease financial/legal transitions that will occur as a result of the disease.
7. **Take regular breaks.** "Respite" means a renewal period for the caregiver. It is important to take a short hiatus from the day-to-day responsibilities (even if it's just a short 10-minute break) so that you can feel revived, refreshed and ready to face the caregiving role with a more positive outlook. Take a break every day.
8. **Find someone to talk to.** You may think that no one understands what you are going through. Holding in your feelings, however, will only make you feel isolated and emotionally neglected. Sharing your experiences with others may help you put things into perspective. Try to talk with someone every day.

Becoming the Caregiver You Want to Be

Becoming a “care-partner” or “caregiver” for a loved one with dementia isn’t easy. It can be the most challenging role you’ve ever taken on. When it comes right down to it, family caregivers are the unsung heroes of our time.

However, as with any demanding job, if you don’t take care of yourself throughout the long process of caregiving for a loved one with dementia (8-10 years or longer), it can make the job that much more difficult. Research is indicating that chronic caregiving can shorten a person’s life by as many as 4-8 years! Common problems include sleep deprivation, poor eating habits, failure to exercise, failure to stay in bed when ill, postponement (or failure to make) doctor appointments, and increased risk for abuse of alcohol, tobacco and other drugs. An estimated 46-59% of caregivers are clinically depressed.

The good news is that caregiving does **not** have to be only a draining, negative experience. It can also be a joyful, fulfilling, and very meaningful one. The truth is, caregiving is neither one **all** the time. The secret is to find and manage the balance.

Again, as with any demanding job, we need to develop the right skills and capabilities in order to be successful at it. If you are a caregiver who’s finding yourself experiencing a great deal of unrelenting stress, it’s important that you don’t ignore these warning signals. Did you know that stress is your body’s way of sending you an S.O.S.?

Some surprising signals of stress include such things as tweaked muscles, eye twitching, ragged cuticles, rashes, headache, nausea, sleepiness or sleeplessness, grouchiness and irritation, forgetfulness and confusion. Stress can manifest itself in the body and emotions in many other ways as well, and every person’s warning signs are unique.

A recent study tracked dementia caregivers all the way from their loved one’s diagnosis through their loved one’s death. The purpose of this study was to try to determine why some caregivers go through the process of caregiving in a much healthier and resilient way than others. Why do some become stronger and others become ill? This study condensed the secret to healthy caregiving down to the following five factors. The most successful caregivers were the ones who:

- Accepted support from others, but in four, very distinct ways: emotional support (e.g., talking with others who understand), practical support (e.g., using helpful services such as an adult day center or home health agency to get regular breaks), spiritual support (e.g., taking time to go to church, enjoy nature, listen to music–, i.e., to continue doing those things that give us the greatest joy and keep us connected with our innermost self), and social support (e.g., having lunch with a friend, going to movie, and maybe not mentioning “caregiving” once during that time).
- Had a positive personality and developed a resilient coping style. This includes being open to ways to make the situation better and trying new things (e.g., home help or an adult day center) even if you’re convinced they won’t work. When we get stuck in routines that deplete our energy, spirit, and strength, the stress can become toxic.

- Maintained a personal identity and “perspective” so as not to be consumed by the caregiving role. Caregivers usually have many other roles to fill besides being a caregiver – like being a mother/father, husband/wife, grandmother/grandfather, sister/brother, friend, artist, craftsman, golfer, card player, reader, etc. Healthy caregivers are those who accept help so that they can “recharge their batteries” and connect with these other roles as often as possible.
- Maintained their own health. Too many times caregivers skip their own doctor’s appointments and neglect their own health because they are consumed with helping their loved ones. However, if you are not healthy yourself, you cannot be a good caregiver. Your loved one is depending on you to stay well.
- Maintained positive memories and experiences within the caregiving process. Caregiving is not always a negative and stressful experience, and it doesn’t last forever (even though it sometimes seems like it will). Caregiving can include moments that are the most joyful and meaningful of your life. Learn ways to cultivate joy within the caregiving experience by slowing down and “being in the moment” with your loved one with dementia. You may experience the blueness of the sky, the sounds of each bird in your garden, and the sweet taste of ice cream on your tongue with the same wonder as when these experiences were new. Persons with dementia live in the moment, and they can teach us how to re-experience the newness and freshness within the present moment.

As a “care partner” or “caregiver,” it is important to be gentle with yourself and cut yourself some slack. Too often, we blame ourselves for the mistakes we make in caregiving rather than give ourselves credit for all the many things we’ve done right. It is also important to recognize that you are **actively grieving**. Some of the stages of grief include struggling with emotions such as denial, anger, guilt (over involvement) and depression, before being able to work toward acceptance of each change in our loved one. Each new change triggers the cycle of grief. This is the natural process for all human beings that are grieving a loss of any kind. Acceptance does not mean “liking” “approving” or “condoning” the change. It just means coming to serenity about what IS and learning to stop fighting against things over which we have no control.

The bottom line is that caring for yourself is not selfish. In fact, it’s your number one priority if you want to be a good caregiver for your loved one. Caregivers need to make every effort to be in the best shape of their lives, as caring for a person with dementia is the “Olympics of caregiving.” If you are stressed out and not in good physical and emotional health, it undoubtedly will affect the quality of care you are giving to your loved one-- in direct proportion. YOU are the only one who can give that special love and fulfill that unique role/bond with your loved one with dementia, whether it’s being their daughter, sister, brother, wife, husband, etc. NO ONE else can do that job but YOU. Others, however, can cook for, clean for, entertain, bathe and dress your loved one. If we’re so worn out from doing everything -- the cooking, cleaning, entertaining, bathing and dressing -- that we’re too tired to fulfill that one role that no one else can, we’re sacrificing the best part of our relationship with the one we’re trying so hard to care for.

And that's cheating both of you from savoring one of the richest relationships of your lives.

In a perfect world, it would be wonderful if all caregivers had a twin that cared for them as diligently and consistently as they are caring for the ones they love. But it usually doesn't work that way. When it comes right down to it, good self care is a choice, a conscious decision, that's up to no one but YOU!

Tips for Getting the Most From a Family Meeting

Part One: PLANNING THE MEETING:

- Agree on a “spokesperson” to organize and lead the meeting. This might mean an objective third party if there are many different opinions or dissension among family members.
- Assess and determine whether this meeting will include the person who needs care or assistance. If the person has dementia and is in denial about his/her diagnosis or lacks the capacity to understand the diagnosis/issues, it would be counter-productive to include them in this open-forum type of discussion.
- Agree to certain ground rules: who will attend, time, place, length of meeting, and how to include family members who cannot attend (e.g., telephone conferencing). Make the purpose of the meeting clear, and establish an agenda and priorities for the topics to be discussed.
- Gather all pertinent information beforehand, such as financial/legal/ insurance documents, current medical information, etc. and share this information before the meeting, if possible.
- Request that all family members prepare a list, in advance of the meeting, of their concerns as well as suggestions as to what actions might be appropriate (this can also include writing down what they believe are the three most important values held by the person with the disease).

NOTE: Depending on the complexity of the situation, meetings may need to be broken down into two sessions. In this case, the first meeting could concentrate on identifying the needs and desires of the family member who requires assistance, and exploring options and resources that are available. The second meeting could be a session for finalizing plans and implementation. Keep in mind that the care-receiver’s needs will change over time and that solutions need to change accordingly.

Tips for Getting the Most From a Family Meeting

Part Two: ACTUAL MEETING GUIDELINES:

- Create an agenda and pass it out to all attendees. Keep the main issues for the meeting clear, that is, the needs of the person with the disease, and stay on task!
- Keep expectations realistic. Don't be surprised if emotions run high, but agree to stick to the topic at hand: the best care for your loved one. Table side issues and disagreements over other issues. Allow each person to express his/her viewpoint without judgment. Encourage people to use "I" statements and don't interrupt.
- Define what the situation is. What is the diagnosis/prognosis? What are immediate/long-term care needs? What assistance will be needed?
- Brainstorm various options, even "silly" ones, with no criticism of ideas. An easel or "assigned" note-taker can help keep track of them.
- Outline what jobs will need to be done and who will do them. Recognize that help can be offered in various ways – hands-on, financial, or emotional. All are valuable. Try to match the person's job with his/her interests/capabilities, e.g., if Bob likes to do yard work, perhaps he can be the one who takes care of the care-recipient's lawn.
- Discuss community options that are available (e.g., home health, adult day centers, adaptive home equipment such as a hospital bed, etc.)
- Focus on the actions that further the best interest of the person with the disease. Develop an action plan that everyone can agree to. If you are unable to reach consensus, review the key goals and try finding smaller steps of agreement. Recognize that many situations require time and a variety of approaches.
- Keep to the stated time frame and set a date for a follow-up meeting, if necessary. If discussion is getting circular, deadlocked or overheated, table the discussion for a second meeting.

Follow-up with a written summary of what was discussed and agreed to, along with specific jobs that were agreed to by each person.