



# Life, Death, and Democracy

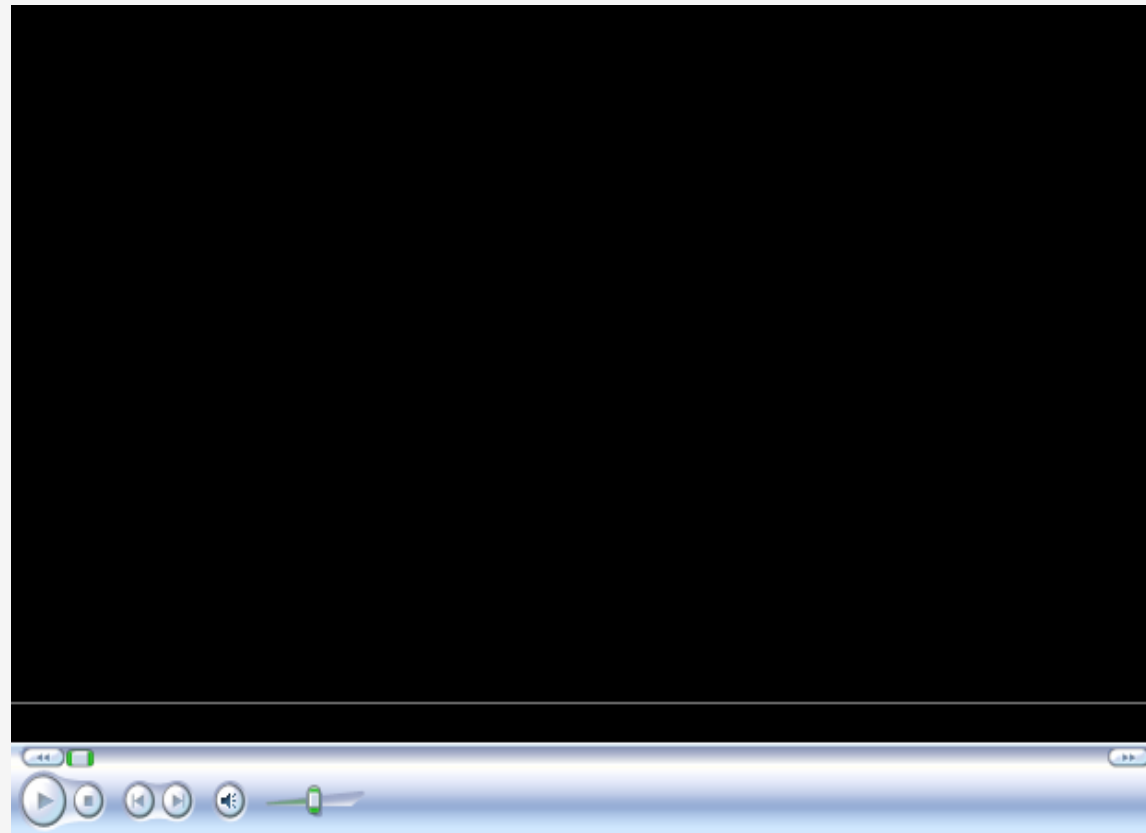
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**Piero Welby to the Italian President: I want euthanasia**



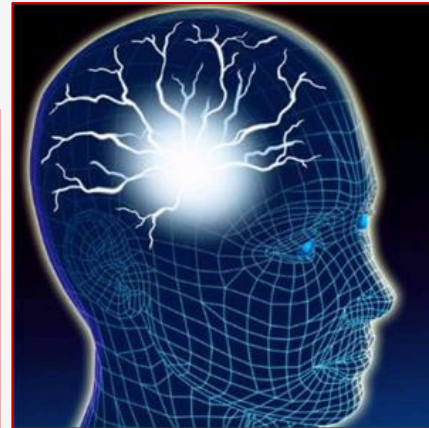
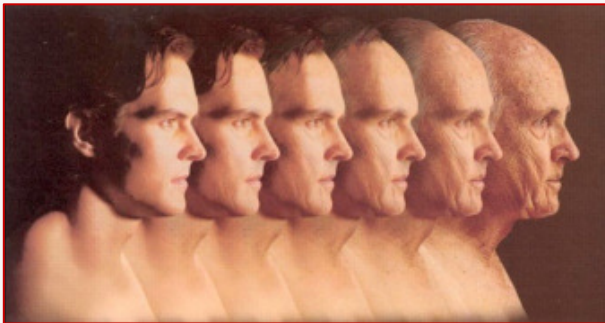
## The Welby case

- September 2006: Piergiorgio Welby, suffering from amyotrophic lateral sclerosis (ALS) writes an open letter to the Italian president Napolitano
- Napolitano invites the parliament to pass a law about end-of-life-decisions, especially euthanasia and patient self determination act (testamento biologico).
- December 2006: Welby's treating physician Mario Riccio disconnects respirator. Riccio is accused murder as voluntary euthanasia is strictly forbidden by Italian law.
- July 2007: Riccio is acquitted by court.



Piergiorgio Welby  
Source: [www.rainews24.it](http://www.rainews24.it)

## Shaping, Making, Ending Life: Controversies Often Intractable





## Life and Death Politics: Emerging Characteristics and Contexts

- ▶ Life and Death Politics: end of life interventions, human embryonic stem cell research, abortion, human cloning, embryo/fetal research
- ▶ Life at stake: Foucault/Agamben
- ▶ Cultures of life – cultures of death: political stalemates
- ▶ Decision-making vs. non-decision making
- ▶ Multiplicities of politics
- ▶ Visible vs. invisible politics
- ▶ Politics of silence
- ▶ Rise of “virtual politics”
- ▶ From experts to stake-holders
- ▶ Emotions that matter



## Decision-Making Crisis: Particular Challenge for Democracy

- Inherent to life-political issues is that there cannot be, at least not self-evidently, a 'binding, authoritative allocation of values for society as a whole' by the centre of formally institutionalised state power (parliament, president etc.)
- Intractable (policy) controversies: immune to resolution by appeal to facts.
- No a priori unity or an implicit notion of 'the common good' as a motive for political action may be assumed
- No possibility of taking recourse to an 'objective truth' for knowing what to do as a community.



## Chronology of the Englaro-case I

- January 1992: A 21-years old woman, Eluana Englaro, falls into a deep coma caused by severe brain damage as result from car accident.
- Brain damage diagnosed as irreversible by several experts. Her father, Giuseppe Englaro, says that earlier in her life Eluana had spoken against live-saving-treatments for analogous situations
- 1999: Giuseppe Englaro requests from civil court right to stop Eluana ´s artificial nutrition. His request is rejected with the argument that a persistent vegetative state is not equivalent with brain death and that artificial nutrition cannot be defined as a medical treatment, but as nursing, which a patient is not allowed to refuse.
- October 2007: The Italian appeals court declares the abandonment of live-saving-treatments as legal when the will of the unconscious patient is certifiable and his vegetative state is irreversible.
- July 2008: After countless hearings before different courts, Englaro gets authroization by Court of appeal in Milan to stop Eluana ´s artificial nutrition.



## Chronology of the Englaro-case II

- February 2, 2009: Eluana is transferred from the nursing home "Beato Luigi Talamoni" in Lecco to "La Quiete" in Udine, where she would spend her last days.
- February 4, 2009: Eluana's artificial nutrition is reduced to its half and it is planned that it will be fully stopped during the following days.
- February 6, 2009 The Italian parliament plans to adopt an emergency decree, which should prohibit the termination of artificial nutrition of patients in vegetative state.
- February 9, 2009: In the middle of a heated debate in Senate arrives the announcement of Eluana Englaro's death. Diagnosis: cardiac arrest as consequence of renal failure caused by the lack of nutrition.





## Emotions in end-of-life-politics



All pictures taken from [www.corriere.it](http://www.corriere.it)



## **From artificial nutrition to the redefinition of life and death**

The question if Eluana Englaro's artificial nutrition should be stopped had turned into a more fundamental question: the question of what should be defined as life?

Was a person without any consciousness still a person? If Eluana was just a being without the abilities to think and feel, would it then make any difference if machines were turned off?

The question if Eluana was still a person and the redefinition of life and death overlaid the quest for a law which should regulate end-of-life-decisions.

Bottom-up movements replace the immobility on the part of the Italian government and single individuals raise their voices...




## Endless hESC controversy in US

- ▶ Dolly the sheep: already on February 27, 1997, Missouri senators Kit Bond and John Ashcroft introduced in the U.S. Senate the first anti-cloning bill, which stated that no federal funds can be used to finance cloning
- ▶ Extreme polarization of opinion in this field in the United States
- ▶ Mid 1990ies: The arrival of Dolly had coincides with a crisis of the anti-choice movement after high-profile assassinations of doctors and clinic staff in Florida, Massachusetts, and Canada and an escalation of death, bomb, and anthrax threats as well as actual bombings and arsons.
- ▶ Christian patriots”and the “militia movements” on the far Right had started to define the battle against abortion, which, in addition, with a Democratic, pro-choice president in power seemed to be more than unlikely than ever to be won on the legal battlefield.

**Michael J. Fox**



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- ▶ August 23, 2010: a U.S. district court issues preliminary injunction against federal funding of human embryonic stem cell research
  - ▶ Chief Judge Royce Lamberth ruled in favor of a suit filed in June by two researchers and several activist groups who had said that federal funding for hESC research would harm research on adult stem cells by increasing competition for limited federal funding, and that federally funded human embryonic stem cell research involved the destruction of human embryos which was prohibited by law (U.S. District Court 2010)
  - ▶ Culmination of almost 15 years of political battle around human embryonic stem cells in United States: no law by Congress



## **New Politics of Emotions and Intimacy**

- ▶ Emotional language used in politics gains of importance
- ▶ Exact boundary between public and private blurred
- ▶ The intimate is increasingly political
- ▶ Michael J. Fox video: public display of individual condition
- ▶ His visible suffering speaks to us
- ▶ The development of his disease is not concealed to us
- ▶ Through YouTube his message and presentation creates a virtual space for a temporary community to discuss, think about, “experience” Parkinson’s disease – and what can be done about it in the political sphere



## Michael J. Fox Video: Comments by Viewers on YouTube

- ▶ b: This literally made my mouth drop. Powerful ad.
- ▶ c: go Michael, we love you
- ▶ d: this is heavy duty doc.
- ▶ e: Thank you for four years serving in Senate, Senator Talent. Enjoy your retirement.
- ▶ f: For all the people who think he is "nervous" - it's called Parkinson's Disease nitwits.
- ▶ g: For all those ignorant and cynics, Michael J. Fox is showing the symptoms of Parkinson's Disease...he is not ashamed to show himself and to the world, that he is one more victim of the many out there...educate yourselves before making negative comments.



## Political Discourse



## Virtualization of Politics

- ▶ Throughout human history have technologies shaped selfhood, communities, self-images, collectivities
- ▶ Symbols open up imaginary worlds that imitate and/or extend real world features
- ▶ Television: creates collective parallel worlds
- ▶ Cyberspace as new meeting place and linking up tool
- ▶ Michael Fox video: viewed on YouTube nearly 3 million times
- ▶ Elicited 6400 comments since broadcasted on TV and shown on YouTube
- ▶ Counter-mobilization in YouTube and Internet from Religious Right






## Politics of silence and invisibility


- **Suspicious silence:** Ethically sensible issues are abandoned in a legal vacuum. Instead of making clear regulations legislators choose ways of “keeping things quiet.”
- **„Eutanasia clandestina in Italy “:** Even if euthanasia is forbidden in Italy, that does not mean, that it doesn't exist. In intensive care units decisions of live and death are taken every day. The hidden and clandestine euthanasia takes place in a legal grey area.
- **The politics of “non-fetus research” in the United States:** despite legality de facto moratorium in research community because of “political concerns.” Impact on transplantation practices in neurodegenerative diseases (e.g. Parkinson)
- **Politics of abortion on state level in the United States:** in many states defacto prohibition of abortion, despite Roe vs. Wade



## Conclusions: Life, Death, and Democracy

- ▶ New dynamics of the political process: multiple, networked, virtual
- ▶ Challenge: Intractable controversies “without space”
- ▶ Traditional interest groups, political parties, and lobbies seem to loose of importance
- ▶ Politics of non-decision making
- ▶ Politics of silence/submerged decision-making
- ▶ Politics of repressed emotions: fear, anxieties, contempt, pity, shame operate submerged without being argued in political institutions
- ▶ Flows of communications take new forms (blogspheres, Youtube etc.)
- ▶ New communities emerge (such as end of life communities) with new political identities
- ▶ Simultaneously: modernist institutions hesitant to make decisions

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- ▶ New conflict dynamics: modernization critics vs technocratic elites is history
  - ▶ In "Republic 2.0." the "Common Interest" has not disappeared, but is more difficult to generate and symbolize
  - ▶ New "*politics of intimacy*" in cyberspace
  - ▶ Emotional display and expression might be at least as important as "channelling" preferences
  - ▶ Modes and "rituals" of authenticity will gain of importance
  - ▶ Public participation and consultation supported the modernist order to the extent that it channeled concerns into the political decision-making apparatus.
  - ▶ Creating spaces for dealing with new developments in life politics topics might be as relevant as traditional consultation exercises (from consultation to blogging networks)
  - ▶ Voices of authority and expertise have disappeared to a considerable extent

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- ▶ Authoritative policy-making in late-modernity?
  - ▶ How can trust for politics of life and death be generated?
  - ▶ How and where to argue emotions?
  - ▶ What can be done to move the submerged and silenced into the open realm of civic debate and public decision-making?



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