

# Belgian says he was alert but mute for 23 years

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(AP) -- For 23 torturous years, Rom Houben says he lay trapped in his paralyzed body, aware of what was going on around him but unable to tell anyone or even cry out.

The car-crash victim had been diagnosed as being in a vegetative state but appears to have been conscious the whole time. An expert using a specialized type of brain scan that was not available in the 1980s finally realized it, and unlocked Houben's mind again.

The 46-year-old Houben is now communicating with one finger and a special touchscreen on his wheelchair.

"Powerlessness. Utter powerlessness. At first I was angry, then I learned to live with it," he said, punching the message into the screen during an interview with the Belgian RTBF network, aired Monday. He has called his rescue his "renaissance."

Over the years, Houben's family refused to accept the word of his doctors, firmly believing their son knew what was happening around him, and gave no thought to letting him die, said his mother, Fina. She was vindicated when the breakthrough came.

"At that moment, you think, 'Oh, my God. See, now you know.' I was always convinced," she said in a telephone interview with The Associated Press.

The discovery took place three years ago but only recently came to light, after publication of a study on the misdiagnosis of people with consciousness disorders.

While a 23-year error is highly unusual, the wrong diagnosis of patients with consciousness disorders is far too common, according to the study, led by Steven Laureys of Belgium's Coma Science Group.

"Despite the importance of diagnostic accuracy, the rate of misdiagnosis of vegetative state has not substantially changed in the past 15 years," the study said. Back then, studies found that "up to 43 percent of patients with disorders of consciousness are erroneously assigned a diagnosis of vegetative state."

The issue is fraught with difficult medical and ethical questions. Patients diagnosed as being in a vegetative state with no hope of recovery are sometimes allowed to die, as was done in 2005 with Terri Schiavo, the severely brain-damaged Florida woman at the center of the biggest right-to-die case in U.S. history. Her feeding tube was removed.

"It makes you think. There is still a lot of work to be done" to better diagnose such disorders, said Caroline Schnakers of the Coma Science Group.

Houben was injured in an auto accident in 1983 when he was 20. Doctors said he fell into a coma at first, then went into a vegetative state.

A coma is a state of unconsciousness in which the eyes are closed and the patient cannot be roused. A vegetative state is a condition in which the eyes are open and can move, and the patient has periods of sleep and periods of wakefulness, but remains unconscious and cannot reason or respond.

During Houben's two lost decades, his eyesight was poor, but the experts say he could hear doctors, nurses and visitors to his bedside, and feel the touch of a relative. He says that during that time, he heard his father had died, but he was unable to show any emotion.

Over the years, Houben's skeptical mother took him to the United States five times for tests. More searching got her in touch with Laureys, who put Houben through a PET scan.

"We saw his brain was almost normal," said neuropsychologist Audrey Vanhaudenhuyse, who has worked with Houben for three years.

The family and doctors then began trying to establish communication. A breakthrough came when he was able to indicate yes or no by slightly moving his foot to push a computer device placed there by Laureys' team. Then came the spelling of words using the touchscreen.

Houben's condition has since been diagnosed as a form of "locked-in syndrome," in which people are unable to speak or move but can think and reason.

"You have to imagine yourself lying in bed wanting to speak and move but unable to do so - while in your head you are OK," Vanhaudenhuyse said. "It was extremely difficult for him and he showed a lot of anger, which is normal since he was very frustrated."

With so much to say after suffering for so long in silence, Houben has started writing a book.

"He lives from day to day," his 73-year-old mother said. "He can be funny and happy," but is also given to black humor.

Recently he went to his father's grave for the planting of a tree.

"A letter he wrote was lowered into the grave through a tube," his mother said. "He closed his eyes for half an hour, because he cannot cry."

There is little hope that Houben's physical condition will get better, but his mother said she refuses to give up: "We continue to search and search. For 26 years already."

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