THE ENGLARO CASE: WITHDRAWAL OF TREATMENT IN ITALY FROM A PATIENT IN A PERMANENT VEGETATIVE STATE
The Englaro Case:
Withdrawal of Treatment in Italy from a Patient in a Permanent Vegetative State

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Abstract

In 2009, the international media reported the case of Eluana Englaro, a 38-year-old woman in a Permanent Vegetative State (PVS) who died following the withdrawal of her feeding tube. By the time of her death, she had been unconscious for 17 years. For many years, her father had been seeking permission to allow her to die. His request was rejected by the courts several times and on different grounds, until the Italian Supreme Court finally granted him his wish. The case caused considerable political turmoil. The Government, the President, the Constitutional Court and the European Court of Human Rights all became involved. This paper gives an account of the history of the case, enriched by personal comments from the people directly involved and a memoir by Eluana’s father.¹

Keywords

Italy, Regulation of Medical Behavior, Right to Die, Courts, Parliament.

¹ Englaro B, Nave E. Eluana. La libertà e la vita [Eluana, or: on life and liberty]. Milano: Rizzoli; 2008.

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Regulation of refusal of life-prolonging treatment in Italy

The right to refuse unwanted invasions of physical integrity, and specifically medical treatment, is established in the Italian Constitution and was applied by the courts in recent cases involving competent patients. However, incompetent patients seem to lose this right in practice. There is as yet no legal regulation of advance directives in Italy. In a 2003 statement of opinion, the National Bioethics Committee (an advisory body to the Government) supported the introduction of advance directives in the Italian legal system, and several bills to this effect have been introduced in Parliament, but not a single one has become law. Refusal of treatment by a representative was not regulated until 2004, and the new regulations give the Surrogate Judge ample power of supervision over (and interference with) the choices made by the representative.

The decision-making process over administration of life-prolonging treatment is regulated in the Code of Medical Ethics, drafted by the Board of the College of Physicians. The Code prescribes that treatment decisions involving incompetent patients should be based on the patient’s earlier competently expressed views. The views of the patient’s health-care proxy should also be taken into account. However, the Code does not have the same status as parliamentary law. It represents the position of a large part of the medical profession with regard to the regulation of ethically sensitive decisions in medical practice. However, it offers no legal certainty to doctors, patients and their families because it has no influence over the civil trials and criminal prosecutions, based on statutory law, that may result from the behavior of the doctor.

It is within this context that the Englaro case developed.

A young girl in a Permanent Vegetative State (1992)

In 1992, Eluana Englaro was involved in a car accident. At that time, she was a 21-year-old girl. The people who knew her describe her as a very lively, independent, self-confident, strong-willed young woman, with a very rich social life. Eluana was admitted to the ICU in a state of deep coma. She had suffered severe brain damage. Her father approached one of the IC-doctors and said that Eluana would not have wanted to be kept alive artificially in a condition she regarded as undignified. Eluana and her father had discussed the issue only a year earlier, after she had seen a friend in an irreversible coma. However, the doctor explained to the father that IC-protocols prioritize preservation of life over all other considerations. A few days later, Eluana received a life-saving tracheotomy. Eluana’s father was opposed to the surgery, but the head of the ICU told him that his consent was unnecessary.

Eluana spent about a month in a coma, then started to breathe spontaneously and opened her eyes. However, she remained unconscious. She was completely paralysed, incontinent and was fed through a tube. The head of the ICU told her parents that the girl was to be kept under observation for two years before a final word could be given about her chances of recovering consciousness. Her father asked whether withdrawal of life-prolonging treatment was an option. The doctor’s answer was negative. Eluana was transferred to a long-term care ward in another hospital, located a one-and-a-half

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4 See note 2, Moratti 2008:408-409.
7 See note 1, Englaro, Nave 2008:24-25.
8 See note 1, Englaro, Nave 2008:12-15 and 33-35.
hours journey from her parents’ home. Eluana’s father reports that his daughter received considerable attention from the medical and nursing personnel, including constant attempts at sensory stimulation. Between 1992 and 1994, Eluana’s mother spent most of her time in her daughter’s hospital room. ⁹ Notwithstanding all efforts, Eluana’s condition did not improve. In 1994, she was diagnosed as in a Permanent Vegetative State.

PVS patients are IC-independent and have a life expectancy of several years if attached to a feeding tube. The 1990s saw an international debate on artificial nutrition, which according to the Roman Catholic Church¹⁰ is not medical treatment but ‘basic care’ that should never be withdrawn. In its very influential 1994 report, a Task Force on PVS based in New York argued instead that artificial feeding is medical treatment.¹¹ The controversy on artificial feeding played a major role in the Englaro case.

After the Englaro case had attracted the attention of the media, studies were made on the prevalence of PVS in Italy. A 2005 Ministerial Report based on data from regional studies estimates the prevalence of PVS as 3.5 to 5 cases per 100,000 adults. In the report, the average survival time of young adults in a PVS is estimated to be 5 years.¹²

In 1994, Eluana was transferred from the hospital to a nursing home in Lecco (Lombardy), where her parents live. She never left the nursing home, until shortly before her death in 2009.¹³ The nursing home is an NHS-attached private institution. It receives public funding for some of its patients, among them Eluana. The NHS had also covered the costs of all previous treatment and hospitalizations. Her family never had to pay for her care. Based on data from six Italian regions, the 2005 Ministerial Report shows that the majority of PVS patients in Italy reside in NHS-attached nursing homes, which provide medical and nursing care and physiotherapy to PVS patients as well as psychological support for family members.¹⁴

After Eluana’s transferal to the nursing home, Englaro started to look for an advocate who would represent him in court. It was a long and difficult search that took him two years.¹⁵

Nine years of court proceedings (1997-2006)
In 1996, her father had Eluana examined by a well-known professor of neurology. In a written statement, the professor described her condition and concluded that there was no hope of recovery. Another prominent neurologist visited Eluana and confirmed this.¹⁶ Englaro had Eluana declared legally incapacitated and he was appointed her guardian by the Surrogate’s Court. The so-called ‘incapacitation procedure’ exists in all Civil Law countries to protect individuals who are of unsound mind and therefore unable to see to their financial interests. This procedure was chosen for lack of a more suitable legal instrument of substitute decision-making in the health-care setting.

Englaro sent a formal request to the director of the nursing home to stop Eluana’s artificial nutrition

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⁹ See note 1, Englaro, Nave 2008:37-38.
¹⁰ See note 2, Moratti 2008:398.
¹³ See note 1, Englaro, Nave 2008:39.
¹⁶ See note 1, Englaro, Nave 2008:41.
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and hydration, but the director, replying in a letter, refused to do so. In early 1999, Englaro addressed a petition to the First Instance Court of Lecco for authorisation as guardian to direct the nursing home personnel to withdraw artificial feeding and hydration from his daughter. The court argued that the Italian legal system grants unconditional protection to human life. Englaro appealed, but the Court of Appeals of Milan argued that artificial nutrition must be regarded as ‘basic care’. In late 2000, the Minister of Health appointed a working group on artificial nutrition and hydration in PVS patients, called the Oleari Commission, after its president. The Oleari report makes express reference to the Englaro case. According to the Report, artificial nutrition and hydration is medical treatment and withdrawal decisions are legitimate, if based on the will of the patient. If the patient did not express his or her wishes before becoming incompetent, decisions should be made by the patient’s guardian. In early 2002, Englaro lodged a new claim with the First Instance Court of Lecco, arguing that the Oleari report had settled the controversy over artificial nutrition and hydration. The court did not accept this claim and stressed that the Italian College of Physicians had never issued a position statement on artificial feeding and hydration. The court observed that the Italian legal system protects human life. Englaro appealed and produced new evidence. Eluana had written in her diary that she found death preferable to permanent unconsciousness. She had discussed the issue with some acquaintances after having visited her irreversibly comatose friend in hospital. In late 2003 the Court of Appeals of Milan rejected the claim, arguing that advance directives, whether in writing or based on testimonies, have no legal status in Italy and do not provide a legal ground for decisions to withdraw life-prolonging treatment. The court also observed that the Oleari Report is not binding on the courts. Englaro appealed again. In 2005, the Italian Supreme Court declined to review the case. In the court’s view, there was a potential conflict of interest between Eluana and her guardian. In such cases, the Civil Code prescribes the appointment of a curator who shares the decision-making power with the guardian. Eluana’s father arranged for the appointment of the curator and again sought a declaration that withdrawal of treatment would be lawful from the First Instance Court of Lecco. In early 2006, the court denied the petition. Again, reference was made to the protection of human life in the national legal system. Furthermore, the court made reference to an influential position statement on artificial nutrition and hydration, issued a few months earlier by the National Bioethics Committee. About two thirds of the members of the Committee had supported the majority statement, to the effect that artificial nutrition and hydration is ‘basic care’. Englaro appealed, but the Court of Appeals of Milan affirmed the decision of the lower court in late 2006.

The breakthrough (2007)

With Englaro’s appeal to the Supreme Court in 2007, however, the situation changed. In late 2007, the Supreme Court ruled that withdrawal of artificial nutrition and hydration from a PVS patient is permissible, under specific circumstances: (1) accurate medical controls show that the patient’s condition is irreversible (2) artificially prolonging the patient’s life is inconsistent with his or her express wishes, character, or outlook on life. The Supreme Court remanded the case to the Court of Appeals of Milan. In July 2008, the Court of Appeals of Milan ruled that, in Eluana’s case, the two requirements set by the Supreme Court were met. Therefore, the court reasoned, her feeding tube could be withdrawn. The Court of Appeals also referred to two well-known European cases involving judicial permission for withdrawing nutrition and hydration from PVS patients: Hervé Pierra (France) and Tony Bland (UK). The final paragraph of the ruling was written with the help of a palliative care expert and prescribed how the withdrawal of treatment had to be carried out in practice. Satisfied with the decision of the Court of Appeals, Englaro asked the media not to give the case

17 See note 1, Englaro, Nave 2008:49.
18 See note 1, Englaro, Nave 2008:50-52 and note 2, Moratti 2008:410-413.
19 Supreme Court, first Civil Chamber, 6 October 2007, no 21748. Il foro italiano 2007(1):3025.
further publicity.21

However, Englaro’s wish was not followed because the highest institutions of the country intervened. About one month after the Court of Appeals’ ruling, a few conservative MPs took the initiative to involve the Constitutional Court in the case. Their initiative received the formal support of the majority of MPs. The Constitutional Court rules over, among other matters, cases of conflict of competence between the judiciary and the legislature. The MPs argued that the courts cannot grant permission for an action that leads to the ending of a human life; the matter must be regulated by statute. In late 2008 the Constitutional Court rejected the claim and observed that what the parliamentarians had done amounted in fact to an attempt by Parliament to criticize the contents of the Englaro rulings. The Constitutional Court added that if the Parliament deemed statutory regulation of end-of-life issues necessary, it could enact a law to that effect.22

At the same time, the Prosecutor’s office attached to the Court of Appeals of Milan appealed to the Supreme Court. In late 2008, the Supreme Court held that the Prosecutor’s office was not entitled to lodge an appeal. The Englaro case was not a criminal trial; according to statutory and case law the Prosecutor can only appeal if there is a ‘public interest’ in doing so.23

The ruling of the Court of Appeal of Milan requires that the withdrawal of treatment is carried out by a health-care professional and that Eluana should end her days in a hospice. The head of Lombardy’s regional NHS division issued a statement, to the effect that withdrawing artificial nutrition and hydration from a PVS patient constitutes a violation of a doctor’s or caretaker’s professional duty.24 This statement was criticized by the president of the Italian Association of Private Health Care Institutions. Englaro sought contacts with hospitals and hospices in other regions. The presidents of Piedmont and Tuscany stated that they could see no obstacle to admitting Eluana to one of the health-care institutions in their respective regions. However, some directors of health-care institutions and local politicians voiced their opposition.25 In December 2008, the Minister of Health issued recommendations to NHS-attached health-care institutions, against withdrawal of artificial nutrition and hydration from PVS patients.26 Notwithstanding the Minister’s position statement, a few days later the board of directors of an NHS-attached nursing home in Udine (in the region Friuli-Venezia Giulia) volunteered to admit Eluana. A team of health-care professionals (led by an anesthesiologist and head of the ICU of the local university hospital) volunteered to withdraw Eluana’s treatment and take care of her in the last phase of her life. Several doctors and nurses from all over the country wanted to be part of the team of volunteers and contacted the anesthesiologist (personal communication). The Minister of Health stated that the Udine nursing home could in principle lose its entitlement to public funding for allowing the team of volunteers to withdraw Eluana’s feeding tube. The Governor of Friuli Venezia-Giulia (the region where Udine is) replied that the Italian Constitution grants his region special independence from the central government. The Governor, not the Minister of Health, has the ultimate power to make decisions on health care at the regional level, including decisions on the

allocation of public funds. Some local politicians released statements supporting the Governor. The Governor and the Minister of Health are members of the same political party.

In the midst of this political turmoil, a number of associations of families of PVS patients brought a case before the European Court of Human Rights (ECHR). They held that the ruling permitting the withdrawal of Eluana’s feeding tube contrasts with the right to life and the principle of non-discrimination laid down in the European Convention of Human Rights. The ECHR argued that the petitioners had no relationship with Eluana Englaro and rejected their demand.

End of life (2009)
Englaro’s choice eventually fell on a private, not NHS-attached home for the elderly, also located in the city of Udine. Eluana was transferred in early February 2009. The anesthesiologist and his team kept her under observation for three days. It appeared that she was in a much poorer condition than had been reported in the media. Despite what some media reports had suggested, feeding her without a tube would have been impossible. Even her saliva had to be drained, because she was not able to swallow (personal communication).

The anesthesiologist and some members of his team drafted a protocol, a step-by-step regulation of treatment withdrawal and end-of-life care for Eluana. The local Prosecutor saw to it that the protocol was consistent with the contents of the 2008 ruling of the Court of Appeals of Milan. Two medical experts appointed by the local court monitored the behavior of the team of volunteers and its consistency with the protocol.

In the meantime, several politicians of the center-right coalition then in power called for government intervention. Prime Minister Silvio Berlusconi’s primary political focus was always on economic issues rather than civil liberties. He usually did not take a position on controversial ethical issues, thus avoiding having to commit his party or his coalition to a particular position. However, in the case of Eluana Englaro he intervened personally. He said there were plans to pass a bill prohibiting withdrawal of artificial nutrition and hydration from PVS patients. A spokesman for the Vatican reported its satisfaction with Berlusconi’s action, while a major ally of Berlusconi, Gianfranco Fini, reported that he was in favor of treatment withdrawal. The bill was discussed in Parliament.

In the Italian legal system, a bill does not become law unless signed by the President. The President is not the Prime Minister, the leader of the Government. The President is elected by the Parliament in joint session every 7 years, and roughly speaking his role is the same as the monarch in a constitutional monarchy. In an open letter to the Prime Minister, the current President, Giorgio Napolitano, stated that he was not willing to sign a bill prohibiting withdrawal of artificial nutrition and hydration from PVS patients. He argued that it would be unconstitutional to pass a bill in order to prevent a judicial ruling from taking its effect. Napolitano’s letter was published in all the major newspapers.

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29 Anonymous. Lei non è più quella delle fotografie [She is not the girl in the pictures anymore]. Corriere della Sera 2009, Feb 4.


31 The letter of the President is available online at http://bit.ly/IdLCcV (last accessed 10 April 2012).
On the fourth day after her admission, Eluana’s feeding tube was withdrawn. Media attention was at its peak. The Government announced its intention to bypass the opposition of the President by enacting an emergency decree. In the meantime, the media reported contradictory information on the condition of PVS patients. Englaro stated that he would never show pictures of his daughter in a PVS (all images of Eluana in the media therefore portray a smiling, lively and healthy young lady) and suggested that the Prime Minister and the Minister of Health should see his daughter personally. However, they did not do so. On the evening of 9 February, during parliamentary discussion of the emergency decree, the President of the Chamber of Deputies announced that Eluana Englaro had died. One minute of silence was observed and parliamentary discussion of the decree stopped.

Afterthought

In the Englaro case, the courts were looking for evidence of the patient’s refusal of life-prolonging treatment. The focus was on Eluana’s wishes and not on the futility of artificial nutrition and hydration, which was not benefitting Eluana. The patient’s consent to life-prolonging treatment was presumed throughout the trial. However, it is open to question whether people would actually consent to be kept alive artificially in PVS, a condition that is at odds with our intuitive notion of a life worth living. One of the health-care professionals involved in the care of Eluana said (personal communication):

Even here in the ward we were also victims of the media storm. They sold us daily images of a beautiful, young Eluana. It was quite another thing and far more shocking to see her after she had been bed-ridden for 17 years. [...] Ramón Sampedro’s words came back to my mind: “a living head attached to a dead body” – but in Eluana’s case her head was as dead as her body! The sight of a human being in that condition makes one reflect, and one’s reaction is instinctive – one thinks: “I do not want this to happen to me, ever”.

PVS patients are unconscious, dependent on the care of others even for the most elementary physical needs, and face gradual physical degradation. Immobility and the impossibility of ingesting food – among other conditions – cause extreme weight loss, sores, and mean that patients are highly vulnerable to infections. The physical appearance of the patient changes dramatically, notwithstanding passive physiotherapy and nursing care. The fact that Eluana, being unconscious and unable to experience pain and suffering, was not aware of her own condition, did not make her situation any less undignified. There was no hope that her situation would improve. Keeping her alive under those circumstances cannot be regarded as beneficial. This is a fundamental question that did not receive adequate attention in the Englaro case.

Contrary to what seemed to be the assumption in the Englaro case, it is not the withdrawal of life-prolonging treatment that needs to be justified, but rather its initiation or continuation. Intensive care and artificial feeding under these circumstances constitute an invasion of the patient’s physical integrity. Such an invasion is justified only if the treatment benefits the patient.

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32 The Decree is available online at http://bit.ly/HxEpVX (last accessed 10 April 2012).
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Developments after the Englaro case
The 2008 ruling of the Supreme Court in Englaro set a precedent and its effects on the prevalence of PVS in Italy are yet to be seen. However, its impact on medical practice will be limited, because one of the requirements for lawfully withdrawing treatment is producing evidence of the patient’s will. Furthermore, the Englaro judgment could be overruled. A few weeks after Eluana’s death, a conservative MP introduced a bill in Parliament, regulating Advance Directives (ADs) and substitute decision making in the health-care setting. The contents of the bill contrast sharply with the Englaro ruling. A guardian cannot refuse life-prolonging treatment on behalf of the incapacitated patient. The patient can refuse life-prolonging treatment via an AD, provided that the treatment is “medically futile” or “experimental” or “highly invasive”, and with the exception of artificial nutrition and hydration that is not “medical treatment”. The bill was passed in the Senate and is at present under consideration in the Chamber of Deputies.

In June 2009, the Italian College of Physicians issued a position statement, expressing concern with the possible reflections of the proposed bill on the doctor-patient relationship, should it become law. In its statement, the College argues that artificial feeding is “medical treatment”. The College observes that some provisions in the bill seem vague, and urges more clarity on the conditions that make a non-treatment decision permissible and on the possible legal consequences for doctors. As some MPs noted, it is open to question whether the bill is consistent with some constitutional provisions, in particular the right to physical integrity and personal liberty. The President may refuse to sign the bill and remand it to the Chambers for further consideration. With the President’s signature, the bill becomes law. However, if a law is unconstitutional, the Constitutional Court may invalidate it.

The Englaro case bears substantial resemblance to other cases of withdrawal of life-prolonging treatment from PVS patients, including Bland in the UK, Pierra in France, Kristina in Norway and Schiavo in the US. There is much yet to be discussed on the ethical and legal implications of the PVS. The Englaro case deserves to be discussed together with these cases, in a comparative framework.
