Caregiver's Manual for Men (CMfM)

Caregiver's Manual for Men

My cancer Caregiving

By Dan Zeorlin

All Was Well

My heart was light, my soul was gay,
so ever mindful of the bliss
I took a chance to spy my love
and all was well because of this.
I raised a banner to the world
unfurled before her soggy stare.
It brought such respite from the rage
that all was well, while I was there.
With spiriting I sought to bring
a break to those who long for rest
But times were changed and life was good,
since all was well—I might have guessed!

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Introduction

How will you know if the advice in a Caregiver's Manual is for you? Are you presently a caregiver, will you potentially provide care to someone or are you in need of a caregiver? Do you wish to become a better caregiver? You might substitute your issue (EG: aging, Myasthenia Gravis, diabetes, cerebral palsy, stroke, Down Syndrome, Parkinson's disease, or others) for the word "cancer" throughout this text if it helps you relate to the circumstances.

In general, this manual makes a broad appeal for men to become better caregivers. A manly caregiver is he who is strong enough to change. For a moment, let's explore male resistance to high maintenance.

What causes guys to "drop the ball" when stakes are uncertain to take a "cut your losses" approach in relationships? Does it necessitate hypnotherapy or medication in order for people to become less "negligent?" How can guys bolster their own self-sufficiency and self-confidence through times of uncommon demand if their whole sense of stability is falling apart? This Caregiver's Manual is a narrative of my breakthrough to become a benevolent supporter.

Am I ever going to understand my wife, Linda? I wore a pink bracelet on my wrist with the reminder, "Early Detection Saves Lives." On the flip side I marked, "WWLD" (What Would Linda Do). I shall seek answers to that question for the rest of my life.

Linda discovered a lump in her breast in February. Her persistence in obtaining medical attention resulted in a March diagnosis confirming cancer. The development provided me with an impetus to set the single greatest goal I could ever hope to accomplish. As a direct result of her needs, I chose to become a caregiver. Nurturing is a true gift, changing people in the way childbirth changes mothers. A profound respect settled over me and I let confidence guide my spirit. Learning to give care was an epiphany! Linda asked me to accompany her on the fight of her life and so I chose to become more dependable.

It was tough to stay positive about Linda's condition and behave in a normal (unpanicked) manner while those people around me unloaded the baggage of their fear. I made it a priority to not burden her with details from my dilemmas, and I avoided adding grief to her consternation and woes. I think this helped because she was able to concentrate on recovery with fewer distractions.

A couple of years later, I authored a short article about the transformation. ("How to Become a Better Caregiver" was published by Coping Magazine.) Next I was invited to present ideas through the Community Care Coalition of Kansas City. The opportunity to co-author a "Caregiver's Guide for Men" arose based on reaching a more scholarly marketplace to increase the understanding of caregiving men. I also visited with other men who were equally devastated by cancers on the women in their lives. In collaboration with the caregiving community, I am working to develop the "ITN Men's Caregiver Support Group" program "In Their Names." The point I wish to illustrate is that you don't have to be professionally qualified or perfectly practiced to have an impact on the health and life of the ones you love. And you don't represent

unrealistic expectations to do it. Just be open to the possibility of healing and allow others to express their needs. Listen and be open to alternative answers.

A Caregiver's network makes you realize you are not by yourself and stumbling is part of the journey.

A few winters later a woman told me, "Thank you for rescuing Linda."

"You're welcome."

We may not eliminate the cause of adversity but we can all be part of a solution.

How to Become a Better Caregiver

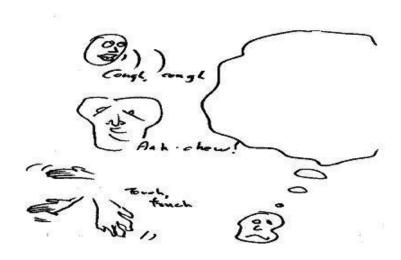
Being a caregiver can be overwhelming at times. And becoming a better caregiver involves some discipline and hard work. The hardest part about being the caregiver of a person living with cancer is dealing with feelings of helplessness. That's why it is important to develop the ability to make a difference in ways that are meaningful to your loved one.

When Linda detected cancer, some of our roles reversed. I became more supportive and loving. I learned to trust and was inspired by Linda's faith. I lived with a heightened sense of endearment and tenderness. We achieved greater harmony as a couple and were blessed with forgiveness, growth, and peace.

We shared the experience of various stages of cancer—discovery, treatment, and recuperation—and did not become fixated on the cure. The clinicians did their part in monitoring progress; as a caregiver, I learned how to do my part by bringing the following positives into focus.

Advocate for Change—A caregiver becomes an advocate for change. Resolve to make a plan and stick to it. Caregivers cannot be passive observers and must act when change is required. Learn to identify your dependant's needs and wants. Make lists of "Where To's, How To's, and To Do's" so that whenever the moment becomes "too much" you'll be able to find necessary relief without losing your momentum.

Change Your Perception—Caregivers are affected by many experiences, real and perceived. My wife's cancer was real; the idea that cancer was bad or an unrecoverable event was perceived. The feeling that I was alone, denied companionship, without support, and deprived of recourse was ridiculous but also a perception. So I spent energy convincing myself that our situation was not hopeless. Caregivers must shrug off the impossible and concentrate on those things that are still viable. Therefore I needed to learn a great deal of patience while I became a more compassionate caregiver.



"I should wait until after they leave to purify the house with antibacterial spray."

Focus on Priorities—Learn to let go and do things out of love. Priorities shift, and some things no longer seem important as they once were. You need to place faith in the competency of the medical team and in the healing process. Also, realize the patient has insights about their body. You hope your commitment to having a positive attitude will be inspiring and disease loses its grip on the life you cherish. Attempts to minimize exposures and reduce risks for the care receiver can become many of the caregiver's highest priorities.

Accept That You Won't Know Everything—Nobody wants to be unprepared, disoriented, or clueless in a serious dilemma. Our problem is we are preconditioned to be a worldly people. A caregiver acknowledges he or she will not always know what to do and that sometimes there are no right answers.

Encourage Hopefulness—One of the first things I learned about cancer was no two cancers are identical; throw out the stereotypes. Just as no two people are the same, no two courses of treatment have exactly the same results.

Improve Communication—The caregiver must find words to describe feelings and improve communication. Have the courage to say, "This happened and it makes me feel..." Until we recognize, acknowledge, and accept our circumstances, we do not move on or improve the situation.

Try to categorize dialogue with interaction models and renew your exchange of information. For example, there are five W's that make up the body of each conversation: Who? What? Why? When? Where? 1) Who loves you, baby? (Gratitude) 2) And now...the rest of the story. (Fresh consideration) 3) I don't understand; I don't comprehend. (It's a mystery) 4) I go crazy whenever... (Protest with request to change.) And 5) I want to be here. (Aspiration)

Recognize the ability to communicate effectively is often limited by external things, such as words, language, situations, feelings, opportunities, and choices. Don't give up—the reward is worth the effort.

At times you may feel like an escapee. You may be ashamed. You may feel unworthy. You may not be selfish but you definitely won't feel selfless. You would never wish to repeat this ordeal. As a caregiver you are called on to love someone more than life itself. Caregivers find ways to say, "Life will get better."

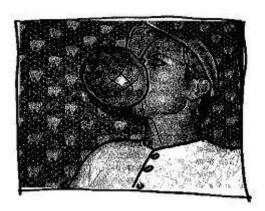
Ripening

Look through the portal at suffering people. Why can't they get on board? We won't all be leaving this place. Don't rock the boat.

As a result of the diagnosis, I elected to live as though I could accept whatever happened. A startling development occurred: I started taking my own advice. I quit broadcasting accusations. I stopped being dissatisfied and I began to have fun. Now I wish I'd have promoted more enjoyable experiences much earlier for my sake, for Linda's sake, and for the benefit of everyone in our lives. Life is beautiful and it can be very rich, especially when we are grateful and playful.

Linda and I both grew up in the city of Wichita, Kansas. We wed there in 1982 and in the early 1990's, we moved with our young family to Chanute and joined a rural population in the southeast corner of the state. Clearly the cultural inconsistencies became evident. A lifestyle change was required before we could fit in—but we were game!

In that small town, we assisted community leaders, enabling philanthropic interests to stretch further. Later on, we relocated to St. Joseph, Missouri. Fireworks vendors there proclaimed, "Get the most bang for your buck." This phrase embodies the same principles professed by many groups. If using caution and spending wisely, each of us achieves maximum benefits for our situations.



Like bubbles blown into chewing gum, sometimes we give until we break.

My entitlement attitudes had to be broken before I could grasp the meaning of "serious illness." I looked for a resource, a tool, something to provide quick answers for a modest investment of time; I found nothing. I needed to slow down. Space had to be incorporated into the process in order for the possibility of healing to develop along with the other consequences. I required a reality check before I could join the team.

My priorities prior to the prognosis and subsequent to the treatments were completely different. There are no guarantees and side effects always seem to prevail. I was devastated. The crux of the predicament was the information had to be processed in small pieces in order for me to keep it "do-able." My walk with difficulty—anyone's, really—is the parameters of change aren't easily digested. Unlike instructions for installing a carburetor kit on a chainsaw, the secret to restoration remains abstract.

I was unqualified. I was afraid. I walked by myself.

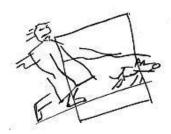
Caregiving ideas and concepts are bite-sized. Don't get caught up with finding the optimum way to affect change. Just act when the effect of change can be improvement. You need to explore your beliefs before you can identify what you're going to do about them.

This <u>Caregiver's Manual</u> offers a few practical suggestions for appreciation of people. It is not a "How to" instruction booklet designed to solve problems. It does attempt to list ingredients that successful caregivers have determined add meaning to life for care receivers and for themselves.

A Caregiver's Packet

What do you see? I think I'm going to be sick!

- **Practice fanfare**—Root, cheer, encourage, praise, and invest! Nothing is more uplifting to a patient with serious illness than a little TLC. "I'm giving my all for you." Become tired together.
- **Don't worry; be happy**—Because the physical challenge of chronic demand is exhausting, it is essential we keep good attitudes, for negativity causes psychological damage. Laugh every day. Turn your fears away and stop worrying. Lighten the load. Do not surround yourself with negative people. Acknowledge family and friends through encouraging roles. A positive support system is a must.
- Adapt—If it can be lost, don't be possessed by it. Bikers get sick. Beauty queens fall ill. Scholars lose advantage. Do something out of the ordinary. Buy a new shirt. Get tattoos or a body piercing. Make changes in your routine. Demonstrate your willingness to take risks. Operate without a safety net. Get outside the box, beyond the limits of your own personal comfort zone. How does it feel to live with increased vulnerability? Walk in solidarity.



You know it's time for a change when your favorite pet runs away with your catheter bag.

- **Support unconditionally**—Be a friend. Walk lightly, not as a guide, not as a mentor, not as a judge, not as a mourner. Show your companion, "I am here for you." Don't pretend to make troubles go away and minimize the situation. Sometimes there are no words. Just read, pray, or sit quietly. Physical presence can be healing.
- Learn to swear—Cursing doesn't fix anything but it can be a sign of exuberance and exuberance proceeds from hope. Swearing does not imply damnation. "Bless it" is a wonderful modifier to tag onto unexpected pleasures.
- Communicate your feelings—Learn to humbly accept conditions while concentrating on important issues. View recovery as one positive, life-affirming image. Don't allow yourself to be drawn into the notion diminished capacity dehumanizes people. Seek the solution...find the solution...<u>be</u> the solution. Neither apologize for feelings nor blame others. Embrace them...hugged until trauma dissolves into acceptance.
- Loosen up—Everyone desires respect and deserves dignity. Strive for quality. Learn to relax. Help the patient to freely adopt things to promote rest. Breathe deeply. Listen to nature's sounds. You will receive grateful observations: "I never knew you could be so supportive." "I'm glad you're with me." "I didn't realize how much you cared."
- **Music**—Shake. Create. Soothe. Enhance. Embrace. Heal. Touch. Drift. Relax. Nurture. Allow music to voice mysteries in life. Listen. Propose. Prepare. Appreciate. Find peace and be filled with it. Make holy sounds of acceptance.
- **Live charitably**—Our vision of truth is sharpened when we actively work to clean up the debris. Recognize the joy of shared humanity. Nobody's words can ever describe "your situation," or "their encounter," or "our plight" with accurate sympathy. Be nonjudgmental and tolerant.
- Expose your true self—Now is a difficult time for visitors. Show them charity when they encounter discomfort. Control yourself so you do not become angry. Welcome strangers into an alien land. All who are connected to you and your designee will be affected.
- **Find gratitude**—Be appreciative. Say, "Thank you," often and mean it. Some gifts are not fully appreciated until much later, after time has passed with opportunity for reflection.
- Let go—Set the stage with mutual regard. Adopt flexible plans. Remove conflicts, for peace of mind comes from letting go. If you could eliminate 100% of the difficulties brought into a relationship, think about how personalities could blossom and grow into the void!
- **Be Tender-**The fact you care makes all the difference. Try everything affordable, such as giving up unnecessary obligations or channeling your energies into less-expensive habits.
- **Nurture**—Fill in with extras and little things that need to be done. Ask questions. Identify your unique needs. Determine a plan to resolve issues and find steps to work for you. Consider procuring items to advance medical relief (see examples in Appendix).
- **Listen to your experts**—We heard many rumors. Some were true and others were false. We visited with the surgeon and learned about reconstructive surgery. We spoke with the oncologist. Linda tried, through localized application of Vitamin E, to relieve pain of open sores in her mouth. We talked with the radiologist. I obtained the names of recommended lotions that might soothe her skin after radiation treatments. After weighing the benefits and the risks, choose to do what is right for your situation. Investigate new resources and check them out.
- Take extraordinary measures—Here are a few cases of precautions we took:

- ✓ Purchased an ample supply of furnace and humidifier filters and changed them often to reduce air-borne impurities.
- ✓ Prepared our car compartments to relieve anxiety and carried buckets for nausea.
- ✓ Packed towels and pillows to provide extra cushions for a weary traveler.
- ✓ Possibly the probability all fingernails and toenails would fall out was lessened through the daily coating of Tea Tree Oil.
- ✓ Collected hairpieces and a complete set of headgear, expressing the uniqueness, determination, and beauty of the patient during treatments.
- ✓ Found ways to give better care.
- **Imagine a happy ending**—Dream good dreams and believe they can become real. Look for value in everything. Create goals that both of you will be able to reach together.

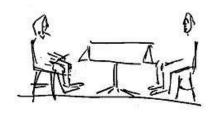
Cancer Vocabulary

Beautiful Vessel– Hairless, misshapen, alive Your presence warms my blood I am drawn into contentment by your side

Linda was put on display with cancer—she was placed in a clinical study, and she had to deal with becoming an exhibit—but she was not alone. I would have paid any price to be part of Linda's life and/or have her in my life. This was a choice we made.

While some people live together briefly, others live together for a lifetime, and many find the meaning of life changes when shaped by love. Some of the richest pleasures come from spending time with someone you love.

• Try to see uniqueness and a bright side for every situation—We honor when we refrain from harsh judgment and the resulting compassion helps alleviate the feeling of hopelessness. Some things are better left unsaid—write them down and get them off your chest without becoming a burden to someone else.



"Thank you for taking such good care of our sister."
"You're welcome. It's my privilege. Besides,
I've sunk too much into her to back out now."

- Say aloud, "I love you"—Repeat this frequently. Your life will become more peaceful. Say it again: "I love you." That sounds nice. "I love you." And again. "I love you." Just listen to yourself...and soon you'll find that you have fallen deeper into love. Love is not limited to the relationship between a husband and wife nor the bond between a parent and child. It is an ideal for all peoples. We are social creatures, requiring love in order to reach our full potential as human beings.
- What we say and do <u>does</u> impact recovery—Restate the following expressions, or compose others that resonate with you:
 - ✓ "You have the nicest friends."
 - ✓ "I didn't break it on purpose."
 - ✓ "How are you feeling? You look great!"
- **Keep trying**—Be persistent. Overwhelming odds are daunting, but you needn't be stymied by adversity. If pessimists try to grind you down, don't listen. The inside track to success is this: <u>Do your best</u>. Be satisfied only with <u>your</u> best performance. Know that good shall come from your best effort, even if you never taste the fruit produced by your love. Mother Teresa said, "The good you do today, people will often forget tomorrow. Do good anyway." The opportunity to affirm goodness is always present.
- **Remind yourself to practice wisdom**—Maxims like the following can be taped onto a bathroom mirror or placed in your daily planner:
 - ✓ Send encouraging notes to people in your circle. Tell them how proud you are and you want everyone to know it. Be positive. Give hints and suggestions on how to help.
 - ✓ Celebrate the little steps you take. Don't let a day pass without telling everyone in your family, "I love you." Take the initiative and try new things to introduce harmony.
 - ✓ If you pray, do so daily. Meditate often. Find repose. Learn to release tension. Heal despair with silent communion.
 - ✓ Respect everyone's privacy and treasure other (different) opinions.
 - ✓ Don't ever give up.
 - ✓ Decide to be happy. A playful attitude is a must. Find things to laugh about.
- Summarize lessons learned from cancer—Shout from stadium bleachers and into speaker boxes at the drive-through: "I have a cancer in my life!" Compose updates in email messages and address them to the whole planet. Face facts and don't hide in ignorance. Sending group messages can be a good way to present information consistently in a non-burdensome arena.

Dialogue is healing. This freedom eventually led me to publish my caregiver feelings on a blog. We stayed current and shared progress reports within our network of believers. We gained enthusiasm to defeat our fears, replacing doubts with confidence and filling isolation with hope. Ask for assistance in the strangest places—you shall find it there! Don't be embarrassed. And don't ever be ashamed. After cancer is gone, remember to acknowledge the happiness and the

disappointments—in short, the abundance of life—you experienced because of cancer's ordeal. This can bring closure to the question, "Why?"

- **Prevent burnout**—This should be your #1 priority. Maintain a positive attitude. Find out what works for you. Push yourself to 1.) Set goals, 2.) Keep an updated status, and 3.) Reach your targets. Keep in touch without losing your sanity. Measure life one hour/one day/one week at a time. Incorporate peace into your home. It helps if your spirit flows with acceptance.
- Allow compassion to heighten your awareness—Recognize stress is also in the lives of
 others. Become sensitive to people's afflictions. Gentleness is contagious. If, as the result
 of caring, the life and dignity of the human person is respected and appreciated more,
 then the issue had beneficial results.
- **Rekindle the fire**—Hairless people are incredibly sexy and attractive! Train your perceptions to mature into appreciation for the experience.



Maybe mine will thicken while yours is growing back.

- **Be expressive**—Take chances. Read aloud to the patient. Coax yourself into sharing secret thoughts. Write poetry. Remember familiar tunes and insert "ow" words, substituting new verse into old songs. Add entries into a journal and allow yourself to sort out reasons for your beliefs. Make notes to remind you of episodes too easily forgotten.
- **Be sustaining**—Set up a calendar and remove uneasy meetings. Highlight your appointments and schedule quiet time.

New Creations

He leaned over the bed, Kissed her head, and then Stood erect, a mouthful of hair on his lips!

Caregivers are people too. Sometimes the individual is consumed by the responsibility of caregiving.

I'm not a journalist. Nor am I a miracle worker. But while I may not be an expert, I have valuable things to say. We all do. Try to contemplate the feelings evoked during caregiving.

Essentially, Caregivers need to drop ownership of pressures. Perhaps you can carry a journal for recording everything you do not immediately understand.

Reinvent yourself. Believe it or not, you are changed by your experiences. Allow yourself to delight in pleasing others.



Hey Good Lookin', Do ya' mind if I rub your feet?

How I feel affects what I'm doing. I found by keeping a journal, I learned more about myself. Need impacts the Caregiver by ricocheting fear and uncertainty off the patient's composure. Take breaks from your demand-shadowed identity and rejuvenate the "I" that is you.

Cancer Builds a Bridge

Gypsy Woman With your hair all away– Would you like a tattoo for your head?

Linda presented her beautiful contemplation of cancer to the congregation at a Lenten church service. It is repeated here with permission:

"I have been told I had a cross to bear. Last year, I was diagnosed with breast cancer. Some of those around me viewed my cancer in a much different light than I did. A "cross" is a burden for many people, something heavy to carry. I felt differently. It may be forced upon you and you might have to hoist it unwillingly, but it can be lifted. Now some are saying that I have been taken down from my cross, that I passed the test.

I do not believe God tests us in this manner; no parent tests his or her child with such a practice. We (parents) prepare our children for life and offer advice, granting guidance and

love with constant support along the way. Our children determine the outcome for which their trials will affect them by the approach they take to every situation.

The cross can be a bridge that spans from point A to point B. It is not a load to weigh you down. In fact, when you take time and listen to the Spirit, you will journey from one side of a canyon to the other. You do not necessarily emerge unscathed, but you are better for the experience.

I was asked, "To what do I attribute my rapid recovery from the year of cancer, surgery, chemotherapy and radiation? How have I maintained such a positive attitude?" Without hesitation, I answer: I never viewed myself as sick, unfortunate or without hope. My focus was to turn everything over. I embraced each day and was immersed in the present. Ritual was out of the question. Some days I was just too weak to pray. Yet I sat in Yahweh's quiet presence without thought or direction and was nourished by the silence.

I clung to my cross, my "Bridge to New Awareness." I accepted the awakening by letting go of the past (as I knew it). My dear life and I traveled with my cross. The bridge brought me through the emptiness.

The cross serves a purpose. I survive and must accept the changes that have occurred. I recognize the person I have become and use this experience to help others cross over. I am resurrected. I have been reborn."

Cancer Sings

Cancer. Cancer in the morning. Cancer in the evening.

Cancer. Cancer when the sun goes down.

Linda's serenity in the face of cancer is deeply moving. For me to enter the room where Linda convalesces is to feel God's mighty presence. She is in relationship with Yahweh. Her dedication calms turbulence, inspires tranquil lyrics, and gives witness to the life-giving, healing power of trust: Behold, this is holy ground.

Giving Care

Loving a bald-headed wife is like kissing your father-in-law.

Caregiving is not an impossible burden. Dare to be bold with your display of affection. Early in the identification process, an associate told me, "Cancer is a very survivable disease these days." Hope was born in the darkest hour! Thank you my friend.

Build your treasury of warm thoughts and happy words. Add these to your list:

- ✓ I appreciate the good work you've done.
- ✓ Let's have (some) fun!
- ✓ Your smile is gorgeous.
- ✓ I'm happy to be with you.

We are pampered, favored, and gifted by connections; thus, if we alter the issue's reason for existence, love becomes incurable, like a sweetheart never wishing to leave.

Caregiving fulfills basic human needs. The avenue of caregiving can lead us to happy acceptance.

The Obtuse View

Make it go away.

Don't touch my things, my identity.

Don't mingle with my people, my friends, my family.

Don't invade my space, ever, again.

Unlink your propensity to change the world disproportionately

And become common, a hangnail.

You can be irritating, exacerbating, exasperating even...

But please, don't metastasize.

Look at misinterpretation. "How could <u>I</u> possibly accompany you on a journey to be made alone? How could <u>you</u> possibly accompany me on a journey to be made alone?" What did you hear when sickness whispered in <u>your</u> ear?

We bear grudges. We don't wear our best smiles. We are angry. What are we to do? Thank God for failure! What insolence is this? How do we control the anger?

Win or lose, we are bound by the requisite we need healing from our illnesses. Imitation may be the best we can hope for—act like winners! Become an advocate. Give hope!

Food for Thought

Oh Wonderful Solution!
Oh Happy Acceptance.
I cannot quit; I must go on.
From dawn to dusk and dusk to dawn.
Connectedness with humankind...
Endow my soul, transcend the mind.
The truth of myth is oft concealed,
For greater noise hath truth repealed.
A glorious end will come, at last,
When present sting escapes the past!
Accept, therefore, and share good will
Lest you be damned to private hell.

Leaders like these, with unresolved destinations, trailed constantly from my meandering spirit...

- ...after diagnosis confirmed cancer in Linda's breast, I thought of nothing else and found no peace of mind...
- ...my expertise, my career, my purpose for being-everything I am and all I have become-all for naught. My ego was stroked by Linda's hand-was I wrong to trust so completely, to love so blindly?...
- ...be strong...I am weak...have no fear...I don't know what to do...don't hold back...I can't hold on...it is okay...it's not okay...I dread the unknown...I am afraid of death...
- ...shock isolates me...I cannot survive alone...how will we do this together...?
- ...chemotherapy's first bite...
- ...discarded like a mate-less slice of bread at the bottom of a sack...

A Caregiver's Delight

Strength is in your resolve, courage courts your efforts, faith abounds where you dwell, and love finds a way to share the beauty that is you.

Throughout the ordeal, I wondered why I felt so alone. Hadn't anyone ever experienced this before? Why didn't somebody announce "heads up" to warn me so I could have prepared better? Although I was too despondent to recognize it then however, there's not a good reason to ignore the ones who help others—us, the Caregivers!

Conclusion

I became so focused on being the best caregiver for Linda that I didn't have energy for anyone else. I figure other people are that way too. And we all make choices. I found help because I just realized that I did my best with the choices that I made.