

# *Let's learn together to live*

## *«our end of life»*

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### • **Chers amis**

Re-birth is the theme of this journal since after great turmoil I decided as "guarantor" of AAVIVRE, with our management committee, to relaunch 'AAVIVRE our end of life' in order to be able to continue to work for the freedom that enables each of us to choose an end of life as he/she wishes, in peace and if possible surrounded.

The years pass but unfortunately the behaviors remains the same, which saddens me deeply. We had hoped that "The Choice" was going to be different than what happened at the ADMD, but unfortunately the power grab and the unacceptable behavior of those who initially took over this association caused me to walk away from it. Sad to see once again that the egos and the destruction these few operate not only do not advance our cause but in the process damage the beings of good will who by their attitude and their dedication have advanced the RIGHT TO DIE with Dignity. Fortunately, in Toronto, I met Annie Wallet who represented LE CHOIX there, with whom I was able to discuss and see a positive evolution of their organization.

As far as I am concerned, I am surrounded by a few reliable people who understand my commitment and who work to enable me to assert our positions, dialogue with the authorities and continue to accompany as I have always done the people who contact "us" for help. The revival of AAVIVRE is

not about reviving a large-scale organization, but about making sure we are heard. Heard in our diversity, and especially our approach which is radically different from that of the associations which work for this right in our country.

I remind you here of the principles that drive us:

"Thou shalt not kill" is one of the founding pillars of all social organization. We must therefore find a way to accompany the end-of-life by circumventing this principle, which is used strategically as **the** argument by our detractors. Remember that our society in France is based on written legal texts inherited from Napoleon, while the societies around us are based on principles of legal decisions which gradually change the law.

By offering physicians a partnership that agrees with them that medicine is an art and not a science, it clears them of being considered as scientists, and therefore of being accountable for any medical act that could go wrong (1 medical specialist out of 2 and 1 in 10 GPs are sued every year!). Medicine is an ART and not a science because each of us is different and responds to medical acts and medicines differently. The doctors, as they are requesting here in France by asking for an increase in their rates, ask that they be able to practice medicine which means having the time to hear their patients. To be able to create this "TRUST RELATIONSHIP" where care decisions are made in common, one knowing it scientifically and the other (the person concerned)

based on his understanding of his own life.

Our proposal must also insist on respecting the Kushner law of 2002 which tried to put the person in control of health decisions concerning him. This has been circumvented by the Leonetti law of 2005 and further in 2016. I practice this right is not recognized by the Medical Professional Council as can be seen in the persecutions of doctors who work to support their patient's wishes at the end of life.

Legislation which dictates "the good death", even if only at the request of the individual concerned, is legislation which will be ignored by the medical world on the grounds that each case is particular and that in the "present case" is not appropriate.

## A CHANGE OF PERSPECTIVE IS NEEDED

Legislation that would say that **all** medical acts that "fundamentally change the way of life of the individual", **Irreversible Medical Acts**, must necessarily proceed via a protocol that guarantees:

- doctor-patient dialogue
- medical diagnosis
- confirmation that the patient understands the diagnosis and treatment proposals (with a prognosis) as well as the risks still present due to the individuality of the responses to the treatments
- consultation of healthcare teams on the prognosis chosen by the patient. Their deliberation in conclusion is communicated to the patient.
- support for people around them who need to accept the diagnosis, respect the patient's decision, and prepare for the future. This is achieved through appropriate social assistance which also makes it possible to manage the administrative procedures.
- complete documentation, from the first identification of a possible Irreversible Medical Act, of its history, interviews, decisions, medical elements and a report of the medical action taken.

This protocol would also allow for an a-posteriori control by an organization representing:

- the state
- the council of the order of doctors
- Justice
- an association for the defense of patients' rights specializing in the type of medical action.

This totally independent control organization, which could be regional or established by the ARS (Regional Health Agency), would have the following objectives:

- improve medical practices
- establish statistics and analyzes (social, psychological, medical)

and would review a case at the request of patients or relatives, in order to determine whether the protocol required by the legislation has been respected. If the protocol is respected, then no legal action should be possible. If the protocol is not followed, then this oversight body would make recommendations to the Attorney General.

At the national level, this body would draw up an annual report and recommendations to the High Authority for Health (HAS) to change practices and to legislators to change legislation.

The list of IRREVERSIBLE MEDICAL ACTS would be drawn up annually by the High Authority for Health (HAS) in consultation with associations representing patients. This list would certainly include ablations, transplants, treatments having a psychological impact and imperatively medical support at the end of life.

- **Our Objectives :**

## Irreversible Medical Procedures – End-of-life support

1/ Make end-of-life support (Terminal Sedation) an act that should be included in the care environment as an option in the same way as palliative care, which is often a prerequisite for the patient's decision for a “rapid terminal sedation”. We will use "rapid terminal sedation" because it is the characterization of the medical act desired by our movement and practiced in many countries (patient is put to sleep and then is injected with a drug for cardiac arrest).

### **End of Life Support under conditions**

2/ Suicide is accessible to all and a recognized right here in France. We distribute a "Self-Deliverance" booklet which allows any competent person to commit suicide without trauma for the person concerned or for those around him. In the event of a person calling for assistance in the form of end of life support, we recognize that the medical world (in the interest of the person on the physical and mental level) and society (which must protect individuals against the external influences, the recognized deficiencies of those who are incapable of self determination and the protection of the individual rights of all) must be involved. In this type of case a protocol guaranteeing the rights of all parties involved is required.

### **An End of Life whose context can be chosen**

3/ There are several steps in the search for solutions, decision-making and finally the action for an irreversible medical act procedure. But that does not mean that the act of accompaniment itself must be carried out by a doctor. It must be possible to die in a context chosen by the person. If the doctor is, it seems, the competent professional to prescribe medically, the actor should be able to be a person chosen by the patient. This person must be either accompanied or trained and certified. This is so that the protocol defined by the legislation is respected and correctly followed (for example the need for the

patient to be able to decide to cancel until the last moment), but the absolute priority must be to respect the will of the person concerned.

A place for a “trust relationship”

4/ We ask that everyone recognize that in any medical situation the doctor needs a "competent" patient contact. The decision-making process is necessarily an agreement based on medical competence on the one hand and the competence of an individual concerning his life on the other hand. Two competent people are required so that, in the dialogue of doctor-patient there be sufficient trust so the decisions required for the good of the person being cared for are successful (at least from the point of view of the patient).

### **A representative Person of TRUST**

5 / We ask that the legislation allow each individual, in the context of his "advance directives" to designate a "PERSON OF TRUST" who can either advise the patient or if needed represent him with the same rights as the individual , and make decisions on behalf of the patient if the latter is unable to do so.

It should be understood that this trusted person cannot be a "potentially interested" person. This means that a person affected by the inheritance or the outcome of the death cannot be appointed as a Trusted Person. This eliminates the spouse, children, descendants, parents and any third party who could benefit financially, materially, or in any situation from the change in the life of the individual or from his death. Any person who accepts this legal role of “person of trust” should have the obligation to follow within 3 months after his appointment (except in an emergency situation that does not allow it) training to know the rights of the patient, the roles of the actors ( medical and social services) and the protocol for Irreversible Medical Acts.

Why we need to impose a « Person of Trust »

In the event of an accident, the emergency doctor makes the patient survive, but the situation is temporarily stabilized very quickly, the medical team must

then understand the treatment options, find out if the abusive treatments should be stopped, if the will is to continue with amputations, transplant etc, choose a curative or palliative treatment ... etc. The patient, whether in an emergency or at the end of life, is not always able to communicate. It is absolutely necessary that as soon as the decision is not immediately urgent, that the doctor be not in charge of these decisions. Medical decisions must be professional and not personal where the CHOICE of living condition is the motivation for the decision. The health professional is neither trained nor competent for a decision that involves the future lifestyle of the individual. YES we are told that in some cases the individual who does not want healing, once past the recovery stage, says they are "happy to live" even in situations where their life is greatly reduced.

### **The freedom of CHOICE**

6/ The problem is that if we accept that society or its representative(s) knows better than the individual what is good for him, then we open Pandora's box to impose the morality of "good" on individuals. It is the possibility for society to impose a way of thinking, a behavior, and all the excesses that we recognize in dictatorships.

We must recognize, as part of the social agreement between individuals in a society, that even if the individual is wrong, he has the right to be wrong for himself. Freedom imposes a responsibility: that of deciding for oneself.

Society cannot guarantee the freedom of individuals and impose decisions "for their own good". On the contrary, society must promote the self-responsibility of the members of its community. Here we touch on the essentials of a "free" society where the principle is that the freedom of the individual is limited only insofar as it affects the freedom of another individual of this same society.

### **• Our Actions**

Following our withdrawal from the association LE CHOIX, at the time of the unacceptable takeover of its new leaders, we took a step back and took the

time to take stock of the situation. Obviously our links with our members and those who referred to us have been lost except for the loyal circle of those who have adopted the course that Pascal LANDA had initially set for AAVIVRE. The year 2022 saw the resumption of activities by relaunching the newspaper and the decision of the Management Committee to revive AAVIVRE as it was originally defined.

### **On the financial side :**

1/ decision of the committee to set membership yearly fee at €10, plus any donation that a member wishes to make to help the operation of the association. The 10€ are required to guarantee that the person really adheres to the objectives of the association and allows the legal recognition of this membership.

2/ Expenses will be reduced to a minimum by favoring electronic communication, electronic payment and automated management.

3/ It was decided that Hubert LANDA will represent AAVIVRE with international bodies at the Toronto congress and request the renewal of AAVIVRE's membership in the International Federation of Associations for the Right to Die with Dignity (World Federation of Right to Die Societies)

4/ We wrote to the President of the French Republic to ask for our participation in his Citizens' Convention on end-of-life legislation. He referred us to the Economic, Social and Environmental Council (CESE) to which we sent the enclosed letter (see below).

5/ We have opened an account to allow financial monitoring

6/ We collected 1500€ from members in order to initially finance our activities.

7/ We continue to offer "Person of Trust" training. If you want to have a training session near you, you need at least 6 people registered, a place capable of accommodating up to 16 people (maximum number of participants) and if

possible an overhead projector with a wall or screen.

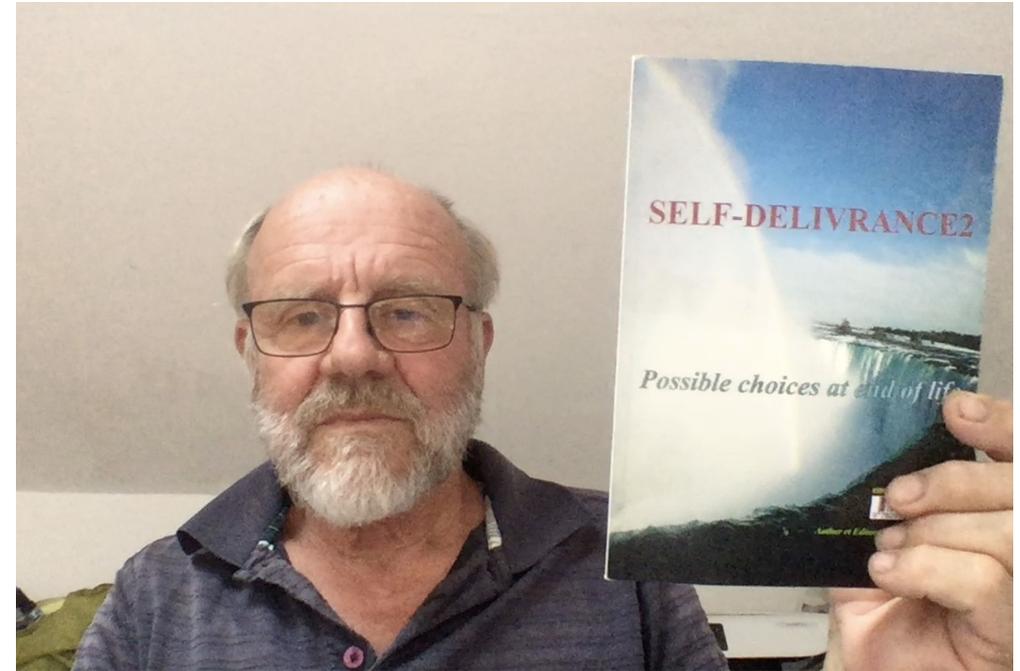
*The Trusted Person training is free, however, you must plan to pay travel costs (petrol or train ticket, food on site for an elderly person, and probably at least accommodation depending on the distance). These costs, if required in cash, are paid to AAVIVRE who pays the speaker (eg: if you host the speaker at your home there are no costs, the same for food)*

8/ On the international level, we are now again recognized as a full member of the World Federation of Right to Die Societies, agreement voted at the conference in Toronto.

9/ We close this year by transmitting to our members of the past and our friends who have e-mail addresses the newspaper N°15. This journal will only be sent by email and those who want a hard copy will have to print it.

10/ We continue to inform, support all people who contact us considering an end of life in accordance with their ethics. If today we, members of AAVIVRE, respect the current legislation, we are discussing internally the possibility of initiating an action of the type "150 Sluts" as the movement for abortion did. *(for our international readers, this would mean declaring that we have accompanied ourselves one or more persons to enable them to die peacefully despite legislation which considers this to be murder)*

- **The PUBLICATIONS**



Pascal LANDA, always as an individual to avoid confusion and legal complexities, will continue to distribute his writings and in particular Le Fascicule de Survie via the internet for free. Those who would like a paper copy can send an email to [contact@aavivre.info](mailto:contact@aavivre.info). If you want a paper copy, we will make a next edition as soon as we have more than 20 requests and, depending on the print run, we can tell you the price.

Autodelivrance 2 - the booklet that offers freedom to everyone at the end of life, is out of print and needs to be re-published. It is a booklet which is both in French and in English We will publish a hundred of them as soon as we have about twenty orders to cover print costs and the price of 50€ plus shipping will be maintained to finance AAVIVRE.

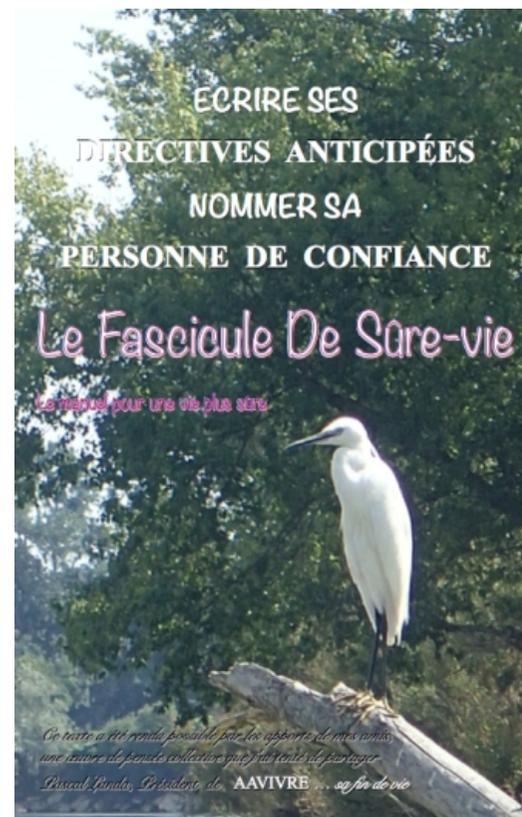
This booklet is only sold to people who request it and are members of an

association affiliated with the World Federation of the Right to Die Societies and with a local Dignity movement, so that legally we are only informing internally on request and do not violate the French law "no incitement to suicide".

The members of the Management Committee appointed to these positions are:  
Mr. Hubert LANDA – Guarantor and Chairman  
Ms. Martine Jouclas – General Secretary  
Mrs. Françoise Vincens – Treasurer

## • **Committee Decisions who met virtually in 2022**

- Relaunch of the association which had been dormant since the merger with LE CHOIX
- Publication of a newspaper (quarterly if possible) to inform those who adhere to our objectives
- Power to Mr. Hubert LANDA (called Pascal within the association) to carry out all the operations required on the administrative level to relaunch the association
- Agreement for Mr. Hubert LANDA to represent the association at the international meeting in Toronto in November 2022
- Asks the Federation of Associations for the Right to Die with Dignity to become a full member again
- Agreement to finance the costs of the association on the contributions (travel to Toronto, international membership, various administrative costs and mandate to Mr. LANDA to do this
- Decision to ensure the continuity of the Management on the only members gathered to date and to review annually the possibility of setting up a management more in conformity with the statutes. As long as there are no more than 100 voting members, leadership will be provided by a core group that will take on the following roles:
  - Guarantor and President
  - General secretary
  - Treasurer



*The following translations are using Google Translate*

**Our letter to the CESE concerning the citizen convention organized by the state.**

**To the members of the CESE Citizens' Convention on the end of life**

Following my proposal to the President of the Republic to participate in shedding light on the debate on the end of life, the latter in a letter invited me to contact you. I am enclosing my letter, his response and useful documents attached.

Having read your mission<sup>1</sup> and the arrangements you have made to carry it out, I propose to you:

1/ an intervention with the members of the convention to present our approach for end-of-life legislation that opposes specific legislation while proposing legislation that reconciles "opponents", "actors", "persons concerned" and enables the state to guarantee the rights of all, including the "weakest in society". This intervention would take the form of a professional presentation followed by a question-and-answer period.

2/ a set of documents which will allow you as an organizing committee to become acquainted with our positions which are very different from the current positions of those who want legislation.

3/ an example of "person of trust" training that we run

A leading actor for more than 40 years in this debate, our association, which I represent, is a member of the World Federation for the Right to Die with Dignity.

I am at your disposal for any further information and for this purpose you will find my contact details attached.

Cordially

Hubert LANDA

PJ. To access use the following link: DOCUMENTS

([https://drive.google.com/drive/folders/1yifacvhC7BtHu9rbO9aK32ZC3X\\_UV62l?usp=sharing](https://drive.google.com/drive/folders/1yifacvhC7BtHu9rbO9aK32ZC3X_UV62l?usp=sharing))

1/ A RIGHT - Founding article of the "Right to Die with Dignity" movement

2/ President's letter 6 Sept 2022 participation in the "Citizens' Convention"

3/ Response from the Presidency Nov 2022

4/ Presentation "End of Life Law, Another Approach"

5/ Me and Vincent Lambert

6/ The Léonetti-Claeys "false road"

7/ Trusted person training

8/ Presentation of Trusted Person Training

9/ Trusted Person Training Documentation

10/ CV LANDA

11/ Links to articles published under the name of Pascal LANDA or AAVIVRE

<https://in-sightpublishing.com/2019/07/08/landa-two/>

<https://www.agoravox.fr/?page=recherche&q=aavivre&sb=Rechercher>

# Proposed Petition to Doctors

by Pascal LANDA

## Our claim

We doctors and caregivers are faced with unacceptable medical situations that must stop. The Léonetti-Claeys law of 2016 puts us in a doubly penalizing situation. Either we follow the dictates of this law and we are no longer doctors who "treat" but execute a "dying well" which can correspond neither to reality nor to the adaptation of care according to the professional assessment that we have of the situation and its evolution, or we practice our art as it has always been done and we become "god" who decides on death (collegial procedure without the patient's opinion) with the personal implications that put us face to face with our own death. In any case, we are trapped by legislation that does not differentiate between the will and choice of life of the patient, who must be the only one to decide on his end of life, and the right and duty of the caregiver, who alone is empowered to decide if treatment or when treatment is appropriate. The hypocrisy maintained between Terminal Sedation and Medically Assisted Suicide, Assistance Médicale A Mourir (SMA; AMAM or MAID in English) is the devil's compromise to give "good conscience" or garnish the wallets with the 50% of medical acts performed unnecessarily in end of life (ref: end of life observatory)

Medicine has always accompanied the patient from the beginning to the end of

his life, with an ethic of listening, concern for his quality of life and the support of care adapted to the patient's wishes. Today, illegally to do our job and out of respect for our patients, we accompany more than 30,000 people in the last acceptable moments of their life out of compassion by risking our careers, our family and social lives. This is due to the Léonetti-Claeys law of 2016.

## Our philosophy

Our profession is an art and not, as the economic actors of the profession would like, a science. We rely on one science but medicine is something else. The difference is that a patient is unique, reacts differently to treatments, is able or not to accept certain living conditions. The care of the living is therefore to adapt our technical knowledge of the human to the individual in a space of trust and essential collaboration. As such, we exclude any legal interference in this area of trust while claiming the need to respect the care wishes of our patients.

## Our request

We ask the government and our legislators for appropriate laws

- ◦ **1/ The revision of the 2002 law**

We want a law concerning the rights of the individual that clearly states that he and he alone is the decision maker of the care, the decisions and the consequences of his decisions concerning his life. That he is entitled to demand that the carer offers him all the care adapted to his medical situation and that he can change carer at any time to find a carer who offers him a course of care

adapted to not only his situation medical but also to his ethics of life.

Include all the provisions concerning the Advance Directives and appointment of the Trusted Person.

That the patient can appoint a trusted person with the same rights and decision-making powers as the patient himself in the event of his partial or total incapacity. Indeed, we must have a contact with whom to discuss treatment options without NEVER replacing the patient regarding the treatment option chosen from among those we can offer.

This clearly means that he can either ask to be kept alive as long as a cell in his body is viable or ask for medically assisted suicide which we will grant or not depending on the unique and unpredictable situation at hand.

## ◦ 2/ Drafting legislation on IRREVERSIBLE MEDICAL ACTS (AMI or IMA)

Doctors are now constantly sued for having carried out medical acts, care or prescriptions (1 expert out of 2 every year and 1 general practitioner out of 10 every year according to statistics from insurers). We ask for protection against these abuses of justice which are costly both financially and in other dimensions such as their impact on the care that we believe we can achieve and the very conditions of the practice of medicine. Any Irreversible Medical Act, if it is carried out strictly according to the same protocol which guarantees its proper execution, must not be able to be challenged in court.

**Concerned medical acts :**  
**Annually the High Authority for Health (HAS) will define a list of acts that correspond to the following definition:**

- medical procedure according to which the person does not find the way of life that he had before this procedure –

examples: amputation, tube feeding, organ removal, any implantations, any cosmetic changes, etc.

These acts impact the life of the patient but also of those around him. It is sometimes necessary to develop facilities, obtain aid, re-educate or educate, finally for all these acts there is a social dimension which is not the responsibility of medicine. This is why we ask that in the collegial team of "caregivers" be added a social worker who takes charge of both the administrative and personal environment of the patient. Obviously in the acts appears the Medical Aid To Die AMAM (MAID in English), or the treatment of terminal sedation as it is already carried out illegally on a daily basis (not the hypocritical terminal sedation of the law).

The protocol

This protocol has already been widely discussed and defined in the context of Terminal Sedation. We remind you that it includes:

- Identification of a potential case of irreversible medical procedure which will systematically lead to the opening, with the patient's agreement, of a Personalized Medical File where the entire course of care must be documented.
- establishment of a diagnosis and validation by a second opinion independent of the diagnosis
- the presentation of the care options, correctly explained and ensuring that the patient or his legal representative (eg trusted person) understands them. The

explanation should include current statistics on the successes and failures of the proposed treatments.

- The decision of the patient or his representative (the family being consulted only as a last resort) with a period of reiteration of the decision which is adapted to the nature of the act (in any case not more than 2 days unless the patient requests it, and can be a few minutes if urgent).

- the detailed description of the act

- a complete review of all the meetings, events, decisions and reports associated directly or indirectly with this act in order to establish a final summary of the declaration.

### **The controle**

The legislation will establish at the level of each court a body representing justice, medical, social and patient (via a federative association example UK).

This body will be responsible for publishing an annual report noting the practice of Irreversible Medical Acts (AMI) and will establish recommendations on its development. Its national coordination body will validate with the Minister of Health by consensus the list of Irreversible Medical Acts (AMI) of the year defined by the HAS.

This body by survey and in the event of a seizure by a patient or his representatives, will review the files of "Irreversible Medical Acts" which are all systematically available because they are documented in the Patient's Personalized Medical File.

Files that do not correspond to the defined protocol will be referred to justice, the

others being the subject of a recommendation for dismissal in the event of a dispute.

Every year, a report on practices and recommendations for changes to the protocol will be produced.

### **o 3/ Cancel legislation that interferes with the above**

Repeal or modification of the law "non assistance to person in danger"

Repeal or amendment of the "incitement to suicide" law

These laws dating one from the Second World War and the other from the publication of the book "suicide mode d'emploi" are inappropriate and can be manipulated to harm the will of the legislator. The existing laws concerning the same subjects are quite sufficient to guarantee the protection of citizens.

### **o We who have signed this document**

Demand that "terminal sedation" be carried out at the patient's request according to our professional assessment of the situation and in clear agreement with the patient or, in the event of a partial failure or inability to communicate, with the Person of Trust who must be able to represent the patient .

We refuse, except in an emergency, to be under the obligation to take the decision of irreversible care or treatment which belongs only to the person concerned or his representative, as implied by the legislation on the consent but which is currently flouted in practice and in the interpretation of the texts.

We ask to be protected in our medical practice because too often dragged into

court when we are only practicing our art.

### **Conclusion**

The constant demand for more than 40 years by the French for a medical context allowing them to consider a secure end of life is in total agreement with the medical practice of supporting the individual from birth to death. Legislation for the protection of the medical profession in its humanistic practice, of the patient, allowing support for their will to live and die in accordance with their ethics and the assumption of responsibility by society to guarantee the rights and duties of everyone is essential. . This legislation must put an end to the fears, the emotional and financial pressures and the taboo of death that each of us must experience one day. Going abroad, committing suicide preventively, surviving in human conditions that are unacceptable for the person concerned can no longer be accepted in today's world.

A RIGHT is the freedom to live well until the last day.

## Formation des Personnes de Confiance

Since the 2005 law, the role of the Trusted Person has been debated and misunderstood by both professionals and the public. With the Law of February 2, 2016, which aims to reinforce the importance of this role among professionals, it is obvious that we must contribute to giving meaning and a framework to this mission. Too often our associations have to replace or support a person in distress because the

designated person is unable to assume this role due to lack of knowledge of the medical and legal contexts, lack of understanding by his interlocutors, forgetfulness of his prerogatives and responsibilities towards the relatives of the person he is supposed to represent.

Training should be offered to Trusted Persons and all those who may have to interact with a person in this role (medical personnel, justice actors, health and social affairs administrations).

This training contains:

- The Trusted Person's mission seen by the client
  - relations with the person that names him
  - relations with the medical team
  - family relationships
- The Rights of the Trusted Person
  - what the legislation and related texts say
  - modes of intervention with the medical team
  - modes of intervention with justice
- Accept or refuse the role of trusted person
  - have an indisputable and well-understood mandate
  - to question one's own motivations and convictions
  - be able to act and commit

Resources and assistance available to Trusted Persons

The participants receive practical and operational training while being led, according to their positioning vis-à-vis this role, to ask themselves the essential questions that they must answer individually in order to be able to be effective in their actions in real situations.

This training is planned over an entire day in order to allow a sufficiently in-depth work so that everyone can take with them the tools required to integrate this training into their daily lives. A course documentation file is available.