

Foreword

When the galley proofs for this book first arrived, with a request to write a foreword, I had just been “fired” as my own twin sister’s guardian, conservator, and hospital contact person.

People often think I became a psychiatrist to try to help my sister, but the truth is I became a psychiatrist in spite of her. Unlike Barb Hawkins, whom you’re about to meet, Pamela has spent decades in and out of hospitals because of schizophrenia. For many years there was no predicting when an emergency call about her would jolt me out of bed. Never as her doctor, you understand, just as next of kin. Recently she’s been in-patient for weeks. Last night, I refused to sign her out AMA (Against Medical Advice), and now I’m *persona non grata*? I don’t know whether to be angry or ecstatic.

As it turns out however, the timing is perfect. Without a hospital visit to Pammy looming, I have hours to spend reading this manuscript with the intriguing title, *How We Got Barb Back*, comfortably ensconced on the sofa.

The pages slip quickly by as I welcome Margaret and Barbara and the whole of the Hawkins clan into my home and I almost finish the memoir in one sitting. I’ve never met Margaret, and yet I feel I know her... *like a sister* is what I say the first time we talk a few days later. Nevertheless, as I read, the puzzling words *home invasion* keep popping into my head. The words usually refer to something *violent*, like breaking and entering. Then I realize--of course, the Hawkins home *and* family *have* been invaded by schizophrenia, just as it invaded my own home years ago, as it has invaded homes for millennia, silently unraveling lives and destroying dreams.

Worse, the stigma of schizophrenia marks entire families as modern-day lepers, alienating many patients *and* caretakers from friends, family and community. Readers of my own book (and Pammy’s) *Divided Minds* may remember what stigma did in the early years to the Spiro family. In Ms. Hawkins’s book the stigma of schizophrenia is so powerful that Barbara’s father has to die before she can get help. To understand what both the Hawkinses and my family

experienced years ago, you have to keep in mind that forty years ago many people, even psychiatrists, didn't think of schizophrenia as a bona fide physical brain illness.

When Pammy first got sick in the mid 60's, we were in junior high. Our younger brother and sister were both still in elementary school and our parents had their hands full. Schizophrenia may have been at work in the background *but there was nothing obvious*. Despite hearing voices inside her head, Pammy didn't tell anyone what was happening. Just like Barb Hawkins, for a long time she seemed only depressed or withdrawn, but she didn't act or talk "crazy" in the way most people expect. Gradually though, as she got worse, schizophrenia affected the lives of everyone in the family.

In my second reading of *How We Got Barb Back* I focus more on Mr. Hawkins. What kind of man fears doctors so much that he risks his children's well-being and sometimes even their lives? At nine, Margaret herself almost loses a toe because her father refuses to take her to a doctor. Years later, Barb has returned home ill and unable to function; Mr. Hawkins mistrusts psychiatrists at least as much as she does. It is Mr. Hawkins' love-as-best-medicine-twenty-four-hours-a-day, seven days a week, personalized attention to his daughter's care that allows her to go for years without getting professional help. Other parents insist that their adult children undergo treatment *as a condition* of their living at home. He takes pains to do the opposite and it seems to work...

More surprising, a psychiatrist, psychologist, social worker and even probate court judge, despite serious reservations, all go along with him. Why do all these professionals enable him (to borrow a phrase)? Is this stigma? Is this family served or are they neglected by the system? Couldn't *someone* have helped the Hawkins family a long time before? How many illnesses get reduced to whispers in courtrooms like those in which Mr. Hawkins plies his case? If that isn't stigma, what is?

I don't know the answers except that we cannot allow stigma to silence us. That's why books like *How We Got Barb Back* are so important. The Hawkins family is just beginning to talk. I hope this book makes it easier for all of us to keep the conversation going.

The devastation schizophrenia wrought in my sister's life and how it changed the direction of mine is the focus of our book, *Divided*

Minds: Twin Sisters and Their Journey Through Schizophrenia, published in the fall of 2005 by St. Martin's Press. Shortly after our memoir came out, we were invited to talk on a National Public Radio show. We arrived at an NYC radio station and were ushered into the waiting area with a few minutes to spare. I sat down next to an elderly gentleman while Pam shuffled to a seat at the far end of the bench. She slumped there, eyes staring at the carpet while her right hand traced figure eights rapidly over and over again into her jeans.

"May I take a look at your book?"

The face was familiar, but the voice was unmistakable.
Art Buchwald.

I shot him a quick glance, and handed him my copy. He flipped it over and scanned the back cover. Then he thumbed through the book and peppered me with questions about schizophrenia, before lapsing into silence.

A minute before our call came to go on the air he spoke.

"You know," he said, his gravelly voice wavering from age or possibly from emotion, "My mother had schizophrenia. They put her away in an institution for thirty-five years and I never knew her..."

Schizophrenia silenced his mother for sure. But who silenced him and who silences us?

Schizophrenia doesn't silence us. Stigma does, but it shouldn't.

Art Buchwald is gone now, but how many other celebrities will talk publicly about their battles or their relatives' battles with depression, alcoholism, drug abuse, even bipolar disorder, but still won't mention the word schizophrenia? Is schizophrenia the disease "that dare not speak its name?"

In the Spiro family much has changed since 2005. Pammy is welcome at all family gatherings though sometimes *she* chooses not to attend. I hope that our parents now understand that schizophrenia is an illness, a brain disease, *and that it has never been their fault*. I'm sorry that Mr. and Mrs. Hawkins will never get that chance.

When Margaret and I talked, for me it was like talking to a sister I'd never met. We both note that our experiences with sisters with schizophrenia were strikingly similar, as were many experiences in our families even though Barbara is almost a generation older than we are and Pam is my identical twin. I look forward to meeting in person someday soon.

I have come to see schizophrenia as a journey, caregiver or patient, ill or well, family or friend, our journeys differ only in the details.

The more you speak out about the schizophrenia, the easier it becomes.

The more you ask others for help, the less alone you feel.

The more hope you give, the more hope you have.

If stigma were no more, patients like Barb would get earlier treatment and families would not spend years divided. Sisters and brothers, mothers and fathers would not feel like outcasts in their homes and communities.

Untreated schizophrenia has the power to destroy neural connections in the brain, and often much cognitive and interpersonal functioning, but—

Schizophrenia's power to destroy a person, a relationship, a family, is only as great as we allow it to be.

This journey is one I didn't choose, but one I *do* choose to continue. If you're reading this book, I wager, so do you. The truth is, none of us can make this journey of schizophrenia or any journey of life alone. For all the help I've received along the way, I'm grateful more than words can say.

Recently I came across this quote from Albert Schweitzer, "Sometimes our light goes out, but it is blown again into flame by an encounter with another human being. Each of us owes a debt of gratitude to those who have rekindled the light."

Margaret Hawkins's book *How We Got Barb Back* has been a light for me. Thank you, Margaret.

My advice: Read this book. If your light isn't blown into flame after reading it the first time, Read It Again. Then, buy it for a friend. As a thank you gift.

BTW, a couple of days ago Pammy called. She's better. She apologized for her anger. Of course, she reinstated me....

—Carolyn S. Spiro, MD, 2010

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Thank you finally to Tom for going along with my impossible dream for Barb.

PART I
1943 – 2006

Chapter One

On a promising summer day in 1974, my family's life blew up, though we didn't know it at the time. That was the day my beautiful, bright, and very American older sister returned home from Iraq.

We hadn't seen Barb in nearly three years, not since she and her Iraqi husband had moved to Basra in the summer of 1971. She'd been a radiant twenty-seven-year-old seemingly in her prime when Karim, finished with his two-year post-doctoral appointment at the University of Kentucky and unable to find a job in the States, was offered a full professorship in chemistry at Basra University. He'd had qualms about returning to the Middle East, but he wanted the job, so my sister, in love and eager for adventure, gamely went along.

Now three years later our beautiful Barb, the family star, was back for a visit. Except, she wasn't. Something had changed during those years she was gone, and the Barb we knew never really returned. The woman my parents collected at the airport that June day, whom I rushed home from college on a Greyhound bus to welcome back, was not the Barb any of us remembered saying goodbye to three years before. That Barb had vanished, and though her husband tried to bring her home, she was already gone, schizophrenic.

For the next thirty-two years, Barb lived, some might say languished, in the house she came home to—first with my parents

and then, after my mother died, alone with my father until his death at the age of eighty-nine in December 2006. During that time she was never hospitalized, never evaluated by a psychiatrist, never prescribed medication, and after the first few years, she never left the house. Then suddenly my father was gone, I was her guardian, and both our lives were changing fast. I had no idea what would happen next, no idea that the dark tunnel we'd entered in June of 1974 was about to open into light.

But to explain how extraordinary these changes were—and continue to be—I need to go back to the beginning of the story, to the beginning of my sister's journey from suburban Chicago to Basra, Iraq, through schizophrenia, and back.



My sister was born in 1943 and grew up as the eldest of three children in a conservative, comfortable commuter suburb north of Chicago known in those days for its good schools and quiet streets. Three years later my brother, Tom, was born, and then eight years after that, when my sister was eleven, I arrived. We were a family of five, six if you count George the dog.

My real memories of Barb don't begin until I was four or five, when she was almost out of high school. Memory isn't always—or even often—real, though, and many of my recollections are composites constructed from family stories collaged together with pictures taken before I was born or at least before my own memories began to form.

I studied these photos as a child, memorized them as I sat on the floor leafing back and forth through the wide, black pages of big photo albums, trying to piece together what happened before I was there to see for myself. I'd come late to the party, and I could never learn enough about Barb, who always seemed to slip out the door

just as I was arriving and who left for college when I was starting second grade. I could never catch up with her, and even before anything overtly strange happened, she was mysterious to me in ways that made me try to understand her without simply asking, which didn't seem possible. Instead, I chose the more indirect and secretive process of spying on the past through the peephole of someone else's camera lens.

Photographs of my sister as a child show a dreamy, pretty, dark-haired girl with a willowy figure and a faraway gaze in her big gray stunned-looking eyes. Even when she is smiling in the photos, which she often isn't, she appears distracted by some thought or only half awake, affable but abstractly so.

One early photo shows Barb with my father at a Camp Fire Girls father-daughter dinner. Maybe she is eight or nine. She wears her uniform, complete with a vest full of earnestly stitched-on patches and leans wispily, almost shyly, toward my father who, in his business suit at the end of a long day in the financial district, looks gruff and a little combative. Another photo, taken about the same time, shows my sister and brother looking waifish and sweet with their heads tilted together, tucked into a narrow bed with all their dolls and toys. There are studio portraits with Santa and a Halloween snapshot showing seven-year-old Tom, in my father's fedora, sticking my sister in the ribs with a toy gun. Ten-year-old Barb, always a bit dramatic, leans back to expose her vulnerable neck in a fair pantomime of death.

In the early photos, my mother, a cool, smoky beauty, looks lushly voluptuous in her shirtwaist dresses and pearls as she presides over cascades of children. She shows up less often and less happily later on. Off to the side stands my father, always in a suit, suspenders, and a crooked bowtie; he frowns and bites down on the stem of his pipe.

The surroundings in these photos are telling. Here we are, the so-called prosperous middle class, but of a sort constrained by WASP

reserve and thrift. Our furniture is solid and old, slightly beat up and mostly passed down, with no sign of the 1950s anywhere except in my mother's waist-cinching dresses and my brother's ubiquitous Danny O'Day ventriloquist puppet. In the background, details of our genteel but already crumbling old house are visible—wide molding, bay windows, brick fireplace. What doesn't show is what isn't there and won't ever be. Modern conveniences—dishwasher, garbage disposal, laundry dryer, garage door opener, air conditioner—were not for us.

The pace of regular family photo taking quickened when Barb received a camera around the age of eleven. Even though she's not in many of the photos from that era, the subjects she chose reveal the texture of what appears to have been her very normal life. Two album pages devoted to My Slumber Party show a dozen or so grinning girls in pajamas and braces, circa 1955, lying in various arranged patterns on the floor. There are photos of George, looking like a canine tornado barely contained on a kitchen chair, and there's a whole page titled Baby Margaret, in which I appear as a somber, glowing bundle propped against various chair backs wearing a too-large cowboy hat.

Fortunately Tom got seriously interested in cameras early on so there are pictures of Barb too. One shows her standing on a beach in a wet, baggy bathing suit, straight and skinny as a stick. Another shows her at twelve or thirteen sitting on our scratchy old couch in a tight-bodied, full-skirted party dress that shows off her slim figure. She wears a bow at her neck and appears perfectly symmetrical except for the slight, ingratiating tilt of her head that softens the pose from stiff to winsome. In another she stands on a tennis court, rail thin in shorts with a racket dangling from one wiry arm. Another shows her sitting at the secondhand Story & Clark upright piano my father bought her when she started taking lessons. She's a little older here, maybe fourteen, and fresh faced with her wrists raised gracefully over the

keys. She smiles at the photographer over her shoulder. Behind her, we see sheet music for show tunes.

What strikes me most about these photos now is how cooperative my sister looks, how sweet. Childhood pictures of me show a different sort of child, a small girl with her hand on her hip and her eyebrows knitted, with one corner of her mouth raised in a wary half smile. I look challenging, intense, wry, dubious, cautious, worried. But Barb appears soft and unfailingly compliant, not eager to please, exactly, but willing to if asked. I look for clues in these photos but, honestly, other than a bit of dreaminess, I don't find them. All they're proof—and reminder—of is that her life, her many activities, her friends, and even we, her family, were once apparently quite normal.

Then the Barb in these photos changes. She goes from being a dreamy sylph, often photographed with my brother, who even as a small boy looks perpetually droll, to a stunning and self-aware young woman. Here is where the photos and my actual memories of Barb converge. She's fifteen, sixteen, seventeen, and though her figure never seems to really fill out—she'll be thin her whole life—she blooms, and her face sharpens a little. There is a new confidence, a consciousness of her own beauty.

Here is a photo I often returned to as a child, taken at some family gathering. It shows Barb sitting in the midst of a whirl of activity, detached and unsmiling. She wears dark lipstick and her dark hair is held back in a high severe ponytail tied with a crisp ribbon. She holds a Pepsi bottle and turns away from the camera, her elegant neck swiveling to show us her haughty profile, her slender legs crossed in a tight skirt. Here is the actual Barb I remember, suddenly a high school goddess.

In the background I see a blur of swinging white blond hair, me. I look about five, which means it would have been the year my mother's mother walked into the lake to die. Barb would have been sixteen. It is impossible to find the impact of that event in any of these

photos except for the fact of my mother's absence from them for a long time.

Then a yellowed newspaper clipping dated a year later picks up the thread. It's a rave review of *Publicity Mad*, the story of aspiring actresses in Greenwich Village—that year's senior class play. Tucked in the back of the photo album along with the review is the program, which indicates that Barb Hawkins played a beatnik named Marcille Benedict.

My earliest memory of my sister in real time is Christmas morning when I was five and she was sixteen. She gave me an enormous stuffed bear I named Timmy, a grand gesture. The summer before, she'd had her first job; she must have felt flush, generous. Every year after that she gave me a different oversized stuffed animal, next a dog named Sam, and then a lion I named Gunther.

In these early memories my sister is nearly a young woman, and to me a distant figure, as radiant and unapproachable as a god, and as dangerous and capricious as one too, to be adored and feared. She was even less interested in homemaking than my mother was, and this indifference—she let it be known—included children. I don't think she ever babysat, and she wouldn't cook. The only concession she made to the domestic arts was to sew, and though she became very good at it, covering the dining room table with expanses of starchy-smelling stiff fabric pinned with tissue paper patterns I was not allowed touch, it was for her love of clothes and design, not out of any interest in housewifery.

I remember her clothes in aggregate but also as individual garments. I remember circle skirts and straight plaid ones hanging in her closet, and her neat piles of thick, bleached-white bobby socks. She kept a box of rolled silk hair ribbons on her dresser organized by color and ironed to perfection, and she wore them to match her outfits, tied in bows around the rubber bands that kept her ponytail in place. When she wasn't there I stole into her room to fondle them

though she would have been furious if she'd known.

I remember her stacks of sweaters, first short-waisted ones with three-quarter-length sleeves and tiny pearlescent buttons down the front and later bulky mohair sweaters in every pastel color piled up in drawers that reeked of mothballs. Pink, cream, turquoise, chocolate, lavender, big and puffy on her tiny frame, all the rage in the 1960s. I remember her sewing machine and the clothes she made on it, the beautiful things she couldn't afford to buy, and I remember the beautiful things she did buy when she started working.

One summer she worked as a supervisor at the park district and came home tan and sinewy every day at noon in a white blouse and navy shorts that showed off her pretty legs. She'd sit at the kitchen table and wolf down mountains of food—ham salad, macaroni salad, and something called Hawaiian salad made from marshmallows, coconut, and mayonnaise that my mother bought at Barb's imperious request and, after that, big slabs of Sara Lee cheesecake—her dark brown ponytail swinging arrogantly as she complained about the brats she had to supervise. I was afraid of her that summer, afraid I was too much one of the brats she hated. Being near her was like getting too close to a fire. I might be burned by her random wrath or just by the heat from her immortal glow. She did glow, the red lipstick, the shiny hair, the perfect white teeth—she was as formidable and thoughtlessly cruel as any perfect sixteen-year-old girl could be.

In the summers she lay in a plastic lawn chair in the back yard wearing big dark glasses and reading fashion magazines, wetting her finger on her tongue before turning each page with a dramatic flick, hoping for boys to walk by so she could snub them. I remember how the house smelled of her perfume every morning and how the smell of it as she got ready for high school blended chokingly with the salty smell of bacon as my mother sadly cooked breakfast. Barb played tennis well enough to win trophies, played bridge with her friends, and played boogie-woogie on the piano.

More than four decades later, I dig her high school senior yearbook, dated 1961, out of a pile in the pantry. When I open it a cloud of mildew escapes, but there, untouched by time, is my sister's shining face on every other page. Here, she is kneeling in the front row of a group shot of girl gym leaders, smiling adorably. There, she is editing the school newspaper. On another page, she poses with the aspiring writers on the *Wet Paint* staff and on the next with members of the Quill and Scroll Society. Here she is yet again, twice, in a double-page spread on the school play, dressed all in black, reclining on a couch at center stage, staring moodily at the camera as the rest of the act unfolds around her.

Her face leaps out clear and bright among all these faces, most of which, in that era of helmet hairdos and terrible clothes, look strange and lost. My sister, though, looks neither strange nor lost. She looks anointed by luck, not only beautiful but self-aware, put together, confident, and even well coifed. Most of these others will grow up and out of their awkwardness into their own beauty and beautiful lives, but my sister's life is reversed, it begins with beauty. She appears not to have had an awkward day in her life.

Next to my sister's senior picture is a list of her school activities, the longest on the page. *Barbara Hawkins: Pioneer [year] 4, Feature Editor 4; Senior Class Play 4; Gym Leader 3, 4; Quill and Scroll 4; Creative Writing Magazine 4; Class Council Representative 1; '61 Blueprint Staff 3; Biology Club 1, Social Chairman 1; Future Teachers Club 3; G.A.A. 1, 2; Chemistry Club 2; French Club 3; Stagecrafters Club 1.*

Underneath this formidable catalog of accomplishments and memberships—social chairman for the biology club!—Barb has added her own list in blue ink. It names her activities outside of school: Model on Fashion Board, Church Choir, Corresponding Secretary for Community Church Youth Group. My heart seizes at the sight of this careful addition which, written so purposefully in her neat, round, girlish hand, reminds me of her patch-filled Camp Fire

Girls vest. Both are proof of how much she cared about belonging, doing, and achieving.

Then she was off to college at the University of Illinois. What I remember about that year is not her absence but the way the house, and particularly my father, filled with excitement when she came home. On the Friday evenings of her arrivals television was banned. Instead of watching *Route 66*, as I would have preferred, we sat in a circle and watched Barb tell stories as if she were Marco Polo. Everything in her telling was larger than life—her professors, her friends, the books she was reading. Everybody and everything was *brilliant*, the world was wide, and she loved her life away from us.

Midway through her sophomore year, Barb came home and stayed for three semesters. She'd been put on academic probation. The official story was some combination of too much fun, too many boyfriends, too much homework. Now it seems like it may have been something darker but it's impossible to know whether her coming home was a retreat or a reining in. Maybe, probably, my father had insisted.

She lived in her old room that year and commuted to the city branch of the university by train. It must have been difficult to come home after the freedom and exhilaration of being away, and I remember her in those days sitting on her bed smoking an endless succession of cigarettes, which she sometimes shared with me, although I was only nine. My father displayed a new frustration with her that year, complaining that she dragged her feet when they walked to the train together in the morning. He preferred military bearing and a crisp marching gait.

These days, I search for the thing—the sign that tells me the sickness had begun. Was this it, this early, I wonder now, brought on by the stresses of being away at college, or was it just a normal phase in her young life? Was my father being overbearing and intrusive, trying to curtail her independence, or helpful in insisting she come home?

Or did she want to come home? Looking back, it seems strange that this bright, socially successful, ambitious girl would suddenly move back into her childhood bedroom just as her life outside it had begun.

Whatever the reason, though, I liked having her there, particularly when she signed up for biology and brought home her own rat to dissect on the kitchen table. We named him Boris and kept him in the pantry. The kitchen smelled of formaldehyde that winter.

One day, without preamble, she sat me down on her bed, drew a uterus and some fallopian tubes in her spiral notebook, and explained the female reproductive system to me. It must have been on her mind, possibly the result of the same biology class that required her to carve up poor Boris, but maybe she had more practical reasons as well. As for me, at nine, my interest was purely theoretical, though I was glad to be the first among my friends to know.

This was 1963. She wore perfume and lipstick, no other makeup or jewelry, with black turtleneck sweaters and wheat-colored jeans. She started to wear her long hair loose and wild, no more neat ponytails. She listened to Barbra Streisand, turned up loud on the rickety portable record player in her bedroom. She talked about Bob Dylan. She dated a succession of fascinating—to me—men including an Arab named Maurice who came to pick her up at the house once dressed in a dark suit. I was so intrigued I named one of my trolls after him. She dated lots of men but, as she had in high school, seemed scornful of them, accepting their gifts but dodging their calls and disparaging their attentions. Men were louts and a little beneath her, her behavior seemed to suggest. She made it clear she didn't plan to get snared by a life of love, marriage, and motherhood.