

The truth about "The Diving Bell and the Butterfly"

Family and friends of Jean-Dominique Bauby speak out about how Julian Schnabel's Oscar-nominated film honors and defames Bauby's real story.

By Beth Arnold



PARIS -- The quietly stunning film of Jean-Dominique Bauby's phenomenal memoir, "[The Diving Bell and the Butterfly](#)," is nominated for four Oscars this year. They include directing by [Julian Schnabel](#) -- an honor he won for the film at the Cannes Film Festival and Golden Globes -- and best adapted screenplay by Ronald Harwood, who won an Oscar in 2002 for his adaptation "The Pianist." "[The Diving Bell and the Butterfly](#)" is also nominated for cinematography and editing, and has won numerous awards in film festivals across the world.

There is every reason for the film's success. It recounts the remarkable life of Bauby, the debonair editor of French Elle magazine who in 1995 suffered a massive stroke. He slipped into a coma that lasted 20 days and awoke to find himself paralyzed from head to toe. He was diagnosed with a rare neurological disorder called locked-in syndrome.

A prisoner inside his useless body, Bauby, 43, could think and reason, smell and hear (though not well). With the only part of his body that he could move -- his left eye -- he could see and later learn to express himself. His speech therapist and later his friends would read him an alphabet, and Bauby would blink at the letter he wanted. He formed words, phrases and sentences, and ultimately, over the course of two months, working with ghostwriter Claude Mendibil, who took down word for word what he said, he completed his memoir.

The evocative title comes from Bauby's notion that while his body was submerged and weighted down -- impossible to move -- his imagination and memory were still free and as light as a butterfly's wings: "My cocoon becomes less oppressive, and my mind takes flight like a butterfly. There is so much to do. You can wander off in space or in time, set out for Tierra del Fuego or for King Midas's court." A few days after the book was published to rave reviews in March 1997, Bauby died of an infection.

Released last spring, the film is a visual knockout. Schnabel draws on Bauby's fantasies to blast moviegoers with a kaleidoscope of dreamy images -- some subtle, some banging loud -- and an array of captivating music and sounds. The

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wonderful script takes the point of view of Bauby himself. The fourth wall between the audience and film has fallen away and the audience experiences the world through his eyes.

The film is said to be "based on a true story," which, of course, is from Bauby's book. The problem is that mixing his factually accurate journey through locked-in syndrome with a personal life that has been fictionalized for film has affected real people who were intensely involved in Bauby's life before and after his accident. Now some of his closest friends feel the movie may forever obscure the truth of his life. They fear this collision between art and reality has created a revisionist history that is accepted by filmgoers around the world, and that this is what will remain in the collective cultural memory. For the first time, they are speaking publicly about it. As one of Bauby's friends says, "There's the Real Story. The Film. And the New Real Story."

The Real Story

When books are made into screenplays, dramatic action takes first seat to writerly fluff or facts. In this case, there are minor differences between the book and the film that don't change the meaning or spirit of Bauby's life and text. He had two children instead of three. Sylvie de la Rochefoucauld, Bauby's partner of 10 years and mother of their two kids, Théo and Céleste, says Schnabel liked all three child actors and couldn't make a decision of whom to cast. He called her and asked if it was OK to use them all, and she said yes.

In the movie, Bauby feels guilty when his friend "Roussin" (Jean-Paul K in the book) comes to see him. Roussin was captured and held hostage in Beirut, Lebanon, after Bauby had given up his airline seat to him. Jean-Paul K was captured but it wasn't when Bauby gave him his seat. If Jean-Paul K did come to see him, Bauby didn't write about it. What Bauby says in the book is that he felt guilty for never having seen Jean-Paul K after his release. The movie captures his guilt by dramatically inserting the character into Bauby's hospital life. And in the last section of the film, Bauby is driving through the boulevards of Paris and green countryside to de la Rochefoucauld's house to pick up his son. In real life, a chauffeur was driving him. Which is more cinematic?

But the biggest difference between Bauby's book and the film is the story of the women in his life. The movie shows Bauby, known to his friends as Jean-Do, as an invalid babe magnet and the women surrounding him as vying for his attention. Bauby doesn't write about this or anything like it in his book, although friends describe him as having been very charming with a great sense of humor -- quick and sometimes biting. He was a bon vivant and engaging. One friend portrayed him as having power in his silence once he became ill.

The major difference between book and film is that the mother of Bauby's children -- this is how he refers to her in the film as he points out that they were never married -- pays him saintly visits day after day, despite the fact he doesn't love her, and the girlfriend he is in love with never shows up at the hospital at all. In the most devastating scene of the movie, Bauby's girlfriend tells him on the phone that she can't come visit him because she cannot bear to see him like that. He painfully spells out his response to the mother of his children so that she can interpret it to his girlfriend. Bauby's touching reply is that each day he waits for her. At that point, his wounded former partner slams the phone down, and the audience withers with the pain of her rejection.

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In real life, this scene never happened. His girlfriend, Florence, was at the hospital day after day spending time with him. (De la Rochefoucauld was at that point his ex.) In the book, de la Rochefoucauld is only mentioned in one bittersweet chapter in which she brings the children to the hospital to celebrate Father's Day for the first time, and they experience a wonderful day on the beach together.

Florence is mentioned several times, including an indelible memory of her on the day of his accident: "I pressed my forehead against the windowpane to gauge the temperature outside. Florence softly stroked the nape of my neck. Our farewells were brief, our lips scarcely brushing together. I am already running down stairs that smell of floor-polish. It will be the last of the smells of my past."

Bauby also writes: "And here I had no problem identifying the watchers on either side of the bed: they were members of the personal bodyguard that spontaneously sprang up around me immediately after the disaster." They include Florence; Bernard Chapuis, a writer and his best friend; Anne-Marie P rier, his boss at Elle, and her husband, Michel Sardou; and Patrick McClellan, his cousin.

With affection, he writes about the rest of his close gang: his other best friend, photographer Brice Agnelli; and his old buddy, editor Vincent Lahu, with whom he had worked as an accomplished journalist for many years before editing Elle. Florence, Chapuis, McClellan and Agnelli drove the 300 kilometers to the hospital at least once or twice a week. These were the frontline troupers throughout the ordeal.

As for the women in the hospital who were important, Chapuis says there were three: 1) Bauby's speech therapist, Sandrine Fichou (called Henriette in the film), who set up the communication code, which became his silent voice. He called Sandrine his guardian angel in his book. 2) Mendibil, who transcribed the book, which is dedicated to her and his children. 3) Florence.

The Film

In France, a publisher owns book and film rights. But just as in the U.S., after the advance is paid back, the author receives a percentage of the royalties. When Bauby died, his children, Th o and C leste, were the inheritors of their father's rights and royalties, and, naturally, Sylvie de la Rochefoucauld acted as her minor children's representative in their business matters. De la Rochefoucauld is a successful businesswoman and a fierce mother. She has her own public relations company and formerly ran television chain Canal +'s Jimmy channel. She is chic, sophisticated and fluent in English.

The publisher, Editions Robert Laffont, sold the rights of "The Diving Bell and the Butterfly" first to Steven Spielberg and Dreamworks, and one of Hollywood's most successful screenwriters, Ron Bass, wrote the first script. Bass won an Academy Award for best original screenplay for "Rain Man" in 1988 and has also written other emotional and visual stunners such as "The Joy Luck Club" and "Snow Falling on Cedars."

But as often happens in the movie business, the project stalled and switched companies -- to Universal and then to Path , who finally made the movie with producer Kathleen Kennedy. Kennedy, who has produced such movies as "**Munich**," "**Seabiscuit**" and "**The Sixth Sense**," asked Harwood to write another script, and it was his screenplay that Schnabel read and

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directed. Johnny Depp had been attached to play Bauby early on but couldn't proceed because of "Pirates of the Caribbean," and, happily for all involved, French actor Mathieu Amalric was brought in.

Because de la Rochefoucauld was the mother of Bauby's two kids, the publisher extended her the courtesy of being involved with the film. She was contacted to speak with Bass about his script, and she was put in touch with Kennedy. The two women became friends. "Kathleen Kennedy is the godmother of the movie," de la Rochefoucauld says.

Editions Robert Laffont and de la Rochefoucauld had a good relationship, and the publisher looked upon "The Diving Bell and the Butterfly" as an extraordinary publishing adventure. Everyone involved made money and benefited. Then, just as the movie was finally about to be filmed, de la Rochefoucauld (again, representing Théo and Céleste) brought a lawsuit against the publisher, which was shocking to them. Simply put, the point was to question the rights of the book and the film, increasing the royalties for the Bauby children.

The first judgment was in de la Rochefoucauld's favor. The case went to appeal, and the parties are working on an agreement on the court's demand. One notion of French law that doesn't exist in the U.S. is the ownership of "droit moral" or moral right. This is an intellectual right of an artist to protect his work. When an artist dies, the "droit moral" goes to his heirs unless he appoints someone else. For example, a John Huston movie was colorized in the U.S., and the movie is shown this way in the States despite the opposition of the Huston heirs who are trying to honor their father's artistic wishes. But in France, where the Huston heirs argued their father didn't want his film to be in color, the colorized film can't be shown because of droit moral.

Being the mother of the Bauby children, de la Rochefoucauld also represented their droit moral. In this capacity, she could make sure the movie adaptation protected her children in the way that she saw fit. "She [de la Rochefoucauld] was very much involved in the screenplays," one person close to the situation told me. "She could have opposed this or that version of the screenplays because of the children."

Changes are made when books are adapted to film, and some make the transition better than others. This is the screenwriting business as usual. Harwood, whose credits include "The Dresser" and "Being Julia," is a master adapter and playwright. He says the book and de la Rochefoucauld were his main sources. Incredibly, his screenplay was greenlighted on the first draft. "I took what she [de la Rochefoucauld] told me as gospel," Harwood says. "I don't believe in research. You have to tell a story in a movie. Sometimes the facts disturb all that. I was asked to adapt, and that was what I decided to do."

Harwood says he became friends with de la Rochefoucauld, and she'd given him a dinner party in Paris. He also had an interview with Bauby's transcriber, Mendibil. "All the women were so good-looking," he says. "All fell in love with him. They found him deeply attractive. I used the things I thought were valuable."

To de la Rochefoucauld, the film hits all the right notes, especially the portrayal of Bauby by Amalric. "Everything with Mathieu is right," she says. "The entire movie is right. We couldn't dream the movie would be so beautiful." "For me, the movie was amazing," Théo says. "It was like a flashback for me, the way Mathieu looked and acted like my dad."

Bauby's circle of friends agree that Amalric did an amazing job of portraying Bauby and his condition. "I think Julian Schnabel got it," says Véronique Blandin, director of the [Association of Locked-In Syndrome](#), which Bauby founded in the

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last month of his life. "It gives the right feeling of the locked-in syndrome people and problems in their communication. We can really recognize the book." The problems begin for Blandin and others where Bauby's private life is concerned. "I don't agree with the personal story," says Blandin, who now works with Bauby's friends in the association. "It's not the truth."

The New Real Story

In the new real story, the mother of Bauby's children took charge at the hospital, even if she is portrayed as jealous. She keeps coming back time and time again to support the man she loves even if he doesn't love her. In reality, say Bauby's friends, his girlfriend Florence was the one who came day after day and carried out his wishes. Bauby died in her arms. Sylvie de la Rochefoucauld was in the U.S. with her new boyfriend, rock journalist Philippe Manoeuvre, when Bauby passed away.

"The mother of the children was there every time -- not the truth," says Blandin. "Florence didn't want to be in the movie. The mother of the children is there. OK. But it is really nasty in the way she [Florence] is presented as not brave, and she refused to come [to the hospital]. It's so incredible to put this in front of the whole world. You just want to make your life. Ten years later you are attacked like that." Florence declined to comment. In fact, to protect her privacy, she requested that her name not even be used in this article.

But Bauby's friends have decided to break their silence. They say they have never spoken publicly about the film before because it was hard enough to live through his illness and death the first time. Bringing it all up again is painful. "Brice, Florence and I had to cling to each other," says Chapuis. "Otherwise, we would have died." The friends were bonded in their sense of loss and protection of Bauby. Then once they realized what was happening in the film, they wanted to protect Florence. They also kept quiet because of Théo and Céleste. But now they want to set the record straight. "It [the movie] is not the story of my friend," Agnelli says. "It is a story for Hollywood."

Schnabel knew the role that Florence and Bauby's friends played in Bauby's life and hospitalization. Chapuis, Florence and others met with him and various actors, including Amalric, to help them get the feel for Bauby. In the end, they felt burned, though not necessarily by the actors. Bauby's friend Lalu says that in the middle of filming, Chapuis saw the script and realized it was inaccurate. Lalu chose not to see the film. "I know it's a great movie," he says. "I make a big difference between the work of the director and the storyboard."

The straw that broke the camel's back for Bauby's friends and colleagues was a recent article in the London Daily Mail in which de la Rochefoucauld is quoted as saying: "I was at his [Bauby's] bedside day after day. I never abandoned him. I was never aware of Jean-Do's girlfriend visiting him in the hospital." De la Rochefoucauld denies she said this.

Chapuis, who is godfather to Théo, says he thought de la Rochefoucauld came to the hospital three or four times; Agnelli says the same. "The situation was difficult," says Chapuis. "Jean-Do had left her, and he was ill. When she says Florence never went, it's stupid. To have the revenge like that, well ..." De la Rochefoucauld is very specific about her visits. "I was at Berck [the hospital] every Tuesday for one year and a half," she says, "plus weekends with the kids every three weeks except during the school holidays."

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Of Bauby's friends, she says, "They were pissed off that I didn't ask their permission. They're reproaching me for having done that movie. It is very hard for me because I was sure I was doing the right thing. They [the filmmakers] did the adaptation they wanted to do. They made the movie they wanted to make."

Théo says he was asked to be a grown-up when he was 11 years old, when his father died, and being his father's son has been a burden to him at times. He appreciates his mother's portrayal in the film. "I don't have anything against her [Florence]," Théo says. "I respect my dad fell in love with her. [The thing was,] all my dad's friends kept sticking to that girl. [I liked] the way Julian showed my mom strong and getting over my dad. She [his mother] will always be the love of my father's life."

"Not so," says Agnelli, godfather to Théo's sister, Céleste. "The love of his life was the kids -- not the mother."

Bauby's speech therapist, Fichou, didn't return my phone calls for this article. But Marie-Josée Croze, who played her in the movie, was quoted in [CanMag.com](#) as saying that Fichou "didn't like the script ... She said, 'No, it wasn't like that in real life. I remember Jean-Do never said that he wanted to die. She was against lots of stuff in the script.'"

Bauby's transcriber Mendibil says the whole experience with Bauby affected Fichou deeply, and that she was afraid of the film. For Mendibil herself, "Julian Schnabel understood the essential of the story and the relationship between Jean-Do and me," she says. Mendibil was also there for the telephone calls to Bauby's father, and says they're accurately depicted, although Mendibil was not with Bauby when he was dying, as the movie suggests.

Schnabel filmed in the real places where Bauby spent his life, but French Elle didn't let him film in its offices. In May, the magazine didn't cover the release of the film. Instead, editor Valérie Toranian wrote an homage for her old mentor and friend, which included this paragraph: "At your side, Florence, always Florence, your companion journalist at Elle, present, vigilant, courageous, this woman that you loved and who loved you until the end, until the last lullaby, your last breath."

Torianian also drew attention to the Association of Locked-In Syndrome, founded by Bauby, which in the film is only mentioned in a brief credit at the end. Blandin says that de la Rochefoucauld has never contacted nor contributed to the association. Since Théo has gotten older, he has attended one of the association's meetings, which greatly pleased them. Florence has helped the association since its inception and continues to do so.

In France, directors -- not producers -- get final cut. In a [Guardian interview](#), Schnabel says that he was terrified of death his whole life. "I made this movie, and I'm not scared to die," he says. But in exorcising his demons, he has conjured new ones for Bauby's closest circle of friends.

In the end, "The Diving Bell and the Butterfly" is a beautiful film, deserving of the awards it has won and may win Sunday night. Does it matter that a revisionist history -- the New Real Story -- has replaced the truth and affected the real people involved?

Agnelli saw the film at the Cannes Film Festival, and after it was over a woman beside him said, "Oh, the poor wife!" This is the common reaction. "No," he said, "you don't understand. That's not what really happened." And he explained.

In the end, "The Diving Bell and the Butterfly" is a beautiful film, deserving of the awards it has won and may win Sunday night. Does it matter that a revisionist history -- the New Real Story -- has replaced the truth and affected the real people involved? Agnelli saw the film at the Cannes Film Festival, and after it was over a woman beside him said, "Oh, the poor wife!" This is the common reaction. The Diving Bell and the Butterfly (original French title: *Le Scaphandre et le Papillon*) is a memoir by journalist Jean-Dominique Bauby. It describes his life before and after suffering a massive stroke that left him with locked-in syndrome. The French edition of the book was published on March 7, 1997. It received excellent reviews, sold the first 25,000 copies on the day of publication, reaching 150,000 in a week. It went on to become a number one bestseller across Europe. Its total sales are now in The Diving Bell and the Butterfly (French: *Le Scaphandre et le Papillon*) is a 2007 biographical drama film directed by Julian Schnabel and written by Ronald Harwood. Based on Jean-Dominique Bauby's memoir of the same name, the film depicts Bauby's life after suffering a massive stroke that left him with a condition known as locked-in syndrome. Bauby is played by Mathieu Amalric.