

# SELF CARE FOR CAREGIVERS

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***THE MOST IMPORTANT PERSON IN  
THE EXPERIENCE IS YOU!***



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## SELF CARE

Often we feel our loved one should be top priority. In reality the **CAREGIVER must be top priority**. Yes, YOU! If you are going to make it through this long journey of coping with Alzheimer's, or cancer, or Parkinson's, or stroke or ???? YOU must remain healthy and strong. Otherwise your loved one will have no one they can count upon! How can you possibly look after yourself while being a care giver? **By putting yourself first!** Begin right now to prepare for the future.

- **BEGINNING-** In the beginning we go through a series of emotions when confronted with the illness. First **suspicion, denial, diagnosis** and then reluctant **acceptance**. Next we begin to search for **answers, cures, new research and new medicines**. Finally we begin to **educate** ourselves and decide how we will meet this challenge with dignity and power.

*“The bamboo that bends is stronger  
than the oak that resists.”  
-Japanese Proverb*

- **EDUCATE-** Gain as much information as possible through Internet Research with the Alzheimer’s Association, specific Cancer web sites, the Parkinson’s disease web site and other sources for your particular concern. Find research projects that are currently accepting volunteers. Check them out and decide if they are for your loved one. Check out these resources for support: The National Council on Aging, informational websites and telephone hot lines. Attend caregiver’s conferences. Go to lectures, read magazine articles and keep a file on new drugs.

*“I have always believed, and I still believe, that whatever good or bad fortune may come our way, we can always give it meaning and transform it into something of value.”*

*-Hermann Hesse*

- **WEB SITES-**

[www.adifferentmonday.com](http://www.adifferentmonday.com) - Got 30? Willow Sibert

[www.alz.org](http://www.alz.org) - Alzheimer’s Association

[www.Caring.com](http://www.Caring.com) - a web site for care givers dealing with many diseases

[www.parkinsons.org](http://www.parkinsons.org) - Parkinson’s Disease Information

[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org) - National Family Caregivers Association - A series of pamphlets like Sharing The Caring and Doctor/Caregiver Communications

[www.ncoa.org](http://www.ncoa.org) - The National Council on Aging

- **BOOKS-**

**BE ACTIVE-** “An exercise program for people with Parkinson’s disease”  
from American Parkinson’s Disease Association (APDA)

**Coach Broyles’ Playbook for Alzheimer’s Caregivers** “Tips and Strategies  
for all stages” [www.alzheimersplaybook.com](http://www.alzheimersplaybook.com) Especially good for male  
caregivers.

**Fighting Cancer With Knowledge And Hope** “ A Guide for Patients,  
Families and Health Care Providers “ - Dr. Richard Frank  
[www.cancercare.org](http://www.cancercare.org)

**I’m Still Here** – John Zeisel, Ph.D. “A breakthrough approach to  
understanding someone living with Alzheimer’s”

**Learning to Speak Alzheimer’s** – Joanne Koenig Coste “A practical  
approach to the emotional well-being of both patient and caregiver”  
[www.alzheimersplaybook.com](http://www.alzheimersplaybook.com)

**Memory Magazine-** free downloadable copy at Fisher Center for  
Alzheimer’s Research: [www.alzinfo.org](http://www.alzinfo.org)

**My Stroke of Insight** – Jill Bolte Taylor, Ph.D. “A brain scientist’s personal  
journal”

**Parkinson’s Disease Handbook** “A guide for patients and their families”  
from American Parkinson’s Disease Association (APDA)

**Stand Up For Your Life** - Cheryl Richardson “Develop the courage,  
confidence and character to fulfill your greatest potential”

- **HOT LINES-**

**Alzheimer's 1-800-272-3900**

**1-800-4CANCER**

**Parkinson's 1-800-327-4545**

**Stroke 1-800-553-6321**

- **National Caregiver's Conference- held annually**

*“God didn't promise days without pain, laughter  
without tomorrow, sun without rain --- but He did  
promise strength for the day, comfort for the tears and light  
for the way.”*

*-Anonymous*

- **JOURNAL-** A journal will help you in a variety of ways. This journal is your connection to you — **Your** thoughts, **Your** needs, **Your** fears. Record the steps you have just been through and write down how it is affecting you. Cut out **positive quotes** and tape them in your journal for **spiritual support**. Write down your **feelings and concerns**. Cut out articles you find helpful and research what you read. Start a list of **resources** you might need in the future. Make a note of support group phone numbers and web sites you like. Keep a list of **questions** and changes you notice in your loved one for the doctor. Later you will

begin **recording daily** notes that you will find invaluable if hospital visits or major medical concerns begin to happen.

You will have “evidence” of dates, places and problems that will help in diagnosing new concerns. Most of all, you will have a **connection** with your own inner voice, a connection with you.

- **STAND UP-** You will very quickly learn that as your loved one begins their journey, you must take charge. Your loved one may no longer have the ability to make good decisions. You must become the **decision maker**. Many of us have never played this role with our spouse, parent or friend and find it uncomfortable. However, it is a responsibility we must accept. How can we do that when it has always been the reverse? We can strengthen our backbone with help from a book called “Stand Up For Your Life” by Cheryl Richardson. This book leads you step by step to a **stronger you!** Do all of the exercises in the book even if they seem trite or silly. They have the ability to give you the **power** you will need to be the decision maker. The experience you gain as decision maker will prepare you for the future when you will be required to be a strong **advocate** for your loved one.

*“I’m living proof that your choice of how to respond to a situation constitutes your ultimate power.”*

*-Naomi Judd*

- **STAND FIRM-** BIG decisions you might have to make could be taking away the **car keys**. Hard? Yes. How would you feel if your loved one fatally injured someone? Or hiring **live-in-help**. Hard? Yes. How would you feel if your loved one fell or scalded themselves making tea? Emergency room visits and **hospital stays**? Difficult? Yes, and more so if you are not strong enough to be a firm **Advocate**. Moving to **permanent care**? Difficult and demanding. However, you know it may be best for your loved one's safety and your health.

**Legal paperwork** like living wills, power of attorney and end-of-life issues will be a part of this new life. **Decision Maker** will become your new roll. **Gain your personal power now and be ready for anything that might come your way.**

*“The only way out is through.”*

*-Mary Manin Morrisey*

- **TIME OUT-** There will be many times when you need a short break and no one is around. You can still *take a time out*. Secure your loved one, if possible, and go sit in another room for awhile. Step out onto the porch or into the backyard and get some fresh air. Do a little stretching or dance around the living room to release tension. Play

soft music. Pray. Read the positive quotes in your journal. Just sit in the beauty of a moment of *silence*.

- Here's a **30 second idea** from Got 30? ([adifferentmonday.com](http://adifferentmonday.com)).  
Cup your hands over your eyes and shut out all the light. Open your eyes and just look ... at nothing. Or just plain BREATHE 4-7-8!  
Breathe out through your mouth. Close your mouth and take a deep breath in through your nose to a count of 4. Hold your breath for a count of 7. Breathe out completely through your mouth making a blowing sound to a count of 8.

*“When you think you can't go on, just keep breathing.”*

*-Tom Hanks in Cast Away*

- **PAMPER YOURSELF-** Do something wonderful for yourself every day. Buy a **robe** that makes you feel like a king or queen. Stock up on **bubble bath** with lavender or use lavender cologne for stress reduction. It also comes in a shower product. Use one of those pretty loofa balls with bath cream to make your body shine. Purchase gel filled **booties** from EARTH Therapeutics that keep your feet feeling pampered. Just pop them on your feet when you go to bed at night. Wear them daily to remind yourself that you are worthy. Buy small inexpensive **trinkets** that make you feel happy; a little jeweled heart-shaped box or a leather case that holds your watch. Put your bathroom products in crystal bowls or leather cases. Have a **crystal** pitcher of water with sliced fresh fruit

available at all times and drink out of a crystal glass. Buy beautiful paper plates and napkins that fit the season. Place fresh **flowers** on the table or one rose floating in a bowl. Go to a **beauty salon or spa**. We want to feel like a queen or king everyday in small ways. It is proven that we are a better care partner when we are willing to take good care of ourselves. Our loved one will like the fact that we **look vibrant** instead of stressed.

**FOR MEN**– Everything in this booklet applies to men but here are some tips especially for you. Get a shave in a **barber shop** where they use hot towels and offer a **scalp massage**. Have friends over for **poker or pool**. Find a group of women who can be with your wife or loved one on your night out. Have these women visit another day while you get in a round of **golf**. Learn something new that has nothing to do with the illness. Become an expert in **astronomy** or become a **wine specialist**. Find or start a **Men's Support Group** through your church, synagogue or Council on Aging. Be sure and check out the book under resources by **Coach Broyle**. Although it is written for Alzheimer's it applies equally well to any illness. Use the web site [Caring.com](http://Caring.com). It has readily accessible information by experts in every field. Contact a **Home Health Care** agency to come in. Some even provide services covered by Medicare. Hospice Palliative Care is another option.

- **ME DAY**- Really pamper yourself once in a while with a **ME Day**. On a ME day go out for the day by yourself. **How? Call** a member of your Support Team (see below) and **ask for a day off**. Go to a beautiful **hotel** and sit in

the lobby and read a good book or write in your journal. Browse the shops and have coffee. It is a wonderful private day for the cost of a coffee! You could also go **shopping** alone, go to the **library**, take in a **movie**, have **lunch** with a friend, visit a **bookstore**, walk in a **park**, **exercise**, play a sport like **tennis or golf** or sit in your favorite coffee bar and just **be “normal”** around well people.

- **BIG ADVENTURE**– Run Away From Home. Let someone take over for a full day and night. This is excellent for people who want to help but live far away. On their first day in let them **learn your routine**; orient them to the situation using the ideas in your Tool Box (see below). The next morning, pack a little suitcase and go to a **hotel** for the night. Have **dinner** on the patio. Take a long hot bath. **Sleep in** the next morning, treat yourself to **breakfast in bed** or better yet, use their free coffee and bring along a sweet roll. Write, **read a good book** and visit with others in the hotel lobby or out by the **pool**. Check out the **reader board** and find out who is meeting there. Visualize being a part of that experience and go there, don't talk yourself out of meeting others. Don't forget to browse the **shops!**
- **ASK**- How do you get away for a ME Day or overnight? Have the courage to ASK. Step up and **Dare to ASK** and you will find people more than willing to help. Begin a list for your **Support Team** (see below). First, make a list of **who might help**. Who can you think of who could play the role of a **care sharer**? Check with **respite** facilities in your community. See if there is a

church or synagogue who offers this kind of service. Children and friends want to help you but they don't know how. You need to **be specific!** Trade something with a friend, like doing her baking. If you start asking around you can have a ME Day while you work toward running away. When you have your lists and daily schedules in your Tool Box, it makes it easier to let someone else take over.

You will find that time is the greatest gift you have ever received. The giver will receive a gift as well. Giving provides the giver with the enjoyment of being needed and spending quality time with a friend or loved one.

*“Know yourself well enough to do what you can, accept what you can't, and avoid deceiving yourself into believing that you can achieve the impossible.”-*

*John Zeisel, Ph.D. author of “I'm Still Here”*

- **TOOL BOX-** Approach care giving as a business. Create a **TOOL BOX** of resources that you will need in the next few years. Start with your **journal** and use it to prepare a **doctor's letter** before every appointment. This letter includes anything that has happened since the last visit. Use your journal to **collect and record resources**. Design **business cards** with your phone number and the phone numbers of your children or Support Team.

Laminate them and keep them in every coat and pants pocket. If they go through the wash, they are still OK. They are great to have when traveling. Pick up **cards** that say, “The person I am with has Alzheimer’s. Thank you for being patient.” You can secretly hand these to a waitress or security personnel. These are available free at many local Alzheimer’s Associations. Create your own card for other illnesses. Develop a **medical wallet**. Include current copies of all medicines, the Medicare card and any supplemental insurance cards, doctor’s telephone numbers, power of attorney and a list of your Support Team with phone numbers. Keep the wallet in your purse or in a ready **to go bag**. A “to go bag” is everything you might need if you must go to the emergency room. Be sure and include a good book or magazine. As you move through the stages add additional **systems**. Have one for the **bathroom routine**, one for **dressing**, a separate daily **journal for medical issues** and **medications** and add a printed copy of the **daily routine**. Choose or hire an **Advocate**. If for any reason someone else has to take over, you have made the transfer of your loved one’s care easy.

*“Change: Blessed are the flexible for they shall  
not be bent out of shape.”*

*-Michael Mc Griffy MD, [www.inspirelist.com](http://www.inspirelist.com)*

- **SUPPORT TEAM-** What would happen to your loved one if you got sick or, heaven forbid, you went to the hospital? That is one reason why you must put yourself first and form a team. **Want help?** First write down a list of what you do daily. Now, what else would you like help with? Don’t be

afraid to put it on paper. You are not actually asking right now — you are just doing some wishful thinking. **Brainstorm**, alone or with a friend. What would you like? One or two meals a week delivered? Visit a grocery store or mall alone? Time to take a shower? Have your nails or hair done? Leave for 24 hours? A maid to do the laundry and ironing? Grocery shopping? Maintain your car? Pay the bills? Mow the lawn? We all have different needs and your housework time is worth more spent elsewhere. **Write your list** and make it as long as necessary. Add to it from time to time.

When you are ready to ask for help, **be very specific**. “I would like to go to the **grocery** alone. I will be gone just 1 ½ hours. Would you stay with Jane? You could choose your own day and time. ” “My **car** needs to be washed and filled with gas. Could you do that for me?” “Could you come over and have a cup of coffee with Jim while I take a long **shower**?” You must **be willing to ask and delegate** because you are worth it! You need help to get through this challenge. Ask your Support Team. Ask your children, friends, a church group or neighbor to help you. Check out respite or day care in your town. **ASK and ask and ask** until you find help. **Don’t feel guilty**. People really want to help and there is a marvelous gift for them in the experience. It is the joy they will get from serving another person.

*“We are all angels with one wing.*

*We need each other to fly.”*

*-Karen Drucker, songwriter/singer.*

- **SYSTEMS-** Having certain “systems” in place will make it easier to get away and you will feel confident that your loved one is being properly cared for. Keep a clearly defined **Daily Routine** sheet. Keep it up to date. Spell out exactly how the day is structured from bathroom routine, breakfast, lunch, dinner and bedtime. Include the time that those things generally happen. List within that routine what **medicines** are given, when and where to find them. What **activities** does your loved one enjoy? Have a page of examples. If for any reason someone else has to **take over** for a day or when you **hire a care giver**, you have made the transfer of your loved one’s care easy.
  
- **LIVE IN THE MOMENT-** Live right now, in this moment. **STOP! LOOK.** Right now, what do you see? A beautiful bird, a **flower** in bloom, an airplane soaring overhead or cloud pictures in the sky? Have you looked at your loved one today and really **connected**? As you read their emotions, is your loved one having a wonderful day? Go out for a ride, **play music** on the radio and **sing along**. **Smile** at strangers. Look for five things you haven’t noticed before as you travel along what might be a familiar route. These little things can be pointed out to your loved one in the car. With Alzheimer’s particularly, your loved one lives their life in “**moments of time**,” which is a good lesson for us all. Check out the **moonlight** when you are up at night, a full bright moon is a spectacular sight. Take time to **enjoy**

**the beauty** of God's world every chance you get. That's living in the moment.

- **TOGETHERNESS-** Each week or so go to a **nail salon**. One week both of you get a manicure, the next time a pedicure. This is relaxing and enjoyable for both loved one and care giver. Both of you should have a **massage** each month. Massage clubs and schools keep the price lower or try a chair massage in a mall. Pedicures, manicures and a massage are very good for **circulation**, keeping the **skin** soft and **reducing stress** for both of you. Some nail salons offer in house services or a private massage therapist will come to your home. Go to a favorite **coffee shop** one day a week. Become regulars and everyone will remember you. Go out for **pizza**. If you are dealing with dementia, go to the same place every time and drive the same route to get there. You will find that continuity is important and puts your loved one at ease.

Find **activities** that are good for both you and your loved one. Find interesting and exciting things to do together. Prepare a **memory box** that includes family DVD's and treasures. Sort through old pictures and make small **photo albums** by topic; trips, friends, grandchildren, funny pictures, etc. Transfer any old **VCR tapes onto DVDs** for easy watching. Select a small lap DVD player. Purchase a large **map** and put pins in where you have traveled or lived or want to visit someday. You can pretend travel through pictures and DVDs.

*“You can’t do anything about the length of your life,  
but you can do something about the width and depth.”*

*-Evan Essar*

**LAUGHTER AND JOY**– Play DVDs of **old television shows** like Johnny Carson, Carol Burnett or Red Skelton. Check out old **TV series** like Hogan’s Heros or Gilligan’s Island. Watch the **Jay Leno and Ellen DeGeneres** programs or record them to view at a more convenient time. Record other programs that bring joy on **PBS, the Travel Channel or the History Channel**. These are great channels where you will find an interesting variety of programs. Enjoy humorous **movies** old and new. Movies and DVDs can be checked out at most libraries. (A good thing to have a friend pick up for you.) Attend a **Laughter Yoga** class or an **art therapy** exercise like a **Memories Through Art** experience at your local museum. Read **poetry**. Share good **books** together. Go to **art galleries, science museums to lectures**. Learn something new, like **Tai Chi or Chair Volleyball**. Ask friends to send the style of **greeting cards** where they can **record their voices**. Purchase **talking picture frames**.

- **GIFTS IN THE EXPERIENCE**- Yes, there are beautiful gifts if you just look for them. You may hear something humorous; notice a new innocent sweetness, share a special outing, remember a wonderful memory or develop a new special closeness. When you discover these **gifts**, record them in your journal. Sometimes reviewing them is the way to cope on tough days. Write down what you are **thankful for**, a **gratitude list**.

Remember to list all of the things that your loved one is **still able to do**. Make a list of the **lessons** you are learning from the experience. At the top of most lessons are **patience**, a **slower pace** to life and learning to **live in the moment**. Perhaps **communication** has improved or the **love** between you has grown stronger? Record the **humor** and find some **fun** every day. **Touch** more. **Hug** more. **Laugh** more. **Talk** more. **Enjoy** more. Find **Joy** in each other and in every day.

**Don't waste a minute of this precious time you have together!**

*"Yesterday is history,  
tomorrow is a mystery  
and today is a gift,  
that's why they call it the present."*

*Eleanor Roosevelt*

**CARE GIVER, CARE PARTNER, CARE SHARER.** These new terms can help you to see that in reality one person does not give and the other take. We are a **team** each playing our role. In the book titled "Learning To Speak Alzheimer's", author Koenig Coste says, "We are **care partners**, together seeking creative solutions to the challenges we face." See how many creative solutions you can discover and I guarantee **you will find beautiful gifts in the experience.**

*"As a Care Partner I am the love of God in action."*

*-Joy J Golliver*

**WHO IS JOY GOLLIVER?** Joy Golliver is an Involuntary Expert who got On-the-Job Training beginning in 2000 when her husband was diagnosed with Alzheimer's. She has "been there and done that" while maintaining a positive, bright attitude. She didn't choose for this to be her life-work but in May 2008 at a spiritual retreat, it became clear that God had other plans.

"At the retreat I kept telling people "my life was on hold," that I was attending the retreat because I wanted to find a sense of peace and calm while caring for my husband, Bob. In a meditation session, God made it perfectly clear that my life was not on hold. He had moved my husband of over 54 years into a memory support unit and me into Splendido, a Continuing Care Retirement Community (CCRC) in Tucson, Arizona, for a reason. It was a Call to Serve. I "let go and let God" and resources began to flow in. I am to use my skills in research, writing and speaking and pass on what I have learned about caring for a loved one with Alzheimer's with dignity, love and a positive attitude."

Joy has written a series of booklets and has a web site where resources can be found. She is available for speaking engagements around the United States. Joy Golliver is a professional speaker and author of two books on creative community service and was founder of Ignite The Community Spirit. She can be contacted at email: [Joy@joygolliver.com](mailto:Joy@joygolliver.com) or [www.joygolliver.com](http://www.joygolliver.com).

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