



Margaret Hawkins

AT HOME WITH
SCHIZOPHRENIA

A Family's Journey

Disability Studies

Collection Editor

DAMIAN MELLIFONT

LIVED PLACES
PUBLISHING



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For my sister Barbara and in memory of my parents, Barbara Faxon Hawkins and Thomas Rhodes Hawkins

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Abstract

At Home With Schizophrenia tells the story of the author's older sister Barbara, who lived cloistered in their family home in suburban Chicago from her early 30s to her early 60s, a prisoner of an undiagnosed mental illness. Hearing voices and paralyzed by fear, she was never evaluated, never treated, and refused to leave the house. Their parents fiercely protected Barb from the outside world but were unable to figure out a way to help her get better. After their parents died, the author became Barb's legal guardian. She sought and received help from psychiatrists and social workers who agreed to home visits so that Barb could stay in her house. There, she began to recover.

Key words

Schizophrenia, stigma, shame, secret/secretcy, silence, fear, anger, respect, help, family

Learning objectives

1. Develop empathy for the mentally ill and their families.
2. Learn to recognize symptoms of schizophrenia early so that prompt steps can be taken to find help.
3. Improve communication with people with mental illness so that they feel respected and heard.

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PART I
1943-2006

Chapter 1

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 that earlier summer, seemingly in her prime, when Karim finished his two-year post-doctoral appointment at the University of Kentucky and accepted a full professorship in chemistry at Basra University. He'd had qualms about returning to the Middle East, but, unable to find a job in the States, he felt he must. My sister, in love and eager for adventure, gamely went along.

Now, three years later, our beautiful Barb, the eldest child and 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 received medication, and, after the first few years, 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 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 for good schools and quiet streets. Three years later, my brother Tom was born, then eight years after that, when Barb was eleven, I arrived. We were a family of five, six if you count George, our 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 real, though, or even often so, and many of my recollections are composites constructed from family stories collaged together with pictures taken before my own memories began to form.

I studied these photos as a child, memorized them as I sat on the floor leafing through the wide black pages of big photo albums, trying to piece together what happened before I was there to see for myself. I could never learn enough about Barb, who always seemed to slip out the door just as I was arriving, who'd left for college when I was starting second grade. Even before anything overtly strange happened, she was mysterious to me in ways that made me try to understand her without simply asking, through 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 stunned-looking eyes. Even when she smiles, she appears distracted by some thought or only half awake, affable but abstractly so.

An early photo shows Barb with my father at a Campfire Girl father-daughter dinner. She's eight or nine. She wears her uniform, complete with a vest covered with earnestly stitched-on patches, and leans wispily, almost shyly, toward my father, who, in his business suit at the end of a long day, looks gruff and a little combative. Another photo, taken about the same time, shows Barb and Tom looking waifish and sweet with their heads tilted together, tucked into a narrow bed with their dolls and toys. There are studio portraits with Santa and a Halloween snapshot

showing my seven-year-old brother, in my father's fedora, sticking my sister in the ribs with a toy gun. Ten-year-old Barb, always dramatic, leans back to expose her vulnerable neck in a fair pantomime of death.

In early photos, my mother, a cool smoky beauty, looks lushly voluptuous in shirtwaist dresses and pearls as she presides over cascades of children. She shows up less often and less happily later. Off to the side stands my father, in suits, suspenders, and crooked bowties; he frowns and bites 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 white Anglo-Saxon Protestant thrift. Our furniture is solid and old, slightly beat up, and mostly passed down. 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 were not for us.

The pace of family photo taking quickened when Barb received a camera around the age of eleven. Her subjects reveal what appears to have been a normal life. Two pages devoted to My Slumber Party show grinning girls in pajamas and braces lying in various arranged patterns on the floor. There are photos of George and a whole page titled Baby Margaret, in which I appear as a somber, glowing bundle under a cowboy hat.

Fortunately, Tom got seriously interested in cameras early on, so there are pictures of Barb, too. She stands on a beach in a wet, baggy bathing suit, straight and skinny as a stick. She sits on our scratchy old couch in a tight-bodied full-skirted party dress

that shows off her slim figure, perfectly symmetrical except for a slight, ingratiating tilt of her head that softens the pose from stiff to winsome. She poses at the secondhand Story & Clark upright piano, which my father bought her when she started taking lessons. She's a little older here, maybe fourteen. Her wrists are raised gracefully over the keys. She smiles at the photographer over her shoulder.

What strikes me about these photos is how cooperative Barb 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, one corner of her mouth raised in a wary half-smile. I look challenging, dubious, and worried. Barb appears soft and 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 of is that my sister's life, her many activities, her friends, and even we, her family, once appeared quite normal.

Then the Barb in these photos changes. She goes from being a dreamy sylph to a stunning, 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. Barb sits amid a whirl of activity, detached and unsmiling in dark lipstick. 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 off her haughty profile, her slender legs crossed in a tight skirt. Here is the Barb I remember, suddenly a high school goddess.

In the background, I see a blur of swinging white-blond hair, me. I was five, which means it would have been the year my mother's mother walked into Lake Michigan to die, turning our homelife upside down. Barb was 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.

My earliest memory of my sister in real time is Christmas morning when I was five. Barb gave me an enormous stuffed bear, which I named Timmy. The summer before, she'd gotten her first job. She must have felt flush, generous.



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 uninterested in homemaking, 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 domestic arts was to sew, and although she became very good at it, covering the dining room table with stiff, starchy-smelling fabric pinned with tissue paper patterns I was not allowed to touch, it was for her love of clothes and design, not any interest in housewifery.

I remember her clothes, circle skirts, and straight plaid ones, and neat piles of thick, bleached bobby socks. She kept a box of silk hair ribbons on her dresser, organized by color and ironed to perfection. She would have been furious if she'd known I stole into her room to fondle them. She often seemed furious.

I remember stacks of sweaters, first short-waisted ones with three-quarter length sleeves and tiny pearlescent buttons down the front, then 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, beautiful things she couldn't afford to buy, then 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. She'd sit at the kitchen table and wolf down mountains of ham salad, macaroni salad, and Hawaiian salad that

my mother bought at her imperious demand. She'd finish with big slabs of 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 like one of the brats she hated. Being near her was like getting too close to 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 backyard wearing big sunglasses, reading magazines. She turned each page with a dramatic flick, maybe hoping for boys to walk by so she could snub them. The house reeked of her perfume, and every morning 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, bridge, and boogie-woogie.

More than four decades later, I would dig her high school yearbook 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 in a group shot of girl gym leaders, smiling adorably. There she is editing the school newspaper. On another page, she poses with aspiring writers on the Wet Paint staff, then with the Quill and Scroll Society. Here she is again, twice, in a double-page spread on the school play, dressed as a beatnik, reclining moodily on a couch at center stage. Drama unfolds around her.

Her face leaps out clear and bright among all these faces, most of which, in that era of helmet hairdos, look awkward

and lost. Barb looks neither awkward nor lost. She appears anointed by luck, not only beautiful but self-aware, put-together, confident. Most of these others will grow up and out of their awkwardness into their own beautiful lives, but my sister's life is reversed.



Next to Barb's senior picture is a list of her school activities, the longest on the page.

BARBARA HAWKINS: Pioneer, 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, and 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 Campfire Girl vest. Both prove 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 arrival, television was banned. Instead of watching Route 66, as I would have preferred, we sat in a circle and watched Barb tell stories. Everything 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 dates, too much homework. But Barb was conscientious and not really boy-crazy. Now it seems like something darker, more of a retreat than a reigning in.

She lived in her old room that year and commuted to the city branch of the university by train. She didn't seem to mind. 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 has begun. Was this it, this early, I wonder now, brought on by the stresses of being at college, or was this 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 had he? 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 began.

Whatever the reason, 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, I was glad to be the first among my friends to know.