

LEAVING THE HALL LIGHT ON

*A mother's memoir of living with her son's bipolar disorder
and surviving his suicide*

MADELINE SHARPLES

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*For the loves of my life
Bob, Ben, and Marissa*

I could not have gotten through this without you.

*And in memory of
Paul Ian Sharples*

December 31, 1971 to September 23, 1999



Poem Credits

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under title, “What Is Loss?”

Mania—Survivor Chronicles (2010)

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Years, Months, and a Day—unFold (2010)

My Jazzman—Survivor Chronicles (2010)

The Bully—Didi Hirsch Survivors after Suicide Newsletter (2006)

Buddha—Survivor Chronicles (2010)

Lunch excerpt—Perigee Publication for the Arts (2009)

Making It Hard—ONTHEBUS (2004)

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The Dreaded Question—Survivor Chronicles (2010)

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Black Bomber—The Great American Poetry Show Volume 1 (2004)

Today I Saw You on the Hill—poetsespresso (2010)

NOTE: THE AUTHOR HAS CHANGED THE
NAMES OF MANY CHARACTERS IN THIS
BOOK TO PROTECT THEIR PRIVACY.

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LEAVING THE HALL LIGHT ON





May 1973, at Grandma and Grandpa's piano



When I held Sam alone for the first time..., I was nursing him and feeling really spiritual, thinking, please, please God, help him be someone who feels compassion, who feels God's presence loose in the world, who doesn't give up on peace and justice and mercy for everyone. And then a second later I was begging. Okay, skip all that shit, forget it—just please let him outlive me.

Anne Lamott, *Operating Instructions*
Anchor Books, 1995

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February 1997, playing piano at his dad's sixtieth birthday party

CHAPTER ONE

.....HOW IT ALL BEGINS



Sometime during the night or early morning of September 23, 1999, my twenty-seven-year old son Paul walked out of his dark bedroom in his bare feet, entered his bathroom, and closed and locked the door behind him. Still wearing the white, long-sleeved shirt and khaki pants he had worn to work the day before, he went to the far side of the room, stepped into the bathtub, closed the sliding glass shower door, and sat down in the tub. Using a box cutter, he slashed both of his wrists. Then he slashed his throat and bled out into the tub.

That seemingly painless and swift act—it took approximately thirty to forty seconds for Paul to die—brought our tight, average suburban family to the depths of despair. My husband, Bob, age sixty-two at the time and a successful aerospace engineer for most of his professional life, had to touch the cold, lifeless body of the child he deeply loved. Our second son Ben, age twenty-five, two and a half years younger than Paul, was in San Francisco performing with his fellow classmates on the

main stage of the American Conservatory Theater and almost ready to receive his masters degree in fine arts in acting. His brother's death was almost the end of his dream. Though I had struggled through the years of Paul's bipolar disorder highs and lows, I, then age fifty-nine and retired from the aerospace industry as a proposal expert, was writing grant proposals for non-profits, active in my community, and enjoying life with my friends, my gym, my book clubs, and walks along the beach. I was also an avid journal writer and beginning to take an interest in creative writing. Though I was healthy, the stress of Paul's illness kept me thin.

Because writing was a constant in my life, I felt compelled to write the story of my oldest son's life-and-death struggle with his bipolar illness (also called manic depression) before the memory faded. I could never forget those few months in the spring and summer of 1993 when Paul had his first mental breakdown—or crackup as he called it—and the years of worry, weight loss, rescue attempts, and grief ever since. And, I don't ever want to forget. I want to remember everything about him—how his fingers trickled up and down the keyboard as he played the piano; his dark blond hair cut close to his head in a buzz; his passion for second-hand plaid shirts, washed out jeans, and Doc Marten oxfords; his appetite for burgers and steaks, pizza, and ice cream; his brilliance with all things related to computers; his wonderful ability to write and draw; and his obsession for order and regimen in the way he treated his belongings.

Even after all these years reminders are everywhere—his room in our home that I've turned into my office; his piano that no one ever plays, still up in the family room; our living room where he used to wrestle with his dad and brother before it was furnished; the downtown Manhattan Beach Starbucks where he liked to sit outside; the Manhattan Beach pier; the hundreds of photos either on display in our home

or scanned into our computer; his books and records packed away in boxes in our garage, and things I couldn't possibly part with—his black bomber jacket, his poems and short stories, his photos, anything in his handwriting, his CD collection, and, of course, recordings of his original compositions, now on CD and on my iPod courtesy of his best friend from high school.

The doctors told me it wasn't my fault when my son was diagnosed with bipolar disorder. They said this disorder, caused by a chemical imbalance in the brain and triggered by stress, usually hits young people in their late teens or early twenties, like Paul who had just turned twenty-one. One day he was perfectly fine, playing the piano at his grandmother's eighty-fifth birthday party. Two weeks later he was calling us up every few minutes, writing all over his walls with a blue felt-tipped marker, saying people were lurking in doorways out to get him and poisoning his food and cigarettes.

He was no longer able to sit still long enough at the piano to play a song through from the beginning to end. Was he acting like a crazy person or someone high on drugs? At first we didn't know which.

But deep down I felt guilty. Why hadn't I seen the signs? Why didn't I take better care of him? He was my son. I should have known how to protect him from the danger he was in. I didn't know then that I had no control over what happened to him. I could only care for him the best I could. I couldn't spoon-feed him like a child anymore. He didn't allow it. He was an adult, and he controlled the outcome. Even so, my feelings of guilt have never gone away.

From the time he was born—in fact even before he was born—Paul was special. He presented himself feet first. All the Lamaze classes my husband and I attended went by the wayside when the doctor kicked Bob out of the delivery room and performed a Cesarean section. Paul was stubborn even in utero—he wouldn't come out the natural way.



September 1972, nine months old

When I finally was allowed to see and hold him twenty-four hours after the delivery, I was the first to notice that both of his hands were deformed—the middle and ring fingers of both his hands were stuck together. I was in so much shock as I held him and peered into his face that I couldn't keep it in focus. His face seemed to recede and disappear as I held him in my arms. My worst fears and bad dreams had materialized. My child was born with a deformity. What had I done to cause that? As was the hospital's custom with Cesarean deliveries, he had been thoroughly examined by a pediatrician and observed in an isolette around the clock for the first twenty-four hours of his life. Yet no one who had given him his initial exam noticed. When I looked at his fingers, I started screaming, and Bob took off down the hall to get the doctors to reexamine him. If they had missed something so obvious as his webbed fingers, what else did they miss?

Throughout my pregnancy we had never let up on our fears about how our child would turn out. I would be over thirty at the time of the birth and in the early 1970s that was considered old to have a first child. I had already had two miscarriages, and Bob was the father of a Down's Syndrome child born from his first marriage. I was also under a lot of stress, mostly caused by my mother's jealousy. She couldn't stand that Bob and I were happy; she couldn't stand the attention I was getting while I was pregnant, she couldn't stand that I didn't need her anymore, and she couldn't stand that she had no control over me anymore. Whenever we spoke on the phone, she picked a fight. One time when I was about six months pregnant with Paul, I called my parents from a pay phone to check in during our return trip from a weekend at Big Sur. I was happy and relaxed from our trip, and we wanted to drive through to our home in Riverside rather than stop and see them in Beverly Hills. I stood in the phone booth at a gas station for at least half an hour with Bob waiting in the car while she told me how disrespectful and inat-

tentive I was. “You left us all alone while you were away having a good time,” she yelled. I finally yelled back, “If something is wrong with my baby it will be your fault.” As a result she, too, was very worried about how Paul would turn out. She had a vested interest in him being born perfect. He was except for the “funny finger thing”—as we began to call his deformity.

Otherwise, Paul was diagnosed as a healthy baby, and we immediately fell in love with him. He was so easy. He nursed well and slept well in between feedings. From the beginning he was the love of Bob’s life. He would hold Paul in his arms and constantly talk to him. He’d hold him close to the pictures on the wall and tell him their stories as he described the books, the chairs, the kitchen items, his parents, his grandparents, and the wonderful future we wanted him to have. This child was loved, and the doctors reassured us his fingers could be easily fixed—a simple surgery, they said, when he was older.

The word “simple” was the understatement of the century—at least to us. At age two Paul was in surgery for over eight hours to separate the two fingers with perfectly normal bone structure on both hands and remove skin from his groin area to build the webs in between his fingers. He was barely conscious when he was rolled away in his hospital crib with the high bars all around. I wanted to go with him, to be there with him at least up to the surgery room, but there was no way. In those days, hospital rules were so insensitive that they didn’t allow for the needs of the little patients or their parents. Then we sat all those hours in the waiting room—my dad was with us—and we didn’t move until we knew he was safe and in recovery. And still we weren’t allowed to see him until after he was out of recovery and fully conscious. Unfortunately, it was during the four-hour recovery time that all the damage was done.

“Mommy, I can’t move my fingers,” were the first words I heard when Paul was brought out of the recovery area. I was devastated to see him this way. I had only done what I had thought best for him in the long run, but at the moment I felt I had made a terrible mistake. And, maybe so. The happy-go-lucky little boy was now gone. Still beautiful, still bright, and immediately agile with all his little fingers once his casts were finally removed, but he was never the same again.

The happy, smiley boy who had embarked on that surgery with full trust in us and confidence that his adored Dr. Lane (he said, Dr. Yane) would separate his fingers just like we fixed his broken toys—in an instant—just like that, awoke to find both his hands and arms up to his elbows in heavy casts so he wouldn’t do any damage to the one hundred stitches the doctor had sewn in each hand. Before the surgery he was able to suck those fingers. Now he was cut off from that security “blanket” cold turkey. Before the surgery he went to anyone. He was a child full of trust and love. Afterward he had a list of fears: pictures of clowns, people with masks on Halloween, Santa Claus, and old men with beards. These things would trigger hysteria. Fortunately, those fears were finally allayed once he started watching Sesame Street. He would shriek with laughter at the fuzzy monster puppets that spoke to him in a language he could understand and learn from.

The only explanation for his fears that we could think of was his half-conscious state during the recovery and that the doctors and nurses all wore surgical masks in the cold, sterile atmosphere of the recovery room. I wasn’t allowed in. I wasn’t allowed to help him. For the first time I wasn’t in control—except that I had allowed the surgery. I knew we had to get his fingers separated, but maybe we should have waited until he was older when he could better understand the procedure and the aftermath. Had I known how long the surgery would take, had I known beforehand he would have to wear such debilitating casts for so



February 1974, with casts after finger surgery

long, I might have decided to wait. Even the doctor had misgivings. He said that had he known the procedure on both hands would take eight hours, he would have done one hand at a time.

I, at least, was allowed to stay with him the night of the surgery, though both of us hardly slept. He would not allow anyone but me to touch him. “Mommy will do it,” he said, whenever a nurse came to change a dressing or give him a sip of something to drink. I sat up with him on my lap through the night.

That incident was the first of many traumas that Paul suffered during his terrible twos, perhaps precursors to his bipolar diagnosis nineteen years later. Very shortly after the surgery we moved to a house we purchased in Manhattan Beach, California. Later that year his brother Benjamin was born. The first time Paul saw Ben, he quickly remarked, “He’s already had his surgery,” thinking that all little babies are born with funny fingers. And soon after, one of his favorite people, my father, was diagnosed with cancer of the bile duct system. From the time Paul was a baby, my dad loved to take care of him whenever he got the chance. He would feed him juice or water from a bottle (not milk since I breastfed Paul until he was fifteen months old), take him for buggy rides, readily change his diapers, and proudly hold him on his lap as Paul, with an adoring look on his face, gazed up at him.

My dad had encouraged us to have Paul’s hand surgery sooner rather than later. He would lie down with Paul for their afternoon naps and he could see Paul trying to pull his fingers apart. He worried that he would try to separate them himself. Once Paul asked for a screwdriver (he said “foogiver”) so he could open his fingers. We were all worried that he would harm himself unless we acted quickly.

After my dad had bypass surgery, he couldn’t be Paul’s playmate and caretaker again. “Why doesn’t Grandpa play with me anymore?” Paul asked when we would visit, and by the time Paul was three and a half, his grandpa was gone. Paul missed him and he never forgot him. They

were alike in many ways. My dad was short; so was Paul—not quite five foot nine inches. My dad was small boned; so was Paul. Otherwise they didn't look alike. My dad had dark skin and dark hair and big brown eyes. Paul was pale with dark blonde hair and amazing blue eyes rimmed with dark lashes. But like my dad, Paul was gentle with little children. They were both quiet and inward. They both loved to read and listen to music. And Paul walked fast like him.

Looking back, I think a couple of other events in Paul's life were warning signals about how he would turn out. One was his strong reaction to Bob's possible job transfer to the East Coast. Paul was so adamant about not wanting to go, about not wanting to leave his high school, jazz ensemble, and his life in Manhattan Beach, that we went to family therapy for help. The rest of us were okay with the move—including Ben—but Paul couldn't be placated. While in therapy the doctor recommended that Paul take a series of psychological tests. These showed he was slightly depressed, but both Bob and I and the doctor didn't see that as a major problem. Maybe we were sticking our heads in the sand, but we chalked the depression up to his being a fifteen-year old who wasn't getting what he wanted. The job transfer never happened, and although Paul was elated at the news, he continued with the psychologist for about a year on his own.

The second event started when Paul was seventeen. He met a thirty-two-year old divorced woman at a party given by his high-school jazz teacher and began a full-fledged love affair that lasted about two years. Instead of crying rape, we tried to end the affair by urging him to attend college in New York City at the New School jazz program in place of one of the California schools that had offered him admission. And in enthusiastic agreement, he entered as a freshman in August 1989. By the summer after his sophomore year the affair was over, but not without a lot of pain for him. He acted like an adult while he was inside the relationship, but when she decided to end it he was like a hurt little child. And I could do nothing to help him through it.

It is so hard for a parent to say what impact a first love has on a child. It appears that Paul matured greatly with respect to the opposite sex, but the effect of that love affair on Paul's later approach to and choice of women stayed with him for the rest of his life. He really didn't know how to behave in a give-and-take relationship with women. I always thought the affair was a major stressor and trigger to the onset of his first manic episode in 1993 when he was living in New York City.

Still, I was shocked that Paul had bipolar disorder. When the doctors asked me if my family had any history of mental illness, I said no. But, after thinking about it, I realized that he had the family curse. He would have to live a life faced with the mood swings I had seen in my mother and uncles. And I felt guilty because I kept thinking Paul went crazy because of my genes. I couldn't get that out of my mind.

Paul's bipolar disorder diagnosis was based on a combination of my family history, his age and artistic bent, lab tests to rule out drugs, brain scans, and his response to the antipsychotic and mood-stabilizing drugs the doctors prescribed. The cruelty of this illness is that he, like other manic-depressives, liked the highs so much he refused to stay on his meds once he was stabilized. Consequently, it took more episodes, the breakup of his last long-term love affair (not the older woman he fell in love with when he was seventeen), the loss of all his friends in New York, and the inability to stay focused enough to play the piano for more than a few minutes at a time before he finally understood what havoc his mania caused in his life and in the lives of those around him. But that didn't deter him. From the beginning of his illness he was edging toward his destiny.

I couldn't help feeling guilty, and I know I shouldn't have, for his illness and its effects. But seeing what had happened to my beautiful boy, hearing his constant babbling about how his food and drinks were poisoned and that the Mafia was out to get him, seeing his vacant, glazed-over eyes, I couldn't help it. My stomach was in turmoil. I couldn't

eat. I couldn't sleep. I couldn't think about anything else. Every few minutes I would break down in tears. Even with a new discovery by scientists at the University of California at Irvine that two genes on chromosome eighteen are involved in manic depression—one gene helps the brain cells receive chemical messages, and the other has to do with the body's hormonal response to stress—I still blamed myself and my family's history for our misery.

When Bob and I decided to have children we never imagined that a mental illness could appear in one of our children—our son Ben shows no signs of it—and had we known would we have done anything differently? I doubt it. We didn't connect my grandmother and uncles' mental health to anything our family had to worry about. We didn't even know what manic depression meant in those days.

The doctors didn't seem to know enough about it to treat Paul properly when he was diagnosed. Most of the drugs he took were hit or miss, experimental. The recurring theme was: "Let's try this and see if it works." He had side affects from Lithium, the usual drug of choice for his illness, so he was prescribed Depacote. And as he still had side affects and delusions and hallucinations, he was given new medications that we now know can cause teenagers and young adults to have suicidal thoughts. Who knows if those drugs caused Paul to commit suicide? I do know he abused his drugs. He took them, he stopped taking them, he took them sporadically. He never was consistent. Could that abuse of his medication have caused his suicide? We'll never know.

I do know one does not have control over manic depression or of someone who has it. One does not get it because one is bad or selfish or their mother didn't raise him or her right. One gets it when some chemical in the brain goes out of balance—most often when a person is just approaching adulthood—and as a result that person and the persons around him are never the same again.

And now the literature says that heredity is definitely the cause of bipolar disorder with researchers getting closer to the genes that cause it.

I know all of that rationally, and still I look at the fat smiling Buddha on my office shelf and think about Karma and the guilt I have always felt about my role in the breakup of Bob's marriage. (His former wife had just had a beautiful little boy badly damaged with Down's syndrome, and Bob was intent on seeing me and being with me.) He had wanted to leave her before she got pregnant, but stuck it out throughout her pregnancy. I was attracted to him as soon as we met. He was extremely articulate about almost anything, and he was so sexy. We had lunch together several times and then went out on our first date the night of March 11, 1967. We fell in love that night. We still think of it as our real anniversary. We married three years later. But at what cost? In my mind, guilt and bad Karma.

In my least rational moments I believe the bad Karma took away my son in exchange for me taking Bob away from his former wife. I tell myself over and over that he would have left her anyway. But that doesn't assuage my guilt. It doesn't absolve me of what happened. It doesn't bring Bob back to his former wife or Paul back to me. Losing Paul was our punishment; I irrationally think that when I am down in the deepest doldrums. Women have stolen husbands away in the past but didn't lose their sons as a result, but I bet they lost something else. Something else very dear to them. And that doesn't matter to me at all. I lost Paul. That's what matters. I lost Paul.

And then I bring myself back to my rational self and my work on healing, getting over it, and really living a complete life without him. Someone recently said, "There is no healing from a loss of this kind, there is only getting used to it." Parade Magazine recently reported cancer patients saying, "Patients won't go back to normal after cancer. But they can find a best new normal." Both statements are true for me. I'm getting used to living a life without Paul, living a life after my loss. I am moving on in so many ways, such as in the poem I wrote just one year after his death:

One Year

*It's a year, they say,
time to stop mourning for your dead son,
get on with your life.
Okay, I will, I reply.
Look—I work, I work out, I write, I travel,
I read, I go to movies, I make love, I eat out,
I enjoy the company of friends.
And—I nurture myself with new hairdos,
makeup, massages, and manicures.*

*After all, Paul took his own life a year ago
He didn't take mine
At least not completely.*

*What they don't know is
my life now is just playacting
meant to fool others as well as myself
into believing that I can move on
and begin to live my life again.*

I'm fully aware that my life is filled with diversions—going to the theater, the opera, the movies; reading one book after the other, traveling on weekends and for weeks at a time, and having dinners out with friends. Playacting meant to fool others as well as myself into believing that I can move on and begin to live my life again? Maybe. But, this playacting is doing the trick. I used to spend a lot of time wondering what would happen if I let it all hang out and finally quit work, and lived without all the crutches I've set up for myself? I hung on to the crutches for a long, long time—over ten years—and I've finally let the biggest one go. I retired from my job in aerospace in April 2010, and I'm doing very well working on my own now. I've made a life for myself as a writer. But more about that later.

Before I move on, I want to explain the title of this book, *Leaving the Hall Light On*.

At first I believed—my magical thinking—that if I left the hall light on, if we didn't move away from our house, if we didn't change our telephone number, Paul would know how to make his way back. Paul would know we were still here waiting for him. For a long time I waited for that familiar sound of his Volvo coming into the garage, the sound of the door from the garage slamming as he entered the house and went down the hall to his room, the sound of him walking around the house at night, the sound of the door opening and closing as he went in and out of the house. In fact, for a while I thought I heard those sounds. And for a long time I left most of the things in his room and closet alone for fear of removing his presence there. For a long time I refused to give away his things in case he would need them when he came back.

Once those sounds in my imagination and my magical thinking fell away, my need to keep the hall light on became another one of the

things that helped me get through it. We left the hall light on for him when he was home. I just couldn't break that routine.

And while that was all going on Bob and I had a push-me, pull-you interaction about it. Bob always had a habit of turning off all the lights before he went to bed. Since he usually went to bed after me, I would wait until he got into bed. Then I'd get up and turn on the hall light again. And mind you that was a trek across the living room and down the steps of our tri-level house to the garage entry hall on the ground floor where the office that Bob and I originally shared, the guestroom, and Paul's room (that became my private office) were. Sometimes we'd go back and forth on this several times in one night. If he forgot his glass of water he'd get up and turn the light off again. If he needed a certain vitamin from the kitchen cabinet, he'd get up, go into the kitchen to get what he needed, and then go down and turn the light off again on his way back to bed. And, if I fell asleep before him, I'd wake in the middle of the night and go back down to turn the light on once more.

Once in a while I'd ask him to leave it on. If he asked why I'd give him the lame excuse that I needed a light on to guide me through the house when I left to go to the gym in the dark of the early morning. Sometimes he'd buy that. Most of the time he'd forget and turn off the light.

Gradually though, say in the last two, three years, leaving the hall light on became less and less important. That I could leave it off night after night meant I was healing. And it also meant that I was over the magical thinking stage of my grieving process.

Leaving the Hall Light On

*I lose my keys or sunglasses
and find them in my hand all along.
I lose my little boy in the department store
and he pops out squealing with laughter
from under the clothes display,
I lose important papers
and find them
in the stack of other papers on my desk.*

*I didn't lose my son, Paul.
Paul is dead.
Death is forever.
There's not a chance of finding him.*

*The light I've left on in the hall for him
every night since he died
doesn't show him the way back home.
There are no more piano gigs out there for him.
The Sunday paper entertainment guide
doesn't list his name at any jazz club.
He can't join the young guys at the Apple Genius Bar
and help people solve their computer problems.
Paul would have loved that job.
He was made for that job,
but he checked out too early.
The new meds and surgery for manic depression,
the new information about mental illness
are not for him.*

*Why do people refer to death as loss?
Maybe just to encourage
people like me.
Maybe just to keep me looking for him.
Maybe so I can pretend he's still out there.*

*Maybe that's why I long to mother
the strong young men at the gym
who hardly notice me
and the bright ones at work.
They are the right age.
They have the same look.
They have the same appeal.*

*Every time I see a young man
with close-buzzed hair,
well-worn jeans,
a white t-shirt, and a black jacket,
sitting outside of Starbucks,
sucking on a cigarette,
every time I see a skinny guy
walking fast across the street
carrying a brown leather bag over his shoulder,
I look to make sure.*