

# The Caregiving Years

Six Stages  
to a  
Meaningful Journey



Denise M. Brown

Why Me?

Why Now?

What Now?

# The Caregiving Years

## Six Stages to a Meaningful Journey

*By Denise M. Brown*

Your Map to Your Answers.

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The Caregiving Years, Six Stages to a Meaningful Journey, Fourth Edition  
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Published by Tad Publishing Co. and Consulting Co., Chicago, IL  
773-343-6341 | [www.caregiving.com](http://www.caregiving.com)

Published in the United States of America

ISBN: 978-0-578-00689-5

To Bette and G-J—thank you. You keep me going!!



# The Caregiving Years

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Parenting teaches you how to love.

Caregiving teaches you how to live.

"The road of life twists and turns and no two directions are ever the same. Yet our lessons come from the journey, not the destination." ~ Don Williams, Jr.

"To get through the hardest journey we need take only one step at a time, but we must keep on stepping." ~ Chinese Proverbs



**W**hen you expect a child, the community (your family, friends, coworkers) rally around you and your spouse. When you expect your first child, you receive gifts, well wishes and the encouragement that you are entering a wonderful, albeit challenging, chapter in your life. As you prepare to welcome your child, you feel pride at the thought of your role as parent: How you will shape the mind of a youngster, impacting him or her with your wisdom, insights and knowledge.

Now think about a similar life experience, one on the other end of the spectrum. When you care for an aging relative, spending the last years together as caregiver and caree, you might feel isolated from the community. Friends, coworkers, even other relatives may say about your caregiving responsibilities: "I could never do that! Why do you?" Or, the more common response: "Why don't you just put your mother (or your wife, or your grandfather) in a nursing home? That way you won't be so stressed out."

With support like that, no wonder you might find yourself fighting self-doubts, asking yourself, "Why me? Why am I the one to do this?" These self-doubts can erode your ability to handle your caregiving responsibilities effectively and efficiently. Even worse, these self-doubts cloud your ability to understand how important this caregiving journey is--to your caree, your family, yourself.

Which is why I've developed *The Caregiving Years: Six Stages to a Meaningful Experience*. Much like books for expecting parents, *The Caregiving Years* describes what to expect throughout the journey. And, because no journey is completed without wrong turns, unexpected delays and unplanned crises (we'll call these "stumbles"), our map also includes ways to "steady" these stumbles. By having information about your role as caregiver, as well as understanding the information needed and actions to take, you can spend more time making this experience meaningful--for your caree, your family, yourself.

*The Caregiving Years* is separated into six stages, each stage defined by the intensity of the caregiving role. You may feel you've already passed through the first stage. That's okay. Do as much as recommended in the first stage as soon as you can.

I welcome your feedback to this concept. I also encourage you to share what stage you find yourself in, what stumbles you've encountered and how you've steadied yourself. And, I'd love to know what insights, understandings and meanings you've garnered about your journey because of *The Caregiving Years*.

"You can't stay in your corner of the Forest waiting for others to come to you. You have to go to them sometimes." ~ Winnie the Pooh

"You are braver than you believe, stronger than you seem and smarter than you think." ~ Christopher Robin

# Stage I: The Expectant Caregiver

*In the future, I may help an aging relative.*

## **Who are you?**

You have a growing concern that, within the near future, your aging relative will need more and more of your assistance and time. You're concerned because of your relative's age, past and present medical condition, and current living condition.

## **Your keyword: Ask**

- Ask questions of your caree.
- Ask questions of health care professionals.
- Ask questions of lawyers and financial planners.
- Ask questions of your family members who may be involved in the caregiving role.

## **Your Challenge**

To learn and understand your caree's needs: health, financial and emotional.

## **Your Purpose**

You expect to become a caregiver; this is your time to prepare. You should research options, gather information, and provide the opportunity for your caree to share his or her feelings and values. This is also your time to concentrate on taking care of yourself--keeping up with family and friends, enjoying your hobbies and interests, pursuing your career goals.

## **The Caregivers:**

### **Judy and Frank**

Judy has worried about her husband, Frank, since his retirement five years ago. It seems that once he stopped working, he sat in his recliner and never moved--except to refill his beer and light up his cigar. Once a vibrant, competitive, intelligent man, Frank now just seems like a heart attack or stroke just waiting to happen. And, no words of encouragement from her, their children or Frank's doctor have been able to get him up and off the couch.

Frank's doctor has warned that unless Frank gives up the cigars and alcohol and begins a regular exercise program, Frank is doomed to be a victim of his unhealthy lifestyle choices.

Judy can see what's in her future: a husband who will need her full-time care.

### **Andy and Abigail**

Andy and his mother, Abigail, have always been close. Although they live across the country from each other (Andy in Denver and Abigail in Brooklyn in the same home Andy grew up in), they still remain as close as ever. Daily telephone conversations make the distance seem no more than a few city blocks.

Abigail is nearing 80-years-old. Andy counts his blessing that his mother has been healthy and independent most of her life. But, Andy has noticed some subtle changes in his mother's routine: getting to the grocery store every week seems to tire his mother; cooking and baking seems to interest his mother less and less and his mother relies more and more on frozen dinners; outings with friends to Atlantic City to play the slots have become fewer and fewer. Abigail is slowing down. Andy knows that the change in his mother's abilities and condition could very well change his mother's living situation.

Andy has two siblings (a brother and sister) who moved away from Brooklyn, just as Andy did. Their move became as much emotional as physical. They rarely keep in touch with either Andy or Abigail.

Although an immediate crisis does not face Judy or Andy, the threat of one seems to hang in the horizon. Rather than closing their eyes to avoid seeing that horizon, Judy and Andy can take some proactive steps now that will make their future caregiving days easier.

### **As an "expectant caregiver," what can you do?**

1. Consult with a good lawyer familiar with eldercare issues.

Find out about durable powers of attorney for finances and health care as well as living wills; start the process to ensure your caree has the necessary legal papers in order. Ask the attorney: What do we need to know to be prepared for the future? What additional documents will we need? What should we keep in mind? (A durable power of attorney for finances and health care appoints an agent to make decisions on behalf of your caree when he or she is unable to. If you live in one state and your caree in another, consider having documents created for both states.)

***A Stumble: Judy assumes Frank won't want to discuss important issues about his death, his funeral and their will.***

***A Steady: Wouldn't you want to the opportunity to tell your family members how you want to die? What kind of funeral you envision? Allowing your caree to share this information now will be a relief to both Judy and Frank in the future: Judy will be able to confidently make decisions about Frank's care treatments and care plans.***

2. Determine financial situations.

Knowing the financial status of your caree can help determine future health care choices. Determine monthly income from pensions and social security; learn about annuities, stock investments and bank accounts. Meet with financial planners to understand how to ensure investments last as long as possible.

***A Stumble: Your aging relative(s) refuses your request to disclose financial information.***

***A Steady: If your aging relative won't disclose particulars about his or her financial situation, be sure to at least know at which banks he or she has accounts and where important papers can be found.***

3. Investigate community health care options.

For Judy, what home health care agencies in her area offer quality, affordable home care? For Andy, what housing options are available for Abigail-- retirement communities, assisted living centers? Contact community organizations to request brochures and pamphlets.

In addition, consider your aging relative's current living condition. Will your aging relative be able to reside safely in her home if she uses a wheelchair, becomes bed-bound? What changes can you make today that will prevent future barriers to providing care in her home? Or, are the necessary changes almost an impossibility? If so, what other options do you have: your home, an assisted living facility, a retirement community?

4. Determine the current health care providers.

Judy will be familiar with her husband's physician; Andy should learn just as much about his mother's physician. In addition, he should learn about his mother's medications and why the medications have been prescribed.

5. Concentrate on the reality of the situations.

Both Judy and Andy can keep a realistic view of their situation: What's the worst that could happen? What's the best possible outcome? Then, determine what options are available for each of these outcomes. For instance, if Abigail is no longer able to live on her own, is it realistic of Andy to consider moving back to Brooklyn to be closer to his mother? For Judy, is it in her best interest to stay at home and watch Frank on his collision course with a health disaster? Or, would it be better for her to develop her own friends and interests?

***A Stumble: Believing that nothing could possibly happen to you or your aging relative. As such, you believe finding this type of information is unnecessary and a waste of time.***

***A Steady: Understanding that information is power. The more you know about your caree's medical condition, financial situation and the community options, the better and more informed your future decisions about your aging relative's care will be.***

6. Start a journal; chronicle your feelings, your concerns and your actions. You may be surprised at feelings of loss. Your preparation of the future allows you to see what your caree--and you--might lose. You both will experience changes in your relationship, your schedules, your amount of freedom. Write down your thoughts about the potential losses--and how you might be able to hang on to them, through minor adjustments and changes, for a little longer.

7. Take time to sort out your own issues. It's easy to overlook these issues when life seems easy. Caregiving, especially as it intensifies, will make life hard. And, it's harder if you have unresolved emotional work as it relates to your caree or other family members. For instance, Judy can work with a social worker or therapist to manage any resentment she may feel toward her husband. Andy can make contact with his siblings to let them know of his concerns. If they choose to keep their distance, Andy can touch base with a therapist or life coach to create a plan for future communication with his siblings.

If you have difficulty standing up for yourself or finding your voice, this is a good time to work with a therapist or life coach to gain confidence in your decisions and your voice.

Do you struggle with the idea of asking for help? Now is a good time to figure out why and start practicing. Knowing how and when to ask for help is a great skill, which will become a huge asset for you.

“The Four Agreements, A Practical Guide to Personal Freedom,” a book by Don Miguel Ruiz, offers insights about our personal codes of conduct. As your caregiving journey continues, you'll interact with family, friends and health care professionals who will drive you nuts. This book will give you the tools so you can stay sane.

8. Find your best shape—physically and financially.

Find a work-out routine you like. Maximize the amount of healthy foods you eat. Pay off your debts. Save as much as you can. Uncomfortable managing money? Read books and take classes (online and in your community) to become comfortable. You'll need to be at your best—physically, emotionally and financially.

9. Learn your caree's life story.

Document the story in a journal, video or audio recording. Collect recipes, photos, letters, poems and records that reflect your caree's life and achievements. Ask questions about your caree's childhood, parents, siblings and first loves. Involve other family members, including children, in the discussions.

10. Begin each day with the knowledge that you have love.

Perhaps the toughest battles in caregiving begin within. Most battles really are about whether or not you are loved—by your caree, by other family members, by friends, by your significant other. End the battle now: Know you have the love. Know it now so you can remind yourself later.

11. An apple a day...

What can you do on a regular basis to keep yourself healthy? Be good to yourself—you are too important today (and tomorrow and every day after that) to let your own health slip. In other words, what's your apple?

### **A Quick Tip:**

Do your attempts to begin discussions about difficult conversations find you sputtering and your caree spitting? It's okay. It may take a few times to begin such a discussion. If you feel completely overwhelmed by the thought of such a discussion, enlist the help of a

trusted, objective third party, such as a physician, clergy or rabbi, or another family member.

Have you completed your own important legal documents? If not, that's a great way to start the discussion with your caree. Suggest you both meet with an attorney to complete your durable powers of attorney, advance directives and wills.

Lastly, simple is your friend. Think of a simple way to start the conversation, even, "I have no idea how to ask you about something that's very important to me. Please be patient with me. I'm a little nervous."

As your journey continues, keep in mind the simple solutions. Caregiving is complicated, which is why it calls for simplicity.



# **The Expectant Caregiver**

## **Your Reflections**

(Have you passed this stage? Just jot down your memories of this stage for you and your caree.)

In this stage, what are your goals?

—For your aging relative?

—For you and your family?

How will you achieve these goals?

Who can help you achieve these goals?

What are your worries?

—For your aging relative?

—For you and your family?

How can you overcome these worries?

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Recollections, Doodles, Hopes, Dreams:

"One does not have to stand against the gale.  
One yields and becomes part of the wind." - Emmanuel

"It's not the load that breaks you down,  
it's the way you carry it." ~ Lena Horne

## Stage II: The Freshman Caregiver

*I am starting to help an aging relative.*

### **Who are you?**

You've begun to help your family member on a regular basis, weekly, perhaps even a few times a week. Your duties range from errand-running and bill-paying to some assistance with hands-on care.

### **Your keyword: Find**

- Find services that help.
- Find support that comforts.
- Find ways to enjoy your hobbies and interest.

### **Your Challenge**

To discover solutions that work.

### **Your Purpose**

This is your entry into the caregiving role. This is your time to experiment, to get your feet wet and see what works. This is your opportunity to learn how the health care industry works with, or in some cases, against you. Now is the time to shape your caregiving personality: What duties are you comfortable with? What duties make you uncomfortable? How well are you and your caree getting along? What situations would create overwhelming stresses for both of you? (To help you determine your caregiving personality, we've included information on how to create your Caregiving Mission Statement; see page 99.)

This is also the time when you get a feel for the present and future budgets needed to provide the care your caree requires.

In addition, keep up with your hobbies and interests (you may be able only to keep the ones that you enjoy most), ensuring you have made a habit of spending time on your own, enjoying yourself.

### **Judy and Frank**

Just as his physician predicted, Frank suffered a series of strokes that have left him paralyzed on one side. Now, Judy helps bathe, dress and feed her husband. Frank suffered his first stroke 13 months ago, almost one year after Judy consulted with an eldercare attorney and their accountant.

### **Andy and Abigail**

Abigail fell in her home and broke her hip eight months ago. After a short-term stay in a nursing home for rehab, Abigail has returned home--for now. Andy has arranged for Meals on Wheels to deliver daily meals. A home health aide visits twice a week to bathe Abigail as well as do the laundry and light grocery shopping. Andy has begun to discuss alternative housing with his mother. He shares his concern that the house has become too much of a burden for Abigail. He asks his mother, "How long do you want to live in the house? What other options you would consider?" Andy, who took a week off work to help his mother when she first returned home from the nursing home, plans a trip home for a long weekend to discuss options with his mother.

Andy continues to update his siblings with email messages. His siblings continue to choose to be uninvolved.

### **As a "freshman caregiver," what can you do?**

1. Learn as much as you can about your caree's illness, disease or condition. Consult the local branches or chapters of national organizations such as The Arthritis Foundation, the Alzheimer's Association, The Cancer Society. What does the future hold for you and your caree?

2. Learn how to provide proper care from health care professionals or from health care videos, manuals or books.

If your caree is hospitalized or receives short-term therapy at a nursing home, ask the staff to show you proper caregiving techniques: lifting, transfers, bathing. Or, search the Internet for hands-on care information.

It's very difficult to provide care when you are unsure of what you're doing. You'll feel much better when you're confident of your skills.

***A Stumble: During the discharge process from the nursing home to home, the social worker quickly explains Medicare benefits that will cover Abigail's services at home. Three weeks later, Abigail receives a notice that Medicare will no longer cover in-home services. Both Abigail and Andy are taken off guard--they thought Medicare benefits were available as long as Abigail needed them. They had not budgeted to pay for service privately.***

***A Steady: A hurried explanation from a health care professional about insurance coverage, care treatments or follow-up appointments can mean miscommunication and misunderstanding, creating the potential for***

***future disasters. If the health care professional is hurried during any discussion with you, ask if you can contact her at a better time to discuss the information in greater detail. In addition, ask for any explanations regarding insurance coverage in writing.***

3. Join a support group--online or in your community.

It's so isolating to be a caregiver! Support groups will hook you up with others in similar situations; often, you'll learn of community resources and options from other caregivers that you were not aware of.

4. Count on regular breaks from caregiving.

Plan for regular breaks--an hour daily, an afternoon weekly, or a day monthly--whatever you can manage. Enlist the help of relatives and community services (such as a volunteer group at your local church) so you can take time off regularly. Relatives can help in many ways--through financial support, social support (calling the caree regularly just "to talk") as well as respite support.

5. Rely on help from community organizations.

Meals on Wheels, home care agencies and day care centers, to name just a few, may offer services that your caree needs.

Contact your local Area Agency on Aging for a listing of services and organizations in your community. Visit your local medical equipment supply store to find devices and gadgets that enhance your caree's abilities--and independence from you. Remember, allowing the help of others is a sign of strength.

In addition, ask about local, state or federal programs (like the Veterans Administration's Aid and Attendant Care Program) that might provide financial assistance for you and/or your caree. As your caree's care needs increase, so will the costs associated with his or her care. Understanding what programs can help, in addition to understanding what your caree can afford, will help you plan appropriately for the future.

6. Keep your caree's wishes in mind.

If appropriate, ask for his or her input and ideas.

Does your caree still feel good about living at home? What does your caree fear or dread? (These are also good questions to ask yourself!)

***A Stumble: Because you are informed about community services and options, you may overlook your caree's ideas and suggestions.***



***A Steady: Your caree may be able to provide valuable insights and ideas about the services being provided. Be sure to include your caree, when appropriate, in any discussion regarding the care plan.***

7. Reflect the changes in your journal.

How do you feel now? What are your concerns? Fears? What outcomes are you working toward? What losses have you noticed during this period? What changes in the relationship cause you to feel sad? What changes have given you comfort?

8. Start a second journal that you use to detail your caree's needs and your caregiving responsibilities.

Note any changes in your caree's health and condition so that you can confidently discuss your concerns during physician appointments. Use your journal as a caregiving manual, which will help when others step in to provide care. Continue to chronicle your caregiving journey in your first journal. What causes you to mourn?

9. Create the habit of regularly holding family meetings.

Judy, for instance, can meet with her adult children regularly to provide updates. Andy, whose family is uninvolved, can plan regularly meetings with those who help Abigail. And, if you and your caree share a household with other family members (including children), consider creating House Rules. Rules for the household include:

- Who does what, how and when;
- Guidelines for fights, fun, and festivals (celebrations);
- Schedule of meetings and their purposes;
- Expectations in regard to support, engagement and participation.

10. Manage the money: Develop a budget, keep track of expenses, set up a filing system for bills and receipts.

Keep your caree's expenses separate from yours and your family's. Keep track (and receipts) of any of your caree's bills that you pay. If you're overwhelmed, consider having a professional, like a financial planner or bank trust officer, oversee your caree's financial situation, including paying bills.

11. Start a Solutions Fund so you can hire solutions.

The account funds solutions for boredom, breaks and back-up plans.

Contribute a monthly amount; allow yourself flexibility in how you use the monthly budget. Use the fund for your caree, for the house, for you.

Use the Solutions Fund for your caree to hire services such as home health, adult day or to purchase games from Marbles the Brain Store ([www.marblesthebrainstore.com](http://www.marblesthebrainstore.com)) or products from The Alzheimer's Store ([www.alzstore.com](http://www.alzstore.com)) or activities from eNASCO ([www.enasco.com/senioractivities](http://www.enasco.com/senioractivities)).

Use the fund for your house (or your caree's) to hire cleaning service, lawn maintenance, snow removal. The fund buys you services from a counselor or life coach, or for pampering services, adult education classes and activities.

Ask family members to contribute to your Solutions Fund.

12. Have back-up plans and then back-up plans for your back-up plan. Ask yourself, "What if..." and then create a plan to manage the "What if's." If it can happen, most likely it will. Be ready with a plan. A geriatric care manager can be invaluable in developing your back-up plans. (You can learn more about geriatric care managers and locate one near your caree here: [www.caremanager.org](http://www.caremanager.org).)

13. Build your own paradise of privacy. Call a spare bedroom or a corner in the basement your own. Add your favorite things (books, chocolate, candles, scrapbook, journal, music, TV, videos, photography, family photos) to make the space a retreat you love to use.

14. Continue to maintain your healthy lifestyle. Take note when the stress causes too much comfort food or too few walks. One of your best defenses against the impact of stress is a healthy lifestyle.

15. An apple a day... What's your apple in this stage? What helps you to feel good on a daily basis? Enjoy your apple every day.

### **Three Quick Tips:**

1. You may find yourself "taking away" from your aging relative--the keys to the car, the solo trip to the grocery store, her hosting the large family get-togethers. **To balance the scales, try to replace what you take away.** The exchange may not be equal (and in most situations, it

won't be), but giving back some of what you take away will help your caree maintain her dignity and independence.

For instance, you feel that it's just too much for your mother to continue hosting Thanksgiving dinner every year. Your mother reluctantly relents to having the celebration at your house. As you plan for the day, try to incorporate some of your mother's traditions in the celebration: her favorite recipes, her special dishes, her most honored prayer. While your mother may miss hosting the tradition at her home, she'll feel that some of her house is at yours.

2. Making a decision on behalf of an aging relative can be intimidating, causing you anxiety, guilt and confusion. You may be plagued by this thought: What is your responsibility?

Keep this in mind as you struggle to make the best decisions for an aging relative: **You are responsible for providing a safe and healthy environment for your aging relative.** That environment may be your caree's home. It may be your home. Or, it may be the nursing home.

It may be helpful to break down the decision and determine: Where will my caree be safest? Where will she enjoy the healthiest environment? Sometimes the answers become clearer when we have a goal to work toward.

3. **Have a bag packed with your toiletries and change of clothes ready in case your caree is suddenly hospitalized.** This way, you'll arrive at the hospital with your bag, ready to stay as long as needed. You can easily settle in to your caree's hospital room to ensure proper care. Some suggested items to pack in your hospital bag:

- Pair of pajamas;
- Change of clothes, including a few pairs of underwear;
- A water bottle and healthy snacks;
- Toothbrush, toothpaste and other personal care items;
- Your medications;
- Phone numbers of family members and friends;

- A copy of your caree’s durable power of attorney for health care and finances;
- Contact information for your caree’s physician(s);
- List of prior hospitalizations, surgeries, and medical conditions (along with dates);
- Insurance cards;
- A list of your caree’s current medications;
- A favorite book or magazine;
- Notepad and pen so you can take notes when doctors and other health care professionals make visits.

# **The Freshman Caregiver**

## **Your Reflections**

In this stage, what are your goals?

—For your aging relative?

—For you and your family?

How will you achieve these goals?

Who can help you achieve these goals?

What are your struggles?

—In caring for your aging relative?

—In caring for you and your family?

How can you overcome these struggles?

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:



"Never, never, never, never give up." ~ Winston Churchill

## Stage III: The Entrenched Caregiver

*I am helping an aging relative.*

### **Who are you?**

Your involvement with your caree is almost daily--if not constant. Your caree may live with you--or your involvement means that your day is structured to be available to your caree. You begin to wonder, how much longer can you live this way? Your mood is sometimes upbeat--you're proud you've been able to provide such wonderful care and make decisions that support your caree's best wishes--and sometimes melancholy--why you? You've been mourning the loss of your caree's abilities and functions and often long for the days before caregiving. And, you're tired.

### **Your Keyword: Receive**

- Receive help--from anyone who offers;
- Receive breaks from caregiving;
- Receive support.

### **Your Challenge**

To find the support and strength to continue.

### **Your Purpose**

To develop a routine, create a familiar schedule for both yourself and your caree. A routine will help you deal with the overwhelming stresses and responsibilities that wear you out. A routine will provide comfort for you and your caree--this stage may be the most difficult for both of you. The changes you prepared for in Stage I and II are now a reality--you have become something of a lifeline to a family member or friend.

In addition to your caree's routine of care, create a routine for yourself. In your routine include: Time for the unexpected; a ritual which begins and ends your day; and a "healthness" activity that nurtures your spiritual, emotional, physical, mental needs.

### **Judy and Frank**

Frank is now confined to a hospital bed in the dining room of his home. A severe stroke two years ago has left him incapacitated. While her children

wanted her to consider nursing home placement, Judy felt she owed it to Frank to care for him at home. She turned the dining room into his room because of its convenient location--home care workers don't have to trudge through the house and up the stairs, home care equipment delivery (like his oxygen) is easy, and Frank remains close to all family functions when the children and grandchildren visit. Home health aides visit three times a week to help Judy, and her children provide respite on Sundays so that Judy can go to church and then out to lunch with friends.

Lately, her children have been asking Judy, "How much longer can you do this?"

### **Andy and Abigail**

Abigail has moved from her home to a retirement community. Andy found a Realtor, sold the home and packed up his mother's belongings. He held garage sales during his week-long "vacation" at his mother's home. He helped his mother settle into the retirement community.

The move, although initially difficult, has been successful--Abigail has new friends and feels a new-found freedom without the burden of a large house. Andy continues to talk with Abigail daily for the next two years.

During this time, Andy notices that Abigail becomes more and more dependent on Andy, calling regularly to ask him what time it is, when her friends will meet her for lunch and what time the van will leave to take her and her friends shopping. As the calls increase in length and frequency, Andy finds himself becoming his mother's only connection to reality.

The social worker at the retirement community confirms that Abigail has exhibited signs of a dementia. At the social worker's urging, Andy schedules a physician's appointment for his mother--and another trip home for a long weekend. The appointment confirms Andy's fears--his mother suffers from a dementia, possibly as a result of mini-strokes.

Now, Andy has to face more decisions. The retirement community cannot provide the care that Abigail's dementia requires. The social worker indicates that Abigail can stay in the retirement community as long as she's able to make her way to the dining room for meals and manage her personal care. How long will that be, Andy wonders?

Andy keeps his siblings up-to-date on his mother's situation. They appreciate his updates, but tell him that they trust his decisions. He asks them to visit their mother; they refuse. After speaking with a sibling, he often closes his eyes and winces, as if they have caused him a physical pain. Because it feels so much like a physical pain.

### **As an "entrenched caregiver," what can you do?**

1. Determine your limits in your day and in your role.

How long can your caree remain at home? What's your comfort level in providing care in your home? For instance, some family caregivers feel uncomfortable providing care when their caree becomes incontinent. Others determine they can provide care at home as long as insurance or Medicare benefits offset some of the home care expenses. Others feel they can provide care as long as their other family members, like spouses and adult children, will put up with it.

Just as important as understanding your limits in your role is recognizing your limits during your day. Consider:

- Which tasks and responsibilities feel like a struggle?
- What times during the day do you feel the greatest amount of stress?
- When do you find yourself running late, losing your temper, scrambling for a solution?
- What do you find yourself dreading or hating?
- When do you find yourself in a tug-of-war with your caree?
- What times of the day are tough for your caree?
- When during the day does your worry about your caree intensify?

When you understand your limits, you can look for help to manage what's beyond your limits. Understanding your limits will ensure you, your caree and your family will stay in a safe place.

Everyone has limits. What are yours?

2. What are your caree's limits?

Understanding your caree's limits will help schedule your day and organize your help. Limits will change regularly, so be aware of change in tolerance and fatigue. Not sure how much help to schedule? Add more than you think. You can never have too much.

3. Continue regular breaks.

Consider annual weekly breaks--investigate short-term respite stays in your community's nursing homes. Or, ask relatives to take over the caregiving role for a week or two every year or every two years. Continue to take daily, weekly and monthly breaks. Keep up with your own interests and hobbies as best you can. Take time to enjoy the paradise you built in Stage II.

***A Stumble: Believing you are the only one who can provide the care your caree needs. So, when family members or friends offer to help out--***

*feeding your caree, bathing your caree, or visiting with your caree--you politely decline. "Joe just likes me to be with him at mealtime," you say.*

*A Steady: You may be the best caregiver in your family, but you're not the only one. Sharing the experience helps your family grow, keeps your caree connected with others, and helps you maintain a healthy perspective.*

4. Use your Solutions Fund. Make deposits and take withdrawals, using the money for boredom, breaks and back-up plans.

5. Keep up with a support system--a caregiver's support group or empathetic and understand family members or friends.

*A Stumble: Because you are so tired and overwhelmed, you may forget how great it feels to unburden yourself. When others ask how you are doing, you say fine. When your best friend says, "Tell me what's bothering you?" You assure her you are okay.*

*A Steady: Discussing your concerns, your stresses and your burdens with a non-judgmental, caring listener will prove to a weight-lifter. You'll feel pounds lighter--and be able to view your caregiving role in a refreshed perspective.*

6. Continue to learn about your caree's illness or condition.  
What's next for your caree? Are you up to the next steps in his or her illness?

7. Increase help as your caree declines.

Become comfortable with adding more help as more help is needed. You may think, "I'm okay keeping the level of help as it is." Unfortunately, keeping the level where your caree *was* rather than where he or she *is* will hurt both of you. Note the struggles in the day, then work to add help for you and your caree to manage the struggles.

8. Manage the budget as much as you manage the care.

As care needs increase, so does the budget. When your caree has funds to pay for about 18 months in a nursing home, then take note of the situation. This is the time to consider nursing home placement, when your caree's funds will afford the best choices. Hold a family meeting, tour local facilities, consult with professionals, such as a geriatric care manager. You may decide this isn't the time to decide. That's okay. It's important to be

aware that sometimes the budget determines the decision on where a caree continues to receive care.

9. Continue writing in both journals—yours and the other about your caree.

10. Forgive yourself for your bad moments and bad days.  
They will happen. After they do, give yourself a clean slate to start over.

11. Set boundaries which protect: Your Time; Your Values; Your Well-being  
Your Priorities; Your Self. Examples of communicating boundaries include:

- “I'm taking a two-hour break after lunch. I have everything that you'll need set up in the living room. Thank you so much for helping me enjoy this time. I'm so grateful for your support.”
- “I'm uncomfortable with the tone of our discussion. Let's table our talk until tomorrow.”
- “I'm booked, so can't handle that request. Thank you for thinking of me.”

12. Give you and your caree room for your difficult moments and bad days.  
When you're having a tough time, simply say: “I'm having a bad day. I'm taking a few minutes for myself.” When it's your caree's turn, say, “I'm sorry you're having a bad day. I'm going to step away for a few moments.”

13. An apple a day...

What's your apple in this stage? You may feel tempted to sacrifice your apple in this stage. Your apple can't be sacrificed. Your apple is what makes you feel normal, like yourself. Keep it.

### **A Quick Tip:**

In order to survive a trying and emotionally-charged experience, we need to find the meaning. Your experience has a family caregiver is meaningful. You can find the meaning when:

--You receive help for yourself and your caree from community organizations, your house of worship, your family members, your caree's friends and neighbors. Regular breaks mean you can gain a healthier perspective.

--You allow yourself, and your caree, to feel the emotions of the experience. Is your caree angry that she has had to leave her own home? Allow her to tell you about it. Do you miss your old life--its action, its freedom, its spontaneity? Allow yourself to vent your frustration in a healthy way, in your journal, to your support group, in your artwork.

--You accept the imperfections of the experience and of the people in the experience, including yourself. Accept that this journey is about helping a family member or friend die well. Accept that the journey will have many difficult moments. Accept that you can have just as many good moments. And, accept that people may not be able to step up in the way you want. As Maya Angelou says, "The first time someone shows you who they are, believe them." Accept that help will come from unusual and expected sources. Most important: It's okay. And, you're okay, too.

When you receive, allow and accept, you make room for meaningful moments between you and your caree. And, that's when you find the meaning of your caregiving journey.

## **The Entrenched Caregiver Your Reflections**

In this stage, what are your goals?

—For your aging relative?

—For you and your family?

How will you achieve these goals?

Who can help you achieve these goals?

What overwhelms you?

—In caring for your aging relative?

—In caring for you and your family?

How can you unload some of the burdens?



Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

"Through humor, you can soften some of the worst blows that life delivers. And once you find laughter, no matter how painful your situation might be, you can survive it." ~ Bill Cosby

## Stage IV: The Pragmatic Caregiver

*I am still caring for an aging relative.*

### **Who are you?**

You've been through it all: hospital admission and discharges; short-term rehab stays in nursing homes; a vast array of community services. You may appear to doubt the advice given by health care professionals; you've just been through the health care system long enough to know that sometimes health care professionals may not seem to have your best interest in mind.

Some family members and health care professionals worry about your ability to find humor in situations they find offensive. They view your attitude as "calloused" and "uncaring." Far from it, you have a very practical, very realistic approach toward your caregiving role--and your sense of humor has been a critical tool for your survival. Without your sense of humor, you would have given up a long time ago.

### **Your Keyword: Welcome**

- Welcome the joys of your relationship;
- Welcome forgiveness (of yourself, of your caree, of other family members and friends);
- Welcome shared activities.

### **Your Challenge**

To gain a greater understanding of yourself and your caree.

### **Your Purpose**

To gain a better understanding of yourself and your caree. You've settled into your role and your routine; now is your opportunity to step back and reflect. The first three stages laid the groundwork for this stage, your period of personal growth.

### **Judy and Frank**

Frank insists that he is continent, that he can make it to the bathroom when he needs to. Judy knows better, as she continually scrubs and cleans soaked linens, clothes, furniture and carpeting. Judy watches with a steady gaze as visiting nurse after visiting nurse insist that Frank wear adult disposable briefs. Then, after they leave, she watches Frank curse the nurse and the

briefs, throwing the new box of 32 briefs brought by the nurse against the wall. As a monument to Frank's stubbornness, Judy stacks the dented boxes on top of each other on the back porch. Her children refuse to use the back door and pass the pyramid of briefs--a display they find to be distasteful. Judy, when she needs a good laugh, stands in the middle of the back porch.

### **Abigail and Andy**

Over time, Andy finds he enjoys his mother's phone calls and her requests for the time, the names of her friends, the departure of the facility van for the shopping mall. When the calls first became intense, Andy resented the infringement on his time, as well as the need for him to keep in touch with the facility's social worker. Now he realizes his phone calls with his mother are a major reason why Abigail has been able to remain in her retirement community.

When the social worker calls with updates--and never good news--about his mother's situation, Andy finds himself asking the social worker: Did my mother kill anyone today? Did my mother steal anyone's dinner roll off their plate? Did my mother pick a fight with anyone today? The social worker repeatedly insists she finds these questions offensive, but for Andy, these questions encourage a good laugh, and remind him it's not the end of the world.

In his email updates to his siblings, Andy includes more reflections on his role, which he now sees as critical to his mother. He shares that with his siblings, without pain toward them. Instead, he feels grateful that he has done all he has.

### **As a "pragmatic caregiver," what can you do?**

1. Work on finding joy in your relationship with your caree.

The biggest joy-killer are your hands-on duties: bathing, dressing, incontinence care. But these duties bring you together, this is your time together. Add some fun to your hands-on care: sing songs, tell jokes, share goals and dreams.

***A Stumble: You care for your mother-in-law and, quite honestly, you don't like her. And, she doesn't like you. At all. Because of your shared dislike, you toss aside the possibility that you might find joy in the relationship.***

***A Steady: You do have more in common than your shared dislike--you both love the same man. Use this as a bridge to gain a more positive perspective toward your mother-in-law.***

2. Work on forgiving your caree for past hurts.

Resentment toward past wrong and injustices will make your present caregiving role very difficult. Let go of what was and concentrate on making what is healthy and productive. Forgiving your caree is one of the best ways you take care of yourself.

3. Develop a habit of enjoying shared activities.

Develop a routine of time shared as husband-wife, mother-daughter, father-son rather than as just caregiver and caree. Releasing the roles of caregiver and caree allows you to enjoy each other.

4. Begin to think about your future.

What goals have you yet to achieve? How can you achieve them? How can your caree help you achieve them?

5. An apple a day...

What's your apple in this stage? What helps you to feel good on a daily basis? You may feel like trying something new. That's good! You can never have too many apples.

# **The Pragmatic Caregiver**

## **Your Reflections**

In this stage, what are your goals?

—For your aging relative?

—For you?

—For your family?

How will you achieve these goals?

Who can help you achieve these goals?

What do you most love/respect about your career?

What do you miss about your career?

How can you recreate some of the good times you shared?



Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

"Perhaps they are not stars, but rather openings in heaven where the love of our lost ones pours through and shines down upon us to let us know they are happy." ~ Eskimo Proverb

# Stage V: The Transitioning Caregiver

*My role is changing.*

## **Who are you?**

You've been a caregiver over a period of several years and have recently made a decision about your role as caregiver. As a result, you've changed your role--or are just about to.

## **Your Keyword: Allow**

- Allow time to mourn and grieve;
- Allow remembrances to remain;
- Allow reflections of your experiences.

## **Your Challenge**

To walk with your caree during his or her last months and weeks; to begin the transition into your new life.

## **Your Purpose**

To walk with your caree during his last months and weeks, implementing his or her decisions about end-of-life care that you both discussed during Stage 1 (or as soon as you could). As you both feel the journey end, this is also a time to mourn and grief. And, this stage is about loving and feeling good about the shared journey. You also will begin to question and worry about the next chapter in your life.

## **Judy and Frank**

Caring for Frank at home became an exhausting task for Judy. She lost the fight against bed sores several times--not out of neglect but just because the enormity of the task was too much for one person. The home health aides helped--but they weren't there at night to change and turn Frank. Besides, they only helped six hours a week. Judy didn't sleep well at night and was just too exhausted to do much of anything, including enjoy her Sunday morning excursion to church and lunch--a ritual she once never missed.

At her children's insistence, she visits nursing homes near her home and finds one that she can afford and that she feels can provide the care Frank needs. Frank is admitted--and now Judy struggles to find a new daily routine.

### **Andy and Abigail**

Abigail's condition has worsened--and a CAT scan indicates that what had been "just dementia" is really a brain tumor and a terminal diagnosis. It seems that overnight Abigail has become a very confused, very fragile and very unhealthy 86-year-old woman. Rather than admit his mother to a nursing home in Brooklyn, Andy moves his mother to his home in Denver. He takes a leave from his company, opting to take advantage of the Family Medical Leave Act.

With the assistance of a Hospice organization, Andy cares for his mother in his home until her death. His siblings are with their mother when she dies, a blessing Andy relishes. He knows how important their visit was to their mother.

Just weeks after his mother's death, Andy returns to work, but finds "transitioning back into the real world" very difficult. His concerns for his mother had engulfed him for more than three years. He's having difficulty "turning off" her caregiving role. Who am I, he wonders?

As a "transitioning caregiver," what can you do?

1. Use your best judgment as to when you take breaks.

You now have a limited amount of time to spend with your caree. Trust your gut and spend as much time as feels right for you. When others encourage you to take a break and you know it's not the right time, let them know: "Time with my caree is my priority. I appreciate your concern. I'm okay."

2. Allow yourself time to mourn and grief.

Both Judy and Abigail are experiencing tremendous losses. For Judy, this may be a time of greater mourning than when her husband dies.

***A Stumble: You may find that your current support group no longer meets your needs--you just seem to be on a different wave length than the other caregivers.***

***A Steady: Find a bereavement or grief support group. Your local Hospice agency can be instrumental in helping you understand and deal with your grief. You may find that your period of mourning lasts a long time--maybe your lifetime. That's normal--as long as, at some point, you're able to move on with your life. It's not normal if you feel paralyzed. A professional counselor may be able to help you transition into a new chapter of your life.***

3. Remember your caree.

You don't have to give away clothes or remove pictures--until you want to. When family and friends seem hesitant to talk about your caree (they worry they will upset you), assure them that sharing memories, laughs and stories brings you great comfort.

***A Stumble: Your daughter tells you that your husband's clothes, which still hang in your closet, should be given away--it's unhealthy to keep his clothes for so long after his death.***

***A Steady: Consider your daughter's comments. Are you ready to give away his clothes? If not, can you pinpoint what's holding you back: a fear, worry, or a concern? What's best for you?***

4. Reflect back on your caregiving responsibilities and decisions with pride. Find comfort in knowing that you did the best you could.

5. Review your journal.

How are you different today than you were on the day you first started writing in your journal? How will you use this experience to enhance your future relationships?

6. An apple a day...

What's your apple in this stage? You may feel that an apple in this stage is unnecessary. Take an apple. It's what keeps you feeling like you.

## **The Transitioning Caregiver Your Reflections**

In this stage, what are your goals?

—For your aging relative?

—For you?

—For your family?

How will you achieve these goals?

Who can help you achieve these goals?

What are you most proud of as a family caregiver?

What memories of your caree are most comforting to you?



Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

"For my part I know nothing with any certainty, but the sight of the stars makes me dream." ~ Vincent van Gogh

# Stage VI: The Godspeed Caregiver

*My caregiving role has ended.*

## **Who are you?**

Your role as caregiver ended more than two years ago. You find yourself compelled to make a difference in the lives of other caregivers. You share information readily with caregivers in the earlier stages, you start a business dedicated to helping family caregivers or you find a job in which you assist family caregivers. And, you treasure each relationship you have in your life, recognizing that each day, and your health, should never be taken for granted.

## **Your Keyword: Treasure**

- Treasure your dreams;
- Treasure your challenges which led to your opportunities and new skills;
- Treasure your opportunities to share lessons learned;
- Treasure memories of your career.

## **Your Challenge**

To integrate your former role as a caregiver into your new life

## **Your Purpose**

To implement your lessons learned from your role as caregiver, from your career and from your family members and friends. During this stage, which can last as long you wish, even your lifetime, you reap the benefits of your efforts.

## **Judy**

Frank died after living in the nursing home for eight months. During those eight months, Judy found herself somewhat lost. She struggled to relate again to her friends, to enjoy the old hobbies and interests she used to enjoy. She eventually joined the support group for family members at the nursing home. She found the other family members in the same fate: trying to rebuild their lives. After she shared the story of the pyramid of disposable briefs, she discovered the caregivers turned to her for assistance.

Now Judy facilitates two support groups--one through the Stroke Club at her local hospital, and one through the nursing home at which Frank was a

resident. In addition to her work as a facilitator, Judy has become the "home care guru," answering questions that other family caregivers have.

Judy feels grateful for the peace she has found. She sleeps well at night.

### **Andy**

When Andy returns to work after his mother's funeral, he finds himself looking at his coworkers differently, his job differently, his life differently. He decides his job doesn't match his passion--website design--and takes a sabbatical in order to explore opportunities to start his own business.

He communicates with siblings when the mood strikes. Although he has a casual relationship with them, he appreciates that he has them in his life.

He keeps in touch with his coworkers, who contact him regularly with eldercare issues. Andy is often told: Thank you for listening. Your support means the world to me.

The world, to Andy, is so much bigger and better than he ever imagined.

### **As a "Godspeed Caregiver," what can you do?**

1. Follow your dreams.  
Make your goals a reality.

2. Family caregivers will look to you as a mentor and leader. Allow caregivers in earlier stages the same freedom to stumble and steady themselves that you had. Share your experiences with expectant caregivers, freshman caregivers, entrenched caregivers and pragmatic caregivers. They can learn from you!

### ***A Stumble:***

***Underestimating the importance of your caregiving journey***

### ***A Steady:***

***Review your journals and diaries and then ask: How am I different today?***

3. Treasure the memories you have of your caree.  
Continue to remember your caree regularly through rituals, such as enjoying an ice cream cone in her honor on her birthday, or by planting trees in his honor. Reading and reviewing your diary will be a great way to remember.

Of course, your best memorial to your caree's memory is a life you build for yourself filled with healthy relationships, productive careers and joy and laughter.

#### 4. An apple a day...

Your apples kept you going. Now, consider how you'll use them to create your future. How did your apples change? How did you change? What would you like to try next? Go for it. The world is your apple.

## **The Godspeed Caregiver Your Reflections**

In this stage, what are your goals?

—For you?

—For your family?

How will you achieve these goals?

Who can help you achieve these goals?



Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

Your Notes, Photos, Doodles, Recollections, Hopes, Dreams:

"Heroes take journeys, confront dragons, and discover the treasure of their true selves." ~ Carol Lynn Pearson

"It is good to have an end to journey toward; but it is the journey that matters, in the end." ~ Ursula K. LeGuin



# Stories, Tips, Tools for The Caregiving Years

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## Meet a Family Caregiver in Stage 2: Joan

Joan is of the sandwich generation. But, her sandwich has a little mayo on it--a little white hair.

Two years ago, Joan and her husband welcomed three teen-aged grandchildren into their home. Unable to live with their parents, the children moved from out-of-state to Joan's home in Florida just prior to the start of a new school year. In the blink of an eye, the 63-year-old grandmother found herself registering three children for school--something she hadn't done in some thirty years. Already caring for his mother, Joan's caregiving school enrollment swelled to four.

"My faith in God and in my husband help and they really helped in the very beginning," Joan says. "All I could think was: The kids need me now. And, my mom needs my help now." So, she did. She does.

Two years and one high school graduation later, Joan and her family have survived better than their household appliances; they've replaced a backed-up septic tank (from teen-agers who enjoy those one-hour showers), a washing machine, a TV--and have added a punching bag to the garage. "The kids asked for one," Joan says. "They use it to vent and get their anger out. I've used it a few times myself," she adds.

Her 88-year-old mother who lives nearby in a retirement center continues to meet her own personal goal of remaining in her apartment. Joan helps by ensuring his mother has her medications and groceries, transports her to doctor appointments, and manages her finances. Joan also calls his mother every morning, just to makes sure that she's up and okay.

Joan and her 64-year-old husband continue to work as well as raise their grandchildren and care for her mom. Her husband works full-time, hoping to retire when the last grandchild leaves home. Joan is self-employed, working a flexible schedule in order to be available for the children. Joan and her husband work as a tag team, backing each other up with decisions about restrictions (disciplinary action such as loss of phone or computer usage), taking breaks, and taking weekend trips away. This fall, Joan took a weekend trip with a friend to St. Augustine, Fla.; the next weekend, her husband enjoyed a weekend away at a music fest.

The adjustment for the children and for their grandparents has been rocky. The paperwork, required by the state, Joan faced to enroll her grandchildren in school, to apply for their benefits, and to provide for their well-being was overwhelming. "You don't come out of those (state and local) offices with any dignity," Joan says.

To further Joan's frustration, state agencies have high turn-over rates with case workers. In the first year, the family had four different case workers. Luckily, they've had one case worker during this past year; that case worker was able to get counseling for the kids this past summer--an immense help. "I'm very proud of the kids," Joan says. "They all have good grades. And, our grandson plays on his school's football team." Her middle grandchild has a part-time job and attends high school; the youngest, her grandson, mows lawns to earn extra money. Her oldest granddaughter, the high school graduate, lives nearby, working and attending college courses.

Holidays, in particular, are difficult. "The first Christmas, Mother's Day and birthdays were really tough," she says. "They're tough no matter what you do." Joan and her husband have faced tough times before throughout their 45-year marriage, but "we're feeling it more now because of our own physical aches and pains," Joan explains.

The challenge of being available to three children and her mother can be exhausting. "I value any free time I can get," she says. She makes time to take art classes and journals whenever she can. She created her own sanctuary in her Florida backyard, complete with its own swing and flower garden. "I'll sit in the swing and just write," she says.

Keeping space for herself is critical to her survival, as is extra support from family and friends. She attends a monthly support group for family caregivers of aging relatives, searches the Internet to meet other grandparents raising grandchildren, and enjoys a new hobby: Television. "I just don't have the energy that I had when our children were growing up," she says. "I'm tired at the end of the day. I watch TV now, which I didn't do before. But, it's just nice to sit."

What does she like to watch on TV? "Antiques Roadshow," she says. "I like antiques. I'm becoming one myself."

An antique that her family will always call priceless.



## Meet a Family Caregiver in Stage 3: Rob

He worried the situation would tear his family apart. Two years later, the situation did cause a tear, but to his shoulder. His family is okay.

With the doctor's order that he must not lift for three weeks, Rob worries a bit about a back-up plan to care for his mother. Currently, his mother is hospitalized, which gives him a little breathing room and time to heal before his mother returns home.

Rob's caregiving journey began when his then 68-year-old mother was misdiagnosed as having had a stroke. After rehab, another "stroke", more rehab and then another "stroke", the doctors began discussing the possibility that his mother may have Amyotrophic Lateral Sclerosis (or ALS, or Lou Gehrig's Disease). But, spinal taps and a spinal biopsy proved otherwise; instead, she was diagnosed with a disease called sarcoidosis of the spine. It has left her without the ability to walk.

In order to find the right diagnosis, Rob decided to bring his mother, who lived about five hours away, to a hospital closer to his home, near a large city. The move brought the correct diagnosis, then another tough decision. After being discharged from the hospital with the correct diagnosis, his mother transferred to a nursing home for rehab. But, the nursing home was not a positive experience for his mother—nor for Rob. When a doctor said, "Most nursing homes in this area are like this," Rob said, "I'm taking Mom home."

"I was sure I could do a better job," Rob, a 44-year-old music educator and performer, says. "I would have more control over her care in my home."

The first six months were difficult; Rob's home wasn't working with the caregiving situation (small doorways made wheeling a wheelchair difficult, for instance) and it wasn't allowing enough space for everyone: Rob, his mom, his wife and their now 13-year-old daughter. His mom moved into the smallest of their home's three bedrooms, a bedroom which had been a home office. "It was hell," Rob says. "I thought I'd lose my marriage. My daughter was having trouble in school. The situation required family therapy."

The house was retrofitted two years later; a handicap-accessible addition was built, complete with ramp to the front door, a large front door, and a bath with grab bars. His mother has a reclining, remote-controlled bed as well as a recliner chair which allows for easier transferring. A van with a power chair makes outings, including to doctor appointments, easier to manage.

“I brought my mom here because I knew I couldn't live with myself if I did anything else,” he explains, “and because I wanted my daughter to know her grandmother, even if her grandmother was sick. In, short this was the right thing to do.”

Rob adds: “It’s amazing what I can do when I have to. Never in my wildest dreams would I imagine being a parent to my parent, taking on the role of nurse, home health aide, physical therapist, wound care specialist. I lift my mom from the wheelchair to her bed to the toilet to the shower bench. I’m in the best shape I’ve been since I was 23. Physically, I’ve also changed in the last two years.” (Although Rob practices all the safety techniques possible, lifting his mother probably caused the tear in his rotator cuff.)

Once situated with a new addition for his mother, Rob and his wife faced another set of struggles: His wife was laid off and Rob didn’t receive a full-time teaching position for which he had hoped. With his mind focused on keeping the family together, Rob pushed his music--he plays the saxophone--in the background, playing at home, but not professionally at venues. Recently, he took his sax out for his first paid gig in almost a year. It was good to be back; although he worried about being away from home, he felt comfortable enough to make plans to play for another gig the following weekend.

Teaching at a local university affords Rob a flexible schedule; he readies his mom in the morning, then leaves for class just as the home health aide arrives. Because of a wound, his mother receives care from a visiting nurse once a week and a home health aide three times a week. Rob teaches three days a week, which coincide with the days the home health aide visits.

With his house in order, Rob set out to put his own house, so to speak, in order. Depression has followed Rob during his caregiving experience. He had sought treatment in the past, but the medications prescribed did little to help. Recently, his depression became worse, but he hesitated to talk to his doctor: “If any medication didn’t work, it would just mean I had failed at

something else.” With his wife’s urging (she actually made a doctor’s appointment for him), he spoke to his doctor again about his depression; this time, his doctor prescribed another drug. “It’s working,” Rob says. “I feel better than I have in years.”

Rob’s mother hospitalization came as a result of the disease’s progression, which now has caused fluid to build up in her brain. After surgery to relieve the pressure, she rebounded for a few days until her symptoms reappeared. During this hospitalization, Rob finds himself not only missing his mom, but missing the routine of providing her care. His daughter catches herself before going to her grandmother’s room to say “Good night.” The dogs miss the treats provided by Grandma: Toast in the morning, pretzels in the evening.

The reasons Rob moved his mom into his home have been fulfilled: “My daughter and my wife have learned that they are greatly loved by my mother. I’m most thankful for this.”

## Meet a Family Caregiver in Stage 3: Marilyn

When you've worked for more than 20 years, you dream of the day you can say to your boss: I'm outa here!

For Marilyn, that day occurred one day in March. A year in the making, her decision to stay at home to care for her mom just seemed right. A full-time caregiver to her mom and a full-time employee to a hotel corporation worked for a good nine years. Then, the company's headquarters, which had been two miles from Marilyn's home, moved; with that move came an increased commute--to 12 miles. A longer commute time meant that Marilyn could no longer make a quick trip home at lunch to attend to her mother's feeding tube. And, if the aide didn't show up for her shift...

"Caring for Mom did affect my work," Marilyn says. "I was worried all the time about Mom." And, when the corporation wanted Marilyn to attend one-of-town training, she had to decline. "It would be too expensive to have to pay someone to take care of Mom while I was gone," she says.

Marilyn began caregiving for her mother after her mother's 1993 car accident. As a result of the accident, her mother suffered a stroke and permanent right-side paralysis. After a hospitalization, her mother was admitted to a nursing home. During a visit to her mother, Marilyn asked one of the nurses: Can I do this (provide care) at home?

Her mother, from a small town in northeast Georgia, moved into Marilyn's Atlanta apartment. Her mother cannot take anything by mouth, so nutrition and medications are administered through a feeding tube. She's bed-bound, incontinent; a contracted leg is susceptible to sores.

Marilyn does have worries about her decision to leave her job. "I feel like I'm missing out on things for my career." And, there are other sacrifices: "I haven't had a manicure in a while," she says. "But, what's that?"

She adds: "But the pros really outweigh the cons. I can get Mom up and in her wheelchair and out on the patio. The aides weren't as good about doing that. And, I'm not as nervous as I used to be."

Marilyn does worry about taking a break (such as weekend away) from her caregiving role because the cost of in-home care would be too much for

their budget. But, she's comfortable leaving her mom for a few hours, where she enjoys the pool and fitness center in her apartment complex and runs to the library to use the computer to check her e-mail messages. Last spring, she and her boyfriend enjoyed a performance by Cirque Du Soleil. Her boyfriend, who, she says, is "so good to Mom and so supportive of me with her," is someone with whom she hopes to make a long-term commitment.

Her commitment to caring for her mom full-time hopefully will also lead Marilyn to on a new career path. "I feel I may be called to do something different," she says. "I think I'd like to work in a hospital setting or in a physician's office."

In addition to hoping for a firm commitment from her boyfriend, Marilyn also weighs other changes in the near future for her and her mom. "I think about moving back to Mom's house (which they currently rent)," she says. "Mom would be closer to her sister. But... it's a small town. You know what they say: You can't go back."

For other working family caregivers considering eliminating their full-time job, Marilyn says: "Just try it. See if it works!"

## Meet a Family Caregiver in Stage 4: Sue

Some stories are best told from the first-person perspective. So it is with Sue, who cared for her parents and now her husband (at one point, she cared for all three). In addition to sharing her story about caregiving, we asked Sue about her hobby, quilting. She's in the midst of completing five quilts and excited about starting another. In the future, she also hopes to create a quilt made from her father's ties.

Sue has a wonderful sense of humor, which you'll appreciate as you read her words. You'll also appreciate a very honest look into life as a family caregiver.

Denise: Tell us about your parents.

Sue: I was my parents' only child. My father was an Army Officer who retired as a Lt. Col. Since we moved approximately every 18 months, my mom and dad and I were like the Three Musketeers. We were very close and, except for having problems adjusting to new schools (12 schools in 10 years), I can say that I had an ideal childhood. I always felt protected and loved and well cared for. My mother was a stay-at-home mom and, as far as I know, was happy in that role.

I was married at the age of 19. My parents thoroughly enjoyed all three of their grandchildren. Things became somewhat strained with my mother as she got older. I always felt close to my Father and never felt judged by him. He loved me unconditionally--always.

Denise: How long did you care for them?

Sue: My father had cancer surgery and was given four to six months to live when he was in his early 60s. I stayed with my parents for a couple of weeks and helped as much as I could. My father recovered completely and lived a very healthy life for many, many years. My mother's health began to fail when she was in her early sixties. She had several non-life threatening surgeries over the next 10 years. I felt that she was trying to turn herself into an invalid. During this time I was still raising my children but helped as much as I could.

My caregiving began in earnest when my parents moved into a retirement complex about 25 miles away from where my husband and I live. Within a few months my mother became almost completely wheelchair bound. She was very demanding with my father and I.

A year or two after that she was diagnosed with Parkinson's Disease. I was working full-time during this period but would go and spend the night on a rollaway bed a couple of times a week so that my dad could get some rest. Finally, after Mother was hospitalized for severe stomach problems (she insisted on adjusting her meds to suit herself), I insisted that she be admitted to the nursing home section of their complex. I thought that the nursing home care would solve the problems but I was so very wrong. On most days and into most evenings, my father was down in the nursing home caring for my mother--at her insistence.

About six years ago he became very ill with a bad case of the flu. He continued to make the long walk to the nursing home to care for my mother until one day he collapsed in the hall. I was at work at the time but left and went to the facility as soon as I was called. My dad was in very bad shape and was taken to the hospital where he stayed for almost a week. I knew then that if I wanted my dad to survive, we were going to have to make other living arrangements for him and my mother.

After making some changes to our home, my husband and I moved my dad into our home and my mother into a nursing home about five miles away. Unless there was a special occasion or he was sick, my dad visited my mom every other day. I made the rule but I think that my Dad was relieved to be able to just sit in his chair and read his paper and not do anything that he didn't have to do. I was still working full time and my husband was working at night so things hummed along pretty well for a couple of years. Then came the changes...

My father began having problems with his balance and confusion; my husband began to have problems with his balance, with walking, with weight loss and with his vision. Both were having such significant problems that I began searching for a doctor and a diagnosis. At this time I hired my daughter to come in and take care of both of them while I worked. I took my husband, father and mother to as many of their doctor's appointments as was possible. My daughter did the rest.

After many false starts we found a doctor that said that my dad was suffering from Normal Pressure Hydrocephalus but that surgery could help. My husband was diagnosed with diabetes, macular degeneration and Progressive Supranuclear Palsy which is degenerative and fatal. I felt that I had fallen into a very deep hole but if I worked hard enough I could climb out and make everything OK.

During this time my mother's health continued to decline slowly but steadily. She required no more emergency trips to the hospital because her medications were handled by the nursing home staff. I visited her a few times a week and my daughter visited occasionally. My daughter continued to help her father and grandfather. I continued to work and continued to go further down into that dark hole.

About two years later, my dad had shunt surgery for his hydrocephalus. Then the nightmare began in earnest. The surgery that the neurosurgeon described as a "piece of cake" turned into three surgeries. I took time off from work and stayed in the hospital with him. He was restless, confused, thought that people were trying to do awful things to him--it was horrible. This surgery was followed by another surgery the next day and a third a week later. A few more hospitalizations followed and during that time I had words with several interns, residents, surgeons etc. The surgeon seemed to feel, "Oh well, he's old. What do you expect?" The interns and residents felt that if he knew his name and where he was that he was OK.

I lost it one day in the emergency room and screamed at a resident/intern/whatever: "Yes, he knows his name and where he is. But he also thinks he was in part responsible for the Terrorist Attack on the World Trade Center!" I finally got their attention although it did little good. When my dad was released after this third brain surgery, I was able to get him into the nursing home near my home where my mother lived.

I thought that after some recovery time and some physical therapy that he would be able to come home. Somewhere during that time I decided that I had to stop working or I was going to end up on the Psych Ward: I just couldn't do it any more.

My mother's health took a turn for the worse. She had been well enough to come home for Christmas with the family, as did my dad, but it was obvious that she wasn't doing well. She was hospitalized a couple of days after New Years. I left my daughter in charge of my husband and father and went to the



hospital with my mom. Several days after she was admitted, she had an "awakening," and asked me what day it was. I told her that it was Wednesday and she very clearly said, "Oh, I have a hair appointment today!" I had to laugh because it was so typical of my mother. Earlier that day she also admonished me for always staying at the hospital with my father but not staying with her. This hurt me more than I can express and I told her that I hadn't left her since she had been admitted.

She began drifting off the following day and was discharged from the hospital the following Monday. I stayed with her in the nursing home until her death the following Friday. Her last words to me, when I told her that I loved her, were "I know." She would have been 85 in March.

It became evident to me not long after my mother's death that I wasn't going to be able to bring my dad home. He was no better after his surgeries. If anything he was worse, he fell easily, was confused and would wander in his confusion. The staff at the nursing home took wonderful care of my mother and provided the same for my dad.

I really felt that they loved them both. My father, who was a very "proper gentleman," would say some of the most outlandish things; at times he thought he was fighting the war and he would hold meetings with his imaginary staff. It broke my heart. In February of this year he began having seizures and I took him to the hospital where the residents, as usual, acted like it was all in everyone's imagination because AGAIN he knew his name and where he was...so he must be fine!

His confusion grew steadily worse; he fell and had to have stitches in his head. Not long after that he had another seizure and I again took him to the hospital. We spent another week in the hospital. He was constantly trying to get out of bed, at times he wouldn't/couldn't speak, becoming almost unresponsive. My daughter looked after her dad.

Eventually my dad was sent back to the nursing home, where he later died.

Denise: You also worked while caring for your folks. How did you manage?

Sue: Not very well.

Denise: While caring for your parents, your husband was diagnosed. Did you feel that you couldn't get a break from bad news?...

Sue: During this time my son and my younger daughter had some significant problems in their lives and I really thought I would disappear into a dark hole of sadness. During the time that my three carees were alive, I was put on anti-depressants by my family doctor. I don't think I would have made it if I hadn't had some medical help.

Denise: ...And, that life was asking too much of you?

Sue: YES! I have days that I am so depressed and sad that I can hardly move. I just want to run away and never come back but then I know that I have responsibilities and I must take care of John to the best of my ability.

Caregiving: Did you feel that, whatever came your way, you would manage?

Sue: I have always felt that I should be able to manage everything but I know without a shadow of a doubt that I can't. Most of the time I feel that I fail miserably. I am impatient, I speak sharply to John, I could go on and on. I have never been good at caring for sick people other than my children and I HATE the "dirty work" involved in caregiving. I think that I am better at it now than I was but I will never be good at it...ever.

Denise: Losing your parents, understandably, has been very hard. In many ways, you haven't had time to just be sad about your parents because you've had to be there for John. What are your bad days like?

Sue: My bad days are a sea of sadness. On very bad days, I never manage to even get dressed. I do what I absolutely must and no more. I want to cry for my parents but can't, I want to not have to worry but I can't, I want to be by myself but I can't. I shudder when I hear John shuffling across the floor. I just want to be invisible.

Denise: And, then, what keeps you going?

Sue: I know that I must because there is no one else. I also have several very supportive friends, two of which have been caregivers so I know that they understand, at least to some extent.

Denise: You've been with the same online support group at Caregiving.com for four years. Do you remember what led you to try an online support group? And, what have been the benefits?

Sue: I have two grandchildren that were born at 32 weeks. The little girl, now 7-years-old, had and still has some problems. I was surfing the net looking for helpful information about premature babies when I stumbled across an online support group and I joined it. Although I didn't fit the group (they were all mothers not grandmothers) I got some really good information just by reading the posts. I started looking for a support group for caregivers and found this group.

This group has been a help to be because the members are people who are going through what I am going through. My friends have been there and done that but are now finished doing that. Even though they both had a rough time, it is over for them and they look at things through different eyes than someone who is going through it right now. I don't seem to be able to read as much as I used to nor do I write very often but I still feel that I need the group and read and write what I can.

Denise: Tell us about your quilting and about the break you took last month for the quilting event. Leaving for a weekend can bring such feelings of guilt, but you managed to go and enjoy yourself. Did you worry about leaving? If you did, how did you manage? How else do you take breaks from caregiving?

Sue: I have always enjoyed working with my hands. I have done needlework and sewed for my children all of my married life. I became interested in quilting when my children were still at home and took a few classes but never did much with it.

About a year ago, I was suddenly bitten by the bug again and took a quilting class. I have found it to be a wonderful release for me. It requires some concentration but not an enormous amount. It requires some skill and allows for some creativity, but if you stick to simple patterns not a lot of either. When I am quilting I am in another world.

In October a friend and I went to a Quilting Retreat and had a wonderful relaxing weekend. I didn't know until two days before I left if my oldest daughter would take care of her dad. Since he requires more care, she has been pulling away. Although I can understand her discomfort at providing personal care to her dad, I also knew that I needed to get away. After much going back and forth, I decided that I was going no matter what (I don't

know if I would have actually left but I don't think so), that one of our children would have to step up to the plate and give me a break.

My daughter did eventually come and they got along fine. I kept my cell phone with me, much to the annoyance of the other women at the retreat, and we kept in touch several times a day so that I knew that things were OK. I am sure that the others at the retreat got annoyed when my cell rang but I just couldn't explain the situation to them because I didn't want to talk about it, I wanted to be away from it as much as possible.

I am now in the process of arranging with my father's trust officer for the trust to pay for respite care three or four times a year so that I can have a break. I am also looking forward to taking a trip with a friend in February. My husband will have to be in the nursing home near my home for about two weeks and I will do it even if I have to borrow the money to do it.

This is the third year that Wendy and I have traveled together and it has made a huge difference for me to have this long break. We are going to cruise the Eastern Caribbean: I can't wait! I only have to provide my spending money and for John's care. You couldn't get a better vacation than that.

Caregiving: What are your three current priorities for yourself?

Sue: I have thought seriously about getting some counseling to help me keep all this in perspective. One of my biggest fears is that when this is all over there will be nothing left of me. I don't want to be one of those bitter, complaining old women no one wants to be around. I want to be able to enjoy whatever time I have left on this earth, to spend time with my grandchildren and spend time with friends and just relax. I take a quilting class once a month and work hard to arrange things around being able to go to that.

I want to take care of John for as long as I can and I want him to be as comfortable as possible for as long as possible.

One release for both of us is our pets. We have three dogs and two cats. They provide us with a wonderful comic relief and a lot of comfort. They also keep John moving. He is still able to walk but does very little unless one of the dogs or cats wants out or in the house.

As John's health deteriorates, I will become more and more confined to the house. I am trying to maintain some interests such as our pets and my quilting and needlework and reading so that I will not be a complete recluse when, as a friend puts it, I get my walking papers.

## Meet a Family Caregiver in Stage 5: Ann

Ann's artwork is intricate, detailed, lovingly constructed. When you see her artwork, you see Ann.

In one year, both her grandfather and step-father died. Ann's mother moved in with her grandmother to care for her; Ann occupied an apartment on the same property, in back of the main home. The three became each other's support system.

Then, the tables turned: Ann's mother became ill; her grandmother became her caregiver until her death.

Ann stayed on at her grandmother's, continuing to work full-time. Prior to her death, Ann's mother had commented that "Gram was losing her mind." Ann wasn't quite sure what to make of these comments--until she began receiving phone calls at work from a very agitated grandmother. Ann, constantly worried about her grandmother, overwhelmed with settling her mother's estate, and in a job she didn't like, decided the time was right for a change. She initially took a three-month sabbatical from her job, but eventually quit to become full-time caregiver to her grandmother, the woman who had been Ann's full-time caregiver as a child.

Ann moved with her mother to Florida as an 11-year-old girl, after her parents divorced, to live with her grandparents, already settled in Florida. Her grandparents raised Ann as her mother worked to make a better life for them. "My grandparents raised me," Ann says. "They put me through college. My relationship with my mother was much more of a sister relationship."

When she became her grandmother's caregiver, she gained a wonderful day-trip companion: The two often took off for the mall, the beach, anywhere they could go to enjoy a break from the four walls of the house. The Christmas holidays meant trips to see the holiday lights. And, "we loved to go to Cracker Barrel," Ann says. "It was a thirty- to forty-minute drive for us to the nearest one, so we always stopped at the beach or mall to break up the trip."

A member of her local camera club, Ann enjoyed a day away each month on the club's day excursions. Backed up by a cell phone and an Emergency

Response System, Ann knew that her grandmother would be okay alone. “I was always back in time for dinner,” Ann says. “It was great to get away.”

They managed well--until a March evening. Their evening ritual was a card game after dinner. While Ann was setting up the card game, Gram walked outside to the patio to feed her favorite cat.

Ann knew right away that the fall was a doozy: After helping Gram up from the patio, Gram began looking for a cat that had died 10 years prior. During the next 30 days, Gram continued to decline and Ann’s caregiving duties increased--bathing, dressing, washing, feeding—until one day Ann couldn’t get her grandmother out of bed. A trip to the Emergency Room finally brought the correct diagnosis: subdural hematoma.

While her grandmother recovered in the hospital, Ann found herself crying in the doctor’s office. The doctor, an old friend, said one simple phrase to Ann: “When you’re ready, let me know...” And, with that, Ann, now 44-years-old, agreed to place her grandmother in an assisted living facility after being discharged from the hospital.

“I was physically and mentally kaput,” Ann says. As for keeping Gram home, Ann’s goal had been “to do the best I could for as long as I could,” she says. “And, I did.”

Gram, now 93-years-old, moved into a nearby assisted living facility, sharing a room with her best friend of 30 years, 97-year-old Agnes. The transition has had its challenges as Gram becomes accustomed to the facility. As a result of a recent fall, Gram was hospitalized and then transferred for rehab at a near-by nursing home. Residing in the nursing home created an intense reaction in Gram—anxiety, confusion, extreme paranoia, even violent reactions against the staff.

During the first few days at the nursing home, Ann wavered about her Gram’s adjustment: Was this a “normal” adjustment for a person with dementia? Or, was this just not the right place for Gram? Her visits would find Gram covering her eyes, terrified. “I knew then that Gram was frightened to be there,” Ann says. “She reminded me of a child, who tries to hide by covering her eyes.” Ann decided to bring Gram back to the assisted living facility to receive her daily physical and occupational therapies.

“As soon as we walked back into the assisted living facility, Gram began to smile and laugh,” Anne says. “I knew I had made the right decision.”

For Ann, the adjustment of Gram living in an assisted living facility means trying to find a new way in the world. Through trial and error, Ann discovered a good visiting schedule: Twice a week with daily phone calls. While her priorities still include ensuring Gram’s safety and well-being, a new priority is “getting out of limbo,” Ann says.

“I put my life on hold for three years,” she explains. “My retirement years are coming. I want to be sure I’m ready for them.” And, as she considers her next career, Ann also wonders: What is my purpose in this world? And, where do I go next?

Ann admits that she feels displaced; Gram is alive, but not living with her. Gram’s house remains as it did when Gram lived at home; Ann doesn’t feel right about selling any of her possessions or changing anything in the home. “Gram’s alive,” Ann explains, “but she’s just not here (with me).”

Her art (creating greeting cards and jewelry; painting) took a backseat while she cared for Gram. “I stopped after my mother died,” Ann says. “It was too much, I had to let something go.”

In July, Ann found herself concentrating more on her art. When caring for Gram at home, “my mind was so geared toward her and her well-being,” she says. “And, I was exhausted.” Knowing that Gram receives the care she needs in the assisted living facility frees Ann’s mind, allowing room for the art to begin again.

Ann, her boyfriend and his mother enjoyed a trip this fall to see the changing colors on the East Coast. Ann admitted to some apprehension in leaving her grandmother for a multi-week trip (which was cut short by Gram’s fall) but found the trip rejuvenating. “It was great to focus on something else,” she says, “and to enjoy a change in scenery.”

Ann will soon start her next project: Finding a new career. Her plan is to start slowly, working temporary placement jobs, hoping one will lead to a job she’ll like. And, no matter what the direction her life takes, Ann keeps her commitment to caring for Gram. When you see Ann’s artwork, you see her loving, intricate care for Gram.



## Meet a Family Caregiver in Stage 6: Terri

For Terri, her caregiving experience began in her childhood, when she was five and her younger brother was born with heart disease. Not expected to live, he defied the odds and lived until 17 years of age.

"I became a nurse because my brother was so sick," Terri says. "We were constantly at the hospital. I saw the bloopers that happened in the hospital, like my brother developing a serious infection that was overlooked by the hospital staff. And, I saw how the doctors treated my folks."

Her career as a nurse led her to work as a consultant, helping health care organizations manage the change needed to stay competitive in a changing health care industry. As she helped companies prepare for change, she found herself unprepared by a change in her family: Caring for another family member, this time, for her mother, diagnosed at age 50 with Parkinson's.

Her mother received care at home, primarily from Terri's father and with Terri's help, until she was 60, when the care needs intensified to such an extent that nursing home was the only option. "I was so frustrated and so conflicted" by the experience of caring for her mom, Terri says. "I am a Registered Nurse with a Master's Degree and I had a heck of a time trying to help. There just weren't many options. And, I felt so lost, not sure where to go for help."

The nursing home decision was awful. "I cried three days straight. I felt I had betrayed her."

The adjustment to the nursing home was difficult for her mother, but Terri and her father made a pact: One of them would always be with his mother every day. "There's never any way you're going to get one-on-one care at the nursing home," Terri says. "The intent is there, but the one-on-one care is just not a reality."

Terri also learned that the staff just did not understand her mother's care needs, including the necessity of dispensing his mother's Parkinson's medications on time. Without timely medication, her mother would freeze-- while on the toilet, while dressing, while walking. (The disease causes muscles to freeze without warning.) The staff misunderstood the disease process as attempts by Terri's mother to manipulate them.

So, to ensure her mother's care needs were met, Terri and her father remained vigilant in overseeing the care her mother received. Their daily visits provided emotional support to Terri's mother and kept the nursing home staff on their toes.

But, the experience--of not having enough home care options and of the inexperience of the nursing home staff to manage her mother's care needs--stayed with Terri long after her mother's death. And, as she cared for her mother, Terri began to question her life's purpose. "I was giving care and searching for myself," she says. "I went to psycho-therapy. By constantly searching for what I didn't want and searching for my boundaries--me versus caregiving-I didn't lose myself."

In some regard, in that caregiving experience, Terri found herself. Terri and her second husband began researching small business opportunities, including opening an art gallery. But, obstacle after obstacle made the gallery opening seemingly impossible--which led to her husband's discovery of a home care franchise. They opened their own home care franchise, which currently cares for 60 clients and employs 50 professional caregivers.

"I believe we were directed to this opportunity," Terri says. Because of her family caregiving experiences, Terri trains her staff to have "consumer-level education of the diseases" of her clients. Terri believes it's critical that her staff have the same knowledge of the disease as does the family of the patient. In addition, Terri helps the staff learn how to relate to their clients on a personal level, by hearing their life stories. With the personal knowledge of their clients, the staff has a better understanding of their clients so that they can best help them on a professional level.

Terri understands that many families are "grossly unprepared for caregiving. We need to teach families to manage the care," she says.

Caregiving changed Terri in a profound way, a change she compares to the changes people have after a near-death experience. "I didn't want any of my family members to die in vain." And, that's now Terri's life's work.

# Family Caregivers Sound-Off

*We asked family caregivers: What advice would you give to a new family caregiver?*

Count your blessings. Be grateful for every thing positive. Take care of yourself. Maintain a schedule. Work through a primary care physician for needed medical services.

Don't be afraid to ask for help--there are so many people who don't know how to help but will do small and large things if you only ask.

Join a support group of some kind to alleviate guilt feelings of situation; be nice to yourself. Learn someway to minimize resentment toward family members who do not take part in situation.

Have patience. Care for yourself.

Don't be offended, have lots of patience, become knowledgeable about disease and about business affairs. Be prepared that others may be jealous of the possibility of you inheriting any assets.

Find someone in a like circumstance and learn from them. Gain strength in knowing you are doing the right thing.

It could be a long-term project--relax, find ways to keep yourself active outside your eldercare.

To have hope.

Relax, enjoy the patient and life. Don't think of yourself as being used. What better job could you be doing? It is service to the patient and to God.

Make it your aim to care for a parent without superseding their authority. Assist in such a way so tender and delicate that you do not awaken suspicion that you want to "supplant" him or her, nor make them feel they are incapable of doing without you. Utilize music therapy. Know your nutrition.

Learn all you can about your care person's illness and treatment options. Be assertive with the health community and insurance companies to get the care needed.

Don't lose your sense of humor.

(It's) hard work. You give up everything to care for your loved one. Don't expect other family members to help...

Have hobbies. When people ask how you're doing, tell the truth.

Toughest job you will ever have. You will find love grows on love. Love grows with compassion. Since I started this job, I have learned all that I have needed to and I marvel at how I have been able to cope and how it has all worked out. I don't know what has happened but I love me! For being able to do the job so well!!

Be patient; try to keep your spirits up.

Make sure you have help lined up ahead. Make sure you have time for yourself and your husband. Plan out what things you can add to your home to make things easier.

Don't be afraid to ask for help; take time for yourself.

Be financially prepared.

Seek information **before** the **need** arises!! Plan ahead by creating "what-if" scenarios. Assess your own abilities and seek "fill-in-the-gap" services available.

Take the job as a privilege and opportunity to learn personal skills like loving patience, humor, etc. Do it joyfully. Listen to your patient.

Learn as much as you can about the patient's limitations. Adjust your expectations to fit the patient's limits. Get as much help as possible. Try to keep the patient moving and doing as much as possible for himself. Exercise the patient, even a bed-ridden person can contract and expand many muscles. Reward him when he does. Exercise yourself to reduce stress.

Watch the caree's mail for scams. Turn money requests of any kind over to responsible family.

Don't sit around and wait for help, get out and be aggressive about finding help and support. It is out there. Just don't give in.

Try not to have pre-conceptions. Try to put yourself in their shoes. Take care of your health and sanity. Listen.

Don't try to do or be all encompassing; seek helpful sources; everyone needs a game plan.

Accept help; keep asking questions.

Set limits to protect your emotional and physical health.

To give the system a try.

Take it one day at a time.

# UGH! A Diagnosis. Now, What?

Life seems to stop after you hear a family member's diagnosis of an illness like cancer or Alzheimer's. But, life goes on. So how do you?

We've got tips to help manage the difficult few days after learning of a family member's medical diagnosis:

**1. Believe the diagnosis gives you time.** You have time to research, plan, communicate. You have time to get a second opinion; you have time to research the disease, its progression and treatment options. You have time to talk with your family member who has been diagnosed, with other family members and friends. You have time to make the most of the time you have.

**2. Know denial about the diagnosis will steal your time.** You may be tempted to disbelieve a diagnosis, to hide it. Denial, not the diagnosis, is the true enemy. In denial, you deny yourself the chance to learn, prepare, plan and understand. The progression of a disease will arrive on time; denial will make you late for its arrival. Playing catch-up after its arrival will waste precious time. And, before you know it, there won't be enough time. Don't let denial take your time.

**3. Consider how well you and your family member respect and like your family member's health care professionals.** The right physician and care team can make a huge difference. If you feel disconnect during the discussion about the diagnosis, consider getting another opinion and finding another physician.

**4. Talk about the diagnosis with your family member (if appropriate).** Then, let your family member talk about the diagnosis with his or her own support system. Do the same for yourself; call a friend or a family member to talk about how it feels. And, talking about it with someone will help keep you from denial.

**5. When you talk about the diagnosis with your family member, talk about your priorities.** What's a priority for your family member? The most aggressive treatment? The best quality of life? Time with family? Time traveling? How do these priorities align with yours? How can you make the priorities a reality?

**6. Let the news sink in.** You've had a shock, no matter how expected the diagnosis. The news is shocking. You will feel different. Allow yourself to get used to your new skin, so to speak.

**7. Start a journal to document how you feel and what this feels like.** Even if you think you won't like journaling, you will like going to a place (your journal) where you get to let it all out. When it comes out, it somehow sorts itself out.

**8. Contact organizations, like disease-specific agencies, that can provide information.** Gather information and look for online communities that can provide help and support.

**9. Take deep breaths.** Sounds so simple but when news takes the wind out of you, breathing seems to be the last thing we remember to do. Take deep breaths.

**10. Get out of the house.** Take a walk, pick up take-out for dinner, stop at a friend's, go to the library. A change of scenery and the motion it takes to get there will help.

# The FAQs of Caregiving

You're worrying that your parents may need help in the near future. Or, you're starting to help your parents, which means you're starting to ask a lot of questions. To help, I've compiled the most frequently asked questions about caregiving—and the answers you need.

## 1. Am I up to this? And, what if I'm not?

Everyone has his or her limits as a family caregiver. It's important to respect yours. It's impossible to do it all so look to the community, family, friends, health care professionals and volunteers to fill in the voids.

## 2. How much will this cost?

A large misconception exists that the government, through Medicare and/or Medicaid, will pay for care of an aging relative (your caree). Medicare, the federal insurance program typically for person's 65 and over, has very limited benefits to cover long-term care needs, either in a home or in a nursing home. Medicaid, a state-funded program typically for low-income persons, pays for the costs of in-home and nursing home care only when an aging relative's income is low enough to qualify for benefits.

The majority of costs associated with a chronic illness or disability are assumed by the family and/or the caree and/or private insurance (including long-term care insurance). According to *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update from AARP*, the average family caregiver for someone 50 years or older spent \$5,531 per year on out-of-pocket caregiving expenses in 2007.

MetLife Mature Market Institute estimates the cost for caregiving services to be:

- Home health aide (provides dressing and bathing assistance): \$20 per hour
- Adult day service (provides socialization and meals): \$64 per day
- Assisted living facility (base rate): \$3,031 per month
- Nursing home (semi-private room): \$191 per day

A financial planner can help you explore ways to finance care. You'll also want to get a durable power of attorney for health care and finances for your caree; an elderlaw attorney can help execute this important document.

## 3. How long can I expect to do this?



In our most recent survey, family caregivers told us that they expect to be a caregiver for at least five years.

Because this is a long-term commitment, planning for the future is key. Take into account your caree's financial resources, your emotional resources and the community's resources. All these connect to make caregiving doable.

#### **4. Who can I contact for help?**

The ElderCare Locator which can refer you to your local Area Agency on Aging. Call 1-800-677-1116. You also can search for help at the BenefitsCheckup website: [www.benefitscheckup.org](http://www.benefitscheckup.org).

#### **5. How do I know when my family member can no longer live safely at home?**

Put systems into place which help to avoid a crisis. Personal emergency response systems, adult day services, home health aides, telephone check-in services, Meals on Wheels, and volunteer programs all help keep your caree safe.

In addition, AARP has checklists available to help you make changes in your caree's living environment: [www.aarp.org/universalhome/home.html](http://www.aarp.org/universalhome/home.html)

Often, a caree will resist changes. Usually what's behind the resistance is fear. Respect and recognize that these changes will be difficult for your caree. Start slowly, involve your caree, when appropriate, in any discussions and decisions. Ask for your caree's commitment to try any services for a month. Allow your caree to vent, without judgments or recriminations.

Reassure your caree that these services will keep him or her at home, safely, and that you want to work together to achieve this goal.

If your caree still refuses, then back off, at least for the time being.

However, don't give up. Contact local organizations (such as home health agencies, Meals on Wheels, assisted living facilities, rehab centers) for information about their services, costs and availability. In case a crisis occurs, you'll have the information you need to make good decisions about your caree's future.

#### **6. This is so depressing! I didn't realize I would feel this way. What can I do?**

Often, family caregivers overlook an important part of their experience: The grief they feel at the losses suffered by the caree, by the family and by themselves.

It is depressing, which is why taking regular breaks is important. It's also critical to maintain some hobbies and interests you enjoy. Rejuvenating yourself on a regular basis will help you manage the experience.

In addition, finding support will help you unburden yourself, which will lighten your load. You can join a online support group and/or a group in your community. A problem shared is a problem halved.

### **7. How can I get help from other family members?**

Often, family caregivers feel abandoned by family members, usually siblings, the very people they expected to help. So, how do you get your five brothers and sisters to help out?

Recognize that people are caregivers in different ways. Your brother the CPA breaks out into a rash at the idea of visiting your mother in the nursing home. Suggest that he call her every Sunday afternoon or write letters. Or, ask him to manage her financial affairs. Your sister is conveniently busy every time you ask her to spell you so you can take a break. Suggest that your sister help offset the costs of the companion sitter or home health aide you hire.

Should you force them to help? No. Be specific in your requests, but never demand that help be given. If your siblings refuse your requests for help, accept it. But, don't accept the idea that you are alone. Look to the community for help and for support.

You may find that the caregiving experience changes you and your relationships—another good reason to find support and camaraderie among those who will understand.

### **8. I feel so guilty—about everything.**

Your caree will make you feel guilty. Which makes it only worse, as you already carry around enough guilt. How do you keep it at bay?

Keep your perspective. Consider, whose problem is this? Does your caree expect you to make him or her happy? That's not your job. Does your spouse badger you about the time you spend with your caree? Try to work

out a compromise, so that you have a workable schedule for your spouse, your caree and yourself. And, remember, you can only control yourself, your reactions, your words and your feelings. The rest is up to everyone else.

Asking for and receiving help also can help minimize your guilt. The wider you cast your net, the more help you receive, the better your caregiving experience will be for you and your caree.

Your Caregiving Mission Statement:

## Shaping your Caregiving Experience

Fate may have brought you to this place, this caregiving role. Fate through a car accident, a sudden stroke or just your caree's age-related frailties.

Fate may have waved her hand and tapped you to be the family caregiver. But, you can add some controls to your caregiving destiny—with your own caregiving mission statement.

Your mission statement reflects your caregiving goals and your caregiving personality. Your mission statement will serve as a reminder of what you can and cannot do as a family caregiver, as well as what's most important to you and to your caree.

In your mission statement, consider including the following:

**--Your respite schedule.**

For instance, your respite schedule may include breaks on Wednesday evenings, Sunday afternoons, one weekend every three months, two weeks annually. You'll know best: What breaks do you need to stay on purpose with a healthy perspective?

**--Your respite service plan.**

In order to take regular breaks, you'll use myriad help in various combinations, from family and friends, to community programs (volunteer respite programs, adult day centers) to various service providers (home health agencies, assisted living facilities, nursing homes).

**--Your ongoing care goals.**

Your mission statement also reflects your comfort level in continuing to provide care as your caree's care needs increase.

**--Your hopes as a family caregiver.**

Consider: What are your barometers for success as a family caregiver? Your caree's? How can you achieve success?

**--Your wishes for your caree.**

You'll want to include your thoughts about quality medical care and dignified interactions with health care professionals.

**--Your caree's wishes.**

A helpful mission statement also includes your caree's wishes about who he or she wants to receive care from (which family members, which friends), where care can be provided (in his or her home, your home, the nursing home) and how he or she would like to spend his or her last years, months and days. If your caree is unable to communicate these wishes to you, your knowledge of his or her past lifestyle and relationships will help you determine these issues.

Your mission statement is a work in progress. As you change, as your caree changes, as community services change, as your own immediate family changes, so shall your mission statement. Keep each version of your mission statement in your caregiving journal; you'll enjoy reviewing and revisiting each one.

## Your Caregiving Mission Statement

## Your Caregiving Mission Statement

# The Six Myths of Caregiving

You'll have ideas and thoughts about caregiving that would logically seem to be true. These ideas and thoughts seem like truths. Unfortunately, they are really myths.

Here are six myths about caregiving:

**1. The government has programs, like Medicare, that will off-set the costs of care.**

Sure, Medicare exists but its benefits for long-term care pay only in the short-term. And, Medicaid helps those whose low-income qualifies them for help. Care falls to the family (and typically one family member), who organizes, oversees and provides care. Home care agencies, adult day services, assisted living facilities and nursing homes can be part of a care plan for an older relative, but often the caree (and sometimes the family caregiver) assumes the costs of services.

**2. "My mom raised five children with little help. Surely, I can care for her on my own."**

Caring for a frail older adult with chronic illness is not even in the same ballpark as raising children. Sure, you'll find similarities but the toll of caregiving on your emotions will wear down even the most resolute. Caregiving can be depressing, lonely, overwhelming. Parenting has challenging moments, but it's an experience that can light up your world. Sometimes, you'll feel like caregiving has darkened it. And, that's why it's good to find help and support.

**3. Everyone you helped in the past will gladly pitch in to help now.**

Move in your elderly grandfather with dementia and watch your close circle of friends scatter. Tell them you're feeling stressed and witness eye-rolls and impatient sighs. "Why not just put him in a nursing home?," they'll advise. Ask for help—hey, haven't you always been there to pitch in?—and you'll be asking to an empty room. Not everyone disappears, but the number of those who do can be heartbreaking.

**4. Your caregiving situation is so strange and bizarre you'll never find anyone who can help or understand.**

A husband who urinates in the planter. A grandmother who swears like a sailor. A mother who believes a clean house is one cleaned 20 years ago. You may think you've got a caregiving situation to take the cake and that



there is absolutely, positively no help. Try. Professionals who work in social services agencies and eldercare agencies will not bat an eye when you share your story. (And, if they do, find another staff member or agency.) It's embarrassing to you, but to a professional, it's just part of their day.

**5. Conversely: All your friends and family members will understand exactly how you feel.**

You can look at your caree and feel like you can read his heart and mind. So, depending on what you read, you react. You take care. So, because you can, you think others can, too. Sigh. Many can't. It would be wonderful if they could, but they can't. It's not a poor reflection on them or on you—it's just a fact. Because they can't, you can: Tell them what you need and how you feel. You'll both feel better for it.

**6. It's easy to find the treatment and care your caree needs.**

With a good doctor, it can be a fairly smooth ride (bumps to be expected) to an appropriate diagnosis, treatment and care plan. But with a bad doctor, it can be a nightmare. Trust your gut, advocate for your caree and demand answers. Often, you are working against the clock, so move quickly if you feel your caree (and you) need better and different physicians and professionals. A support group can be particularly helpful; members can suggest alternatives and options that work for them.

# The 3 Be's of Caregiving

Caregiving conundrums will be a part of your caregiving experience; to help you stay on track we've developed The Three Be's of Caregiving: Be Prepared, Be Honest and Be Well. To help you look at your Three Be's, we've developed the following questions to ask yourself:

## **Be Prepared:**

- What does the future hold for your caree? What will his or her care needs be? What community services are available to provide the needed care? If in-home will not meet the care needs, which housing options will?
- What can your caree afford in terms of care? If budget restrictions are a concern, what other community programs or services (or state or federal) programs can offset the cost of care?
- What information or training do you need to be a qualified, effective caregiver? Where can you gather the information or learn the caregiving techniques?

## **Be Honest:**

- What are your limits as a caregiver? Can family members, friends or community services fill those voids? If not, what other options are available?
- How long can you afford (emotionally, financially, physically) to provide care in your home or in your caree's home?

## **Be Well:**

- What interests and hobbies are important to you? How can you maintain these?
- How can you integrate a fitness program into your routine?
- How can you maintain a regular support system?
- How can you release all those negative emotions of caregiving in a healthy way?
- How can you better express your feelings and your beliefs so that family members and friends understand your goals as a caregiver?
- In what areas do you need help? How can you get that help?
- In what ways can you bring joy and laughter into your life (and your caree's) on a regular basis?

# Forming Your Caregiving Team

The lie about caregiving is that you have to go it alone. It's a powerful lie because it seems like you must go it alone because it looks like you're the only one who does.

The truth is that caregiving is too big and too demanding for one person. You deserve a team to help. And, if you think about it, you already have some team members; you just haven't seen them as such. For instance, on a bad day, maybe your dog, Trixie, provides the love and healing you need. Well, guess what, Trixie is on your team. And, maybe, your trips to the drugstore are helpful because of that nice pharmacist, Bruce, who always has a smile and a helpful tip to share. Yep, Bruce has made the team.

The first step to forming your team is to determine why you need a team. So, write your answers to this question: Why do I need a team?

Your answers may be:

- For support
- For answers
- For breaks
- For laughs
- For reassurance
- For errand-running
- For bill-paying
- For hands-on care
- And on and on.

Next, answer this question: What responsibilities do I want to delegate to my team?

Your answers may be:

- Provide a three-hour break twice a week.
- Provide a one-week break every year.
- Research community options for me.
- Lend an objective ear.
- Keep me realistic in my role.

Once you understand the purpose and role of your team, you're ready to build it. Again, you may already have some members, some you may have

to recruit. Some family members and friends will run when you appear clipboard in hand, ready to recruit. That's okay—they are not the team members you need.

Next, answer: Who do I want on my team?

Your answers may be:

- The caregiver specialist at the Area Agency on Aging
- The home health aide
- The librarian
- My best friend
- My support group
- My neighbor
- My local assisted living facility
- My brother

Here's an example of how we can put it all together:

I'm a full-time caregiver to my mom. I manage well except on Saturday afternoons when I feel cooped up. I find that I hate staying home with my mom on Saturday afternoons. I also want help with cooking because my cooking is awful. I wish I could find more time to read a book each week. I also have lots of anger about my situation and want someone to vent to.

With this in mind, I decide I want a team to help me get out a few Saturdays each month, relieve me of some of cooking responsibilities, free up some time for me to read more and provide an objective ear.

I decide that my team can include a home health aide to stay with my mom, a family member to prepare frozen meals that I can microwave, the librarian to update me when a good book arrives and a support group member to be my venting buddy.

I'm ready to start recruiting!

### **Home health aide**

I call local agencies to find an agency that can best meet my needs. I interview home health aides and work with the agency to find the right professional caregiver for myself and my caree. And, what the heck, I ask my brother to foot the bill. I call him and say, "I'd love your help with Mom.

I'd like to take three hours off two Saturdays a month. I found a great aide to stay with Mom while I'm gone. Can you help out with the expense--it would mean so much to me."

### **Frozen meals**

I send my family members and friends an update e-mail. I let them know how much it means to be able to take care of our caree and how grateful I am for their support. I am running into one problem, though, I write. I'm a terrible cook! I'd love some help. Would you be able to help with a few frozen meals each week that I can microwave?

### **Books**

I call my local library and explain my situation to the librarian. I miss reading great books, I explain, but my time constraints make getting to the library difficult. In addition, I'm completely out of ideas as to which books are worth reading. Can you help?

### **Venting Buddy**

I ask a member of my support group if he or she would be interested in being venting partners. We'll call each other every week, I suggest. I vent for 10 minutes while my support group friend merely listens. Then, it's his turn.

As with all things, the recruiting process may have starts-and-stops--that is okay. Keep asking until you find the right solution.

And, for those team members you didn't have to recruit (like Trixie and Bruce) be sure to include them in your regular thanks to the team. Your gratitude and appreciation keeps your team full.

## My Care Team and Their Responsibilities

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# The Power of Requesting Right

Can we get the help we want? Beth Ruske, a managing partner at Tiara Coaching ([www.tiaracoaching.com](http://www.tiaracoaching.com)), assures us we can. She shares ways to make clear and powerful requests for help.

Here's how:

1. Recognize it is our own responsibility to know what we need or what would be helpful. Spend some time asking yourself what kind of help you need or want. Is it financial, is it time away from your career? Is it sharing the burden or caregiving responsibilities? Get clear about what would be helpful for you.
2. Be willing to make specific requests. We think others can read our minds and anticipate our needs. They can't.
3. Make the request and then allow the other person the freedom of three responses:
  - Yes. If they say "yes," thank them and expect them to fulfill the request.
  - No. "No" is a little more challenging. Remember the person is NOT saying no to you. They are saying no to the request you made. Beth's standard reply is, "Thanks for saying no. I'd like to ask why? Is there a perspective that would be useful for me?"
  - Renegotiate. Renegotiating is a wonderful reply. The person is willing and engaging with you, telling you exactly what would work for them. Now you get to answer their renegotiation with your own "yes", "no", or counter-renegotiation. It's about give and take.

Remember that if you are attached to a "yes" from someone, then you're making a demand, rather than a request. Others have to have the freedom to say "no."

Beth also shared tips when you're working with service providers, like home health agencies.

- If we know what would be helpful, then ask straight out. If we don't know what help we need, then explain the situation and ask, "What special help do you think you could provide that would help this situation?"

- Be open to a win-win solution. Often times, that means compromises and negotiation. Be open to the idea of looking at solutions in a different way.
- Relieve yourself from having to make the “right decision.” If you can gather the information from trusted resources, then let it sit and know you will make the best choice you can. Your instincts are still the best guide you have. No one can tell you what to do—that will come from you.
- If you come from a win-win perspective and you are willing to make the best choice you can at any given moment, you are doing the best you can. And that is all that you can do: Your best in any given moment. And, your best today doesn’t mean the same thing as your best tomorrow. Just commit to giving your best in any given moment.

Finally, don’t expect perfection from yourself or others; just strive to provide your best in any given moment. And, in those moments, have compassion with yourself and others.

# Taking the Edge Off Socializing

It took a few years, but you've finally got a caregiving system down; home health aides you like, an adult day center your mother will attend, and a brother who will help foot the bill. Now, you finally have time to go out and socialize with friends.

It should be great; but why does it feel so awkward?

You hear it all the time: Get out! Take a break from caregiving! It's great in theory, but sometimes the outside world can be scarier than caregiving. And, if you've been inside concentrating on caregiving and not necessarily keeping up with the rest of the world, well, once you get out, you may want to run back in.

If you've been out of circulation, re-entering the social scene can be awkward, scary and confusing. The world may have changed while you were doing load after load of laundry. And, understanding how you fit within the changes can take time.

Being out of the house means being out of your comfort zone. And, there's nothing like questions (which seems so simple) from friends and acquaintances about your life (which seems so complicated) to increase your discomfort. To help you gain confidence, here are some suggested answers you can use to avoid feeling tongue-tied:

## 1. "What's new?"

This seems like such an easy question, but in the world of caregiving, the answer is always complex. A few ideas on how to answer:

--"We're all doing well." (If the questioner is an acquaintance, it might be easier to provide general answers. And, even if you're not all doing well, sometimes it feels better to say you are.)

--"Mom is having a bad week, but I'm doing okay. And, I'm so glad to be here with you today!" (If the questioner is a friend or good friend, this answer works great. You've told the truth, but then moved on to your goal: To enjoy your time out of the house.)

--“With Alzheimer’s, there’s always something new! This week, the dog is new. But, overall, Frank is doing okay and I’m glad to have some time with you today. I’ve been looking forward to it all week.”

--“I’m out of the house—that’s what new! Let’s start the fun!”

## **2. “What do you do?” (i.e., What’s your career? Are you working?)**

All too often, society equates one’s worth with a great career. Remember, caregiving is an amazing role. Be sure to share that when you talk about your career.

--“My mom needs help these days. So, I’m taking care of her. Because I’m her caregiver, I’m thinking about a new career when I can get back out working. So, right now, I’m taking online classes toward a nursing degree.”

--“I’m home with my husband, who has Alzheimer’s disease. Are you working?” (Providing a short answer and then asking a question can help deflect any awkwardness you may feel.)

--“I’m raising my family and taking care of my parents. Two full-time jobs! But, I’m still walking and talking, although my friends often ask me how I do it. How about you?”

--“I left the corporate world to take care of my parents. It was a tough decision, but one I’m very proud of. How about you?”

And, consider that, in social interactions, a good listener is highly valued—there aren’t many good listeners left in the world. If you find yourself without any words, then go ahead and listen. Smile and nod; ask questions when you feel comfortable. And, then, when you find common ground, share something about yourself. Your listener will be in awe at what he or she discovers about you.

When you start socializing again, give yourself time to find your comfort zone, to find your way. Small steps will lead to great social success, so that your caregiving world and your break from the caregiving world will co-exist peacefully.

# In or Out? On the Bad Days of Caregiving

Liz has a debate going on in her head and a torment going on in her heart. It's been a bad day. And, not for any particular reason that Liz can pinpoint. It could be that her youngest will turn 10 soon. Or that next week her mom will be living with them for three years. Or that her husband will leave for another week-long business trip in a few days. Or it could be all three. It's been a day that's kept her eyes full of tears.

Now, it's 7 p.m. And Liz should leave for her book club meeting in a few moments. She loves her monthly book club meeting; she usually can't wait to leave. But, leaving for a book club means opening up the possibility that the very nice librarian who runs the book club will say: "Liz, is everything okay?"

How in the world do I respond without just sobbing, Liz thinks.

On those bad days, do you stay in? Take a chance and go out?

A few suggestions as you consider what's best for you:

- 1. Sometimes, a change of scenery can make a huge difference.** The act of getting ready—a shower and fresh clothes—can help.
- 2. Focusing on another task or responsibility can take your mind off your sadness.** And, sometimes, it's a nice break to think about something else.
- 3. The worry over how to answer the simple question, "Are you okay?"**, may make you think twice about leaving the house. Having a ready answer may help you feel like you can be in control. "I'm struggling today," you can explain, "but I want to take my mind off that and it's important for me to be here." Then, take a deep breath and say, "Thank you. I'm feeling better already."
- 4. Call a good friend.** Let it out. Explain that you have an important engagement you'd like to attend but you're not feeling up to it. Then, just talk it out.
- 5. Write it out.** Write that you don't feel well, that you worry about crying in front of others, that you want to take some time for yourself and enjoy it

but can't convince yourself that it's possible. Write out the pros and cons of leaving the house. Sometimes, the pen can provide a perspective.

**6. Consider: Tomorrow, what will you wish you would have done today?**

Thinking into your future can sometimes propel you forward in your present.

**7. Allow yourself the freedom to go and then return home if it's all just too much.**

If it does become too much, you can simply say, "I'm having a bad day today. I usually love being here which is why I came. But, I think I would do better at home. Thanks for understanding." Leaving is absolutely okay. You know what's best for you.

## 7 Traits of a Hope-full Family Caregiver

In “The Seven Desires of Every Heart” by Mark Laaser and Debra Laaser, the authors tell us what every heart wants: to be heard, affirmed, blessed, safe, touched, chosen. This book's title reminded me of Stephen Covey's book, “The Seven Habits of Highly Effective People, Powerful Lessons in Personal Change.”

Which brings me to consider family caregivers. What characteristics or traits are important to have in a caregiving role? I created the seven traits, but then stumbled: What do these traits lead to? Empowerment? Health? And, then it hit me: Hope. Caregiving seems bereft of hope. These traits, I think, can help bring it back.

### **Resilient Backbone**

It's a war out there. Or, rather in there--the bedroom, the bathroom, the car. And, then when you leave the house, it's a war in the doctor's office, the hospital, your sibling's house. Or, so it seems.

Battles become part of the experience: The battle of the wills with your caree; the battle to find and receive the care you want for your caree; the battle to find and receive the help you want; the battle with yourself to stay patient, positive, to persevere. You'll get battle-weary, but a rebounding backbone is the best ammunition. Your resilient backbone means you keep an objective viewpoint (it's often not about you, but them), a belief in yourself and your abilities, a faith that props and comforts you, and a reliance on your best asset—your gut.

### **Flexible Goals**

When you begin your caregiving experience, your goal may be to keep your caree home until the end. But, then, the disease progresses, the house becomes an obstacle, the help disappears. Your goal may change to finding the best possible place to provide the care your caree needs.

It's okay when your goals change. Very little about the caregiving experience stays the same. Your goals should be as fluid as the experience, refining and updating as you go. Your Caregiving Mission Statement can help you set and revise your goals.

### **Escape Routes**

Maybe it's not Route 66, but your escape route takes you to the place where you can vent, scream and cry. The highway may lead to be your support group, your best friend, your pet.

Your road also may wind to the sanctuary you create in your house. Your sanctuary may be a corner of your bedroom, complete with your favorite photos, music, books and flowers. Your sanctuary may be that monthly golf game with your friends. Or, it could just be five minutes alone in your kitchen, when you can sit at the table with your eyes closed and day dream.

Plan your escape routes and put them into practice.

### **Bulldog Tenacity**

Caregiving can be a bull-dozer. To avoid tire marks on your forehead, be tenacious in a bulldog way. Know that your efforts will bring you answers, help and support. Accept no less.

### **Loud Laughter**

Caregiving strips you naked, leaving you raw. That's good. Now you know what's important. Your loudest laugh, demonstrating how much you appreciate the joy and blessings in life, proves that. You can laugh because, amazingly, you've discovered life's secret: the moments, those 30-seconds of shared smiles of knowing, of close contact of love, of the combined power of compassion, matter most.

### **Resourceful Network**

You're only one person which is why you tap into a network of resources. Be truthful with yourself about what you need. Then, build a team to get it.

### **Forgiveness and Then Some**

Oh, so many to forgive—family members, friends, your caree, the disease and its relentless progression, your community, your faith, yourself. Does your heart and soul have enough to go around?

Yes, because living in unforgiveness only hurts you—no one else, not even those you may perceive to be unworthy of your forgiveness. The persons most difficult to forgive are those who act, and react, from fear. Resenting the fear-ful in your life weighs you down with their fears; forgiving them frees you. Although it can sometimes seem otherwise, people are doing their best. Believe that and move on to find the best possible for you and your situation.



So, you ask, where's the hope? The hope in caregiving lies in knowing that the cure for life is to live it, regardless of severity of struggles. Living fully, even around and within the struggles, opens you to unimagined blessings.

# Should Mom Move In?

Karen and her husband thought they had the answer: Her father was living alone. They worried about him. They found it difficult to be at his house to help him and be at their home to provide for their two children. So, her father moved in with them.

A year later, Karen finally feels the family is adjusting to the living arrangement. “It was so much harder than I ever thought it would be,” Karen says. Karen had a difficult time understanding how to help her father, who sat day after day in front of the television. Her suggestions to join the local senior center or a men’s club were met with a “No, thanks.” Much to her surprise, Karen often found herself feeling frustrated, helpless, and even resentful.

Moving your aging relative to your home does make caregiving more convenient. But, it also significantly changes the make-up of your household. Questions to keep in mind as you consider such a move:

- 1. Does your house have room for everyone?** Will a family member be “uprooted” from a bedroom in order to make room for your aging relative?
- 2. Will each family member have some privacy, either their own room or their own space within a room?** If everyone has their own space, everyone can get a break. And, on a regular basis, everyone will need a break from each other.
- 3. Is your house conducive to a possible increase in your aging relative’s care needs?** With increasing care needs comes the need for handicap accessible rooms. Is your home disability friendly?
- 4. Do you and other family members, especially your spouse, enjoy the relationship with your aging relative?** Living under one roof intensifies the relationship. If you don’t get along when you don’t live together, chances are you really won’t get along when you live together. If that’s the case, is it best to house the relationship under one roof?
- 5. How will your aging relative receive the socialization that she needs?**

In order to make the decision that right's for your family, research all options in your community: retirement communities, assisted living facilities, home health care, adult day centers. (To learn about options, call the ElderCare Locator at 1-800-677-1116 or visit [www.benefitscheckup.org](http://www.benefitscheckup.org).)

You may find that your aging relative can remain in her home with home care and by attending an adult day center. Or, you may find that an assisted living facility offers the help and activities she needs and enjoys. Or, you may find that your home is just the right place.

# The Qualities of a Stellar Family Caregiver

I recently heard two radio DJs discuss the “five qualities of a stellar mom.”

They are, as described in an article at PsychBlog.com:

1. A Strong Intuition
2. A Knack for Nurturing
3. The Ability to Keep Your Cool
4. A Willingness to Ask for Help
5. A Playful Attitude

Of course, hearing about a list like this makes me wonder: What are the qualities of a stellar family caregiver?

My list follows.

## **1. A respect for limits.**

Caregiving can make you feel like a door mat. It also has the potential of leading you beyond your capability (or your home's or your budget's). Understanding your limits and then respecting them by getting help and making adjustments keeps you and your caree safe. You also understand that opinions and judgments about your limits cannot impact how you define your limits. Your limits, however wide or narrow, are just that—yours.

## **2. A knack for problem-solving.**

Caregiving breeds problems. You solve one and, bam!, another knocks on the door. The problem with caregiving's problems is that solutions are often not readily available. So, knowing when to punt, how to think outside the box and how to piece together a solution is critical.

## **3. A resilient spirit.**

Caregiving will kick you and then kick you again when you're down. It can be tough to get back up. The ability to do just that—keep trying, start over, face another day—ensures you'll get where you want to be.

## **4. A thick skin.**

Caregiving will introduce you to insensitive family members and friends, an uncaring health care system and an uncooperative caree. If you let every upsetting comment or situation affect you, you'd never get out of bed again.

Your thick skin helps you remember: It's not about you.

### **5. An abundant sense of humor.**

The beauty of caregiving lies in its incredibly funny experiences. You laugh, and laugh a lot, because, simply, it's funny. And, in the laughing, you keep crippling stress at bay.

# Is This Normal?

Caregiving stirs up so many emotions—emotions sometimes too embarrassing to acknowledge. You may wonder: Is this normal?

Take this quick test (just answer yes or no) to find out how normal your caregiving experience is:

1. I often long for the days prior to my caregiving role.
2. On a regular basis, I fight to maintain my composure.
3. Sometimes, I just dread interacting with my caree.
4. I often think I am not doing enough.
5. I feel shame about my emotions, particularly the resentment and anger.
6. I have wished that my caregiving days would end.
7. I have hidden from my caree (in another room, in my car, in the bathroom).
8. I am not the person I was.
9. I have lost my temper.
10. I am really, really tired.

Did you answer yes to any of the questions? To all of them?

Guess what? You're normal!

Caregiving can test you unlike an other life experience. The emotions associated with a caregiving experience can be so negative—even if you really, really love your caree. These emotions can wear you down faster than the transfers you make from the bed to commode. To stay well emotionally, consider joining a support group, seeing a counselor, hiring a coach, or creating another way for you to vent regularly about what's really happening.

The worst part about your caregiving challenges? Keeping it to yourself. Find a safe haven to be who you are.

## Sigh. If Only It Was Vomit

Stacey stood in line at the pharmacy. Actually, she jumped up and down in line at the pharmacy. She shouldn't be here, she should be at home. But her siblings won't return her calls, her husband is out of town and her father is in need of his refills.

She waited until the last minute, but she waited hoping, hoping, hoping that someone could run this errand for her. She needs to be at home.

So, while she waits, she jumps. Her anxiety seems to propel her up and down. It's like she's stuck in the ball that the gerbil at home spins in his cage—moving all around but stuck. Stuck in line. When she needs to be home.

And, then before she knows it, it's like an out-of-body experience. She hears herself yelling at the pharmacist, who inexplicably chooses this day to work in slow motion. "What's taking so long," she hears herself shout. "Why can't you move faster? The service here sucks!"

It's only then, after the words leave her mouth, that she realizes the slow-motion pharmacist is actually her favorite pharmacist, the one who diligently and kindly explains why each medication has been prescribed, what side effects to watch for, and how to dispense each one (with or without meals, without grapefruit juice, etc.). The pharmacist who any other day feels like her best friend in the whole world.

Oh, no, she thinks, I just spewed. If only it were vomit instead of words.

Now what?

You hope to avoid moments that lead to a spew. You do your best—listening to relaxation tapes, participating in an online support group, writing in your journal. Even with your best efforts, caregiving can get the best of you. So, how do you clean up after a spew?

A few suggestions:

1. Apologize.
2. Apologize again.
3. Quietly slip away.

It's these kinds of days when memory problems seem like problem-solvers.  
Oh, to be able to forget.

Do your best to do just that—forget. Let go and give yourself a chance for a  
better day tomorrow.

It will be better tomorrow.



## Quiz: Is Your Blow-Up Around the Corner?

Caregiving can test your patience like no other life experience. Day after day, it seems that caregiving chips away at your patience, bringing you closer and closer to a blow-up.

How close are you? Take our quick test to find out.

**A. Your mother calls you to her room for the umpteenth time in 10 minutes. You know what she'll ask before you reach her doorway. Sure enough: You find her in her bedroom, ruffling through her nightstand drawer. "Yes, Mom," you say, in your calmest possible voice. "What do you need?"**

Your mom turns around: "I need my Rosary," she says, "that's what I need. What did you do with it?"

You:

1. Say, "Mom, we've been through this 20 times already today. I don't know where it is. I didn't take it. You'll just have to find it yourself" and leave the room. Thirty minutes later, you check back on your mom and find her room in disarray. An hour later, you've put her room back in place—and forgot to pick up your daughter from school.

2. Say, without a twinge of guilt, "Susie (your sister, your mom's favorite) took it. I don't know why she keeps taking your Rosary from you. She knows how important it is to you. I would never do that." (Serves Susie right, you think, as you head out the door. She never helps, she might as well take some of the blame.) This, of course, becomes the only thing your mom remembers all day. She follows you from room to room asking, "Why doesn't Susie love me? Why would she take my Rosary?"

3. Help her find it. You say, "I know how important the Rosary is to you," you say. As you move things around in the drawer, you place one of the replacement Rosaries you keep handy in the drawer. You let your mom find it. "There it is," you say. "I'm so glad you found it. Let's go in the kitchen and make some tea."

**B. Your husband starts bellowing for you: "Take this oxygen tank outside," he says. "I'm going to have a cigarette."**

You:

1. Take the oxygen tank outside, but make as much noise as you can and ding as many walls as you possible. You stand outside with the oxygen tank for 30 minutes (this will show him, you think!!) and, once you feel frostbite take hold of your fingers, drag the tank back inside. Your husband looks up from the paper as you bang, ding and swing the tank back into the living room. “You put some dents in the wall,” he says as he calmly points to the living room wall. “You’ll have to paint and spackle tomorrow.”
2. You scream and stomp one foot, then another: “You can’t smoke!! You can’t smoke!! I’m calling the doctor!” You call the doctor’s office; as a result of your phone call, the doctor prescribes Valium—for you.
3. You say, “I think we’ll keep the oxygen tank in here. I’ll open the door for you so you can go outside and smoke.”

**C. You finally are out of the house (your neighbor volunteered to stay with your caree), although it’s only to run to the grocery store. You’ve run out of hard candy, the only thing that seems to keep your caree calm in the afternoons. Sucking on the hard candy seems to keep her distracted, keeping her late afternoon agitation at bay. On your way to the store, an older driver pulls in front of you, almost causing an accident.**

You:

1. Lay on the horn, which keeps blowing and blowing and blowing and... You applied so much pressure it seems you’ve stuck your horn. You drive to the store and all the way with your horn blowing. In addition to the hard candy, you also bring home a splitting headache.
2. Without thinking, you raise a particular finger which relays a particular message. And, then because you know the driver is probably hard of hearing, you roll down your window and yell: “Don’t you know how to drive?? Get off the road!” Ten minutes later, the guilt is so great about the finger and the screaming that you purchase the wrong hard candy at the store. It’s a long evening for you and your caree.

3. Say a quick “Thanks,” with a look to the sky, that no one was hurt as you change lanes. “I think I’ll take the long way home,” you say to no one in particular. You call home and speak to your neighbor: “It’s such a nice day,” you say, “that I’m going to take 15 minutes to sit in the park.” “Good for you,” your neighbor says. “Enjoy!”

**D. Your spouse is having a bad day today—so you’re having one, too. No matter what you do or how you do it, it’s not right. Now, she wants lunch and is requesting the very meal you don’t have.**

You:

1. Run out to the store and buy what she wants. Inside, you’re cursing her. You call your daughter and say, “I can’t stand your mother today. You’ll have to come here and take over.” Your daughter arrives and takes advantage of the opportunity to lecture you: “I can’t keep rescuing you,” she says. “If you can’t handle this, we’ll have to talk about nursing home placement.”

2. Fix the meal you had planned. You’re so burned up about her lack of gratitude that you burn lunch in the process. You tell her, “Too bad! It’s what we have, so it’s what you’re getting.” You and your spouse spend the rest of the day in silence. The silence lingers overnight and into the next day.

3. Stop for a minute to take a few deep breaths. “Let’s sit and talk for a minute,” you say to your spouse. “What’s going on today? We’re having such a bad day. I love you too much to spend a bad day with you. How can we make it a good one?”

### **How did you do?**

**Mostly 1’s:** The bad news: You’re angling for a blow-up. The good news: It hasn’t happened yet. Take as much time on your own as you can; whether it be at night after your caree has gone to bed, or early in the morning before your caree gets up. And, give yourself a break from some scheduled activities when you can. Your rest is the top priority. And, continue to vent and rant to your support system—letting it out to them is healthy.

**Mostly 2’s:** The bad news: You’ve had your blow-up. The good news: What goes up, must come down. Give yourself a break, let anything but the most important caregiving responsibilities go. Call in the reserves, schedule extra help, go to bed early, get up late—whatever you can manage. Everyone has

blow-ups. Move on, but be sure you move on by taking some important time to yourself. And, look to your support system to share those bad days; they often can turn a bad day into something that's amazingly not so bad.

**Mostly 3's:** The good news: You're in good shape! The bad news: The challenge is keeping yourself in good shape. Give yourself time, even if you feel you don't need it. And, continue to participate in your support system; they'll be great to have on your bad days.

# When the Bombs Drop (and They Will)...

Many years ago, a member of one of our online support groups regularly reminded the group members: Life is for the living.

In caregiving, you sometimes feel stuck between life and death. How do you go about life when death and decline won't go away?

I'm reminded of a documentary I watched of life in London during WWII. In the film, we saw how Londoners managed during the war, when bombings became a normal part of living. The Blitz (sustained German bombing) occurred from September 7, 1940 until May 10, 1941, with smaller attacks continuing until the war ended.

We saw footage of London devastation—lives lost, homes ruined, a city rubble. But, we also saw footage of Londoners walking around the wreckage to go about their days: shopping, sending children to school, even attending a dance.

They never stopped living, even as death and destruction surrounded them. For you, caregiving can seem like another kind of blitz; you get bombed and bombarded by bad news, unsuccessful treatments, continual losses, sadness.

And, so during the bombings, you may catch yourself thinking: "I'd better pass on that bit of fun. Our life is just not so good right now." You may think enjoying life means disrespecting the seriousness of your life.

On the contrary.

You sacrifice so much. Don't sacrifice a moment to laugh or to dance or to simply smile. These are moments given to you, just for you. Take them.

And, then share them. If the Londoners could do it, you can, too.

# Caregiving or Your Career?

You're facing a big decision—should you quit your job in order to focus solely on your caregiving responsibilities? Such a decision comes after researching and exploring options. Here are some areas to consider:

**1. The budget needed to provide care at home in your absence.** Will you better meet the budget if you work and hire in-home care? Or, quit your job to stay home and provide the care yourself? Your budget should also include regular breaks for you. If you stay home, budget an amount to spend on services weekly so you can take a break. If you continue to work, still budget an amount for regular breaks, whatever you feel you will need. And, whether you continue to work or choose to stay home, budget an amount that provides for a two-week annual vacation for you from caregiving.

**2. Community services.** Are you taking advantage of all of the services available to your relative? Visit this site to see what services your aging relative is eligible to receive: [www.benefitscheckup.org](http://www.benefitscheckup.org). How would availability of services, services you were not aware of, impact your decision?

**3. Your caregiving personality.** Will you manage okay at home, without heading out to the office every day? Do you enjoy the break from caregiving that your job provides? Or, will you be miserable at work worrying about your mom? Or, would a part-time job that allows you to get regular breaks from caregiving while pursuing a career and earning income work best for you?

**4. Your future.** How will a loss of income affect your future?

**5. Input of other family members, friends, support group members.** What are their concerns for you? What suggestions, insights can they offer?

**6. The length of time your caree may need your help.** Can you afford to stay home for two years? Five years? As long as your caree needs you? In our most recent survey of family caregivers, almost 1/3 of respondents indicated that they expected their role as family caregiver to last another ten years. Would you be able to manage that long without a salary? With a full-time job?

As you know, chronic illness and disability can be deceiving; longevity often cannot be predicted. And, there's no better cure than loving care from a family member. If you stay at home, be sure you understand how long you can manage without a salary. And, start making plans now for when that time comes when you need a salary. Which assisted living facilities are good in your community? Which nursing homes provide the best care? Which home health agencies have staff qualified to care for your caree?

**7. Your human resource department.** Does your company offer flex time? Sabbaticals? Telecommuting? Job sharing? Family Medical Leave Act? What options does your employer offer? Would these options make caregiving and working easier?

**8. Your current needs.** Do you need a short period of time off from work, to find services, to hire in-home caregivers, to remodel your home? Would taking such a leave make it possible for you to accommodate your caree's care needs so that you can return to work full-time? Sometimes, we tend to view solutions as being all or nothing, but the best solution may exist somewhere in between.

**9. Assistance of other family members and friends.** Would other relatives be willing to share the care, commit to a schedule of caregiving? (I know you're shaking your head "No", but why not ask? If they say no, you're in no worse shape than before you asked.)

**10. Your own health.** If you quit your job, what provisions will you make for your own medical insurance? Will you have the insurance coverage necessary to ensure you stay healthy?

**11. Your peace of mind.** Compromises are always involved, whether you stay at home, take a part-time job, or work a full-time job. Which compromises can you live with?

# Lasting Caregiving: Embrace Your Limits

Limits are our reality check; they are the facts that relate to our self-control. We have the idea that we have a limited amount of self-control. Not so. Self-control is a limited resource, which must be protected. When you have control, we behave as we want. When we are out-of-control, well... We behave in a way that brings remorse, shame and guilt. Limits protect our self-control.

Limits also take care of your ability to give care. Limits are just like your body getting tired at the end of the day. Limits let you know when you need a break, a change, a difference.

Lasting caregiving very much depends on understanding and embracing your limits.

Understand your limits as they relate to:

- Time: Our day imposes a natural limit.
- Space: Everyone (including caregiving) needs their own space.
- Money: There's only so much; how can you use it well?
- Stomach: Caregiving is not for the faint of heart or stomach.
- Strength: Sometimes, it's physically demanding. It's always emotionally draining.
- Disease Process: Your caree will decline. While it feels unnatural, it's the natural part of life.

Consider your limits as they relate to:

## **Time**

- What's your limit in how much time you spend with your caree?
- What's your limit in spending time with family who can't support?
- What's your limit in when and how much you talk about caregiving (i.e., updates to others)?

## **Space**

- What's your limit in how much space you share?
- What's your limit in how much space caregiving takes?

## **Money**

- How much is available to spend on care?
- How much is needed?



- What options are available?

### **Stomach**

- What can't you stomach?
- When you can't, who can?

### **Disease Process**

- If the disease-process becomes bigger than you, your team and the house, who and what can take over?
  - Once in awhile
  - During the day
  - During the night
  - During the role

### **Your Strength**

- What's your physical limit during the day and week? During your role?
- What's your emotional limit during the day and week? During your role?

When we set limits, we live life on our terms. We live the life we want, not the life others think we “should.”

With limits, you give care your way.

## My Limits

## My Limits

## My Limits

## Tip for a Tough Day: Appoint a Love Substitute

As you work to stay healthy in your caregiving role, consider the five traits of well-being, as described in Positive Psychology: Hope, Gratitude, Zest, Curiosity and Giving and Receiving Love.

The first four traits of well-being build from our capacity to love and be loved. When we accept love (and help) from others, we allow them to fulfill one of their basic needs (to love).

In caregiving, you may feel you are the only one who gives to your caree. And, you will have days when giving love to your caree just seems like an impossible task. When you can't, you feel incredibly guilty or awfully resentful. UGH!

Instead of feeling guilty or resentful, appoint a love substitute.

A love substitute can be a letter written to your caree from someone your caree loves. You can ask family members to regularly write letters to your caree. During those tough moments, when your caree needs love and you need a break, share one of the letters. That's a love substitute.

Take advantage of the times you do feel the love by writing a letter to your caree that expresses that love; this letter becomes a love substitute. When you feel empty and your caree needs to feel full, you can share your letter. "Here's something I wrote the other day," you can say, "I'd love to read it to you."

Love substitutes also may be a pet, a phone call from a family member, a DVD of a family member's wedding, a comforting photograph or a favorite song. It's okay sometimes that it's not you. Stock up with a stable of love substitutes for your caree. Knowing your caree can receive love from several sources—not just you—can help you feel like you have room to breath and time to feel that you also are loved.

## “Either/Or” Can Become “And”

In caregiving, the world can seem to consist of “either...or.” The world, then, might become these thoughts:

- Either I put my needs second or my caree doesn’t have his needs met.
- Either I stay with my caree constantly or bad things will happen.
- Either I put my life on hold or my caree will not have what he needs when he needs it.

Thinking these statements is much different than reading them. When you think them, they may seem to make sense. Because you worry about your caree and because you understand your caree’s complicated care needs, it’s easy to understand why these thoughts seem to make sense.

But, when you speak them, they seem insane. With these thoughts, you put qualifiers on caregiving, that all hangs on you; you control the outcomes, the results. Oh, my, that’s a heavy burden to bear. And, truly, how much of a disease process can you really control?

Not much.

Consider how you can move from “either...or” to “and.” With “and” in the mix, your thoughts may be like this:

- I can take time for myself to pursue my own interests and my caree will be okay.
- I can make myself a priority and my caree’s care needs will be met.
- I can set boundaries in my relationship with my caree and we both will better because of it.

These statements, when both thought and spoken, sound loving, kind and respectful—thoughts deserving of you. It is possible to have both—times when you become the priority and your caree still receives quality care.

Do you get caught in the “either...or” mindset? How can you move toward adding “and?” Write your “ands” on the next page.

My “Ands”

# As Caregiving Rules, Re-Write the Rules

What rules you? Consider the following thoughts which may rule you:

- “My caree has more pressing needs than I, so my self-care must take a back seat to my caree’s.”
- “I’ll take care of myself if I have the time.”
- “I have too much to do to think about myself.”

You can see how these rules can limit as well as harm. Consider creating new rules that reflect the importance of self-care, such as:

- “I provide the best care I can to my caree. During the day, I devote as much time as I can to activities and relationships important to me.”
- “I balance caring for my caree with caring for myself.”

More rules which may keep you less than you:

- “A good daughter would stay home in her mother's time of need.”
- “You are responsible for my happiness.”
- “So many depend on me—I must stay strong.”
- “My caree is seriously ill; my attitude and behavior must reflect the serious nature of this situation.”

You can re-write those rules with these:

- “I am a good daughter.”
- “I am responsible for my own happiness and for decisions related to my happiness.”
- “I stay strong by giving and receiving in equal amounts as much as possible.”
- “I can see how precious life is, so now I'm the first to share a laugh and enjoy a good time.”

These rules will change as you and your caree change. For instance, when your caree is terminal, you probably can't imagine spending time away from your caree. This priority (time together) becomes one of your caregiving values. You know that time may be limited so it's critical you spend the time you have together.

In this situation, a rule may be:

- “I take care of myself because I want to be in good health so I can enjoy every moment I have with my husband.”



You hear this all the time: You must take care of yourself. It's true, but it's also true that how you take care of yourself must align with your current caregiving values. And, as your caregiving role changes, so will your caregiving values. For instance, when you first begin to help your caree, you may value the time you have away from your caree. In this case, your self-care rule may be:

- "I help my caree every evening. When I'm not helping my caree, I focus on my own relationships, needs and goals."

During an intense caregiving period (when your caree has the flu, for instance, or is recovering from a set-back), you may value the home health aide you've hired. Your rule may be:

- "Because of the pressure I feel in my caregiving role, I am taking breaks while the home health aide cares for my caree. My breaks are important to my endurance, so I will schedule the home health aide for three days a week for four hours at a time."

And, during those times when you feel trapped by caregiving, your self-care rule may be:

- "I have formed a team who can provide what my caree needs in order to be safe and cared for. Because of the team, I can take regular time away from my caregiving role. I cherish these breaks and know they are good for me and for my caree."

When your caree is experiencing heightened anxiety, your rule may be:

- "It's important for me to be available to my caree in order to relieve his anxiety. I will plan my breaks to write in my journal and listen to my favorite music when my caree naps and sleeps."

Your self-care rules work in tandem with your caregiving mission statement. And, your rules and your mission statement are yours to create. They are individualized just for you.

Take some time to write your self-care rule, which reflects what you value right now.

## My Self-Care Rules

# Holding Effective Family Meetings

Hold a family meeting when:

- Caregiving begins and one individual takes on the role of primary family caregiver;
- Your caree experiences a change in condition, including a hospitalization;
- You and other family members have differing opinions about a care plan or course of treatment;
- End-of-life care must be decided.

Create “Rules of Engagement” for your meetings; these rules hold everyone accountable for expected behaviors. The rules may be:

- Only one person speaks at a time;
- Everyone has an opportunity to be heard;
- An agenda, complete with time restraints, accompanies every meeting;
- The agenda is limited to the Top 3, but no more than the Top 5, priorities;
- Meetings end with consensus on action items;
- Agree to disagree.

Let this question guide your discussions and decisions: What’s best for our caree?

When your family is ready to make a decision, you can use a tool called Fist-to-Five Consensus Building to gauge support for or against the action or plan. It’s a terrific, objective vehicle to express opinions while taking steps to resolve any outstanding concerns.

When making a decision or finalizing a plan, ask meeting participants to vote by showing a fist or a number of fingers that corresponds to their opinion.

## **Fist**

A “No” vote, which will block consensus. A fist says “I need to talk more on the proposal and require changes for it to pass.”

## **1 Finger**

One fingers says, “I still need to discuss certain issues and suggest changes that should be made.”

**2 Fingers**

“I am more comfortable with the proposal but would like to discuss some minor issues.”

**3 Fingers**

“I’m not in total agreement but feel comfortable to let this decision or a proposal pass without further discussion.”

**4 Fingers**

“I think it’s a good idea/decision and will work for it.”

**5 Fingers**

“It’s a great idea and I will be one of the leaders in implementing it.”

Anyone holding up fewer than three fingers should discuss their objections. The group then works to address these concerns. As you modify and adapt the plans and decisions, then continue to vote until you reach consensus (each individual votes with three fingers or higher) or you decide to move on to the next issue.

Source: Fletcher, A. (2002). *FireStarter Youth Power Curriculum: Participant Guidebook*. Olympia, WA: Freechild Project.

# Your Contingency Plan

*What if I'm sick? Who will take care of my caree?*

*What if I need to help my daughter and her new baby? Who will take care of my caree?*

*What if I need to go back to work? Who will take care of my caree?*

These questions, which can seem to plague, actually are helpful--they propel you to create your contingency plan.

Here's how to create your plan:

Research is your first step. If you haven't called local social services agencies and services providers (including churches and synagogues) in more than one year, then start by checking with them. Funding changes, personnel changes, goals and missions change. An agency that couldn't help in the past now may have a program that will help you.

Remember: Your goal is to gather as much information as possible. If you learn about a program that you don't think your caree will like...wipe the thought from your head! Gather information about all programs--costs, availability, qualifications, contact person. The program may not be appropriate now, but may very well be the answer to your prayers down the road.

Next, check with family and friends. In an emergency, what kind of help can they offer? Who will be the second contact in case of an emergency?

Once you've researched all available options in the community (home health agencies, adult day services, assisted living facilities, nursing homes, Meals on Wheels, volunteer programs, personal emergency responses, phone check-in services, etc.), and with your family and friends, then make a list. Include agency name, program name, program description, program details (cost, availability, etc.), agency phone number. You may also want to jot down appropriate times for these services to be used. For instance, short-term stays in nursing homes could be used when you need to take a week off.

During this process, you also can create your safety net, the net that catches when something falls. Consider:

**Financial safety net**

Who manages the finances? Who's the back-up? And, who is the check who makes sure finances are in good order?

**Day-to-day caregiving**

Who can back you up? Who can step in if you are sick? Your back-up can be family, friends, home care workers, adult day centers, Meals on Wheels, assisted living facilities, nursing homes or a combination. Does your back-up have the necessary knowledge and training to back you up? And, what's your back-up for your back-up?

**Losses**

As your caree declines, how will you compensate for the losses? When driving, meal preparation, housekeeping and other responsibilities can no longer be completed? When caregiving needs intensify? Which services, family members, providers and other options can compensate?

**You're out of commission**

The flu, unexpected responsibilities, or a sore back makes caregiving that much more difficult. What gadgets and equipment can help until you feel better?

As a family caregiver, you know that the world can change without warning. You don't want to be caught off guard and without options. Your contingency plan and safety net ensure the well-being of you and your caree just in case "What if" really happens.

# Your Bad Weather Back-Up

You watch the snow build from your office window. Or, you watch the storm clouds roll in--you know another doozy is on its way. You're supposed to stop at your mom's house on your way home from work. If you stop to help her, you wonder how you'll ever make it home. If you don't stop to help her...

When bad weather comes between you and your caree, consider these quick tips:

1. **Check with your caree's physician and specialists for suggestions** on how to ensure your caree is safe during weather emergencies.
2. If your caree receives care from a home health aide hired by a home care agency, **check with the agency's director to determine its protocol during snowstorms**. If an aide can't make it to work, will another be assigned? What other options are available?
3. If your caree relies on important regular treatments (dialysis, chemotherapy, wound care, oxygen delivery), **work with the service provider to create a safe back-up plan**.
4. If you've hired a home care worker privately, **be sure to create a back-up plan if the home care worker must cancel because of weather conditions**. (Use this back-up plan year-round, if your home care worker becomes ill, quits, or just doesn't work out.)
5. If you have family in the area and they regularly help, **create a "tag team" system that you can use during a weather emergency**. Determine which family member will stop at your caree's home, which family member is the back-up and how communication between the "tag team" will occur.
6. **Keep extra caregiving supplies** (incontinence supplies, over-the-counter medications, medications, canned goods, frozen meals) and extra boredom-fighting supplies (books, videos, puzzles, crossword puzzles, stationery) on hand at your caree's house and at your house, just in case.

7. **Create a space in your caree's house for your own personal supplies** (a change of clothes, toiletries, medications) that you may need in case you must spend the night.
8. **Use online services to order medications and food for delivery** to your caree's home.
9. **Check with your caree's town and county about assistance they offer to homebound frail older adults during weather emergencies.** You can call the ElderCare Locator at 1-800-677-1116 for a referral to the Area Agency on Aging in your caree's community.
10. **Ask neighbors of your caree if they can pitch in by stopping to check on your caree.** Let them know how they can reach you in case of an emergency. Be sure someone you trust who lives near your caree's home has an extra set of keys.
11. **Hire teen-agers in your caree's neighborhood to shovel.**
12. If your caree lives in a rural area or has a long walk to the mailbox, **check with the local post office to ensure that mail delivery occurs at your caree's front door.**
13. If you work, **check with your employer's Work/Life benefit and Human Resources department to learn about your options** if you must miss work to stay home with your caree.
14. **Check with current services that you use** (adult day centers, Meals on Wheels, volunteer programs, phone check-in programs, senior centers) and ask about their protocol during a weather emergency. Ask for their suggestions to fill any voids in care.



## My Back-Up Plans

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## My Back-Up Plans

# Time Out! Signs You Need a Vacation

Home bound for too long? We've developed the Top 10 (plus one) Signs You Need a Vacation:

1. You set up your lounge chair---accessorized by a hand-held fan, reading material and water bottle---in your caree's bedroom;
2. You form a line, just like they do at Disney World;
3. You become a tourist in your own home, asking for directions to the nearest bathroom;
4. You write postcards from your dining room table to your friends;
5. You wear flip flops that feature a large plastic flower on top of your big toe;
6. Your sun visor remains perched on your head all day long; your fanny pack, clipped to your waist;
7. Your sunglasses and sunscreen go on each morning, even though you never set foot out of the front (or back) door;
8. You regularly refer to a map, any map;
9. You ask your spouse for good restaurant suggestions—something that's within walking distance of your hotel;
10. Your swimming goggles become your new every-day jewelry, dangling from around your neck;
11. (The "Plus One") You photograph your caree throughout the day, encouraging smiles and "Cheese's" during meals and "Jeopardy"; you click snapshots of your caree with the home health aide.

You know that you're in need of a break, but you can't help but think, How? When? We've got some quick fixes for you:

1. Go somewhere in your area you've never been, such as a park, nature preserve or museum;
2. Start planning a trip that you'll take in the future;
3. Cook something different or unusual for dinner (even better--order in something unusual or different);
4. Do something special to end your day, such as enjoy a cold drink outside while listening to your favorite music;
5. Visit your community's local pool;
6. Take advantage of a nearby outdoor festival, even for a few hours;
7. Read a great book;
8. Watch a wonderful movie;
9. Write a letter to a good friend;
10. Daydream, traveling to a favorite destination.

Your vacation will come!

# Ask Denise: How Do I Train My Replacement?

Dear Denise,

Finally, I'm going on vacation! I'll be gone for two weeks in September. My sister will stay at the house and take care of my mom.

Here's my problem: How in the world do I tell my sister what I do every day to take care of my mom?

Hello,

Good for you! It's wonderful you'll be able to take a well-deserved vacation. Because you do so much, it can seem daunting to communicate so much, not only about what you do, but what your caree likes, dislikes, tolerates, can't tolerate. It's also hard to explain how you know how to manage your caree on a bad day--because it seems that you just know.

Some suggestions:

- I encourage family caregivers to keep two journals: One for their eyes only, about their experiences; the other, about their carees and their medical conditions. If you don't already keep journals, now's a good time to start. In particular, a journal about your caree will really be handy for your sister. In this second journal, document your caree's day: Meals, disagreements, hands-on care, challenges, moods, activities, and conversations. A good time to update this journal during the day is after every meal and after personal care (morning and night). Your sister can read your journal entries well before she takes over; she'll have time to ask questions or clarify information.
- Create a calendar that reflects your day's routine: Bedtimes, medications, naps, meals, etc.
- Have your sister shadow you for a period of three days. Do this about two or three weeks before you're set to leave.
- A week or so after the shadowing, have your sister stay with you and your mom for a weekend. This time, though, she is the primary

family caregiver. Schedule activities for yourself outside the house (and alone) so your mom and sister can start to develop their own routine. You'll be close by, though, in case of an emergency.

- Allow your sister to ask any "What if" questions she can think of--no matter how crazy or unrealistic they may be. One question I like to ask when I start a new job is: What's the worst mistake I can make? Or, What's the worst that can happen? If I know the worst that can happen and have some solutions--just in case--then I know I'll be okay.
- Develop a back-up plan for your sister so that she'll have options if she becomes ill or encounters other emergencies.
- Be open to mistakes--from both of you. You always can re-group and move on. Keep your sense of humor and perspective and you'll be okay.
- Agree on your communication timetable while you're gone. Will you check in every day at a certain time? Will your sister call you every evening? What constitutes an emergency or a crisis and triggers a phone call to you? Meaning, how much do you want to know while you're gone?
- You can check with your local Area Agency on Aging and Red Cross to see if the agencies have any upcoming training classes for family caregivers. Additional training for your sister would be great.

The goal is increase everyone's comfort level so that all three of you feel okay during your vacation. You also want to allow your sister and your mom the freedom to develop their own routines and habits. If it's different than how you would do it, that's okay!

Have fun!

# Ten Tips to Beat the After-Break Break-Up

Ahh... you got a break.

Maybe it was just for one day or for a weekend or maybe even for a week. And, on your break, you did just what you wanted.

It was heaven.

Then, it ended.

Now, you're in the anti-heaven.

You have to go back. You must go back. You want to want to go back. But, honestly, all you want is a break up. You want to break up with Caregiving.

How do you end the break without a break-up? Some tips:

**1. Everyone needs a goal or a reward or a possibility to look forward to, especially family caregivers.** Once you go back, what can you look forward to next? When can you take your next short and extended breaks?

**2. Express your dread about going back to an empathetic, non-judgmental ear (your support group, your best friend, your journal).** It's okay you don't want to go back. It's understandable. Expressing yourself may release some of its hold on you.

**3. Energize your environment.** Paint your favorite room your favorite color. Add an area to your room for a hobby. Create your sanctuary. Reconfigure your furniture. Changing how your environment looks may help change how you feel.

**4. Mix it up.** Order dinner in on a Wednesday rather than on Friday. Rent a movie to watch on a Monday. Take a car drive with your caree on Tuesday rather than Sunday. Do something different on a regular basis.

**5. Keep the photos you took during your break handy.** Review, reminisce, relax. Know you'll have a chance for another break.



**6. Take a deep look at what's causing your dread.** Are certain tasks becoming too much for you? Does your relationship with your caree make you feel like a door mat? Are you worried about the reality that will greet you? Use your introspection to find more help, set new boundaries, increase the support you need. Dread can be a signal that you'd like something to change. Find it and then work to change it.

**7. What did you love about your break that you'll miss in your caregiving role?** Will you miss the naps? The leisurely pace? Being off-call? Whatever you missed: How can you add a little bit of that into your routine?

**8. Are you ready for a transition?** Your dread may be a signal that you're ready for a transition in your role. Research and consider your options. Maybe you won't be ready for the transition for another six months—that's okay because it may take six months for the transition to work.

**9. Feel it.** However you feel, feel it. Feel without resentment or guilt. You are entitled to your feelings. If your feelings frighten or sadden you, seek help.

**10. Bank it.** Save something every week, even if only a buck. Having your own savings plan means you can plan for your future.

Finally, this too shall pass. It will.

## My Caree Won't Cooperate!

You've finally decided the time has come: You need help in your caregiving role; you'd like to hire a home health aide to help with your caree's personal care. With your job, your kids, your spouse and your other commitments, you've discovered it's just impossible to do it all yourself. Amazingly, it's a relief to come to this decision.

Until you think about breaking the news to your caree. You know the news won't be welcomed with open arms—and neither will the home care worker. Worrying about the tussle between you and your caree about getting help can cause you to re-think your decision to get help. It's tempting to give in to guilt, but in the long run, you'll jeopardize your caree's health and safety without the help.

If a caree refuses help in the house, work to get a commitment to use in-home care on a trial basis. For instance, when your caree says: "I will not have strangers in my house!," you might try this approach:

"Mom, I can understand your concerns about strangers in the house. I think you're wise to be skeptical that this will work. But, I also worry about you and want you to be safe at home. So, what if we try this? Let's try using a home health aide for a month. I'll be with you the first few times the aide comes. We'll have her come three days a week for four hours. I'll make sure you have a notebook and pen so you can jot down notes about the aide and how it's working out. I'll still call you every day, but we'll set aside Saturday mornings just to discuss the aide. So, I'll stop by to have coffee with you and we'll go over your notes. What do you say? Can we try this for a month and see how this works?"

It's important to get a commitment on a trial basis because often it's the springboard to a permanent commitment. And, if you take time to listen to your caree's complaints, you may be able to nip small problems before they become huge problems (and huge barriers to a permanent commitment). If, when you have your Saturday morning meeting, your caree shares complaints that concern you, you can contact the home care agency immediately on Monday morning to resolve them.

When introducing the idea of in-home (or any new service) to your caree, keep in mind these tips:

**1. Listen for the meaning behind the words.** Is your caree angry, sad, depressed? Love and fear are our two motivating emotions; most times, we act out of love or fear. It's easy to see actions from love. Actions from fear are trickier, though, because the fear can manifest itself in anger or guilt. And, those are very difficult emotions to deal with.

**2. Once you've understood the message, then acknowledge your caree's feelings.** An acknowledgment can sound like this: "It's absolutely understandable why you would so angry and upset, Mom. How can I help?" Acknowledging means you've heard your caree and that's a great way to bridge communication. We all want to be heard.

**3. Involve a third-party, a trusted professional or family friend, who can help mediate discussions with your caree.** Physicians, lawyers and ministers or rabbis often can help smooth rough waters with your caree. And, bad news is often best delivered from a third-party, rather than from you.

**4. You may feel that you wear a t-shirt with a bulls-eye, at which your caree is constantly taking aim.** Take off the t-shirt! If discussions become verbally abusive, end the phone conversation, walk away, take a walk, escape to your room. Remember that the disease and illness (and sometimes the caree's disposition and circumstances) are to blame—not you.

**5. Give back some control.** Be sure your caree has some control (when appropriate) over the decisions about care.

**6. Show gratitude with words and action.** Give your caree a hug and say, "Thank you for being such a trooper. It's great to be on the same team with you. Who knows what we can do together?" Positive words often create positive actions.

**7. We all adjust to changes at our own pace.** Your caree may need more time to adjust than you. That's okay. Take one step a time.

**8. Bad moments during the adjustment are just that—bad moments.** Don't give the bad moments the power to become bad weeks and months. And, when your caree has bad moments, love him or her through them, as Dr. Phil would say.

**9. Be flexible in the strategies you use to help your caree with the transition.** Some will work, some won't. If a strategy doesn't work, try something else. Think outside the box. Ask others for suggestions and ideas. Focus on your efforts, rather than on trying to control an outcome you think is right. When you keep your attention on your efforts, you control what can be controlled—you. Trying to control an outcome, which is trying to control your caree, will only frustrate and exhaust you.

**10. Take breaks from the situation.** Breaks will refresh you and provide you with different perspectives. During a difficult transition, you may feel like spending time with your caree is like sitting in front of the TV watching a barrage of bad news. When you take a break, you take a break from the bad news. You give yourself a chance to see the good news, to see what's working and to regain a confident footing.

Finally, have a back-up plan in place. If your caree won't accept help, still contact home health agencies, adult day centers and facilities in your caree's community. Meet with the staff to learn about services and programs so you'll know which ones will best meet you and your caree's needs. If an emergency happens, you'll know which organizations will help. And, when your caree is ready to accept help, you'll be ready with the right organization.

To find a home health agency in your area:

1. Call the ElderCare Locator at 1-800-677-1116; you'll be referred to your local Area Agency on Aging, which can tell you about local home care agencies.
2. The National Private Duty Association consists of home care agencies throughout the country. To find a member in your area, visit the association's web site at [www.privatedutyhomecare.org/](http://www.privatedutyhomecare.org/).

## Quiz: Are You On Overload?

Well, sure, of course, you are. You're worried, worn-out, weathered. You may also be way over your limit in terms of what you're doing. Take our quick quiz to find out how much you are over on your load.

**1. It's the fifth time you must take your caree to the doctor this month. You're not sure how you're going to manage to pick up your caree, get to the doctor, take your caree home—and all during your lunch hour from work.**

a. You ask your sister to take the day off and accompany your mom. You call your sister five times the night before and six times the morning of the appointment to make sure she'll remember to pick up your mom. By 11 a.m., you're so exhausted from worrying you fall asleep in your cube and wake up three hours later—but only because your boss is shaking you, hard, by the shoulders.

b. You run out of the office at 11:30, drive home, get your caree, arrive at the doctor's office, wait, accompany your caree into the appointment (but forget to ask your questions because you're too busy watching the clock), schedule a follow-up appointment with the nurse on your way out, then breathe a sigh of relief as you realize you'll just make it back to the office on time after dropping off your caree at home. "That wasn't too bad," you turn and say to your caree. Horror fills you: The passenger in your car has white hair but that isn't your caree!

c. You call the home care agency and arrange for a home health aide to bring your caree. You call the doctor's office, find out if the doctor is running behind schedule (surprise!, he is), explain to the office nurse that a home health aide will be accompanying your mother today, and then schedule a time tomorrow to speak with the doctor about the appointment. You then call home and update the aide on the status of the appointment.

**2. Your out-of-town brother calls and says: "I took a week off work to come stay with Grandpa so you can get away." After you pick yourself up from the floor:**

a. You book a hotel room five minutes from home. You know your brother will need your help.

- b. You tell him: “I don’t need a week off. Thanks, but that’s not necessary.”
- c. Spend one day acclimating your brother to your caree’s needs and routines. Then, you hit the highway: You’ve been dreaming (and planning) about such a road trip for months.

**3. A good friend invites you to dinner and a movie (his treat). During the movie (the one you’ve been dying to see):**

- a. You excuse yourself every 20 minutes to call home and make sure all is okay with your caree.
- b. You sleep. You snore so loudly you wake yourself up.
- c. You enjoy. Afterward, you invite your friend out for dessert—your treat.

**4. You invite your caree’s best friend, Pat, for dinner.**

- a. You worry so much about how Pat will react to your caree’s change in condition that you hover over the two of them, so much so that Pat finally loudly whispers to your caree, “How do you get any privacy around here?”
- b. You serve your caree’s pureed meal to your caree—and Pat. You don’t realize this until you clear the dishes.
- c. Make a simple meal and then excuse yourself; you’ve rented a good movie to enjoy while your caree is occupied.

**How did you do?**

**Mostly A’s:** You’re nearing an overload. It’s okay to trust that others can care for your caree. It won’t be your same loving care, but it will be okay. And, you’ll be okay, too.

**Mostly B’s:** You’re on overload! Stop—whatever you’re doing. Sit, rest and let yourself off the hook. You’re not meant to be perfect. You’re only meant to do your best—and you are. Remember: You can plan, but you can’t control. Put your plans in place: What happens while you take time for yourself is beyond your control; let it go.

**Mostly C’s:** Hurray, you’re in good shape. Stay in shape by taking advantage of any and all opportunities to share the load.

# 10 Steps to a New Beginning

When you hit the pillow at 10 p.m. last night, you thought: I hope tomorrow will be better.

But, tonight, at 12:30 a.m., you think: This starting over every day is just killing me.

The constant of caregiving is change. With change, comes its sister: Starting Over. Every day, you may feel like you're starting over. You start over with different services as your caree's health declines, as help burns-out and disappears, as your caree's abilities lessen, as your patience wears thin, as funding for the programs you use dries up. Just when you feel like you've made progress, a change causes you to start over. It's like yesterday's accomplishments and successes were simply a dream.

So, how can you stay positive when starting over drains you faster than a family member's insensitivity? We've got 10 suggestions:

**1. Start your day with a routine that refreshes.** Several of the family caregivers who visit Caregiving.com say they start days with time for reflection. Other family caregivers start their day with a few moments to journal. Others start their day with prayer or meditation or devotion. Create a ritual that's just right for you, that helps you find and keep your perspective.

**2. Live in the present.** Fretting about the past and worrying about the future takes you out of what you can control: Today. Take one day at a time, focusing on today's needs, planting seeds for tomorrow's.

**3. Express frustrations to a comforting support system.** Caregiving can be so lonely, but it's awful when you feel you must go it alone. Vent to a comforting support system that neither judges or "should's" you. Let it out so you let it go.

**4. Really and truly embrace forgiveness.** We know it as the best gift we can give ourselves. Sounds cliché, but it's true. Most important, forgive yourself.

- 5. Take a daily temperature of your situation by asking these two questions:** Do I have what I need? Does my caree have what he or she needs? Then, take action.
- 6. End the day by listing three gratitudes.** Count your blessings because that's how your blessings count. And, when you keep track, you keep building the blessings.
- 7. Practice your faith, whatever your faith may be.** Faith in a Higher Power who has called you to a Greater Good adds meaning to an experience that spurs more questions than answers.
- 8. Enjoy the humor in the day.** It's funny. When it is, laugh. When you laugh, you show appreciation for an incredible gift we're given: A sense of humor. Exercise it.
- 9. Keep in mind: This too shall pass.** Oh, boy, it can seem like loss and darkness has settled in your home permanently. They may overstay their welcome, but they will be replaced by growth and light. They will.
- 10. Believe in yourself.** It keeps everyone else believing. And, on those days when you just can't believe all that's happened or believe in your ability to manage it, keep the faith. It keeps you.



# When Accept, You Gain

Caregiving is a journey of acceptance.

Think about the first thing you accepted in your caregiving role: A diagnosis.

The diagnosis led to worries. “Do I have enough?” you may have thought. It's a worry that stays: You worry if you'll have enough money, help, resources, information and support. You worry if you'll know what to do and how to do it.

You worry about life without your caree and how you'll manage.

Then, once the diagnosis sinks in, you begin to see the bigger picture, which leads to more worries about what you'll lose: Freedom. Money. Opportunities. Travel. Friends. Fun.

And, then resistance arrives. “I like how my life is,” you may think. “I don't want anything to change.”

As you worry and resist, time marches on, leaving you in the past.

Then, you become really attached to all the drama created from worrying and resisting, like:

- Self pity;
- Excuses not to do;
- Excuses not to handle.

Oh, that drama can deceive, leading you to believe the self-pity and excuses are reasonable. Worse than deceiving, the drama can lead to the the village of martyrdom. The drama tricks you into sacrificing too much (of your life, of yourself) until you feel absolutely empty.

And, still you resist. Because if you accept what life has become, you feel you will lose. You may lose:

- an expectation of your future;
- a reason to be upset;
- a protective shield;

- the right to be right;
- the way it was yesterday;
- an opportunity to judge;
- the sympathy from others;
- your own self-pity;
- the good life you share with your caree.

You may think: “If I accept this diagnosis, then I may lose the love I share with my caree.”

Or:

“If I accept my siblings' limitations, then I may lose the opportunity to sit in judgement (and feel superior).”

Or:

“If I accept more help, then I may lose my significance.”

So, you hold on, believing any other action will be a loss.

The best way to manage a loss, like the ones that come with caregiving, is through acceptance. With acceptance, you gain:

- Peace. The internal battle ends. All that resisting and worry takes its toll.
- Plan. You can now plan your days.
- Preparation. You can now prepare for what's to come. You'll be ready.
- Priorities. You now wisely choose how to spend your time.
- Perspective. You no longer take it personally. You move from asking “Why me?” to “Okay, it's me. What's my next step?”.
- Prosperity. You have energy, time, resources and love.

Most important, with acceptance, you gain today. Your life (and your life with your caree) is in the today. With acceptance, you live in today, for today.

How great is that.

# Resilience: Bounce Back from Bad Days

Sarah has had a rough day. Even rougher than yesterday--and she thought a day couldn't get worse than that one.

Her father has been with her for three years. He's living on borrowed time, at 88-years-old he's suffered three strokes and was recently diagnosed with terminal colon cancer. She knows that he won't be with her for much longer and tries to draw strength from that. She can be with him now, she thinks, because this is the last time they will be together.

If only her sister would help her more! Her sister seems to be someone new, someone she's never met before. Her sister used to be such a caring person, always available to lend a helping hand, to listen with an open heart. But, these last few weeks... Her sister can only be described as, well, awful.

And, yesterday, her husband was rushed to the emergency room from work. A slight heart attack. Scared them both to death. He's home now and expected to recover, as long as he makes changes in his lifestyle. On Tuesday, he was a strong, virile man. Today, two days later, he's a baby who can't heat up his own soup.

How in the world will Sarah make it through these next few weeks, with her husband home recovering from a heart attack and her father in the spare bedroom dying of cancer and her sister, well, angry at the world? Sarah stares at the television, at the Oprah show, which usually cheers her up. She's too spent to cry. How am I going to do this? How am I going to survive this?

Ah! Resilience is a caregiver's secret weapon. It's what will get Sarah up the next day. It's what will keep her going. Every caregiver knows the feeling of those low points. And, we know we somehow wake up the next day, get out of bed, and face it again. We don't know any other way.

Staying resilient also means staying healthy. And, when you're a caregiver, your mental and physical wellness may sometimes be jeopardized. If you don't feel good about one area of your life (especially an area such as caregiving), how you feel about the remaining areas (your job, your marriage, your children, your friendships) may be at risk. Keeping your

caregiving role in check is imperative so that when life's darts get thrown, you're in shape to handle the hits.

Some reminders to maintain your wellness as a family caregiver:

**1. Welcome help.** You're probably the best caregiver in your family--but you're not the only one. Your spouse can read to your caree on a Saturday afternoon so you can get out with friends. Your siblings can provide financial support so you can hire home health aides--and give yourself a regular break from laundry, cooking and cleaning. Your adult children can spend an evening with your caree so you can enjoy dinner and a show. Your out-of-town relatives can telephone your caree regularly so you're not the only one providing social interaction with your caree. And, ask for help--don't wait for others to offer. You'll wait forever.

**2. Define your caregiving role--don't let it define you.** Enjoy activities on a regular basis that remind you of you--your interests, your ideas, your opinions and your values. And, make adjustments in your caregiving duties that allows time for those activities--daily, weekly, semi-monthly--whatever you can manage.

**3. Make sure caregiving in some way affects your life in a positive way.** Reap some benefits, rather than just making sacrifices. Has caregiving taught you about the positive power of giving? Have you gained an understanding about your caree that you never had before? Have you learned about patience and virtue? Have you learned how strong and successful you can be--no matter what the obstacles or stresses?

**4. Seek a support system--and nourish it.** Does a relative, friend or caregiving acquaintance support and validate your efforts? Everyone needs a empathetic ear and sympathetic shoulder--especially caregivers. In turn, be supportive to other caregivers. Our online support groups at Caregiving.com offer both support and comfort. In addition, our family caregivers who blog on Caregiving.com tell us the process of writing and releasing their worries and anxieties is very cathartic. You can start your own blog on a variety of websites, including Caregiving.com.

**5. Make sure your motivation as a caregiver is honest and healthy.** For instance, in your caregiving role, are you hoping to right the wrongs of past relationships? Is that realistic? And, most important, is that healthy? Or, are you a caregiver because you understand and appreciate its importance--to

you and your family? Keep on top of your motivation--and if you find yourself slipping into the motivating ways of a martyr, pull up and re-examine your role. Is it best for you, your caree, your family? Counselors and life coaches can be a resource for you as you work to stay in a healthy place.

**6. Educate yourself about your caree's illness or disease.** Learn how to handle difficult behavior, provide hands-on care and administer treatments. Ask your caree's physician, your home care workers and organizations such as the Alzheimer's Association for suggestions and information to make you a well-informed, trained caregiver. Knowledge is the best way to minimize your frustration and uncertainty.

Resilience holds its power. The better you get at bouncing back, the easier it will be to recover from caregiving's bad days.

## Quiz: How Well Do You Bounce Back?

How well do you recover from your day-to-day challenges as a family caregiver? Take our quick test to find out.

**A. Your sister-in-law pops in for another visit—unannounced, of course. And, of course, it's on your worst day: You're still in your pajamas (splattered with oatmeal, smelling of, well, just smelling), your husband is angry and defiant (I won't go to adult day care today!) and your dog is throwing up.**

"I thought I'd drop off a plant for Frank on my way to work," she says. Before you can say another word, she's in your house and staring at her brother. And, then lashing out at you: "What have you done to him?"

You:

1. Let her have it, venting all the frustrations and anger you've held in for the past five years.
2. Take a deep breath and explain: We're having a bad day. But, I'm so glad you're here. I'd love your help. I'll just run upstairs and take a quick shower while you visit with Frank. (Before you've finished your sentence, you're calling to her from the upstairs bathroom--you don't give her a chance to refuse. You've amazed yourself at your ability to bound up the stairs in seconds. You can't remember the last time you moved so fast.)
3. You sit on the couch and cry. This is too hard!

**B. Your mother calls you, for the 20th time, at work to let you know that she can't find her purse. Yesterday, she called you, at work, 25 times to let you know she had missed her dental appointment. You're going to lose your job if this keeps up.**

You:

1. Quit your job, even though your lack of income jeopardizes your future.
2. Call your local Area Agency on Aging, local chapter of the Alzheimer's Association, your church. There's got to be a solution to this—and you're going to find it.

3. Put your phone on “Do Not Disturb.”

**C. The home health aide is late--again. You’ve spoken to her about how important her promptness is to you. But, she seems to go by a different clock than you.**

You:

1. Tell the aide you’ve changed her start time, to 9:30 a.m. You’d like her at your house at 10 a.m. You know she’ll be on time now. That’ll teach her!
2. Call her supervisor and explain the situation. What suggestions can she offer to solve the problem?
3. Do nothing—what can you do? It’s hard to find good help.

**D. The nursing home staff promised to keep track of your mother’s laundry. But yet another visit uncovers yet another problem—no matching socks. Your mother is wearing a pink sock and a yellow sock. Neither of which match her favorite purple housecoat. This makes you crazy.**

You:

1. March to the administrator’s office, bursting into a closed-door meeting. You demand to know: Why am I paying you \$4,000 a month to dress my mother like a clown?
2. Decide to do your mother’s laundry. Actually, you’ll ask your granddaughters to help.
3. Spend the rest of the visit looking for that one pink sock and that one yellow sock. Somebody’s got to be wearing them!

**What’s your score?**

**Mostly 2’s:** You’re in good shape! You face everyday challenges well, compromising when necessary, but never giving up that solutions exist. You’re resilient!

**Mostly 3’s:** You have good intentions, which will help you on your way to being resilient. But, you struggle to find the positives in situations which can

lead to effective solutions. And, you give up too easily. Work on strengthening your emotional and physical well-being.

**Mostly 1's:** You're a walking time bomb! Your anger and mistrust seem to get the best of you—and every challenging situation you encounter. Practice keeping your patience, thinking of creative and unusual solutions, and viewing a situation from all sides. Sometimes, all is not what it seems.



# Ask Denise: Is the Guilt About Esteem?

Dear Denise,

I schedule time away from my caree, but feel guilty for doing so—even though I know I want and need the time away.

I wonder: Is feeling guilty related to self-esteem?

Hello,

What a great question.

The short answer: Yes.

Let's break it down.

Here's the good about your guilt: Your ability to feel guilty shows your great capacity to feel for another. You can appreciate another's pain or sadness or loneliness; you can put yourself in another's shoes. Your caring is a good virtue.

It can become a problem, though, if you seem to care more for others than you do for yourself or if your guilt seems to get in the way of you living your life (when you can, given the constraints of caregiving).

Here's the definition of guilt:

1. the fact or state of having committed an offense, crime, violation, or wrong, esp. against moral or penal law; culpability: He admitted his guilt.
2. a feeling of responsibility or remorse for some offense, crime, wrong, etc., whether real or imagined.
3. conduct involving the commission of such crimes, wrongs, etc.: to live a life of guilt.

Consider the second definition: A feeling of responsibility or remorse for some offense, crime, wrong, etc., whether real or imagined.

Hmmm....

Let's say you're taking a break you want to take\*, you've put back-up care in place, you've provided solutions to all anticipated problems, and you've created a phone tree of persons who can be contacted in case of an emergency.

But, when you leave, you still feel guilty. What offense could you have committed?

It could be you feel guilty because you will enjoy a life outside of caregiving when your caree cannot really enjoy a life outside of a disease process (or frailty or permanent injury). Your offense, truly, may be that you are healthy enough to enjoy an activity, a vacation, an experience.

Is that really an offense worthy of that awful feeling of guilt?

So, what could keep you in a place where thoughts such as "I don't deserve to have this time away because I don't deserve to have health" live? Yep, a lack of confidence. So, when a caree says, "I don't know how you can feel good about leaving me here while you traipse around the city," you'll think, "Oh, he's right. I don't deserve this time away."

Seems kinda nutty, doesn't it?

If you come from a place of confidence, you may be able to say, "I am taking this break because I deserve time for just me. I work hard—I deserve a break." And, when your caree says, "A good daughter would stay here with her mother in her time of need," you can say, "I am a good daughter. I'll be back tonight about 10 p.m. I'll stop by your room to say 'Good Night'."

When our self-esteem takes a dip, we leave more room for others to fill it with their own baggage. When we're not feeling good about ourselves, we open the door for others to plunk down their own luggage of self-doubt in our room. Their own dirty laundry—insecurities and lack of confidence—spills over and adds to our own.

Worse: When we're low, we often allow others to dictate how we feel.

When we're full, we own our own emotions.

Believe in your own goodness. Believe that you make good decisions about your own needs and wants. It's okay if others can't be happy for you or support you. That's their choice. You choose otherwise.

\*Please note that you'll have times during your caregiving experience when others will encourage you to take a break and you know it's not the time to take a break. In this article, we're only referring to the times you've made plans to take a break and it's a break you really want.

# Ask Denise: How Do I Leave Without Guilt?

Dear Denise,

I have taken care of my mom and dad for the past almost 10 years (my dad died a year ago) and now I must relinquish that responsibility due to her inability to stay alone while I work. At her last hospitalization, she was diagnosed with an aggressive lymphoma for which, due to her heart health, aggressive treatment can not be done. I have huge guilt feelings about placement in nursing home but at the same time I know she is being well cared for. How do you walk away without the guilt when she appears fine and is extremely angry with me about where she is?

Hi,

What a rough road for you and your mom this last year. While grieving for your dad, you find out really upsetting news about your mom. And, then, because of this news, you have to make a really difficult decision. It would be nice if you could get a break with some good news.

A few thoughts for you:

It's okay that your mom is angry. It may seem she's angry with you but she's much angrier at her disease, her circumstances, her twist of fate. But, how can you be mad at something you can't see or hear or touch? It's much easier to be angry at you because you're a tangible target.

When she expresses her anger, acknowledge and empathize, but don't take it on as your own. You can say, "I understand how difficult this situation is, Mom. Given all the losses you've experienced this year, it's understandable that you feel so angry." Then, give her a few moments to vent.

After a few minutes, tell her: "I wish it were different, too. I know you're doing your best to adjust. I'm so grateful for every minute we have together. Let's talk about this weekend. How do you want to spend Saturday?"

Often times, when we're angry we just want someone to say: Given all that's happened, you deserve to feel angry. If someone tries to minimize or diminish our anger, it just adds more fuel to the anger fire.

When you leave her, simply say, “I love you, Mom. I’ll call you tomorrow and see you tomorrow night (or whatever your calling/visiting schedule will be). Thank you for all you do for me.”

I think it’s hard to leave your mom without feeling any emotion. So, when you leave, acknowledge to yourself that you leave with sadness. It is such a sad situation! Give yourself time to feel that sadness. And, find a way to let it out. Ask the nursing home social worker if the facility has a support group for family members. Talk to family members and friends. Tell us here. Write about it in a journal.

Do your best to fight the guilt. If she lived with you, you would feel guilty for leaving to go to work. If she lived in her own apartment, you would feel guilty that she lived on her own and not with you. There’s so much to feel guilty about--which is why I hope you’ll let yourself off the hook.

## Mom Promised That to Me!

When my grandmother died, she left her entire estate to her oldest son, my Uncle Con. My father, the only other child, did not receive anything.

Leaving one and excluding the other would seem to create a situation ripe with ill will and bad feelings. On the contrary, my father was in full support of his mother's decision.

My uncle had been my grandmother's primary caregiver. My parents and I helped. But, my uncle and aunt bore the brunt of my grandmother's care, even during the difficult years when my grandmother's manipulation made your head spin. (During one hospitalization, my grandmother was prescribed an anti-depressant. The result changed my grandmother and, thankfully, our relationship with her.) My grandmother had expressed her desire for Uncle Con to receive her entire estate, including possessions and assets. After her death, my uncle and father calmly settled her estate.

We were lucky. The inheritance of possessions can become a game of power that can be used to settle old scores, reinforce favorites, dredge up old family disputes. Sometimes, the greatest disputes seem to happen over who gets the good dishes rather than the bank accounts.

As the primary family caregiver for an aging relative, you'll see it all with your caree's possessions: You already may have seen a glimpse of the relatives who want the things, but don't want the responsibility of caregiving. You may find yourself asking: Why should George get so much of Mom's things when he's done so little?

What's fair when distributing a caree's possessions? And, how can you best handle discussions with your caree about how to dispense his or her personal possessions after his or her death? The following tips, adapted from *Who Gets Grandma's Yellow Pie Plate* by Marlene S. Stum, Ph.D. Family Social Science, University of Minnesota Extension Service, can help:

**1. Be clear about your own motives for raising the issue.** What are your concerns, what do you want to have happen, and why? Before beginning a discussion, you may want to use a friend as a sounding board to express any frustration toward other family members you may feel. You'll want your

discussion to focus on your caree's wishes, rather than any frustrations you may feel, no matter how just.

**2. Look for natural opportunities to talk with your caree.** For example, perhaps a friend or relative recently dealt with transferring personal possessions after a death or a move. Use that situation to introduce a discussion with your caree. Ask, "What would you have done if you were in that situation?"

**3. Keep using "what if" questions during your discussion.** For example, "Dad, what would you want to have happen with the things in the house if you and Mom were no longer able to live here?"

**4. Remember that listening is the part of communication we too often forget.** After asking questions, listen to the answer with an objective ear. And, listen for the emotions behind the words. Anger often masks fear. Express empathy toward your caree: "I know this is an upsetting topic. I'm worried we won't handle your matters as you'd like. What do you worry about?"

**5. Recognize that family members will have differing feelings and opinions.** Conversations should focus on discovering those agreements and disagreements. If the disagreements seem to cause a divide too great to overcome, consider involving a mediator or elder law attorney. An objective third-party can keep the conversation focused on the objectives, rather than on any hurt feelings.

**6. Be willing to listen and talk when another family member raises the issue.** The situation only becomes personal if you make it so.

**7. Remember: Not speaking up means others will not know your opinions or feelings.** Express your thoughts assertively and graciously.

You may find that, even with your best attempts, you have a houseful of possessions to divide after your caree's death. Keep in mind that fair division of possessions is almost impossible. But, a fair mechanism to divide the possessions can be used. Here are some ideas:

**1. Hold a raffle.** Each family member picks a number out of the hat. Each family member takes a turn selecting a possession based on the number he

or she picks. If your brother, Rick, picks the Number 1, then he selects first; your sister, Sylvia, who picks Number 2, selects next, etc.

**2. If more than one family member indicates they would like the same possession, then put the names of all interested parties in a hat.** The selected name becomes the owner of the possession.

**3. Sell all the possessions and divide the proceeds.**

**4. Take turns sharing a prized family possession;** a family treasure (family Bible, family piano, family jewelry) spends five years with each sibling before moving on to the next sibling's home.

### **Resources**

- Grandma's Yellow Pie Plate:  
[www.yellowpieplate.umn.edu/indexB.html](http://www.yellowpieplate.umn.edu/indexB.html)
- National Academy of Elder Law Attorneys: [www.naela.org](http://www.naela.org)
- “The Boomer Burden: Dealing with your parents lifetime accumulation of stuff” by Julie Hall



# End-of-Life Care: Working Within the Laws of Nature

This is hard to hear, but important to know: When caring for an aging relative, you are helping a family member die well.

The process of helping someone to die well begins early on in your caregiving journey. It begins when you first hear a diagnosis. Or, when you first notice that your mother just isn't able to keep up the house as well as she used to. Or, when you celebrate your grandmother's 95th birthday and wonder: Where did the time go?

Early on in your caregiving journey, you were proactive in your efforts—finding the best doctor, uncovering the best treatment option, and providing the best care, such as nutritious meals, helpful home health aides, appropriate social stimulation. Your efforts worked. For awhile. But, then the laws of nature took over, causing further frailty, greater declines.

Once the laws of nature became too much, you looked to achieve the status quo—holding on to what's left for as long as possible. You encouraged your mother to continue folding laundry, singing show tunes, reading the Bible.

But, then the laws of nature take over again and the status quo keeps moving down a notch. Your mom likes to watch you fold the laundry; she likes to listen to show tunes on tape but can no longer vocalize the words; she wants your husband to read from the Bible.

This is how you give a good death.

And, when the laws of nature really begin to win, you wind down, together.

You sit together, no words. You allow longer and longer periods of rest. You give in to the clock.

But, this is when you become proactive again. You're setting the stage for the last hours, putting into your motion your caree's last wishes.

You prepare your house--you keep fresh flowers, you buy your mother's favorite CD, you ask your husband to polish up his rendition of your mother's favorite tune on the piano. You prepare the relatives and friends,

inviting, encouraging visits. You prepare yourself, sharing with your caree your favorite memories, saying the words that have been left unsaid for too long. And, you prepare your caree, allowing her to gain strength for her last trip.

You celebrate life as you join forces to complete your last, and most important, work. And, you do it well, as you've done throughout your caregiving journey.

# Remember Your Future

I once attended a seminar given by Alan Seale, a leadership and transformation coach. During the workshop, Alan taught us his take on how to manifest our goals and dreams.

One tip he suggested was to “Remember the future.” Sounds like a oxymoron, doesn’t it? How can we have a memory of an event that has yet to occur?

The more I gave thought to this, the more I thought: What a cool idea. When you remember the future, you focus on the outcomes of an event or experience—how you will feel, how you will act, what you will create. Remembering the future takes you out of the present fear and worry and opens the opportunities to feel good.

In your caregiving role, you can remember the future. Remembering the future is a way of writing your caregiving story. You truly have the power to end the story your way. Some ways you may remember the future:

- “After my caregiving role ended, my siblings and I found peace with each other.”
- “When my caregiving role ended, I understood my caree so much better. Understanding my caree means I understand myself that much better. I am grateful for this opportunity to learn, grow and forgive.”
- “When my caregiving role ended, I gave myself the time I needed to regroup. During that time of healing, I took care of myself so that I could make the most of the next phase in my life. Caregiving gives clarity. I now have the focus I want to create the life I deserve.”
- “When my caregiving role ended, I knew my caree felt wrapped in love. And, I felt blessed that we both managed our experience together to the best of our abilities.”
- “When my caregiving role ended, I could find comfort in the knowing I always did the best I could. No matter what obstacle, challenge or problem, I focused on doing the best I could. And, more importantly, I forgave myself along the way.”

- “When my caregiving ended, I felt great about the strong, loving, focused person I became. While not easy, my caregiving experience helped me become the best I am today.”
- “When my caregiving role ended, I started the business I long dreamed of. Now, I am a successful business owner making a difference in the world.”
- “When my caregiving role ended, I traveled the world. It was wonderful.”
- “When my caregiving role ended, I was blessed to be in great shape. I had decided my health was a priority so to take care to eat right and exercise. Now that I’m healthy, I find myself living life at a different level.”
- “When my caregiving role ended, I missed my caree very much. I did my best every day to live a good life. I had good days and bad days. I was gentle with myself as I found my new footing. I leaned on my support system, which helped me find my way. I am now in a better place than I ever thought possible.”
- “When my caregiving role ended, I found ways to honor my caree’s memory on a regular basis. I miss my caree dearly, but am comforted by the rituals which keep loving memories close to my heart.”
- “When my caregiving role ended, I thought for sure that caregiving would get the best of me. But, it didn’t. I took the good from the experience in order to make my life better. I am surrounded by riches and blessings greater than my imagination.”

Some questions to ask yourself to bring that future closer to you:

After caregiving ends for you:

- What will be your proudest moments?
- How did you express your feelings for and about your caree?
- How did your life change for the better?
- How did your relationships change for the better?
- Which lifelong dream came true for you?

Feel it, believe it, see it. This is the vision to reflect on during your dark moments. Remembering your future brings comfort to you today.

## How Do You Remember Your Future?

# Your Resources

American Association of Homes and Services for the Aged:  
202-783-2242 or [www.aahsa.org](http://www.aahsa.org)

Assisted Living Federation of America:  
703-894-1805 or [www.alfa.org](http://www.alfa.org)

Benefits CheckUp (you can search to learn about services that may help):  
[www.benefitscheckup.org](http://www.benefitscheckup.org)

ElderCare Locator (will refer to you local Area Agencies on Aging):  
800-677-1116

Five Wishes (a wonderful handbook to document end-of-life care wishes):  
[www.agingwithdignity.org](http://www.agingwithdignity.org)

Financial Planning Association:  
800-322-4237 or [www.fpanet.org/](http://www.fpanet.org/)

Medicaid:  
[www.cms.hhs.gov/home/medicaid.asp](http://www.cms.hhs.gov/home/medicaid.asp)

Medicare:  
1-800-MEDICARE (1-800-633-4227) or [www.medicare.gov](http://www.medicare.gov)

National Academy of ElderLaw Attorneys:  
520-881-4005 or [www.naela.org](http://www.naela.org)

National Adult Day Services Association:  
877-745-1440 or [www.nadsa.org](http://www.nadsa.org)

National Family Caregivers Association:  
800-896-3650 or [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

National Library of Medicine (terrific research resource):  
[www.nlm.nih.gov/](http://www.nlm.nih.gov/)

National Association for Home Care and Hospice:  
202-547-7424 or [www.nahc.org](http://www.nahc.org)

National Association of Geriatric Care Managers (you can hire a GCM to find resources, develop care plans, complete an assessment of your aging relative):

520-881-8008 or [www.caremanager.org](http://www.caremanager.org)

National Association of Senior Move Managers:

877-606-2766 or [www.nasmm.org](http://www.nasmm.org)

National Center on Senior Transportation (works to increase transportation options for older adults and enhance their ability to live more independently within their communities)

[www.seniortransportation.easterseals.com](http://www.seniortransportation.easterseals.com)

Next Step in Care website (the website offers a range of guides and checklists—most intended for family caregivers of persons with serious illness, with some specifically for health care providers—designed to make patients' transitions between care settings smoother and safer)

[www.nextstepincare.org](http://www.nextstepincare.org).

Social Security Administration:

[www.ssa.gov](http://www.ssa.gov) or 1-800-772-1213

U.S. Administration of Aging:

[www.aoa.gov](http://www.aoa.gov)

U.S. Department of Veterans Affairs Caregiver Support:

[www.caregiver.va.gov/](http://www.caregiver.va.gov/) or (toll-free) 1-855-260-3274



# The Caregiving Years Tip Sheet

## Your Steadies



### THE EXPECTANT CAREGIVER

*Your Challenge: To learn and understand your caree's needs: health, financial and emotional*

Your Steadies:

- ✓ Information now is power later.
- ✓ Work within your obstacles, but don't give up.
- ✓ The more clearly you see now, the better you handle the future.



### THE FRESHMAN CAREGIVER

*Your Challenge: To discover solutions that work*

Your Steadies:

- ✓ Ask for clarification from health care professionals about benefits and coverage.
- ✓ Value your caree's insights.



### THE ENTRENCHED CAREGIVER

*Your Challenge: To find the support and strength to continue*

Your Steadies:

- ✓ You are the best caregiver, but not the only one.
- ✓ Discuss your concerns, your stresses, your burdens.



### THE PRAGMATIC CAREGIVER

*Your Challenge: To gain a greater understanding of yourself and your caree*

Your Steadies:

- ✓ Let forgiveness live.
- ✓ Find common ground with your caree.
- ✓ What can you learn from your caree for your life's next phase?



### THE TRANSITIONING CAREGIVER

*Your Challenge: To walk with your caree during his last months and weeks; to begin the transition into a new life*

Your Steadies:

- ✓ Find new areas of support.
- ✓ What changes are needed to begin the next chapter?



### THE GODSPEED CAREGIVER

*Your Challenge: To integrate your former role as a caregiver into your new life*

Your Steady:

- ✓ Review your journals and diaries and then ask: How am I different today?

# The Caregiving Years Tip Sheet

## Your Six Stages

### **1 THE EXPECTANT CAREGIVER**

Your Keyword: Ask

Your Purpose: To prepare.

- x Ask questions of your caree.
- x Ask questions of health care professionals.
- x Ask questions of lawyers and financial planners.

### **2 THE FRESHMAN CAREGIVER**

Your Keyword: Find

Your Purpose: To experiment, to get your feet wet and see what works.

- x Find services that help.
- x Find support that comforts.
- x Find ways to enjoy your hobbies and interests.

### **3 THE ENTRENCHED CAREGIVER**

Your Keyword: Receive

Your Purpose: To develop a routine, create a familiar schedule for both yourself and your caree.

- x Receive help—whenever you can.
- x Receive breaks from caregiving.
- x Receive support.

### **4 THE PRAGMATIC CAREGIVER**

Your Keyword: Welcome

Your Purpose: To gain a better understanding of yourself and your caree.

- x Welcome joys of your relationship.
- x Welcome forgiveness.
- x Welcome shared activities.

### **5 THE TRANSITIONING CAREGIVER**

Your Keyword: Allow

Your Purpose: To walk with your caree during his last months and weeks.

- x Allow time to mourn.
- x Allow remembrances.
- x Allow reflections.

### **6 THE GODSPEED CAREGIVER**

Your Keyword: Treasure

Your Purpose: To implement and share your lessons learned from your role as caregiver.

- x Treasure your dreams.
- x Treasure your opportunities to share lessons learned.
- x Treasure memories of your caree.

## **Your Take-Away**

Your caregiving journey is first about your caree, then about you and your caree together, then just about you. And, when it's just about you--you decide, you choose, you become.

Become your dream.

### About the Author:



Denise M. Brown, Professional Caregiving Coach and Speaker, began working with family caregivers in 1990. She was an early developer of online support groups for family caregivers, launching her first in 1996 through her website, Caregiving.com. Through her seminars, writings, educational materials and coaching practice, Denise helps family caregivers and health care professionals find meaning in their caregiving journeys.

Denise also operates:

- SharingStore.com, a classifieds site to buy and sell caregiving supplies and equipment;
- CareGifters.org, which funds caregiving solutions;
- AfterGiving.com, which helps you after caregiving ends.

You can write to Denise at [denise@caregiving.com](mailto:denise@caregiving.com).

