



Oliver Sacks

The Mind's Eye

From the bestselling author of
THE MAN WHO MISTOOK HIS
WIFE FOR A HAT

Oliver Sacks

THE MIND'S EYE

PICADOR

CONTENTS



[*Preface*](#)

[Sight Reading](#)

[Recalled to Life](#)

[A Man of Letters](#)

[Face-Blind](#)

[Stereo Sue](#)

[Persistence of Vision: A Journal](#)

[The Mind's Eye](#)

[*Bibliography*](#)

[*Index*](#)

PREFACE

I grew up in a household full of doctors and medical talk—my father and older brothers were general practitioners, and my mother was a surgeon. A lot of the dinner-table conversation was inevitably about medicine, but the talk was never just about “cases.” A patient might present as a case of this or that, but in my parents’ conversation, cases became biographies, stories of people’s lives as they responded to illness or injury, stress or misfortune. Perhaps it was inevitable that I myself became both a physician and a storyteller.

When *The Man Who Mistook His Wife for a Hat* was published in 1985, it was given a very pleasant review by an eminent academic neurologist. The cases, he wrote, were fascinating, but he had one reservation: he thought I was being disingenuous in presenting patients as if I had come to them with no preconceptions, with little background knowledge of their conditions. Did I really read up on the scientific literature only after seeing a patient with a particular condition? Surely, he thought, I had started with a neurological theme in mind and simply sought out patients who exemplified it.

But I am not an academic neurologist, and the truth is that most practicing physicians have, apart from their broad medical education, little in-depth knowledge of many conditions, especially those which are considered rare, and thus not worthy of much time in medical school. When a patient presents himself with such a condition, we must do some research and, especially, go back to original descriptions. Typically, then, my case histories start with an encounter, a letter, a knock on the door—it is the patients’ description of their experience that stimulates the more general exploration.

As a general neurologist working mostly in old-age homes, I have seen thousands of patients over the past decades. All of them have taught me something, and I enjoy seeing them—in some cases, we have been seeing each other regularly, as doctor and patient, for twenty years or more. In my clinical notes, I do my best to record what is happening with them and to reflect on their experiences. Occasionally, with the patient’s permission, my notes evolve into essays.

After I began publishing case histories, starting with *Migraine* in 1970, I began receiving letters from people seeking to understand or comment

on their own neurological experiences, and such correspondence has become, in a way, an extension of my practice. Thus some of the people I describe in this book are patients; others are people who have written to me after reading one of my case histories. I am grateful to all of them for agreeing to share their experiences, for such experiences enlarge the imagination and show us what is often concealed in health: the complex workings of the brain and its astounding ability to adapt and overcome disability—to say nothing of the courage and strength that individuals can show, and the inner resources they can bring to bear, in the face of neurological challenges that are almost impossible for the rest of us to imagine.

Many of my colleagues, past and present, have generously shared their time and expertise to discuss the ideas in this book or to comment on its various drafts. To all of them (and the many whom I have omitted here) I am most grateful, especially to Paul Bach-y-Rita, Jerome Bruner, Liam Burke, John Cisne, Jennifer and John Clay, Bevil Conway, Antonio and Hanna Damasio, Orrin Devinsky, Dominic ffytche, Elkhonon Goldberg, Jane Goodall, Temple Grandin, Richard Gregory, Charles Gross, Bill Hayes, Simon Hayhoe, David Hubel, Ellen Isler at the Jewish Braille Institute, Narinder Kapur, Christof Koch, Margaret Livingstone, Ved Mehta, Ken Nakayama, Görel Kristina Näslund, Alvaro Pascual-Leone, Dale Purves, V. S. Ramachandran, Paul Romano, Israel Rosenfield, Theresa Ruggiero, Leonard Shengold, Shinsuke Shimojo, Ralph Siegel, Connie Tomaino, Bob Wasserman, and Jeannette Wilkens.

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Several correspondents have contributed ideas or descriptions to this book, including Joseph Bennish, Joan C., Larry Eickstaedt, Anne F., Stephen Fox, J. T. Fraser, and Alexandra Lynch.

I am grateful to John Bennet at *The New Yorker* and Dan Frank at Knopf, superb editors who have improved this book in many ways; and to Allen Furbeck for his help with the illustrations. Hailey Wojcik typed many of the drafts and contributed research and virtually every other type of assistance, to say nothing of deciphering and transcribing the almost 90,000 words of my “melanoma journals.” Kate Edgar has, for the past twenty-five years, filled a unique role as collaborator, friend, editor, organizer, and much else. She has incited me, as always, to think and write, to see from different perspectives, but always to return to the center.

Above all, I am indebted to my subjects or patients and their families.

Lari Abraham, Sue Barry, Lester C., Howard Engel, Claude and Pamela Frank, Arlene Gordon, Patricia and Dana Hodkin, John Hull, Lilian Kallir, Charles Scribner, Jr., Dennis Shulman, Sabriye Tenberken, and Zoltan Torey. They have not only allowed me to write about their experiences and quote their descriptions; they have commented on drafts, introduced me to other people and resources, and, in many cases, become good friends.

Finally, I must express my deepest gratitude to my physician, David Abramson; to him I dedicate this book.

O.W.S.

New York
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Sight Reading

IN JANUARY OF 1999, I received the following letter:

Dear Dr. Sacks,

My (very unusual) problem, in one sentence, and in non-medical terms, is: I can't read. I can't read music, or anything else. In the ophthalmologist's office, I can read the individual letters on the eye chart down to the last line. But I cannot read words, and music gives me the same problem. I have struggled with this for years, have been to the best doctors, and no one has been able to help. I would be ever so happy and grateful if you could find the time to see me.

Sincerely yours,
Lilian Kallir

I phoned Mrs. Kallir—this seemed to be the thing to do, although I normally would have written back—because although she apparently had no difficulty writing a letter, she had said that she could not read at all. I spoke to her and arranged to see her at the neurology clinic where I worked.

Mrs. Kallir came to the clinic soon afterward—a cultivated, vivacious sixty-seven-year-old woman with a strong Prague accent—and related her story to me in much more detail. She was a pianist, she said; indeed, I knew her by name, as a brilliant interpreter of Chopin and Mozart (she had given her first public concert at the age of four, and Gary Graffman, the celebrated pianist, called her “one of the most naturally musical people I've ever known”).

The first intimation of anything wrong, she said, had come during a concert in 1991. She was performing Mozart piano concertos, and there was a last-minute change in the program, from the Nineteenth Piano Concerto to the Twenty-first. But when she flipped open the score of the Twenty-first, she found it, to her bewilderment, completely unintelligible. Although she saw the staves, the lines, the individual notes sharp and clear, none of it seemed to hang together, to make sense. She thought the difficulty must have something to do with her eyes. But she went on to perform the concerto flawlessly from memory, and dismissed the strange incident as “one of those things.”

Several months later, the problem recurred, and her ability to read

musical scores began to fluctuate. If she was tired or ill, she could hardly read them at all, though when she was fresh, her sight-reading was as swift and easy as ever. But in general the problem worsened, and though she continued to teach, to record, and to give concerts around the world, she depended increasingly on her musical memory and her extensive repertoire, since it was now becoming impossible for her to learn new music by sight. “I used to be a fantastic sight reader,” she said, “easily able to play a Mozart concerto by sight, and now I can’t.”

Occasionally at concerts she experienced lapses of memory, though Lilian (as she asked me to call her) was adept at improvising and could usually cover these. When she was at ease, with friends or students, her playing seemed as good as ever. So, through inertia, or fear, or a sort of adjustment, it was possible for her to overlook her peculiar problems in reading music, for she had no other visual problems, and her memory and ingenuity still allowed her a full musical life.

In 1994, three years or so after she had first noticed problems reading music, Lilian started to have problems with reading words. Here again, there were good days and bad, and even times when her ability to read seemed to change from moment to moment: a sentence would look strange, unintelligible at first; then suddenly it would look fine, and she would have no difficulty reading it. Her ability to write, however, was quite unaffected, and she continued to maintain a large correspondence with former students and colleagues scattered throughout the world, though she depended increasingly on her husband to read the letters she received, and even to reread her own.

Pure alexia, unaccompanied by any difficulty in writing (“alexia sine agraphia”) is not that uncommon, although it usually comes on suddenly, following a stroke or other brain injury. Less often, alexia develops gradually, as a consequence of a degenerative disease such as Alzheimer’s. But Lilian was the first person I had encountered whose alexia manifested first with musical notation, a musical alexia.

By 1995 Lilian was beginning to develop additional visual problems. She noticed that she tended to “miss” objects to the right, and, after some minor mishaps, she decided that she had best give up driving.

She had sometimes wondered whether her strange problem with reading might be neurological rather than ophthalmological in origin. “How can I recognize individual letters, even the tiny ones on the bottom line of the eye doctor’s chart, and yet be unable to read?” she wondered. Then, in 1996, she started to make occasional embarrassing mistakes, such as failing to recognize old friends, and she found herself thinking of a case history of mine she had read years before, entitled “The Man Who Mistook His Wife for a Hat,” about a man who could see everything clearly but recognize nothing. She had chuckled when she had first read it, but now she started to wonder whether her own difficulties might be eerily similar in nature.

Finally, five years or more after her original symptoms, she was referred to a university neurology department for a full workup. Given a

battery of neuropsychological tests—tests of visual perception, of memory, of verbal fluency, etc.—Lilian did particularly badly in the recognition of drawings: she called a violin a banjo, a glove a statue, a razor a pen, and pliers a banana. (Asked to write a sentence, she wrote, “This is ridiculous.”) She had a fluctuating lack of awareness, or “inattention,” to the right, and very poor facial recognition (measured by recognition of photographs of famous public figures). She could read, but only slowly, letter by letter. She would read a “C,” an “A,” a “T,” and then, laboriously, “cat,” without recognizing the word as a whole. Yet if she was shown words too quickly to decipher in this way, she could sometimes correctly sort them into general categories, such as “living” or “nonliving,” even though she had no conscious idea of their meaning.

In contrast to these severe visual problems, her speech comprehension, repetition, and verbal fluency were all normal. An MRI of her brain was also normal, but when a PET scan was performed—this can detect slight changes in the metabolism of different brain areas, even when they appear anatomically normal—Lilian was found to have diminished metabolic activity in the posterior part of the brain, the visual cortex. This was more marked on the left side. Noting the gradual spread of difficulties in visual recognition—first of music, then of words, then of faces and objects—her neurologists felt she must have a degenerative condition, at present confined to the posterior parts of the brain. This would probably continue to worsen, though very slowly.

The underlying disease was not treatable in any radical sense, but her neurologists suggested that she might benefit from certain strategies: “guessing” words, for example, even when she could not read them in the ordinary way (for it was clear that she still possessed some mechanism that allowed unconscious or preconscious recognition of words). And they suggested that she might also use a deliberate, hyperconscious inspection of objects and faces, making particular note of their distinctive features, so that these could be identified in future encounters, even if her normal “automatic” powers of recognition were impaired.

In the three years or so that had elapsed between this neurological exam and her first visit to me, Lilian told me, she had continued to perform, though not as well, and not as frequently. She found her repertoire diminishing, because she could no longer check even familiar scores by vision. “My memory was no longer fed,” she remarked. Fed visually, she meant—for she felt that her auditory memory, her auditory orientation, had increased, so that she could now, to a much larger degree than before, learn and reproduce a piece by ear. She could not only play a piece in this way (sometimes after only a single hearing); she could rearrange it in her mind. Nonetheless, there was, on balance, a shrinkage of her repertoire, and she began to avoid giving public concerts. She continued to play in more informal settings and to teach master classes at the music school.

Handing me the neurological report from 1996, she commented, “The doctors all say, ‘Posterior cortical atrophy of the left hemisphere, very

atypical,' and then they smile apologetically—but there's nothing they can do."

When I examined Lilian, I found that she had no problem matching colors or shapes, or recognizing movement or depth. But she showed gross problems in other areas. She was unable now to recognize individual letters or numerals (even though she still had no difficulty writing complete sentences). She had, too, a more general visual agnosia, and when I presented her with pictures to identify, it was difficult for her even to recognize pictures *as* pictures—she would sometimes look at a column of print or a white margin, thinking it was the picture I was quizzing her about. Of one such picture, she said, "I see a V, very elegant—two little dots here, then an oval, with little white dots in between. I don't know what it's supposed to be." When I told her it was a helicopter, she laughed, embarrassed. (The V was a sling; the helicopter was unloading food supplies for refugees. The two little dots were wheels, the oval the helicopter's body.) Thus she was now seeing only individual features of an object or picture, failing to synthesize them, to see them as a whole, much less to interpret them correctly. Shown a photograph of a face, she could perceive that the person was wearing glasses, nothing else. When I asked if she could see clearly, she said, "It's not a blur, it's a mush"—a mush consisting of clear, fine, sharp but unintelligible shapes and details.

Looking at the drawings in a standard neurological test booklet, she said of a pencil, "Could be so many things. Could be a violin . . . a pen." A house, however, she immediately recognized. Regarding a whistle, she said, "I have no idea." Shown a drawing of scissors, she looked steadfastly at the wrong place, at the white paper below the drawing. Was Lilian's difficulty in recognizing drawings due simply to their "sketchiness," their two-dimensionality, their poverty of information? Or did it reflect a higher-order difficulty with the perception of representation as such? Would she do better with real objects?

When I asked Lilian how she felt about herself and her situation, she said, "I think I am dealing with it very well, most of the time . . . knowing it is not getting better, but only slowly worse. I've stopped seeing neurologists. I always hear the same thing. . . . But I am a very resilient person. I don't tell my friends. I don't want to burden them, and my little story is not very promising. A dead end. . . . I have a good sense of humor. And that's it, in a nutshell. It is depressing, when I think of it—frustrations daily. But I have many good days and years ahead."

After Lilian left, I was unable to find my medical bag—a black bag with some similarities (I now remembered) to one of the several bags she had brought. Going home in the taxi, she realized that she had taken the wrong bag when she saw a red-tipped object sticking out of it (my long, red-tipped reflex hammer). It had attracted her attention, by its color and shape, when she saw it on my desk, and now she realized her mistake.

Returning, breathless and apologetic, to the clinic, she said, “I am the woman who mistook the doctor’s bag for her handbag.”

Lilian had done so badly on the formal tests of visual recognition that I had difficulty imagining how she managed in daily life. How did she recognize a taxi, for example? How could she recognize her own home? How could she shop, as she told me she did, or recognize foods and serve them on a table? All this and much more—an active social life, traveling, going to concerts, and teaching—she did by herself when her husband, who was also a musician, went to Europe for weeks at a time. I could get no idea of how she accomplished this from seeing her dismal performance in the artificial, impoverished atmosphere of a neurology clinic. I had to see her in her own familiar surroundings.

The following month, I visited Lilian at home, home being a pleasant apartment in upper Manhattan where she and her husband had lived for more than forty years. Claude was a charming, genial man about the same age as his wife. They had met as music students at Tanglewood nearly fifty years earlier and had pursued their musical careers in tandem, often performing onstage together. The apartment had a friendly, cultured atmosphere, with a grand piano, a great many books, photographs of their daughter and of friends and family, abstract modernist paintings on the wall, and mementos of their trips on every available surface. It was crowded—rich in personal history and significance, I imagined, but a nightmare, a complete chaos, for someone with visual agnosia. This, at least, was my first thought as I entered, negotiating my way between tables full of knickknacks. But Lilian had no difficulty with the clutter and threaded her way confidently through the obstacles.

Since she had had such difficulty on the drawing-recognition test, I had brought a number of solid objects with me, wondering if she would do better with these. I started with some fruit and vegetables I had just bought, and here Lilian did surprisingly well. She instantly identified “a beautiful red pepper,” recognizing it from across the room; a banana, too. She was momentarily uncertain whether the third object was an apple or a tomato, though she soon decided, correctly, on the former. When I showed her a small plastic model of a wolf (I keep a variety of such objects, for perceptual testing, in my medical bag), she exclaimed, “A marvelous animal! A baby elephant, perhaps?” When I asked her to look more closely, she decided it was “a kind of dog.”

Lilian’s relative success in naming solid objects, as opposed to drawings of them, again made me wonder whether she had a specific agnosia for representations. The recognition of representations may require a sort of learning, the grasping of a code or convention, beyond that needed for the recognition of objects. Thus, it is said, people from primitive cultures who have never been exposed to photographs may fail to recognize that they are representations of something else. If a complex

system for the recognition of visual representations must be specially constructed by the brain, this ability might be lost through damage to that system by a stroke or disease, just as the learned understanding of writing, say, or any other acquired ability may be lost.

I followed Lilian into the kitchen, where she set about taking the kettle off the stove and pouring boiling water into the teapot. She seemed to navigate her crowded kitchen well, knowing, for instance, that all the skillets and pots were hung on hooks on one wall, various supplies kept in their regular places. When we opened the refrigerator and I quizzed her on the contents, she said, “O.J., milk, butter on the top shelf—and a nice sausage, if you’re interested, one of those Austrian things . . . cheeses.” She recognized the eggs in the fridge door and, when I asked her, counted them correctly, moving her finger from egg to egg as she did so. I could see at a glance that there were eight—two rows of four—but Lilian, I suspect, could not perceive the eightness, the gestalt, easily and had to enumerate the eggs one by one. And the spices, she said, were “a disaster.” They all came in identical red-topped bottles, and, of course, she could not read the labels. So: “I smell them! . . . And I call for help some of the time.” With the microwave oven, which she used often, she said, “I don’t see the numbers. I do it by feel—cook, try, see if it needs a bit more.”

Though Lilian could scarcely recognize anything in the kitchen visually, she had organized it in such a way that mistakes rarely, if ever, occurred, utilizing a sort of informal classification system instead of a direct perceptual gnosis. Things were categorized not by meaning but by color, by size and shape, by position, by context, by association, somewhat as an illiterate person might arrange the books in a library. Everything had its place, and she had memorized this.

Seeing how Lilian inferred the character of the objects around her in this way, using color, above all, as a marker, I wondered how she would do with objects of similar appearance, like the fish knives and the steak knives, which looked almost the same. This was a problem, she confessed, and she often confused them. Perhaps, I suggested, she could use an artificial marker, a little green dot for the fish knives, a red one for the steak knives, so that she could see the difference at a glance. Lilian said she had already thought about this but was not sure she wanted to “flaunt” her problem to others. What would her guests think of color-coded cutlery and dishes, or a color-coded apartment? (“Like a psychological experiment,” she said, “or an office.”) The “unnaturalness” of such an idea disturbed her, but if the agnosia got worse, she agreed, she might need it.

In some cases where Lilian’s categorization system did not work, such as using the microwave, she could operate by trial and error. But if objects were not in their place, major difficulties could appear. This showed itself startlingly at the end of my visit. The three of us—Lilian, Claude, and I—had sat down at the dining room table. Lilian had laid the table, put out biscotti and cakes, and now brought in a steaming pot of

tea. She chatted as we ate, but retained a certain watchfulness, monitoring the position and movement of every dish, tracking everything (I later realized), so that it did not get “lost.” She got up to take the empty dishes into the kitchen, leaving only the biscotti, which she saw that I especially liked. Claude and I chatted for a few minutes—our first talk alone—pushing the plate of biscotti between us.

When Lilian came back, and I packed my bag and prepared to go, she said, “You must take the rest of the biscotti with you”—but now, bizarrely, she could not find them, and became upset, almost frantic, at this. They were right on the table in their dish, but since the dish had been moved she no longer knew where they were, or even where to look. She seemed to have no strategy for looking. She was, however, quite startled to see my umbrella on the table. She failed to recognize it as an umbrella, noticing only that something curved and twisted had appeared—and wondered, for a half-serious moment, if it was a snake.

Before I left, I asked Lilian to go to the piano, asked if she would play something for me. She hesitated. It was clear that she had lost a good deal of her confidence. She started beautifully, on a Bach fugue, but broke off, apologetically, after a few bars. Seeing a volume of Chopin mazurkas on the piano, I asked about those, and, encouraged, she closed her eyes and played two of the Opus 50 mazurkas without faltering, and with great brio and feeling.

She told me afterward that the printed music was just “lying around,” saying, “It throws me off to see the score, people turning pages, my hands, or the keyboard,” and that, in such circumstances, she might make mistakes, especially with her right hand. She had to close her eyes and perform nonvisually, using only her “muscle memory,” and her fine ear.

What could I say about the nature and progress of Lilian’s strange disease? It had clearly advanced somewhat since her neurological examination three years before, and there were hints—though no more than hints—that her problems might no longer be purely visual. In particular, she occasionally had difficulty naming objects even when she recognized them, and would speak of a “thingmy” when she could not get the word.

I had ordered a new MRI to compare with her earlier one, and it showed that there was now some shrinkage of the visual areas on both sides of the brain. Was there any sign of real damage elsewhere? It was difficult to tell, although I suspected that there might have been some shrinkage in the hippocampi, too—parts of the brain crucial for the registration of new memories. But the damage was still largely confined to the occipital and occipitotemporal cortex, and it was clear that the rate of advance was very slow.

When I discussed these MRI findings with Claude, he stressed that in speaking with Lilian I should avoid certain terms, above all the frightening label of Alzheimer’s disease. “It’s not Alzheimer’s disease, is it?” he said. Clearly, this had been much on their minds.

“I’m not sure,” I said. “Not in the ordinary sense. One should see it as

something rarer—and more benign.”

Posterior cortical atrophy, PCA, was first formally described by Frank Benson and his colleagues in 1988, although it has undoubtedly existed, unrecognized, for much longer. But Benson et al.’s paper provoked a rush of recognition, and dozens of cases have now been described.

People with PCA preserve elementary aspects of visual perception, such as acuity or the ability to detect movement or color. But they tend to experience complex visual disturbances—difficulties reading or recognizing faces and objects, occasionally even hallucinations. Their visual disorientation may become profound: some patients get lost in their own neighborhoods or even in their own homes; Benson called this “environmental agnosia.” Other difficulties commonly follow: left-right confusion, difficulty in writing and calculation, even an agnosia for one’s own fingers, a tetrad of problems sometimes called Gerstmann’s syndrome. Sometimes patients with PCA may be able to recognize and match colors but unable to name them, a so-called color anomia. More rarely, there can be a difficulty in visual targeting and tracking movements.

In contrast to these difficulties, memory, intelligence, insight, and personality tend to be preserved until late in the course of the disease. Every patient described by Benson, he writes, “could present his or her own history, was aware of current events, and showed considerable insight into his or her predicament.”

Although PCA is clearly a degenerative brain disease, it seems quite different in character from the commoner forms of Alzheimer’s, where gross changes in memory and thinking, in the comprehension and use of language, and often in behavior and personality tend to occur, and insight into what is happening (perhaps mercifully) is generally lost early on.

In Lilian’s case, the course of the disease seemed to have been relatively benign, for even nine years after her first symptoms, she did not get lost in her own home or neighborhood.

I could not help making a comparison, as Lilian herself had, with my patient Dr. P., “the man who mistook his wife for a hat.” Both of them were highly gifted professional musicians; both developed severe visual agnosias, while remaining remarkably intact in many other ways; and both had discovered or developed ingenious ways around their problems, so that it was possible for them to keep teaching at the highest level in music colleges, despite what might appear to be quite devastating disabilities.

The actual ways in which Lilian and Dr. P. coped with their illnesses were very different, though—a reflection in part of the severity of their symptoms, and in part of differences in temperament and training. Dr. P. was already in grave trouble when I saw him, barely three years after his initial symptoms. He had not only visual difficulties but tactile ones, too—he grasped his wife’s head and mistook it for a hat. He showed a sort

of levity or indifference, and little insight into the fact that he was ill, and he often confabulated to make up for the fact that he could not identify what he was seeing. This was in strong contrast to Lilian, who, nine years after her first symptoms, had no substantial problems outside her visual ones, was still able to travel and teach, and showed acute insight into her own condition.

Lilian could still identify objects by inference, using her intact perception of color, shape, texture, and movement, along with her memory and intelligence. Dr. P. could not. He could not, for instance, identify a glove by sight or by feel (despite being able to describe it in almost absurdly abstract terms, as “a continuous surface infolded on itself [with] five outpouchings, if this is the word . . . a container of some sort?”)—until, by accident, he got it onto his hand. He was, in general, almost wholly dependent on *doing* things, on action, on flow. And singing, which for him was the most natural, irrepressible activity in the world, allowed him to bypass his agnosia to some extent. He had all sorts of songs that he would hum or sing: dressing songs, shaving songs, action songs. Music, he had found, could organize his activities, his daily life.¹ This was not the case with Lilian. Her great musicality was also preserved, but it did not play a comparable role in her daily life; it was not, for her, a strategy for dealing with agnosia.

A few months later, in June of 1999, I again visited Lilian and Claude in their apartment—Claude was just back from his weeks in Europe, and Lilian, I gathered, had been moving freely within a four-block radius of their apartment, going to her favorite restaurant, shopping, doing errands. When I arrived, I saw that Lilian had been sending cards to her friends all over the world—there were envelopes addressed to Korea, to Germany, to Australia, to Brazil, scattered all over the table. Her alexia, clearly, had not diminished her correspondence, though the names and addresses sometimes straggled over the envelope. She seemed to be managing well in her own apartment, but how did she deal with shopping and the challenges of a busy New York neighborhood, even her own?

“Let’s go out, let’s wander,” I said. Lilian immediately started singing “*Der Wanderer*”—she loves Schubert—and then the elaboration of this in the *Wanderer Fantasy*.

In the elevator, she was greeted by some neighbors. It was not clear to me whether she recognized them visually or by their voices. She instantly recognized voices, sounds of all sorts; indeed, she seemed hyperattentive here, as she was to colors and shapes. They had assumed a special importance as cues.

She had no difficulty crossing the street. She could not read the “Walk” and “Don’t Walk” signs, but she knew their relative position and color; knew, too, that she could walk when the sign was blinking. She pointed out a synagogue on the corner opposite; other shops she identified by shapes or colors, as with her favorite diner, which had

alternating black and white tiles.

We went into a supermarket and got a cart—she headed instantly to the alcove where these were. She had no difficulty in finding the fruit and vegetable section, or in identifying apples, pears, carrots, yellow peppers, and asparagus. She could not at first name a leek but said, “Is it a cousin of an onion?” and then got the missing word, “leek.” She was puzzled by a kiwifruit, until I let her handle it. (She thought it “delightfully furry, like a little mouse.”) I reached up for an object hanging above the fruit. “What is this?” I asked. Lilian squinted, hesitated. “Is it edible? Paper?” When I let her touch it, she burst into somewhat embarrassed laughter. “It’s an oven glove, a pot holder,” she said. “How could I be so silly?”

When we moved to the next section, Lilian called out, “Salad dressings on the left, oils on the right,” in the manner of a department-store elevator operator. She had obviously mapped the entire supermarket in her head. Wanting a particular tomato sauce, one of a dozen different brands, she picked it out because it had “a deep-blue rectangle and below that a yellow circle” on its label. “Color is of the essence,” she emphasized again. This is her most immediately visible cue, recognizable when nothing else is. (For that reason, fearing we might be separated, I had dressed entirely in red for our visit, knowing that it would allow her to spot me instantly if we did.)

But color was not always enough. If confronted with a plastic container, she might have no idea whether it contained peanut butter or cantaloupe. Often, she found that the simplest strategy was to bring in a used can or carton and ask someone for help in matching it.

As we left the market, she accidentally crashed the shopping cart into a pile of shopping baskets to her right. Such accidents, when they happen, are always to the right, because of her impaired visual awareness to this side.

Some months later, I arranged to see Lilian in my own office rather than at the clinic, where she had come before. She arrived promptly, having made her way to Greenwich Village from Penn Station. She had been in New Haven the night before, where her husband had given a concert, and he had seen her onto a train that morning. “I know Penn Station like the back of my hand,” she said, so she did not have problems there. But outside, in the melee of people and traffic, she noted, “there were many moments when I had to ask.” When I inquired about how she had been doing, she said her agnosia was getting worse. “When you and I went to the market together, there were many things I could recognize easily. Now, if I want to buy the same things, I have to ask people.” In general, she had to ask others to identify objects for her, or to help her if there were awkward steps, sudden changes of level, or irregularities in the ground. She depended more on touch and on hearing (to make sure, for instance, that she was facing the right way). And she depended increasingly on her memory, her thinking, her logic and common sense

to help negotiate what would otherwise be—visually—an unintelligible world.

Yet, in my office, she immediately recognized a picture of herself on a CD cover, playing Chopin. “It looks slightly familiar,” she said with a smile.

I asked her what she saw on a certain wall of my office. First, she turned her chair not to the wall but to the window, and said, “I see buildings.” Then I rotated her chair for her until she faced the wall. I had to take her through it bit by bit. “Do you see lights?” Yes, there, and there. It took a little while to establish that she was looking at a sofa beneath the lights, though its color was commented on at once. She observed something green lying on the sofa, and astonished me by saying, correctly, that it was a stretch cord. She said she had been given such a cord by her physiotherapist. Asked what she saw above the couch (a painting with abstract geometric forms), she said, “I see yellow . . . and black.” What is it? I asked. Something to do with the ceiling, Lilian hazarded. Or a fan. A clock. Then she added, “I haven’t really found out whether it is one item or many.” It was in fact a painting done by another patient, a colorblind painter. But clearly Lilian had no idea that it was a painting, was not even sure that it was a single object, and thought that it might be part of the structure of the room.

I found all this puzzling. How was it that she could not clearly distinguish a striking painting from the wall itself, yet could instantly recognize a small photograph of herself on a CD? How could she identify a slender green stretch cord while failing to see, or recognize, the sofa it was on? And there had been innumerable such inconsistencies before.

I wondered how she could read the time, since she was wearing a wristwatch. She could not read the numbers, she said, but could judge the position of the hands. I then showed her, mischievously, a strange clock I have, in which the numbers are replaced by the symbols of elements (H, He, Li, Be, etc.). She did not perceive anything the matter with this, since for her the chemical abbreviations were no more or less unintelligible than numerals would have been.

We went out for a walk, I in a bright-colored hat for recognition. Lilian was bewildered by the objects in one shop window—but so was I. This was a Tibetan-handicrafts shop, but they could have been Martian handicrafts, given the exotic unfamiliarity of everything. The shop next to this one, curiously, she recognized at once, and mentioned having passed it on her way to my office. It was a clock shop, with dozens of clocks of different sizes and shapes. She told me later that her father had had a passion for clocks.

A padlock on the door of another store was a total puzzle, though Lilian thought it might be something “to open up . . . like a hydrant.” The moment she touched it, though, she knew what it was.

We stopped briefly for coffee; then I took her to my apartment, on the next block. I wanted her to try my grand piano, an 1894 Bechstein. Entering my apartment, she immediately identified the grandfather clock

in the hall. (Dr. P., by contrast, had tried to shake hands with a grandfather clock.)

She sat at the piano and played a piece—a piece that I found puzzling, for it seemed familiar to me in a way, yet unfamiliar, too. Lilian explained that it was a Haydn quartet she had heard on the radio and been enchanted by a couple of years before and which she had longed to play herself. So she had arranged it for the piano, and had done so entirely in her head, overnight. She had occasionally arranged pieces for the piano before her alexia, using manuscript paper and the original score, but when this became impossible, she found that she could do it wholly by ear. She felt that her musical memory, her musical imagery, had become stronger, more tenacious, but also more flexible, so that she could hold the most complex music in her mind, then rearrange it and replay it mentally, in a way that would have been impossible before. Her continually strengthening powers of musical memory and imagery had become crucial to her, kept her going since the onset of her visual difficulties, nine years earlier.²

Lilian's obvious confusion about what was what in my office, and in the little streets and shops around it, brought home to me how dependent she was on the familiar, the memorized; how anchored she was to her own apartment and her own neighborhood. In time, perhaps, if she were to visit a place frequently, she would gradually become more familiar with it, but this would be a hugely complex enterprise, demanding great patience and resourcefulness, a whole new system of categorization and memorization. It was clear to me, after this one visit of Lilian's to my office, that in the future I should stick to house calls, visiting her in her own apartment, where she felt organized, in control, at home. Going out, for her, was becoming an increasingly surreal visual challenge, full of fantastic and sometimes frightening misperceptions.

Lilian wrote to me again in August of 2001, expressing growing concern. She said she hoped I might be able to come soon for a visit, and I suggested the following weekend.

She stood by her door to welcome me, knowing, as she did, my own (lifelong) defects of visual and topographic recognition, my confusion of left and right, and my inability to find my way around inside buildings. She welcomed me with great warmth, but also a touch of anxiety, which seemed to hover throughout the visit.

"Life is difficult," she began, after she had seated me and given me a glass of seltzer. She had trouble finding the seltzer in her refrigerator, and, not seeing the bottle, which was "hidden" behind a jug of orange juice, she had taken to exploring the refrigerator by hand, groping for a bottle of the right shape. "It is not getting better. . . . The eyes are very bad." (She knows, of course, that her eyes are fine, and that it is the visual parts of the brain that are declining—indeed, she realized this before anyone else—but she finds it easier, more natural, to refer to her

“bad eyes.”) When I had gone shopping with her two years before, she had seemed to recognize almost everything she saw, or at least had it coded by shape and color and location, so that she hardly ever needed help. At that time, too, she moved infallibly about her kitchen, never losing anything, working efficiently. Today, she “lost” both the seltzer and the schmaltz herrings—a losing that entailed not only forgetting where she had put them but not recognizing them when she saw them. I observed that the kitchen was less organized than it had been before—and organization is crucial in her situation.

Lilian’s anomia, her problems with finding words, had increased, too. When I showed her some kitchen matches, she recognized them at once, visually, but could not say the word “match,” saying, instead, “That is to make fire.” The Sweet’n Low, similarly, she could not name, but identified as “Better Than Sugar.” She was well aware of these difficulties, and of her strategies for dealing with them. “When I can’t say something,” she explained, “I circumscribe.”

She said that although she had recently traveled to Ontario, to Colorado, and to Connecticut with her husband, she would not have been able to do this by herself, as she had only a few years before. She felt that she remained quite capable of looking after herself at home when Claude was away. Still, she said, “When I am alone, it is lousy. I’m not complaining—I’m describing.”

While Lilian was in the kitchen at one point, I asked Claude how he felt about these problems. He expressed sympathy and understanding, but added, “My impatience is provoked sometimes when I think that some of her weaknesses may be exaggerated. I’ll give you an example. I get puzzled, annoyed sometimes, because Lilian’s ‘blindness’ is sometimes ‘selective.’ Last Friday, she noticed that a painting was hung lopsidedly by a few millimeters. And sometimes she comments on people’s facial expressions in tiny photographs. She will touch a spoon and ask, ‘What is this?’ and then five minutes later look at a vase and say, ‘We have a similar one.’ I have found no pattern, only inconsistency. What should my attitude be when she grabs a cup and says, ‘What’s this?’ I sometimes don’t tell her. But this may be wrong, and the effect disastrous. What should I say?”

This was, indeed, a very delicate matter. How much should he intervene when she was faced with perceptual bewilderment? How much should we prompt a friend or a patient when he has forgotten someone’s name? How much do I myself—with no sense of direction—wish to be saved from blundering off in the wrong direction or left to battle out the right way by myself? How much do any of us like to be “told” anything? The question was especially vexing with Lilian, for, while she needed to work things out, fend for herself, her visual difficulties were becoming more severe all the time, and they sometimes threatened, as Claude observed, to throw her into a panic of disorientation. I could suggest no rule, I said to Claude, except that of tact: each situation would call for its own solution.

But I, too, was puzzled by the extraordinary variations in Lilian's visual function. Some of them, it seemed, went with the reduced and unstable function of her damaged visual cortex—just as, ten years earlier, when the first problems appeared, her ability to read music would come and go. Some of the variations, I thought, might reflect fluctuations in blood flow. But some of the variations seemed to go with a decreasing ability, for whatever reason, to compensate in her usual way. Her ability to make use of her memory and her intellectual powers in place of direct visual recognition, I now felt, might also be diminishing at this point. Thus it was more important than ever for Lilian to “code” things, to provide easily used sensory clues—above all, color, to which she remained intensely sensitive.

What intrigued me especially was Claude's mention of Lilian's sudden abilities—her ability, for example, to perceive facial expressions on a tiny photograph, even though most of the time she had difficulty recognizing people at all. I could not help wondering whether this was an example of the preconscious abilities she had shown on earlier testing—as when she could categorize words, even though she could not recognize the objects they represented, as “living” or “nonliving.” Such unconscious recognition might be possible to some extent despite her agnosia, despite her cortical damage, because it made use of other, still intact mechanisms in the visual system.

An extraordinary firsthand account of “musical alexia with recovery” was published by Ian McDonald in 2006. It was the first such personal account to be published, and was doubly remarkable because McDonald himself was both a neurologist and a fine amateur musician. His musical alexia (along with other problems, including difficulties with calculation, face-blindness, and topographic disorientation) was caused by an embolic stroke, and he was to make a complete recovery.³ He stressed that, even though there was gradual improvement in his ability to read music, especially associated with practice, his musical alexia fluctuated considerably from day to day.

Lilian's physicians initially thought that she, too, had had a stroke and that the variations in her abilities might go with this. But such fluctuations are typical of any neural system that has sustained damage, irrespective of the cause. Patients with sciatica from nerve-root compression have good and bad days, as do patients with impairments of sight or hearing. There is less reserve, less redundancy, when a system is damaged, and it is more easily thrown off by adventitious factors such as fatigue, stress, medications, or infections. Such damaged systems are also prone to spontaneous fluctuations, as my *Awakenings* patients experienced constantly.

Lilian had been ingenious and resilient in the eleven or twelve years since her illness started. She had brought inner resources of every kind to her own aid: visual, musical, emotional, intellectual. Her family, her

friends, her husband and daughter, above all, but also her students and colleagues, helpful people in the supermarket or on the street—everyone had helped her cope. Her adaptations to the agnosia were extraordinary—a lesson in what could be done to hold together a life in the face of ever-advancing perceptual and cognitive challenge. But it was in her art, her music, that Lilian not only coped with disease but transcended it. This was clear when she played the piano, an art that both demands and provides a sort of superintegration, a total integration of sense and muscle, of body and mind, of memory and fantasy, of intellect and emotion, of one's whole self, of being alive. Her musical powers, mercifully, remained untouched by her disease.

Her piano playing always added a transcendent note to my visits, and it recalled her, no less crucially, to her identity as an artist. It showed the joy she could still get and give, whatever other problems were now closing in on her.

When I revisited Lilian and Claude in 2002, I found the apartment full of balloons. "It was my birthday, three days ago," Lilian explained. She did not look well and seemed somewhat frail, although her voice and her warmth were entirely unchanged. She said that her visual powers had deteriorated further, and this was all too evident as she groped for a chair to sit down on, walked in the wrong direction, and got lost inside her own apartment. Her behavior now looked much more "blind," reflecting not only her increasing inability to decipher what faced her but a complete lack of visual orientation.

She was still able to write letters, but reading, even the painfully slow letter-by-letter reading that she could do a few years before, had become impossible. She adored being read to—Claude would read to her from newspapers and books—and I promised to send her some audiotapes. She could still go out a little, walking around the block on her husband's arm. The two of them were closer than ever, with her increasing disability.

Despite all this, Lilian felt that her ear was as good as it always was, and she had been able to continue a little teaching, with students from the music college coming to her apartment. Apart from this, though, she no longer played the piano much.

And yet, when I mentioned the Haydn quartet she had played for me before, her face lit up. "I was absolutely enthralled by that piece," she said. "I'd never heard it before. It's very rarely played." And she described for me again how, unable to get it out of her head, she had arranged it, mentally, for the piano, overnight. I asked her to play it for me again. Lilian demurred, and then, persuaded, started for the piano, but went in the wrong direction. Claude corrected her gently. At the piano, she first blundered, hitting wrong notes, and seemed anxious and confused. "Where am I?" she cried, and my heart sank. But then she found her place and began to play beautifully, the sound soaring up, melting, twisting into itself. Claude was amazed and moved by this. "She hasn't played at all for two or three weeks," he whispered to me. As she

Recalled to Life

PATRICIA H. was a brilliant and energetic woman who represented artists, ran an art gallery on Long Island, and was a talented amateur painter herself. She had raised her three children and, nearing sixty, continued to lead an active and even, as her daughters put it, “glamorous” life, with scouting expeditions to the Village and frequent soirées at home—she loved to cook, and there would often be twenty people for dinner. Her husband, too, was a man of many parts—a radio broadcaster, a fine pianist who sometimes performed at nightclubs, and politically active. Both were intensely sociable.

In 1989, Pat’s husband died suddenly of a heart attack. Pat herself had had open-heart surgery for a damaged valve the year before, and had been put on anticoagulants. She had taken this in stride—but with her husband’s death, as one of her daughters said, “She seemed stunned, became very depressed, lost weight, fell in the subway, had accidents with the car, and would show up, as if lost, on our doorstep in Manhattan.” Pat had always been somewhat volatile in mood (“She would be depressed for a few days and take to her bed, then leap up in an opposite frame of mind and rush into the city, with a thousand engagements of one sort and another”), but now a fixed melancholy descended on her.

When, in January of 1991, she did not answer her phone for two days, her daughters became alarmed and called a neighbor, who, with the police, broke into Pat’s house to find her lying in bed unconscious. She had been in a coma for at least twenty hours, the daughters were told, and had suffered a massive cerebral hemorrhage. There was a huge clot of blood in the left half of her brain, her dominant hemisphere, and it was thought that she would not survive.

After a week in the hospital with no improvement, Pat underwent surgery as a last-ditch measure. The results of this, her daughters were told, could not be predicted.

Indeed, it seemed at first, after the clot was removed, that the situation was dire. Pat would “stare . . . without seeming to see,” according to one of her daughters. “Sometimes her eyes would follow me, or seem to. We didn’t know what was going on, whether she was there.” Neurologists sometimes speak of “chronic vegetative states,” zombie-like conditions

in which certain primitive reflexes are preserved but no coherent consciousness or self. Such states can be cruelly tantalizing, for there is often the feeling that the person is about to come to—but the states may last for months or even indefinitely. In Pat's case, though, it lasted for two weeks and then one day, as her daughter Lari recalled, "I had a Diet Coke in my hand—she wanted it. I saw her eye it. I asked, 'Do you want a sip?' She nodded. Everything changed at that moment."

Pat was conscious now, recognized her daughters, was aware of her condition and her surroundings. She had her appetites, her desires, her personality, but she was paralyzed on the right side, and, more gravely, she could no longer express her thoughts and feelings in words; she could only eye and mime, point or gesture. Her understanding of speech, too, was much impaired. She was, in short, aphasic.

"Aphasia" means, etymologically, a loss of speech, yet it is not speech as such which is lost but language itself—its expression or its comprehension, in whole or in part. (Thus, congenitally deaf people who use sign language may acquire aphasia following a brain injury or stroke and be unable to sign or understand sign language—a sign aphasia in every way analogous to the aphasia of speaking people.)

There are many different forms of aphasia, depending on which parts of the brain are involved, and a broad distinction is usually made between expressive aphasias and receptive aphasias—if both are present, this is said to be a "global" aphasia.

Aphasia is not uncommon; it has been estimated that one person in three hundred may have a lasting aphasia from brain damage, whether as the consequence of a stroke, a head injury, a tumor, or a degenerative brain disease. Many people, however, have a complete or partial recovery from aphasia. (There are also transient forms of aphasia, lasting only a few minutes, which may occur during a migraine or a seizure.)

In its mildest forms, expressive aphasia is characterized by a difficulty finding words or a tendency to use the wrong words, without compromise of the overall structure of sentences. Nouns, including proper names, tend to be especially affected. In more severe forms of expressive aphasia, a person is unable to generate full, grammatically complete sentences and is reduced to brief, impoverished, "telegraphic" utterances; if the aphasia is very severe, the person is all but mute, though capable of occasional ejaculations (such as "Damn!" or "Fine!"). Sometimes a patient may perseverate on a single word or phrase which is uttered in every circumstance, to their evident frustration. I had one patient who, after her stroke, could say nothing but "Thank you, Mama" and another, an Italian woman, who could utter only "Tutta la verità, tutta la verità."

Hughlings Jackson, a pioneer explorer of aphasia in the 1860s and '70s, considered that such patients lacked "propositional" speech, and that they had lost internal speech as well, so they could not speak or

“propositionize,” even to themselves. He felt therefore that the power of abstract thought was lost in aphasia, and in this sense, he compared aphasics to dogs.

In his excellent book *Injured Brains of Medical Minds*, Narinder Kapur cites many autobiographical accounts of aphasia. One of these is from Scott Moss, a psychologist who had a stroke at the age of forty-three, became aphasic, and later described his experiences, which were very much in accord with Hughlings Jackson’s notions about the loss of inner speech and concepts:

When I awoke the next morning in the hospital, I was totally (globally) aphasic. I could understand vaguely what others said to me if it was spoken slowly and represented a very concrete form of action. . . . I had lost completely the ability to talk, to read and to write. I even lost for the first two months the ability to use words internally, that is, in my thinking. . . . I had also lost the ability to dream. So, for a matter of eight to nine weeks, I lived in a total vacuum of self-produced concepts. . . . I could deal only with the immediate present. . . . The part of myself that was missing was [the] intellectual aspect—the sine qua non of my personality—those essential elements most important to being a unique individual. . . . For a long period of time I looked upon myself as only half a man.

Moss, who had both expressive and receptive aphasia, also lost the ability to read. For someone who has only an expressive aphasia, it may still be possible to read and to write (provided the writing hand is not paralyzed by the stroke).¹

Another account was that of Jacques Lordat, an eminent early-nineteenth-century French physiologist who provided an extraordinary description of his own aphasia after a stroke, sixty-odd years before Hughlings Jackson’s studies. His experiences were quite different from Moss’s:

Within twenty-four hours all but a few words eluded my grasp. Those that did remain proved to be nearly useless, for I could no longer recall the way in which they had to be coordinated for the communication of ideas. . . . I was no longer able to grasp the ideas of others, for the very amnesia that prevented me from speaking made me incapable of understanding the sounds I heard quickly enough to grasp their meaning. . . . Inwardly, I felt the same as ever. This mental isolation which I mention, my sadness, my impediment and the appearance of stupidity which it gave rise to, led many to believe that my intellectual faculties were weakened. . . . I used to discuss within myself my life work and the studies I loved. Thinking caused me no difficulty whatever. . . . My memory for facts, principles, dogmas, abstract ideas, was the same as when I enjoyed good health. . . . I had to realize that the inner workings of the mind could dispense with words.

Thus in some patients, even if they are totally unable to speak or understand speech, there may be perfect preservation of intellectual powers—the power to think logically and systematically, to plan, to recollect, to anticipate, to conjecture.²

Nevertheless, a feeling remains in the popular mind—and all too often in the medical mind, too—that aphasia is a sort of ultimate disaster which, in effect, ends a person’s inner life as well as their outer life.

Something along these lines was said to Pat's daughters, Dana and Lari. A little improvement, they were told, might occur, but Pat would need to be put away for the rest of her life; there would be no parties, no conversation, no art galleries anymore—all that had constituted the very essence of Pat's life would be gone, and she would lead the narrow life of a patient, an inmate, in an institution.

Scarcely able to initiate conversation or contact with others, patients with aphasia face special dangers in chronic hospitals or nursing homes. They may have therapy of every sort, but a vital social dimension of their lives is missing, and they frequently feel intensely isolated and cut off. Yet there are many activities—card games, shopping trips, movies or theater, dancing or sports—that do not require language, and these can be used to draw or inveigle aphasic patients into a world of familiar activities and human contact. The dull term “social rehabilitation” is sometimes used here, but really the patient (as Dickens might put it) is being “recalled to life.”

Pat's daughters were determined to do everything they could to bring their mother back into the world, to the fullest possible life her limitations allowed. “We hired a nurse who retaught my mother how to feed herself, how to *be*,” Lari said. “Mother would get angry, sometimes strike her, but she, the nurse, would never give up. Dana and I never left her side. We would take her out, wheel her to my apartment. . . . We would take her out to restaurants, or bring food in, have her hair done, her nails manicured. . . . We never stopped.”

Pat was moved from the acute care hospital where she had had surgery to a rehabilitation facility. After six months, she was finally moved to Beth Abraham Hospital, in the Bronx, where I first met her.

When Beth Abraham Hospital was opened, in 1919, it was called the Beth Abraham Home for Incurables, a discouraging name that was changed only in the 1960s. Originally accommodating some of the first victims of the encephalitis lethargica epidemic (some of whom were still living there more than forty years later, when I arrived), Beth Abraham expanded over the years to become a five-hundred-bed hospital with active rehabilitation programs aimed at helping patients with all sorts of chronic conditions: parkinsonism, dementias, speech problems, multiple sclerosis, strokes (and, increasingly, spinal or brain damage from bullet wounds or car accidents).

Visitors to hospitals for the chronically ill are often horrified at the sight of hundreds of “incurable” patients, many of them paralyzed, blind, or speechless. One's first thought is often: Is life worth living in circumstances like these? What sort of a life can these people have? One wonders, nervously, how one would react to the prospect of being disabled and entering such a home oneself.

Then one may start to see the other side. Even if no cure, or only limited improvement, is possible for most of these patients, many of



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