



A Legacy of Madness breaks down the barriers of silence
that shroud mental illnesses within families for generations.

—ROSALYNN CARTER,

Former U.S. First Lady and Chairperson, the Carter Center Mental Health Task Force

A LEGACY OF MADNESS

Recovering My Family
from Generations
of Mental Illness

TOM DAVIS

A LEGACY OF MADNESS

Endorsements for *A Legacy of Madness*

A Legacy of Madness breaks down the barriers of silence that shroud mental illnesses within families for generations. It also details the larger problem of stigma and the failures of a system ill-equipped to provide adequate treatment and support. By sharing the story of his family history and his own personal journey, Tom Davis provides hope and inspiration to others.

—Rosalynn Carter, Former U.S. First Lady and Chairperson,
the Carter Center Mental Health Task Force

This is a book from the heart, and for any family with somebody who has mental illness, this is a must-read.

—Former New Jersey Governor Richard Codey,
Mental Health Advocate and Author of *Me, Governor?*

A LEGACY OF MADNESS

Recovering My Family
from Generations of Mental Illness

TOM DAVIS

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The names, details, and circumstances may have been changed to protect the privacy of those mentioned in this publication.

This publication is not intended as a substitute for the advice of health care professionals.

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CONTENTS

Preface		VII
Chapter 1	The Awakening	1
Chapter 2	Awareness	21
Chapter 3	Paradise Lost	47
Chapter 4	The Working Life	69
Chapter 5	The Sobering Life	95
Chapter 6	The History	127
Chapter 7	The Blues	151
Chapter 8	Eating Disasters	175
Chapter 9	Deliverance	201
Chapter 10	The End Is Just the Beginning	221
Epilogue		255
Acknowledgments		271
About the Author		275

PREFACE

A CENTURY AGO, THE SYMPTOMS of mental illnesses such as schizophrenia and multiple-personality disorders, among others, were well-known. But there was a dearth of treatment options that could have saved the millions who suffered. Many people with mental illness were locked away in psychiatric hospitals—or facilities commonly known as “asylums”—and treated in decrepit, inhumane conditions.

At the time, on October 4, 1928, my great-great-grandmother, Lydia Winans, and her son, Frederick, ended their long, yet troubled lives by flipping on the gas jets of their kitchen oven and suffocating themselves. Five years later, Lydia’s other son, Edward, did the same thing, taking painstaking care to make sure that he was more successful in death than he was in life. They found a way out because there was no way back in, since their only alternative was evaluation, medication, and then a world of confinement or mistreatment.

All three were believed to have suffered from symptoms that would eventually be identified as obsessive-compulsive disorder or neurosis: perfectionism, low self-esteem, depression, and fear. None of them were ever diagnosed, because all of them likely feared the consequences.

In the 1950s and 1960s, psychotropic drugs that could have alleviated my

PREFACE

family's symptoms of mental illness became more prevalent. My grandfather, Richard, who was Edward's son, saw many of these advances while serving as personnel director at Greystone Park Psychiatric Hospital in Morris Plains, New Jersey. Ironically, he was a sufferer himself; some say he took the job because he saw much of the same sickness in the patients that he saw in his family—and maybe even in himself.

Instead of seeking treatment, however, Richard, who was known as Dick, chose the path of his ancestors, using alcohol to suppress his own symptoms of obsessive-compulsive disorder (OCD)—particularly his perfectionism and fear of germs—that would eventually overwhelm him too.

As my mother Dede battled postpartum depression in the late 1960s, she became an alcoholic, and her fear of germs became much more pronounced after her third pregnancy. She was the first member of my family to be treated for mental illness; as a result, she was the first to be diagnosed with obsessive-compulsive disorder. Like her father Dick, she was ultimately overwhelmed by those symptoms. She died in 2003, decrepit physically and emotionally, never having fully recovered after two long stints in Ancora Psychiatric Hospital near Camden, New Jersey.

As my mother's condition steadily deteriorated, my brother and I suffered from anorexia and bulimia, and I have been diagnosed with obsessive-compulsive disorder. I have, at times, found myself heading down a familiar destructive path, and I've sought assistance through counseling, psychiatric treatment, and medication.

But I feel like I'm on the back end of a long, perilous ride that came to a head on January 18, 2003, the day my sister found my mother dead.

I never feel safe.

Even after generations of my family suffered, and died largely because of their inflictions, my family had very little contact with mental health professionals, and we read very little material that could have guided us as we battled the symptoms of mental illness. We knew my mother's repeated hand washing, her fear of germs, and her stubborn possessiveness were signs of neurosis. I knew my tendency to force myself to vomit

PREFACE

as a way to relieve stress and fear didn't seem right. But we followed the path of self-destruction rather than treatment, largely because we chose the path of ignorance and fear. Treatment and the unknown, downright scary consequences of it were, as many say, a fate worse than death.

We knew that many of the same problems that existed when my grandfather was personnel director at Greystone, from 1949 to 1979, remained. Housing at mental health facilities was still overcrowded. Treatment options and insurance coverage to pay for them were lacking. Psychiatric facilities that took insurance, and provided what could be considered the right level of care, were scarce.

Perhaps most important, the stigma of diagnosis has been, and still is, the kind of thing that could destroy a reputation, kill a career, and ruin a life.

Since I was a child, I've often wondered why I am so imperfect, why my mother wasn't a so-called "typical" mother, and why my father was so stressed about it. I had the belief that other people didn't experience the same issues. I'd see people participate in sports or Cub Scouts and they just seemed too perfect. To me, they always seemed to have "perfect" clothing, to be "perfectly" groomed, and to be "perfectly" mannered. My family was jealous, because we knew we'd never be like them.

Now, as a parent, I've come to understand that the so-called perfect people are often more imperfect, more ignorant, and more helpless than I had ever imagined. Standing on a playground for an hour and talking with parents whose children play with your children can lead to some interesting revelations. You find out things about others that are surprising, if not shocking.

I still encounter people who don't fit the image of people who are suffering through mental illness. But, once I get to know them, I ultimately learn that they're experiencing some sort of dysfunction that is very familiar to me, and they're suffering through the same sort of crises.

In fact, as a person who won a Rosalynn Carter Mental Health Journalism Fellowship and has written extensively on mental illness in

PREFACE

families, I'm viewed as sort of a sage on the subject—particularly since my mother died and I sought ways to learn more about why we are what we are. What I tell my friends is perhaps the first lesson I learned after my mother's death:

Knowledge is power.

I write to the people who feel powerless because of their inability to understand or help others suffering from mental illness. I want to connect to the compassion people have for others who are suffering. Those who are dealing with mental disorders may be people in the reader's family or someone they know.

They're definitely in my family.

THE AWAKENING

March 2003

“WOODY GUTHRIE AT GREYSTONE” was a photo exhibit of the folk singer’s stay at Greystone Park Psychiatric Hospital in Morris Plains, New Jersey. While looking at the photos, I was struck by the hospital’s Gothic-style architecture, so different from another psychiatric hospital that once housed my mother within its bland, concrete walls.

In the photos, I saw vast expanses of grass and trees, long sidewalks that snaked through the hilly campus, and stately nineteenth-century buildings with Romanesque columns. The mountainous backdrop made New Jersey look more like Utah, with large white clouds hovering just above the peaks. The “main building,” as it was often called, had bars on the windows. You may never leave, the bars seemed to say.

I thought I knew everything about Greystone. My grandfather worked there for thirty years as its personnel director. I had heard about how my grandfather, my grandmother Dorothy, and my mother Dede lived there at the same time, paying cheap rent for a multi-family house, and about how my mother would look out her bedroom window and brood over the “lunatics running wildly outside.” This was where she was forced to live her teen years, at an age when many develop their first perceptions of

A LEGACY OF MADNESS

humanity. My mother had wanted to be anywhere but there. My grandfather, on the other hand, always spoke of the place with reverence, acting as though it was a castle and he was its king.

Even after hearing these stories, I never got a real sense of what it was like to be there, to live there and endure the despairing atmosphere that seemed to permeate through the aging, decaying walls. In those pictures, I saw it. In Woody Guthrie, the man who wrote the iconic song “This Land Is Your Land,” I could see the pain of Huntington’s Disease through his forced smiles as he struggled to survive there in the 1950s and 1960s.

The exhibit was at the Teaneck, New Jersey, headquarters of the Puffin Foundation, a nonprofit group that supports art and musical programs. The exhibit hung on the walls while an event on Mideast peace was taking place. I was there for an assignment for my newspaper, the *Record of Bergen County*, New Jersey, but as speakers took to microphones and talked about the Arab-Israeli conflict, I was distracted. The black-and-white photos of the folk singer with the clenched teeth at the mental hospital transfixed me. *I wonder if my grandfather knew he was there, I thought. I wonder if my mother knew he was there.*

My grandfather had passed away in 1991, and my mother had died two months before I saw the exhibit. So I was left to my imagination. I looked at Guthrie’s face and wondered if he endured something similar to what my grandfather and mother endured. They weren’t patients, my mother and grandfather, but they were forced to look at the same things and make peace with the same elements as he was: barred windows and “lunatics.”

When the event ended, I ran into a colleague, Mary Ellen Schoonmaker, an editor at the *Record of Bergen County*. I pointed at the pictures of Guthrie being visited by his family on the grounds of Greystone. “My mother lived there,” I told her. “She was probably there at the same time he was.”

“Wow—how did your mother deal with that?”

THE AWAKENING

“I don’t know if she ever did.”

I then told her about my mother and my grandfather and about how the rest of the family put up with their bizarre behavior—severely obsessive-compulsive behavior, in fact—that wasn’t diagnosed until it was much too late, but had dominated our lives for so long. I talked about how they both soaked themselves in alcohol as though they were numbing a pain. I told her about Ancora Psychiatric Hospital in South Jersey where my mother was committed twice. I told her that I had often walked around Ancora, my teeth clenched like Guthrie’s, smelling the urine and observing the zombie-like patients. When my mother was there, dealing with the frequent screams of the residents and the constant stench of urine, I thought *I should write a story on this*.

“You should,” Mary Ellen said. “Why don’t you do one for us?”

Two months later, I did, writing an article on the last five years of my mother’s life—beginning with her bladder operation in 1998 and ending with her death in 2003—which was published in the *Record of Bergen County* in May 2003. The article, “Trapped by Mental Illness . . . and a Health-Care System That Failed Her,” followed my mother’s journey through a series of assisted-living facilities, nursing homes, and Ancora as her illness clouded any sense of logic and prevented her from getting the care she needed. The writing went well as I easily found words to describe the pain and heartache of her final years. Recalling the scenes of her despair brought it all back to life for me and reminded me why I went into writing in the first place: to learn from others and to educate.

Afterward, I sent it to just about everybody I knew. “This was the best thing you ever wrote,” some said. “I never knew you went through this,” others said.

For me, the day I had that article published, a cause was born. I had fourteen years of service in journalism, but I had grown jaded by the changes in the field, the diminishing quality of news reporting, and the low pay. I felt as though I finally had some sense of purpose, and

A LEGACY OF MADNESS

journalism would be my tool. I would discover what really killed my mother. I would discover the causes of mental illness—and, of course, the possible cures.

I had had many of the same impulses as my mother and grandfather, enduring years of eating disorders and obsessive compulsiveness. I wanted to know why we were the way we were, and whether there was some family curse that I was failing to stop.

The first way to learn, I thought, was to learn about others who have endured similar issues. After the article was published, I started writing a column on mental health issues for my newspaper that won praise from a variety of advocates and mental health groups. From there, I used my work as a springboard toward acceptance into the Rosalynn Carter Fellowships for Mental Health Journalism program, for which I completed a reporting project on the treatment of the mentally ill in jails.



Ironically, I was motivated by people like Woody Guthrie and the singers he inspired, such as Johnny Cash and Bruce Springsteen. All of them sang about the powerless and the imprisoned and, to use Springsteen's words, how it's "more than this" that compels people to behave in an odd manner or to perform unspeakable acts.

Springsteen, in particular, was an inspiration: I was a Jersey Shore kid who always connected with his songs because many of them were about me—the poor working stiff who couldn't catch a break. He also wrote about how it's more than evil that drives people to go insane and kill people for money, drink, or drug to the point that they get behind the wheel and drive into a wall. He wrote about how it's more than sinister for someone to choose a life behind bars, and how the imprisoned often come to either regret what they did or fail to understand why they did it.

To me, Ancora Psychiatric Hospital was like a prison, and the patients were its inmates. The hospital looked very much like the jails I had vis-

THE AWAKENING

ited in Texas and Alaska for the fellowship, and the patients who walked around in jumpsuits looked much like the prisoners who lived in jails in San Antonio and Anchorage.

The journey, however, never felt complete. After I wrote the Carter Center series, prisons continued to be the primary home for the mentally ill, and psychiatric hospitals continued to be decrepit, downtrodden shelters that—as they did with my mother—forced patients to leave long before their treatment was finished because they didn’t have the space or the money to keep them.

I entered the Columbia University journalism master’s degree program in 2007 and was accepted into an acclaimed book course taught by Sam Freedman, a respected author and Columbia professor, in the spring of 2009. He was struck by my story of a family that could never get out of the way of itself. He saw me as a person who wanted to lift the curse by educating himself and others.

We both agreed that the best way for me to begin this journey was to look back on that day, January 18, 2003, when we found my mother. That event, more than anything, was the “awakening” of my life. It was the moment that illuminated every little suspicion I had of her and her illness, and that brought back all the troubles my family suffered through, going back to when I was three years old and used to think to myself, *Mommy’s crazy*.

January 2003

I let my four-year-old son Tommy call my parents’ house in Point Pleasant, New Jersey. It was a whimsical thing to do, something to erase the boredom of a January day, just weeks after Christmas, when the wet, ten-degree weather in New Jersey leaves a kid’s skin chapped and itchy. Having him call seemed right, and cool, because it was something that could always make the grandparents say, “Oh, how cute.”

I wanted my son to get to know his grandparents and see them in ways

A LEGACY OF MADNESS

he hadn't before. I wanted him to know them away from the mental health facilities, doctors, and patients who had dominated my mother Dede's life in the years before he turned four. I often took him to the nursing homes and assisted-living facilities where he'd see these people, and then hide beneath my chair and wait anxiously for the visit to end. Or I'd take him to my old home, in Point Pleasant, where my mother's moods ranged from chipper to downright gloomy to, on occasion, plum drunk. Sometimes she'd be sitting in her living room chair, passed out after drinking from the case of Budweiser cans she stuffed in the refrigerator.

In 2000, I took Tommy to see her on Mother's Day at Ancora Psychiatric Hospital, where she spent two months before moving, reluctantly, to Rose Mountain Care Center, a nursing home in New Brunswick, New Jersey, just a few miles from my home in Metuchen. At Ancora and at Rose Mountain, Tommy played around my feet, rolling cars along imaginary roads on the carpet while my mother ranted about the food, the people, and the care, repeating, over and over, about how much she desperately wanted to go home. Tommy jumped to my side and grasped my arm every time he saw people hunched over, moaning, or talking to themselves.

By January 18, 2003, my mother had been in Point Pleasant for sixteen months since leaving the nursing home—her longest stay at her home in nearly five years. Finally, she was showing signs of stability, even recovery. She was still obsessive, filling the freezer with five or six containers of Breyers vanilla ice cream, and only eating an occasional spoonful every few days or so while leaving the rest to freeze. She still felt the need to shove cold, creamy food down her esophagus to quell the burning sensation of acid reflux that constantly tinged her throat.

At home, Dede still peppered my father Stan with repeated questions: "Am I going to be okay? . . . Are you sure I'm going to be okay? . . . Do you still love me best of all?"

She was still drinking coffee out of oversized mugs, filling them to the top, to the point that drips were spilling over the side. My father got a

THE AWAKENING

health care aide, and then another, and yet another, all of them eventually leaving because they couldn't deal with my mother.

But the fears she had about her debilitated body—all of which had finally forced my father to take action and seek help from an endless list of counselors and physicians—had finally abated. She no longer stuffed the refrigerator with six-packs of Budweiser and Michelob—cans she drank to numb herself from herself and the world. She stopped fretting about her bladder, the one that was successfully fixed in an operation in 1998, but had initially left her worried about the post-operative effects.

"I think there's something wrong with me," she'd said for years after the operation. "I think they didn't fix it right."

She also stopped taking medication that, in the rare times she had taken it, seemed to stabilize her mind and personality. Whenever she stopped, she'd plunge into a depression that would compel her to take a taxi to the liquor store, buy two cases of beer, bring them home, and drink until she passed out, with her head hanging off the side of the living room reclining chair. Or her moods would swing so wildly that we fully expected to get a call from a neighbor—as we did once—reporting that she was in her stocking feet, standing on somebody's lawn, fretting that the nurse's aide was out to kill her. All those incidents usually led to another visit to the emergency room and, if she talked of suicide, would land her in a nursing home, assisted-living facility, or, on two occasions, Ancora Psychiatric Hospital.

Once she left New Brunswick's Rose Mountain Care Center in September 2001, she finally seemed to tire of that life of getting pulled out of her favorite chair in the living room, where she spent countless hours watching news programs, to be hauled into a treatment program that would never treat her. For those sixteen months, she was showing flashes of her old charm, smiling through her tired face, crumbling legs, and shrinking arms. She seemed safe—and sane enough to be the grandmother she never really was. She even tried hard to connect with my boys Tommy and Jonathan whenever they came to visit, using much

A LEGACY OF MADNESS

more effort than she had earlier when Tommy would play around my chair at the nursing home.

On January 18, 2003, around 5 p.m., I instructed my son on what numbers to push. Usually, either my father or no one answered, because my mother always refused to answer the phone. She sat in that same reclining chair all day, even though she never reclined in it. Her knee was too wobbly, and the muscles in her thighs and calves had atrophied, making her legs look like sticks. It was just too painful for her to get up, even though the phone was ten feet away, hanging on a wall.

This time, Tommy heard a click, and then wondered aloud why a panicked woman's voice was coming from the other end. "I don't know who it is," he said, handing me the receiver, his brown eyes opening wide. "It sounds like a woman."

I moved it closer to my ear and heard the voice of my older sister Carolyn.

"Thomas," she said. "Mommy died!"

"What?"

"She died!" she said, sobbing. "You've got to come here."

I hung up. Tommy looked at me. "What? What happened?"

I looked at him and his sweet brown eyes. He had seen enough of the tragedy of my mother in recent years. *Should I tell him? I wondered. Does he really need to know this?*

"Grandmommy died," I said.

Tommy looked at me, his face pale, and walked into the living room. He bowed his head, but didn't cry. He didn't seem to know what to do. Frankly, I didn't know what to do either.



That day was like most others of the previous sixteen months. My mother woke up early, no longer staying up until 3 a.m. and passing out over beer and potato chips as she did as far back as I could remember.

THE AWAKENING

No longer was she waking up at noon and getting dressed at 3 p.m., tired and hungover from her own little parties with booze and chips. On this day, as she had been doing lately, she was in the reclining chair by 8 a.m. and in day clothes by 11 a.m., wearing everything but socks or stockings for her feet.

The television was on as soon as she got up, with the sound low. She used to enjoy the conservatives who yakked a lot on the cable news programs. She'd watch them and bash Bill Clinton, yearning for the days of her favorite president, Ronald Reagan. She'd watch the faces of Pat Buchanan and Wolf Blitzer on the screen, staring at them for hours, only shifting her attention when my father or the nurse's aide walked by.

At the time, my father was mostly sleeping in my sister's room. For many years my parents shared the same bed, even when my mother's behavior filled him with rage. The bladder operation in 1998 was the tipping point—the final straw for my father. My mother's repeated questions and obsessions increased after her operation, so much so that my father couldn't handle it.

"There's something wrong with my bladder. . . . Don't you think there's something wrong with my bladder? . . . I don't want to get another operation. . . . Is there something wrong? . . . I think there's something wrong with my bladder."

He appeased her and took her to several doctors who all said the same thing: "Your bladder is fixed. It is no longer a problem."

But she didn't believe it.

"Dear, what if they're wrong? . . . Something doesn't feel right. . . . There's something wrong with my bladder."

Like the nurse's aides, my father threatened to leave a number of times; he even visited with a divorce lawyer. He ultimately stayed with her, saying the divorce lawyer warned him that he stood to lose a lot of money by leaving her, particularly if she needed long-term care. But he also grudgingly admitted that he never stopped loving her, even when she drove him crazy. He never gave up hope that the woman he had married in

A LEGACY OF MADNESS

1959—a sweet, loving, and charming woman who had had many boy-friends before him—would return. Whenever she flashed her smile, he saw the same woman he fell in love with, and he always hoped that that person could somehow resurrect and rebuild herself.

As soon as he woke up, he was usually out, heading up to the Ocean Grove beach cottage that my mother inherited from my grandfather after his death, and disappearing until night. He took long walks on the boardwalk, went to the movies at a second-run theater in Bradley Beach, watched television, and worked as a part-time desk clerk at a nursing home. He enjoyed being alone, but even more so, he yearned for a life without someone being as dependent and obsessed with him as my mother was. Even as my mother showed signs of stability, he still wasn't getting the life he wanted, the one he had hoped for when he married her more than forty years before.

After my father retired from his school principal job in 1996, he tried to play the role of the domesticated retiree, spending much of the day with my mother. He began to experience many of the things we as children had dealt with when we came home from school: she turned the heat up to eighty degrees on a sixty-degree day, taped the cookie boxes with electrical tape so we couldn't share, fussed whenever we were in the kitchen hovering near her food that sat on the stove or the kitchen counter and breathing our germs near it. He began to escape to Ocean Grove, about ten miles to the north, rarely taking my mother with him. If he needed to communicate with her, he spoke with her on the phone.



On January 18, my mother woke from her bed in the Point Pleasant house, waddled on her wounded leg to the living-room recliner, while my father headed out to the movies. It was a Saturday, not the typical day for news shows. My mother got up from her chair once, around 3 p.m., leaving a message with my father at Ocean Grove to pick up the mail there.

THE AWAKENING

She also got her coffee in the kitchen and walked toward the mailbox that hung outside. She would sit in her recliner, like she did every day for hours at a time, and look through the mail.

She opened the heavy door, then pulled out the screen door, feeling the frozen breeze of the ten-degree day on her bare feet. She leaned her small, rickety frame on the wobbly hydraulic closer as she reached for the mail that was sticking out of the box, being very careful not to touch the cold cement porch with her feet.

The closer snapped and my mother fell face-first on the cement. She didn't stick out a hand to break her fall. The force of the fall was so strong that blood gushed out of both nostrils.

A neighbor who saw her lying on her face hustled across the street and helped her back up, supporting her as she reentered the house and helping her to her chair. The neighbor got some paper towels from the kitchen, which my mother used to blot the blood coming from her nose.

"You okay?" the neighbor asked.

My mother waved off any additional assistance. "I'm okay," she said. "It's okay. I'm okay."

The neighbor left as my mother continued to sit and blot her nose with the towels.

Within the next half hour or so, something—we don't know what—compelled my mother to get out of her recliner and rush toward the telephone in the family room at the far end of the house. She ignored the one that was closest to her, choosing the phone that sat on the old dusty bar. There she leaned against the rim of the bar while she pushed the buttons on the phone, trying to reach my father in Ocean Grove.

She called my father, I thought later. She didn't call 911.

My father still wasn't home from the movies. My mother left a panicked message on the answering machine. "Dear, something has gone terribly wrong!" she said in a rushed, breathless voice. Then there was more heavy breathing before the message ended.

She left the phone off the hook and made it across the kitchen before

A LEGACY OF MADNESS

she collapsed on her back on the couch. The phone receiver dangled in the family room, making the loud buzzing noises with an operator message: "If you'd like to make a call, please hang up. . . ." No one was there to hear it.



Around 4 p.m., my father returned from his movie in Bradley Beach to the Ocean Grove house. He listened to my mother's message and then tried to call home, getting only a busy signal. He called my sister.

"Could you go to the house and see what's going on there?" he asked.

On this day, in 2003, Carolyn was the natural choice to check on my mother. My brother, Edward, lived three hours away in Maryland. I lived an hour to the north. Carolyn stayed the closest to the family and our history, never moving more than five miles away from my mother or father. Carolyn lived in Manasquan, so she was much closer than my dad to where my mother was. She drove a few minutes to get there, pulling into the wide driveway around 5 p.m. and seeing the dark house.

Of the three of us, Carolyn was the child who suffered the most. She was the oldest and the one who was beaten the most by my mother when my mother started to show signs of illness. She struggled to have a relationship with my father, since my mother would often act nervous whenever she saw them together, just as she did whenever we were near her food in the kitchen. My mother didn't want my father near any women except her, and if he did spend time with Carolyn, he was subjected to the routine interrogation.

"What did she say? . . . What did you two do together? . . . What did she say, dear? . . . Can you tell me what she said? . . . Are you going to do anything with her later? . . ."

To Carolyn, the long, burnt-blue ranch was still home, even if it reminded her of everything she went through growing up. It was the

THE AWAKENING

darkest home on a street filled with 1950s ranch houses, a little slice of modest Jersey Shore suburbia that had recently become one of fastest-growing regions in the country. Beginning in the 1980s, the wealthy began to buy what property was left, building two- and even three-story mini-mansions that they claimed as “beach houses,” even if those homes were three or five miles from the water’s edge. On our block, the small, single-floor houses remained, reminding people of what Point Pleasant once was before the wealthy came: a blue-collar, middle-class refuge for people looking to escape the growing crime and ugliness in Newark and New York City.

When my sister arrived, she saw my mother lying on the couch, almost directly in front of the picture window. Carolyn rushed over to her and tried pick her up. She couldn’t move her, or even bend her.



Tommy had called just minutes later. Tommy and I, as well as my one-year-old boy, Jonathan, had spent the day doing little of anything. I was deterred by the cold weather and my own exhaustion, having just returned from a reporting trip to Fort Drum near Watertown, New York, where I had interviewed troops who were gearing up for the upcoming invasion of Iraq.

My father arrived just as I called back again and heard my sister’s heavy words. “Here—talk to Daddy. . .”

“I did everything I could!” my father cried into the phone, sobbing.

“I know you did,” I told him.

I then called my wife, who was at work. On Saturdays my wife worked in the city running an acting school for children. I always hoped that on Saturdays she could avoid the stresses of parenthood. Not on this day.

“Oh my God,” she said. “I’m so sorry, Tom.” She arranged for a neighbor to come to the house and watch Tommy and Jonathan, our youngest,

A LEGACY OF MADNESS

who had been napping through all this. The neighbor arrived minutes after I got off the telephone, and I immediately headed south.

Throughout the hour-long drive, my mind raced. *Wow. I can't believe it. What do we do now? What does this mean?* I was still tired after the long, four-hour drive I'd made from Watertown, New York, the day before.

I yawned, but I couldn't cry. At times, I thought, *Why am I not crying?* I never felt the urge. I asked myself repeatedly *Why? Why? Why?* but never asked *Why did she die?* I asked myself *Why did it have to be this way? Why couldn't we be normal?*

When I got closer to Point Pleasant, I found myself on Route 34 and other roads I used to take when I drove back and forth to school in Rutgers in the late 1980s. My mind drifted back to those times, when I used to take those lonely drives home—especially after Jessica, my old girlfriend, left me.

Jessica was my first love, and I loved Jessica as much as I loved my mother; her leaving me sparked a fifteen-year battle with eating disorders that I could never completely shake. I saw those exit signs that pointed to roads that led to Jessica's old house. I felt chills. Again, I asked myself *Why? Why? Why?* It was the same question I asked myself when Jessica left me, when I felt as though my soul had been ripped out of my chest. It was the same question I asked whenever I made myself vomit in the months after we broke up and I lost nearly sixty pounds during a sixty-day stretch in 1988. *Why? Why? Why?*

The wide four-lane roads near Jessica's house that led to my parents' burnt-blue home in Point Pleasant were always so dark and empty in the winter. The darkness only fed my loneliness and pain. Other than the radio, there was little that could fill or replace the emptiness I felt around and inside me.

I arrived in Point Pleasant around 6:30 p.m. The house was now the best-lit one on the block, with a police car spinning its red lights and the big picture window fully lit and exposed. I pulled behind the cop car and

THE AWAKENING

got out. The cold air had a sharp, wet bite to it. But I barely felt it, even though I was wearing the same thin, blue sweatshirt I had worn the day before on my trip from Watertown.



My mother lay there on the couch, her legs stiff as wood, eyes closed, and mouth wide open. She looked like one of my children's dolls after they'd finished with them: lifeless and done. *God*, I thought, *if only my mother could see herself now*. She hated people knowing about her health problems. How could she hide being dead?

It was hours after she collapsed when I saw her. She was on the couch, but apparently she had been on her way to the bathroom, where she always hid in times of crisis. She always hustled to get there, pumping her arms as she dragged her weak right leg across the kitchen and living room floors. She'd slam the door and run the water for an hour, washing her hands until they were red and flaky. Then she'd sit on the toilet, and try to force out every drop of urine from her swollen bladder after drinking nearly a half-gallon of coffee.

By this time, the streams of blood from her nose had created streaks of red that had dried up under her nostrils. Her arms were locked at her sides and the heels of her feet dug into the carpet, preventing the rest of her stiff, ravaged body from slipping off the couch.

I screamed.

My sister and brother-in-law grabbed me and pulled me into the family room, through the patch of police officers who were carrying notebooks and listening to their radio calls. My father stood to the side, watching as my face contorted into a scream.

"If she would only take the damn medicine" was one of the first things I heard him say, minutes after I had entered the family room.

I'd heard him say that a hundred times. It was always his cry for help. Going back to November 1998, when my mother's thirty-year battle

A LEGACY OF MADNESS

with mental illness was first addressed and we made our first visit to a psychiatric emergency room after she threatened suicide, my father would rant and rave about his inability to solve her problems. He hoped that whoever was in the room at the time was listening. No one ever seemed to be.

My head was so blurred with confusion, anger, and sorrow at that moment that I couldn't yet feel what was probably the most logical feeling: relief. It was the end of five years of hell, five years of bouncing around mental health facilities, assisted-living facilities, and nursing homes. It was the end of five years of fighting over psychiatrists, medicines, doctors, healthcare aides, and nurses.

It was the end of a life that never quite fit in the world. My mother had spent her life tolerating it, but never really accepting it. Her aversion to pills and doctors, her incessant repeating of questions, her constant worrying about spots or pimples she saw on her hands and arms, and her drinking at the kitchen table, keeping empty cans of Budweiser and a bag of potato chips at her side as her head fell to the table's surface—it was all over.

It was the end of decades of suffering from obsessive-compulsive disorder and its bedeviling symptoms that divided a family and destroyed a life.

At sixty-five years old, she was finally at peace.



After seeing my mother, stiff and lifeless, I felt something I didn't expect: fear. I had a bond with my mother that transcended bloodlines and, to some extent, sheer logic. I often felt as though I was my mother, just as she, too, probably felt like her father, as we both embodied his quirky obsessions and mannerisms and struggled to live the "normal" life that always seemed so distant.

My grandfather, in turn, was like the people before him, suffering from

THE AWAKENING

the same self-destructive urges that were nearly impossible to control for him and his ancestors—some of whom killed themselves. I felt that my mother and I had the same compulsions, urges, and quirks that forced us to confront and, sometimes, succumb to the worst challenges of life, and we dwelled on the lingering, ugly certainty of obsession, pain, and death.

When I saw her cold, stiff body, I remembered how I could feel her sense of isolation whenever she obsessed, and how everything she did made her different from all the other mothers I heard about at school. I felt fear because I saw my future, because I realized I had many of these same obsessions that had caused my grandfather to resort to drinking more than a half-case of beer each day.

They were the same obsessions that had challenged and doomed the lives of his father, uncle, and grandmother, all of whom died when they isolated themselves in their houses, turned on their stoves' gas burners, and breathed in the fumes. These same obsessions nearly compelled me to take my own life when I threw my guts up in college four to five times a day, ripping the will to live and succeed out of me.

In my mother's final years, I felt her pain and weaknesses, but I also shared her strength and stubbornness. In the end, her body was contorted and twisted, with a leg that was as stiff as a wooden plank and a face and hands that looked as if they had been scraped with Brillo pads. But she kept holding on, limping on her leg even after she fell several times on the sidewalk and scratched her face. She refused to let her ailments change what she was or what she wanted to do.

I felt her love, even when that seemed nearly impossible. She could be mean, even brutal, as well as distant and perverse. But the hard mask covered a soft soul. She wouldn't let us kiss her face, forcing us to plant one under her ear. But she wanted us to kiss her anyway, even if the germs from our lips may have, in her mind, endangered her health. She had a loud laugh that was infectious, and she often worried or even cried when any of her three children—or even her dogs—suffered.

She loved pets and young children. She held them tightly in her lap

A LEGACY OF MADNESS

despite her fear of germs, dirt, and anything that normally drove her away. When I sat in her lap as a young boy, I could feel the touch of her palms as she rubbed them up and down my spine. I could sense her loneliness when she felt cold and she hugged me tighter. I could feel her fear whenever she descended into a raging argument with my father, and I climbed into her lap, worried that she would go.

I hold my children the same way. Even as they grow older, I keep them close, just as she did with me when I was small.

I also fear for my children, because they, too, could have inherited what seems more genetic than coincidental. My wife and I worried about it before we had them; we worry more about it now that we have three, and we worry we'll see certain signs and symptoms arise that will give us reason to believe that history could repeat itself.

If those symptoms do arise, we will keep holding our children and never let go.



In my mother's final years, I didn't need her hug, but I tried to show my love anyway. I scouted around and found a nursing home close to my house that I hoped would bring her the stability she needed. My wife and I visited her twice a week, and even as the decline of her body and obsessions kept others away, it was a way for us to stay as close as possible.

After she died I wanted to be the one to do something, or something more. I wanted to be the one to do something about this curse, to do the research and discover the background of our life. While I had long known something was amiss, something about that moment on January 18, 2003, and the events that led up to it, would force me to address what it was about this family that made us seem destined for self-destruction. I would have to find out more about my family, because that was the only way to find out more about myself. I would have to find

THE AWAKENING

out what brought me there, with my mother in the other room, dead, and what could have been different.

Indeed, the events of January 18, 2003, were a metaphor for my mother's life, and those before her. Even in her moment of need, she couldn't get help.



By the time I was whisked into the family room, I felt nothing and saw nothing. My eyes were closed shut. After my brother-in-law and sister took me in, I slowly opened them.

"Is it over?" I asked.

"Yes, Thomas, it is," Carolyn said.

"Good," I said.

I stayed in the family room with the family, waiting for my brother, Edward, to arrive and for the cops to leave. "I don't want to go back in there," I told everybody several times. "Don't," they told me.

Even when the police removed the body, and when Edward arrived, I stayed in the family room, sitting in another reclining chair and hanging my feet off the side, far away from the spot of her fall. My sister and brother-in-law left to take my ten-year-old niece back home. My brother and I sat alone in the family room, leaning back in our chairs, analyzing the day.



I always felt comfortable talking to my brother. I always felt he was the one who was most like my dad: disciplined and determined. He succeeded in school better than all of us, and he had a common-sense approach to life. He was the only one among us who could fix a wall, build a bike, or chop down a tree. Only three years apart, we were friends as well as brothers.

A LEGACY OF MADNESS

We talked about how we'd seen it coming, even though it still came as a surprise. We talked about everything that had happened, even before the previous five years, when her behavior went into a tailspin after that bladder operation. We talked about our guilt and how we felt we could have done more. We talked about how we felt we had not done enough for her, even though, in those last years, we did a lot.

We talked about how we saw ourselves, and how we would have to deal with our own lives and prevent the same thing from happening again. I talked about myself and my own battles with eating disorders, and as I did every time I brought it up, I felt a little relieved to be talking, though a little embarrassed too.

As I looked at my brother, I saw a person who bore the brunt of my mother's illness but always seemed strong enough to take it. Unlike me, my brother Edward stood up to our father whenever my mother's obsessions drove our father into rages. Because of this courageousness, Edward took the whacks to the face.

On this night, however, Edward didn't seem like his typically confident self. In the family room, he sat far away from me in a stiff metal chair he had brought in from the kitchen, and he held his head low. As I talked about myself, after a few minutes he finally looked at me kind of sadly, wrinkling his mouth, leaning back in his chair and taking a deep breath as he waited for me to finish.

"You know what, Tom?"

"What's that?"

"I've never told anybody this before," he said. "But I used to make myself throw up too."

AWARENESS

March 1970

MY JOURNEY OF DISCOVERY BEGAN when I was three years old in 1970. I sat in the living room, watching *Sesame Street*. My mother was fussing with the thermostat, just as she always did unless there was blazing heat outside.

Her playing with the dial almost always drove my father into a rage, and they'd launch into a Vaudevillian routine that rivaled anything from Abbott and Costello.

"What do you think? I own the oil company?" he'd say.

"I'm cold," she'd say, flashing her bright smile as a way to charm him away.

"We don't need to turn it up to eighty," he'd say.

"How about seventy-five? . . . Can we keep it at seventy-five, dear? . . . Can we keep it at seventy-five?"

"Okay, fine, seventy-five."

"Let's keep it at seventy-five, dear."

"Fine! Seventy-five!"

"Can we keep it at seventy-five forever and ever?"

"Look, don't start with me!"

A LEGACY OF MADNESS

"Can we keep it at seventy-five forever and ever?"

"Yes!"

"Do you promise to be nice to me? . . . Do you promise that we could keep it at seventy-five?"

"Stop repeating!" he'd yell. "You don't need to repeat it, okay? I heard you."

"Do you promise to love me best of all?"

"Yes, yes."

This time my father wasn't around, so my mother got to fuss with the thermostat at will. As she fussed with it and drew her face close to the dial to get a better look at the small, black numbers, I blurted out what immediately crossed my mind as I watched her.

"Mommy?"

"Yes, Thomas?"

I paused, waiting for her to turn away from the thermostat so I could look at her face.

"Why do you repeat?"

My mother's mouth popped open. I couldn't tell, at the age of three, how she planned to respond. Would she grab a garbage can and hit me—as she often did with Carolyn and Edward, my older sister and brother—to make me understand how naughty I was? Or would she let it go so that I could resume being—as she said again and again and again—her "favorite"?

Even at that age I knew we don't talk about *these* things. My sister and brother knew it, because if they ever talked back or questioned anything, it was usually met with a yell, a scream, a garbage can, or a backhand across the arm or face. Or at the very least, they would have to endure the repeating, which could be as painful as any punch or slap. "Talk nicely to me. . . . Promise? . . . Promise to love me forever and ever? . . ."

This time, my mother paused shortly, seeming a bit flustered. She came up with an answer that, perhaps, she thought sounded good, at least to a three-year-old.

AWARENESS

“Because people can’t hear me,” she replied.

Then she walked away, disappearing into the bathroom and, as always, running the water for what seemed like an hour. She always went in there after fights with my dad or after yelling at my sister and brother, as though she were washing away all the tension she could feel in her body.

As she washed away, I sat there, blankly staring down the hallway at the shut bathroom door, trying to piece it together. I knew we had tension and trouble. I knew people said things to each other they didn’t really mean. I didn’t think anybody was trying to be anything other than what they were—loving, caring, and respectful, especially my mother, whom I worshipped to the point of adulation.

I didn’t think anybody *lied*.

But right then, I knew my mother had lied to me, and by going into the bathroom, she wanted the lie to live, without guilt or consequence. Even at the age of three, I knew: if what she was doing was so innocent, then why would people react so angrily?

Feeding me that line firmly established the protocol for behavior in our family: ignore it, and it will go away.

I loved my mother more than anything. I trusted her and took sides with her always. But as the years went by, I often reflected back to that moment when I was three. I saw what was happening to my father as he raged and yelled at my mother for the repeating, her hand washing, her less-than-stellar cooking, her constant questions, her long bathroom visits, and her thermostat fussing. I saw my brother and sister despair over their lives and bear the brunt of my father’s frustration. I always thought it was their fault, that they unfairly made my mother the target of their venom. With me, it was always “mother knows best,” even when my mother washed her hands until they were flaky red or made me wash my hands whenever I touched the floor. *Why are they so upset?* I would ask myself. *She’s just looking out for us. She wants us to be healthy.*

But as I grew older, I started to see everybody else’s point of view, and I became more curious than trusting. I also knew that it was better to

A LEGACY OF MADNESS

shut up than speak out, even as I watched our world falling apart. If I did speak out, I knew the best thing that could happen was that I'd be lied to. The worst thing was a beating. Ignore it, and it will go away. That seemed to be my family's credo, the foundation of our life together.



Back then, my mother would whisper to me, from time to time, that I was her "favorite." For some time, I believed it. For some time, I saw her more as the victim of the tension and never *really* the cause. I was the one who still got to sit on her lap and be hugged when my mother had long given up doing the same to my brother and sister. I was the one she smiled at, about whom she said, "He's so smart" while my brother and sister were standing right there, seething as they watched me get the princely treatment.

I was the one who screamed one time, pounding my fists on the table when my mother dared to go outside for five minutes to talk to a neighbor. Afterward, she came in and picked me up and promised to never do that again. She didn't, and she let me sit in her lap even more.

Sometimes she made me repeat too. "I'm sorry," I would say. "I love you best of all."

Sometimes I would get upset because I didn't get a toy I wanted or get a cereal I wanted to eat for breakfast. But when I told my mother "I'm sorry" and "I love you best of all," I meant it, and I was willing to say it over and over until I forgot about the toy. She was my protector. She was my soul mate.

At a certain point I started washing my hands if I merely touched the floor. I started to worry and fuss over dying, crying over fears that I was going to die of some disease caused by a germ that I couldn't see or stop. I worried about this stuff because Mommy worried about it. Like her, I asked whoever was in the room whether I was going to be okay. "Are you sure? . . . Am I going to be okay, Daddy? . . . Why do I have a bump on my skin? . . ."

ACKNOWLEDGMENTS

A LEGACY OF MADNESS IS BASED on interviews with more than sixty family members, psychiatrists, photographers, experts, friends, and family acquaintances who captured the moments and places of my families' lives. Newspaper articles and reference books were also useful in both reporting what happened to my family generations ago and recounting the history of mental illness over the past century and how research and treatment evolved.

I had lengthy sessions with my family, including Stan Davis, my father; Carolyn Delp, my sister; and Edward Davis, my brother. My cousins were very helpful in providing answers to the many questions I had about my grandfather's ancestors—some of whom moved out to California to escape the Winans family curse, but nevertheless still endured similar troubles and near-fatal consequences.

I interviewed co-workers and acquaintances of Richard "Dick" Winans, including Karl Marx, his top assistant at Greystone Park Psychiatric Hospital; Shirley Smoyak, who worked under my grandfather as a student nurse at Greystone and later became a professor of continuing education at Rutgers University; and John Lapko, a maintenance worker and groundskeeper who helped take care of my grandfather's house on

ACKNOWLEDGMENTS

the Greystone grounds and drove him to personnel hearings in Trenton, New Jersey.

I used the articles I wrote for the *Record of Bergen County* as resources, and the newspaper granted me permission to use the material.

I collected photographs from my grandfather's photo albums and showed them to historians and other professionals who provided historical analysis on the homes where my mother and grandfather lived, the clothes they wore, the paintings of Bay Head, and also the locked-down, dungeon-like architecture of Greystone where my grandfather worked and where my mother was raised. These professionals included Peg Shultz, the history program coordinator for the Morris County, New Jersey Heritage Commission; Kurt Hirschberg, Bruce Reynolds, and Douglas McVarish, all licensed architects who have studied the Victorian and Gothic styles of construction at Greystone; and Kate Ogden, a Stockton State College professor in New Jersey.

I visited my grandfather's house—where my grandmother and mother also lived—on the Greystone grounds and I took photographs inside. I also took photographs of Greystone's other century-old buildings and showed them to the same historians and professionals, who offered analysis on the buildings' dungeon-like design and style, revealing the reality of the environment that provided the setting of my mother's childhood.

I interviewed criminologists and medical examiners who provided commentary and analysis on the premature and suspicious nature of my family's deaths. They included John Howard, president of the National Association of Medical Examiners; and Julie Howe, executive director of the American Board of Medicolegal Death Investigators.

I reviewed paintings and photographs from people who captured Hightstown, Point Pleasant, Elizabeth, and Bay Head, New Jersey, and other settings in my family's life from the 1600s through the Great Depression to the present day. They include David Martin, the historian

ACKNOWLEDGMENTS

at Peddie High School, where my grandfather was a student; and the family of Dick LaBonté, whose artwork captured life at the Jersey Shore during the 1920s and 1930s.

Interviewing historians and studying the writings, photographs, and paintings of the scenery surrounding my family allowed me to extend their persona to their environment. Peaceful sand-and-sea images at the Jersey Shore were a contrast to my family's personal trauma and hardship. Personal experiences also allow me to describe the horrific psychiatric hospital and suicide scenes that serve as the ever-present but fitting backdrop to the turmoil.

I discussed the history of mental illness with members of the Carter Center Mental Health Task Force, with whom I've developed a close relationship since my fellowship in 2004 and 2005. They included Otto Wahl, a psychology professor at the University of Hartford; and Larry Kutner, co-founder and co-director of the Harvard Medical School Center for Mental Health and Media. I also interviewed my own psychiatrist who provided reference materials regarding the *DSM*.

In addition, I relied on news articles that reported the deaths of my great-great-grandmother Lydia, her son Frederick, and their dog. The October 5, 1928, edition of the *Elizabeth Daily Journal*, under the headline "Woman, Son, Dog Are Found Dead of Gas at Home," and a follow-up article on October 6, reporting the police version of their deaths. I also relied on the *New York Times* from that time period to provide weather reports for the New Jersey area when my great-great-grandmother Lydia, great-grandfather Edward, and great-uncle Frederick killed themselves. The details showed irony: each died on days that were remarkably pleasant, showing a stark contrast from their depressed lives.

For my great-grandfather Edward's death, I relied on July 13, 1933, stories from the *Times of Trenton* and the *Hightstown Gazette*, as well as his death certificate.

I also obtained and reviewed death records and US Census records

ACKNOWLEDGMENTS

for Elias, Lydia, Edward, Frederick, Dick, and Dorothy Winans, as well as my mother Dede (Winans) Davis. I received permission from living family members regarding the telling of their stories.

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ABOUT THE AUTHOR

Tom Davis is the Jersey Shore regional editor for Patch.com and an adjunct professor of journalism at Rutgers University. He has more than twenty years of experience as an editor and reporter at various news organizations. This is his first book. He lives in New Jersey.

Hazelden, a national nonprofit organization founded in 1949, helps people reclaim their lives from the disease of addiction. Built on decades of knowledge and experience, Hazelden offers a comprehensive approach to addiction that addresses the full range of patient, family, and professional needs, including treatment and continuing care for youth and adults, research, higher learning, public education and advocacy, and publishing.

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The story of a loving family coming to grips with its own fragilities, *A Legacy of Madness* relates the author's journey to uncover, and ultimately understand, the history of mental illness that led generations of his suburban American family to their demise.

Dede Winans Davis had worried, fussed, and obsessed for the last time. Her heart stopped beating in a fit of anxiety. In the wake of his mother's

death, Tom Davis knew one thing: Helplessly self-absorbed and severely obsessive-compulsive, Dede led a tormented life. She spent years bouncing around mental health facilities, nursing homes, and assisted-living facilities, but what really caused her death?

A Legacy of Madness portrays Tom Davis's captivating discoveries of mental illness throughout generations of his family. Investigating his mother's history led to that of Davis's grandfather, a top administrator at one of the largest psychiatric hospitals in the country; his great-grandfather who died of self-inflicted gas asphyxiation during the Depression; and his great-great grandmother who, with her eldest son, completed suicide one tragic day. Ultimately, four generations of family members showed clear signs of depression, obsessive-compulsive disorder, and alcoholism—often mistreated illnesses that test one's ability to cope.

Through this intimate memoir, we join Davis on a personal odyssey to ensure that he and his siblings—the fifth generation—recover their family legacy by not only surviving their own mental health disorders but by getting the help they need to lead healthy, balanced lives. In the end, we witness Davis's powerful transition as he makes peace with the past and heals through forgiveness and compassion for his family—and himself.

Tom Davis is the Jersey Shore regional editor for Patch.com and an adjunct professor of journalism at Rutgers University. This is his first book. He lives in New Jersey.

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