



Caregivers

Facing the Challenge Together

THE UNIVERSITY OF TEXAS
MD ANDERSON
CANCER CENTER
Making Cancer History

A close-up photograph of a hand holding a single, bright yellow maple leaf. The hand is positioned at the top of the page, with the fingers gently cradling the leaf. The background is a soft, out-of-focus gradient of light colors.

Facing the Challenge Together

Are you caring for a loved one with cancer? Feeling overwhelmed? You're not alone.

This booklet reflects the observations of other caregivers who have been part of a similar journey. It's intended to serve as a practical guide and an emotional survival kit to help you take care of yourself while taking care of someone else.

A caregiver has special needs, which often are quite different than those of a patient. As you probably know, caregiving brings a sudden set of new responsibilities that demand an enormous amount of time and energy. While the caregiving experience may provide opportunities for growth with positive experiences, it also can take an emotional and physical toll, at times leaving you feeling frightened, lonely, burdened and drained.

Many people travel from near and far to receive the world-class treatment that The University of Texas M. D. Anderson Cancer Center offers. While this carries distinct medical advantages, the adjustments that are needed can bring unique challenges. There are many new things to learn, including navigating a large and unfamiliar setting; gaining understanding of medical terminology; building trust with a new staff; managing medications, side effects and schedules; keeping the home fires burning from a distance ... well, the list goes on and on.

This booklet is designed to share with you how others have faced these challenges and the methods they used to help them get through this stressful time. We hope the guidance provided here will strengthen, soothe and energize you — the caregiver — a pivotal member of the treatment team.

Phyddu Tacchi, R.N., C.N.S., L.M.F.T., L.P.C.
Psychiatric Advanced Practice Nurse and *former cancer caregiver*
Department of Psychiatry
The University of Texas M. D. Anderson Cancer Center



Table of Contents

A Day in the Life of a Caregiver	6
The Tough Times: Caregiver Doubts.....	8
The Emotions of Caregiving	10
1. The Volcanic Feelings of Caregivers: Emotions to the Max.....	11
2. The “Forbidden” Feelings of Caregivers	12
6 Basic Steps of Caregiver Self-Care	14
Feeding Your Body	14
Feeding Your Mind	15
Feeding Your Soul	16
Preserving Your Energy	17
Evaluating Your Priorities	18
Finding Your Strengths	20
10 Practical Tips from Highly Effective Caregivers.....	21
12 Ways to Increase Caregiver Self-Knowledge.....	24
Preparing Yourself for Clinic Visits	26
Caregivers Speak	28
A Caregiver’s Bill of Rights	30
Caregivers’ ABCs	32

A Day in the Life of a Caregiver

“I feel responsible for absolutely everything. I always think I should be leading the patient to do the right thing. I feel I’m becoming such a nag.”

Life can change with just one phone call. When the words “your loved one has cancer” are heard, life changes forever for the caregiver. That moment of first hearing the news will likely live on in your memory. Suddenly, life as you knew it is gone. A whole new expansive set of responsibilities appears seemingly overnight and invades every facet of daily life, as you can see from the chart on the next page.

What new responsibilities do you now have?

Practical

- Finances, insurance, legal
- Child care, meals
- Home: bills, cleaning
- Time management

Physical

- Patient symptom management
- Fatigue
- Own illness

Social

- Family
- Relationships
- School, work



caregiver

Spiritual

- Meaning of life and death
- Suffering vs. control
- Hope vs. uncertainty

Emotional

- Anxiety, depression
- Communication, listening/coping skills

Administrative

- Record keeper: disease facts
- Medications
- Tests and treatments
- Staff, services, schedules
- Finding help
- Transportation
- Training, research

Self-concept

- Confidence
- Self-worth
- Competency

The Tough Times: Caregiver Doubts

“I work all the time, but still feel like I’m behind.”

Because of the all-encompassing duties that caregivers must absorb, fatigue and self-doubt may set in. The more tired caregivers begin to feel, the more they may question their ability and self-confidence.

Which of the following thoughts of self-doubt can you most identify with?

- “Why can’t I keep up?”
- “Why can’t I do everything that needs to be done?”
- “Why can’t I get him/her to eat? To drink? To walk?”
- “Is there something wrong with me because I can’t get him/her better?”
- “Why doesn’t he/she talk with me?”
- “Why can’t I control things?”
- “I’m working as hard as I can and he/she still feels bad.”

- 
- “I don’t have time for anything.”
 - “I feel defeated and burned out.”
 - “My loved one is so irritable with me, I just don’t know how to handle it.”
 - “My loved one doesn’t want anyone else to care for him/her other than me. I’m getting worn out.”
 - “My loved one won’t follow my advice.”
 - “I let picky things get to me.”

The Emotions of Caregiving

“My loved one is so irritable with me and I’m working as hard as I can to help. All I want to do is go home.”

“I don’t have time to take care of myself. Even if I did, I don’t know where to go or what to do.”

“I just want things to return to normal, to the way things used to be.”

“Sometimes, I just have to get away.”

Sound familiar? Sometimes caregivers feel as if their mood changes in relationship to managing the fluctuating nature of day-to-day medical circumstances.

“Help! I’m on an emotional roller coaster and I can’t get off.”

“Sometimes at night, I just lay there waiting for the next earthquake.”

“If I don’t sleep at night, I end up crying the next day.”

Caregivers often work overtime to provide care to their loved ones. This has its pitfalls and blessings. It's often a job requiring 24/7 attention with many physical and emotional demands, filled with highs and lows. The most common complaints of caregivers are emotional and physical fatigue, exhaustion and sleep deprivation. The time and effort it takes to care for your loved one each day can, over time, become very stressful with a gradual wearing down of energy.

There's a high correlation between fatigue and depression in caregivers. When you're under such tremendous chronic stress, you can experience many emotional ups and downs on any given day. One minute you feel as if you have it all together and the next minute it seems like you're falling apart. Not only is physical fatigue a factor, but emotional overload is as well.

1. The Volcanic Feelings of Caregivers: Emotions to the Max

“My feelings bounce around all over the place. Sometimes they are positive and sometimes they are so painful I don't think I can stand it.”

Sometimes you may feel like a virtual volcano when pressure builds without relief. Today may seem too difficult and tomorrow too uncertain.

Where are you today on this spectrum of feelings?



2. The “Forbidden” Feelings of Caregivers

“Sometimes, I can’t talk to anyone about how I feel. I don’t want to burden them or take away the hope of my loved one. No one understands what this is really like unless they’ve been through it.”

It’s not unusual for caregivers to have intense feelings that they’re hesitant to talk about, especially to their patient as caregivers may wish

to protect their loved one from hearing about their distress. These feelings can be strong and seemingly in conflict with what you're trying to do. Although others may tell you to "think positive or be optimistic," there are times when this just doesn't seem possible.

Which of these "forbidden" feelings can you identify with?

- Yearning for "normal"
- Doubt
- Resentment
- Anger
- Guilt, feeling trapped
- Fear
- Hopelessness
- Helplessness
- Worry
- Sorrow
- Grief
- Loneliness

6 Basic Steps for Caregiver Self-Care

In the midst of your expanded role carrying intense emotions and challenges, it's vital that you learn to take care of yourself. Many caregivers feel guilty taking time to do something for themselves while their loved one is ill. You may need to first give yourself permission to do so.

What can you do, starting today, that will make a difference for you? You don't ever have to be the same after today. People can do incredible things, unbelievable things, despite the most impossible or disastrous circumstances. You have lived all your life to come to this day, to this moment. There may be different ways to travel this road that will help you maintain your physical and mental health over the long run.

Take a look at what other caregivers have found to be helpful ...

1. Self-Care: Feeding Your Body

“My body is literally my caregiving machine. I have to take care of it.”

- **Exercise** — pump up your body by walking at least 10 minutes a day.
- **Sleep** — rest your body for six to eight hours a night.
- **Eat right** — feed your body, nutritionally and regularly, including breakfast. Eat lots of vegetables, fruit and whole grains.
- **Drink** plenty of water.

2. Self-Care: Feeding Your Mind

*“I was scared all the time until I learned that the definition of fear is **“Future Events Appearing Real.”** As long as I focus on the present, I keep from getting scared.”*

In part, our energy and mood are direct products of what we think about. During this time of stress, it's vital to control your thoughts to focus on today. Otherwise, thoughts may spin out of control with worry about what tomorrow might bring, creating a sense of chaos, fear, anxiety and uncertainty. Our thoughts are like tools; they can be used for building up our confidence or tearing it down. Only you, not circumstances or other people, can control what you think about.

Are you using your thoughts well and productively, or do you feel victimized by them? You are what you think. You're the boss of what you think about. You're in charge of your mind — no one else.

Some caregivers find writing in a journal a good way to sort thoughts and feelings. It can serve as a soothing process to empty the mind of stress. Support groups also are useful as they provide a safe place to sort things out and to balance one's perception of reality. Others use reading, music or meditation for thought control.

3. Self-Care: Feeding Your Soul

“Where is God in all of this?”

Living a life with cancer at the forefront carries three dimensions: physical, emotional and spiritual. Searching for spiritual sustenance is one of the exercises that many caregivers experience in their quest to make sense of this time in their lives. As their spiritual life begins to broaden in searching for meaning and deeper understanding, many find that their priorities become rearranged. What was thought to be important before cancer — such as striving for material goods or worldly success — may now seem trivial and unimportant. What may

emerge is the growing awareness and appreciation of the importance of faith and relationships with loved ones.

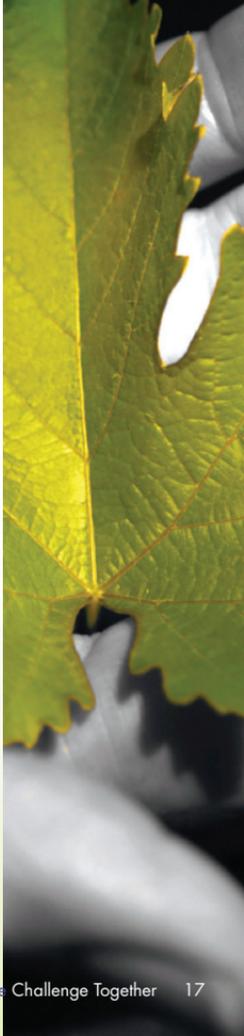
Pray and meditate — feed your soul. Seek spiritual sustenance. Learn from one caregiver who prays,

“Even though my loved one has this cancer, help me to learn to live, really live, this day.”

4. Self-Care: Preserving Your Energy

“My whole life has changed. I have no time for myself.”

When possible, learn to unplug yourself from your patient and replug into something that will energize you and bring a greater sense of peace and pleasure. It's important to get away from cancer to recharge your battery so that you can come back refreshed and fortified to tend to your patient. Sometimes, just carving out 10 minutes for yourself can help rejuvenate and restore.



You have a very hard job. You likely are doing everything you reasonably can to take care of your loved one. Begin to learn to run on “premium caregiver fuel” by feeding your mind, your body and your soul with thoughts and activities that build, nurture, comfort and strengthen. This will conserve your energy over the long run.

Be good to yourself. You have the right and the responsibility to take care of yourself. This is not selfish, it's self-care. Taking short breaks now will give you the energy and strength to stay in this for the long haul.

This is exceedingly important, but difficult for caregivers to give themselves permission to do. Many caregivers may feel guilty when they leave the patient's bedside, when medically appropriate, to go do something pleasurable for themselves. However, research studies show that caregiver self-care is medically necessary for you to stay mentally and physically healthy and strong.

5. Self-Care: Evaluating Your Priorities

“I started to become realistic. I didn't cause this cancer. I can't cure it or control it.”

Becoming realistic can be a mind-altering experience. Starting from there, consider letting go of the idea that you are Superman or Superwoman.

- Practice being clear in your mind about what your job really is. Are you over-functioning for your patient? Are you doing things that your loved one is capable of doing for himself/herself? This is not unusual, especially in the beginning. Be clear in your own mind what is really happening right now, not what “might” happen. Set reasonable limits with your loved one. Determine what self-care tasks he/she can do. A gentle reminder may be: Don't do for your patient what he/she is capable of doing for himself/herself.
- Take stock of the things that are really important that “must” be done, not what “should” be done. As one caregiver said: *“I made a list of the things that I absolutely had to do, like organize medications, schedule appointments, etc. I made another list of things that I was doing that just didn't really matter in the big picture. I just let those things slide off my back.”*
- If possible, delegate some responsibilities. Recruit others to help you.

- Learn some practical problem-solving techniques, such as how to manage medication side effects, organize a medication sheet, and develop strategies for symptom control of pain, nausea or fatigue.

6. Self-Care: Finding Your Strengths

“I’ve been able to do things that I never in a million years thought I could do.”

- Identify your strengths. Some caregivers have a hard time doing this. Your personality is unique and you bring talents and gifts to this demanding role of caregiving. What is it that you bring to the table that strengthens this situation that no one else can, or is willing, to do? What have you learned through this experience?
- Other caregivers have identified their strengths and you can, too. Focus on what you’re good at doing.

10 Practical Tips From Highly Effective Caregivers

- 1.** Take time for yourself. Schedule some quiet time away from cancer, cancer, cancer. Practice blocking out worry, even for 10 minutes. Sit or walk in a special location, imagining a sign that says, “No worry allowed.” This is your “worry-free” appointment with yourself.
- 2.** Create some distractions, such as working with puzzles, crosswords, computer games, knitting, cards, music or yoga. Activities that have a rhythmic mechanical repetition are helpful and soothing.
- 3.** Create a support system. Find someone who will serve as your cheerleader and your encourager. Someone who will lean over the balcony, waving his/her arms as you run the race below in the arena, shouting, “You can do this. Keep pressing forward. Easy does it. First things first. You are stronger than you think.”
- 4.** Cry and laugh. These are all natural stress-buster activities. Find something to laugh about every day. It reduces stress, increases the heart rate and muscle activity, and releases feel-good chemicals into

the brain. Even a smile can produce a moment of pleasure. Sometimes a good cry can discharge stress and bring relief.

- 5.** Open up your horizon a bit. Caregiving can create a narrow, lonely and shrinking world. Talk to someone at least once a day about anything other than cancer. Step outside and just look at the sky, even for a minute. Pray.
- 6.** Learn to walk in beauty. Take notice of our natural world and the miracles of sunlight, fluttering leaves, bright flowers, floating clouds, a squirrel skirting across the grass, rain, thunder, a gentle breeze, morning dew, fountain sprays, the rhythm and rotation of daylight and darkness with the promise of a new sunrise every morning.
- 7.** As you walk, imagine energy and light traveling from your feet up into your mind, with each step visualizing its slow and healing course of travel through your legs, abdomen, torso, shoulders and arms. Breathe in peace deeply and breathe out distress, counting to five each time. Imagine opening your heart and releasing musical notes, filling the air around you as you exhale. Practice.

- 8.** Keep a journal of “Tiny Gratitudes.” Gratitude is the number one positive emotion. Remember that life’s greatest gifts sometimes arrive in small packages. Miracles really are everywhere when we look for them. Become a detective and look for and find the little things — the tiniest moment of beauty, the tiniest blessing, the tiniest thing for which to be grateful. Count your pulse or that of your loved one ... and be grateful.
- 9.** Use positive self-talk. “I can cope. I am being held up by God. I can do this. Others have done it before me and I can do it, too. I’ve been through tough times before.”
- 10.** Join a support group. You don’t have to go through this alone. Check out “Caregivers: I’ve Got Feelings, Too!” at M. D. Anderson’s Place ... of wellness. This group is designed to help broaden your perspective and horizon. Assuming the role of caregiver can be shocking and distressing. This group can provide a cushion of support from fellow comrades going through similar experiences in the war against cancer. It will help you organize the chaos in your head, sort through your feelings, and direct your goals and behaviors in ways you may not have considered.

12 Ways to Increase Caregiver Self-Knowledge

Many caregivers find that learning more about the unique impact of caregiving on their own lives and those of their loved ones helps bring a sense of meaning to this difficult and bewildering time. How would you finish these statements?

1. The ways this experience has been hard on me are:

2. Additional areas of stress that I'm handling are:

3. Things I've learned about myself and my family member are:

4. The skills and talents that I bring to this situation are:

5. The ways that this cancer has impacted our relationship are:

6. The thing that I'm most disappointed about in myself during this is:

7. The blessings that have come as a result of this experience are:

8. The spiritual meaning that I'm finding through all of this is:

9. What I've learned about the concept of control is:

10. The thing for which I'm most proud of myself during this is:

11. What I would recommend to someone just coming into this is:

12. The most helpful thing that my doctor or nurse said to me was:

How do you cope? What have you learned?

Preparing Yourself for Clinic Visits

- 1.** Wear comfortable clothes and shoes. M. D. Anderson Cancer Center is a very large facility and you may be doing a lot of walking for appointments. Also bring a sweater, as room temperatures can be cool any time of year.
- 2.** Bring something to do as you wait for appointments, such as a magazine or book to read, knitting or crossword puzzles.
- 3.** Bring a current list of all medications that your loved one is taking, including dosages, length of time taken, prescribing doctor's name and pharmacy telephone number.
- 4.** Bring an organized list of questions for the doctor, as well as paper and a pen to take notes. Two people can hear two very different things and notes to refer to later will help.
- 5.** Learn who the contact person is for your patient's doctor and collect that person's business card, in case you need to call the clinic later with questions. This may be the doctor's advanced practice nurse, physician assistant or clinic nurse.

6. Remember that you're coming to one of the top cancer centers in the world. Take comfort in the fact that many have been through what you're dealing with now and have gone on to live productive and healthy lives. Through the experience of cancer, you may learn many good and interesting things about life, yourself and your patient.



Caregivers Speak

Which of these statements hits closest to home for you today?

- “I’m learning that I can get through anything.”
- “I’m learning that I’m stronger than I think.”
- “As long as I stay focused on the present, I can decrease my fear.”
- “I have to stay connected to the outside world to keep my sanity.”
- “I learned that despair is presumptuous. How do you know what’s going to happen?”
- “Be good to yourself.”
- “My children have seen a marriage in action during a very hard time.”
- “Take power naps.”
- “Through all of this, we’ve become closer. We’re now like a tube of Super Glue.”
- “Focus on today and only today. Take it one day at a time.”
- “Every day, treat yourself to a good and new thing.”
- “Don’t watch the news. It’s way too depressing.”

- “Have the courage to be joyful. Laughter is like internal jogging.”
- “During this time, ask ‘given what is, what am I now to do? What is the lesson here?’”
- “Hug someone you love.”
- “I can’t fix everything, but today I can do at least one thing.”
- “I’m resilient.”
- “I’m the organizer. I can see the reality of things.”
- “Prayer works.”
- “Material things don’t matter anymore.”
- “Control? Ha! It doesn’t exist.”
- “Somehow, some way, maintain positive experiences. I try to keep a ‘Positive Things Happen List’ at the end of each day, no matter how small the event.”
- “This whole thing has brought us closer together.”
- “This is the hardest thing I’ve ever done in my life, but it is the most honorable.”



A Caregiver's Bill of Rights

I have the right:

To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.

To seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.

To maintain facets of my own life that do not include the person I care for, just as I would if he or she was healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.

To get angry, be depressed and express other difficult feelings occasionally.

To reject any attempt by my loved one (either conscious or unconscious) to manipulate me through guilt, anger or depression.

To receive consideration, affection, forgiveness and acceptance for what I do from my loved one as long as I offer these qualities in return.

To take pride in what I accomplish and to applaud the courage it has sometimes taken to meet the needs of my loved one.

To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.

To expect and demand that, as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

Add your own statements of rights to the list. Read it to yourself every day.

Reprinted from "Caregiving: Helping An Aging Loved One," a book by Jo Horne.

Caregivers' ABCs

To be a good giver of care, take care of yourself every single day. Perhaps this poetic list of reminders from a fellow caregiver will encourage and offer ways.

- A** an apple each day, attend, appreciate, ask
- B** breathe and remember to brush
- C** cry, crosswords, crochet, climb stairs, connect
- D** dream, draw, doodle, delegate
- E** exhale, eye drops, exercise
- F** friends and family, feelings, fresh fruit
- G** giggle, gratitude, ground yourself
- H** hold hands and hug, regard hope, honesty
- I** intention, inhale, improvise, interact
- J** jog, joke and journal writing
- K** kindness, knowledge, knit
- L** love, listen, laugh and live the moment

M music, meditate, movement and muse
N navigate, notice, nurture
O observe objectively, remain open
P patience, pray and read a bit of poetry aloud
Q quiet the self, questions, quick naps
R read, reflect, rest and relax
S stretch, smile, sleep, shop, sushi
T tea, time away, treasure and trust
U unload feelings on paper
V vitamins, vegetables and new point of view
W walk, drink water and wash hands often
X eXercise
Y yoga and yes to yourself
Z zest — add flavor with enjoyment
remember the zoo in Hermann Park

*Edi Klingner
Caregiver, wife, poet, artist*

Your Notes



The background of the page is a stylized, layered leaf pattern. The top half is a light lime green, and the bottom half is a dark blue. The leaves are layered and semi-transparent, creating a sense of depth and texture.

THE UNIVERSITY OF TEXAS
MD ANDERSON
CANCER CENTER
Making Cancer History

Funding provided by M. D. Anderson's
Holiday Letter Program

9007 | gr | db | 11.08 | 30k