

**Not Now, Cancer,
I'm Busy**

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Facing a Health Crisis
in Early and Midlife

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Universal-Publishers
Irvine • Boca Raton

*Not Now, Cancer, I'm Busy:
Facing a Health Crisis in Early and Midlife*

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Universal Publishers, Inc.
Irvine • Boca Raton
USA • 2022
www.Universal-Publishers.com

ISBN: 978-1-62734-397-8 (pbk.)

ISBN: 978-1-62734-398-5 (ebk.)

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Typeset by Medlar Publishing Solutions Pvt Ltd, India
Cover design by Ivan Popov

Library of Congress Cataloging-in-Publication Data

Names: Trevathan-Minnis, Melissa E., author. | Meeks Brown, Deanne, 1966- author.

Title: Not Now, Cancer, I'm Busy : Facing a Health Crisis in Early and Midlife /
Melissa Trevathan-Minnis, Deanne Meeks Brown.

Description: Irvine : Universal Publishers, [2022] | Includes bibliographical references.

Identifiers: LCCN 2022022560 (print) | LCCN 2022022561 (ebook) | ISBN 9781627343978
(paperback) | ISBN 9781627343985 (ebook)

Subjects: LCSH: Cancer--Psychological aspects. | Cancer--Patients--Mental health. |
Cancer--Patients--Rehabilitation.

Classification: LCC RC262 .T74 2022 (print) | LCC RC262 (ebook) |

DDC 616.99/40651--dc23/eng/20220714

LC record available at <https://lcn.loc.gov/2022022560>

LC ebook record available at <https://lcn.loc.gov/2022022561>

To Riley, Casey, and Maggie

Deanne

To Cade, who was my motivation for developing a fighting spirit and my reason for smiling on dark days, and to Asher, who was my wish realized and the evidence of my healing. You are my sun and my moon. To Donald, who held onto hope in the moments when I couldn't find it and loved me when I felt broken. To my mom and dad for helping me navigate life and childcare when it felt very messy, and for letting me cry when I needed to most. To my astute therapists and fellow group members who shined a light in a dark tunnel and helped me see my way out. To my close friends who cooked, cried, laughed, and showed up for me. To all the fellow survivors who contributed their stories and quotes. We hope we captured your journeys, too. To Daisy, Oliver, LadyBoots, Ayla, and Torty, who offered their unconditional devotion and calming presence. To Deanne, who willingly and graciously jumped headfirst into this project and stayed the course to completion.

Melissa

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Introduction

A cancer diagnosis or health crisis is a unique and ongoing trauma. At 44, Deanne was young for being diagnosed with breast cancer, which forced itself into a midlife already crowded with a husband, three children, homeschooling, and a rock band. At only 33, Melissa was juggling developing roots in a new city, a burgeoning career, a husband and a toddler, and future family planning when she learned she had colon cancer.

Cancer in people under 50 is becoming increasingly more common. According to the American Cancer Society, in 2018 over 80,000 new cancer diagnoses were given to persons aged 20 to 39 in the United States alone. The Centers for Disease Control lists malignant neoplasms (cancerous tumors) as the third leading cause of death in the U.S. for persons 15 to 44.

A cancer diagnosis at any age is traumatic, but 18- to 49-year-olds, a cohort we call *young and middle adults* (YMAAs), are particularly unprepared. YMAAs carry a unique set of challenges compared to children and older adults. For individuals in this age range, cancers more frequently go undiagnosed until the cancer has progressed or becomes terminal. Clinical trials that could result in life-saving answers for YMAA cancer patients are rare. Balancing cancer treatment with family and career is a dizzying high-wire act, then add fears of bankruptcy and infertility. Anxiety, depression, exhaustion, and hopelessness can sap our mental and physical health—and therefore our reserves of strength for the fight for our lives.

The connection between body and mind means that the trauma of cancer goes beyond the physical. Physical trauma not only begets psychological and spiritual trauma; physical trauma *is* psychological and spiritual trauma. The good news about this connection is that when we treat one traumatically affected area of ourselves, we are also treating the others.

As Cheryl Strayed (2012) points out in *Tiny Beautiful Things: Advice on Love and Love from Dear Sugar*: “The healing power of even the most microscopic exchange with someone who knows in a flash precisely what you’re talking about because she experienced that thing too cannot be overestimated” (pp. 21–22). But resources for people in our predicament—including people to talk to who are in the same boat—are scarce, and the obstacles we face are too infrequently discussed. There are plenty of books on the biology of cancer, the history, as well as the foods you can eat or avoid to give yourself the best odds. But what about dealing with the roller-coaster of emotions after a diagnosis? What about being told you are now infertile? What about facing death at the age of 30, or the constant fear of recurrence? What about dealing with societal shame and self-blame, about the *Why me?* question, about transitioning back to “normal”?

As not only young cancer survivors but also mental health professionals, we know these battles firsthand. We know that bodily trauma and emotional trauma have a reciprocal relationship—and that cancer elicits both. We know that trauma can plant seeds of anxiety, fear, and shame. We recognize how these seeds can grow into maladaptive coping mechanisms. And we know it is necessary to heal these psychological wounds in order to recover and rebuild our lives.

If you are reading these words, most likely you or someone you love has been diagnosed with cancer. We want you to know that we see you, and that you are not alone. We are fellow travelers who have walked ahead of you on this path, and we wrote this book so that you do not have to walk the path of recovery without a compass.

The pages that follow include research and information (which we present with the collective pronoun “we”) in addition to personal stories from each of us, along with insights from other young cancer survivors. All of us, open kimonos—honest, vulnerable YMA cancer survivors sprawled out naked before you, going out on a limb, bucking convention, and living to tell about it. In the Appendix, we also address some possible solutions to the cancer crisis that YMAAs face, in the hopes of reducing this group’s burden. We hope that our stories will help you get back to your life and will prove a useful resource as well as welcome companionship in your journey.

This is not a medical book, nor is it a substitute for medical information. It is essential that you connect with a first-rate medical team, and that you get second, third, and fourth opinions, utilizing the wisdom of as many trusted sources as you can. Being a self-advocate means providing yourself

with as much good information as possible and carefully selecting what is useful to you in your diagnosis.

Although each of us was initially devastated by our diagnosis, it was also a turning point in our lives, which included a shift in our priorities. As many young survivors do, we discovered that despite the obstacles, this challenging journey can lead to exponential growth. Yes, our bodies and minds are fragile, but we—you—are resilient. May this book help you on your journey to becoming a healthier, stronger, and more vibrant you.

*I will stay with it and endure. And if the heaving sea has shaken
my raft to pieces, then I will swim.*

—*The Odyssey*

Part I

**An Untimely Crisis:
Facing a Diagnosis
in Early to Midlife**

Chapter 1

I'm So Sorry—It's Cancer: Prelude to an Awakening

*My body turned a cold back on me, at less than
Forty-three
It started a war
whatever for
in the middle of the middle of my life...*
—Gilda Radner

–Melissa–

This Was Not the Story I Wanted to Write

Mortality is easy to ignore until it whispers in your ear. Until someone looks you in the eyes and recites with rehearsed compassion, “I’m so sorry—it’s cancer.”

The beginning of a story, I thought. I had been working on several writing projects as a professor of psychology, having recently jumped from only seeing clients in therapy to integrating into the world of academia, in part because the flexibility of academia would allow me more time for my growing family. But writing about having cancer was not the story I wanted to write, and facing cancer was certainly not how I wanted to spend my time. It was the last thing I would have chosen for a personal narrative, had I been given license to choose. Yet in that moment, a lightbulb turned on, and some part of me seemed to know that I was on a new journey now—one that warranted documentation and deep personal reflection. So, here we are—in chapter 1 of a book about cancer. Luckily, this book

became so much more than *just* a cancer book, if there is such a thing. It also became the story of how I found and rebuilt myself. Deanne, too, as you'll soon learn.

Up until my diagnosis, my life was beautifully normal. Not perfect, but the product of a lot of hard work and just enough good luck to see many of my hopes and dreams come to fruition. I had faced enough trials and tribulations to know I had a great life. I had earned a PhD and become a licensed and practicing psychologist. My husband and I had moved to Austin less than two years prior to my diagnosis after living as newlyweds in Baltimore for four years and traveling voraciously. Both working comfortably in ambitious careers, we now had a toddler we loved fiercely and were beginning to establish roots in a city we enjoyed, going so far as to invest in land and real estate we had slated for a business, a home, and rescue animals. The sky was the limit. Until the sky started to fall.

The story I had been living had been hijacked by some sadistic novelist, and a doctor I barely knew and didn't particularly like would start to write my next chapter for me. Holding the results of the pathology report from my recent colonoscopy, he began speaking before I had time to adjust to the seat cushion, my pulse racing.

"I'm so sorry—it's cancer." He continued, after a short pause for emphasis, "Colon cancer in a 33-year-old is exceptionally rare, which is why we don't screen for it until people are in their fifties. It could have been one cell that just went crazy. There has been a recent spike in colon cancer patients in their twenties and thirties. Just last week, I heard of a 27-year-old diagnosed. You are my first young cancer patient." (I would learn later that it was stage 3b—a breath away from a terminal diagnosis).

I felt like a two-headed calf floating in a jar of formaldehyde. An anomaly. An oddity. Exceptional in a way no one wishes to be. Now I would add cancer to my list of early accomplishments. *Cancer at 33*, I thought, *exceptional indeed*.

Before leaving, I asked, "Should I be hopeful or prepare for the worst?" Donald, my optimistic, happy-go-lucky husband, trembled as he held my hand. His story had just been hijacked, too. "Hopeful," the doctor said with forced optimism, as if he didn't really believe it.

Donald and I drove home to find our son, Cade, and my mom playing in the front yard, Cade wearing his favorite rain boots and a Stormtrooper costume. As Donald explained to my mother that her daughter had a mass in her colon too large to remove, I listened, perplexed and paralyzed in

fear—not of death per se, nor of being gone, but of leaving, abandoning my family. That thought was an unbearable hurt. Having lived through several divorces as a child, I'd struggled with my own abandonment baggage—and so I'd be damned if I'd leave my own child.

I watched a video once of a skateboarder who landed wrong after attempting an ambitious trick and broke his arm. Instead of turning away at the sight of his mangled limb bent at an unnatural direction, he stared with fascination or confusion, as if he couldn't quite believe it was his arm. Walking into the house, my tiny boy leading me by the hand, I understood exactly that feeling. Instantaneously my life had been contorted, and all I could do was stare blankly.

I went outside and called my dad. I was hardly able to communicate, and the call was short. "I don't think God's through with you yet," he said, then offered a measured prayer through tears. I remembered being seven or eight years old and driving between Amarillo and Lubbock, Texas. We began hearing reports of a tornado in the area, but because we were driving we were unsure whether we should turn around or keep going. Eventually the winds picked up, and we parked under a bridge, my mom, grandmother, and I huddling together in the front seat. Soon it became clear that the tornado was close. My mom started to pray, almost yelling as she begged for help: "Please, God, protect us!"

The tornado didn't scare me—I was too young to grasp the implications. It was the emphatic prayer of the person whose role it was to protect me that struck terror in my young mind. Now, listening to my tearful father petition God for help, I was a scared kid again as I realized that no one—not my parents, not even doctors—could spare me from what was coming.

The next day, I maintained my composure as I drove Cade to preschool—a small, charming Montessori cooperative school that a few other families and I founded and facilitated out of a friend's home. I was highly involved not only in my career but also in maintaining this community for my son, as well as my time with him. I knew all of that was about to change. I'd occasionally steal glances through my rearview mirror at the beautiful child for whom I felt so grateful, and I'd look away each time sentimentality began to overcome me. In conversation with a friend the previous week, I had offhandedly mused on the optimal time to have a second baby, saying I planned to wait another year before trying to get pregnant. Now I prayed I'd be alive to finish breastfeeding this one. How could I be

an effective parent while dealing with cancer? Would I be able to continue working? Should I reveal my diagnosis to colleagues or keep it under wraps? Would all of my family's dreams come to a halt? Would our savings all go up in flames? Would any of my friends still be able to relate to me?

As Cade sang and danced with classmates as we walked into the building, I greeted a pair of good family friends bringing in their own child. Typically, I would have stayed and chatted, but watching Cade play, with no knowledge of the disease that had infiltrated his innocent life, brought me to tears, and I turned away from them. I hugged Cade from behind and rushed out before he could absorb my heartbreak.

"Oh, Cade's lunch!" his teacher shouted as I walked away. I had forgotten I was holding that and his water bottle. I ungracefully dumped both onto the kid's picnic table and practically sprinted to my car before driving away with tears streaming down my face, thinking, *Whose life is this?* Things had changed so quickly.

That day, I knew I would never be the person I had been just two days earlier. But what I didn't yet realize was how the curse of a cancer diagnosis, and all that was to follow, would change me for the better, opening me up in new ways to life, love, self-reflection, and self-compassion. And while it was my body that was demanding attention on that day, it was speaking for my entire being—body, mind, and spirit. Busy with my life and family and career and now this small preschool, I would soon begin to realize that I had been ignoring my own needs for too long, too busy to heed the warnings that my body was sending. But my bleeding colon, and the cancer that caused it, was the impetus for an awakening.

—Deanne—

The Perfect Mess

I do not believe cancer is what happens to other people. I know better. My grandmother died of colon cancer, and my grandfather died of mouth and lung cancer. At 21, before I was born, my dad was diagnosed with giant follicular lymphoma, or non-Hodgkin's disease. But he survived. Maybe that is why I was eerily calm when the call came.

"Where are you?" the radiologist asked.

"I'm driving."

"I'll call back," she said.

That's when I knew I had cancer. "No, hang on a sec." I pulled off the road onto a dark neighborhood street. Maggie—my mature and anxiety-ridden 10-year-old daughter—objected, worried that she would be late for her weekly tutoring session at the local library. I reassured her that we would make it on time.

"Deanne, you have invasive ductal carcinoma and ductal carcinoma in situ, high nuclear grade," she told me. She did not know what stage yet—that would depend on the MRI and whether the cancer had spread to other parts of my body. "You'll probably need a lumpectomy, some chemo, a little radiation, and hormone therapy," she added, as if prescribing decongestants and nasal spray for the common cold.

As it would turn out, things were worse than she thought. The cancer had already broken through my milk ducts and grown into the fatty tissue of my breast. It would be several more invasive tests, doctor's appointments, and sleepless nights before I understood the extent of my situation.

It is strange to hear someone tell you that you have cancer. You hear the words, but you do not quite feel their sting. There is a disconnect of sorts, like watching two people having a conversation on television after pressing the mute button. The people's lips are moving, but you have no idea what they are saying. I don't remember driving the last few miles to drop Maggie off. I called my husband from the library parking lot. It was late, but he was still at the office, having just started a new job after being out of work for an entire year.

"Reorganization," they said when they laid Kevin off. It was the 2008–09 recession. It was in fact the most dramatic economic downturn since the Great Depression. For a while, we lived off our 401(k) and our wits, doing our best to hold on to a trace of normalcy and sanity. To our relief, the bank had allowed us to defer our mortgage payments, but now they were demanding the last three payments, plus interest. We couldn't pay. Already faced with losing our home, I was now confronted with losing my breast—or worse. I began to shake uncontrollably as I listened to the ringing on the other end of the line, feeling bitterly cold even though the warm Santa Ana winds were blowing.

He answered with a big "Hello!," finally sounding happy after struggling so long to find work. I hated to deliver such foreboding news, but I told him what little I knew. I found myself apologizing, as if I had done something wrong. We had already been through so much—I didn't want to bring on more stress. Kevin asked a few questions, then said, with his usual excessive

optimism, “Deanne, everything is going to be okay. We’ll get through this, too.”

Somewhere deep inside, I knew he was right, yet my rational brain could not ignore the fact that women die every day from breast cancer.

The call was quick, and then I was alone. Utterly alone. Sitting in my car in a dark parking lot, I began to repeat “I have breast cancer,” over and over again, emphasizing each word in turn, as if reiteration would dull the impact. Despite the shock, I felt a strange lucidness. Instead of wondering *Why me?* it was more like: *Of course, why not me? I am human, just like my grandmother, grandfather, and father. No more or less special. Cancer is a fact of life for many, and now I am faced with that fact.*

My first suspicion that I had cancer had come a week earlier while doing the dishes one evening. I was distracted by an annoying pain in the lower part of my right breast. I went to my bedroom, slipped out of my bra, and massaged the area, like rubbing your feet after dancing in high heels all night. Then my hand and heart stopped. Located an inch below my nipple near the crescent was, for lack of a better term, a lump the size of a marble, except neither smooth nor round. It was fixed, as if stuck in concrete—not at all what I expected cancer to feel like.

Doing my best to stay in control, I called out to Kevin. “What is this?!” I shrieked as I placed his hand on my breast, then whispered, “It’s a lump,” afraid that saying it too loud would make it true.

Today, I know from my training and experience as a therapist that naming a thing doesn’t give it power. Quite the contrary: doing so gives *you* power. But I wasn’t privy to this yet. After saying goodnight to my two six-foot-tall teenage boys and tucking my daughter into bed, I could not sleep. I tossed and turned as my mind vacillated between sheer panic and the belief that everything would be fine. I woke up early the next morning and called my doctor, who told me to come in at 11 a.m.

Today? I thought, both shocked and relieved by the urgency. It was Kevin’s birthday, and our 20th wedding anniversary was a few days later. I had a busy day ahead of me—cleaning, shopping, cooking dinner for the planned celebration. Plus, I had to get the boys to their music lessons, Maggie to soccer, and I had to pack. We were heading to Phoenix—my hometown—for the Thanksgiving holidays. Now I had to make room for one more thing.

It’s astonishing how quickly one’s life can change. I had just turned 44—*young* for breast cancer—but I didn’t feel young. But neither did I feel old. I was sandwiched between the first and second halves of life.

With three kids to raise and reeling from the aftereffects of my husband's layoff—not to mention a separation from him a year earlier (more on that later)—I was simply not ready to take on cancer, too.

Midlife is not an easy time to be faced with cancer—not to imply that there is ever an easy time. Although I counted my many blessings—living in Southern California a stone's throw from the beach, a loving community of homeschooling friends, and a family I treasured—midlife can be particularly difficult, a time when one's fairly homogenous life may get stirred up a bit, especially if dealing with rebellious teenagers, aging parents, debt, job loss, or divorce. A shift in how many of us see ourselves during this time—in some cases, an identity crisis—is not uncommon, as we begin to realize the ambitions that ruled countless decisions in our early adult years are no longer relevant or serve our soul. If not carefully navigated, this shift can have lasting effects.

I saw this play out in my own life. The old way wasn't working anymore. Life was difficult now. Kevin's job loss, losing our home, and the stresses of marriage were piling up with the bills. Everything we worked so hard for during those last two decades we either lost or didn't seem to matter like it once did. Then add cancer to the mix. It was as if a meteor had come crashing down from the heavens at 26,000 miles per hour. Precious moments with my family and friends pilfered little by little by a few out-of-control cells. Every ounce of normal—or what I perceived as “normal”—was gone. *Poof!* Faced with so many uncertainties, I was scared. *Where are we going to live? How much money is left in our savings? Do I need to get a job? Can I continue homeschooling? The treatments and doctor's appointments—how will I get through it all? Will I die? What will happen to my family? Oh god, my children!* The thought that I may not be there for them was too much.

When I was a little girl, I could never rip off a Band-Aid. I wouldn't allow my mom to do it, either. Instead, I would let it come loose of its own accord, bit by bit, until days later it dangled there, blackened and frayed around the edges, finally falling off when I least expected it. I was hoping cancer would do the same—just disappear while I wasn't looking. But avoidance and denial were not options. So I gathered every amount of energy I could muster, and I fought like hell to regain my health, and my life. My doctor was spot-on the day of my diagnosis when she emphatically told me, “Deanne, you have a new full-time job.”

So while my peers were heading off to work or chauffeuring their kids to soccer games, I was driving to and from doctors' offices. While they were

volunteering at school or going out to dinner, I was in surgery or hooked up to an IV slowly dripping poison into my veins. While they were getting their hair done, I was buying a wig. While they were reading the classics, I was reading *Anticancer: A New Way of Life*. While they were trying to live in the moment, I was trying to stay alive for the future. I was angry that cancer had stolen my 45th year from me, and I ached to be like how everyone else seemed to be at this stage of life: normal and oblivious to their own mortality.

One evening, after a particularly difficult day of juggling doctor's appointments and getting my kids to where they needed to be, I had a revelation. While emptying the dishwasher to make room for the dinner dishes to come—a never-ending chore in our home—several glasses slipped from my fingertips and shattered on the Saltillo tile. The crash was deafening. Barefoot and mystified, tears welled in my eyes as I surveyed the damage. It was as if the last few years of our lives had just smashed into a million tiny little pieces. I was struck by the strange beauty formed by such disarray. Shards of glass littered the kitchen floor like constellations in the November sky. Each luminous piece seemed precisely and painstakingly positioned by something beyond my understanding. It was the perfect mess—which I will come to realize was the key to my healing. For out of suffering and imperfection comes adaptability, creativity, and grace—essential elements in overcoming any traumatic experience.

Upon hearing the crash, the kids rushed into the kitchen. Without saying a word, 17-year-old Riley, the eldest of the lot, came and wrapped his arms around my trembling body. Normally he would rather hug a cactus than his mother. “I love you,” he whispered, then handed me my shoes and fetched the broom from the closet, and together we swept up the mess.

Chapter 2

Cancer Has Found Us: The Impact on YMAAs

It took me seven years to realize I wasn't alone. I believed for seven years that I was the only 20-something with cancer in New York City.

—Matthew Zachary, Stupid Cancer Founder

A Growing Epidemic

Our cancer diagnoses reflect a growing trend in the United States today. The rate of colorectal cancer has more than doubled among adults younger than 50 in the last 30 years. It is also a leading cause of death among people under 50, and there is no evidence of this trend slowing down (Siegel, 2020). The same holds true for breast cancer. Between 1976 and 2009 there was a greater increase in the incidence of breast cancer in 25- to 39-year-olds than in any other age group (Johnson, 2013). Skin cancer presents a similar case, with melanoma rates increasing by 250 percent over the past four decades (Mitsis et al., 2015).

While there are no hard-and-fast lines encompassing a given age bracket, for the purposes of this book we consider YMAAs (young and middle adults) to be survivors between the ages of 18 and 50.

Research suggests that some cancers may develop differently in YMAAs than in other cohorts. For example, a recent study found distinct differences in the characteristics of cancer tumors in younger patients compared to older patients. Breast cancers in young adults are usually larger, frequently possess the triple-negative phenotype, and are associated with