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GLOBE STAFF PHOTO/BILL POLO

Brian Sass (center) was the focus of attention at a recent celebration of his successful — but slow — recovery from a coma.

After a coma

Comebacks are slow and patchy, and almost never miraculous

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By Carey Goldberg
 GLOBE STAFF

Last Aug. 13, Lorelei Sass leaned down to give her severely brain-damaged son, Brian, a kiss, as she always did before leaving his hospital room. In the month since his near-fatal car accident, Brian, 23, had never responded. But this time, she felt a light answering peck against her cheek.

“Did he kiss me?” she recalls demanding of her husband, Arthur. “Did you see that?” And then, she said, “We both just started bawling our eyes out, because it was his way of saying, ‘I’m in here.’”

In the 11 months since, Brian has come a long way in tiny steps. Wiggling one finger one day and a second one the next, knowing his sister’s name one day and forgetting it the next, he has reached the point where he can live at his parents’ home in Avon, feed himself, speak a little, and totter a bit with a walker and extensive help.

In the world of severe brain injury, that makes Brian Sass a fabulous success story.

The path to recovery after an extended coma is far different from the splashy reports of sudden “miracle recoveries” that have proliferated since the Terri Schiavo case attracted national attention.

Schiavo was in a coma for two months and a persistent vegetative state for 15 years after her heart stopped for reasons that are still unclear. Supporters said she should continue to be kept alive with the aid of a feeding tube, because there was a chance that one day she would wake up.

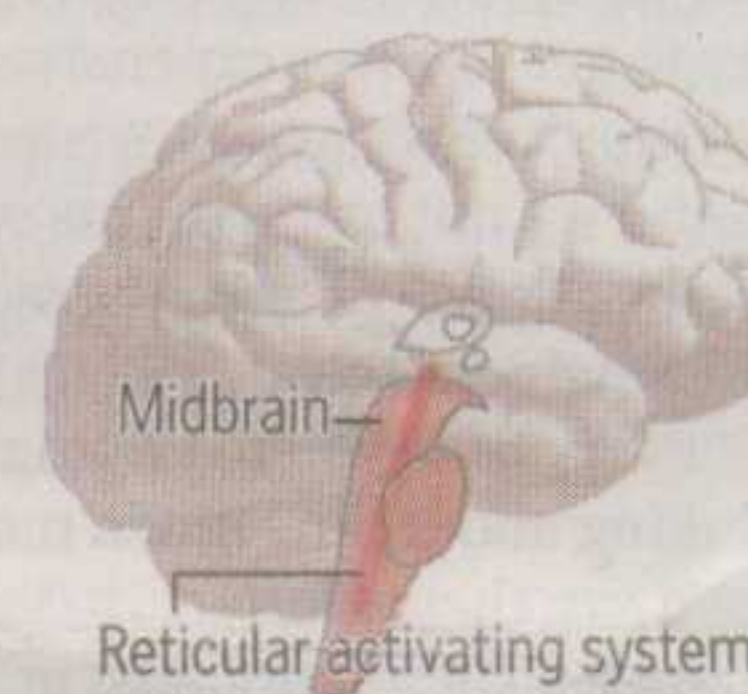
But that’s not how recovery happens after a prolonged coma, spe-

Recovering from brain damage

If people recover from severe brain injury, they tend to emerge from unconsciousness slowly and pass through higher states of “impaired consciousness.” Their recovery can stall out in any of these states, leaving them moderately to severely disabled, or even permanently unconscious.

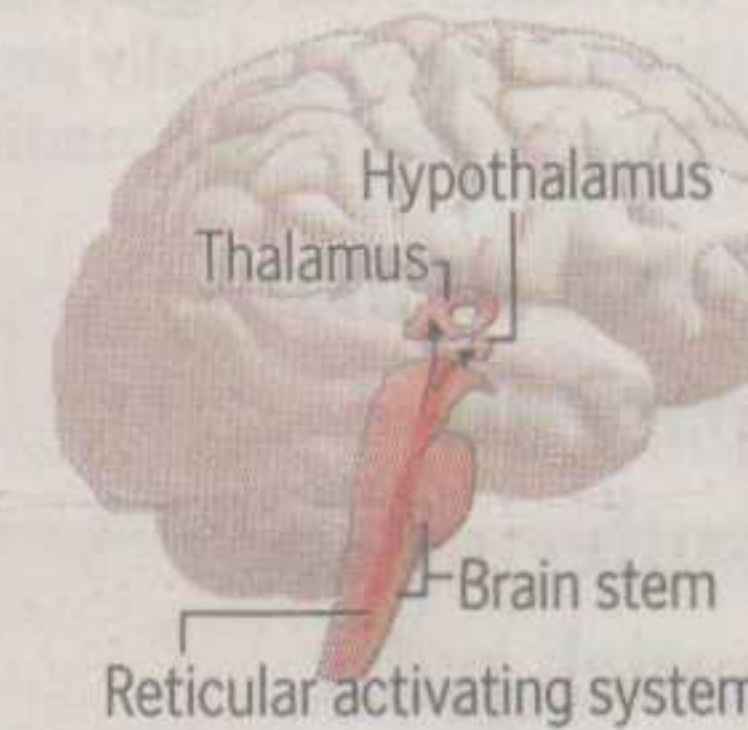
COMA

The lowest state of impaired consciousness, in which the patient remains with eyes closed, but may be able to breathe unassisted. The reticular activating system, which is responsible for wakefulness is not functioning properly. Very few patients stay in this state for more than three weeks.



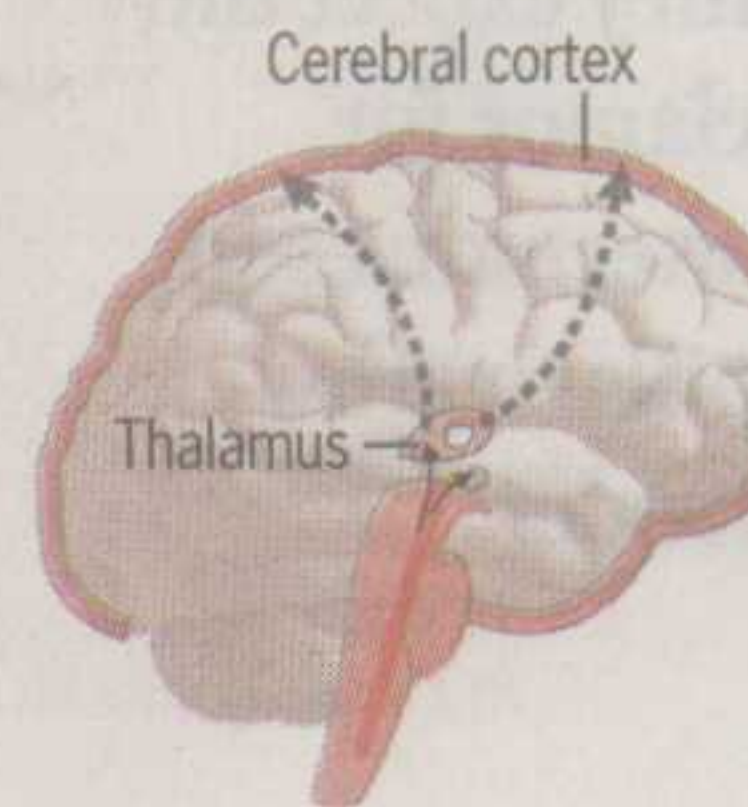
VEGETATIVE STATE

A state of unconsciousness in which people can have eye opening and regular cycles of sleep and wakefulness, as portions of the reticular activating system begin to function. The cerebral cortex is not adequately activated by the thalamus, therefore there is no conscious awareness or purposeful behavior.



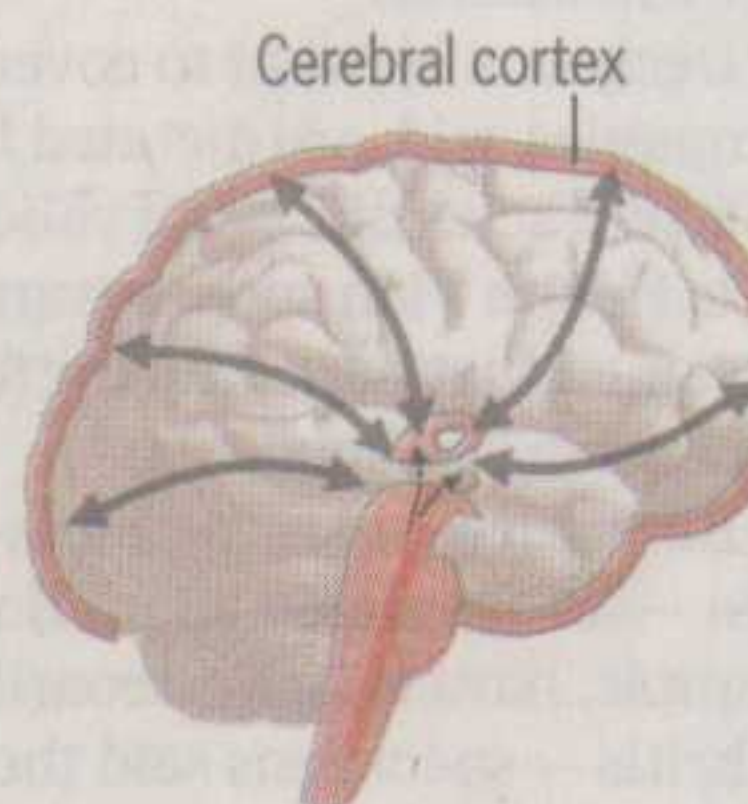
MINIMALLY CONSCIOUS STATE

A state of unconsciousness in which people can have eye opening and regular cycles of sleep and wakefulness, as portions of the reticular activating system begin to function. The cerebral cortex is not adequately activated by the thalamus, therefore there is no conscious awareness or purposeful behavior.



HIGHER STATES OF CONSCIOUSNESS

In these last three states, connections within the cerebral cortex and between the cortex and the rest of the brain are restoring themselves, and patients are slow in regaining their ability to act in a more goal-oriented and consistent manner. Memory recovers, independence increases, self-awareness returns and social skills normalize.



SOURCE: Dr. Douglas Katz, Boston University

GLOBE STAFF GRAPHIC/AARON ATENCIO

Recoveries from brain injuries are slow, limited, and unsteady

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cialists say — if it happens at all. When progress comes, it is virtually always slow, painstaking, patchy. It can apparently be helped along sometimes by drugs and rehabilitation. The patients improve but almost always remain very disabled.

And such late recoveries are far from the norm. “It does happen and it is remarkable, but this is rare,” said Dr. Steve Williams of Boston Medical Center, who has seen two surprising late recoveries in a dozen years of practice. “There’s a fine line of giving people hope, but not false hope.”

Also, specialists say, when a brain-injured patient suddenly talks or seems to click in after months or years, he or she was almost definitely not in a coma or vegetative state. More likely, the patient took a modest step up from a so-called minimally conscious state — a higher level of

awareness in which patients can sometimes respond consistently, if only with a blink or a raised finger.

Schiavo never emerged from a vegetative state, and her prolonged unconsciousness indicated a terribly severe injury, as her autopsy confirmed. In contrast, Sass began to come around after a month, and because his brain damage came from trauma rather than lack of oxygen, his outlook is much more hopeful.

When a long-unconscious patient begins to recover, it means “their brains are already set up, the potential for consciousness is already there to let them respond, and it somehow gets turned on” — perhaps because of the brain’s ability to reorganize itself, said Dr. Douglas Katz of Boston University.

“It’s not going to happen a lot, but in rare cases, the substrate is there, and you’ve just got to turn it on a little more,” said Katz, the medical director of the brain injury program at HealthSouth Brain-

tree Rehabilitation Hospital, where Sass received care and therapy for seven months.

The trouble is, turning awareness back on is more trial-and-error than science at this point. There have been no gold-standard, controlled, long-term studies following brain-injury patients’ recoveries, specialists say.

But a few rules do seem clear: Recovery is likelier when an injury comes from trauma than when it comes from oxygen being cut off to the brain, as happens in a heart attack.

Patients with Schiavo’s type of oxygen-starved injury almost always start to recover in three months or not at all, while trauma patients like Sass can keep getting better for up to a couple of years.

“Better,” however, is a very relative term. Even when patients recover after prolonged unconsciousness, it is important to understand that they will likely remain severely disabled, said Dr.

Nancy Childs, executive medical director of the Texas NeuroRehab Center in Austin.

“You have to be careful with the word ‘recover,’ because we’re only talking about some improvements in consciousness,” she said. “These patients remain severely physically and cognitively disabled.”

Once they are even partially conscious, however, extensive physical and occupational therapy can help them improve even more. Therapists with saintly patience work for weeks or months on helping patients turn grunted sounds into words, or progress from saying “yes” with an eye-blink to a thumbs-up.

For families hoping for miracles, there is yet another caveat: Sometimes, sudden recoveries evaporate. In one famous case, a Tennessee police officer started speaking for an 18-hour period after eight years of silence, and then never regained that lucidity.

At Braintree Rehabilitation Hospital and other specialized centers like it, staff members work to gauge a patient’s level of consciousness and response to treatment as systematically as possible, to avoid the knotty uncertainties that arose in the Schiavo case.

But such high-level treatment is reserved for patients whose insurance or personal finances will cover it. Oftentimes, brain-injury patients are sent directly to nursing homes rather than rehabilitation centers, and never have the chance to try the medications or training that can sometimes help, said Katz, an associate professor of neurology.

Sass goes to outpatient therapy three times a week, and his family dares hope that he will continue to improve, maybe even someday returning to 90 percent of his old, happy-go-lucky self.

His family described his progress recently, as he sat in his wheelchair in the downstairs

room that houses his hospital bed, 35-inch TV, and clothes. As they spoke, he occasionally dozed off, but when they gently prodded him, he responded. His 26-year-old sister, Heather, said that she still sometimes sees flashes of the old Brian, like when she eats something appetizing, and he says: “Hook me up!”

But he was child-like as well, sucking from juice boxes.

When his mother asked him his name, he responded: “I don’t know.”

“You know it,” she prompted. “Br . . .”

“Brian!” he said, in a more nasal voice than he used before the accident.

This is the lesson she has learned, said Lorelei Sass: “You don’t wake up from a coma like, ‘Hi, where am I?’ It’s an emerging process that’s very slow.”

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Drug study aims to help coma patients

Because the outlook for most patients who awake from prolonged coma is so grim, it has been hard for researchers to marshal funding for studies on treatments for brain injury.

But the first major controlled trial to test whether a drug can help is underway; Dr. Douglas Katz, an associate professor of neurology at Boston University, and seven other teams around the United States and in Germany are collecting data on whether amantadine, an antiviral drug, helps increase consciousness in brain-injury patients.

Amantadine is just one among a bouquet of drugs that neurologists have been trying for about two decades on patients with “disorders of consciousness” —

from the stimulant Ritalin to antidepressants of the Prozac generation. Neurologists theorize that if they can act on a patient’s alertness, motivation, even mood, they can clear the way for more consciousness.

The drugs’ performance is spotty, however. They help some patients and not others, for unclear reasons; sometimes they even seem to hurt. And even when they work, they do not always keep working.

In the case of Donald Herbert, a Buffalo firefighter who recognized his family April 30 for the first time in a decade, drugs seem to have played a role in his improvement.

Herbert’s doctor, Jamil Ahmed, who trained at Boston Medical

Center, attributed the recovery to medications he had begun administering three months earlier. Ahmed declined to name them publicly, but told the Associated Press that they were drugs normally directed at improving attention, thinking, mood, and symptoms of Parkinson’s disease — indicating they were among the usual medications for such patients.

Even drug-fueled recoveries have been known to peter out, said Dr. Nancy Childs, executive medical director of the Texas NeuroRehab Center in Austin. She said she’s had patients in whom the improvement “lasted for a while, with communicating and stuff, and then it fell off again.”

CAREY GOLDBERG