

ARE PEOPLE IN A PERSISTENT VEGETATIVE STATE "VEGETABLES" ?

I. WHAT IS A VEGETATIVE COMA?

Playing tennis in your head

The case which has clearly contributed the most to broadcasting the issue of people in a persistent vegetative state is the one of Terri Schiavo. In medical history, persistent vegetative state (PVS) is relatively recent (start of the 70s). The technical developments in intensive care made during the 60s have in effect allowed patients, showing a serious deterioration of brain functioning, to survive.

Most recently (1), two teams - one directed by the neuropsychologist Adrian Owen (University of Cambridge), the other by Steven Laureys, neurologist (Centre de Recherches du Cyclotron, University of Liege) - established that the brain activity of a patient in a permanent vegetative state (a 23 year old English female) indicated that she was conscious of herself and of her surroundings. The experiment consisted of giving oral commands to the young lady whilst a functional magnetic resonance imaging machine measured her brain activity. The scientists asked her to imagine that she was playing tennis and walking around her house.

The parts of the brain which control spatio visual and motor functions showed an activity identical to that of dozens of healthy volunteers who were asked to do the same. The researchers concluded that the patient, although meeting all the criteria of being in a persistent vegetative state, maintained the ability to understand oral instructions and respond to them with brain activity, despite not responding with words or movement. This experiment raises the attention of those working in the scientific, medical and nursing world who are confronted with the harsh reality of people living in a persistent vegetative state.

Falling into and coming out of a coma

These days, many people – among whom are young people - are victims of accidents or of illnesses (2) causing acute and serious and brain injuries with a period of coma which is more or less long term. Coming out of a state of coma is characterised by the opening of the eyes. This "awakening" does not necessarily mean that the patient resumes communication with their environment.

Some patients, who have come out of a coma, find themselves in a qualified "vegetative" or "minimally conscious" state. This state, after a certain period of time, generally fixed at a year (3) is known as "persistent".

(2) Among which it is necessary to mention traumatic brain injuries, cerebral anoxia and strokes in the form of cerebral haemorrhages or cerebral infarction.(3) The concept of a persistent vegetative state is based on duration. The literature agrees that an unchanged situation for three months, for non-traumatic injuries, and six months to a year for traumatic injuries is classified as a persistent vegetative state. Medicine cannot categorically affirm that a persistent vegetative state is irreversible. Indeed there are rare cases of late recovery. However, the probability of recovery is extremely low, tiny even.

(1) See *Detecting Awareness in the Vegetative State*, Adrian M. Owen, Martin R. Coleman, Matthew H. Davis, John D. Pickard (University of Cambridge), Steven Laureys, Mélanie Boly (Centre de recherches du cyclotron, University of Liege), *Science*, 08/09/2006, vol. 313, p.1402

Every expression of life from these people is based on the activity of the brain stem, the latter providing vegetative functions to the brain. Dignified functions, which depend on the cortex, are out of service. Judging from appearance, no ideas or emotions cross the minds of people who show no sign of consciousness.

Vegetative state

The two big circumstances contributing to or creating a vegetative state are, on one hand, anoxia (deprivation of oxygen), the result of hanging, drowning, suicide from an overdose, a diabetic coma, and on the other hand, traumatic brain injury, of which the main cause is represented by car accidents. A persistent vegetative state corresponds to damage of the cerebral hemispheres.

A person in a vegetative state shows the following characteristics:

- they show no signs of consciousness of themselves or their environment;
- they show no sign of understanding or expression of language;
- they do not show any significant or voluntary response to stimulation;
- they still follow the "wake-sleep" cycle;
- they still have brain activity which controls the basic vital functions (breathing, elimination, sometimes swallowing, etc.).

Sometimes, the subject shows a certain level of consciousness of themselves and their environment. They may be capable of an orientation movement or respond to some stimuli by crying or

laughing or signalling "yes" or "no" by movements or articulation. The constant presence of one of these signs allows the state of the patient to be considered "**minimally conscious**" (MCS).

These states are in no way a form of prolonged coma, neither brain death, the brain continues to ensure vital functions. People in PVS are living and are not in agony nor at the end of their life. On average, a patient in PVS shows a life expectancy of a further 2 to 5 years, but in certain cases, the latter can rise to 10, even 20 years. The degree of dependence of a patient in a vegetative state is comparable to that of a baby : it concerns functions relating to food, hygiene and prevention of illnesses or complications, notably the appearance of bed sores.

In Belgium, in 2004, the registered number of people in a vegetative state (PVS and MCS) came to 359. Each year, on a national level, it is necessary to count from 50 to 60 new cases of persistent vegetative state.

II. TESTIMONY

How does the family of a person in PVS react? What do they go through daily? What are their doubts, their questions? These questions, surely, do not call for standard responses: the grade of the "case" gives way to the most personal kind of experience. We asked Mrs Régine de Launoit some questions. Her daughter, Madeleine has been in a vegetative state for fifteen years.

It all started with an accident...

It was a gloomy Wednesday of February 1987. At 18h50, Madeleine left the house to drop a friend off at tennis and drive to Brussels. At 21h30, the telephone rang: our daughter was in hospital. On the spot, I immediately understood, from the look of the doctors, the severity of the situation. Madeleine, having been ran off the road, had suffered a traumatic brain injury. Two days later, the doctors attached an external drainage tube to her in order to regulate her intracranial pressure.

Very intensive care...

For eight days, she swayed between life and death. The pressure reduced, the doctors attached an internal drainage tube to her. The cosmetic surgery "repaired" her brow bone. The days were extremely stressful. We watched out for and observed the least of her reactions.

For example ?

Throughout the two weeks which followed the accident, a night nurse recorded in the report: "blinking of the eyes?" Two nights later: "slight movement of the right toe". Thereafter, but it was only six to seven months after, she started to have small reflexes. Finally, she reacted to hot and cold, she shouted, coughed, moved her hand.

And after three months?

It was an important stage in her recovery. Every day, I went to the hospital, from 9 o'clock in the morning until 9 o'clock in the evening. My daughter - who had undergone a tracheotomy in the ambulance - was living under a medical respirator. I was there when it was unplugged. In fact, she did not need it : she began breathing by herself, free from the device.

And what happened next?

After eight months; the doctors explained to me, with much kindness: "Madam, nothing more can be done for Madeleine. She only needs nursing. We cannot mobilise this bed any longer." At that time, there were little adapted structures. There was the William Lennox neurological centre, in Ottignies. Personally, I did not hesitate, I took her to my house where she stayed until 2002, taken away by a violent septicaemia.

Such a decision went without saying.

It's true. I have an extraordinary husband who has always supported me. We recognised a very strong external pressure. I heard myself saying: "you cannot take her back to your house, it is too heavy going for your family. Stop." With my hus-

band and my three children (they were 15, 22 and 24; Madeleine was 20), we sat around the table. I simply said: "Okay, we can place Madeline in the William Lennox centre where they will take care of her. But logically, if one of us becomes hemiplegic, then that person will not stay at home. So, unanimously, we have decided to look after her. "

Did you think her state could improve?

We argued about taking her out of it, if she stayed in that state, to give her the best possible quality of life. For feeding, Madeleine was permanently attached to a feeding tube which passed through her nose. I proposed taking it out in order to put it back, twice a day, directly into her mouth. She was freed from the tube.

In short, you were her personal nurse.

I was not alone. The family was organised around her. Nurses came in the morning and in the evening. For those fifteen years, she never had bed-sores. You know, I was a bit prepared for the situation. I lived with a sister who suffered from multiple sclerosis. We always looked after her, at home, until her last breath.



Madeleine de Launoit

1966 - 2002

Close family members do not always have as much time and energy.

I know some absolutely extraordinary parents. Mireille's parents, Christophe and Costia, for example, have been looking after their child who is in PVS for at least ten years. The young Mireille was eleven when she had her accident. She is now twenty. Her father is a teacher and her mother is a nurse. She decided to work at night. They both take turns around their daughter: For example, they installed a pulley so that she can have a bath. Costia was two, when he stayed at the bottom of a swimming pool for several minutes, he is now seventeen. His mother looks after him at her house but she also looks after two other children.

How did you envisage this stay at home?

We saved a bedroom for her, on the first floor. She remained a full part of the family. I always spoke to my daughter as if she understood me. We never said to ourselves: there is no longer anything to do. A true network of solidarity was organised around Madeleine. You cannot imagine to what extent we were helped and supported.

Did you ever happen to leave your daughter alone at home?

At the beginning, it was total stress, I did not want to leave my house. There was a full time nurse, day and night. Bit by bit, I learned to leave Madeleine

alone at home. The first time was in 1992. I only left for half an hour. Next, it increased to three quarters of an hour; an hour. One day, I went to a marriage reception, which was near to my house. And then, I also said to my daughter: "you have your life in your state and I have mine, I am taking back a bit of freedom". But I was always more reassured when someone was able to stay at the house.

(Jean-Jacques, Madeleine's father, joins the discussion)

And Madeleine, what did she bring you?

She changed my life, she turned my set of values upside down. When you live easily, people do not come to tell you their problems. Thanks to Madeleine, I received a number of confidences. Other people tell themselves: you, suffering, you know what it is, we can talk about it. It is the biggest lesson that she taught me: the person next to you has problems that you do not suspect.

One last question: and if you were to do it again?

Jean-Jacques de Launoit: I do not regret anything. I would do exactly the same thing again. We had some extraordinary moments.

II. CARE IN BELGIUM

Until recently, Belgium did not have a health structure adapted to the care of patients in PVS. A system was put into place in 2004 in order to offer patients adequate care, at the right moment, in the right place and with the right means, while assuring continuity within the same health circuit.

A protocol was then concluded between the federal government and competent authorities concerning the Health policy to be put in place for patients in a persistent vegetative.

When it comes to hospitals, an annual budget of around 625,000 euros has been granted for the functioning of 80 "neurological rehabilita-

tion" beds adapted to patients in EVP/MCS. 46 of these beds are located in Flanders, 26 in Wallonia and 8 in Brussels. Each bed represents a cost of a little over 7,800 euros.

Concerning long term care for patients in a persistent vegetative or minimally conscious state, an annual budget of some 3.66 million euros allows for the care of 200 people (that being the equivalent of around 18.230 euros per person). These places are divided up as follows: 20 in the Capital of Brussels, 114 in the Flanders region and 66 in the Wallonia Region.

II. ETHICAL REFLECTIONS

How far should we go with care?

From the medical ethics point of view, a wide consensus prevails in Western Europe in order to consider that the affirmation of the chronic character of a vegetative state must not prompt the end of nutrition and hydration. There is a duty to continue ordinary care. On the contrary, there is no place for "persisting in" prolonging life in the case of a serious illness or intercurrent complications.

It is to be noted that the nutrition and hydration of a patient, whether achieved or not with the help of a feeding tube, does not constitute medical treatment but rather a basic level of care. Not feeding or giving water to such a patient amounts to killing them deliberately.

"Vegetable" or human being ?

What attitude should be adopted with regard to people in PVS? What view does society and the medical world have about them? Is it that they are fully human and with this title deserve to be cared for and treated with the utmost respect? Or rather that they are simply bodies which only have human appearances?

This question has been addressed in France since 1986 (5) by the National Consultative Ethics Committee. The committee had then considered that patients in PVS "... are human beings who have even more right to respect due to being in an extremely fragile state."

In practice, the caring of people in a vegetative state proves to be demanding. On a medical level, it highlights the limits of technology; when it comes to care, it is exhausting and does not seem to give anything back to carers or close family members.

Moreover, society, extended family or friends seem inhabited with this underlying thought: "it would be better if this person was dead" because "their life is no longer worthy of the name." There seems to be a contrast between, on one hand, the dignity of every human being, whatever their condition, and, on the other hand, the decline of their living conditions.

Nevertheless, it is precisely because of their human dignity, that everyone, even if they have fallen into PVS, has the fundamental right to be cared for. Objectively, care improves a patient's quality of life, even if it is judged by some people on the outside as useless and absurd. What a paradox if, a patient's quality of life was deemed insufficient, nothing was done to precisely improve their condition.

According to another approach, which is rather common in the Anglo Saxon world, people in PVS apparently eventually become strangers to the human community. For this reason, it would apparently be better, it seems, to leave them to die. With this lies the idea that the brains of people in this condition, which contain the finest element - the neocortex - no longer work. The death of the neocortex is apparently synonymous with brain death.

Others claim that these people are no longer human given that they have apparently lost what specifies them as human, namely the reason or the communication. It is followed by saying that they apparently at best belong to the vegetable kingdom, they are apparently valued as "vegetables".

For still others, these patients are apparently not full humans but rather living bodies following an independent biological destiny. They have apparently been cut off from the moral human community.

Ultimately, these three points of view seem to link to a central statement according to which "a man who no longer thinks stops being part of humanity". (6)

(5) See notice n°7 of 24th February 1986 concerning "experiments on patients in a chronic vegetative state"

(6) In this sense, see Maurice Cara, Honorary Professor of Anaesthesiology, in *Agressologie*, 27, 11, p. 959-960, 1986.

Without going into detailed explanations, we wish to challenge this statement, that 'Individuals are excluded from humanity on the basis that they are apparently incapable of explaining their purpose or that they are deprived of self-awareness or even that they do not/no longer have the ability to communicate with their surroundings.'

Is humanity, in its essence, defined by its operations? Affirming humanity comes back to considering that there are people who are more or less human than others, in measuring the exercise of their faculties. Following this logic, people who are more gifted are apparently more human than others, carrying out human operations in a better way (thinking; wanting; communicating).

This position seems false and dangerous to us. The essential characteristics of a human being, those that aim to determine its essence, cannot be susceptible to more or to less, neither can it be subject to variations. What belongs to the essence of a person is surviving in a rational nature. As for the attributes and functions which can grow, diminish, disappear, they cannot be considered essential, even if they result from the essence. In this way, people endowed with reason have the ability of speech. However a mute, deprived of speech, does not remain less of a human being. It is the same for someone in PVS/MCS deprived of the ability to communicate, because they continue to belong to a free and rational nature.

In conclusion, a human being is defined by what it *is*, and not by what it *does* or by the exercise of its essential attributes which is evaluated as adequately efficient. This approach leads to recognising and protecting the human dignity of every individual, without wanting to establish precluding criteria which, ultimately, open the doors to arbitrariness and injustice.

Further Reading:

Detecting Awareness in the Vegetative State, Adrian M. Owen, Martin R. Coleman, Matthew H. Davis, John D. Pickard (University of Cambridge), Steven Laureys, Mélanie Boly (Centre de recherches du cyclotron, University of Liege), *Science*, 08/09/2006, vol. 313, p.1402.

Etats végétatifs chroniques. Répercussions humaines. Aspects médicaux, juridiques et éthiques. Sous la direction de F. Tasseau, M.-H. Bougand, J.-R. Le Gall, P. Verspieren, Rennes, Editions ENSP, 1991, 167 pp.

Les états végétatifs chroniques, *Revue Laennec*, n°2, décembre 1995.

Sylvie Dellus, *Le coma. La vie silencieuse*, Flammarion, 1999, 267 pp

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