

Marian Sallery was 36 years old when she was found at home, in a coma in 1983. She was alone, her husband having been away for the night, so it is possible that she had been unconscious for between ten and eighteen hours.



She was rushed to hospital, and admitted to the Intensive Care Unit. While she was there, her parents, John and Lilian, were told that the outlook was grim. Marian had severe brain damage and if she recovered, the doctors said, she would be “a cabbage” and succumb to the first infection she picked up. Lilian says that “to hear your loved one called a cabbage is more than devastating.” Indeed, it is a term that should never be used to describe a human being, because it is offensive and inappropriate to compare a person to a vegetable

Three weeks later, the doctor told John and Lilian that it would be better to “let her slip away” by removing her feeding tube. He said this in Marian’s presence. John and Lilian asked how long it would take for her to die if this was done, and were horrified to learn that the doctor considered it would take about two weeks. They refused permission, and were then told to leave their daughter in the hospital, go home and “live your lives.” In other words, the doctors wanted to starve and dehydrate Marian to death, and when her parents refused, he suggested that they abandon her in the hospital, and forget about her.

To give the best chance of recovery vigorous efforts should be made to help a person in a coma who has a head injury to wake up, but no one even tried to do this at the hospital.

After three months Marian was moved to Denbigh Community Hospital and was expected to die at any time. She was nursed there “with exceptional loving care” but in the expectation that death would come soon, little treatment or stimulation was attempted. It was not thought possible that she could survive, and any movement she made was declared to be “only a reflex.”

In 1985 the doctor who had first been in charge of Marian's case gave his diagnosis. He explained that he had been unable to come to any conclusion about the cause of her brain damage, but that the "best theory" was that she must have had an epileptic convulsion and stopped breathing, with subsequent severe brain damage. He said, of himself and the Denbigh Community Hospital doctor

[We] are both of the opinion that she is currently in what amounts to "persistent vegetative state." This means that there has been complete and permanent loss of all her higher functions. There is not, and we believe that there never will be, any capability for any intellectual function, or that there will be any substantial or meaningful contact with her surroundings or with her family. With regard to the future, I am of the opinion that there will be no improvement from her current state. As a result, it is very likely that at some stage in the next few years she will be overcome by some complication and so that long term survival is not likely.¹

Two years later, the same doctor was consulted, and gave a further diagnosis:

My previous assessment and diagnosis remains unchanged. I am sure that there are no chances of further improvement or recovery. Further assistance in the way of treatment programmes or physical aids are not going to alter her current state. She remains with extremely severe brain damage with complete and permanent loss of her higher cognitive functions as well as some of her motor functions.²

Note again the prejudicial terminology used by many doctors to describe profoundly disabled people. "Vegetative" implies yet again that profoundly disabled people are somehow less than fully human. A more appropriate term for a person who appears not to be able to respond is Persistent Non-Responsive State, or PNS.

John and Lilian said that "When one gets that message from a doctor, it takes quite a lot of faith to carry on, but we said that as long as Marian could breathe on her own, we would continue to fight for her." Three years after her injury, Marian smiled for the first time since her injury.

Over the years John and Lilian noticed slight improvements in Marian's awareness and started to try to find somewhere where she could be given specialised stimulation, despite the doctor's assertion that no such treatment would be of any help.

In 1990 Marian was admitted to the Royal Hospital for Neurodisability in Putney for a three month assessment. Marian did so well that she was kept there for another three months. Lilian says Marian went to Putney from Denbigh Community Hospital in an ambulance, on a stretcher, and returned sitting up in a wheelchair on the train.

¹ "Futile or Fruitful" Paper given by Lilian Sallery at a Conference "Implications of the Bland Judgment" organised by Alert at the House of Lords 25 May 1993

² Proceedings of the Alert Conference. Ibid.

At the end of her six months treatment Marian returned to the Denbigh Community Hospital where she was given very good nursing care but no stimulation. When the doctors and nurses discussed her case, it was decided not to offer her physiotherapy, as they believed that once brain cells are damaged, any stimulation is a waste of time. John and Lilian did not agree with that decision, especially since they had seen such an improvement in Marian's condition after her stay at the Royal Hospital for Neurodisability, so they decided to move Marian to Eithinog Cheshire Home in Colwyn Bay, where each person is treated as a challenge, and where every effort is made to stimulate and help every resident.

At the Home, Marian was given physiotherapy twice a day and many different kinds of stimulation including yoga. She enjoyed an interesting and happy life. She recognised both her parents, who said that she gave "a lot of pleasure to many people." Her friends at the Home described her as "the life and soul of the party" and she would laugh when teased about her love for Liverpool Football Club. She started to move her left leg independently, and could eat soft foods. She was also learning to speak again. Lilian said "We have never seen her so happy."³

The extent of Marian's awareness was clear when tears began to flow down her cheeks as footage of the Hillsborough Football stadium disaster was shown on television. Hillsborough is a football stadium in Sheffield, and during a game in which Liverpool Football Club was taking part 95 people died of crush injuries in an accident in 1989.⁴ Marian's parents could not help wondering what more she could have achieved if she had received the treatment she eventually got at the Home from the start.

In 1988 Marian was declared to be no longer in "Persistent Vegetative State" – five years after the initial diagnosis.

Sadly Marian died in 1994 of pneumonia.

A post-mortem found that her higher brain functions had been intact, and showed that she was almost certainly aware of her surroundings.

She was not in "Persistent Vegetative State" as her doctors had indicated, but she was in fact in Locked-In syndrome, a condition in which the person is fully aware but unable or virtually unable to move or communicate.

This meant that she would have been completely aware when the doctors discussed removing her feeding tube. It is difficult to imagine how terrifying that must have been for her.

³ "Don't let Tony die, urge coma woman's parents" by Gareth Hughes. Liverpool Daily Post 21 November 1992

⁴ "Coma blunder ends in horror" by Zoe Brennan. *Sunday Times* 21 February 1999

Since Marian's death it has been found that misdiagnosis of profoundly disabled people is by no means uncommon.

A survey by Dr. Keith Andrews of the Royal Hospital for Neurodisability, where Marian was treated, found that of 40 people diagnosed as being in "Persistent Vegetative State" nearly half were completely misdiagnosed. Of these 40 people seven had been wrongly diagnosed as being in "PVS" for one year and three for over four years.⁵

It is salutary to note here that the British Medical Association, backed by the Royal College of Physicians, has stated that starvation to death should be permissible after only one year in "PVS."⁶

Marian's case highlights again the huge dangers in assessing profoundly disabled people as having "lives not worth living." Had her parents had not been determined that that she should get the best possible treatment, and had they not refused to accept the doctor's suggestion that she be allowed to "slip away" Marian would have been denied the last 12 years of her life, and it would never have been known that the future held such happiness for her and her family.

Regarding the initial attempt to remove Marian's feeding tube, Lilian said "To starve a person to death is barbaric. The law does not allow us to starve an animal to death. Surely with all the medical research going on, one should be thinking of saving and improving life, not terminating it. It would seem that money means more than life itself."

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⁵ K. Andrews et al. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. *BMJ* 1996; 313: 13-16

⁶ "British group presents vegetative-state criteria" by Sarah Ramsay. *The Lancet* 1996; 347:817