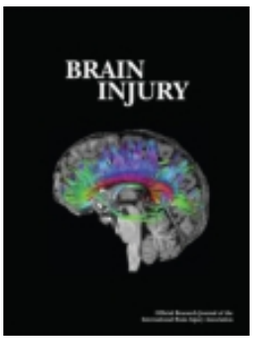

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Events and decision-making in the long-term care of Dutch nursing home patients in a vegetative state

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Abstract

Objective: To clarify characteristics of long-term care and treatment of patients in a vegetative state.
Design: Qualitative, descriptive study in a Dutch nursing home.
Methods: Review of clinical records of patients in a vegetative state after acute brain damage between 1978–2002.
Results: Five patients received intensive care of a multi-disciplinary team and showed considerable co-morbidity. There was no standard scenario for end-of-life decisions. Physicians play a more proactive role by evaluating the total medical treatment instead of withholding therapy in case of incidental complications. The families' attitude is a crucial factor in their ultimate decision.
Conclusions: There is no standard solution to alleviate the fate of patients in a vegetative state and their families. Withdrawing all medical treatment, including artificial nutrition and hydration, can be an acceptable scenario for letting the patient die. More research is needed to identify the factors that contribute to acceptance of the physician's decision by the family.

Introduction

Patients in a vegetative state have survived an acute brain accident, but did not regain consciousness. In contrast to coma patients, patients in a vegetative state open their eyes and show a sleep-wake cycle; they are 'awake, but not aware' [1, 2]. Reviews of diagnoses and prognoses show that recovery after 1 year is highly unlikely [3, 4]. Questions about the futility of continuing medical treatment after that period have bothered caregivers, family and society. Unfortunately, long-term follow-up studies on the clinical course and decision-making after 1 year are lacking [4–6].

Long-term care is mainly based on learning by experience. There is, however, much disagreement about which treatment decisions are appropriate and which factors should influence decision-making [7].

This study analyses the long-term care in the total caseload of patients who spent more than 1 year in a vegetative state after acute brain damage in a Dutch nursing home. The aim is to determine the key factors in the long-term course, the characteristics of treatment and care and appropriate scenarios for preventing a long-term vegetative state. This study will try to answer the question of if withdrawing artificial nutrition and hydration (ANH) can be appropriate when no recovery is expected. Recent news reports made clear that this is still a controversial topic [8, 9].

Methods

A retrospective, descriptive review was conducted of the clinical records on all the patients in a vegetative state who were admitted to one of the four nursing homes—that currently form the Zorgboog-foundation—between 1978–2002. These records comprise the medical, paramedical and nursing records.

All patients met the following criteria:

- A diagnosis of vegetative state [3] or coma vigil after an acute traumatic or non-traumatic brain accident;
- Confirmation of the diagnosis by a neurologist or nursing home physician;
- A Glasgow Coma Scale score of E4-M4-V2 maximum [10] and/or observations described in

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accordance with the criteria of the Multi-Society Task Force on Persistent Vegetative State [3]; and
- A vegetative state lasting more than 1 year.

From the records, the following data were derived: patient characteristics, co-morbidity and medical treatment, consultations, decision-making and scenarios of dying. In all cases, the first author (JL) was involved in the diagnosis, management and review of case notes. The second author (HB) was involved in the evaluation of each case as medical director. Learning points were formulated after each case and then taken into account in the next cases.

Results

Between 1978–2002, nine patients were admitted with the above-mentioned diagnosis. Three of them regained consciousness within 6 months, of whom two were discharged to a psychiatric clinic and one to a rehabilitation centre. Another patient, who nowadays would have met the criteria of Minimally Conscious State [11], was discharged to an institution for mentally disabled people.

Five patients were identified as being in a vegetative state for more than 1 year. Table I shows the main characteristics of these patients.

The case reports in the Appendix provide a qualitative insight into the long-term course and the different medical end-of-life scenarios. In addition to the individual data, this study will present general patterns in nursing care, medical treatment, clinical course and decision-making.

Patterns of similarity

None of the patients studied regained consciousness. Long-term care was provided by a multi-disciplinary team consisting of several nurses, a physiotherapist, speech therapist, occupational therapist, dietician, pastor, social worker, and psychologist, under the leadership of a nursing home physician. Daily nursing care was intensive: washing, changing incontinence materials, supplying ANH six–eight times a day, frequent turning to prevent bedsores, fixing splints, cleaning the tracheal tube, providing mouth care, supplying laxatives and other medicines and regular changing of the urinary catheter and nasogastric feeding tube. Later on, feeding pumps and PEG (Percutaneous Endoscopic Gastrostomy) tubes facilitated the care and diminished the problems.

All patients showed considerable co-morbidity, as seen in Table I. The medical problems included: chronic constipation, spasticity with contractures, mouth and dental problems and regular infections of airways, urinary tract and skin. Severe infections were not always lethal in this young, well-fed population. Despite immobility, bedsores occurred only incidentally. Remarkable findings were filamentary keratitis in patients 4 and 5 and spontaneous recovery of hormonal deficiencies after more than 1 year in cases 2 and 5.

Chronic medicines were administered, especially laxatives, and various medical specialists were consulted (Table I).

Decision-making as a learning process

None of the patients had made a living will and the three youngest patients had previously never expressed any wishes as to treatment in this context. As regards the two patients older than 40, their partners' views were mentioned in the medical records. They both assumed that their partner did not want to continue life under such conditions and they ultimately accepted the medical decision to withdraw ANH.

At the time, the scenario of withholding medical treatment for complications was the only option to end the vegetative state in case 1. Decisions were made in reaction to events and no structural meetings were planned to discuss treatment policy with family or colleagues. Locum doctors made their own decisions, as was the case in the treatment of life-threatening urine obstruction in case 1. Ultimately, withholding antibiotics for infection did not lead to the expected death, but resulted in a chronic infectious state that turned out to be an inappropriate way to let the patient die.

The learning point was that, instead of only withholding therapy for incidental complications, regular evaluation of the total medical treatment is necessary.

This scenario was applied in case 2, in which the complications caused us to make such an evaluation. Interventions regarded as futile were withheld and the medical treatment including ANH was withdrawn. All the people involved witnessed a quiet and dignified dying process without signs of discomfort. This scenario was seen as appropriate. The family was informed that the decision was entirely the responsibility of the physician and not theirs to make. Several consultations, especially with colleagues and the family's general practitioner, contributed to this decision-making. The case was published in Dutch medical and lay press and brought to the attention of the Public Prosecution Service [12]. After the case was broadcast on television, a preliminary judicial investigation was started. The conclusion was that 'the decision to withdraw ANH was made with due care from a medical and ethical point of view' [13]. This conclusion confirmed the view that withdrawing ANH can be regarded as withdrawing futile

Table I. Main characteristics of patients and events.

n	Age[a]	Sex	Cause and year of beginning	Survival	Medical problems	Nursing problems	Medication	Consultations
1	17	M	Trauma in 1978	11.5 years Died of sepsis (not treated)	Temperature peaks; Weight loss; Eye/ear infections; Chronic constipation; Caries, broken teeth; Extreme spasticity; Respiratory infections; Haemoptysis; Chr. urinary tr. infections; Urinary stones, obstruction; Haematuria; Fistula, abscess; Repeated skin infections; Bedsore in terminal phase	Contractures; Mouth care; Teeth grinding; Tube problems; Catheter problems; Skin infections	Antibiotics (11 courses); Laxatives (chronic); Muscle relaxants (chronic); Antacids; Anti-inflammatory drugs; Antipyretics; Anticholinergic agents; Antifungal ointments; Mucolytics	Urologist (5×); General practitioner (3×); Dermatologist (3×); Neurologist (3×); Surgeon (3×); Orthopaedist (1×); Internist (1×); Colleagues NHP[b] (1×)
2	43	F	Trauma with 12 days later anoxia due to bleeding spleen in 1983	6 years 5 months Died after withdrawal ANH[c]	Eye/ear infections; Chronic constipation; Caries, loose teeth; Extreme spasticity; Respiratory infections; Haemoptysis, dyspnoea; Urinary tract infections; Incidental bedsore; Temporary amenorrhea	Contractures; Mouth care; Teeth grinding; Tube problems; Catheter problems; Compulsive crying	Antibiotics (4 courses); Laxatives (chronic); Antiemetics; Benzodiazepines (chronic); Muscle relaxants; Mucolytic agents; Neuroleptics	General practitioner (6×); Colleagues (6×); Neurologist (4×); Surgeon (3×); Dentist (2×); Internist (2×); Dental surgeon (1×); Ophthalmologist (1×); Orthopaedist (1×); Pharmacist (1×); Ethicist (1×)
3	44	M	Anoxia after cardiac arrest in 1989	1 year 3 months Died after withdrawal ANH	Temperature peaks; Eye infections; Repeated skin infections; Chronic constipation; Regular vomiting; Respiratory infections; Urinary tract infections; Convulsions	Contractures; Foetus position; Agitation; Mouth care; Tube problems; Catheter problems; Myoclonus	Antibiotics (5 courses); Laxatives (chronic); Antacids; Anticoagulans (6 months); Antiemetics; Benzodiazepines; Muscle relaxants (chronic); Corticosteroid ointments; Histamine H_2-antagonist; Anti-cholinergic agents	Colleagues NHP (11×); Internist (5×); Pharmacist (5×); Surgeon (3×); General practitioner (2×)

(*continued*)

Table I. Continued.

n	Age[a]	Sex	Cause and year of beginning	Survival	Medical problems	Nursing problems	Medication	Consultations
4	15	M	Trauma in 1991	8 years 4.5 months Died after pneumonia (despite treatment)	Skin infections; Chronic constipation; Keratitis filamentosa; Eye/ear infections; Moderate spasticity; Incidental seizures; Respiratory infections; Haemoptysis, dyspnoea	Contractures; Excessive salivation; Frequent administration of medication (eye)	Antibiotics (17 courses); Laxatives (chronic); Anticonvulsants; Antifungal ointments; Benzodiazepines; Mucolytic agents; Histamine H_2-antagonist; Anticholinergic agents; Corticosteroid ointments; Indifferent eye ointment	Colleagues NPH(3×); Internist (3×); Ophthalmologist (2×); Dermatologist (2×); Neurologist (2×); Surgeon (2×); Dentist (1×)
5	18	M	Trauma in 1987	Still alive after 16 years in a vegetative state	Temperature peaks; Pituitary dysfunction; ADH deficit (until 3 years after accident); FSH/LH deficit (until 3 years after accident); Cortisone and MSH-deficit; Chronic constipation; Seizures; Crurus fracture; Osteoporosis; Keratitis Filamentosa; Caries, Fungal infections; Skin infections; Incidental bedsore; Respiratory infections; Urinary tract infections	Contractures; Catheter problems; Mouth care; Excessive salivation; Frequent administration of medication (eye)	Antibiotics (52 courses); Laxatives (chronic); Antipyretics; Muscle relaxants; Anticholinergic agents; Antifungal ointments; Benzodiazepines; Mucolytics; Hormonal supplements (cortisol, vasopressin); Corticosteroid ointments; Indifferent eye ointment	Ophthalmologist (17×); Internist (9×); Colleagues NPH (7×); General practitioner (6×); Dentist (3×); Neurologist (3×); Surgeon (3×); Orthopaedist (2×); Pharmacist (2×); Urologist (2×)

[a] At the time of the accident.
[b] NHP: Nursing Home Physician.
[c] ANH: Artificial Nutrition and Hydration.

medical treatment. Moreover, this experience led to the insight that an earlier evaluation of the total treatment could possibly prevent a long-term vegetative state.

This approach was taken as a starting point in case 3, which also involved informing the family that the decision to withdraw treatment would entirely be up to the physician. The family accepted this, after they were intensively guided in their coming to terms with the situation and in their grieving process. In this scenario, a long-term vegetative state could be prevented.

Cases 4 and 5, however, showed that this scenario cannot be applied in all situations. The parents of these young patients could not agree to the withholding or withdrawal of medical therapy. In case 4, there was no other option than to wait for a fatal complication, which ultimately occurred 8.5 years after onset of the vegetative state.

In case 5, the proactive approach, numerous family meetings, incidental complications and consultations and discussions have not led to any other scenario than to continue treatment. The medical record mentions that this happens at the request of the parents who do not want to lose their loved one, despite the fact that the physicians are convinced that continuing medical treatment is futile for the patient.

Discussion

This study shows that the long-term care of these patients is complex and intensive. The fact that no patient regained consciousness after 1 year in a vegetative state confirms the general conclusion in the literature [4]. All patients were fully dependent on intensive nursing, medical and paramedical care and developed considerable co-morbidity, requiring polypharmacy. The course depended on co-morbidity and the physicians' and families' attitudes. There was no standard solution, not even when physicians were convinced that continuing medical treatment was futile.

This is the first time that events and decision-making in the long-term care of vegetative state patients have been described. The results can be of advantage to other caregivers. This study may have a quantitative limitation, but it is recognized that only a small number of patients is available, usually widely dispersed away form academic centres in hospitals, nursing homes or at home [5].

Comparison with the few other studies of long-term care is impossible, because these include developmental or degenerative disorders [14–16]. Single case reports have shown similar co-morbidity (constipation, contractures and infections) [17–20]. As far as is known, filamentary keratitis and spontaneous recovery of hormonal deficits have not been documented before in relation to a long-term vegetative state.

As demonstrated, the role of the physicians has changed over time: from reacting to complications to a proactive role in which evaluation of the total treatment, including ANH, has become the starting point. Case 2 was a landmark case in that attitude shift, because of the positive experience, positive reactions and judicial confirmation of due care. Since then, this scenario has been applied in other cases in and outside the nursing home. This positive experience contrasts with an article previously published, in which the author expressed feelings about letting someone 'starve' [21].

It is essential that the physician makes a state-of-the-art diagnosis of the vegetative state with the help of a multi-disciplinary team [22]. Different phases can be distinguished in the medical treatment: the acute phase in hospital, the transitional or 'waiting' phase in which there is stabilisation and hope of recovery and the irreversible or permanent phase in which there is no hope left [7, 23]. In each phase, it is important to hold regular team and family meetings and discuss the goals of medical treatment against the background of the diagnosis and changing prognosis [22].

In the Netherlands, it is justifiable to withdraw ANH as medical treatment of patients in a vegetative state as part of a careful decision to withdraw other forms of life-sustaining treatment, when the chance of recovery is negligible [23, 24]. This policy is in line with a broad consensus across many countries that prolonging the survival of patients in a permanent vegetative state brings no benefit to the patient [6, 25].

It is also essential to emphasize that withdrawing treatment is a medical decision. Statements made by the families (Table II) and the evaluations show that this is a crucial factor in the families' acceptance of the decision. In the authors' opinion, the burden of such a decision should be borne by the physician.

Attitudes of families were crucial in the ultimate decisions of physicians. Intensive guidance of the family towards the key decisions in the different stages of a vegetative state is a necessary condition for preventing a permanent vegetative state. Nevertheless, accepting the consequences of the decision to withdraw medical treatment remains difficult, in this study particularly for parents who have found a new balance in the stable phase. In cases 4 and 5, the families told that they could have accepted the death of their son in the acute phase, but they could not agree to the withdrawal of treatment once a new reality in their relation with their child had emerged (Table II).

Table II. Key statements made at family meetings.

Doctor:	The parents told me that, should they be confronted with a recurrence of the life-threatening urine stoppage, they would probably insist on medical treatment, but if the physicians were to say that treatment is not the most sensible choice, they would understand (case 1).
Doctor:	The husband explained that he was afraid to decide himself whether or not complications should be treated. He requested not to involve him in the decision making concerning the withholding or withdrawal of medical therapy, but only to explain to him what has been decided (case 2).
Doctor:	I have told her that I think the time has come that I should decide to withdraw artificial nutrition and hydration. No one raised any serious objections (case 3).
Parents:	We recognize that our son would never have wanted this situation to continue like this; who would? With hindsight, it would have been better for him if he had died in hospital. We hope that he doesn't realize in which situation he is (case 4).
Parents:	This is a fate worse than death, but we don't want to lose him (case 5).

The current questions are how long this situation can be justified when no benefit for the patient is assumed and how it can be prevented by making decisions at an earlier stage. These questions are the subject of further investigation, with a focus on adequate timing of interventions and coping of the family. The 'waiting phase', in which the different scenarios are explained to families, can be a crucial period for preventing a permanent vegetative state. Ultimately, the withdrawal of all medical treatment is better accepted when families are informed.

Hopefully, this insight will promote the co-operation of physicians in acute and long-term care in preventing this desperate situation. Co-operate is the least one can do in a situation created by modern curative medicine, which has ultimately only palliative care and compassion to offer to patients in a permanent vegetative state.

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Appendix

Case 1: Withholding antibiotics

This patient was admitted to the nursing home in 1978, 2 months after a motorbike accident and survived for 11.5 years in a vegetative state. At the time, there was little-to-no experience with these patients.

The first day of admission, the family was preparing for his death because of a temperature peak of 40°. However, the medical situation stabilized spontaneously. After a neurologist had confirmed the permanent character of the vegetative state, the parents lost their hope of recovery after 2 years. They maintained their request for curative treatment of complications, because they could not accept that they would lose their son.

The first 7 years, complications were treated in a curative way at the request of the family. In total, nine courses of antibiotics were given, six for airway infections, two for urinary tract infections and one for folliculitis of the skin. Surgical interventions were also made. An urologist removed bladder stones and, later, at the request of the parents and a locum doctor, stones which had caused bilateral ureteric obstruction were removed.

After this, the futility of medical treatment was discussed in the multi-disciplinary team, which also consulted the family's GP in this matter.

Seven years after admission, the family was finally willing to accept the physician's decision to withhold curative treatment of complications. This scenario did not lead to the patient's death, but to a state of chronic urinary infection; he survived periods of high fever in which antibiotics were withheld. Four years later, the result was purulent outflow from his penis, bedsores, purulent sputum, fistulas on his scrotum and a suprapubic abscess, which required surgery and antibiotics for palliative reasons. He died of sepsis in 1989.

Case 2: A reactive approach to withdrawing ANH

This patient was involved in a car accident at the age of 43. After 12 days in hospital with varying levels of consciousness, she was found unconscious in hypovolemic shock with asystole and apnoea, because of a ruptured spleen. After reanimation and splenectomy, she did not regain consciousness. After 2 months in hospital, she was referred to the nursing home in a vegetative state.

In the first months, the physician administered antibiotic treatment twice for infections of the bronchial tubes. After 6 months of unchanged vegetative state, the physician and the family had lost all hope of recovery. After consulting the GP and the family, the physician decided not to treat life-threatening complications in this patient any longer. The family accepted that decision, which was considered to be what the patient herself would also have wanted under the circumstances. However, in the first years after this decision, no life-threatening complications occurred. Compulsive crying was treated with benzodiazepines.

After 5 years, problems with the feeding tube arose. The nasogastric tube often did not run through and was regularly vomited out. Using a Percutaneous Endoscopic Gastrostomy (PEG) tube was considered. At the time, the patient survived an aspiration pneumonia without antibiotic treatment. The problems with the feeding tube increased: more vomiting, sometimes with blood, with an increasing risk of choking to death in the thick mucus. Ultimately, only a few nurses were able to change the feeding tube. Re-evaluation was undertaken at that time to evaluate whether or not the total medical treatment actually contributed to the patient's well-being. The physician concluded that continuation of medical treatment was futile and also not according to the values and wishes of the patient. A gastrostomy was considered not to be in the patient's interest and, without consent, it might be construed as an encroachment of the integrity of the human body. After consulting his colleagues, the GP and a professor in ethics, the physician decided not to continue medical treatment and to withhold a PEG tube. It was agreed to stop all medical treatment including ANH.

On neurological grounds, the medical team assumed that she would not suffer from the discontinuation of ANH. Moreover, there was extensive experience with the physiology of normal dying processes in nursing home patients who stop eating and drinking before they die. These patients die peacefully within 1 or 2 weeks and do not show any sign of suffering.

The decision to withdraw ANH was discussed extensively with the family and the multi-disciplinary team, who thereupon gave their consent. The benzodiazepine dosage was gradually reduced to prevent withdrawal effects and replaced by a once-only depot injection of Haloperidol-decanoate because of the risk of recurrent compulsive crying.

After the tube was removed, a peaceful and tranquil phase set in for the patient and the family. The family paid intense farewell visits and their postponed mourning process could finally be completed. The patient's body gradually became less bloated. A week after removal of the

tube, the patient died peacefully in the presence of her family. No one had seen any sign of suffering or discomfort. On the contrary, the family had experienced the dying process as humane and worthwhile. For this reason, they consented to making this information available to others.

Case 3: A proactive approach to withdrawing ANH

The same scenario as in case 2 was applied in this case of a 44-year old man who went into a vegetative state after resuscitation for cardiac arrest. The vegetative state lasted 15 months. Flexion spasm and contractures were the main problems in this case, which made nursing care rather difficult. Passive exercises could not be done, nor was mouth care possible. An occupational therapist adapted the clothes to make nursing easier. Two hospitalizations were necessary due to problems with the PEG tube, which was regularly vomited out. The patient was treated for aspiration pneumonia, which occurred 6 months after admission. Only after a relapse did the family show a willingness to accept the proposal of the nursing home physician not to hospitalize the patient any more.

Each month the multi-disciplinary team discussed the main problems. The GP was consulted for coping problems in the family. The family was advised to seek support and to contact fellow sufferers. At the monthly family meetings, the physician proposed withdrawing medical treatment in the future. In case of urinary tract infections, antibiotics would be administered for palliative reasons. Because there was no more hope of recovery, the discussions about withdrawing treatment were intensified. The family was brought into contact with the family of the patient in case 2.

One year after admission, the nursing home physician concluded that all the parties concerned were ready for the decision to withdraw the ANH. Consultations had confirmed the diagnosis of the vegetative state and justified the decision to withdraw treatment. The physician made clear to the family that it was her decision to withdraw ANH. After removing the feeding tube, a depot injection of haloperidoldecanoate was given. In the first days after withdrawal, periods of smiling alternated with (motor) agitation and signs of convulsions, which were treated with benzodiazepines and neuroleptics. Eleven days after removing the feeding tube, the patient died in the presence of his family. The final phase had been difficult for them, but his wife told us 'it is better this way'. In the next 6 months, intensive meetings were held to support the family in the grieving process.

Case 4: Waiting for a fatal complication

Before admission, this 15-year-old boy, who was in a vegetative state due to a traffic accident, had stayed 3.5 months in a rehabilitation centre specializing in stimulation programmes for patients in a vegetative or minimally conscious state. Because he had not regained consciousness, he was referred to the nursing home. He was fed by a nasogastric tube.

His parents visited him every day and they had not lost hope. They accepted the physician's decision not to resuscitate in emergencies, but they requested him to treat any other complications that might occur. Family meetings were planned on a regular basis to discuss medical treatment in the future.

In the first 6 months, the main problems were: contractures, constipation, two respiratory infections and repeated filamentary keratitis (Table I). A dentist was consulted for the problems with dental hygiene and a speech therapist to reinvestigate the possibility of oral feeding, which proved not to be a feasible option. The physician decided to treat infections with antibiotics and to discuss the significance of tube feeding with the family. There were no changes in the vegetative state.

One year after admission, the physician told the family that the 'waiting phase' in which there is usually still hope of recovery had passed and he subsequently discussed the consequences. Overwhelmed with grief, the parents were not able to consider any future steps. They were not ready yet for the decision to stop all medical treatment, but accepted the decision to withhold hospitalization and curative treatment for life-threatening complications. They insisted on antibiotic treatment for infections. Meetings were held on a regular basis to prepare the family for the medical decisions in the future, including withdrawing ANH.

In the next 2 years, the situation remained stable. Another physician took over the treatment and considered inserting a PEG tube, because of repeated coughing out of the tube. He expressed his opinion as to the futility of continuing medical treatment on a patient who could not experience the benefits and again withdrawing ANH was discussed. Nevertheless, terminating treatment was no option for the family and they agreed to insertion of a PEG tube.

Almost 8.5 years after admission, the patient developed high fever with dyspnoea, due to pneumonia. Although the physician expressed his doubts about the effect of antibiotics, the family insisted on curative treatment and on continuation of artificial feeding. In spite of the treatment, the situation deteriorated within a few days, the patient had excessive salivation, green,

thick mucus and dyspnoea. On the last day, the administration of antibiotics was stopped and Morphine and Midazolam were given to provide relief of dyspnoea. On the fourth day after onset, the patient died in the presence of his family.

Case 5: In search of a solution

This patient has survived in a vegetative state for 16 years and never regained consciousness after hospitalization due to a traffic accident. From the very beginning, the parents had requested curative treatment of complications. In the first years, monthly family meetings were organized by the physician and nursing staff. At each meeting the following themes were discussed: observed reactions, actual care plan with problems and actions, prognosis, goals of treatment and coping of the family. Scenarios for terminating this vegetative state in the future were discussed, of which withdrawal of the tube feeding was not acceptable to the family. Although the permanent character of the vegetative state was confirmed by a neurologist 3 months after admission, the parents did not lose hope and consulted alternative healers. They visited their son daily and spent a lot of time taking care of him. The situation lead to increasing physical, psychological and social problems in the family. Support of the family was a recurring theme in the contacts between the physician and GP, but the family rejected additional professional support.

Three years after the accident, the fluid balance recovered spontaneously without the daily supply of vasopressin. At the same time, as a sign of a recovered testosteron production, his beard began to grow again. After consulting an internist, further investigations were considered futile, as the patient was not likely to regain consciousness.

The parents requested curative treatment of complications, but the physician told them that this would be futile. As the patient had never stated his own wishes as to treatment in a case like this, the physician consulted the GP, his colleagues, a neurologist, the multi-disciplinary team and the medical management of the nursing home to check his opinion about the futility of further medical treatment. The two sisters of the patient were also invited to express their views on the situation.

After these consultations in the fifth year after admission, the physician decided not to treat medical complications in a curative way any more. All consulted disciplines agreed with the palliative goals and the parents were subsequently informed. They did not accept the decision, because they did not want to lose their son. There was a scenario for supporting the family and the team in times of crisis (e.g. when life-threatening occurred). In the first years after this decision, no life-threatening complications occurred. After 45 family meetings, it was clear that withdrawing all medical therapy would still not be acceptable to the family.

Eight years after admission, another physician took over the responsibility. An acute aspiration pneumonia which the patient developed that year was not considered life-threatening by the physician who was on duty. He supplied antibiotics at the parents' request, which led to discussions in the medical team as to whether this had been a 'missed opportunity'.

Until 2003, 52 times a course of antibiotics was administered to treat infections of the urinary and respiratory tract. In the past few years, anti-epileptic agents were administered for regular seizures. The patient is still alive today.