



WORLD ASSOCIATION FOR MEDICAL LAW

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Editor's Note December 2023



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This special issue of the Newsletter consists primarily of articles on Medical Assistance in Dying (MAiD). It has been Guest Edited by the WAML Governor from Hungary, Prof. Judit Sandor. All statements made are the beliefs of the authors and none reflect any WAML position on the subject because WAML has none and does not plan to take a position on this or any other such subject. WAML provides a forum for the expression and exchange of views on medical, legal and ethical matters. Just as with all cases at law there are always at least two points of view for a jury to choose

from. In the United States, some states have passed MAiD laws and others have rejected them. Likewise, Newsletter presentation of differing positions on subjects such as MAiD is welcomed.

Medically Assisted dying



Judit Sándor

Introduction

Death was as a taboo for a long time in public discourses. Terminal or incurable illness is regarded as a source of frustration for the doctors who want to save patients' lives. It is also painful for the family members to face such a diagnosis. In this turbulent emotional process, the suffering patient is often left alone. During

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the last decades in many legal systems attempts were made to include the voice and decision of the most vulnerable in this process, the concerned patient. We are very far from consensus, and there are significant differences across cultures and health care systems. There are many dilemmas about how to assess suffering. Is it just a physical or also an emotional pain? What should be done when the mere passive attitude does not help in alleviating the suffering and the patient requests an active help in dying? How to preserve the integrity of the medical profession and to respect human dignity at the same time when patients seeks the doctors' assistance to relieve their pain? During the past couple of years there have been significant changes towards the recognition of patients' self-determination. In this collection we provide an overview of relevant laws from jurisdictions where some forms of assistance in dying is legal. The collection is far from being complete, we did not mention examples from U.S. and from Columbia, for instance. We still hope that this Newsletter would be equally useful for educational, as well as comparative legal purposes.

BELGIUM

Medical Decisions at the End of Life in Belgium



Thierry Vanswevelt

In Belgian legal literature a distinction is made between several end-of-life-decisions. In the Belgian Euthanasia Act of May 28, 2002, euthanasia is understood to be the act which intentionally terminates the life of a person at his/her request and which is carried out by another (a physician) than the person in question.

Assisted suicide is described as the act in which a person intentionally helps another person to terminate his/her life. Assisted suicide is not mentioned in the Euthanasia Act and is not regulated by law. But in Belgium it is unanimously accepted that the physician who provided assisted suicide in accordance with the terms of the Euthanasia Act, can invoke the Euthanasia Act as a ground of justification. This is the opinion of the Federal Control and Evaluation Commission of Euthanasia, the National Council of the Order of Physicians, and the legal doctrine.

This is logical, because the difference between euthanasia and assisted suicide is very small from an ethical point of view. Even stronger, assisted suicide implies a less far-reaching intervention of the

physician. In assisted suicide cases the patient performs the life-ending act himself, while in the case of euthanasia the lethal injection is given by the physician. Assisted suicide is also from a psychological point of view, less burdensome for the physician. Finally, in assisted suicide cases, the patient himself can decide when, where and under which circumstances he/she will end his life.

1.2. Fundamental and Procedural Conditions

The Euthanasia Act distinguishes between fundamental and procedural conditions. The physician who performs euthanasia commits no criminal offense when he/she ensures that:

- (1) the patient has attained the age of majority or is an emancipated minor, and is legally competent and conscious at the moment of making the request;
- (2) the request is voluntary, well-considered and repeated, and is not the result of any external pressure; and
- (3) the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident.

The physician must also meet the following procedural conditions:

- (1) inform the patient about his/her health condition and life expectancy, discuss with the patient his/her request for euthanasia and the possible therapeutic and palliative courses of action and their consequences. Together with the patient, the physician must come to the belief that there is

no reasonable alternative to the patient's situation and that the patient's request is completely voluntary;

- (2) be certain of the patient's constant physical or mental suffering and of the durable nature of his/her request. To this end, the physician has several conversations with the patient spread out over a reasonable period of time, taking into account the progress of the patient's condition; and
- (3) consult another physician about the serious and incurable character of the disorder and inform him/her about the reasons for this consultation. The consulted physician reviews the medical record, examines the patient and must be certain of the patient's constant and unbearable physical or mental suffering that cannot be alleviated. The consulted physician reports on his/her findings.

The consulted physician must be independent of the patient as well as of the attending physician and must be competent to give an opinion about the disorder in question. The attending physician informs the patient about the results of this consultation:

- (4) if there is a nursing team that has regular contact with the patient; discuss the request of the patient with the nursing team or its members;
- (5) if the patient so desires, discuss his/her request with relatives appointed by the patient;
- (6) be certain that the patient has had the opportunity to discuss his/her request with the

persons that he/she wanted to meet.

Finally, there are two additional conditions when the patient is not terminally ill. If the physician believes the patient is clearly not expected to die in the near future, he/she must also: 1) consult a second physician, who is a psychiatrist or a specialist in the disorder in question and inform him/her of the reasons for such a consultation. The consulted physician reviews the medical record, examines the patient and must ensure himself about the constant and unbearable physical or mental suffering that cannot be alleviated, and of the voluntary, well-considered and repeated character of the euthanasia request. The consulted physician reports on his/her findings. The consulted physician must be independent of the patient as well as of the physician initially consulted. The physician informs the patient about the results of this consultation; 2) allow at least one month between the patient's written request and the act of euthanasia.

ALS (amyotrophic lateral sclerosis) and Assisted Suicide

The Belgian Euthanasia Act requires a serious and incurable disorder which causes an unbearable physical or mental suffering of the patient. No difference is made between active and passive euthanasia. The patient does not have to be terminally ill.

In Belgium there is no case law about euthanasia/assisted suicide and ALS. This is no surprise, because it is generally accepted that a patient with ALS can ask euthanasia. ALS is a serious and incurable illness. When an ALS patient suffers unbearably, he/she can request euthanasia. The Federal

Control and Evaluation Commission of Euthanasia which is informed of all euthanasia cases in Belgium and writes to Parliament every two year a report, has also accepted ALS as a serious and incurable disease which allows the patient to request euthanasia and it allows the physician to perform euthanasia or to provide assisted suicide.

Alleviation of Pain

According to the Patient's Rights Act of August 22, 2002, each patient has the right to receive the most suitable care from health professionals to prevent pain, to have attention, to evaluate, take into account, to treat and to ease the pain.

Sometimes administering pain medication to terminal patients has a life shortening effect. In Belgium, alleviation of pain with life-shortening effect falls within the scope of 'normal medical practice' that a physician is authorized to perform. The legal basis is the Patient's rights Act. The death of the patient will be considered 'a natural death'. Two conditions must be fulfilled: the patient gave his informed consent and there has to be some proportionality between the dose of administered opioids and the pain of the patient. Palliative sedation is the intentional lowering of the awareness of the patient to relieve his pain. Since palliative sedation is a form of alleviation of pain, the same conditions must be fulfilled to be accepted.

Non-Treatment Decisions

Non-treatment decisions include both withdrawal and withholding of (potentially) life-prolonging treatment. When a competent patient refuses a treatment, even a lifesaving or life-prolonging treatment, this refusal is binding for a physician, according to the

Patient's Rights Act. This refusal can be formulated orally or in an advanced directive (e.g. a do not resuscitate order). When the patient is legally incompetent, a non-treatment decision can be taken by a legal representative. However, a physician can never be obliged to perform a medically futile treatment.

CANADA

Medical Assistance in Dying in Canada



Jocelyn Downie

Under Section 241.1 of the Canadian Criminal Code, medical assistance in dying (MAiD) means “the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death (“provider-administered MAiD”); or the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death (“self-administered MAiD”).

The Eligibility Criteria for MAiD

To be eligible for MAiD, a person must be eligible for government-funded health services, at least 18 years old, have decision-making capacity, have a grievous and

irremediable medical condition, have made a voluntary request for MAiD, and have given informed consent to receive MAiD. To have a “grievous and irremediable medical condition,” a person must have “a serious and incurable illness, disease or disability,” “be in an advanced state of irreversible decline in capability,” and “that illness, disease or disability or decline in capability must be causing them enduring physical or psychological suffering that is intolerable to them and cannot be relieved under conditions that they consider acceptable.”

The Procedural Safeguards for MAiD

There are two “tracks” for procedural safeguards for MAiD. If a patient’s natural death has become reasonably foreseeable, then they proceed along Track One. If not, then they proceed along Track Two.

Both tracks require careful assessments by two independent clinicians, the information that must be shared with the patient (including information about means available to relieve their suffering and that they can rescind their request at any time), formal documentation of the request with an independent witness, and express consent immediately prior to the provision of MAiD.

Track Two has additional safeguards including consultation with a clinician with expertise in the condition causing the person’s suffering, informing the patient about counseling services, mental health and disability support services, community services and palliative care and offering consultations with relevant professionals who provide those services or that care, the person

has given serious consideration to the means available to relieve their suffering, and 90 days have passed between the first assessment and the day of the provision of MAiD.

All requests for MAiD received by health care professionals must be reported to the federal government. Clinicians in some provinces/territories report directly to the federal government and others to the federal government through a designated provincial/territorial body. This allows for annual reporting on the number of MAiD requests and deaths as well as the underlying conditions; gender, age, race, Indigenous identity; the nature of the suffering; access to palliative care and disability support services; locations of MAiD; specialties of MAiD practitioners; reasons for finding individuals ineligible; and withdrawal of requests. The federal Minister of Health is required to report annually on the results of this data collection.

Some provinces/territories have additional monitoring and oversight. For example, the Office of the Chief Coroner for Ontario, Office of the Chief Medical Examiner for Alberta, British Columbia’s MAiD Oversight Unit, Quebec Commission on end-of-life care review all MAiD cases for compliance.

The Role of Neurodegenerative Conditions in MAiD in Canada

Plaintiffs with neurodegenerative conditions have been at the heart of court challenges to Canada’s MAiD laws. In *Carter v. Canada*, the Supreme Court of Canada found that the Criminal Code prohibitions on MAiD violated the Canadian Charter of Rights and Freedoms. Gloria Taylor, a woman with ALS, was a central plaintiff in this case. No doubt with Gloria’s words

echoing in their ears, the Court wrote “It is a crime in Canada to assist another person in ending her own life. As a result, people who are grievously and irremediably ill cannot seek a physician’s assistance in dying and may be condemned to a life of severe and intolerable suffering. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel.”

While cancer was the leading underlying condition of those receiving MAiD (65.6%) in 2021, neurological conditions were the underlying conditions for 12.4% of MAiD deaths. The most common neurological conditions were amyotrophic lateral sclerosis (21.1%), Parkinson’s disease (17.7%), multiple sclerosis (13.9%), spinal stenosis (8.1%), and progressive supranuclear palsy (5.0%).

Dispelling Myths

There has been no legal expansion of, or slippery slope in relation to, the eligibility criteria. The criteria were first established by the Supreme Court of Canada in Carter. Bill C-14 narrowed those criteria (with the added criterion of “natural death has become reasonably foreseeable”). This criterion was struck down by the court in Truchon. Bill C-14 narrowed the criteria temporarily (with the temporary exclusion of persons with mental disorders as their sole underlying medical condition). This temporary exclusion will be automatically repealed in March 2024 at which point the eligibility criteria will be returned to the parameters established by the Supreme Court of Canada in Carter.

People are not receiving MAiD for poverty, loneliness, or other forms of socioeconomic vulnerability. Indeed, it is a breach of the Criminal Code to provide MAiD in such cases as the law requires that the person’s enduring and intolerable suffering be caused by their serious and incurable illness, disease, or disability or their advanced state of decline in capability. Furthermore, “[i]n every country with available data, AD is more common in people with higher income and education, and less common in people who are widowed or institutionalized” and “studies consistently show that an inverse relationship shows that structural vulnerability is, if anything, statistically protective against MAiD these data make it clear that there are powerful drivers.”

People are not choosing MAiD because they cannot access palliative care – over 95% of those who received MAiD received or had access to palliative care (with 2.5% unknown).

The legalization of MAiD has not had a detrimental impact on palliative care – “funding/support for clinical palliative care has increased dramatically in much of the country since MAiD became legal.”

There are no reported cases of clinicians being charged or disciplined by their regulatory bodies for abuses of patients or breaches of the law or practice standards despite allegations, reports, and exhaustive reviews. Evidence from the review of all cases by the Ontario Chief Coroner and the Quebec Commission refute the claims of abuse.

France

Euthanasia and the End of Life in France Framework and Ethical Reflection



Anne-Marie Duguet



Roxane Delpech

The term “euthanasia” does not appear in any legal text in France, but euthanasia is commonly defined as giving voluntary death to a person at the end of his or her life or to a person suffering from a serious pathology, whose suffering is to be shortened. This voluntary act (active euthanasia) is currently prohibited and constitutes a crime.

For a long time, doctors were criticized for keeping patients alive at the cost of unreasonable obstinacy. Families felt that these patients were dying in undignified conditions. Some doctors also limited the prescription of opiates, to prevent the side effects from impairing patients’ judgment and

hastening their death (double effect). In addition, they were reluctant to stop care even if patients requested it, on the grounds that they had to protect life.

In order to describe the current situation in France, we first present the criminal sanctions, second the different stages of ethical reflection, then the evolution of the laws on patients' rights, with specific provisions for patients unable to express themselves, and finally the prospects of forthcoming legislation on active assistance in dying.

Deliberately Causing Death (Active Euthanasia) Is a Crime

Deliberately causing death to another person is a positive act with the intent to cause death (*animus necandi*). The victim's consent does not constitute justification for the offence. It is murder (according to Article 221-1 of the Penal Code), or poisoning (Art. 221-5 CP), if substances are administered to cause death. The delivery to the victim of drugs likely to cause death, to be absorbed is considered as the act of administration. These two qualifications are crimes, judged by the Cour d'Assises. The presence of a popular jury, sensitive to compassion, explains the many acquittals of perpetrators.

The Ethical Debate

Legislating on euthanasia is a societal demand that is regularly debated in France. The CCNE (Comité Consultatif National d'Ethique or National Ethics Advisory Committee), which advises the government on social issues and draft legislation, has been considering the ethical issues following cases of euthanasia carried out by family and relatives or by healthcare professionals. The

opinions are available in English on the website www.ccne-ethique.fr.

In 1991, the CCNE disapproved of the legitimacy of voluntarily giving death to a patient (Opinion No. 26). Opinion No. 63 (2000) evoked an exception for euthanasia in certain circumstances, out of compassion and solidarity. Opinion No. 121 (2013) calls for improve expression of advance directives. Opinion No. 139 (2022) proposes strengthening the existing palliative care system (universal access) and, for the first time, envisages the decriminalization of active assistance in dying, with ethical requirements to be defined.

We have moved from a rejection of decriminalization to an acceptance limited by ethical criteria.

Current Legal Framework on Patients' Rights at the End of Life

1. The Act No. Law 99-477 of June 9, 1999, on Guaranteeing the Right to Access Palliative Care allowed patients to refuse any further investigation or treatment and seek palliative treatment.
2. The Act No. 2005-370 of April 22, 2005 on Patients' Rights and the End-of-Life Care (Leonetti Law) authorized the cessation of treatment that appeared to be useless, disproportionate or artificially prolonging life. This cessation of treatment can be considered as passive euthanasia and raises the question of the right to life.

In the Lambert vs. France case, the European Court on Human Rights had to decide whether French legislation authorizing the cessation of treatment violates Article 2 on the right to life. According to the facts of the case, Vincent Lambert

was in a vegetative state, and his doctor decided to discontinue artificial nutrition and hydration, a decision confirmed by a panel of three doctors. The Conseil d'Etat, France's highest administrative court, ruled that the decision was in accordance with the law. The family took the case to the ECHR, arguing that stopping artificial nutrition and hydration was contrary to the right to life. The ECHR found that the EC's assessment of the French legislative framework justified the medical decision and concluded that there had been no violation of article 2 (Lambert/France CEDH 185 06.05.2015).

The 2005 law also introduced advance directives by which patients specify their wishes for end-of-life care in advance, in order to stop or limit treatments to be carried out when they no longer have the power of discernment. If they have been established less than three years before the unconsciousness of the person, the advance directives are binding on the physician for any investigation, except in the case of a vital emergency and where the advance directives appear to be manifestly inappropriate or not in accordance with the medical situation. This decision of refusal is taken after a collegial procedure is defined and is recorded in the medical file. The refusal is brought to the attention of the *personne de confiance* (person of trust), designed by the patient or, failing that, of the family or the relatives.

3. The Act No. 2016-87 of February 2, 2016 on New Rights for Patients and Terminally Ill Persons (Claeys-Leonetti Law) introduced the concept *sédation profonde et continue* (continuous deep sedation until death)

At the request of the patient, after cessation of all life-sustaining treatments, a continuous deep sedation (CDS) is maintained until death associated with analgesia. CDS can be implemented at home or in a health facility in 3 cases when: 1) a serious and incurable condition endangering life in the short-term, and the person presents a suffering refractory to treatment; 2) the decision of the patient with a serious and incurable condition to stop treatment is life-threatening in the short-term and can lead to unbearable suffering. 3) When the patient cannot express his or her will when the medical team stops a maintenance treatment, the CDS is implemented according to the collegial procedure, to avoid suffering caused by cessation of treatment.

The implementation of continuous deep sedation (CDS) has shown that this system has its limits, particularly for people suffering from ALS, since some of them met the conditions, but others request for sedation were refused because they did not meet these conditions, which is why they went to Switzerland or Belgium to benefit from active assistance in dying.

Legislation in Preparation to Enable Active Assistance in Dying.

With a view to a legislative revision, a Citizens' Convention on the End of Life was set up in December 2022, made up of 185 members chosen by lot and representative of the French population. The question to be debated was whether the framework for end-of-life support is adapted to the different situations encountered, or whether any changes should be introduced. The final report proposed: (1) to make the right to palliative care

effective to all citizens and (2) to open up active assistance in dying in cases of intractable physical or mental suffering (assisted suicide and euthanasia).

For its part, the CCNE has asked the Espaces Régionaux d'Ethique (Regional ethics reflection groups) to plan public meetings to raise citizens' awareness of the ethical issues surrounding the end of life. 350 debates in 122 towns and cities brought together 45,000 citizens, demonstrating the diversity of end-of-life situations and the painful experiences of loved ones.

The government is currently drafting a bill that would authorize the prescription of a lethal product as *aide active à mourir* (active aid in dying) after a "collegial medical decision" for adults whose prognosis is "medium-term" and whose suffering is "physically unbearable", if they have expressed their "free and informed" wishes. The "conscience clause" of professionals who do not wish to participate may be used. Palliative care professionals are very reluctant to participate, while other professionals would like to be able to rely on legislative changes to respond to exceptional critical situations. Will we move towards a strictly medical French model, or will we rely on associations? Will active aid in dying be limited to assisted suicide, in which a doctor prescribes the lethal substance, which is then dispensed by pharmacies and self-administered? The bill project of the government and parliamentary debates will answer these questions shortly.

NETHERLANDS

Report on Assistance in Suicide in the Netherlands



Liselotte Postma



Laura De Vito

In the Netherlands, a patient can make several decisions when it comes to the end of life. In order to die he can refuse lifesaving and life sustaining treatment, decide to stop eating and drinking or ask a physician for euthanasia or assistance in suicide. Euthanasia and assistance in suicide are criminal offences under section 293 and 294 of the Dutch Penal Code. According to the same provisions these acts are not punishable if it is committed by a physician who fulfills specified due care criteria. When a patient cannot be cured, palliative care, including palliative sedation, is seen as good medical practice. The patient can also appoint an attorney to make medical decisions on behalf

of him, but this attorney is not allowed to ask for euthanasia or assistance in suicide. Patients with a neurodegenerative disease like ALS can apply for euthanasia or assistance in suicide. This note is about the legality of euthanasia and assistance in suicide in general and contains a brief overview of decisions that are made regarding to patients with ALS or another neurodegenerative disease.

The Law on the Regulation of Euthanasia and Assistance in Suicide

Euthanasia and assistance in suicide are both (and still) criminal acts according to Articles 293 and 294 of the Dutch Penal Code. Euthanasia is punishable by a custodial sentence of 12 years. Assistance in suicide incurs a much lower custodial sentence of 'only' three years, provided that the suicide is performed and has resulted in the death of the involved person. However, when euthanasia or assistance in suicide are performed by a physician who fulfills the due care criteria of the Termination of Life on Request and Assisted Suicide Act, and the acts are reported to the municipal coroner, they are excluded from punishment. The requirements of due care mean that the physician: (a) holds the conviction that the request by the patient was voluntary and well-considered; (b) holds the conviction that the patient's suffering was lasting and unbearable; (c) has informed the patient about the situation he was in and about his prospects; (d) the patient hold the conviction that there was no other reasonable solution for the situation he was in, (e) the patient has consulted at least one other, independent physician who has seen the patient and has given his written opinion

on the requirements of due care, referred to in parts (a) to (d); and (f) has terminated a life or assisted in a suicide with due care.

A review committee assesses in every specific case whether physician-assisted-dying has been carried out in accordance with the due care criteria. Only if the committee finds that the physician did not fulfill one or more due care criteria, the case is handed over to the Public Prosecutor who in turn judges whether there are grounds for prosecution. An exception to liability to prosecution of assistance in suicide has been made for physicians only, not for friends or relatives.

Case Law on the Scope of Assistance in Suicide

In case law (in which friends or relatives were involved) is decided what is seen as assistance according to Article 294-2 of the Penal Code and what not. When the assistance means the distribution of means to commit suicide, it is clearly an offense, provided that the helper knows that the involved person will commit suicide with these means. When the assistance is given in another way, the law is not that clear about the scope of the provision. That scope must therefore be derived from case law. These sources lead to the conclusion that it is relevant to what extent there is a guiding or directing role from the suspect. Assistance that falls under the scope of the provision involves: giving instructions, carrying out concrete actions or skills and actively taking or directing initiatives to commit suicide. Assistance is not: giving general information, having conversations, being present during the suicide and offering moral support.

Further: assistance in suicide is not only assistance given during suicide; also preparatory acts fall under the scope of the provision. When it comes to the causality, there is a broad scope: all actions (limited by the substantive restrictions mentioned above) that make it possible or easier for the other person to commit suicide count as assistance.

Euthanasia and Assistance in Suicide in the Case of ALS

The law requires the existence of unbearable and lasting suffering, and case law made clear that this suffering must have a medical basis. As ALS is a medical disease, the suffering that follows from it, can be classified as unbearable and lasting. Visiting the website of the review committees, a lot of cases about ALS or other neurodegenerative diseases can be found. Two of them were given the judgment 'not fulfilled the due care criteria', this was due to consulting problems. But in all these cases the assessment committee concluded that the suffering has been unbearable and lasting and that there were no alternatives to relieve the suffering. In a few cases the committees mentioned the decreased ability to speak as a point of attention. In some of these cases a speaking computer brought a solution to this problem. In another case (2016-95) the communication took place by nodding yes or shaking the head no and by pointing to letters on a card with one finger. In all these cases the committees declared the requests that were made in that way as valid. Although most cases concerned older patients, also younger people were involved: women between 50–60, a man in his 50's and in his 40's and a woman in her twenties.

PORTUGAL

Medically Assisted Dying in Portugal: Act no. 22 of 2023 on Medically Assisted Dying



Inês Fernandes Godinho

Act no. 22/2023, of 25 May 2023, regulates the conditions under which medically assisted dying (morte medicamente assistida or MMA) is not punishable in Portugal. The MMA law (as it will be referred to in this report) is the result of a long legislative process, spanning more than one parliamentary term and featuring the particularity of having been the subject of four Assembly of the Republic decrees, four presidential vetoes, two Constitutional Court rulings and one parliamentary confirmation of a vetoed decree until there was, in May 2023, the presidential promulgation that allowed the law to become legislation in force in Portugal.

These factors illustrate that the process was long and intense, and that it was not a law born of simple impulse, but one that benefited from extensive political, social and parliamentary discussion.

These factors have two additional implications, namely the existence of concessions and,

in anticipation, the approval of a piece of legislation that fell short of and went beyond the initial formulations. It fell short, as it is essentially an assisted suicide law, following the changes introduced after the latest Constitutional Court judgement, whereas the previous proposals provided for a broad model of MMA, in which it was up to the patient to choose between assisted suicide and euthanasia. It went beyond, since it covers situations of serious and incurable illness (*doença grave e incurável*) and not just those of incurable and fatal illness (*doença incurável e fatal*), as was the case with the wording proposed until November 2021.

Even with these characteristics, the MMA law represents a milestone in guaranteeing patients' right to self-determination, which is the legitimizing reason for its approval, resulting in the adoption of an altruistic and semi-broad model of medically assisted dying.

The MMA law is fundamentally structured along four lines: its definitions (Article 2), the MMA procedure (Articles 3 and 4 to 17), particular aspects of the law relating to the rights and duties of health professionals (Articles 18 to 22) and, finally, the monitoring and evaluation of the law (Articles 23 to 27).

Like other legal systems, intervention in the field of MMA has followed the model of justification rather than decriminalization. In other words, the offences in articles 134 (Homicide at the request of the victim) and 135 (Inciting or aiding suicide) of the Penal Code will continue to be included in the Penal Code, and acts—only and when—carried out in strict compliance with all the conditions

laid down in the MMA law will not be punishable.

According to Article 3 of the MMA law, we can find subjective requirements (in terms of the patient) and objective requirements (in terms of the grounds and manner of the application).

In subjective terms, the patient must be a national or legal resident in Portugal (Article 3(2) of the MMA Law) and of legal age (Article 3(1) of the MMA Law).

In objective terms, in terms of the grounds for the request, the basic axis is the patient's suffering of great intensity as a result of a definitive injury of extreme severity (*lesão definitiva de gravidade extrema*) or a serious and incurable illness.

As for the requirements of the request, it must correspond to the patient's current, repeated, serious, free and informed will. As the law adopts a non-paternalistic approach, the medical verification of the patient's capacity is only required if there is any doubt about it, and, as in other models, such verification is not required as a mandatory condition (articles 3(1) and 7(1) of the MMA Law).

Given the legitimizing reason for the MMA Law, the procedure is particularly demanding regarding the patient's will and its reiteration and the duty of health professionals to provide clarification, especially the counseling doctor (see articles 2(g); 4(8); 5(1); 6(3) and (4); 8(4); 9(2) and 19(a), (b) and (c) of the MMA Law). Added to this is the concern to ensure that the will of the patient is free, particularly through guaranteed access to palliative care (art. 4, no. 6 of the MMA Law) and psychological counseling (art. 4, no. 7 of the MMA Law). Since the will must be

current, if it cannot be formulated as such, the procedure will be interrupted (art. 9 (5) of the MMA Law); moreover, the patient's request can also be revoked at any time (arts. 3 (7) and 12 of the MMA Law).

As mentioned, the MMA Law in Portugal follows a model that we will call semi-broad. Article 3(4) of the MMA Law establishes that MMA can occur by medically assisted suicide (*suicídio medicamente assistido*) and by euthanasia (*eutanásia*), while paragraph 5 of the same article limits cases of euthanasia to situations in which medically assisted suicide is medically impossible due to the patient's physical incapacity.

The realization of the MMA follows a complex clinical procedure, which opens with the request made by the patient to the doctor they have chosen as their supervising doctor (*médico orientador*) (art. 4, no. 1, of the MMA Law. It must then have the positive opinions of i) the supervising doctor (Art. 5(1) of the MMA Law), ii) the specialist doctor (*médico especialista*) (Art. 6(1) and (2) of the MMA Law), iii) the specialist psychiatrist (*médico especialista em psiquiatria*), in the event of doubt about the patient's capacity (Art. 7 of the MMA Law), iv) the Commission for the Verification and Evaluation of Medically Assisted Death Clinical Procedures (*Comissão de Verificação e Avaliação dos Procedimentos Clínicos de Morte Medicamente Assistida*) (Art. 8 of the MMA Law).

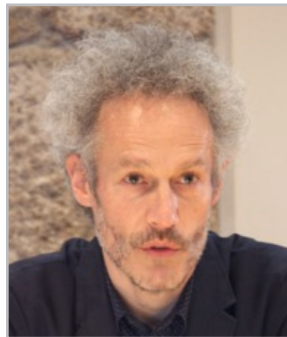
MMA in Portugal respects the altruistic model, which means that only health professionals for whom no direct or indirect benefit from the patient's death derives may practice

or assist in the MMA procedure (art. 18 (1) of the MMA Law).

In short, the MMA is particularly demanding in terms of guaranteeing the patient's will and in the role of the supervising doctor, in order to provide a barrier to the verification of the slippery slope argument and seeking to prevent the trivialisation of MMA. Seeking to avoid "death tourism", by requiring the nationality or legal residence of the possible beneficiaries of the MMA procedure, the MMA Law seeks to make a fair balance between (the protection of) the right to life and (the protection of) the right to self-determination.

SPAIN

End-of-life Decisions in Spain



José-Antonio Seoane

The current end-of-life scenarios in Spain are the result of the evolution of legislation and case law since the 1978 Spanish Constitution. The legal consolidation of patient's rights and autonomous decision-making in end-of-life care has happened along with the transformation of ethical and social values and relevant changes in healthcare field: new ways of getting sick and dying; new definitions of the goals of

medicine –including the relief of pain and suffering, the care of those who cannot be cured, and the pursuit of a peaceful death; and a shift in doctor-patient relationship guided by the respect for patient autonomy.

The first legislative step was the General Health Law (Act No. 14 of April 25, 1986 on General Health), a state legal norm that has acknowledged the right to informed consent and a conditional right to refuse treatments. In this first stage, it also became lawful to donate organs following the requirements of the Act No. 30 of October 27, 1979 on the Removal and Transplantation of Organs. Moreover, the right not to receive treatments against the patient's will was confirmed by the Spanish Constitutional Court in its judgment 120/1990, while asserting that it did not mean a right to die.

A second stage departed from the Convention on human rights and biomedicine (Oviedo Convention, 1997) and was deployed through diverse legal norms at regional and state level. The main state legislative norm was the Basic Law on Patient Autonomy (Act No. 41 of November 14, 2002 on the Autonomy of the Patient and on the Rights and Obligations in Matter of Clinical Information and Documentation), still in force and remaining the legal reference for patient's rights. This law reinforced the right to informed consent and a right to refuse treatments without restrictions and added the right to issue advance directives in order to define the future care on the event of losing competence. The Spanish Constitutional Court has confirmed that the rights to autonomous decision-making and to refuse treatments are in accordance with the Constitution in the case of

minors and proxy decisions too (judgment 154/2002, 18 July), supported by the fundamental rights to physical and moral integrity (article 15 Spanish Constitution) and freedom of conscience and religion (article 16 Spanish Constitution).

The most significant contribution in the third stage came from the Autonomous Communities — Spanish regions—, passing several legal regulations on the dignity in the end-of-life process since 2010. These norms have legally defined the lawful and unlawful end-of-life scenarios (refusal of treatment, withholding and withdrawal of life sustaining treatments, palliative care, palliative and terminal sedation, informed consent or advance directives among the former, being therapeutic obstinacy one of the latter), strengthened patient's rights and autonomy in the process of dying, and clarified healthcare professional's duties and healthcare system's institutional guarantees. Once again, the Spanish Constitutional Court reinforced patient's autonomy and rights through its Judgment 37 of March 28, 2011, stressing the constitutional link of the right to informed consent with the fundamental right to physical and moral integrity (Article 15 of the Spanish Constitution) and stating that respecting patients' autonomy is a guarantee for professional good practice. Moreover, the Supreme Court case law broadened the scope of healthcare standard of care and good practice (named *lex artis* in Spanish case law), demanding not only technical competence and correctness but also to respect patient's informed consent and confidentiality.

The fourth and last stage is characterized by the extension of the end-of-life scenarios by the Organic Law on Euthanasia (Act No. 3 of March 24, 2021 on the Regulation of Euthanasia—LORE), a state legal norm that decriminalises euthanasia—modifying the article 143 of the Spanish Criminal Code—and acknowledges a right to request help in assisted dying through direct administration or the prescription and supply of drugs by a healthcare professional. Later, two judgments of the Spanish Constitutional Court (Judgment 19 of 2023, March 22, 2023 and Judgment 94 of September 12, 2023) have confirmed that the legal conditions for euthanasia as set out in the LORE are in accordance with Spanish Constitution. Nonetheless, the LORE does not acknowledge a right to die, but a right of self-determination to decide how and when to die in accordance with the requirements and procedure established by the Law.

Apart from special situations and requirements, these are the general conditions for applying and receiving the aid to die established in the LORE. The applicant has to be of legal age (18 years or older), of Spanish nationality or legal residence superior of 12 months, and competent and conscious at the time of the request. He/she has to receive written information about his/her medical process and treatment options, including comprehensive palliative care and dependency care. He/she has to present, without external pressures, two voluntary written requests separated at least fifteen days—a period that can be shorter if he/she can lose competence before giving his/her informed consent—, and give his/her informed consent before receiving

the aid to die. A current non-competent patient can also receive the aid to die when he/she has foreseen and issued this request in an advance directives document. And the applicant has to suffer a serious and incurable disease or a serious, chronic and incapacitating illness that causes him/her an unbearable and continuous physical or psychological suffering that cannot be alleviated, being this clinical situation (“euthanasian context” in LORE’s Preamble wording) certified by the responsible physician.

One distinctive feature of Spanish regulation of euthanasia is the requirement of a prior verification of the fulfilment of legal requirements by the regional Commission of Guarantee and Evaluation, that is an independent and multidisciplinary board. Two Commission members (physician and lawyer) check that the whole procedure, where the responsible physician and the consulting physician have examined the patient and ratified the fulfilment of the legal conditions in advance, has been developed correctly and the conditions laid down for the proper exercise of the right to apply for and receive euthanasia are met. Therefore, euthanasia can be implemented only after this confirmation and the positive resolution by the Commission of Guarantee and Evaluation. Once euthanasia has been implemented, the responsible physician communicates it to the Commission and forwards the corresponding documentation to enable the Commission to carry out the ex post assessment, which puts an end to the procedure.

According to the above-mentioned historical overview, the main lawful end-of-life scenarios in Spain are the following:

The refusal of treatment (*rechazo del tratamiento*) is an informed decision made by a patient for withholding or withdrawing a treatment, even if this decision could lead to his/her death. The patient can make this decision through his/her informed consent, when remains competent at the time of implementing the decision, or an advance directives document, when he/she is currently incompetent but has made his/her decision beforehand anticipating a future lack of competence, being recommended that such a document should be the result of a process of a shared care planning.

The withholding or withdrawal of life-sustaining treatment, i.e, not starting or stopping a treatment that has the potential to sustain the life of a patient, are two ways of restriction/adaptation of therapeutic effort (*limitación/ adecuación del esfuerzo terapéutico: LET/AET*). The LET/AET decision is made by the healthcare professionals and is considered ethically and legally correct when it aims to avoid keeping the patient alive through disproportionate and futile treatments. The expression 'passive euthanasia' is not accurate and should be avoided in order to prevent misunderstandings.

The palliative care (*cuidados paliativos*) is a comprehensive approach provided at any stage of patient's illness that addresses the physical, psychological, spiritual, and social needs of the patient and his/her family in order to achieve the best quality of life available to the patient by relieving suffering, controlling pain and distressing symptoms.

The palliative sedation (*sedación paliativa*) is the process of inducing and maintaining deep sleep, in order to relieve refractory

symptoms in the palliative care setting —or even in terminal stages: terminal sedation (*sedación terminal*) —, having previously obtained the patient's consent or, if incompetent, his/her representative's consent. The expression 'indirect euthanasia' is not accurate and should be avoided in order to prevent misunderstandings.

The assistance in dying (*prestación de ayuda para morir*) consists of providing the necessary means to a person who suffers a serious and incurable disease or a serious, chronic and incapacitating illness that causes him/her an unbearable and continuous physical or psychological suffering that cannot be alleviated, and who has expressed his/her previous and informed request to die, either through the direct administration of a substance to him/her by a healthcare professional, or the prescription or supply to him/her by the healthcare professional of a substance, so that it can be self-administered to cause his/her own death. The LORE uses the term 'euthanasia' (*eutanasia*) only in its preamble and applies it to both conducts, not mentioning anywhere the expression 'medically assisted suicide' for the latter.

SWITZERLAND

End-of-Life Issues in Switzerland



Roberto Andorno

Legal responses to end-of-life issues are not very different in Switzerland than in most European countries. For instance, active euthanasia (i.e. killing on request) is illegal, although it is treated as a lesser offense than murder or manslaughter. Also, like in most European countries, the administration of painkillers to relieve serious pain of terminal patients, even though it may lead to the unintended consequence of hastening their death, is accepted. Similarly, like in many other countries, the withdrawal or withholding of life-sustaining treatments, even if not covered by any specific legal provision, is not treated as a criminal offense provided that certain conditions are fulfilled.

The peculiarity of Switzerland regarding end-of-life issues only relates to assisted suicide. This practice, which is permitted, has two significant differences if compared to the situation in the other few European countries that allow it:

Assisted suicide is generally not performed by physicians, but by non-physician volunteers working for nonprofit organizations involved

in this practice. The role of physicians is limited to prescribing the lethal drug and assessing the patient's decisional capacity; they do not perform assistance in the suicide themselves. In this regard, the practice of assisted suicide in Switzerland is similar to the one in the US state Oregon.

The person requesting assisted suicide does not need to suffer from a particular medical condition (such as a terminal illness or unbearable suffering). The only requirement is that the individual must have decisional capacity, because in the absence of it, his or her act cannot be considered a "suicide" in legal terms.

The peculiarity of the Swiss situation is due to the circumstance that, unlike other countries allowing assisted suicide, Switzerland does not have any specific legal norms regulating this practice. This current situation has developed, not as the result of an explicit governmental policy, but rather at the initiative of non-governmental right-to-die organizations, which took advantage of a gap in the legal system. The Penal Code, which was adopted in 1937, already included current Article 115, entitled "inducement and assistance to commit suicide", which reads: "Every person who, for selfish reasons, incites or assists someone to commit suicide, shall be sentenced to imprisonment of up to five years or a fine."

In the 1980s, this article began to be interpreted a contrario by assisted suicide organizations to argue that assistance with suicide is not a criminal offense when it is practiced without any self-interested motivation. There would be a selfish motivation if, for instance, the assisting person would inherit the one who is seeking

to die, or would benefit in some other way from the death of the latter. However, because nonprofit organizations do not have, by definition, any selfish motivations for helping someone to commit suicide, their activities are not illegal. In other words, the practice of assisted suicide was never formally legalized or regulated, but it is nevertheless tolerated due to the loophole in Article 115 of the Penal Code. It must be mentioned that the "selfish motivation" is so narrowly understood by the courts that, in practice, it is very unlikely that the leaders of an assisted suicide organization are condemned on this ground. Even when it is proved that they or their organizations have made profit from the practice, it must be also proved that a selfish motivation was the determinant reason for the assistance with the suicide.

The first two assisted suicide organizations in the country were created in 1982, but independently of each other: Exit Deutsche Schweiz, for the German-speaking part of Switzerland, with headquarters in Zurich, and Exit A.D.M.D (Association pour le Droit de Mourir dans la Dignité), for the French-speaking part of the country, with headquarters in Geneva. During the first years after their creation, both associations concentrated on promoting the use of advance directives. The first assisted suicide was performed in 1985 by Exit Deutsche Schweiz.

Requests for assisted suicide in Switzerland are mainly motivated by medical reasons: malignant tumors, pain, neurological disorders such as multiple sclerosis and amyotrophic lateral sclerosis, and respiratory problems. However, non-medical reasons also play a significant role in the decision and are even the dominant motivation in

many cases. Such reasons include loneliness and social isolation, the desire not to become a financial burden for the family, age-related functional limitations such as reduced mobility, and existential suffering ("being tired of life").

In 2004, the Swiss Academy of Medical Sciences (SAMS) issued guidelines on the care of terminally ill patients, where it expressed serious reservations about the direct involvement of physicians in this practice, considering that "it is not the physician's duty to propose suicide assistance; instead, the physician is required to alleviate suffering that might generate suicidal intent." In fact, "suicide assistance is not part of medical practice" (Section 4.1.). Notwithstanding, the same guidelines reduce the scope of the preceding statements when they stipulate that "if, in exceptional circumstances, physicians decide to assist patients in committing suicide, it is their responsibility to verify compliance with certain requirements," specifically, that "the illness from which patients suffers legitimizes the assumption of their imminent death."

These guidelines were incorporated into the Code of the Swiss Medical Association (Federatio Medicorum Helveticorum, FMH), which is binding for physicians.

However, in 2018 the SAMS changed the directives and adopted a more permissive approach. According to the new directives, assisted suicide is also acceptable for patients who are not in a terminal condition but are exposed to "unbearable suffering", which could be due to any disease or functional impairment (including mental impairments) (Paragraph 6.2.1). This shift created a conflict with the FMH, which considered that the expression

“unbearable suffering” was too vague and refused to incorporate the new SAMS guidelines into the Professional Code. In practice, the new guidelines extend significantly the applicability of assisted suicide, and this raises numerous legal and practical questions. Indeed, the notion of “unbearable suffering”, which is independent of any terminal disease or condition, is too undetermined. This vagueness renders this notion inadequate to have legal effects. Moreover, this notion would justify the assisted suicide of patients who suffer from mental diseases, such as depression, which in some cases can be successfully treated. Allowing the assisted suicide of such individuals would place the State in serious conflict with its own policy of suicide prevention of patients with mental disorders, who are especially prone to commit suicide precisely due to their illness.

In 2009, the government attempted to introduce specific legislation to regulate assisted suicide. However, two years later, after careful consideration, it concluded that specific legal regulation on assisted suicide would not improve the current situation and would carry many disadvantages. On these grounds, the government decided to focus on the adoption of measures to strengthen palliative care and suicide prevention.

