

DEMENTIA SUCKS

A CAREGIVER'S JOURNEY . WITH LESSONS LEARNED



**Free Sample
3 Chapters!**

TRACEY S. LAWRENCE

Advance Praise for *Dementia Sucks*

“When I face the challenges in my life, I use journaling as an outlet for my thoughts and emotions. Never before have I read someone else’s, until now. *Dementia Sucks* is a revealing journal-based story exploring the rapid decline Alzheimer’s brings about. For all the horror of this disease, the journey of this book reveals something beautiful. You will discover the humanity, the joy, and the hope that is ever present, even in the darkest hour with tears streaming down your face.”

—Mike Michalowicz,
author of *Profit First*

“*Dementia Sucks* says it all in two words. But if you are looking for answers to what is happening with someone you know who seems to be in slow mental descent, or has been diagnosed with dementia, Tracey S. Lawrence has left a brave, revealing and valuable diary in your path. Pick it up and read it. You will find humor, pain, honesty, answers, and proof you are not alone. It is on one hand a manual for the multitudes coming to grips with this broad category of brain disease, on the other a love story. Thank you Tracey for sharing your courageous tale.”

—Gary Donatelli, producer of
23 Blast and director of *One Life to Live*

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TRACEY S. LAWRENCE



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Dementia Sucks

A Caregiver's Journey—With Lessons Learned

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For Roz and Herb
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INTRODUCTION: **SPRING 2017**

Upon hearing my story, many people I meet have suggested I write a book. My usual response to that idea has been, “Sure. When I have time. Ha ha ha.” And being the ever-busy, multiple-hat-wearing person I am, the time didn’t seem right. Until now.

I’ve always been a writer. Any time I’ve been in emotional distress and needed an outlet, writing has been my refuge. I have kept numerous journals throughout my life. They have always been private and I have never shared them with anyone. They are my personal ravings. No one else needs to read them.

Caregiving my mother changed that.

I had taken my mother into my home in northern New Jersey to live with my husband and me when it became clear she could no longer live independently, in April 2010. When I brought my mother back to her apartment in Florida in October of that year, I knew it was the beginning of the end for her. And being alone with her for so many hours in that depressing apartment she and my father had once shared, I felt the acute need to write. And I thought, maybe what I’m learning here could have value for others. What the hell? I’ll create a blog.

I kept it going from October 2010 until my mother’s passing in April 2015. I didn’t realize quite how much I had recorded.

Upon review, it dawned on me that the book I needed to write was pretty much written. It just needed some polish.

Looking back, it's interesting to observe how much I'd forgotten. I'm glad I documented what happened. It's good to be able to appreciate all we were able to overcome.

I think it's also important for readers to understand why this is written in the "present tense" when it's so clearly my history. While I felt compelled to clean up the original material, I didn't think it necessary to disguise that it was derived from journal entries. It's more real, honest, and immediate in its original form.

During the course of this journey, I was compelled to start a business applying what I learned in the service of others. I'm not here to sell you anything. But if you come away with anything from reading this, I hope it will be, at bare minimum, that illness is a family affair, and being proactive can save your life.

Denial is human. Procrastination is too. But so is dementia. And long-lasting illness. And death. You can prepare for it, or take it as it comes. Believe me when I tell you that dementia really does suck. But it sucks a lot less when you've planned for it.

Read my story. Understand that this doesn't just happen to other people. It happens to most of us in some form.

And if you're one of the lucky ones to whom it does not happen, please let me know how you did it so I can share your secret with others.

—Tracey

CHAPTER 1: **DROWNING IN STUFF**

October 10, 2010



Bob, Mom and Me, Easter 2009

As my mother's mental state continues to deteriorate, I cling to my own sanity, trying to make some sense of what's happening to her. She is eighty-one years old.

Having lived on her own in southeastern Florida following the death of my father in July 2004, in time it became clear that she was not functioning well. Money she withdrew

from the bank kept disappearing and turning up in places like her clothes hamper. She claimed there was no heat in her apartment when it got cold, but I now suspect that she simply didn't know how to turn it on.

In February 2010, I brought Mom north to try living in a senior apartment twenty minutes from my home in Ringwood, New Jersey. (A small jewel of a town at the north-eastern border of the state, Ringwood is about 40 miles from midtown Manhattan. It gives me access to the city I love as needed, while affording me the joy of spending my days surrounded by trees, mountains, lakes, critters, and fresh air.) She tried it out for a few months. I took her furniture shopping to make the place more comfortable and homey. She still hated it and complained that it was too expensive. I took her to look at other places, and she finally admitted that she would prefer to live with my husband, Bob, and me.

Living with us had been the first option I had offered her, and we had tried it in 2009 for four months as she recuperated from the removal of her gallbladder. She didn't want to "intrude" on us, so once she felt well enough, she returned to Florida. Defusing her initial resistance, I hired an aide to help her four hours a day, five days a week. Mom actually enjoyed the freedom of having a "personal assistant," but the caregiver soon found a full-time job elsewhere and Mom didn't want to try another one. Her attempt at resuming unaided independent living wasn't working.

As I had told her the first time around, of all the lousy options available, living with us was the option that sucked the least. In April 2010, Mom moved into our guest bedroom, and we've been acclimating, making changes to the house, seeking legal estate advice, providing her with a space

heater to keep her room a balmy 90 degrees, and getting her medical needs met.

We still have to deal with her apartment. Fortunately, Dad left her in good shape financially, and we aren't pressured to sell her place immediately. It's a co-op with a great view and fairly low maintenance costs. It is filled with artwork, bric-a-brac, clothes, and remnants of the once-happy consumer frenzy my parents enjoyed together. I've brought Mom down to deal with some of it. Sort, identify what might have value up north, throw out what's expired, useless, or shot, give away what might have value for others, and leave what makes the apartment functional when we need to be there.

My folks bought this two-bedroom, two-bath split on the fourteenth floor overlooking the Intracoastal and Atlantic Ocean beyond in 1987 for eighty-five thousand dollars. At the height of the market ten years ago, similar apartments sold for 350 thousand dollars. Then the crash of 2008 sent the values into the toilet. Comparable apartments now go for about 150 thousand dollars. I think we'll sit for a while, but we still have to start dealing with all this *stuff*.

Mom did give away most of Dad's clothes and personal effects within the first year after his passing. But there is still so much accumulated junk in the five walk-in closets, it's overwhelming. And Mom needs to go through her clothes. She needs warmer items to wear up north as winter approaches. She's lost considerable weight over the last year or so. The gallbladder surgery forced her to curtail the amount of food she ate, and later, she experienced toxicity from all her medications. I got her prescriptions adjusted, and she's on less than half the pills she was before. Losing weight addressed many of the conditions from which she had been suffering,

so she needs a lot less medication. But now we need to figure out what fits her and what doesn't.

The big problem is that she constantly misplaces things. I have managed to narrow down this problem to four reasons: 1) her eyesight is questionable, 2) she spaces out and compulsively puts things together that don't really belong together, 3) she doesn't like to throw things away, 4) she has *way* too much *stuff*.

Having dealt with my father's dementia seven years ago, I've educated myself about the disease, and I'm confident Mom doesn't have Alzheimer's.¹ Day to day, she knows what's going on and remembers important events. She forgets names. She misplaces important items and gets agitated when she can't find things. She's easily distracted. However, she's not paranoid; she knows it's her and she does trust me. So it could be worse.

Meanwhile, I'm trying to keep her on track, focused on the tasks at hand. She avoids my repeated requests that she try on clothes so we can figure out what items should go north, and what should get donated or chucked. It isn't easy, but as my dear father once opined, no one said it was going to be.

¹ I was wrong. Mom did, in fact, have Alzheimer's disease.

CHAPTER 2: **OH, CRAP**

October 11, 2010

One of the few pleasures I have when I'm down here in Florida is swimming in the pool. It's not exactly Olympic-sized, but it's convenient, refreshing, and situated right on the Intracoastal Waterway. And as any caregiver worth her salt can tell you, finding the time for regular exercise is especially important.

Today, after I finished up with Mom for the morning, she was settling in for an afternoon nap, and I went down to the pool. A fellow in a maintenance uniform was opening an industrial-sized barrel of chemicals. I figured he was doing regular pool upkeep. As I walked toward an umbrella table to put down my things, the pool guy looks up at me and tells me I can't swim. "Somebody pooped." He went on to inform me that he was going to put an extra-heavy dose of chemicals in the pool and that there would be no swimming for another two to three days. Just in time for our departure.

Huh boy.

Not wishing to have my fitness thwarted by such a disgusting impediment, I went back upstairs, changed my clothes, and went to walk along the Hollywood Beach Boardwalk. I saw sailboats on the Atlantic. I observed the changes to the local bistros, parks, and hotels.

Tomorrow, I think I'll rent a bike (weather permitting).

When I got back, Mom had actually gone through her clothes; she's pared down the cache of winter clothes she wants to bring back north. Progress has been made.

In spite of the challenges presented earlier in the day, I suppose we could mark this day as being flushed with success.

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CHAPTER 3:

FALSE ALARM

October 12, 2010

Mom likes to hold on to old drugs. She has bottles of my father's prescription painkillers that expired before he did. She keeps them "just in case." I sneak these into the trash whenever I can without her noticing.

The other day, I had been sitting out on the terrace, reading. I walked into the kitchen and spotted a scrap of paper on the kitchen table. On it was inscribed a very sad poem in my mother's handwriting. The words were of love and loss. The last line was "Goodbye." On the table, next to the note, were some empty pill bottles which had once contained Valium and oxycodone.

Now, Mom has been depressed since Dad died six years ago. She has expressed the wish that her life would end. Her morbid attitude was one of the driving reasons for bringing her to live with us in the first place. I know in my heart she doesn't have it in her to end her life by her own hand. However, doing the math (note + empty pill bottles + closed bedroom door), I got a little nervous and walked into Mom's bedroom.

I observed Mom sleeping on the bed. She was breathing normally. I went in and touched her arm. She opened her eyes.

"Everything okay, Mom?"

She responded in the affirmative. I went back to the kitchen to retrieve the note and I showed it to her. She put on her glasses, looked at it, and explained that she had been trying to recall the lyrics of an old favorite torch song from the days of the Dorsey Brothers. Then she sang the song. Mom still has a pretty voice.

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ABOUT THE AUTHOR



Tracey and Penny

Tracey S. Lawrence was born in 1958 and raised in Brooklyn, New York. Her mother, Rosalind, was a “homemaker” and her father, Herby, owned “taverns.”

Excelling in academics and fine arts, Tracey graduated from NYU with a Bachelor of Arts with honors in Psychology at the age of twenty.

She worked as a PBX telephone operator at Macy’s Herald Square and as a marketing assistant at a Japanese travel agency in Rockefeller Center (which afforded her the opportunity to travel to the Orient as a tour escort at twenty-two). She also worked for a small advertising agency and found her way into the graphic arts industry as a typographer. She worked at the leading type shops in New York until the demise of the industry in the 1990s.

Acquiring desktop publishing and production skills, she eventually started her own company, Graphic Detail, Inc. Creating artwork, brand identity pieces, websites, and more, her problem-solving nature led her to continue learning. She taught professionals and undergraduates best practices in file creation with her real-world experience.

When her father got sick in 2003, Tracey took on whatever tasks were necessary to help her family cope. Herby died of congestive heart failure (and many other ailments, including dementia) in 2004.

In 2005, Tracey enrolled in a challenging program at NYU and received her Master of Science in Digital Imaging and Design in 2007. She learned video editing, animation, and broadcast design. She serves her town in northern New Jersey by running their public access TV station.

Tracey and her husband, Robert “Big Bob” Bruning, have been married since 1991 and have lived in Ringwood, New Jersey, since 2002. Together they provided ongoing care and support for Tracey’s mother, Rosalind, as she tried to live independently in Hallandale Beach, Florida. They brought her into their home as her condition deteriorated. Rosalind died on April 14, 2015, on her sixty-fourth wedding anniversary.

Caring for Rosalind gave Tracey a unique perspective on caregiving, keeping a journal in the form of a blog in order to help others learn from her experiences. Her observations formed the basis of this book.

The team Tracey assembled to help with her mother became the core of her new company, Grand Family Planning LLC. Seeking to take some of the stress out of preparing families for their journeys, she is focused on education, outreach, and provision of coordinated services to enable families to

protect themselves from the ravages of a system unequipped for the coming tidal wave of aging, needful people.

Tracey is also a classically-trained rock singer, most recently having performed with a cover band called *Just Play*, with her husband, Bob, on bass and vocals. Their adorable Yorkie, Penny, and their sweet cat, Fletcher, complete their little family. They also enjoy spending time with their nieces, Danielle, Erica, and Jessica, and their respective significant others, as well as Tracey's brother, Seth, and his wife, Teresa, and nephews Alex, Greg, Jonny, Michael, and their dog, Lola.

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CONNECT WITH TRACEY ON SOCIAL MEDIA

Tracey S. Lawrence is the founder of Grand Family Planning.

The website is: <http://www.grandfamilyplanning.com>

Email: tracey@grandfamilyplanning.com

Facebook Page for “Dementia Sucks”:

<http://www.facebook.com/DementiaSux/>

Twitter: [@DementiaBook](https://twitter.com/DementiaBook)

Instagram: [dementiasucks](https://www.instagram.com/dementiasucks)

The surprising true story of one woman's journey through the nightmare of losing both parents to dementia, as she learns that a sense of humor is mandatory for survival.

"Not buying it, huh?" My mother acknowledged her assertion that the woman she pointed out at the rehab center as being her dead husband was a bit of a stretch. But this was the kind of conversation I had with Mom as her cognitive abilities declined and her psychosis fully bloomed.

The true, heart-wrenching, and yet hilarious stories at the center of *Dementia Sucks* were borne of a journal and blog that author Tracey Lawrence kept as her mother transformed from classic Jewish mother, to mildly forgetful Floridian grandma, to geriatric delinquent removed by police for knife-play at a rehabilitation facility. Really.

Tracey's journey takes her from being an established graphic artist in northern New Jersey through bouts of full-time, hands-on caregiving of both her aging parents. She discusses many of the common challenges families face, and provides a humorous and highly educational perspective on her emotionally charged ride through geriatric illnesses, doctors, hospitals, insurance, facilities, family dynamics, and much more.

Anyone who has family members they care about will want to read this book. Whether dementia visits or not, some aspect of Tracey's caregiving journey will likely resonate with, amuse, and enlighten you. The trick to surviving loss after loss is to find the humor in it all and avoid punching anyone, least of all yourself. This irreverent look shows you the way.

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