

No matter what your knowledge base, caring for a parent with a terminal condition is a loving, courageous, yet chaotic journey. Weaving a soulful and heartfelt story and offering over 90 personal and practical tips, Lisa Boesen draws from both her professional and personal experience of caring for both parents to support the caregiver in experiencing life's natural journey of the dying process, grieving and rejoining life with grace and joy.

Managing the End to Bridge the Beginning

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Managing the End... to Bridge the Beginning



Practical tips and encouragement for
caregivers of terminally ill loved ones

Lisa Boesen

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Chapter 2

Adopt TCOY

IF I HEARD ONE MORE PERSON tell me to be sure and take care of myself during the last year of my mother's life, I thought I would literally throw up. I know they had my best interest at heart, because logically I knew that if I was not well, mentally, physically or emotionally, I could not take care of Mom, Dad or my family for that matter.

A good friend gave me some of the best advice. "You will find the strength. It comes to you. You won't know how it happens but it will come to you to help you." And I tell you as the reader, strength comes to you. You can do what life gives you to do. Whether it's getting up in the morning, trying to get to work, sharing time with your husband and perhaps your own children, all the while juggling two parents' multiple medical illnesses, doctor visits, opposition to driving, hospitalizations, worrying about your job or worrying about the end.

Yes, there are days when you wonder how much more you can take. There are days when the unknown seems unbearable, but you find the strength. You try to take a day at a time – but still consider the "what-ifs" and create a plan.

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I'm not sure there is a best way to take care of yourself in times of crisis. Some friends would tell me, "Take a day for yourself." Their advice, though well-meaning, was easier said than done. After all, I knew that one day spent on myself was one less day not thinking or being with my dying loved one. A hard reality for me to accept was that as much as I wanted to be with my mother, she did not want or need to be with me all the time. She had her needs, which included spending time with Dad, travelling, and enjoying her shop.

At first, I wanted to appear independent and a pillar of strength. But the reality is you are human and it's OK to let others help. Why should I deny others the pleasure and satisfaction of demonstrating their own compassion? Why should I steal their opportunity to reach out and care for others?

You get a few suggestions, and hopefully you have a caravan of friends and family that help you with small things. Accept every offer and don't be afraid to ask for help. Invite your support system to run a quick errand, pick up your newspapers that start collecting on the lawn, bring over a treat, send you words of encouragement over the phone, or a card in the mail that sends your strength.

I'm sure there are individuals who can effectively compartmentalize and take a "me" day and I applaud them. But, in

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reality, there is a strong possibility that you start feeling guilty just thinking about taking care of yourself. Even small grooming activities such as a haircut and style, or manicure and pedicure, begin to create a sense of guilt. Ten extra minutes to add color to your hair out of a box every two months – where do you find that?

After all, here's your mother writhing in pain and nausea, you are still working full-time, your job requires a professional look and you are desperately trying to rework your personal schedule in your mind to complete grooming basics and get to work on time.

Fortunately, prior to my mother's diagnosis, I started attending a fitness boot camp with a friend who had just turned 50. I was 48 and thought this would be great way to jumpstart me into a tougher exercise routine. If my friend had the guts to do it, I thought, so could I.

So there we were in January, in Houston, 35 degrees, from 5:00 a.m. to 6:15 a.m., walking, jogging pitifully slowly, attempting sit-ups, pushups, planks, weights, stretch bands, and team activities. I had documented evidence I was the worst in the group. It was physically and emotionally painful, and was my reality check to get my body back in shape.

Boot camp couldn't have come at a better time. One month later in February, my mother received the news she might have cancer and elected to come to Houston for care. My sister was

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already staying with us for eight weeks to complete an internship. My mother and father then came in late February to stay with us for her work-up, final diagnosis, and then, as life would have it, treatment. Our two-bedroom, mid-century ranch was suddenly full of people, with Dad, in particular, needing time, space, and patience with his medical care. I was glad we were all together. We had not been together as a family in decades and it was a good, but poignant time for us.

Getting up first thing in the morning to exercise before everyone was awake was truly a God-send. At one time in my early life, I had been a member of the 5:00 a.m. rising club, but over time, I transitioned to the 6:30 a.m. or later group. Boot camp helped reset my “rising clock” and I could “TCOY” before anyone else woke up.

During the first boot camp round, my mother was in the diagnosis confirmation phase. I woke up at 4:30 a.m. and found it was nice to start the day off with energy and not worry how to fit “TCOY” in between 8:00 a.m. and 11:00 p.m. Just get up early and get it done. Working on my poor physical condition helped me improve myself to get through what was to come later. By the time I got back at 6:30 a.m., I had time to spend a few moments with Mike, make sure Dad was up, spend a few quality moments with Mom, manage breakfast, dishes, garbage and get ready for work.

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As I started the second round of boot camp in April, mother started her first round of chemotherapy and radiation. She was also in the hospital for short stays to manage the fluid accumulation in her left lung. The cancer in the pancreas was pushing on her lungs causing a reactionary pulmonary effusion, or fluid build-up, in her left lung. The fluid needed to be drained, an exhausting process that took a month of weekly treatments. To extract the fluid, the doctor inserted a needle about the size of a turkey basting needle into her back. Although the area is anesthetized, the decompression is very painful. There is also a possible complication of a collapsed lung, so the procedure is done under fluoroscopy. Several x-rays are completed after the procedure to ensure the lung has not collapsed. Mother and I would hold hands and pray during the procedure, and count down as the one to two liters of lung fluid flowed into the bottles.

I was physically progressing, but the best benefit was the de-stressing the exercise provided me. I had an outlet for the stress and the “brain effects” that were happening in my mind. I could shake off the emotional need to be with her when I needed to consider her needs first, and not my own. I could come back to the house and better emotionally manage seeing my mother propped up in bed, praying her rosary with my dad by her side, propped up in his electric recliner. I could look at her and imprint her facial

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image in my mind. We were on a six to nine month timeline now, maybe a year. So many questions, so many things to do, so much I wanted to remember.

Once boot camp was done, I asked myself, “Now what?” “TCOY” can also manifest itself in strange ways you can’t initially imagine. I had not improved my jogging distance much during boot camp. I’m sure it was a mental thing. I hated jogging. As I battled with myself over whether to continue to focus on maintaining my health, I was reminded that we all have to do things we hate. After all, I was sure my mom hated cancer, too.

During a vacation with my in-laws, on a cool, beautiful day, I had my Forrest Gump moment. I jogged a quarter mile non-stop. I felt pretty good so I jogged to the half-mile mark, then three-quarters, then finished the full mile. May not sound like much, but for me, it was a vast improvement. Inspired, I set a goal over the course of the summer and bumped up my distance to a slow and steady three miles. Perhaps unconsciously, jogging was my cancer; my personal enemy to beat.

Stranger things happened. I love gardening, but couldn’t motivate myself to plants that spring. My usual habit was to overbuy and then overcrowd flowers, herbs and vegetables into my small horticulture bed. This year, I could not find the energy or desire to buy and then plant. But in July, I became fixated on basil.

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I ordered seeds and planted 10 kinds of basil. There was basil everywhere. There were trays all over the patio, on the lounge chairs and tables. I had over 120 basil plants I couldn't get rid of, but really didn't care. I was engrossed in the pleasure of watching the seeds sprout, the first tender leaves tucked in the soil, the glossy leaves of the Genovese, the bushy, spicy leaves of Global, and the subtle licorice of each variety. I made pesto. I made a lot of pesto and gave it away. I gave away armloads of cut basil. In the depths of my soul, I received a sense of satisfaction of giving something away. The heady fragrance was intoxicating and reminded me of other brief pleasures of life.

There were definitely moments I thought I might lose my mind. I was still working full-time and juggling mornings, afternoons and days off to attend Mom and Dad's doctor's appointments. If she was hospitalized, I would make a point to be at the hospital in the morning when the doctors were making rounds, interpret the updates, and assist with the discharge.

Throughout their stay, my parents were adamant about being independent and managing the treatment schedule as a couple. I needed to respect that decision, but also consider their overall safety and that of other drivers in the area. They did not want us driving them to the outpatient cancer treatment center. Although my dad had significant limitations from his cardiac surgery and

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had an arthritic neck, causing loss of mobility and rotation, and my mother was now on narcotics, they wanted to drive together. And my dad wanted to actually drive. What to do?

To our knowledge, a doctor had never actually told Dad he could not drive, therefore, it was difficult to force the issue. Finally, I rode with my dad and observed his ability to navigate the route. We found some easy back roads to the cancer treatment center and luckily, her treatments were not scheduled during peak traffic times. It wasn't ideal, but it was manageable. I couldn't forsake the discomfort of arguing with wanting what was best for them – to be able to support each other during this time. So Dad drove Mom the three miles five days a week for six weeks to treatment and I went to work praying hard they made it safely home every day.

“TCOY” also includes career and work. Let's face it. Personal matters cannot be considered in assessing professional performance. As harsh as it sounds, business keeps going and outcomes need to be produced. Fortunately, my organization offered an Employee Assistance Program (EAP), a referral service for employees to help with a wide range of work/life/balance situations. So I added another dimension to “TCOY.” I called the EAP to request personal assistance. I needed someone to talk to

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about my situation and see what I could be doing better, or confirm I was on the “right track.” I was assigned a counselor and went to one appointment. During the first session, my counselor talked more than 50 percent of the time. I thought the session was for me and was disappointed in the interaction. I left feeling dismayed, but willing to give her one more opportunity. But I missed the second appointment due to one of mother’s emergency hospitalizations. I could not call 24 hours in advance, and had to pay the \$100 co-pay. My life lacked structure and emergencies could happen. I didn’t need another “have-to” in my life and cancelled that “TCOY” activity. Fortunately, the EAP also suggested a wonderful service to begin investigating options for Dad.

I submitted my Family Medical Leave Act (FMLA) paperwork. Thank goodness you can use the leave intermittently and your job is protected if your performance meets expectations. But how do you parley out the 12 weeks in a 12-month period when you don’t know the future?

My plan was to work as much as possible, and meet, if not perform above expectations, communicate with my manager on an ongoing basis, use FMLA intermittently as needed and save as much time for when mother became more incapacitated and needed me more. In addition, the family medical leave for

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mother's condition would end upon her death, so once she passed away, the protected leave would terminate, and any additional time off I would need would have to come from bereavement pay, accumulated time off, or time off without pay. In my case, I probably would need to re-apply for family medical leave to help care for my father as his medical condition was going to require intense family caregiver involvement. We had so many things to consider and strategize that it seemed it would never end. But somehow, in the end, it worked itself out.

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Tips and Words of Encouragement

1. “TCOY.”
2. If you are working in an organization required by law to offer FMLA, and you meet eligibility requirements, talk with your manager and apply immediately. Stay abreast of any changes in the law that may affect you. For more information on the Family Medical Leave Act and employee eligibility, visit <http://www.dol.gov/whd/fmla/>.
3. If your organization does provide an Employee Assistance Program, do take advantage of this benefit.
4. It may seem hard to accept help, but no one says you have to do this alone. Consider your religious organization, a support group, a true confidant or some other service to help you process and work through this difficult time.
5. It’s challenging, but stay focused at work. If you receive compassion, that’s wonderful. If not, it may be helpful to reduce your expectations of compassion in the workplace. Just because you may easily feel empathy and demonstrate compassion, that does not mean others demonstrate compassion as you do. In essence, try to suspend judgment.
6. Your manager may express or demonstrate compassion, but he/she cannot treat you differently, even when you are on family medical leave. Although goals and deadlines may be

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modified based on your availability and work schedule, your overall performance still has to meet expectations.

7. Maintain an open and honest dialogue with your supervisor or manager. Keep yourself updated on the policies and procedures related to family medical leave in your organization and follow all requirements. Do document all conversations for future clarity.
8. Hopefully, you will discover an outlet. Keep your eyes open for opportunities however different or distorted they may depart from your norm.
9. Pray hard. Frequently. Okay, all the time. Arms will come from nowhere. They will embrace you and give you comfort.
10. You are human. You may worry. It's okay. Strength does and will come to you. Be open and receive the strength.

No matter what your knowledge base, caring for a parent with a terminal condition is a loving, courageous, yet chaotic journey. Weaving a soulful and heartfelt story and offering over 90 personal and practical tips, Lisa Boesen draws from both her professional and personal experience of caring for both parents to support the caregiver in experiencing life's natural journey of the dying process, grieving and rejoining life with grace and joy.

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