

A view of the future for the Right to Die mouvement in France



Euthanasia2016

PROFESSIONAL CHALLENGES

Subsession 1 - Legal

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A view of the future for the Right to Die mouvement in France

•Key steps of health legislation in France

- Recognition of patient's rights in a medical establishment (no longer just a 'subject')
 - Decree N° 74 of the 14 of January 1974
- Patient recognized as a consumer of health services
 - Law 2002-303 of the 4 of march 2002
 - Patient's appreciation of pain must be treated
 - Patient access to medical file
 - Patient's right to leave a medical establishment
 - Patient's right to designate a representative who's voice must be heard (*not followed!*)
- End of Life rights for the individual
 - Law N° 2005-370 of the 22nd of April 2005 (Leonetti law)
 - Advanced Directives and Patient's representative
 - Access to palliative care
 - Right to stop treatment (let them die)

Leonetti – Claeys law voted on the 2 february 2016

Basic rights & obligations

(often just re-stated from the 2005 legislation with word changes who's impact is questionable)

- The doctor must respect the patient's choice of care once he has informed him of consequences *(no longer urged to convince him)*
- No disproportionate care should be initiated or administered
- Nutrition and hydration are considered treatments
- A patient has absolute right to request not to suffer
- Advanced Directives become binding *(no penalty however)* and have no duration restrictions as prior (3 yrs). The standard appropriate content will be determined by the Supreme Court (Conseil d'Etat)
 - Can be ignored in case of vital emergency
 - Can be ignored if deemed inappropriate due to the situation.

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Basic rights & obligations

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- Patient's representative role becomes primary over family. IT must be accepted by the person named. Even persons under legal care can name a representative. Young children must be listened to and their opinion taken into consideration.
- Right to a sedation until death with the obligation to stop treatments except those for eliminating pain.
 - Only if patient is in what is considered in a terminal condition
 - Only if patient decides to stop treatment causing pain that cannot be treated.
- Patients unable to express themselves, with no named representative, can be sedated to death when medical staff, in a team decision, decide to stop treatment. This can be done at the patient's home.
- A national archive of Anticipated Directives is to be created



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Failures of the legislation

(often just re-stated from the 2005 legislation with word changes who's impact is questionable)

- **Doctor remains sole decision maker** as long as he can both decide Advanced Directives are inappropriate to the situation and that the patient's representative is only there for advice, not decisions.
- **No means of control** of the medical acts are created by the law.
- **No penalties** are defined to insure the law is being applied (*up to now more than 50% of the doctors ignored the law*)
- **Terminal condition** as defined by the medical staff is required for sedation
- **No additional means for Palliative care** even though required by law (*available to only 20% of those who would require this care*)
- **Training of Doctors for end of life care** is not defined nor required
- **No financial means** for the “National archive of Advanced Directives”
- **Advanced Directives to be dictated** by supreme court will create interpretation problems resulting in more legal suits.



What future for the Right to Die Mouvement in France ?

•Educate and communicate to impose present legal rights

- Published '**SURE-VIE**' to inform and guide users so they write their Advanced Directives (*download free on our site*)
- Develop a book on Living your End of Life, provisional title “Autodélivrance en Fin de Vie”
- Create a training course for Patient's Representatives
- Organize meetings and events to insure individuals realize how important it is for them to write their Advanced Directives
- Place patient's representatives in medical institutions to represent patients and initiate medical staff education
- Propose courses in nursing and medical schools on Patients rights in End of Life situations
- Write articles and comment on nonsense being published

What future for the Right to Die Mouvement in France ?

- Project “**Ma Maison de Fin de Vie**”

- A house in which to live a peaceful death in the context you choose for those without a home
- A training center for medical teams to enable them to practice in the individual's home
- A medical response that challenges actual practices

- Issues to solve

- Medical protocols that guarantees that we do not violate present law
- Legal guarantees that we can document our acts and win any court challenge
- Organizational guarantees that we can finance both the project and the consequences (legal, financial, ...)



What future for the Right to Die Mouvement in France ?

•Challenging the law in court

- Collect evidence of the law not being applied
- Defend cases where there are clear violations of the law
- Create situations where either the government or an institution, or a professional organization, or an individual sues us, to put into evidence the fact that the legislation is not pertinent in real life situations

► USE THE MEDIA TO CHALLENGE THE LAW IN THE COLLECTIVE MINDS AND PROFESSIONAL ENVIRONMENTS



•How to make appropriate legislation

•What must be avoided

–Euthanasia is conceptually violating the social contract

“thou shall not kill”

–Dictating professional behavior does not respect the medical profession

–Death is an individualized event, it must be a freedom

•Right to Die is not our issue; **OUR ISSUE IS**

–Freedom to decide on our end of life context and process ourselves, or through a proxy (a person who represents us)

–Freedom to practice medicine as we professionals understand our ART, not an exact science, and accepting death as an inevitable part of life

–Social responsibility to impose guarantees, operate controls and protect care-taking/healing: **the “trust” requirement of proper care**



The future of the Right to Die Mouvement is also an international issue

•Human rights

- Individual freedom to decide on care
 - Ourselves or through our designed representative

•Professional freedom to practice

- Professional freedom to practice medicine
 - Provided we follow a protocol that guarantees process

•Social protection

- Social responsibility to guide and controls
 - Authority to receive complaints, analyze facts, and make recommendations on evolutions

International Institutions can help establish conventions & laws that would help enact laws in countries. Example: UN, EU, AFRICAN UNION, International Organizations of Human Rights, (see hundreds of organizations listed which need to be enlisted to our cause and support our request for End Of Life freedom)



Your turn



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