

A new approach to End of Life legislation

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End of Life is the ultimate truth between me and myself, face to face with GOD *Good Opportunity to Die*.

Here I will focus on the legal context when a person asks another to help/accompany his death. Suicide is not penalized in most countries and our movement has well documented solutions, if we are autonomous, that insure a peaceful non traumatic end a life.

Euthanasia LAW issues – back to basics

We have been facing objections for the last 50 years and it's time we listened. “Thou shall not kill”, “Don't interfere with the will of GOD”, “We cannot control ANY such law” ...

The simple act of asking for a Euthanasia law in the minds of our opposition means we:

- - Violate the social contract
- - Confront “believers” to a reality of death they have delegated to a faith
- - Open a pandora's box of fears, both justified and unfounded

AND, a law of this nature will interfere in the **necessary confidential trust relationship** between a person and his caretaker (medical or not). Each life/death is specific and it's conditions unique. As we can see this is a tall order of objections to overcome and it's very easy for our opponents to formulate simple attention getting messages against our cause.

Language is a key to being heard:

- for Euthanasia we use “terminal or total sedation” and “medical irreversible act”
- for Right to Die we prefer “patient's rights in an end of life or medical environment”
- for Doctor we use “practitioner, care taker, medical professional”

These terms can mean the same thing but allow for a wider vision and thus avoids the blunt confrontations with our opposition. Nelson Mandela said “if you talk to a man in a language he understands, that goes to his head. If you talk to him in HIS language, that goes to his heart”.

What is our objective?

To get legislation enacted in our country so each person can live in peace and security with the knowledge that he/she will be well cared for and, if required, helped to die when the moment of death becomes inevitable.

The rights and guarantees we ask for are: the individual decides, the practitioner called upon is able to prescribe or administer terminal sedation as a legally recognized medical care, and the state has the means of controlling the social pertinence of such irreversible medical acts

All people have common objectives:

For the individual, it's to live well to the last day, to decide about MY life and medical care, to be free and protected from external pressures, to be heard and respected in MY decisions, to be assisted to live or die as required and requested

For the care taker, often but not always a health professional, it's to be recognized as a competent professional decision maker, to be free to act within the realm of his competency including being able to administer or prescribe total sedation, to be free to decline a case for personal or professional reasons and to be protected legally from un-founded lawsuits

For the society it's the absolute requirement that we guarantee the rights of the individual, that we protect the whole population against all types of pressures (private, social and economical) and to control that each actor concerned with end of life is within his allocated rights.

We would add that all three parties have an often an unspoken requirement which is the need to respect the privileged relationship between a patient and his caretaker.

Real objections we have been facing for over 50 years

Moral objections such as “thou shall not kill” or “god decides”

Psychological objections in the realms of doctor patient relationships, mental illness or competency, professional respect ... and others

Economic realities that are just starting to be formally recognized such as the “markets” of end of life, the “laboratory” for science and the well known inheritance, pension, surviving partner issues.

Our Right To Die movement must address these 'real' issues and be able to dialogue with those who need to understand the complex issues of end of life, while insuring we place those who refuse the dialogue into clearly identified extremist positions. Our aim is that the general population find our opponent's objections unacceptable in a “free” society. Our strength is that there is a reality no one can deny. We die poorly, pain is at times unavoidable, euthanasia is widely practiced without any control, and most important the individual's will is not respected.

What are the KEYS to unlock this situation?

First we must all recognize that end of life is the real issue, not just the final act of dying. That asking for a euthanasia law is counter productive. This is especially true in a world which has lost its moral references and is turning to religious doctrines which seem to propose real values. We need to propose a clear legal status for the patient in a medical environment (remember life is a terminal condition) and a legal framework for irreversible medical acts. This means that we can include total sedation as a care in a larger context of medical acts that require a procedural framework that both offers guarantees to the patient and frees the practitioner from legal pursuit. This approach also protects the patient-caretaker relationship required for the improvement of health in all situations where a caretaker is called upon.

The right to die movement must be identified as contributing to the building of our common social well-being, as open to dialogue and able to adapt its proposals to the ever evolving present. Our future action is in accompanying the law once enacted by insuring its practical and ethical application.

Individual values we promote

- Ethical, moral, religious values and quality of life specific to the individual
- To be informed intelligibly about our health, proposed treatment process, consequences, risks ... to make an enlightened decision
- To be recognized by law as sole final decision maker about our health, treatments, care
- To be able to name a legal representative with identical rights to represent us upon request or when unable to represent ourselves
- To have the right to ask legally for care, including total sedation, if we consider that the situation requires it

Professional values we promote

Responsibilities

- To listen to and understand the requests of a patient
- To insure that my patient understands my diagnostic and prognostic in order to make

enlightened decisions

- To validate my diagnostic by consulting two independent professionals
- To document all parts of the process of treating, or not treating, a patient whose condition requires a medically irreversible act and keep his medical file complete and up-to-date

Rights

- Ability to desist from a case that does not meet my moral values*
- Ability to desist from caring for a patient whose demands I consider professionally unrealistic*

*these must be documented in the patient's medical file

- Ability to prescribe a treatment, operate and/or administer a drug, or any medical act that I as a professional consider a 'care', without any legal risks.

Governance requirements and Social values we promote

- Coherence of the whole legal context (revisions required of previous laws to insure complete coherence)
- Individual rights protection & guarantees
- Big Data individual medical file management:
 - Timely and fully documented
 - Immediately available to all competent medical personnel (even in emergencies)
 - Secure & Confidential
- Independent control that irreversible medical acts follow a prescribed protocol
- Recognition that health professionals practice in an environment that is not 100% predictable, thus specific to each case.
- Protection of the patient/care-taker relationship that requires trust to be effective

Legislative proposition

Our legislative approach can work both in statutory and common law environments. In our discussions it appears to satisfy the palliative care proponents, has support from various religious authorities we have been able to discuss it with, and in public presentations has either not been objected to or those who tried have been identified by those present as arguing on unfounded or even extremist's grounds.

A LAW that clarifies patient's rights

- To decide in all matters concerning his health*
- To be assisted or represented by his designated representative with equal rights (Not linked by inheritance).
- To be able to request specific care and have his “living will” legally respected
- Has the right to request terminal sedation as a prescription or treatment
- To have the right at all times to clear and intelligible information on our case

* Person presumed to be competent unless specifically diagnosed as incompetent

A law that creates a framework for irreversible medical acts

- Acts that impact irreversibly the body
- A framework that guarantees:
 - Diagnostics and prognostics are confirmed by 2 independent professionals
 - Practitioners can demonstrate the patient fully understands:
 - The diagnostic
 - The prognostic
 - How the act can/would be practiced
 - The known results and success statistics for the act
 - Acts and communication exchanges are fully documented in the medical file
 - Care takers are free from legal pursuits if they respect the legal procedures
- Treatment can be refused, but then must be documented in the medical file and patient referred to 3 other competent practitioners

The government needs to accompany these laws with measures that:

- create a centralized medical file accessible by all authorized identified professionals
- create an independent legal committee to review, entertain complaints, report
- abrogate or transform existing laws that could interfere with these two new laws.

In proposing these two laws or amendments, we insert them into the present legal situation (depends on countries) which makes these propositions easier to adopt. They clarify the status of the person when in need of medical assistance and free the professionals to practice their art. Having included the care of total sedation in irreversible medical acts, not only makes it an act of care now accepted by most professional health organizations, it would also reduce significantly the malpractice suits that lead to high insurance costs paid by all of us. A winning argument with medical professionals.

Conclusion – Opportunities for the Right to Die movement

In the last 50 years we have been able to make End of Life a social issue recognized by all. Much progress has been made both in the field and in the minds of our legislators. Public opinion is overwhelmingly on our side so we must ask ourselves “what are we doing wrong?”.

- Illegal acts are common practice everywhere, both in the medical arena and by members of our community who skirt with the fine line of legal practice specific to each country. These acts lead to court cases well covered by the media and promote public debate.
- Medical supremacy has been recognized as no longer acceptable in most countries, and the advances in science have made it imperative to pursue the “quality of life” and no longer the “biological” pursuit of life. The doctors who deal daily with end of life issues are convinced that there needs to be legislation that protects them when administering total sedation.
- Economic pressures due to the “baby boom” populations and the ever increasing costs of care administered (usefully or not) in the last 6 months of a person's life, as well as the abuses from the medical industries are forcing governments and insurance companies to reconsider how to handle end of life care.

Our actions can capitalize on these drivers while focussing on the defense of individual freedom, spiritual awareness and choice of End Of Life context and process. Our organizations need to be seen as support organizations promoting a Quality End Of Life for all, each one in his own way.