

Pasquale Striano  
Francesca Bifulco  
Giuseppe Servillo

## The saga of Eluana Englaro: another tragedy feeding the media

Received: 7 January 2009

Accepted: 21 March 2009

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### The story

On 13th November 2008, the Supreme Court in Milan for the first time in Italy allowed stopping fluids and nutrition to a patient in a persistent vegetative state (PVS) who was still alive [1].

Eluana Englaro (born in 1972) is a 36-year-old Italian woman who entered PVS on January 18, 1992, at the age of 19 years, following a car accident. Since 1996, her father, Beppino Englaro, proposed removing the feeding tube and allowing her to die, as the girl “had clearly expressed the wish to die in case of an accident that left her in a vegetative state”. In 1999, the tribunal of Lecco first denied Mr. Englaro’s request. The case was then debated in court and the man’s request was denied both in December 1999 by the Milan Court of Appeal and in April 2005 by the Court of Cassation [2]. A request for a new trial was granted by the Court of Cassation on 16 October, 2007 [3] and, finally, Italy’s supreme court made a groundbreaking ruling that affirmed a person’s right to die [4].

### A legal battle, a legal void

In the last few years, Eluana Englaro’s case has been the object of bitter discussion in the media and her emotionally moving tragedy has often been compared to that of American Terry Schiavo, the Florida woman whose case sparked a worldwide debate over end-of-life issues [5, 6]. Unlike Schiavo’s parents, Mr. Englaro has appeared on TV frequently in the last decade, asking officials to free his daughter from “the inhumane and degrading condition in which she is forced to exist”. He argued that Eluana said plainly during her life that she would not wish to live in a vegetative state. The man has been fighting for 10 years, particularly against Catholic officials and politicians who follow the Vatican’s line, that removing life support is equivalent to euthanasia. During that time, the case has sparked controversy because of the current debate in Italy on end-of-life issues [7–11]. Now, the final decision of the Cassation Court confirms a lower court ruling that authorised doctors may be permitted to let Miss Englaro die. The court rejected an appeal from Milan prosecutors, saying it was ‘inadmissible’ because the case did not concern the general interest, as the prosecutors argued, but individual rights. Meanwhile Eluana’s lawyers labeled this judgment ‘perfect’. Catholic politicians were quick to condemn the ruling and promised a law that would reverse it. Critics of the decision accuse judges of sneaking in euthanasia through the back door. The Vatican harshly criticized the court’s decision. Cardinal Tettamanzi, the archbishop of Milan, says he is hoping civil authorities will ‘change their minds’ about allowing ‘a beloved creature of God’ to be deprived of food and water [12]. Also, the Italian government of Silvio Berlusconi has attacked the court ruling and questioned the ability of judges to determine that her condition is ‘irreversible’. Roberto Formigoni, President of the Lombardy region,

stated that “...any doctor who kills a patient by removing the feeding tube would face disciplinary action for failing to honour commitments to the well-being of their patients” [13]. Indeed, both the government and Catholic officials are worried the Englaro decision will pave the way for a court ruling or legislation in the Italian parliament that would legalize assisted suicide or euthanasia. Luca Volonté of the Catholic party claimed that “the Cassation Court has authorised the first state homicide”. Isabella Bertolini of Premier Berlusconi’s Party accused the Cassation Court of “signing Eluana Englaro’s death warrant and opening a deep wound in the country which will be hard to heal”. Indeed, most political observers admitted that there is currently a legislative void in Italy on issues such as living wills and related end-of-life questions. Thus, Donatella Poretti of the opposition Democratic Party welcomed the sentence and urged parliament to enshrine it in Italian law. “We need a law that will remove the need for other Beppino Englaros to fight for years through the courts”, she said. Dr. Vincenzo Carpino, president of the Italian Hospital Anaesthetists and Intensivists Association, welcomed the ruling, noting that “the vegetative state has lasted nearly 20 years and the parents’ right to carry out their daughter’s wishes must be respected”.

Following the decision of the Supreme Court to stop fluids and nutrition to Eluana, some pro-life advocates promptly looked at the legal possibility of getting appointed or taking her case to the European Court of Human Rights at Strasbourg. However, on February 9th 2009, Eluana died 4 days after the removal of her feeding tubes.

### A controversy fuelled by the media

In the last few years, the tragic history of Eluana has been a staple of print and

broadcast media in Italy. There has been particularly ubiquitous media coverage of her father proposing to remove the feeding tube as well as of the intense political action that was generated on both sides of the debate.

Notably, while many print and broadcast media outlets chose to sensationalize the dispute over the treatment issue, a second area of dispute was whether the girl was in a vegetative state or whether she showed signs of awareness. Sadly, many media outlets interviewed some 'experts' who often reported conflicting messages about Eluana's diagnosis, behavioral repertoire, and prognosis.

Even though Eluana's chances of recovery were practically nonexistent after several years in PVS, claims that she would or might improve or recover were frequent. Some journalists reported that Eluana might improve or recover based only on the description of the girl's nonpurposeful movements such as laughing, crying, grimacing, and eye opening to external stimuli. This caused confusion, misunderstanding, and puzzling questions for most viewers who have no idea that subjects with PVS may occasionally exhibit such behaviors. Furthermore, attempts to define and explain the subject's condition were infrequent, and some provided exaggerated accounts of suffering following removal of a feeding tube. These erroneous or misleading statements, as well as false hopes for recovery, were disseminated in a general absence of adequate critical examination and background information [6, 14].

## Conclusion

End-of-life care is emerging as a comprehensive area of expertise in the intensive care unit [ICU] and demands the same high level of knowledge and competence as all other areas of ICU practice [15]. It is well known that important intercontinental differences exist toward end-

of-life issues, with treatment limitations more acceptable among US and Northern European countries than in Southern European and Middle East societies [10, 15]. In the last few years, the awareness of the problem has reached the level of public opinion. Some recent cases have particularly generated unprecedented public interest in Italy [9–11], indicating the urgent need for clear regulation of end-of-life care. It often happens that when conflicts involving end-of-life issues reach the public, they are considered essentially religious in nature. Instead, such decisions should primarily follow ethical and moral principles. Some medical societies, including the Italian Society of Anaesthesia, Analgesia, Resuscitation, and Intensive Care (SIAARTI), have taken up a position to guide physicians dealing with terminally ill patients [16]. In general, the ideal guidelines when dealing with the end-of-life issues should take into account several aspects, including the distinctions between withholding and withdrawing treatments, adequate pain management, and relieving burden [17, 18]. Information to the families should be delivered in ways that are sensitive to their cultural, religious, and language needs [19, 20]. Because print and broadcast media reports influence public perception and opinion about medical conditions, they have a social responsibility to educate by accurately explaining the basic facts necessary to understand the issues [6, 14]. It is easier to be touched than to reflect.

Statement of Eluana Englaro (after the accidental death of a friend, and shortly before her car crash): If ever I will not be what I am now, I'd rather prefer to leave.

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P. Striano  
Department of Muscular and  
Neurodegenerative Disease Unit,  
G. Gaslini Institute, Genoa, Italy

F. Bifulco · G. Servillo (✉)  
Medical Intensive Care Unit,  
Department of Surgical and  
Anesthesiological Sciences,  
Federico II University, Naples, Italy  
e-mail: servillo@unina.it  
Tel.: +39-081-7463554  
Fax: +39-081-5466338