

Euthanasia in Italy: Work in progress

48 remember this number. To avoid misunderstanding it is not my age.

The first law presented to the Italian Parliament to legalize euthanasia dates to 1984. It was Loris Fortuna, a parliament member, who deposited it, the same politician who brought Italy to adopt a law for voluntary interruption of pregnancy and divorce.

After that proposed law, never discussed in Parliament, the debate in Italy about the end of life stopped until, from 2006 onwards, two cases highlighted by the media, the interruption of therapies by Piergiorgio Welby and Eluana Englaro causing their deaths, turned it again on the political agenda and in the discussions in the civil society.

Piergiorgio Welby asked to be detached from the respirator which kept him alive. Welby died in December 2006 due to respiratory insufficiency following this detachment by the doctor and anesthesiologist Mario Riccio. In a press conference held the day after, Riccio confirmed the circumstances of Welby's death and self-denounced. The prosecutor's office at the Court of Rome initiated an investigation on behalf. In Italy, the principle of mandatory requires that the Public Prosecutor assesses the validity of each information regarding potential crimes and performs the necessary investigations to decide whether it is necessary to formulate the imputation or request the filing.

Meanwhile, in February 2007 the Order of doctors ruled that the conduct held by Riccio was correct and not deserving of any sanction. In July 2007, the judge for the Preliminary investigations of the Court of Rome definitively acquitted the doctor because the fact did not constitute a crime.

According to positions, expressed by the Catholic Church, in this case, the argument "euthanasia" would be improperly brought into question because the issue concerned only if the request of Welby was based on the interruption of any therapy that kept him alive, including detachment from the artificial respirator, which as he was immobilized because of muscular dystrophy, could not be removed by himself.

The doctor's recourse was motivated by the contents of the article 32 –of the Constitution stating that “No one can be obliged to a given health care if not by provision of law. The law can under no circumstances violate the limits imposed by the respect of the human person.”

The Catholic Church refused the widow of Welby, Mina, the celebration of the funeral by the catholic rite.

Much debated in Italy was the case of Eluana Englaro, because of the ethical and political implications that it had, also in relation to the debate on euthanasia and the living will, Eluana a young woman, after a serious car accident occurred in 1992, remained in a persistent vegetative state until her death in February of 2009. Following the request of her father to suspend any therapy, and after a lengthy judicial battle lasting 17 years, a ruling of the Court of Appeal of Milan, confirmed in cassation, that the interruption of the treatment of vital support through artificial feeding and hydration and has provided ancillary provisions in the protocol to be followed for the interruption of treatment.

Before and after her death on February 9, 2009, in a clinic far from the city where she lived, because of the refusal of the doctors of the clinic where she was hospitalized, backed by the Council of the Lombardy Region, to implement the court's decision, the affair strongly affected the public opinion. In October 2018 (nine years later!) the court of Milan ordered the Council to pay a compensation to the father of Eluana, as the decision not to apply the above ruling of the court has caused additional useless suffering.

Following these cases, a law on palliative care and pain therapy was approved in 2010. It is a well-structured law, and therefore a topic that is frequently used by the opponents of euthanasia, objecting that with the diligent care provided to the patient, the need for legislation that allows euthanasia and assistance

in dying would be superfluous. Unfortunately, the care of the sick people in Italy is below an acceptable level and palliative care is accessible for about 35% of the population which percentage comes down to 5% regarding children. Of course, this state of art must not be a reason to request euthanasia.

Gradually, within civil society, a discussion began if human suffering without any prospect was acceptable, and the polls showed a growing acceptance by citizens to allow euthanasia or medical assisted suicide. More than 80% of the population is today in favour of legalization. There are no data available about abusive Medical Assistance in Dying, but there is the impression that it concerns about thousands of patients every year.

In September 2013, the Associazione Luca Coscioni together with other associations started the collection of signatures relating to the presentation of the law proposal through a popular initiative "Refusal of health treatments and lawfulness of euthanasia". The proposal was signed by more than 60,000 citizens, a continuously increasing number (currently around 140,000). The discussion of the proposal in Parliament started only in 2021, 8 years later.

In December 2017, the law called the "Advanced directives of treatment and informed consent" was approved by the Senate after a fierce battle against the conservative opposition, binding hospitals, and doctors to respond to the will of the patient and that civil disobedience is not permitted. To understand the importance of this rule an example. In the law regarding abortion, in force since 1978, the doctor can refuse the abortion referring to the right of civil disobedience. In practice in Italy eighty per cent of gynecologists, in some regions hundred per cent, refuse to accept the request of the pregnant woman, which obliges her to a move from hospital to hospital to find a doctor who assists her.

In February 2017 Marco Cappato, our treasurer, through an act of civil disobedience, accompanied Dj Fabo, following his request, to obtain assisted suicide in Switzerland. After his return in Italy, he self-denounced. The Penal Code (article 580) prohibits any assistance to facilitate suicide. The case came up to the Constitutional Court which gave 11 months time to the Parliament to legislate. If by September 2019 it had not approved a law following the indications laid down in the ruling, it will be the Constitutional Court itself to set the limits for recourse to assisted suicide.

The court's ruling reads among other: *"It is not contrary to the Constitution, the prohibition, sanctioned by the Penal Code, to facilitate suicide. However, it is necessary to consider specific situations, unimaginable at the moment when the incriminatory rule was introduced, but brought under its sphere of application by the developments of medical science and technology, often able to rip of the death, those patients in extremely compromised conditions, but not to give them back sufficient vital functions"and continues stating that "the reference is, more particularly, to the hypothesis in which the facilitated subject identifies itself in a person who is*

(a) suffering from an irreversible disease which is the

(b) source of physical or psychological suffering, which is absolutely intolerable, and is

(c) keeping alive by means of vital support treatments, but remains

(d) able to make free and conscious decisions.

It regards, in fact, the hypotheses in which the assistance by third parties in putting an end to his life, can present for the patient the only way out to end, respecting his own concept of dignity as an individual, the artificial maintenance in life no longer wants and that he has the right to refuse."

The Court ruled too that the ethics committee of the regional health authorities should determine the eligibility.

As the Parliament ignored the request to transform the sentence into law, the Constitutional Court ruled in 2019 that medical assisted dying is permitted if the above-mentioned criteria are met.

The ruling creates a discrimination for those sick incurable patients, suffering in an unbearable way but depending on pharmaceuticals for example patients suffering cancer. Therefore Mina Welby, widow of

Piergiorgio, has performed with Marco Cappato a second act of civil disobedience accompanying a person, suffering of multiple sclerosis, but not in a final phase of his decease, in Switzerland. This accompaniment was followed by a self-denunciation. The Court of Massa (western Italy) acquitted both investigated because the fact, regarding the instigation of suicide, does not constitute a criminal fact within the context of the ruling 242/19 of the Constitutional Court. It is a crucial decision because it clarifies that the requirement for the patient to have life supporting treatments are not limited to the presence of machinery only but also includes pharmacological treatments and assistance. The Court of Appeal of Genoa confirmed the ruling, but it did not come to a ruling by the Constitutional Court.

In August 2020, a quadriplegic patient called “Mario” asked the regional health authority of the Marche region (central Italy) to acknowledge that he met the conditions following the ruling of the Constitutional Court. Before our organization, on his request, informed him about all the possibilities to end his life like permanent deep sedation and the Swiss way. He decided the Italian way. After several trials and following the inaction of that committee Mario, assisted by our legal team, filed a criminal complaint against the committee for the crime of torture and governmental negligence. Finally, after a formal notice to the Italian Government, a commission visited the patient during September (13 months after his request). On October 14, 2021, Mario was informed that their opinion was transmitted to the ethics committee. Silence. On November 15, 2021, he sent a warning letter to the committee and finally on November 23, 2021, he received the message that he meets the four conditions indicated by the Constitutional Court, but they declined to express an opinion regarding the lethal drugs and the method of administration because there was no indication in the ruling of the Constitutional Court and no legislation exists which indicates such information. This was another act of sabotage. After the next warning letter, indicating the lethal drug to be used and the method of administration, on February 9, 2022, he received the final approval that he was free to decide when he will end his suffering, by means of assistance in dying which took place on June 16, 2022. Mario – Federico Carboni – was the first Italian who died following assisted dying in Italy, 48 years, you remember the number, after that the first proposal re assistance in dying was presented in Parliament.

His last words were: "I do not deny that I am sorry to say goodbye to life, I would be false and a liar if I said the opposite because life is fantastic, and we have only one. But unfortunately, it went like this. I have done everything possible to be able to live the best possible and try to recover the maximum from my disability, but now I am exhausted both mentally and physically. I do not have a minimum of autonomy of everyday life, I am at the mercy of events, I depend on others on everything, I am like a boat adrift in the ocean. I am aware of my physical condition and prospects so I am serene and calm about what I will do. With the Luca Coscioni Association we defended ourselves by attacking and we attacked defending ourselves, we made jurisprudence and a piece of history in our country, and I am proud and honored to have been at your side. Now I'm finally free to fly wherever I want."

The scandalous delay of the decision in another request brought forward by “Antonio,” forced him to ask for deep permanent sedation, as he could no longer endure his infernal sufferings. Other requests are pending or in preparation.

The Parliament continued to boycott the legislation of medical assisted dying. Therefore, we started new actions into two directions:

- To assist patients, who are eligible for assisted dying, but their requests are not honored.
- To call for a referendum to repeal partly article 579 of the penal code making it possible the assistance in dying of a consent person.

To obtain this change we have organized the collection of signatures regarding the call for a referendum to obtain the abovesaid repeal.

We collected 1.230.000 signatures (the minimum number according to the law is 500.000) of which about 600.000 through a digital platform. The incredible success of the digital collection was made possible thanks to the approval by the Parliament of a decree which made possible this method of collection but only regarding referendums. In no time we prepared a platform for collecting the signatures after the collection there are required bureaucratic procedures to validate these signatures. Between 30/40 volunteers have worked day and night to complete this process within tight deadlines.

To make it short at the end the Constitutional Court declared the referendum inadmissible as "*the minimum constitutionally necessary protection of human life, and with particular reference to weak and vulnerable people*" was not guaranteed. It should be said that theoretically after the approval of the referendum every adult could kill a person following his consent. It was clearly a political decision. The Constitutional Court, to guarantee the exercise of constitutional rights and in full guarantee of democracy, could and should have admitted the referendum knowing that, if necessary, any further blocks and limits could be decided subsequently by the Parliament or by the Government, by the courts or by the same Constitutional Court. In the short term there would also have been the possibility for the President of the Republic, on the proposal of the Minister concerned, subject to a resolution of the Council of Ministers, to delay the entry into force of the outcome of the referendum for 120 days, giving the possibility to the Government and Parliament to intervene according to their own prerogatives. You understand that this sad story does not stop our battle.

In the meantime, the discussion on a proposal of a law called "medically assisted voluntary dying" was started by the Parliament. Despite that the law is based on the Constitutional Court's decision as described before, it is more restrictive. Conscientious objection has been introduced, the patient must be in a terminal phase of the disease and suffers not only physically but also psychologically. In this regard the Court indicated "or" instead of "and". Moreover, there were no indications about the period (days) within the Committee and other institutions or medical staff have to present their opinions, leaving the possibility of sabotage. The question that the Court's decision discriminates patients who do not depend on vital support treatments but for example on treatments with pharmaceuticals and therefore cannot access medically assisted suicide, has not been taken into consideration. The proposal was approved by the Chamber of Deputies on March 20, 2022 and sent for approval to the Senate where the discussion was blocked by the conservative (Catholic) members belonging not only to the right but also to the left wing parties. Following the dissolution of the Parliament, the proposal lapsed. The elections were an important success for the right wing parties and the discussion of a new proposal will be problematic.

We have organized since 2021 an info line (telefono bianco) to inform citizens about euthanasia and other end-of-life matters like palliative care and the living will. Until today we have received this year about 9.300 requests, between 500 and 600 every month, managed by 30 volunteers which soon will increase to 60.

This stalmat over discriminatoir has made another civil disobedience initiatives mandatory. For this reason Marco Cappato last August 1st accompanied a woman Elena, who suffered from a tumor and did not depend on vital supports, in Switzerland to obtain the MAID. On his return to Italy, he denounced himself for the crime of instigating suicide. The case is awaited for judgment.

In 2019 our Association founded Eumans, an idea of Marco Cappato, with the objective to bring together citizens and activists all around Europe engaged in a bottom political mobilization for socially and democratically sustainable policies by the European Union. In the context of the voluntary end of life argument, one initiative, together with other organizations among other Right to Die Europe and single Members of the European Parliament, is the introduction of a "Living will Pass." On the Eumans website at the link eumans.eu/europeanlivingwill you can find the preliminary study that we prepared, in collaboration also with a significative group of European organisations and RTDE and that was presented for the first time in Warsaw during the Eumans Congress late March 2022. Recently we also circulated a Questionnaire which aims to get an overview of the different state of the art with regards to Advance Directives in the EU Member States, and we kindly ask all of you to support us to gather as much

information as possible. We propose to share the link with those of you who are interested.

We refer to the Recommendation adopted on 28 February 2022 brought forward by the citizens' panels of the Conference on the Future of Europe" stating that *"We recommend the EU should support palliative care and assisted death [euthanasia] following a concrete set of rules and regulations. We recommend this because it would reduce the often unbearable suffering of the patients and families and it would ensure a decent end of life"*.

We believe that the freedom of movement of citizens belonging to the European Union may imply the possibility for all citizens to exercise their rights wherever they are in the Union. The portability of civil rights, including those related to self-determination, is, indeed, to be protected and respected as a human right. Moreover, it should enable, through advanced information systems, to facilitate the access of information regarding the citizens' end of life desires.

In this respect an important initiative, regards a proposal by a number of members of the European Parliament who asked for a study re the "Right to Die in Dignity across Europe". The proposal was adopted and the study will probably be published at the end of 2022, beginning 2023.

Notwithstanding the resistance of the conservative Italian politicians backed by the Catholic Church, the legalization of euthanasia is and remains a high priority on our agenda and we will succeed.

Thank you for your attention.

Johannes Agterberg
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Member of the Council of the Associazione Luca Coscioni, Italy