

## RECALLED TO LIFE

*When patients suffer a loss of language, must they also lose their sense of self?*

BY OLIVER SACKS

Patricia H. was a brilliant and energetic woman who represented artists and ran an art gallery on Long Island, and was a talented amateur painter herself. She had raised her three children, and, nearing sixty, she 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 was a great 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 night clubs, and politically active. Both were intensely sociable.

In 1989, however, 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 now, with her husband's death, as one of her daughters put it, "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, a thousand engagements of one sort and another"), but now a fixed melancholy descended on her.

When, in January of 1991, she didn't answer her phone for two days, her daughters became alarmed and called a neighbor, who, with the Long Island 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, the 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 years. In Pat's case, though, it lasted for two weeks and then, 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 this 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, as neurologists say, aphasic.

"Aphasia" means, literally, a loss of speech, but 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 rather than speech may get a sign aphasia following a brain injury or stroke, an aphasia in every way analogous to the aphasia of speaking people.)

Aphasia is not uncommon—it has

been estimated that one person in three hundred may have a lasting aphasia from brain damage, whether this be the consequence of a stroke, a head injury, a tumor, etc. Many people, however, have a complete or partial recovery from aphasia, and there are transient forms that may occur during a migraine or a seizure.

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

In its mildest forms, expressive aphasia is characterized by a difficulty finding words, or a tendency to use wrong words, without compromise of the overall structure of sentences.

In more severe forms, a person may be unable to generate full, grammatically correct sentences, and may be able to utter only isolated words ("telegraphic speech"); if the aphasia is very severe, the person may be all but mute, though capable of occasional emotional ejaculations (such as "Damn!" or "Fine!"). John Hughlings Jackson, a pioneer explorer of aphasia in the eighteen-sixties and seventies, considered that such patients lacked "propositional" speech, and he thought that they had lost internal speech as well, so that they could not speak or "propositionalize" even to themselves. He felt therefore that the power of abstract thought was lost in aphasia, and on occasion he compared aphasics to dogs.

Scott Moss, a psychologist who had a stroke when he was forty-three which rendered him aphasic and paralyzed on the right side, 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.

But it was very different with 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:

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. This was shown, too, with great clarity in the case of a patient who was referred to by his physicians only as Brother John, a monk who would become completely aphasic for several

minutes in the course of his epileptic seizures. But even when wholly deprived of language or internal speech Brother John was able to tackle complex problems, to negotiate intricate social situations, to show all the characteristic powers of a human being other than language. Had Hughlings Jackson met Brother John, one feels, he could not have compared aphasics to dogs.

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 her outer life. Something along these lines was said to Pat's daughters, Dana and Lari. A little improvement, the neurologists felt, might occur, but Pat would need to be institutionalized 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.

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 aphasics frequently feel intensely isolated and cut off. Yet there are many activities—card games, shopping trips, movies or theatre, dance or sports—that do not require language, and these can be used to draw or inveigle aphasics into a social world of familiar activities and human contact. The dull term “social rehabilitation” is sometimes used here, but really the patient (as Dickens would 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 hospital where she had had surgery to a

rehabilitation facility, and, 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 Beth Abraham Home for Incurables, a discouraging name that was changed only in the nineteen-sixties. 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, traumatic damage from bullet wounds and car accidents).

Visitors to hospitals for the chronically ill are often horrified at first, 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 them may nonetheless be helped to reconstruct their lives, to find other ways of doing things, capitalizing on their strengths, finding compensations and accommodations of every sort. This, of course, depends upon the degree and type of neurological damage, and upon the inner and outer resources of the individual patient.

But if the first sight of a chronic hospital can be hard for visitors, it can be terrifying for a new inmate, who often reacts with horror, mixed with sadness, bitterness, or rage. When I first saw Pat, shortly after her admission to Beth Abraham in October of 1991, I found her angry and frustrated. She did not yet know the staff, or the layout of the place, and she felt that a rigid, institutional order was being imposed on her. She could communicate through

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gestures—these were passionate, if not always understandable—but she still had very little speech (at least of grammatical sentences; she would occasionally, the staff said, exclaim “Hell!” or “Go away!” when she was angry). While she seemed to understand a good deal of what people said to her, it became clear, on examination, that she was responding not to words but to the tone of voice, facial expression, and gestures.

When I tested her in the clinic, Pat could not respond to “Touch your nose,” either in speech or in writing. She could count (“one, two, three, four, five . . .”) in sequence, but could not say individual numbers or count backward. The right side of her body remained completely paralyzed. Her neurological situation, I noted in my report, was “a bad one. I fear there may not be too much recovery of language functions, but intensive speech therapy, as well as physical therapy and occupational therapy, must certainly be tried.”

Pat yearned to speak, but was continually frustrated when, after huge efforts to get a word out, it would be the wrong word, or unintelligible. She would try to correct it, but often would become more unintelligible with every attempt to make herself understood. It started to dawn on her, I think, that her power of speech might never come back, and, increasingly, she retreated into silence. This inability to communicate was, for her, as for many patients with aphasia, far worse than the paralysis of half her body. I would sometimes see Pat, in this first year after her stroke, sitting alone in the corridor, or in the patients' dayroom, bereft of speech, surrounded by a sort of penumbra of silence, with a stricken and desolate look on her face.

But, a year later, I found Pat much improved. She was able to understand language better, and she could communicate better—not by speech but by eloquent gesture and pointing. She indicated, for example, fluttering a couple of tickets, that she would go to the movies if, and only if, a friend of hers could go, too. Pat had become less angry, more sociable, and very aware of all that was going on around her.

This represented an enormous social improvement—an improvement in the ability to communicate—but I was not sure how much it rested on actual neurological improvement. Friends and relatives of aphasic patients, indeed, often think that there is more neurological recovery than there actually is, because many such patients develop a remarkable compensatory heightening of other, non-linguistic powers and skills, especially the ability to “read” others' intentions and meanings from their facial expressions, vocal inflections, and tone of voice, as well as all the gestures, postures, and minute movements that normally accompany speech. Such compensation may give surprising powers to aphasics—in particular, an enhanced ability to see through histrionic artifice, equivocation, or lying. I described this in 1985, when I observed a group of aphasic patients watching a Presidential speech on television, and, in 2000, Nancy Etcoff and her colleagues at Massachusetts General Hospital published a study in *Nature* which showed that people with aphasia were in fact “significantly better at detecting lies about emotion than people with no language impairment.” Such skills, they observed, apparently took time to develop, for they were not evident in a patient who had been aphasic for only a few months. This

seemed to be the case with Pat, who had initially been far from expert in picking up others' emotions and intentions but over the years had become preternaturally skillful at it. If aphasics come to excel in understanding nonverbal language, they can also become more expert in conveying their own thoughts in the same way—and Pat was now starting to move toward a conscious and voluntary (and often inventive) representation of her thoughts and intentions by mime.

But while gesture and mime, lacking the grammar and syntax of real language, are not compromised in aphasia, they are not enough; they have only a limited ability to convey complex meanings and propositions (unlike a true sign language, such as congenitally deaf people use). These limitations often infuriated Pat, but a crucial change came when her speech pathologist, Jeannette Wilkens, discovered that, though Pat could not read aloud, and could not read a sentence, she could recognize individual words (and that, indeed, her vocabulary was quite extensive). Wilkens had found this with other aphasic patients as they started to recover, and had devised a sort of dictionary, a book of words arranged in categories of objects, people, and events, as well as moods and emotions. Pat always carried the book on her lap or near her, and would leaf through it rapidly with her left hand and point to the words she needed.

While such a book often worked when patients were closeted in one-on-one sessions with Wilkens, many of our aphasic patients had difficulty reaching out to others—were perhaps too shy, or too depressed, or too disabled from other medical conditions to initiate contact with other people. None of this was the case with Pat, who had been outgoing and social all her life: she boldly approached people, opened her book at the right page, thrust it at them, and pointed to the subject she wanted to talk about.

Pat's life expanded in all sorts of ways with her "bible," as her daughters call it. Soon she was able to guide a conversation in any direction she wanted, a conversation that was on her part accomplished solely by gesture and mime—and this had to be done primarily with her left arm, for her right side was still completely paralyzed. But, despite this lim-

itation, gesture and mime, plus the verbal categories in her book, allowed her a remarkably full and exact expression of her needs and thoughts.

Inside the hospital, she became a node of gossip, despite being unable to communicate in the usual way. Even now, Pat calls her daughters "a hundred times a day," though the conversations are all passive on her part, awaiting questions to which she can answer "yes" (she communicates "yes" by kisses), "no," or "fine," or by noises of approbation, amusement, disapproval, etc.

By 1996, five years after her stroke, her receptive aphasia had almost disappeared—she was able to understand speech, though still unable to express herself in speech (she had certain fixed phrases, like "You're welcome!" or "Fine!," but could not name familiar objects or utter a sentence). She started to paint once again, using her left hand, and she was a terror at dominoes—her nonverbal representational systems were unimpaired. (It has long been understood that aphasia does not affect musical ability, visual imagery, or mechanical aptitude, and researchers at the University of Sheffield have shown recently that numerical reasoning and mathematical syntax can be entirely intact even in patients who are unable to understand or produce grammatical language.)

It is often said that after a stroke or a brain injury whatever recovery is possible will occur within twelve to eighteen months. While this may often be so, I have seen this generalization proved false in many individual patients. And in the past few decades neuroscience has shown what physicians have often observed: that, provided the initial damage is not too great, the brain has more powers of repair and regeneration than was formerly believed. There is, too, more "plasticity"—a greater capacity for undamaged brain areas to take over some of the functions of damaged ones. And, above all, there are powers of accommodation: finding new ways, or other ways, of doing things when the original way is no longer available—and here various forms of therapy, with a resourceful patient, can be of paramount importance. With Pat, even five years after her stroke I noted that she was still showing a steady (though now diminishing) improvement of her receptive powers, her ability to understand language.

(I knew another woman, Madeleine G., who had a crippling expressive aphasia, with very little recovery two years after her stroke—her physicians said then that she had "plateaued"—but who, five years after her stroke, could shop, speak to strangers, and hold her own in almost any conversation.)

Pat is the youngest of seven siblings; her extended family had always played a central part in her life, and this extended further still when Lari's daughter Alexa, Pat's first grandchild, was born in 1993. Alexa, said Lari, "was born into Beth Abraham." She would visit her grandmother frequently, and Pat always had a special toy or treat for her ("I don't know how she got these things," Lari marvelled). Pat would often ask Alexa to take crackers to a friend down the hall who could not walk. Alexa and her two younger siblings, Dean and Eve, are all fascinated by Pat, and like to call her often on the phone when they cannot visit her. Lari feels that they have a very active, very "normal" relationship with their grandmother, a relationship which they all treasure.

One of the pages in Pat's book contained a list of emotional states (she had picked these out from a word list prepared by the speech pathologist). When I asked her, in 1998, what her predominant mood was, she pointed to "happy." There were other adjectives on the mood page, such as "furious," "scared," "tired," "sick," "lonely," "sad," and "bored"—all of which she had indicated, on occasion, in previous years.

In 1999, when I asked her the date, she pointed to "Wednesday, July 28," a little miffed, perhaps, that I had insulted her with such a simple question. She indicated, using her "bible," that she had been, in the past few months, to half a dozen musicals and a couple of art galleries, and that, now that it was summer, she would visit her daughter Lari on Long Island on the weekends and, among other things, swim. "Swim?" I asked, incredulous. Yes, Pat indicated; even with her right side paralyzed, she could still do the sidestroke. She had been a great long-distance swimmer, she indicated, in her youth. She told me how excited she was that Lari would be adopting a new baby in a few months. I

was especially struck, on this visit, eight years after her stroke, by the fullness and richness of Pat's daily experiences, and her voracious love of life in the face of what one might judge to be devastating brain damage.

In 2000, Pat showed me photos of her grandchildren. She had visited them all the previous day, for the Fourth of July, and they had watched the Tall Ships and the fireworks on television. She was eager to show me the newspaper, with a picture of the Williams sisters playing tennis. Tennis, she indicated, had been one of her favorite sports, too, along with skiing, riding, and swimming. She was at pains to show me that her fingernails were manicured and painted, and she was dressed in a sun hat and sunglasses, on her way to sun herself on the hospital patio.

By 2002, Pat had become able to use a few spoken words. This was achieved by the use of familiar songs like "Happy Birthday" or "A Bicycle Built for Two," which she would sing along with Connie Tomaino, Beth Abraham's music therapist. Pat was able to get the feeling of the music, and some of the words. For a few minutes afterward, this would "release" her voice, and give her the ability to say some of the words, in a sing-song fashion. She started carrying a tape recorder with a cassette of familiar songs, so she could get her language powers working. She demonstrated this with "Oh! What a Beautiful Morning," followed by a melodious "Good morning, Dr. Sacks," with a heavy, rhythmic emphasis on "morning."

Music therapy is invaluable for some patients with expressive aphasia, who, finding they can sing the words to a song, are reassured that language is not wholly lost, that they still have access to words somewhere inside them. The question is then whether the language capacities embedded in song can be removed from their musical context and used for communication. This is sometimes possible to a limited extent, by re-embedding words in a sort of improvised singsong.

But I sensed that Pat's heart was not in this—she felt that her real virtuosity lay in her mimetic powers, her appreciation and use of gesture. She had achieved a skill and intuitiveness here amounting almost to genius.

Mimesis, the deliberate and con-

—continued

scious representation of scenes, thoughts, feelings, intentions, etc., by mime and action, seems to be a specifically human achievement, like language (and perhaps music). Apes, which are able to “ape,” or imitate, have little power to create conscious and deliberate mimetic representations.

In “Origins of the Modern Mind,” the psychologist Merlin Donald suggests that a “mimetic culture” may have been a crucial intermediate stage in human evolution between the “episodic” culture of apes and the “theoretic” culture of modern man. Mimesis has a much larger and more robust cerebral representation than language, and this may explain why it is so often preserved in patients who have lost language. It is this preservation which can make remarkably rich communication possible for people with aphasia, especially if it can be elaborated and heightened and combined, as in Pat’s case, with a lexicon.

Pat has always had a passion to communicate (“This was a woman who talked twenty-four hours a day,” Dana said), and it was the frustration of this loquacity which led to absolute fury when she first arrived at the hospital, and to her intense motivation and success in communicating now.

Pat’s daughters are sometimes still amazed at her resilience. “Why isn’t she depressed,” Dana said, “given her earlier history of depression? How could she live like this, I thought at first. . . . I thought she would take a knife to herself.” Every so often, her mother makes

a gesture that seems to say, “My God, what happened? What is this? Why am I in this room?,” as if the raw horror of her stroke had hit her once again. But Pat is aware that she has, in a sense, been very lucky, even though half of her body remains paralyzed. She was lucky that her brain damage, though extensive, did not undermine her force of mind or personality; lucky that her daughters fought so hard from the beginning to keep her engaged and active, and were able to afford extra aides and therapists; lucky, too that she encountered a speech pathologist who observed her sensitively and minutely, and could provide her with a crucial tool, her “bible,” which worked so well.

Pat continues to remain active and engaged with the world. She is, as Dana said, the “darling” of the family, and of the floor at the hospital, too. She has not lost the power to captivate people (“She has even captivated you, Dr. Sacks,” Dana said), and she can even do a little painting with her left hand. She is grateful to be alive, and to be able to do as much as she can, and this, Dana thinks, is why her mood and morale have been so good.

Lari expressed herself in similar terms. “It’s as if the negativity has been wiped away,” she told me. “She is much more consistent, appreciative of her life and gifts . . . of other people, too. She is conscious of being privileged, but this makes her kinder, more thoughtful to other patients who may be physically less disabled than she is but much less ‘adapted’ or ‘lucky’ or ‘happy.’ She is the opposite of a victim,” Lari concluded.

“She actually feels that she has been blessed.”

Last November, on a cool Saturday afternoon, I joined Pat and Dana in one of Pat’s favorite activities—shopping on Allerton Avenue, near the hospital. We arrived in Pat’s room—it was overflowing with plants, paintings, photos and posters, theatre programs—and Pat was awaiting us, already wearing a favorite coat.

As we went up Allerton Avenue, bustling on a weekend afternoon, I saw that half the shopkeepers knew Pat, and shouted “Hi, Pat!” as she bowed past in her wheelchair. She waved at the young woman in the health-food store where she buys her carrot juice, and received a “Hi, Pat!” back. She waved to a Korean woman at the dry cleaner’s, blew a kiss, and had a kiss blown back. The woman’s sister, Pat was able to indicate to me, used to work in the fruit store.

We entered a shoe shop, where Pat’s desires were very clear—she wanted a boot, with fur inside, for the upcoming winter. “Zip or Velcro?” Dana inquired. Pat indicated no preference, but wheeled herself in front of the boot display and then, with great decisiveness, pointed to the boots she wanted. Dana said, “But they have laces!” Pat smiled and shrugged, meaning, “So what! Someone else will tie them.” She is not without vanity—the boots must be elegant as well as warm. (“Velcro, indeed!” her expression said.) “What size? A nine?” Dana asked. No, Pat gestured, bisecting

her finger, an eight-and-a-half.

We stopped by the supermarket, where she always picks up a few things for herself and for others at the hospital. Pat knew every aisle, and quickly picked two ripe mangoes for herself, a large bunch of bananas (most, she indicated, she would give away), some small doughnuts, and, at the checkout, three bags of candy. (She indicated that these were for the children of an orderly on her floor.)

As we moved on, laden with our purchases, Dana asked me where I had been earlier in the day. I said I had been to a fern meeting, adding, “I’m a plant person.” Pat, overhearing, made a wide gesture, and pointed to herself, meaning, “You and I. We are both plant persons.”

“Nothing has changed since her stroke,” Dana said. “She has all her old loves and passions. . . . The only thing is,” she added, smiling, “she has become a pain in the neck!” Pat laughed, agreeing with this.

We stopped at a coffee shop. Pat clearly had no difficulty with the menu, indicating that she wanted not home fries but French fries, with whole-wheat toast. After the meal, Pat carefully applied lipstick. (“How vain!” Dana exclaimed, with admiration.) Dana wondered whether she could take her mother on a cruise. I mentioned the giant cruise ships I had seen go in and out of Curaçao, and Pat, intrigued, inquired with her book whether they set out from New York. I tried to draw a ship in my notebook; Pat laughed, and, left-handed, did a much better one. ♦