

A group of four people, two men and two women, are walking away from the camera on a paved road. They are holding hands, suggesting a journey or support. The road leads towards a range of mountains under a bright blue sky with scattered white clouds. The overall mood is hopeful and supportive.

A Caregiver's Journey You Are Not Alone

Linda S. Thompson

Dedication

This book is dedicated to all caregivers, be they family members, good friends, or how they make their living. You may be a caregiver to a child, a spouse, an elderly parent, in-law or other loved one. You may be a full time caregiver, work outside the home, or a little bit of both. But each and every one of you is an angel. You are all under-appreciated, overworked, and most definitely underpaid. You are the foundation of this aging society and a lifeline to the many people who just need help. For all that you do, I thank you from the bottom of my heart.

“There isn’t a ruler, a yard stick or a measuring tape in the entire world long enough to compute the strength and capabilities inside you.”

- Paul Meyer

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Introduction

“If we could learn how to balance rest against effort, calmness against strain, quiet against turmoil, we would assure ourselves of joy in living and psychological health for life.”

- Josephine Rathbone

Several years ago, I began giving lectures and workshops on the subject of life planning and elder care. During question and answer sessions, the most frequently asked questions were about caregiver’s concerns. How do I know when Dad can no longer live alone? How can I help Mom when she lives out of state? What services are available to help me do the best I can for my loved one, but allow me to live my life as well? While my first book, *Planning for Tomorrow, Your Passport to a Confident Future*, includes some information for caregivers, the thirst for that knowledge prompted me to write this book, which specifically focuses on caregiving issues.

“Adversity will surface in every life. How we meet it makes the difference.”

- Marvin J. Ashton

The quest for information is never an easy one. Often times we don’t know who to ask, where to start; and once we find it, we discover the mountains of information too intimidating to tackle. There is certainly a lot of good informational material available in book form, on the Internet, and even through referral sources. However, the one thing I’ve found lacking is a single source that puts this information into common-sense format and makes it easy and interesting to read. It is my goal to do just that.

You will read stories from friends and business associates of mine who have contributed their own personal experiences in the world of

caregiving. You will also read about my Mother, who has so graciously shared her journey with me. You will find a lot of humor throughout, because without laughter, we caregivers could easily go off the deep end. Humor is our saving grace. You've got to laugh, because sometimes if you don't laugh, you'll cry. You have to let go of the stress, and humor is the best stress relief I've found.

Parts of this book will address some not-so-easy material to read, such as the final stages of life. Other parts will talk about how to handle guilt and just do the best you can with what you have. You will learn to take care of you, because if the caregiver needs care, you are in crisis mode, and no one can live in that state for long. Practical advice and common sense approaches to difficult circumstances have been inserted throughout.

Fran's Story

In 1994, my Mother was living in Denver, CO and I had recently relocated to Phoenix. I invited her to spend the winter with me and she fell in love with the idea of planting a garden in November. We kicked around the idea of her relocating to the desert and buying a home together. Although nothing was settled, it was obvious that she was giving it serious consideration. She was 79 at the time and still managing my sister's quilt shop in a Denver suburb. She returned to Denver in March and about a month later she called. "Were you serious about me coming to live in Phoenix?" she asked. After a brief hesitation, I said, "Sure. Why do you ask?" Her reply was, "We're having one of our typical spring blizzards and I'm just sick and tired of winter. Start looking for a house."

To make a long story short, within 90 days we had decided to build a new home, she had sold her condo, packed up all her worldly goods and was living with me in a two-bedroom apartment while our new home was being built. This lady doesn't let any grass grow under her feet.! Ten days before Thanksgiving that year, we moved into our new home and she immediately went to work in the yard. She planted

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grass, bushes, a couple of trees, and set aside a good part of the back yard for her gardens, both vegetable and flower.

At that time, it had been 25 years since we had shared a home, and about 15 since we'd lived in the same city. A recipe for disaster, you say? Not at all. We had many brutally honest discussions over that winter, and before she made the move. The main focus went something like this: You are my mother, I am your daughter, but I am no longer your child. If you can accept this, things will go well; if you cannot, it won't work. Yes, there was a lot of give and take on both sides. Yes, the adjustment was uncomfortable at times, but we muddled through and ended up best friends.

As time passed, she volunteered at the local elementary school helping children learn to read. She was a volunteer at the public library for a while. She was able to drive, learned the area, went shopping, and while I held a full time job, she accepted the job of keeping up the house. That was for the first 6 years or so. Gradually, she began to slow down. The gardens got smaller, the house was no longer pristine, and she began to tire during the middle of the day. This was not an easy adjustment for her. She began to have mobility problems; her balance was off and she began using a rollator walker. With this marvelous invention, she could still walk her half mile every day, but it was no longer as easy to accomplish. Her eyesight began deteriorating and her hearing was bad.

Little by little, I took on more and more of the household responsibilities. She stopped driving, although her car was in the garage. Her walks got shorter, and her energy level decreased. She was not happy about these changes. She'd always been a very active, independent lady who absolutely refused to let anyone do anything for her. No longer. I became the primary cook, we hired a housekeeper, and the yard got a new layer of granite.

Because she had continually said she didn't want to be a burden on me, we had planned for this last stage of her journey as much as possible. We have our estate plans done. I have her Power of Attorney,

both medical and financial, she has a living will, her Do Not Resuscitate orders are on our refrigerator, and there is a copy in her purse. She has always said that when it's her turn, to let her go with dignity and preferably in her own bed. She has never spent the night in a hospital, nor has she ever had a major illness or a broken bone. Obviously, I come from some very healthy genes.

One Sunday morning in the Spring of 2005, she mentioned that she had a headache and upset stomach, and was going to go back to bed for a while. I had a feeling something was wrong, because this lady never has a headache. I had researched the symptoms of TIAs or mini-strokes; a headache and upset stomach are two of the major indicators of a Transient Ischemic Attack, or TIA. About 24 hours later, she woke up, headache gone and no indication of any stroke damage. This is also common with TIAs. A few weeks later, she blacked out in her bedroom for a few seconds and fell. Fortunately, she didn't break anything, nor did she hurt herself in any way. She said she lost her balance; I think she had a second TIA.

A couple of months after that, on another Sunday morning, she was experiencing another headache and said she wasn't feeling well. She lay down on her bed, fully clothed and was going to "take a nap." She was able to go to the bathroom a couple of times, but on the third try she called me, and I didn't think I was going to get her back to bed. She went into a comatose state and didn't wake up until mid-afternoon Tuesday. By Sunday night I knew I was dealing with something major, but knowing her wishes about hospitals and the medical industry, calling 911 was not an option. I watched over her all night, changing her bed clothes, keeping her propped up to help her breathing. Early Monday morning I called the non-medical home care agency I've used for several years, and within an hour they had a caregiver at the house to watch over her while I made other phone calls. After several tries, I was referred to a physician in the Valley who works with a local Hospice organization. Once again, within an hour I had an assessment nurse at the house. Mom was diagnosed a stroke victim, in a comatose state, with 5 to 7 days to live.

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Mom did come out of the coma very suddenly and unexpectedly, but we kept her on hospice for the time being. Our hospice physician told us that she could be with me a few more years, a few more months, or she might not wake up in the morning. This is what I mean when I use John Lennon's words, "Life is what happens while you're busy making other plans."

I'm sharing this story, because throughout the book, I will mention conversations Mom and I had and things I should have known but didn't. It is my hope that you won't have to go through some of what I have experienced if and when this happens in your family. It is not possible to make sound, logical decisions in time of emotional upheaval and crisis, and that's why I'm a big proponent of planning for your tomorrows, the subject of my first book, *Planning for Tomorrow*.

You will find lots of references to my Mother, Fran, herein. Fran began her journey to eternal life on January 26, 2006, just one day after I received the press proof of this book. It took me one year to to revisit this manuscript and I've found it very difficult to write about Mom in every instance in the past tense.

Whatever the reason you picked up this book, it is my heartfelt wish that you find something that will be useful to you, either now or at some future time.

When Your Job is Over

As caregivers, we have committed to caring for another person who can no longer care for himself or herself. We move in with them or move them to us. We put our careers and our independence on hold, and very often our family and friends suffer for it. We become so involved with the care of our loved one that we remove ourselves from normal day to day living. Our entire life revolves around caring for our loved one. We protect them at all costs. In a very real sense we have given our life for them. Then one day we wake up, and our mission has reached its inevitable end. We grieve, and then begin the process of finding our way back into the world as we once knew it.

How do we pick up the pieces and start to live again? There is no so-called “normal” guideline for us to follow. We begin by taking one step at a time. Some will move slower than others and some will speed their way back into the world. We will take one step forward and two steps back. This is no easy process; but there is a life after caregiving. We need to look ahead and find opportunities that are available for us. Renew old friendships, find a job that you feel good about, volunteer in your community, find a new or renew an old hobby, but begin to take a few small steps toward living again! One of the best therapies is finding a friend you can talk to; one who will listen and support you as you ease back into the world. Soon you will find your life will reappear, and you are able to move forward. Butterflies are still flying and the birds are still singing. The light of another day appears – through the clouds. We are forever changed by our experience. No one can ever take away that feeling of joy in a job well done, or the sorrow over a job now over.

“I hope never to live with my children. I notice that when I am with them, I quickly become ‘little old lady,’ and when I am among my peers and taking care of myself, I feel vibrant and far younger than my years. I feel that I will much prefer assisted living to the role reversal of becoming my children’s child.”

- Louise “Jaime” Jamison Drews



4 - Long Distance Caregiving

Caring for a loved one who lives far away can be emotionally and financially exhausting. Concerns about your loved one's safety, nutrition, health and care may seem overwhelming. You may also feel guilty and anxious because you cannot be there every day to see how they are doing. This chapter will address coping with long distance caregiving and some things to think about.

Recent statistics show that there are approximately 34 million caregivers in the US, and that over five million are long distance caregivers. The average distance between caregiver and patient is 480 miles, and an estimated \$386 to \$674 comes out of the caregiver's pocket in monthly travel expenses. Nearly 80 percent of caregivers work either full- or part-time, and about 20 hours of work are missed monthly due to caregiving responsibilities. Talk about stress!

Determine the Need

If your loved one lives alone, it is important to monitor his or her ability to manage various daily tasks. Visit your loved one to determine what kind of assistance he or she may need. Make the following observations:

- Is there appropriate and adequate food available?
- Is the person eating regular meals?
- What is the condition of the living environment? Has it changed?
- Are the bills paid?
- Do friends and relatives visit regularly?
- Is he or she maintaining personal care routines, such as bathing and grooming?
- Is he or she still able to drive safely?



5. Family and Friends – Help or Hindrance

“Half of the harm that is done in this world is due to people who want to feel important.... They do not mean to do harm.... They are absorbed in the endless struggle to think well of themselves.”

- T.S. Eliot

Usually one person becomes the primary caregiver to their parents because he or she lives nearby, is emotionally closer to the parent, or a take-charge person. If you are that person, don't try to do it alone. You need help – admit it, accept it, then do something about it. The more help you get, the less likely you are to burn out. Just as important, involving your siblings and other family members allows them to feel closer to the family and have value as family members. It also gives them the opportunity to show their love for their parents or grandparents. On the other side of the coin, siblings and other family members may not want to share in the caregiving responsibilities, may have excuses – real or otherwise – as to why they are unable to help out. But believe me, they will be the very first to offer advice on what you are or are not doing, and what you could do better. That's what I mean by help or hinder.

Some caregivers feel that other family members do their share. There are many very close families who successfully and equally share the responsibilities. However, working with family members in a positive, open manner can sometimes be a challenge. In times of stress, old family roles and resentments can surface. Some siblings are more hindrance than help, and if you were not close to them before, that probably won't change now. Take off the rose-colored glasses and accept that even though the issue is Mom or Dad at the end of their life, it doesn't mean that everything will be smooth, calm and perfectly wonderful – it probably won't happen.

Taking Care of You

Don't let anyone try to convince you that caregiving is not stressful. It is. Whether you are a full time or a part time caregiver, stress and anxiety can be a killer in the most literal sense. Stress related health problems are driving up the cost of health care dramatically.

Ten Signs of Caregiver Stress (courtesy of the Alzheimer's Association):

1. Denial about your loved one's physical condition,
2. Anger at your loved one and the additional responsibilities they are causing you,
3. Social withdrawal from friends and activities that once brought pleasure,
4. Anxiety about facing another day and what the future holds,
5. Depression begins to break your spirit and affects your ability to cope,
6. Exhaustion makes it nearly impossible to complete necessary daily tasks,
7. Sleeplessness caused by a never ending list of concerns,
8. Irritability leads to moodiness and triggers negative responses and reactions,
9. Lack of concentration makes it difficult to perform familiar tasks,
10. Health problems begin to take their toll, both mentally and physically.

The following are proven methods for relieving the stress and anxiety often associated with being a caregiver. Some are easier to accomplish than others, but all are equally important.

- Recognize and admit feelings of frustration, sadness, anger, and depression. Understand and accept that they are normal under the circumstances.
- Become aware of your body's symptoms. Don't let them scare you; let them talk to you.



7. Just Talk About It!

“We never talked in our family. We communicated by putting Ann Landers articles on the fridge.”

- Judy Gold

My mother and I had always had a unique relationship, and the ability to communicate in ways that are totally foreign to most people. We used humor to pave the way to discuss difficult topics, and have used subtle (and sometimes not so subtle) sarcasm to overcome roadblocks.

When we first discussed sharing a home those many years ago, we had some very deep discussions about life style; your stuff-my stuff-our stuff; who gets what rooms; who does what around the house; and so on.

As her ability to get around and do things decreased, her depression increased. It was almost a full time job to keep her mind occupied; not an easy task when her hearing was bad and her eyesight wasn't what it used to be. However, I was able to give her things to do related to my work that made her feel like she was contributing to the process. It may have been as simple as collating and stapling paperwork, but it gave her a purpose. By telling her that what she was doing was important and time saving for me, she was contributing to the success of my company. I continually told her that if not for her sharing her journey with me, my business could not exist.

She would often say, “I'm just worthless. I never meant to hang around so long to become a burden on you. Why can't you just take me out and shoot me?” I would reply with something to the effect of, “Mom, I couldn't do what I do if I weren't walking this road with you. Besides, if I shot you, I'd go to jail, so that's not an option.” This would bring laughter and more discussion about what she could do that would give her a reason to keep going.



9. Planning for the Inevitable

As I've mentioned previously, death and dying are not easy subjects to think about, much less plan for. But the fact of the matter is, we're all going to die at some time – how that inevitability is dealt with is another matter.

Let's take a look at recent moments in history that we all remember and can relate to. Some were totally unexpected and others just crept up on us. The World Trade Center disaster of September 11, 2001, the tsunami of December 2004, Hurricane Katrina in August, then Hurricane Rita in September 2005. Those who lost their lives certainly didn't plan to do so on that particular day, or from the events that occurred. Some of them had plans in place; some did not. Some have experienced unimaginable trauma and chaos, while others were able to grieve knowing that life, while very different, would be okay.

How do we plan for our own, and our loved one's demise? Why should we even bother?

Let's imagine a young family: husband, wife and two children. Husband and wife leave the children with a babysitter to go out to dinner. Both are killed on the way home. Does the babysitter know who to call when they don't come home? Will the children be taken care of financially? Who will raise them? How will the funeral expenses be met? What if life support is involved for one or both?

Not easy to read, is it? But the truth is, this happens somewhere in the world every day. If the young couple had their house in order, they would have life insurance on both to ensure the kids' financial security; guardianship and custody would have been determined and written in legal form; prepaid funeral plans purchased for both; and their wishes written out about life support and quality vs. quantity.

These are things I've discussed in depth in my book *Planning for Tomorrow, Your Passport to a Confident Future*. Here, however, we're going to address just a few things that will make our inevitable passing much easier for those we leave behind.

Do You Know?

- That no burial can or will occur until it has been paid for?
- That without Do Not Resuscitate orders posted in full view, emergency personnel will put you on life support if they feel it is needed?
- That without medical power of attorney, a spouse, son, daughter or other family member cannot make emergency medical decisions for you? Without a financial power of attorney, no one can pay your bills.
- That you cannot collect on a life insurance policy without a death certificate, and that can take as long as a couple of months to receive?
- That the courts will determine the distribution of all your worldly assets if you do not leave a will or a trust that gives written instructions for that distribution?

Wow! That's a lot of things to think about, isn't it? And, the above list is just the tip of the iceberg. That's why I say you have to talk about the tough stuff. You and your loved ones absolutely must accept reality and create the documents that will make things easier for those who are left behind. How many thousands of dollars have been spent unnecessarily when decisions were demanded during times of emotional upheaval? How many decisions were made because the documents you did have in place couldn't be found? AARP estimates that 35% of advance directives can't be found when they are needed. Who knows how many funeral plans have been purchased, yet are unused because no one knew of their existence?

Appendix A-4 End of Life Checklist

The following are some pointers on what you need to understand and know about your loved one's wishes, arrangements, documentation and so forth, regarding end of life issues.

- Gather all legal and financial paperwork and organize it into one box, binder, or desk drawer. This should include prepaid funeral plans, will or trust documents, powers of attorney, living will, advance directives, bank and investment account information, Veteran's benefits information and more.
- You are one step ahead if your loved one has already made funeral arrangements and paid for them. If this planning has not been accomplished, discuss it with your loved one and create a plan of action so that you will not be making decisions during an emotional time of crisis.
- If your loved one is amenable, ask questions like:
 - o What do you want in the way of a funeral service?
 - o What do you want to wear?
 - o Who do you want to attend?
 - o What music would you like played?
 - o Who do you want to speak?

Ask the above questions of your loved one. If you are successful in determining what they want, when the time comes, the decision-making process will be easier for you, knowing that you are carrying out your loved one's wishes. If you anticipate family disagreements regarding these decisions, record your loved one's responses. At the very least, write them down.

- If your loved one has not seen good friends, family members or close business associates for some time, ask them if they would like to see them and if so, invite these people to visit.

- Now is the time to bury the hatchet. If there are unresolved issues between family members, try to reach a mutually satisfactory conclusion to the issue before it's too late.
- Whether or not your loved one has been actively involved in a religious organization, church, synagogue, mosque or temple, they may be in need of some spiritual comfort at this time.
- Try to involve your loved one in interests they have had over the years. Perhaps it is a game of cards, a crossword puzzle, or just a good book. Do whatever you can to give them the best quality of life possible.
- Pain management in some cases will become more and more difficult to handle. Know and accept that your loved one is probably experiencing some level of pain. No matter how difficult they become in this state, listen to them and offer whatever comfort you can.
- As the end draws closer, call a local hospice organization to assist you. Hospice is designed to assist both the patient and the caregiver(s) during this time.
- Listen to what your loved one has to say. Don't gloss over their need to talk about their upcoming journey by saying, "Oh, don't say that. Everything is going to be just fine." They know what's coming, and deserve the respect of being listened to.

About the Author

Linda Thompson an author, professional speaker and educator. For over eight years, Linda has facilitated life planning and elder care workshops for corporate employees searching for information, education and resources. Her experience in this arena gave her the boost to write *Planning for Tomorrow, Your Passport to a Confident Future*.



The success of this book led to more speaking opportunities, seminars and workshops. *Planning for Tomorrow* focused on the need for life planning on the non-financial side, as well as the financial and legal necessities. However, no matter the subject of her talk, the questions most often heard were about elder care. Questions such as, “What do I do when Mom can no longer live alone?” “How do I gently tell my mother-in-law that she should no longer be driving?”

Linda has had over ten years of walking in a working caregiver’s shoes. Because she had done the research, talked to the professionals, and learned the hard way, she soon became the one to call on when someone had an elder care question. Since so many of her clients have expressed having feelings of depression, isolation, and health-related problems associated with being a caregiver, Linda undertook the task of putting common sense suggestions and practical advice into this, her second book.

Linda has since published two more books, *Fran’s Story - The 90 Year Journey of a Kansas Farm Girl* (her Mother’s life story), and *Every Generation Needs a New Revolution*, a survival guide for the multigenerational society we are living in today.

The demands upon adult children with aging parents can impact our physical, mental and emotional health almost to the breaking point. There are a lot of resources available for caregivers, but few as honest and from the heart as *A Caregiver's Journey*. This isn't a job we trained for, and at times we just need to be told it's okay to vent our frustrations – this book gives you permission. Linda has a unique ability to combine common sense with humor while teaching us all valuable lessons on survival.

"Some self-help genre books leave the reader to find such additional information on one's own-to have it all at one's fingertips is a much better idea. Linda's use of short paragraphs and bullet points makes the book easy to read and easy to refer back to at a later date. Best of all are the analogies the author uses to help the reader understand difficult or confusing concepts. Her sense of humor is also greatly appreciated when dealing with an otherwise somber subject."

Judge's commentary from the Writer's Digest 14th
Annual International Self-Published Book Awards.

About the Author

For twelve years, Linda S. Thompson traveled the journey of a working caregiver. As a professional speake and author, she teaches people about the parts of life we would rather not think about.

Linda resides in Chandler, Arizona with her two cats, Sam and Ginger.

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