

LIFE IN REWIND

**The Story of a Young Courageous Man
Who Persevered Over OCD and the Harvard
Doctor Who Broke All the Rules to Help Him**



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WITH Edward E. Zine AND Michael A. Jenike, M.D.

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P R E F A C E

MICHAEL A. JENIKE, M.D.



I T HAS BEEN MANY YEARS since I first met Ed Zine at his house on Cape Cod. He suffered from a most severe form of an illness that I had studied and treated for more than three decades—obsessive compulsive disorder, or OCD. Ed was as ill as any patient I had ever met. His story, his suffering, and his recovery reveal an inspiring young man who has touched my life in a way I had never expected. I met Terry Murphy while I was consulting for a charitable foundation in New York City. I saw some of the brilliant videos and writing that she had done for the foundation, and remember one of the secretaries being reduced to tears when she viewed one of Terry’s videos about the foundation’s director. She has a knack for poignantly capturing the most pristine essence of a person.

Preface

Ed had spoken many times about having someone write his story as an inspiration to other severely ill OCD patients who had given up hope. If he could get better, anyone could. I told Terry about Ed, and she became enthused and offered to work with Ed to write his story. During the course of writing and working with Ed on his story, she asked me why I became so involved with Ed. She pried into my own motivation and reasons why I would be willing to do things differently from most physicians. I had known from my early years that I was willing to do unusual things to help patients. I had even been criticized during my training for making house calls—"Dr. Jenike gets overinvolved with his patients" wrote one supervisor when commenting on my visits to housebound patients. Because I had been in the military for five years and was older, these comments had absolutely no bearing on how I was going to practice medicine, and to this day I make house calls.

However, Terry astutely detected parallels between my life and traumas and Ed's life. Her teasing apart these issues has allowed me to understand my own motivations in light of my past life. This book reveals more about me than I would like, but I felt I had to step up to the plate and be as brave as Ed, for the benefit of patients who suffer from this horrible illness, as well as for the dedicated physicians who treat them.

I suppose the bottom line is that we all have our traumas, histories, motivations, and accomplishments. If this story touches and motivates you like it has touched Ed and me, then Terry will have accomplished more than I ever expected.

Leave No Man Behind



THE PIECE OF LINT HAS been missing for nearly a week. Before its sudden disappearance, it lay coupled with the wilted brown leaf on the basement floor near the back door. Its absence is devastating.

Finally, at the end of a long, tedious search, the particle of fluff is discovered, attached to the delicate hind leg of a cricket that has found its way indoors during the rainy season. The exorcism of lint is done with great care, leaving the cricket unharmed. But reconstructing the comfortable universe where the piece of lint once existed with the brittle leaf takes many anguish-filled hours to complete.

Michael Jenike knows nothing of this as he dribbles the bas-

ketball and pushes through the sweaty bodies of the other players barreling toward him, their rubber soles squeaking against the gym floor as he defends his turf. The tired, but enthusiastic grunts of grown men meld with the pounding rhythm of the ball slamming against their hands, and briefly, they are able to recapture the carefree satisfaction that belonged to them on the basketball courts of their youth.

After the game, adrenaline still pumping, Michael drops his gym bag into the back of his new BMW-Z3, slides his six-foot, two-inch frame behind the wheel, cranks up some country music, and pushes the speed limit down Route 3 toward Cape Cod where, on this spring day in 1996, his life will intersect with a seemingly impenetrable boundary, and he will be forced to confront pieces of his own painful past.

At the same time, the young man who meticulously extracted the piece of lint from the leg of the cricket sits in the basement of a modest raised-ranch house, in a wooded, middle-class neighborhood on the coast of Cape Cod, Massachusetts. He can't get out, and he refuses to let anyone in. The seasons have changed, schoolchildren who board the bus outside his door have been promoted from one grade to the next, and each day, strangers pass by without giving a moment's thought to what's happening behind the closed door at the bottom of the thirteen steps on the side of the quiet house.

Isolated from friends who think he's away at college, he sits on the end of his bed, rocking back and forth, helplessly performing repetitive rituals of forward and backward counting, all multiples of even numbers that stretch well into the tens of thousands. The cable television guide that rolls on the screen in front of him is his only gauge for the time that passes, as he sits with his hands

outstretched from his body, fingers spread, locked into position like the claws of an eagle, while his mind rages with the repetitive pounding of a terrible equation that will not let him go.

Time equals Progression, Progression equals Death. This is the mantra that keeps twenty-four-year-old Ed Zine living on the end of a mental tether with invisible strands attached to every muscle, thought, and spoken word. This tether is his safety net, rewinding and erasing every action that would otherwise propel him forward in time. When the rewind is complete, he is given momentary relief from the anxiety of the equation with which he is so preoccupied.

Ed's obsession is logic gone completely awry. Although it's true that the time line of our lives follows this sequence of *Time equals Progression, Progression equals Death*, few of us ever scrutinize each moment and each movement as a path to our certain end. Surely, such torture would drive us mad. For Ed, who suffers from severe obsessive-compulsive disorder, the perpetual rewinding is a ritual; more aptly, a series of rituals within rituals, which temporarily relieves the madness his intrusive thoughts create. Assaulted by this logical, but paralyzing notion, his illogical mind creates a battle that rages within him every second of every day.

Early in the day, Ed began moving from the end of his bed toward the basement door in anticipation of Michael Jenike's arrival. It is a daunting task that takes him nearly seven hours to complete, and all the while he wonders if this is the one person who will release him from this personal hell.

Dr. Michael Jenike is a professor of psychiatry at Harvard Medical School and one of the world's leading experts in the research and treatment of obsessive-compulsive disorder. He describes OCD as a disorder of "pure suffering," and he brings to

its treatment not only an extraordinary scientific mind, but also a profound depth of compassion for his patients. The message from his secretary is simple: a young man is stuck in his basement and needs help. She knows that Michael's already busy schedule doesn't really allow him to take a full day to see a new patient, but she also knows that nothing she says will stop him from going. Someone is trapped, and that's really all Michael needs to know as he pushes his own life clock forward, driving almost three hours to meet his new patient.

After a brief introduction to the Zine family—who are gathered on the front lawn to greet him, amazed that he has come all this way to respond to their call for help—Michael walks slowly up the driveway along the washed-out gray privacy fence as tentatively as he might test the ice of a newly frozen pond. He cannot see his new patient standing inside the basement at the bottom of the steps, but he does hear the instructions being issued through a small six-inch opening in the door. Ed will not allow Michael into the basement, nor will he allow him to walk into the twenty-foot perimeter outside the basement door, which he describes as his “OCD Holy Ground.” Before Michael can even breach that perimeter, he is asked to stop.

Michael's goal this day is to simply start by building an alliance with Ed. “A lot of times, when people are stuck, they have all kinds of rituals that they're afraid you're going to interfere with,” he says, “so you have to find out what world they're living in, and join it for a while. I wanted to be cautious, listen to what his rules were, and try not to violate them.”

If Michael moves too quickly, or changes the placement of even the smallest leaf in Ed's OCD Holy Ground, there is little hope for an alliance because it will have upended Ed's entire

sacred universe, setting in motion a series of physical and mental rituals to rewind and secure the placement of the leaf to its original state, just as he did with the lint that the cricket moved. “The lint and the leaf gave me solace,” Ed recalls. “Keeping my world exactly as it was kept that good feeling in place. I felt like, right there, everything was comfortable, and nothing bad was going to happen to anybody. When the lint moved, I lost control of time and events.”

Clearly, human contact of any kind is excruciatingly painful for Ed. “It changed everything in my world, and it was physically painful to me,” says Ed. “I couldn’t bear to have anything around me touched or moved.” This was the prelude to Ed’s isolation, his inability to allow anyone near him who might brush up against him or move the possessions that had become the placekeepers of happy moments in time.

But almost immediately, Ed senses in Michael a level of care and respect for his pain that he’s not felt from other medical professionals he’s encountered. “Dr. Jenike had the presence of mind not to invade the grounds which were, to me, so unstained. At the same time, though, I had to let him know what the parameters were. I couldn’t let him inside. I had to tell him, ‘I don’t feel comfortable, and you have to stay there.’”

Michael takes a seat on the ground and gently begins to build on that tiny fraction of trust. Even from this distance, talking through a closed door, he is able to evaluate the depth of Ed’s disorder without ever setting eyes on him. Ed exhibits classic signs of severe OCD—intrusive thoughts, repetitive counting and checking, contamination issues, and hoarding. But Michael discovers another alarming distinction in the way OCD holds his new patient captive. Ed Zine believes through his strict regimen

of rituals—which is essentially organized chaos—he can stop the progression of time.

Ed's OCD mind has convinced him that by reversing every action, he can alter the equation of *Time equals Progression, Progression equals Death*. He figures that if he can protect his time and space by reversing the actions, and if he can, in his own mind, erase events, as if they had never happened, he will be able to prevent time from moving forward and all those people he loves will remain young, healthy, and . . . alive. It is never about protecting himself from death, it is always about others.

The madness of OCD is that while the irrational mind is operating, its victim is able to observe and recognize this behavior. It is a neurologically based anxiety disorder with symptoms that often look “crazy” to outside observers, but the sufferer isn't crazy at all. Individuals who suffer with OCD know that their illogical behavior has no logical basis, and knowing this increases their suffering all the more, because without treatment they are unable to stop it.

Imagine Ed as a child standing on the shore watching the other kids swim and play without a care in the world. He wants nothing more than to jump in and splash around in the “normal” waters that beckon him from just a few feet away, but his swim trunks are covered by layers of winter clothing. He knows it makes absolutely no sense that he's wearing winter clothing on a hot summer day, but he is incapable of shedding his woolen wear to get down to the layers of cotton clothing that make sense for summer and swimming.

Multiple layers of simultaneous thought are occurring at lightning speed in the narrow partition between Ed's logical and illogical minds as he monitors his physical and mental activity. During the seven-hour journey from his bed to the door leading

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outside where Michael now sits trying to get to know him, Ed's brain continuously scans his physical environment for changes, information downloaded from television, and dialogue with members of his family who drop off food outside the basement door, checking and rechecking his mechanisms for holding time in its place hundreds and thousands of times. The fifteen-foot trip across the room is an excruciating testament to this process:

Right foot forward, left foot, right foot forward, left . . . a truck passes by . . . freeze. Left foot still in air, hold perfectly still for one and a half hours and wait for another truck to pass by that sounds exactly the same. With conditions now perfect, reverse process, and go backward to starting place to do it all over from beginning. Left foot down, step backward in same exact spot, now right foot backward, left . . . no. Stop. The fingers of your right hand touched. Freeze. Count in multiples of even numbers all the way to 16,384, and back, touching and untouching your fingers dozens of times to fix mistake. Move your feet into exact position they were in when your fingers touched, then reverse all moves back to spot where truck passed by. Wait. Keep fingers locked so they don't touch. Freeze. Wait fifteen more minutes until another truck passes by. Start again. Right, left, right, left. Was big toe on right foot pointed in exact position for second step as it was for first? No. Go backward. Freeze. Wait. Does everything feel right? Okay, start again. A dog barks. Freeze. Wait until dog barks, again. . . .

In much the same way one describes an out-of-body experience, Ed has watched himself descend into this extraordinary

underground life in his father's basement where his mind holds him hostage.

IT'S POSSIBLE THAT ONE OF the most effective tools in Michael Jenike's medical kit is his disarming sense of humor. Still, he is surprised to find that Ed, as sick as he is, responds, albeit weakly, to Michael's self-effacing jokes, and he has his own sense of humor, too. After hours of talking through the basement door, Ed begins to feel slightly more comfortable—not comfortable enough to let the doctor into the basement, but comfortable enough to consider meeting him face-to-face in the upper level of the house. Michael is given instructions to follow as he comes around the front of the house through the main door, turning the handle back and forth repeatedly, ending on an even number, because odd numbers are bad, and opening and closing the door an even number of times, too, before coming inside. Michael must wait for a considerable period of time as Ed struggles up the few wooden steps, stopping and starting, going forward and backward, as he counts in multiples of even numbers to 16,384. Ed is ashamed of the way he looks, and agreeing to come upstairs creates added layers of anxiety that result in more counting, and more repeating of his steps.

Just four years earlier, Ed was a tall, good-looking athlete, who was determined to try out as a walk-on for the Clemson University football team. It was a long shot of a dream for the lanky kid with an undistinguished high school playing career, but he had a powerful throwing arm and had managed to get the attention of one of the team's coaches. He took classes at the local community college and worked out every night at the gym to build

his strength and develop his body, but the version of Ed Zine who emerges from the basement is someone completely different—at least in appearance

Michael tries to catch his breath. The stench of body waste and rot come back to him from another place and time. Flashbacks and nausea consume him. From the stairwell below, a rancid breeze blows through the air, emanating from piles of human feces stored in Ziploc bags, meshed with the odor of dozens of Gatorade bottles overflowing with ripe urine. But that is only part of the sickening smell. The frail, hunched-over shadow walking up the stairs, forward and backward, has not showered, shaved, or brushed his teeth in nearly a year. Ed's eyes are squinted shut from the sudden exposure to bright light, and his long, curly hair is matted against his crusted scalp, sticking out in every direction. Pale and undernourished, he drowns in his dirty white T-shirt and gray sweatpants, neither of which he's changed for months.

Fighting the urge to vomit, Michael tries to reconcile the sight and smell of this desperately ill young man covered in bedsores, who seems more akin to a wild, injured animal emerging from its den than the gentle, respectful young man he's spent the last few hours getting to know. Obsessive-compulsive disorder has completely stripped Ed of his dignity and of the basic ability to cleanse his body and put on clean clothes.

Ed makes his way to the family room, and for brief periods during this conversation, he suddenly disengages and goes into some kind of trance, mouthing words silently to himself. The interruptions are brought on by his need to repeat his spoken words backward several times, until he meets a perfect rewind and achieves the final even number of repetitions. Incredibly, Ed Zine has taught himself to read and speak backward. He has mastered

perfect English, in reverse. His fluency is extraordinary. He can read this sentence as quickly backward as he can forward.

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The obsession to stop the progression of time and the thousands upon thousands of resulting rituals have turned Ed's mind into a photographic and audiological masterpiece trained on the relentless pursuit of perfection.

Ed and Michael are engaged in a two-way psychological assessment. While Ed is continuing his silent rituals, he is also actively analyzing Michael. He is very wary of anyone new. Recently, he suffered what he feels was a betrayal by his family who had assumed, incorrectly (and quite ironically), that he was a suicide risk and had him committed to the local psychiatric hospital. As much as he wants help to get his life back, he does not want someone who is going to *demand* his trust; he needs someone he can *believe in*. According to Ed, there's a critical distinction. "Believing in somebody means that they give *you* the ability and have the faith that *you* can make your decisions along the way. When we got upstairs and really talked, it hit me, 'BOOM,' this is someone I can really believe in."

In the living room that day, the conversation between doctor and patient did not focus on OCD—there was no need, Ed already knew his diagnosis. Instead, it was an afternoon of relationship building, as Ed shared with Michael the details of his solitary life. He sprinkles the conversation with questions to his new doctor. Is he married? Does he have children? Ed talks about his recent hospitalization, and honor—one of his favorite subjects—and he discovers that Michael is a war veteran, a pilot who

served in the air force in Vietnam. In all of this, there is nothing about Michael's presence that says, "I'm the doctor, you're the patient."

But he is the doctor, and with that he has brought all the years of his considerable experience to bear in that meeting, and he has never seen anyone with OCD this severe. "Ed was very sick, and really stuck. He was so trapped in circular thinking, there was no angle that could be used to help him." But on this first day, Michael hasn't come to see Ed with a big game plan in mind; he is there to make an assessment, form an alliance, and determine whether Ed is able to come to the Obsessive Compulsive Disorder Institute at McLean Hospital for residential treatment. But it is clear that such a move is not possible.

At the end of the day, Michael knows that although Ed wants to get well, "he wasn't going to move for anybody else's ideas and thoughts other than his own. I hoped if we got to know one another better, and tried some medicine and behavioral therapy, we could get him out of there."

If anyone can help Ed, it is Michael. He has the best skill and experience that medicine has to offer, but over the course of the next year, he will discover there are no easy answers. He will watch helplessly as his young patient spirals deeper and deeper into his own mind, haunted by that echoing equation, *Time equals Progression, Progression equals Death*, and the ever-increasing rituals OCD demands of him. Ed will eventually stop wearing clothes altogether and spend most of his time sitting undressed on the end of his bed watching television, rewinding movies backward and forward, while the unwashed sheets oxidize to a shimmering green slime from the filth of body oils and droppings of food. Helping Ed will prove Michael's biggest challenge in twenty

years of treating some of the most extreme documented cases of OCD.

IN SPITE OF WHAT WOULD become his growing belief that Ed might never get better, and would most likely spend the rest of his life living in the basement of his father's home, Michael would continue his visits, driving the distance between Boston and Cape Cod over and over because he knew that no one else would, and he understood his presence mattered in the life of a human being who was suffering inconceivable anguish. He recognized all of the deep, dark feelings that can trap a human mind, for *Captain* Michael Jenike, an honored war hero and recipient of the Distinguished Flying Cross, had also known such depths of despair.

Michael would find himself lost in the hopelessness of Ed's situation. At the end of each visit, he would drive a short distance down the road, pull his car off to the side, turn on the flashers, and cry. It would be a long time before he would realize that deep within him, he possessed everything he needed to lead his patient to a place where the healing process could begin.

The Day Life Stopped



IN THE PICTURE-PERFECT, WHITE-SHUTTERED two-story with its welcoming front porch, nestled among tall trees, with delicate lilac bushes etched against its windows, Rita Zine had created a gentle, loving environment for her children. It was a place where Ed could walk into the sunshine on a glorious New England day and never have to think about stopping time, because *here* time had no special meaning. He didn't need to worry about things being touched, or moved, because *everyone* was safe, and *everything* was in its proper place.

And though life inside the Zine household was far from perfect, it *felt* perfect to Ed because his mother made it so. She sang to him and cooked for him while he sat at the kitchen counter

watching his favorite cartoons on TV. He was her baby boy, and at a time when she was faced with the challenges of an older son who struggled with negative outside influences, she served up an endless stream of affection and support for her youngest, telling Ed that one day, he would do something really important with his life. She snuggled with him while they watched movies together, carried cookies and ice-cold pitchers of lemonade out to the backyard while he played Wiffle ball or swam in the pool. She invited neighborhood children like Rudy Harris, who would later play football for the NFL, to have sandwiches with them after school. Rita was ubiquitous in Ed's happiest memories, and when she would pass away, the tapestry of his life would change *dramatically*, as he would be cared for by his less nurturing, seemingly antithetical father.

Bob Zine was the dark, handsome, volatile son of a Lebanese-born prizefighter-turned-bookie from South Boston who, at age sixteen, forged his mother's signature, lied about his age, and went off to fight for the Marines in World War II. During his induction, as a drill sergeant yelled, "I am your mother and your father, now, son," he was frightened and homesick. Having second thoughts about what he'd done, he called his father to bail him out. "Take it like a man," Bob was told. Whatever gentleness there was inside of him was suppressed that day. His wartime experience would later inform his decisions as a father, and the regimented way he ran his family and home.

After surviving World War II in the Marshall Islands, and serving another term of service in the Korean War, Bob returned home to South Boston where he met, and fell in love with, Rita Grace Nice, a petite blond beauty with a poodle-cut hairdo. Her name perfectly matched her quiet demeanor and style. She was

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“the prettiest girl in the neighborhood,” remembers Bob, “and I fell in love with her the minute I laid eyes on her.” The early years of their marriage were lean but loving, as Bob worked long hours as a plumber to support his burgeoning family. Eventually, though, he became a master builder and came to own his own business, enabling his family to move into Boston’s suburbs to live “the good life.”

Ed remembers his mother’s scent. She always smelled “shampoo fresh,” mingled at times with smoke from the cigarettes she dangled between her fingers as she sat at the kitchen table playing dominoes and Yahtzee. She was the center of Ed’s universe, with television coming in a distant, though *not insignificant*, second.

To this day, Ed can recall the day and time when his favorite shows from the seventies and eighties aired. He never missed programs like *The Incredible Hulk*, *The Greatest American Hero*, and *Magnum P.I.*, and he developed a passion for the ones that had veritable heroes in the leading role. A quiet, sensitive child, he connected emotionally with their power and honor, and he used the story lines of good and evil to begin developing his own simplistic code of ethics. In one episode of *The Incredible Hulk*, Hulk impersonator Lou Ferrigno stops a man from using physical force against his son, and despite the fact that Ed’s father, like so many men of his generation, frequently employed physical discipline to rear his kids, Ed instantly recognized that dads are *not* supposed to hit their children. “In that moment, I realized that it wasn’t something that was inherited or predestined,” recalls Ed, “and I decided right then and there, I didn’t have to be that way. I was never going to hit my children when I grew up.”

But it would be a fallacy to paint Bob Zine as chronically abusive. Ed and his father were actually quite close, and they

shared many special times during his childhood. On weekends, when his dad was at his most relaxed, away from the stresses of work, Ed would crawl up on the sofa next to him in his pajamas and, together, they would watch the Sunday Night Movie of the Week, movies like *The Dirty Dozen*, *The Big Red One*, and the *James Bond* movies. Having a father who was an ex-marine and, in Ed's eyes, a real-life hero only served to make the experience more powerful for Ed, allowing him to connect to his father in an emotional and loving way.

But television also became a necessary audio distraction for Ed. Before VCRs were a regular part of the American household, he would take his audiotope player, hold it up close to the television, and record the sound while he watched the show. When the program was over, he would go to his room and play the sound over and over again, rewinding it to his favorite moments, blocking out the arguments his parents would be having in the other room. "I used to see my mom and dad fight, which was very hard, but I chose to look past a lot of it," recalls Ed.

Bob and Rita Zine fought constantly about their oldest son and issues of discipline. Adding to the stress, around this same time, the formerly petite beauty had nearly doubled in size, making her a target for her husband's explosive and often cruel verbal lashings. Unaware that the reason for her weight gain was ovarian cancer, Bob made little secret of the fact that he was planning to leave his wife.

In fact, no one, not even Rita, knew she was sick. Although Ed compares his mother's size and immobility during this time to the profoundly large mother in the movie *What's Eating Gilbert Grape*, he doesn't ever remember being embarrassed by her size, only concerned when she could no longer climb the steps to her

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bedroom. His older sister Tami recalls, painfully, a comment that her boyfriend made at the time when she told him her dad was going to leave her mom: “If my wife was that big, I would leave her, too.”

Ed’s last great memory of his mother was a trip to a movie theater in May 1980 when *The Empire Strikes Back* came out. It was a special experience that marked the beginning of his *Star Wars* passion. Shortly after, Rita surprised Ed with a set of *Empire Strikes Back* sheets for his bed and a Darth Vader costume for him to wear at Halloween. Whenever he and his friend Rudy got together to play *Star Wars*, he would put on the full costume and swing his light saber, while his mother joined in the fun with her best imitation . . . “Ahhhhhh, Luke, I am your father!”

But Ed’s happier memories are interrupted by later conversations overheard in the kitchen and hallways as he passed by, hushed conversations between his older sisters and aunts when the diagnosis finally came. No one ever said, “Mom has cancer,” but Ed knew something was wrong, even if he didn’t know exactly what it was. Relatives seemed to always be making an effort to get he and his sister Deena out of the house to do as much “fun stuff” as possible. But for a happy, intuitive young boy to suddenly be pushed away from his mother, watching as she spent more and more of her time in bed, there was little fun in leaving the comfort of his home.

These were the days when *Star Wars* fun and pitchers of ice-cold lemonade in the backyard would come to an end. All of those things Rita did so effortlessly to keep the house running smoothly and provide a loving atmosphere—things everyone had taken for granted for so many years—were coming undone. The house, and all of its order, was falling apart, and the ensuing chaos took the

greatest toll on her husband, the ex-marine whose life had been so carefully regimented; Bob was also heavily burdened by the guilt of having cruelly blamed her for her weight gain, all the while having one foot out the door. Worse still, for him, was the realization that his children were about to lose the woman he describes as “their best friend,” and during the holidays, no less. The building frustration, guilt, and sadness were understandably more than any man should have to bear, but his implicit reaction to this perfect storm of emotions would have devastating and lasting repercussions.

On Sunday, December 19, 1982, as his mother lay down the hall in the hospital bed delivered by hospice, Ed spent the wintry day inside, sitting in front of the television set, playing ATARI. Looking back, the only memory that could have clued him into the pending tragedy, had he paid greater attention, was an argument his father had with someone in the background of the day, but he was too wrapped up in his game to listen to what was being said. That evening, he put his video game on pause, went into the kitchen looking for something to eat, and managed to scrape out the last remains of dried-out peanut butter on to a piece of white Wonder bread. After slathering the whole thing with jelly, he returned to his game.

The realization that this might be Rita’s last night on earth was just beginning to sink in for Bob when he walked into the kitchen and saw the jelly jar sitting open on the counter. Ed had no context for his father’s rage. He didn’t know his mother’s life was about to expire nor that his father, who would later say, “She didn’t deserve to die like that, it should have been me,” was on the verge of emotional devastation. Nevertheless, that night, Rita’s

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baby boy, Eddie, became the lightning rod for his father's anguish and despair.

"When he hit me, it just came out of the blue," Ed recalls. It's not that Ed was ever completely surprised by his father's temper, but most of the time it was just words. "A lot of times when my dad would scream," remembers Ed. "He'd throw things in the air and say terrible things, but that night, he came over and started kicking the ever-loving shit out of me. I had no idea what I did, or did not do, to deserve it." It would have been pointless to fight back or even run from his father, so Ed stood there and took the beating, trying not to cry and anger his father further. When it was all over, he did precisely what he was told to do; he went into the kitchen, put the lid back on the jelly jar, and went to bed, head severely throbbing from his father's violent outburst.

ED LAY AWAKE FOR A few hours, still petrified from what had just taken place that evening, but then he began to hear a painful groan coming from his mother's room, and he quietly, carefully, got out of bed, and headed down the hall. Ed stood frozen in the midnight shadows of the hallway across from his mother's room. His eleven-year-old mind knew instantly what his heart rejected. Listening to the gasp, the groan, and that final, unforgettable hiss of life as it escaped her lungs—he watched as his mother took her last breath. It would be years before he would tell anyone what he'd seen, and even longer before his father would accept the possibility that Ed's story could be true.

In the late hours of that December evening, just one week before Christmas, among the whispers of old ghosts living in the

Stoughton, Massachusetts, home—rumored to have once belonged to the cousin of Paul Revere—Ed shivered violently. In that moment, his entire life changed forever. In the recesses of his mind, he worried that his father might catch him out of bed, but as he wandered back to his bedroom, he was in shock over what he'd just witnessed.

It wasn't long before Ed heard the sudden rush of people coming and going outside his door. In a frenzy, his father told him to get up and get dressed, and then he was taken to the home of an aunt. No one *mentioned* his mother's death, and Ed feigned ignorance, still in shock from the physical and emotional trauma of the evening.

TWO DAYS LATER, WHILE ED was having a breakfast of Lender's bagels and cream cheese and hot tea, his father arrived to break the news of Rita's passing. Ed was taken by his father out of the kitchen into the den, where his dad said, "I've got something to tell you, son." But before he had a chance to speak, Ed looked up and said, "Dad, I know. Ma's not here anymore." Surprised, Bob assumed that Ed overheard a conversation, and he asked how he knew, but Ed refused to say anything else. In fact, it was the beginning of a silent treatment Bob would have to endure for a long time.

"Before his mom passed, he was always a quiet kid, always happy," recalls Bob. "But he was a really good kid—who wanted to spend time with me. We always watched movies together and things like that. But after her death, everything changed. I couldn't get him to do *anything*. He was shell shocked. He wouldn't talk to me, at all."

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Even if Ed had the emotional capacity and the words to express what he had seen and what he was feeling, he didn't dare tell anyone; with the beating he had sustained for leaving the lid off a jelly jar, the consequences, he felt, of admitting that he had disobeyed his father by leaving his room and subsequently witnessing his mother's death were too great. He would carry this impossible secret, buried underneath the grief of extraordinary loss, for years to come, until he could no longer manage its profound effects.

AT HIS MOTHER'S WAKE, ED sat quietly in the back of the church, trying to figure it all out, as everyone else was busy dealing with his or her own individual grief. He had become an outsider, alone, left behind in the sorrow of his mother's wake, and his mind was filled with a mix of memories that he could not reconcile. At one point, as he stood in a line at the front of the room, greeting mourners with his family, he turned to look at his mother lying in the open casket and thought he saw a facial movement, a tic of some sort, indicating she was still alive. He watched her for a long time, hoping that her death was a mistake, and maybe that she was just sleeping, because she looked so peaceful and thin, as all of the fluid of her cancer-filled body was gone.

Ed, who had always been at the center of his mother's world, was now someone else's worry. He remembers family members scurrying around to find something of his to place in the casket, and they came up with a toy airplane. It should have been a *Star Wars* toy . . . that would have meant something. His mother would have understood the significance of that, but there was no one listening to him now.

Back at school, after Christmas break, Ed's friend Rudy didn't understand why Ed wasn't in class. Rudy had spent the holiday with family and didn't hear about Rita's death until the principal came in and made the announcement to the class. Rudy, whose own mother had died when he was in the first grade, had not only lost his neighborhood mother figure, but he greatly missed his best friend who would not return to school for a long time. When Ed did finally go back to school, his home life was so unsettled, he struggled to get through the rest of the year.

After Rita's death, everyone in the family seemed to scatter. While his older siblings were off living their lives as they had before his mother's death, his brother Tommy, with whom he shared a bedroom, went off and joined the service. Older sister Tami moved out of the house and into her own apartment down the road, while Deena, who is closest in age to Ed, withdrew into her own world and spent every night crying herself to sleep.

Ed spent a lot of time thinking about the fights and the harsh words that passed between his parents before his mother's death. He wondered if his dad—whom he describes as “disconnected” during the funeral, never crying once—even cared that his mother was gone. But then one night, as he passed outside the room where his father was packing up some of his mother's things, he was witness, once again, to a rare expression of his father's despair as the strong, proud marine broke down and wept.

Like most men of his generation, Bob did not take naturally to raising and nurturing children. It was something that women were supposed to do while men worked for a living. Now, without a wife, he was completely at a loss as to how to deal sensitively with his two youngest children. “I kept Christmas in the new room for them. I didn't know what else to do. I tried to talk to

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them, but I wasn't any good at it. They'd had a bomb unloaded on them. And then Eddie started to act strange, standing in the corner, talking to himself, all mumble-jumble," recalls Bob. "He would stand in the corner making strange noises, waving his arms, and grunting to himself. I didn't know what to do. I swear to God, I didn't." Before heading off to the service, Tommy remembers that Ed would lie in bed at night making the strange sounds in his sleep, and he knew something wasn't right.

As Ed's trauma over the loss of his mother continued to manifest itself in bizarre physical affectations, his inability to articulate his sorrow and pain created concern. "The problem is," says Ed, "nobody knew what I saw; only *I* knew. So they're thinking, 'poor kid, his mom just passed away, and he doesn't understand what's going on.' At that point, I not only understood what had happened, I had more going on inside of me—more emotions stirring—than anyone could possibly understand." The one person who would have understood was gone, and life was confusing. Ed was wrestling with many strange, new feelings and fears. "Suddenly, whenever I would get in the car with my sister to go do something fun," he recalls, "I felt like something bad was going to happen if we went a certain way or did a certain thing."

As the situation grew more desperate, and Bob's frustration increased, he made a decision that he thought was in the best interest of his children: he sent Eddie and his sister to live with his brother and sister-in-law. He hoped they would be better equipped to bring Eddie back to life than he would be on his own. But for Ed, being uprooted from his home, the place where the memories of his mother were alive, was devastating. It was also compounded by a certain fear. Even at his young age, he was trying to conceptualize death; the idea that his mother had gone

to a place where Ed couldn't see or touch her was terrifying. He didn't want the same thing to happen to his dad. He wanted to stay by his side, be near to him, watch him to make sure nothing bad happened to him, even in spite of the jelly jar episode. Ed nevertheless yielded to his father's wishes, and the traumatized boy went to live with his aunt and uncle. "I didn't have the words to express myself, and what I was feeling," remembers Ed. "I could only do what I was told to do."

Ed may not have had the ability to express his thoughts and feelings aloud, but his deepest emotions rose up in silent expression as he related to the scenes of the movies and television shows he watched. He connected with story lines dealing with the issues of love, honor, and family, as they played out before him on the television set.

Ed recalls a specific moment during this time when he was visiting his auntie Queenie's house. Auntie Queenie was upstairs making his favorite chocolate and marshmallow candy, while downstairs he watched *Uncommon Valor* with his uncle "Crunch" Mac in their new entertainment room. "When you see moments like this on television, or in the movies—the love of a son, played by Patrick Swayze, for his father—those are *real* moments of emotion that live inside of us and stir us at the very core," Ed remembers. "I was raised on moments like that . . . television brought it out in me."

According to Ed's father, "not much changed" while Eddie lived with his aunt Betty and uncle Junior. And although Ed was drawn to Junior's strength and integrity and cites him as a role model for living a life of honor—being a man's man who meant what he said, who firmly believed in being truthful, and who never talked bad about anyone—it wasn't enough to erase the

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feelings of being so desperately unsettled. At the urging of Ed's older sister Tami, Bob took Ed to see a psychiatrist, hoping to find answers for his son's silence—but Ed refused to talk to the doctor.

In an attempt to bring his family back together and give Ed and his sister Deena a fresh start, Bob thought it would be a good idea to sell the house in Stoughton and make a permanent move to their summer home on Cape Cod. It was not a discussion he had with his children; he just did it. Suddenly, inexplicably, Ed was taken to live in a world far away from the smell of spring lilacs outside his window, the tire swing hanging from the tall tree in the backyard, and his best friend, Rudy. It was the only home he'd ever known—the refuge he associated with his mother's love and protection. As he watched his dad load boxes into a U-Haul to take to their summer home, Ed had no idea he was leaving his childhood home forever, and he was never given a chance to say good-bye to it.

Time just kept moving forward, and the changes it inflicted upon him were too many, and too fast. He wanted it all to stop. He wanted to turn back time and make everything the way it was. He wanted to stay in the one place where his mother lived in his heart and mind, but it had all vanished in the rearview window of his father's car as they left Stoughton for the last time.

THE HOUSE ON THE CAPE was a brand-new raised ranch with all the modern conveniences. It didn't have a long history, or rumors of ghosts. It didn't smell like an antique store. There wasn't even a hint of his mother's shampoo freshness or the lingering scent of cigarettes she smoked at the kitchen table while playing her games.

Other than Ed's sister Deena and his grandmother Sitto—who temporarily acted as their caretaker—and of course the television, the house was a vast, unfamiliar, five-bedroom emptiness. The joy that Ed once got from playing outside was gone. The scenery was foreign, and he had no friends in the neighborhood to play with. He missed Rudy, he missed the tree swing, he missed the swimming pool. So he retreated inside to live among the things he could touch, that had once been touched by his mother. He began to seek comfort in the physical objects, the toy Transformers, GI Joes, the Star Wars figures, and the Darth Vader costume his mother bought him, all of which had a calming effect on his mind. He would curl up on the sofa, watch his usual cartoons and television programs, and relish in the familiarity of it all, reliving the warm and cozy feelings from the childhood that felt a million miles away. The toys and television had become Ed's mental catharsis.

When Tommy came home from the service, he would come by to help Bob get the kids off to school. He recalls it was hard to get Ed moving in the morning. "The harder I pushed, the longer it took for Ed to get his things together and make his way to the car," says Tommy. Ed, he reports, was always going back to check and recheck things he needed to bring to school, and touch certain things before he could move out the door. "Looking back," recalls Tom, "it was Ed's OCD starting to reveal itself. It wasn't because Ed was lazy, but we didn't know that at the time."

A self-described "geek," Ed was the skinny new kid, in a new environment, and he became the target of the neighborhood bullies. He wasn't comfortable at school, he wasn't completely comfortable at home, and by the time he hit thirteen, he wasn't comfortable in his own body. "I was trying to become an adult and

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deal with the fact that my mom wasn't there, and there was no one in the family for me to talk to about adolescence." Emotionally, Ed says he continued to identify closely with the young kid inside himself and still enjoyed his cartoons and toys in spite of the growing pressures of being a teenager. And while Ed wasn't as close to his father as he had been as a child, there was a constant undercurrent of worry in his life that he, too, might die. His dad wasn't home much, but Ed always made it a point to know where his father was, checking in on him to make sure he was okay. Life was confusing, and he admits, "I lived a lonely, motherf'ing life, always asking myself, 'What the hell about me?'"

Ed says that he quickly realized that his survival, and gathering friends and family around him, depended on his personality. "Being a sweet, geeky, book-smart kid helped me make friends," says Ed. Ed's attachment to his friends was intense and loyal. The more preoccupied he became with his friendships, the more he was distracted from the constant thought of dealing with the loss of his mother. "I didn't get closure to the problem and never developed the coping skills I needed, but I felt I was honoring her by *trying* to be happy," says Ed.

BY THE TIME HIGH SCHOOL rolled around, Ed had grown into a tall, good-looking teenager. Tommy, who had always been a terrific athlete, encouraged Ed to get involved in sports. Ed never considered himself a jock at 140 pounds, but he managed to make the football team in his junior and senior years. By this time, Ed had naturally developed a quick wit that made him popular with his friends, and he had become part of a small group of guys. Kevin Frye, tri-captain of the Falmouth High School foot-

ball team, and one of Ed's closest friends, remembers, "Eddie would always go above and beyond to help his friends out, and he wanted everybody around him to be happy. We all knew he didn't have much of a home life, he and his dad were not the closest, so his friends pretty much became his family."

No one ever really talked about the fact that Ed's mother died, but his friends all knew, and there were times when Ed would become suddenly pensive. When someone would ask, "What's up, Eddie?" he would simply tell them he had a lot of things on his mind. It was clear these sporadic interruptions in his otherwise upbeat mood reflected much deeper issues. Kevin remembers times when it would be hard for Ed to go home after they'd been hanging out together because he really had nothing to go home to but an empty house.

Ed's high school football career was unremarkable. He was tall, but skinny and not by *any* stretch the most physically gifted athlete on the field, and his playing time was usually limited to the few minutes at the end of the fourth quarter. Ed may not have seen a lot of game time, but he remembers overhearing one of his coaches say, "the kid's got a lot of heart," and that made him feel good. But even when he *did* play, there was rarely anyone around to watch who could later pat him on the back and offer words of encouragement. The only reason he played football, he now admits, is that he wanted to make his brother, Tom, proud.

Tom would show up at practice whenever he was in town, but Ed's dad was always too busy working to come to his games. Ed says he never pressured him about it because he figured work was something his father did to bury the feelings he had for Ed's mother. In the back of his mind, though, he always knew that if his mother were alive, she would have been sitting in the grand-

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stands at every game, supporting him even on days when he did nothing more than warm the bench. It was the “what might have been” that was a constant source of heartache and sadness in Ed’s life. On Thanksgiving Day 1989, which marked the last game of Ed’s senior year, when Bob did finally show up with Tom to watch him play, there was another heartbreaking turn of events. Ed was sidelined for the entire game. His dad never got to see him play.

When he wasn’t out with his buddies, Ed found solace in the soft glow of his television set in the basement, but it was the VCR that changed his experience in a whole new way as he watched his favorite television shows and movies over and over again, hitting the rewind button as often as he chose, dissecting and analyzing the actions and reactions of his favorite scenes and characters. If he watched a tape and caught someone saying the word *death*, or what Ed calls the “d-word,”—he would rewind it so they would repeat it an even number of times, because if something was said an even number of times, it was like an “eraser to a chalkboard”—it simply disappeared. If he saw something he didn’t like, he would fast-forward past the scene to “wash it out.” He says he would always time it perfectly, because he could “feel” it, before hitting play again.

Rewinding gave Ed complete control of time within his movie and television world, and gradually between 1992 and 1995, he would transition his power from a videotape process to a mental and physical process that would completely consume him.

FOR THE NEXT SEVERAL YEARS, Ed continued to suppress the painful secret of his mother’s last moments, but as he watched his heroes on television, he made a conscious decision that he would

live his life like a movie. *He* would become a hero, too. The idea that someone would be willing to lay down his life for another human being resonated deeply within him. As a child, he wasn't able to save his mother, but as a man, he would find a way to save the rest of the people he loved.