



SELF CARE *for* CAREGIVERS

161 TIPS
to Make Your
Life Easier



JOY GOLLIVER



SELF CARE *for* **CAREGIVERS**

161 TIPS
to Make Your
Life Easier

*The Most Important Person
in the Experience is You!*

JOY GOLLIVER

DEAR CAREGIVER:

If you are a spouse, friend, family member, or part of the sandwich generation—who might be caring for a parent and raising children at the same time—this booklet is for you. It is a quick and easy way for you to use information that will help you take better care of yourself while caring for a loved one. The 161 tips in this booklet are a short synopsis of the book, *Self Care for Caregivers: The Most Important Person in the Experience is YOU!*

When you are ready for more information, go to our web site at www.JoyGolliver.com and find the complete book, additional resources, articles, and blogs.

Interactive Live Conferences Calls will begin soon, so go to the web site and register to continue to receive current information. Don't hesitate to email me at Joy@JoyGolliver.com if you have a question or need to find a resource.

We are here to support you in your journey.

Remember You Are the Most Important Person in the Experience!

In love and caring,

Joy

Copyright © 2009 Joy Golliver
All rights reserved.

BEGINNING

1. **Suspicion**, then **denial**, finally **diagnosis**, and then reluctant **acceptance**.
2. Search for **answers**, **cures**, new **research** and **new medicines**.
3. **Educate** yourself and decide how you will meet this challenge with dignity and power.



*The bamboo that bends
is stronger than the oak that resists.*

— Japanese Proverb

EDUCATE

4. **Benefit** from Internet access: Alzheimer's Association, specific Cancer web sites, the Parkinson's web site, and other sources.
5. Find **research projects** that are currently accepting volunteers. Check them out and decide if they are for your loved one.
6. **Evaluate** these **resources** for support: Alzheimer's Association, Council on Aging, telephone hot lines, and Care Giver Conferences.
7. **Attend lectures**, read **articles** in magazines, 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, novelist and poet

WEB SITES

8. **www.Caring.com:** a web site for care givers dealing with many diseases.
9. **www.thefamilycaregiver.org:** National Family Caregivers Association offers a series of pamphlets like *Sharing The Caring and Doctor/Caregiver Communications*.

BOOKS

10. *Learning to Speak Alzheimer's*, Joanne Koenig Coste. A practical approach to the emotional well-being of both patient and caregiver.
11. *I'm Still Here*, John Zeisel, Ph.D. A breakthrough approach to understanding someone living with Alzheimer's.
12. *Coach Broyles' Playbook for Alzheimer's Caregivers*, tips and strategies for all stages. Especially good for male caregivers. www.alzheimersplaybook.com.
13. *Parkinson's Disease Handbook*, a guide for patients and their families from American Parkinson's Disease Association (APDA).
14. *BE ACTIVE*, an exercise program for people with Parkinson's disease from APDA.
15. *Fighting Cancer With Knowledge And Hope – A Guide for Patients, Families, and Health Care Providers*, Dr. Richard Frank
16. *Namaste Care Program*, Joyce Simard: End of life care for people with dementia.
17. *My Stroke of Insight*, Jill Bolte Taylor, Ph.D. A brain scientist's personal journal.
18. *Stand Up For Your Life*, Cheryl Richardson. Develop the courage, confidence, and character to fulfill your greatest potential.

19. *Memory Magazine*, free downloadable copy at Fisher Center for Alzheimer's Research: www.alzinfo.org.

HOT LINES

20. Alzheimer's: 1-800-272-3900
21. Cancer: 1-800-422-6237
22. Parkinson's: 1-800-327-4545
23. Stroke: 1-800-553-6321



*God didn't promise days without pain,
laughter without sorrow, 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.

24. **Record** what you have just been through.
25. **Write** down how it is affecting you.
26. Collect **positive quotes** and tape them in your journal for **spiritual support**.
27. Write out your **feelings and concerns**.
28. List **articles** you find helpful and **research** that you hear about.
29. Begin a list of **resources** you might need in the future.
30. Make a note of **web sites** you like and **support group** phone numbers.

31. Keep a list for the doctor of **questions** and changes you notice in your loved one.
32. **Record daily** notes that you will find invaluable if hospital visits or major medical concerns begin to happen.
33. **Have “evidence”** of dates, places, and problems that will help in diagnosing new concerns.

STAND UP

You will very quickly learn that as your loved one begins his or her journey, you must take charge.

34. Consider that your loved one may no longer have the ability to make **good decisions**.
35. Develop skills of a **decision maker**. Many of us have never played this role with our spouse, parent, or friend, and we find it very uncomfortable. However, it is a responsibility we must accept.
36. Strengthen your **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.
37. Progress in your ability to have the **power** you will need to be the decision maker.
38. Prepare 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

39. Seize the **car keys** if necessary. Hard, yes, *but* how would you feel if your loved one fatally injured someone?
40. Hire **live-in-help**. Hard, yes, *but* how would you feel if your loved one fell or was scalded making tea?
41. Anticipate emergency room visits and **hospital stays**. Difficult, yes, *but* more so if you are not strong enough to be a firm **Advocate**.
42. Move them to **permanent care**. Difficult and demanding, but you know that it is best for their safety and your health.
43. Employ a lawyer for the **legal paperwork** like living wills, power of attorney, and end-of-life issues.
44. **Decision Maker** will become your new life style.
45. **Expand your personal power now and be ready for anything that might come your way.**



The only way out is through.

—Mary Manin Morrissey

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**.

46. Secure your loved one, if possible, and go sit in **another room** for awhile.
47. Step out onto the **porch** or into the backyard and get some fresh air.

48. **Stretch** or dance around the living room to release tension.
49. Play **soft music**.
50. **Pray**.
51. Read the **positive quotes** in your journal.
52. Relax in the beauty of a moment of **silence**.
53. Practice a **30 second idea** from Got 30? (www.adifferentmonday.com). Cup your hands over your eyes and shut out all of the light. Open your eyes and just look ... at nothing.
54. **BREATHE, 4-7-8!** 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. This is one deep breath.



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.

55. Buy a **robe** that makes you feel like a king or queen.
56. Stock up on **bubble bath** with lavender or use lavender cologne for stress reduction. It also comes in a shower product.
57. Use a pretty loofa ball with **bath cream** on it to make your body shine.
58. Treat yourself to 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.

59. Buy small inexpensive **trinkets** that make you feel feminine or masculine—a little jeweled heart shaped box, a leather case that holds your watch.
60. Store bathroom products in crystal bowls or leather cases.
61. A **crystal** pitcher of water with sliced fresh fruit is a luxury.
62. Drink out of a **crystal glass**.
63. Beautiful paper plates and napkins that fit the season can make you feel special.
64. **Flowers** on the table or one rose floating in a bowl fill the room with beauty.
65. Enjoy a **beauty salon or spa. Feel like a queen or king every day** in small ways.



It is proven that we are a great 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.

—Anonymous

JUST FOR MEN

Everything in this booklet applies to men, but here are some tips especially for you.

66. A shave in a **barber shop** where they use hot towels and offer a **scalp massage** makes you feel like a millionaire.
67. Remind your friends to come over for **poker or pool**.

68. Locate a group of women who can be with your wife or loved one on **your night out**.
69. These same women could visit another day while you get in a round of **golf**.
70. Start a **Men's Support Group** through your church, synagogue, or Council on Aging.
71. The book under resources by **Coach Broyle is excellent**. Although it is written for Alzheimer's it applies equally well to any illness.
72. Utilize the web site **Caring.com**. It has information that is written by experts in every field.
73. Study something new that has nothing to do with the illness. Become an expert in **astronomy** or become a **wine specialist**.
74. Employ 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**.

75. Enjoy a day alone.
76. **How? Call** a member of your Support Team (see below) and **ask for a day off**.
77. Go to a beautiful **hotel** and sit in the lobby and read a good book or write in a journal. Browse the shops and have a coffee. It is a wonderful private day for the cost of a latte.
78. **Shop** alone.
79. Explore the **library**.
80. See a movie.
81. **Lunch** with a friend.
82. Visit a **bookstore**.

83. Stroll through a **park**.
84. **Exercise**.
85. Engage in a sport like **tennis or golf**.
86. Sit in a coffee house and just be **"normal"** around well people.

BIG ADVENTURE

87. **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.
88. Communicate **the daily routine on the first day**.
89. Orient volunteers to the situation using the ideas in your **Tool Box** (see page 12).
90. Pack a little suitcase and go to a **hotel** for the night.
91. Eat **dinner** on the patio.
92. Take a long hot bath.
93. **Sleep in** the next morning,
94. Indulge yourself with **breakfast in bed**, or better yet, use their free coffee and bring along a sweet roll.
95. **Grow** as an author. Record in your **journal**. Write your **memoirs**.
96. Lose yourself in a **good book**.
97. Visit with others in the hotel lobby or relax out by the **pool**.
98. Fantasize about being a part of a convention that is meeting there.
99. Browse the **shops!**
100. 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.

SUPPORT SYSTEMS

101. Begin a list for your **Support Team**.
102. **Who might help?** Who can you think of who could play the role of a **care sharer**? Write down the names.
103. Call **respite** facilities in your community. See if there is a church or synagogue who offers this kind of service.
104. Be specific! Children and friends want to help you, but they don't know how. You need to **be specific**.
105. **Trade** something with a friend, like doing her baking, or washing his car for some needed time off.
106. Develop your **lists** and daily **schedules**, to make it easier to let someone else take over. If you start asking around you can have a ME Day while you work toward running away. You will find that it is the greatest gift you have ever received and 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. in *I'm Still Here*

107. Approach care giving as a business.
108. Build a **TOOL BOX** of resources that you will need in the next few years.
109. Prepare a **doctor's letter** before every appointment. This letter includes anything that has happened since the last visit plus questions.

110. Use your journal to **collect and record resources**.
111. 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. Great when traveling.
112. Order **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.
113. Create and print your **own card** for other illnesses.
114. Have a **medical wallet** with 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.
115. Fill a **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 and a sweater.
116. 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**.
117. Hire, or select, an **Advocate**. If for any reason someone else has to take over, you have made the transfer of your loved ones care easy.



Blessed are the flexible for they shall not be bent out of shape.

—Michael Mc Griffy MD, 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?

118. Create a list of what you do daily.
119. List everything you would 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.
120. **Brainstorm** with yourself or a friend. What would you like taken care of in your life?
121. **Write your list.** Meals delivered? Time to shower? Nails or hair done? Leave for 24 hours? The laundry and ironing done? Grocery shopping? Keep your car running? Pay the bills? Mow the lawn?
122. **ASK and 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**?”
123. **Ask and delegate** because you are worth it! Ask your Support Team. Ask your children, friends, a church group, or neighbor to help you.
124. Check out respite or **day care** in your town.
125. **ASK and ask and ask** until you find help. Don't feel guilty. People really want to help and there is a marvelous gift in the experience for them. 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

LISTS

Having certain “systems” in place will make it easier to get away, and you will feel confident that your loved one is being cared for.

126. Utilize 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.
127. Clearly identify what **medicines** are given, when you give them, and where to find them.
128. Remember to keep a list of **activities** your loved one enjoys. 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 ones care easy.

LIVE IN THE MOMENT

Live right now, in this moment! **STOP. LOOK.**

129. **What do you see** right now? A beautiful bird, a **flower** in bloom, an airplane soaring over head, or cloud pictures in the sky?
130. **Look** at your loved one today and **really connect**. Is your loved one having a wonderful day when you read his or her emotions?
131. Leave for a **ride**, play **music** on the radio and **sing along**.
132. 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.
133. Live your life in “**moments of time**,” like your loved one does. It is a good lesson for us all.

134. Peek at the **moonlight**. “When you are up at night, a full moon is a spectacular sight!”
135. Delight in **the beauty** of God’s world every chance you get. That’s living in the moment.

TOGETHERNESS

Find **activities** and exciting things that are good for both you and your loved one and enjoy them together.

136. Break for a visit 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.
137. Relax with a **massage** once a month. Massage clubs keep the price lower or try a chair massage in a mall. Massage schools need volunteers to practice on.
138. Reduce stress with pedicures, manicures and a massage. All good for **circulation**, keeping the **skin** soft, and **reducing stress** for both of you.
139. Phone a nail salon or a private masseuse who will **come to your home**.
140. Settle in at your favorite **coffee shop** one day a week. Become regulars so everyone will remember you.
141. 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 them at ease.
142. Prepare a **memory box** that includes family DVD’s and treasures.
143. Sort through old pictures and make small **photo albums** by topic; trips, friends, grandchildren, funny pictures, etc.

144. Move old **VCR tapes onto DVDs** for easy watching. Use a small laptop DVD player.
145. 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

146. DVDs of **old television shows** like Johnny Carson, Carol Burnett, or Red Skelton provide lots of laughs. Check out old **TV series** like Hogan’s Hero’s or Gilligan’s Island.
147. Watch **Jay Leno and Ellen DeGeneres** programs or record them to view at a more convenient time.
148. Record other programs that bring joy on: **PBS, the Travel channel or History Channel**. These are great stations where you will find an interesting variety of programs.
149. **Humorous movies**, old and new, can be checked out at most libraries. A good thing to have a friend pick up for you.
150. Attend a **Laughter Yoga** class now being offered in many cities.
151. **Memories Through Art** is an experience at many local museums.
152. Read **poetry** or good **books** together.
153. Visit **art galleries, science museums, or go to lectures**.

- 154. Participate in something new, like **Tai Chi** or **Chair Volleyball**.
- 155. Ask friends to send **cards** where they can **record their voices**.
- 156. Purchase **talking picture frames** and record your voice.

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.

- 157. Discover these **gifts** and record them in your journal. Sometimes reviewing them is the way to cope on the tough days.
- 158. What are you **thankful for**? Write it down. Remember to list all of the things that your loved one is **still able to do**.
- 159. **Record** 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**.
- 160. Maybe **communication** has improved or the **love** between you has grown stronger.
- 161. **Funny** things happen. Go ahead and **laugh**. It's good for what ails you and brings relief to the situation.

Touch more. **Hug** more. **Laugh** more. **Talk** more. **Enjoy** more. Find **Joy** in each and 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*, the author, Joanne 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



Contact:

Joy Golliver
520-664-6358
Joy@JoyGolliver.com

Visit the ***Touch of Joy*** web site:
www.JoyGolliver.com