

Advance Care Directives: Florida, Italy and the Holy Grail of Wishes

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Terri Schiavo and Eluana Englaro, two young women in persistent vegetative states, have riveted the respective attention of the U.S. and Italian public as their very personal and painful stories were broadcast to the world, while courts and legislatures in both countries have strained to define the conditions under which life sustaining medical measures may be terminated legally.

While the former case was U.S. based with Florida law applicable, the latter is taking place on Italian soil and adjudicated applying Italian law. The Schiavo case took eight years of litigation, while Englaro has racked up nine years of litigation and her case may just now be reaching resolution¹. Different cultures and different legal systems – but these cases come together over the right of an individual to have a choice over his or her care – and to die with dignity.

One of the most interesting aspects of these cases is the way in which the courts have struggled to ascertain what health care Terri Schiavo or Eluana Englaro would have wanted, *implicitly* letting the public know through in their opinions how valuable it would have been to have had the patients' wishes on health care in writing.

Terri Schiavo

In 1990 Terri Schiavo, at the age of 27, collapsed in her home experiencing cardiac and respiratory arrest and was subsequently diagnosed to be in a persistent vegetative state with no expectation of recovery by her physicians. At the time Florida law provided - and continues to provide - for the use of an *Advance Care Directive* ("Directive")².

The absence of a Directive from Mrs. Schiavo was noted in the first petition filed on her behalf by her husband, Michael Schiavo in 1998. In that petition, Mr. Schiavo asked the Florida State District Court for authorization to discontinue artificial life support.

A bench trial was subsequently held by the Court in 2000 to consider Mr. Schiavo's petition which, given the lack of a "written instrument" from Mrs. Schiavo, sought to establish her wishes with respect to life prolonging measures, using other evidence.³ The Florida court proceeded to wrestle with numerous testimonies in its efforts to determine whether, prior to Mrs. Schiavo's collapse 10 years earlier, there was "clear and convincing evidence" that she had made reliable oral declarations to the effect that if she had found herself in such a situation that she would have wanted her feeding tubes removed.

The court, relying on hearsay statements alleged to have been made by Mrs. Schiavo at varying times: after seeing her grandmother on life support, after watching a TV program concerning people on life support and after a movie on TV about a man in a coma, held that these statements rose to the level of clear and convincing evidence and granted the petition for authorization to discontinue life support. It took another 5 years of appeals and petitions before the court's decision for discontinuance was eventually carried out.

Eluana Englaro

Like Mrs. Schiavo, Eluana Englaro – who is known in Italy as the “Italian Terri Schiavo” - was determined at the age of 20 to be in a persistent vegetative state following an auto accident in 1992 which caused her to enter into an irreversible coma. Prior to the Italian Court of Cassation’s⁴ agreement to hear the case, her family had argued unsuccessfully seven times before various lower courts to have doctors remove her feeding tubes on the grounds that artificial feeding was futile medical therapy and that Ms. Englaro had manifested her will against such therapy.⁵

Importantly in the United States artificial feeding is generally viewed as a *medical treatment*. In Italy, on the other hand, there is still debate as to whether it is a *medical treatment* or *basic sustenance*, which is ethically due a patient⁶. The effects as to which side of the debate a court finds itself can be seen in the opinions of the Court of Appeals and the Court of Cassation in the Englaro case.

In 2006 the Milan Court of Appeals heard the sixth appeal on this matter. As the Court did not view artificial feeding and hydration as *medical treatment* but as *basic sustenance*, it dismissed the argument that artificial feeding was a form of futile medical care.

The Court did recognize that competent individuals have the right to refuse even indispensable health care⁷. It then distinguished this from the situation of an incapacitated individual whose wishes were unclear and who was only receiving *nutrition*, without which the patient would die. It noted that the irrevocable consequences of the suspension of artificial feeding must be taken into account as suspension would lead to death in a short period of time and would be tantamount to euthanasia⁸ by “indirect omission”⁹. It reasoned that because of these consequences a balance had to be struck among the Constitutional rights to self-determination and personal dignity and the right to life¹⁰.

The Court of Appeals in order to try to ascertain her wishes, then examined oral statements made by Ms. Englaro to the effect that she thought that a friend who had entered a coma after a car accident would have been better off if he had not survived, and testimony showing that she had manifested her conviction against life prolonging measures in a school discussion on the topic. Unsurprisingly, the Court of Appeals ultimately found that these statements were too general and could not be used to establish her wishes as they did not amount to a conscious decision arrived at on an informed basis. It noted that the comments were made in reference to the condition of another person, that they were made when she was very young and healthy and not living with an illness, that she was lacking in maturity with respect to the themes of life and death and that she could not have even imagined her present condition.

The total effect of the Milan Court of Appeals’ words leads the reader to wonder whether perhaps Ms. Englaro would have needed to have expressed her wishes from the vantage point of actually being in a persistent vegetative state, which of course is an impossibility – a perfect *Catch-22*.

In the Court’s view there was insufficient evidence as to her wishes and it held that Ms. Englaro had to be considered an incapacitated individual who had been silent as to her preference for medical care. Therefore, it could only achieve a balance among her constitutional rights by deciding “in favor of protecting her life”, i.e., continuing artificial nutrition and hydration¹¹.

Ms. Englaro's family appealed the decision of the Milan Court of Appeals to the Court of Cassation, which accepted the appeal despite the opinion filed by the Court of Cassation's own solicitor general to reject the appeal on the basis that artificial feeding was not a *medical treatment*, but a form of *basic sustenance*. In its opinion the Court of Cassation makes clear its position by simply stating that artificial feeding is "without doubt¹²" a *medical treatment*.

As opposed to Florida, which has laws in place authorizing the use of advance care directives, Italy does not have any similar laws¹³¹⁴. In view of the lack of legislation, the Court of Cassation reasoned that it still had a duty to protect the patient's rights within the parameters set by the constitution and thus in its holding of October 2007, it laid down a test for the type of proof necessary to allow for the discontinuance of *medical treatment*.

According to that decision, feeding may cease if:

1. The vegetative state is persistent and, according to internationally recognized scientific standards there is no medical basis to expect recovery of consciousness; and
2. It is clearly, unequivocally and convincingly shown that the patient, before losing consciousness, would have been against continuing treatment.¹⁵

The burden of proof set by this test is extremely high and requires court approval for the discontinuance of feeding- a process that leaves the door open to further litigation. Moreover, without legislation on point and the open debate as to whether artificial feeding is a *medical treatment* or *basic sustenance* the risk that court battles in situations similar to the Englaro case could still occur in Italy for the foreseeable future is high. It is questionable whether even the testimony in the Schiavo case would have met this burden of proof had that case been adjudicated in Italy.

Judicial "End Run"

In a case decided in May 2008, which seems to have been inspired by the Court of Cassation's holding in Englaro, a "guardianship judge"¹⁶ in Modena, Italy used relatively new legislation¹⁷ to devise a way around the legislative void on health care directives. This new legislation created a qualified guardian figure ("*amministratore di sostegno*") who, upon judicial appointment, may take decisions on behalf of an individual without the necessity for a court to declare an individual incompetent.

The case involved Vincenza Santoro Galano, a 70-year old woman hospitalized with end-stage Lou Gehrig's Disease. Upon admission to the hospital she indicated unequivocally that she did not want to undergo a tracheotomy to enable mechanical breathing when respiratory failure occurred. The issue before the guardianship judge however revolved around the fact that at the moment in which she would enter into respiratory arrest she would also be in a state that would render her incapacitated and unable to refuse life saving *medical treatment*. In all probability the medical staff would perform a tracheotomy to place her on mechanical ventilation to save her life. She therefore decided to petition the guardianship judge, with the backing of her family, asking the judge to provide "support [...] so that once she became incapacitated someone could act on her behalf, in the denial of consent to that specific [tracheotomy] medical intervention".¹⁸

In rendering his decree, the judge focused on the woman's unequivocally expressed wish to not undergo the life prolonging medical therapy and devised a solution for carrying out that wish when she became incapacitated. By appointing her husband as her qualified guardian with the specific duty of denying consent to a tracheotomy the judge worked around the legislative void on Directives. The judge even went so far as to brazenly remark that the law which created the guardianship provides that the qualified guardian can be designated by the individual himself in a public deed or private writing in the expectation of a probable future incapacity". Out of the blue he then goes on to express his view that legislation on advance care directives was therefore "absolutely superfluous"¹⁹. This, of course, overlooked the fact that the guardian must ultimately be appointed by the guardianship judge²⁰ and that a tracheotomy is a *medical treatment*.

Directives

However, the Modena Court decree illustrates the important persuasive effect of the Court of Cassation's holding. By providing guidance to lower courts in Italy in the absence of legislation on Directives it stimulated a willing member of the judiciary to use the qualified guardianship legislation to fill this void when the wishes of the patient were unequivocally expressed. These cases all illustrate the courts' search for clear guidance from the patient as to their wishes.

This, however, still begs the question as to what a person can do to leave such proof in a country like Italy which does not have specific legislation providing guidance as to how an individual can legally express his or her wishes unequivocally on end-of-life medical care.

The use of Directives in the United States developed for just these reasons. If Terri Schiavo had executed a Directive her case may not have even been brought to court as there would have been no need to determine her wishes from statements made to family members. Her physicians and her family would have had written evidence that she had thought about her medical care and had made a decision as to its course²¹. Had Ms. Englaro executed a Directive it would have undone to some extent the Milan Court of Appeals' reasoning that she had not imagined her current state and that she lacked the maturity to face such themes as life and death. Further because of the constitutionally sanctioned rights to refuse medical care and to informed consent, the courts would naturally have looked to the Directive for guidance despite the on-going debate over medical treatment v. artificial feeding. It is very likely that Ms. Englaro and her family would have had resolution without having to appeal to the Court of Cassation.

Although there is no legislation on Directives in Italy, the courts' holdings show that knowing a patient's wishes is the holy grail in these matters. The Schiavo and Englaro cases have shown that courts need and look for direction from patients in adjudicating these matters. The Galano case illustrates that when faced with unequivocal direction from a patient the Courts will do the utmost to find a way to honor that request.

Executing a U.S. style Directive in Italy will allow an individual to express his or her health care wishes clearly. To the extent that these wishes can be honored by physicians and courts they will be. While a Directive may not resolve a situation in which the care received is considered *basic sustenance*, such as in Eluana Englaro's situation, in all those cases in which it is clear that what is being refused is a *medical treatment* the Directive will be welcome and highly valued evidence of what medical treatments the individual would have wanted or desired to be withheld, thus sparing the individual's family, physician and the justice system from protracted court battles.

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¹ On June 25, 2008 the first Section of the Milan Court of Appeals on remand from the Court of Cassation handed down a decision in favor of disconnecting Ms. Englaro's feeding tubes. The State's Attorney has up to one year to appeal the holding.

² An Advance Care Directive allows you to specify your wishes and appoint someone to express them at a future time when you may be incapacitated. Directives are typically divided into two sections: a "living will" portion, setting forth your wishes as to the course medical treatment should take in specific situations; and a "health care proxy", in which one or more individuals are appointed to act in a fiduciary capacity to make health care decisions based on your Directives.

³ In re: Guardianship of Theresa Marie Schiavo Incapacitated," File No. 90-2908GD-003, Fla. 6th Judicial Circuit, February 11, 2000

⁴ Final appellate review in Italy is divided between the Constitutional Court (*Corte Costituzionale*), and the Court of Cassation (*Corte di Cassazione*). The latter is Italy's highest ordinary court. It has no original jurisdiction and reviews only questions of law appealed from a decision of a court of appeal. It is divided into five member sections. A case may be reviewed *en banc* (*sezioni unite*) by a panel of nine judges selected from all sections of the Court. The Court also may sit *en banc* where a question of law has already been decided in a conflicting manner by different sections and, in any event, in cases involving questions of great importance. Until an issue has been decided *en banc*, there is the possibility of conflicting Court of Cassation precedents. See Title VI Article 134, Constitution of the Republic of Italy; Royal Decree N. 12 of January 30, 1941.

Since Italy is a civil law system decisions even of the highest courts are not binding as precedent but serve a persuasive function. The Englaro case was not heard *en banc*, but by the First Civil Section of the Court of Cassation -- giving less weight to its holding. Its persuasive function will be compelling to lower courts, but will not be as strong as if the Court had heard the appeal *en banc*. This also means that another section of the Court could hold differently on an appeal arising from a similar factual situation.

⁵ In Italy under the principle of informed consent no one can be forced to undergo medical treatment, except in instances specifically provided by law (such as mandatory vaccination for school aged children) without consenting to it, even in those cases where lack of treatment would damage the patient's health or result in death. The concept of informed consent in Italy is expressly grounded in the Italian Constitution which provides a basic right to "self-determination". Arts. 13, 30 Constitution of the Italian Republic.

Italy is also a party to the Convention of the European Council on Human Rights and Biomedicine (signed in Oviedo, Spain on April 4, 1997; ratified by Italy on March 28, 2001 by Law No. 145). This convention states that if at the time of medical intervention the patient is unable to express an opinion on treatment, the patient's "previously expressed wishes" (emphasis added) must be taken into consideration (Art. 9)

The Italian Code of Medical Ethics (*Codice Deontologico Medico*) also recognizes the importance of informed consent and of a patient's previously expressed wishes. Article 30 creates an ethical duty on the part of physicians to inform patients as to the type of care, alternatives to such care, its purpose, success rate, risks and side effects. Article 32 specifically provides that physicians are to discontinue diagnostic testing and/or medical care if presented with a patient's documented refusal of such testing or care. Article 14 provides that a physician is to desist from futile treatment that cannot improve the patient's health or quality of life, although tempered by a reference to the physician's responsibility to act within the scope of the independence that characterizes the medical profession.

Thus, if the artificial feeding and hydration are considered futile therapy a physician would be ethically bound to discontinue such therapy. Moreover if Ms. Englaro had previously manifested her wishes against the therapy then again physicians would have an ethical duty to discontinue the treatment, or at least document refusal to follow the patient's wishes.

⁶ The Italian National Committee on Bioethics (“Committee”), an important government advisory body created in 1990 by a decree of the President of the Republic of Italy composed of medical professionals, university professors and researchers, religious leaders and legal professionals, provides advice to the government on issues dealing with bioethics. In 2005, it addressed the issue of artificial feeding and hydration taking the stance that artificial feeding is *basic sustenance* and not a *medical treatment*. The opinion was not unanimously taken, but on a majority vote and was published with two dissenting notes.

In its opinion on artificial feeding the Committee referred to one of its earlier opinions on advance care directives in which it had recommended that legislation be passed authorizing the use of Directives. In the advance care directive opinion it had noted that providing for suspension of artificial feeding and hydration in an advance care directive was “very controversial”, but had limited itself to setting out the two points of view held in the Committee without providing guidance on the issue. See *Dichiarazioni Anticipate di Trattamento*, 28 December 2003. After reviewing the positions expressed in that opinion the Committee concluded that artificial hydration and nutrition of patients’ in PVS may only be ethically and legally suspended based on objective parameters, such as when the patient no longer assimilates the nutrition provided or has an intolerance to it, and it becomes futile therapy. In all other instances the Committee advised that a request in a Directive of suspension of artificial feeding would be a request for euthanasia. See *L’Alimentazione e l’Idratazione di Pazienti in Stato Vegetativo Persistente*” Opinion of the National Committee on Bioethics (“Comitato Nazionale per la Bioetica” or “Committee”) approved in plenary session on September 30, 2005, page 2.

⁷ Article 32, Constitution of the Italian Republic.

⁸ Euthanasia is illegal in Italy.

⁹ Cassazione Civile Sezione Prima, 14 October 2007 n. 21748 at page 10, quoting the Milan Court of Appeal judgment

¹⁰ See Article 2, Constitution of the Italian Republic; Title I; Article 13 Constitution of the Italian Republic; Title III, Article 32, Constitution of the Italian Republic; See also Constitutional Court case number 471, October 9, 1990 (personal freedom includes the right to give directions concerning one’s body).

¹¹ *Id.* at page 11, quoting the Milan Court of Appeal judgment

¹² Cassazione Civile Sezione Prima, 14 October 2007 n. 21748 at p. 53

¹³ There are several bills pending before both houses of Parliament on advance care directives. Among these bills is *Proposta di Legge* n. 779 before the Chamber of Deputies which specifically prohibits a patient or a physician from allowing, encouraging or consenting to the suspension of “life sustaining intervention which is not of an extraordinary character *such as artificial feeding or hydration*” (emphasis added).

¹⁴ There are no EU directives regarding advance health care directives. Their regulation is left up to national legislation. However, the European Union nations have enacted The Oviedo Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine, to which Italy is a party. Italy has also ratified the Convention, but it has not yet entered into force in Italy. The Convention provides in article 9 that “the previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.”

¹⁵ Cassazione Civile Sezione Prima, 14 October 2007 n. 21748 at p. 55

¹⁶ A “guardianship judge” or “*giudice tutelare*” is a judgeship created to protect the rights of minors and legally incompetent adults.

¹⁷ Law No. 6 of January 9, 2004

¹⁸ Decree of Dr. Guido Stanziani, Guardianship Judge of the Tribunal of Modena, 13 May 2008.

¹⁹ Decree of Dr. Guido Stanziani, Guardianship Judge of the Tribunal of Modena, 13 May 2008.

²⁰ Article 408 (2) of the Civil Code as amended by Law No. 6 of 9 January 2004. In fact Article 408 also provides that if there are “grave reasons” the guardianship judge can choose a different individual to act as the qualified guardian. The “grave reasons” are not defined by the legislation.

²¹ Florida’s law at the time of Terri Schiavo’s collapse provided that a competent adult could provide a declaration instructing a physician to withhold or withdraw life-prolonging procedures, or designating another to make the decision. See §§ 765.01-765.17 Fla. Stat. (1991). In 1992 these sections were repealed and replaced with broader provisions allowing, in the absence of an advance care directive, a proxy to make decisions for the incapacitated patient.