

Open letter to the President of the Republic, Giorgio Napolitano

From Piergiorgio Welby, Co-President of the Luca Coscioni Association

Mr President,

I am writing to you, and through you I am addressing also those citizens that will have the opportunity to listen to these words, to this cry of mine, which is not one of desperation, but one full of human and civil hope for our country.

Until two and a half months ago, my life may have been marked by rather serious difficulties, but I was able, at any time of the day, to use my computer and write, read, do research and chat with my friends on the Internet. Today, I seem to have fallen into an abyss from which there is no exit.

The day starts with the alarm of the lung ventilator device, while humidifying filter and the mouth catheter is changed, the day continues with the radio in the background, between frequent aspirations of tracheal secretions, the monitoring of oximetric parameters, personal cleaning, medication, and Pulmocare beverages. I used to get up at ten at the latest, and start writing on my PC. Today, my pathology, muscular dystrophy, is in such advanced state, that I cannot make any movements, and my physical balance has become extremely precarious. I get up at noon with the help of my wife and an assistant, but more and more frequently I find myself sitting without opening my computer, because I feel dead tired. I force myself on the chair to assume, for at least an hour, a position other than lying in bed. When I go back to bed, at times I fall asleep, but wake up in a fright, perspiring and more tired than before. I turn on the radio, but listen to it without paying attention. I cannot concentrate because I am constantly thinking on how to put an end to this life. Around six, I make another effort to sit, with the help of my wife Mina and my nephew Simone. Every day I get worse, weaker and more tired. After about an hour they take me back to bed. I watch TV waiting for the Tavor tablet so that I can fall asleep and not feel anything, hoping that I will not wake in the morning.

I love life, Mr President. Life is the woman who loves you, the wind through your hair, the sun on your face, an evening stroll with a friend. Life is also a woman who leaves you, a rainy day, a friend who deceives you. I am neither melancholic nor manic depressive. I find the idea of dying horrible, but what is left to me is no longer a life... it is only a stubborn and senseless obstinacy of keeping active the biological functions. My

body is no longer mine... it is there, spread before doctors, assistants, and relatives. Montanelli would understand me. If I were Swiss, Belgian or Dutch, I could escape from this utter outrage, but I am Italian and there is no pity in Italy.

You are probably thinking, Mr President, that I am appealing for a “dignified death” for myself. But no. That is not it. And I am not talking only about my death.

Death cannot be “dignified;” it is life that should be dignified or decent, especially when it is growing weak because of old age or incurable illness. Death is something else. To define death by “dignified” euthanasia is to deny the tragic dimension of dying. It is tantamount to continuing to conceal and to distort death that, driven from home, hidden by a screen in hospitals, neglected in the loneliness of the homes for the aged, seems to be something that it is not. For what is death? Death is an indispensable condition for life. Aeschylus has written. “It’s hard to struggle. Decay is setting in, like a swelling flood. A blind ocean, a cesspool of pain surrounds me without even a glimmer of hope. There is no landing place. There is no landfall.”

And yet there is a landfall, but euthanasia is not a “dignified death” but an appropriate death, in the words of a man of faith, Jacques Pohier. Appropriate is that which “carries to the port;” for Plutarch, the death of young people is a shipwreck, that of old people a landing at a port, and Leopardi defines it as the only “place” where rest, not bound but secure, is possible.

In Italy, euthanasia is a crime, but this does not mean it does not “exist:” there are calls for euthanasia which are not heeded to because the doctors are afraid of being criminally prosecuted, and conversely, acts of euthanasia may be practiced without the informed consent of patients who are conscious. To grant a request for euthanasia, certain European countries, such as the Netherlands and Belgium, have introduced procedures that enable a “terminally ill” patient to plan with the doctor, the course for “landing” at an appropriate death.

A law on euthanasia is not the incomprehensible request of a few eccentrics either. Even in Italy, there were four or five bills already introduced in the last legislature. The association of anaesthetists, with great circumspection, has asked for a clearer law; the recent decision of the lapsed (and not yet renewed) national bioethics committee on the

advance directives for healthcare revealed that it was impossible to exclude any eventuality of euthanasia in the event that the doctor adheres to the advance provisions drawn up by the patients. Even in the Church's strict position there are certain openings, albeit within the confines of tradition, that allow for a heavy intervention with palliative cures and do not allow for intervention with disproportionate treatments that do not entail concrete benefits for the patient. Public opinion is always more aware of the inherent risks of leaving every decision about treatment up to the doctor. Many have helped a family member, a friend or a relative during an incurable or highly debilitating illness and have come to the decision, that if they were faced with the same predicament, they would not follow the same path. Others have witnessed the tragedy of a person in a persistent vegetative state.

When we face issues connected to the end of life, we are not dealing with a dispute as to who is in favour of life and who of death: all patients want to be cured, not to die. Those who share, with love, the course imposed by the illness on the loved one, want that person to recover. Between wishes and hopes, time passes relentlessly, and with the passage of times, hopes grow weaker and the desire to be cured becomes a desire to shorten the course of desperation before reaching that natural end that the reanimation technicians and machines that support or stimulate the vital function risk posting ever forward in time. As to our technical possibilities of keeping people alive, there will come a day when swarms of living dead will come out of reanimation centres, who will wind up vegetating for years. We will probably all have to learn that death is also a learning process, and merely a matter of falling into a state of unconsciousness.

His Holiness, Pope Benedict XVI, has said that "to the claim often put forward that it is necessary to resort to euthanasia in order to eliminate suffering, we must corroborate the inviolable dignity of human life, from conception to its natural end." But what is "natural" in a reanimation room? What is natural in a hole in the belly and a pump that fills it with fats and proteins? What is natural about a hole in the windpipe and a pump that blows air into the lungs? What is natural about a body kept biologically functional with the help of artificial respirators, artificial feed, artificial hydration, artificial intestinal emptying, of death artificially postponed? I believe that it is possible to play with words for reasons of power

or faith, but I do not believe that it is possible to “play” with the life and pain of someone else for the same reasons.

When a terminally ill patient decides to forego emotions, memories, friendships, and life, and asks to put an end to a survival that is cruelly “biological,” ... I believe that his will should be respected and heeded with the compassion represented by the force and consistency of secular thinking.

I am aware, Mr President, that I have spoken to you, through my sick body, also of politics, and of objectives necessarily to be debated freely in Parliament, that do not call for your intervention or decision as to their merits. What I do take the liberty of recommending to you, however, is the defence of the right of each and every citizen to be apprised of the proposals, reasons, stories, wills and lives which, like mine are faced with this conundrum.

Luca Coscioni’s dream was to free research and to give a voice – in every sense of the term – to those who are ill. His dream was interrupted and it became known only after it was interrupted. So it is now up to us to dream for him too.

My dream, also in my capacity as co-president of the association that bears Luca’s name, my will, my request, that I wish to bring before all authorities, starting with the political and judicial bodies, is today clearer and more precise in my mind than ever before: to be able to obtain euthanasia. So that Italian citizens can have the same opportunity that is granted to Swiss, Belgian and Dutch citizens.

Piergiorgio Welby