

## Cross-border access to end-of-life services in Europe

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Oral version

(Translated by Kalex, A. Poméon and K. Booth)

I would like to thank the organisers for inviting me to this seminar on an issue that is burning on two levels: the issue of the end of life on the one hand, and on the other hand, the crossing of borders by citizens seeking a death that meets their expectations, insofar as we can use this expression. From an ethical and legal point of view, the fundamental question seems to me to be whether dying can be the object of a service in the health field. This question is a necessary step when we think about the consequences of crossing borders on, for instance, reimbursement of expenses or information given on euthanasia or assisted suicide. If the answer is yes, then it should be possible, simple, frequent and transparent to move around in an area of freedom such as Europe in order to obtain what you want and cannot find at home. As everyone here suspects, we are in a rather grey area.

Indeed, it is a grey area at two levels.

On the one hand, in France, from a legal point of view, euthanasia is prohibited and assisted suicide is not permitted. But these prohibitions are crumbling. On the other hand, while in another, different but related area - medically assisted reproduction - the question of crossing the border is regularly put forward as an argument in the debate, this is less the case in France with regard to the end of life. The subject you have chosen to address - end of life and borders - is nonetheless excellent because, beyond the legal aspects of the subject, the matter of crossing a border seems to me to be a metaphor for limits (internal or external, it doesn't matter) but also, as far as the end of life is concerned, a renewal of the age-old theme of the journey into the unknown which implies at some point crossing a space, like the river Styx in Greek mythology. It is therefore no coincidence that literature, which is an even better indicator of society than the law, addresses this subject, including in its cross-border dimension. Michel Houellebecq in *La carte et le territoire* (The Map and the Territory, Flammarion, 2010), depicts a clinic in Switzerland where assisted suicide is practised. The Nobel Prize winner Olga Tokarczuk, in *Histoires bizarroïdes* (Bizarre Stories,

Babelio, 2020), describes in the short story, the ‘Transfugium’, an extraordinary title, an end of life where it is not clear where or how it takes place, but which closely resembles an assisted suicide or euthanasia. In the short story ‘The Heart’, it is not the issue of the end of life, but that of organ transplants that is depicted, again through the medium of travel. It is as if the crossing of a border echoes the ethical and legal question of what is permitted and what is forbidden in terms of intervention in this time and space that is the body.<sup>1</sup>

I/ So what are the main legal rules with regard to euthanasia and assisted suicide in France?

The answer to the first question is simple: there are no such rules, since neither euthanasia nor assisted suicide are legalised in France, despite calls for this to happen.

To be more precise, euthanasia is not prohibited as such, but the person who performs it is liable for offences under the *Code pénal* (French Criminal Code) (chiefly murder, pre-meditated murder, failure to assist a person in danger). Suicide is not an offence and therefore helping someone to die could not be an offence under the classic rule that complicity requires that the act committed by the principal amounts to an offence. However, incitement to suicide is an offence (Art. 222-13 of the Criminal Code) and acts that help a patient to die can theoretically be punishable under various criminal laws.

Does this mean that the end of life is not at all regulated in France and that it is not possible to accelerate death?

No, not at all since the adoption of the Laws of 22 April 2005 and of 2 February 2016 creating new rights for the sick and people at the end of life, as well as Order of 11 March 2020 on protected adults.

Here, in outline, are the rules that apply and that can be found in the *Code de la santé publique* (French Public Health Code) (Part 1, ‘General health protection’, Book 1, ‘Protection of persons in matters of health’, Title 1 ‘Rights of sick persons and users of the health system’, Chapter 1 ‘Information for users of the health system and expression of their wishes’). These details of the structure of the law are important because they show that the end of life is considered through the dual and sometimes contradictory prism of patients’ rights and physicians’ duties. The difficulty arises from the fact that in order to understand exactly what a patient can ask for to end their suffering and what a physician can do to accede to this request, it is necessary to navigate between:

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<sup>1</sup> See the issue of transhumanism. See *Ethics & Politics / Etica e Politica*; 2019, Vol. 21 Issue 2, p77-88, 12p.

- Section 1, 'General principles', applying to all sick people, including those at the end of life
- Section 2, which is more explicit as it concerns people at the end of life, but in fact only addresses one aspect, namely the expression or non-expression of their wishes.

While in my opinion the legislative choices achieve the correct balance between the values at stake, on the other hand, they maintain an ambiguity, in my view detrimental to both patients and physicians, in seeking, while partly refusing, to include the act of causing death under acts of care.

#### 1/ Two prohibitions

As explained by a physician at the *Institut Curie*, a member of the French Society for Palliative Care, whom I have interviewed for this presentation, the rules relating to the end of life are situated between two prohibitions, one relating to euthanasia, the other relating to what was formerly known as therapeutic obstinacy and is now called unreasonable obstinacy. The latter is not the subject of a criminal offence but of an article of the Public Health Code, Article L. 1110-5-1, which states: 'The acts mentioned in Article L. 1110-5 must not be carried out or continued when they result from unreasonable obstinacy. When they appear unnecessary, disproportionate or when they have no other effect than the artificial maintenance of life, they may be suspended or not undertaken, in accordance with the patient's wishes and, if the patient is unable to express his or her wishes, following a collegiate procedure defined by regulation.

Artificial nutrition and hydration are treatments that may be discontinued in accordance with the first paragraph of this Article.

When the acts mentioned in the first two paragraphs of this Article are suspended or not undertaken, the physician shall safeguard the dignity of the dying person and ensure the quality of their life by providing the palliative care mentioned in Article L. 1110-10.'

It should be noted that Article L. 1110-5 provides that, 'All persons shall have the right to receive, throughout the country, the most appropriate treatment and care [...] and to benefit from therapies [...] which guarantee the best possible health protection and relief of suffering in the light of established medical knowledge.'

And at the end of that Article:

‘All persons shall have the right to a dignified end of life with the best possible relief of suffering. Health professionals shall use all the means at their disposal to ensure that this right is respected.’

According to the doctor I interviewed, this means ‘I will not abandon you’, ‘I will not let you suffer’.<sup>2</sup> It is the patient who sets the cursor of what constitutes unreasonable obstinacy. For example: dialysis every two days.

## 2/ What is permitted

The system in place combines two criteria and allows action to be taken to shorten suffering, even if it means accelerating death. The two criteria are the following:

- Whether the circumstances are such that the physician can ask the patient to reiterate their wishes to refuse care.
- Whether the patient is conscious: the way of ascertaining the patient’s wishes and the procedure to be followed are different.

### a.- Conscious patient

#### Stage 1:

Article L. 1111-4 al. 3 of the Public Health Code

‘The physician is obliged to respect the person’s wishes after having informed them of the consequences of their choices and their seriousness. If the person’s decision to refuse or interrupt any treatment puts their life in danger, they must repeat their decision within a reasonable time. The person may consult another member of the medical profession. The entire procedure shall be recorded in the patient’s medical record. The physician shall safeguard the dignity of the dying person and ensure the quality of his or her end of life by providing the palliative care mentioned in Article L. 1110-10.’

NB: palliative care is the subject of specific provisions set out in Art. L. 1110-9 et seq.

#### Stage 2:

Article 1110-5-2 of the Public Health Code:

‘At the patient’s request to avoid all suffering and not to be subjected to unreasonable obstinacy, deep and continuous sedation causing an alteration of consciousness which is maintained until death, combined with an analgesic and

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<sup>2</sup> Telephone interview with Dr. A. Burnod, Thursday 2 June 2022.

the cessation of all life-sustaining treatments, is implemented in the following cases:

1° When the patient with a serious and incurable disease, which is life-threatening in the short term, experiences refractory suffering;

2° When the decision of the patient with a serious and incurable disease to stop a treatment is life-threatening in the short term and is likely to cause unbearable suffering.'

b.- Unconscious patient

Article L. 1110-5-2 of the Public Health Code

'When the patient is unable to express their wishes and, in avoiding unreasonable obstinacy as referred to in Article L. 1110-5-1, in the event that the physician stops life-sustaining treatment, the latter shall apply deep and continuous sedation causing an alteration of consciousness which is maintained until death, combined with an analgesic.

The deep and continuous sedation associated with an analgesic provided for in this Article shall be implemented in accordance with the collegiate procedure defined by regulation [...]"

c.- Authorised acts: shortening suffering to the point of accelerating death

Here again, the legislator provides in a general way that all persons have the right to have their suffering relieved.

Article L. 1110-5-5 of the Public Health Code:

'All persons shall have the right to receive treatment and care aimed at relieving their suffering. This suffering must, in all circumstances, be prevented, considered, evaluated and treated.

The physician shall use all analgesic and sedative treatments to respond to the refractory suffering of the patient in the advanced or terminal phase, even if they may have the effect of shortening life [...]"

d.- Means of expressing wishes and procedure

Article L. 1111-12 of the Public Health Code

'When a person, in the advanced or terminal phase of a serious and incurable disease, whatever the cause, is unable to express their wishes, the physician is obliged to enquire about the patient's expressed wishes. In the absence of advance decisions mentioned in Article L. 1111-11, the physician shall obtain the

testimony of the trusted person or, failing this, any other testimony from the family or close relations.’<sup>3</sup>

- Advance decisions

Article L. 1111-11 of the Public Health Code

‘Any person who has reached the age of majority may draw up advance decisions to be applied in the event that they are one day unable to express their wishes. These advance decisions express the person’s wishes regarding the end of life and the conditions for continuing, limiting, stopping or refusing medical treatment or procedures.

They can be revised and revoked at any time and by any means. They may be drawn up in accordance with a model [...].

Advance decisions shall be binding on the physician for any decision on investigation, intervention or treatment, except in the event of a life-threatening emergency for the time necessary for a full assessment of the situation and when the advance decisions appear manifestly inappropriate or not in conformity with the medical situation.

The decision to refuse to apply the advance decisions, deemed by the physician to be manifestly inappropriate or not in conformity with the patient’s medical situation, is taken following a collegiate procedure defined by regulation and is recorded in the medical file. It shall be brought to the attention of the trusted person designated by the patient or, failing that, of the family or close relations.

[...] Advance decisions shall be kept in a national register which is subject to automated processing in accordance with Law No. 78-17 of 6 January 1978 on information technology, files and civil liberties. When stored in such register, a reminder of their existence shall be sent regularly to their author.’

The referring physician shall inform their patients of the possibility and conditions for drawing up advance decisions.

[...]

- On the trusted person

Article L. 1111-6 al. 1 of the Public Health Code

‘Any person who has reached the age of majority may designate a trusted person, who may be a relative, a close relation or the referring physician and who will be consulted in the event that the former is unable to express their wishes and receive the necessary information to this end. They shall express the person’s wishes. Their testimony shall prevail over any other testimony. This designation

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<sup>3</sup> See, in relation to the general case, Article L. 1111-4, paragraphs 5 and 6.

shall be made in writing and co-signed by the designated person. It may be revised and revoked at any time.'

Adherence to the whole procedure is decisive for a physician to avoid prosecution. It serves as a defence of non-liability.

II/ Which rules imposed by the law in the books could affect the inflow (for countries of destination) or outflow (for countries of origin) of citizens?

Answering this question first assumes that some people leave France to access an end-of-life system abroad that they believe cannot be provided in France (and vice versa).

However, such a reality is difficult to ascertain other than through occasional testimonies.<sup>4</sup>

First, some facts:

- 657,000 deaths in France, in 2021.

- Responding in writing to my question, the National Centre for Palliative and End-of-Life Care explained:

'Issues related to border crossing at the end of life and the movement of people have not (yet, perhaps) been addressed by the National Centre, the reason being that detailed official figures on these situations are not usually made public'.

The only way to find out about possible flows is to look at data contained in reports issued by monitoring commissions in countries that have decriminalised active assistance in dying, provided that these countries have not made nationality of or residency in the country concerned mandatory.

According to them no data from the Netherlands is available. In Belgium, the Monitoring Commission states in its latest report: '*In section II, which is the part of the registration document available to the members of the Commission, only the place of birth is requested. The place of residence is requested in section I, which can only be opened when additional information is requested from the reporting physician. However, some physicians may mention in section II that the*

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<sup>4</sup> See Anne Bert, *Le tout dernier été*, 2017; report '*Fin de vie, le dernier exil*' as part of the television programme *Le monde en face*, broadcast on *France 5* on 23 April 2018 (Aude Rouau, Marie Garreau, not available); <https://www.courrierinternational.com/article/recit-erika-preisig-le-medecin-suisse-qui-aide-les-patients-etrangers-mourir>; E. Bernheim, *Tout s'est bien passé*.

*patient is a foreign national. According to section II of the reports, in 2018 and 2019 45 patients residing abroad came to Belgium in order to obtain a favourable response to their request for euthanasia.*

*This relates to patients with a somatic disorder. These patients mainly suffered from a severe incurable neurological disease (e.g. multiple sclerosis, amyotrophic lateral sclerosis - ALS or Charcot disease) or a disseminated cancer (e.g. breast or pancreatic cancer). More than half of the deaths were expected to be short term. Most of the patients were between 60 and 89 years of age. Euthanasia was carried out in both the Dutch and French speaking parts of the country.' (CFCEE, Euthanasia 2020 Report, p. 44)*

In relation to Luxembourg, it is reported that, *'Among the 844 end-of-life arrangements registered in 2019 and 2020, 12 concerned non-Luxembourg nationals domiciled abroad of unknown age'.* (CNCE, Report 2019-2020, p. 13)

Similarly, there are no further detailed figures on the breakdown of nationalities or pathologies.

In Switzerland, no federal monitoring commission has been established. Dignitas, which states that it does not provide care only to individuals residing in Switzerland, indicates in its 2021 report that it provided care to 45 French nationals, representing 21.2% of the total number of cases.

Therefore, outflows, when they exist, are not massive.

In the other direction (abroad/France), I did not find any statistics related to foreign patients who come to France to receive palliative care, for example. Of course, this does not mean that such patients do not come to France, but since palliative care is considered as care, these patients, if they exist, are included in those who come to France to receive treatment.

What can we learn from this?

Generally speaking, and with little relation to the law, it is probably not easy, either psychologically or financially, to travel outside one's own country to die. People prefer to die, if one can say so, close to home, or even at home.<sup>5</sup> In this respect, we could speak of an anthropological invariant. Irrespective of the level of satisfaction with the health system and the laws in force in their respective countries, this probably explains why few figures are available. It therefore seems to me unconvincing to use these flows (however small) to deduce that the law

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<sup>5</sup> See opinion piece by René Robert, professor of intensive care medicine at Poitiers University Hospital; vice-president of the strategic orientation council of the National Centre for Palliative and End-of-Life Care, *Libération*, 13 January 2020).

should be changed in this or that respect, as was the case, for example, in the area of medically assisted reproduction in deciding to open up this practice to women same-sex couples and single women in France (Law of 2 August 2021), or, as was the case before 1975, to decriminalise abortion. Even today, this type of argument is put forward by supporters of the legalisation of surrogacy.

If, therefore, the French legislation were to change, it seems to me that it should be for intrinsic reasons, other than those arising from an alleged exodus of French nationals going abroad to die. And yet, the advocates of decriminalising euthanasia and assisted suicide in France do not hesitate to use this type of argument, even going so far as to say that those accompanying the patient should not be subject to legal proceedings.<sup>6</sup>

See the Circular of 20 October 2011, available at [http://www.textes.justice.gouv.fr/art\\_pix/JUSD1128836C.pdf](http://www.textes.justice.gouv.fr/art_pix/JUSD1128836C.pdf)

Concerning how such acts are prosecuted in France, see the Angers Criminal Court's decision to acquit on 2 May 2022 a veterinarian who had helped a friend to die by prescribing medication. The legal basis of the prosecution was forgery and use of forgeries, as there had been no murder or premeditated murder, nor even incitement to suicide. The court acquitted the defendant based on the principle of necessity (Article 122-7 of the Criminal Code).<sup>7</sup> The prosecutor has appealed the decision.

What about prosecuting a doctor abroad for committing euthanasia on a French patient?

From a criminal law perspective, it would be conceivable on the basis of passive personality: the victim is a French person, the French law applies even if the behaviour is not a criminal offence under the law of the country where the euthanasia was performed (see article 113-6 al. 1 Criminal Code). But if we are speaking of acts which cannot be characterised as felonies but as misdemeanours (e.g., the furnishing of a non-authorized substance in order to help someone who wants to die), then the rule of reciprocity of incrimination applies, which can prevent the prosecution (art. 113-6 al. 2 Criminal Code).

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<sup>6</sup> <https://www.admd.net/articles/decryptages/suicide-assiste-la-justice-francaise-punit-elle-les-personnes-qui-accompagnent>

<sup>7</sup> Article 122-7 of the Criminal Code:

'A person who, in the face of current or imminent danger to themselves, others or property, performs an act necessary to protect the person or property shall not be criminally liable, unless the means employed are disproportionate to the seriousness of the threat.'

Therefore, while it is difficult to assess the relationship between how the French population views end-of-life legislation and their wishes to leave to die abroad, the fact that euthanasia continues to be criminalised (and not only in the books also in tribunals) is undeniably part of the debate (again, the claim that death tourism is developing as a result of this criminalisation is another matter).

III/ Which restrictions embedded in daily practice (the law in action) could affect the inflow or outflow of citizens?

In daily practice, I think that the following elements may affect the outflow of French nationals abroad:

- poor knowledge of the law;
- the uneven distribution of palliative care units (as opposed to palliative care networks)<sup>8</sup> across the country; one physician described euthanasia as a “poor person’s death” (Dr A. Burnod, 2 June 2022).
- more generally, the fact that the law is, by hypothesis, based on the anticipation of one’s own death, i.e. of something inconceivable. It is not surprising, moreover, that only a minority of French nationals have drawn up advance decisions (13% of French nationals over 50 years of age in 2019 according to a BVA survey for the French National Centre for End of Life and Palliative Care).

IV/ Is there any prospect of a change in the law in the near future?

This is an ongoing issue that is very regularly put on the political agenda.

In January 2021, the National Consultative Ethics Committee set up a working group on the issue (last opinion, No. 121, issued in 2013).

During the presidential campaign in 2022, the Head of State announced that a citizens’ consultation would be organised on this topic.<sup>9</sup>

On 8 April 2021, a bill on ‘the right to a free and chosen end of life’ (rapporteur: O. Falorni), with a quote from the author Anne Bert in its explanatory memorandum, was given a first reading.<sup>10</sup>

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<sup>8</sup> See Senate report, 29 September 2021: <https://www.senat.fr/rap/r20-866/r20-866.html>

<sup>9</sup> [https://www.lemonde.fr/societe/article/2022/04/21/euthanasie-emmanuel-macron-sur-ce-sujet-sensible-avance-une-methode-et-un-objectif\\_6123175\\_3224.html](https://www.lemonde.fr/societe/article/2022/04/21/euthanasie-emmanuel-macron-sur-ce-sujet-sensible-avance-une-methode-et-un-objectif_6123175_3224.html)

<sup>10</sup> [https://www.assemblee-nationale.fr/dyn/15/textes/l15b0288\\_proposition-loi](https://www.assemblee-nationale.fr/dyn/15/textes/l15b0288_proposition-loi)

- Article 1: the following paragraph would be added to Article L. 1110-9 of the Public Health Code:

'Any capable person having reached the age of majority, in the advanced or terminal phase of a serious and incurable disease, whatever the cause, which subjects them to physical or psychological suffering that cannot be alleviated or which they consider unbearable, may request medical assistance, under the conditions laid down in this title, to enable them to die quickly and painlessly by means of active assistance.

-Article 2: new Article L. 1111-10-1 which defines the procedure (consent, collegiality, time limits to be respected, etc.)

-Article 3: new Article L. 1111-12-1 on individuals who are not in a condition to express their wishes

-Article 4: creation of a national commission to monitor practices relating to the right to die with dignity; clarification that persons who have undergone such a procedure are deemed to have died a natural death for the purposes of contracts to which they were party

-Article 5: clause relating to physicians' conscientious objection

-Article 6: establishment of a tax to compensate the State for costs arising from the implementation of the law.

Due to the number of amendments tabled, debate on the bill was impossible.

## Conclusion

- The inflow/outflow argument seems to me to be just a red rag in the debate in France.

- While the situation is unsatisfactory, it is probably due to the very subject of the law, namely suffering and death, and to how it is constructed rather than to the choice of values that underlie it. Indeed, end of life remains embedded in the issue of patients' rights, even though the right to die does not exist as such and probably could not. This presentation remains logical from the point of view of physicians, who consider that there is a form of continuity between providing care and allowing death (but not causing death). Nevertheless, the system is not necessarily understandable for non-specialists, and yet this matter ultimately concerns everyone.

- The question seems to be whether we want to change the model, i.e. move from a right to deep sedation for those who are going to die to a right to active

assistance for all those who want to die, as Alexis Burnod, the doctor whom I spoke, puts it.

- If the model were to be changed, at least four aspects would have to be considered:

\* Which one? It is clear that from Switzerland to Belgium, the Netherlands, Luxembourg or Oregon, models are very different;

\* It would not be a case of simplification or acceleration, as procedures for decriminalising active assistance in dying are very detailed, even bureaucratic;

\* If we consider the active assistance to die as embedded in medical care, then the crossing of borders could have consequences regarding health insurance. For instance, a French person could go to Belgium, pay for a service there and then be reimbursed in France, according to the rules applicable in Belgium. But this is impossible, of course, if the practise at stake is forbidden in France. One can draw a parallel with assisted reproductive technology. It is possible for a French person to go abroad to benefit from special techniques but the reimbursement is subject to the respect of a special procedure (“prior authorisation”) applicable to so-called “scheduled care”. But the ambiguity I was mentioning at the beginning of my presentation is that the physicians who are against decriminalisation of euthanasia also point out that even when they deeply sedate a patient, they are still in the framework of “care”.

\* Finally, and more fundamentally, it is necessary to consider the demand for autonomy that lies at the heart of these request to be helped to die. This is a curious autonomy, in relation to the decision but not to the act, which is achieved by granting great powers to the medical or paramedical profession, whose paternalism is so often challenged.

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