

**DEATH WITH DIGNITY: A HUMAN RIGHT OR CRIME? –
THE LEGISLATION OF END-OF-LIFE DECISIONS IN
EUROPE**

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Abstract

The concept of physician-assisted dying is a divisive topic that most people are reluctant to talk about. In Europe, some States oppose it by criminalizing all forms of euthanasia and assisted suicide and there are States who support it by legalizing some aspects of it. As there is no consensus on the issue, the debate about it will not likely be settled soon. The questions could be raised: Do we have a right to decide on our death? What do we mean exactly by end-of-life decisions? My paper's objective is to reveal a topic often treated as a 'taboo'. Starting with a review of the relevant terms the reader will gain an up-to-date knowledge on what each of them means. After the evaluation of the terminology, the paper will explore the domestic legislation of Belgium, Switzerland, Hungary and the United Kingdom on assisted dying and palliative care. The legislation of the presented countries illustrates the wide variety of ways, which end-of-life decisions are regulated, based on different perceptions of the States. Nevertheless, all of them are Member States of the Council of Europe which, through the European Court of Human Rights (ECtHR) and the European Convention on Human Rights (ECHR), has taken an influential position in the sphere of human rights. Through analyzing the articles of the ECHR, I will address how end-of-life decisions are a component of one's fundamental human rights. Further, the paper will discuss the work of the ECtHR, by researching five cases brought before the ECtHR, in which applicants claimed that their human rights had been violated in connection with end-of-life decisions. Exploring the topic, it will be explained that as there is no consensus, the Court's margin of appreciation doctrine is used in assessing how States ensure the rights in relation to assisted dying. Therefore, despite the presumed decisive position of the ECtHR, the main actors deciding on the regulation of end-of-life decisions are the States.

1. Introduction

The name and condition of Dániel Karsai might be known to most people in Hungary and across Europe. He was a human rights lawyer, who had amyotrophic lateral sclerosis (ALS), a terminal and incurable illness.¹ In its advanced stage, most muscles are paralyzed and the patient cannot control them due to the gradual degeneration of the brain's and spinal cords' nerve cells.² As the cognitive ability of the patient is usually not affected, the patient is aware of him/herself and

¹ Dániel Karsai v Hungary App. no 32312/23 (ECtHR [Chamber], 13 June 2024).

² National Institute of Neurological Disorders and Stroke: Amyotrophic Lateral Sclerosis (ALS) Viewed: 30/09/2024 Available at: <https://www.ninds.nih.gov/health-information/disorders/amyotrophic-lateral-sclerosis-als>.

his disease.³ Mr. Karsai approached the ECHR to make an exception to the criminal ban on physician-assisted dying in Hungary so that he could end his life with dignity when he felt that his suffering became unbearable.⁴ However, the Court found no violation and decided that Hungary has a wide margin of appreciation on whether they legalize or criminalize physician-assisted suicide.⁵

On the opposite part of the continent, in the Netherlands patients facing “unbearable suffering with no prospect of improvement” irrespective of whether physical or mental can request assisted dying.⁶ The decision of a Dutch woman Zoraya Ter Beek made headlines all over Europe, as she was granted euthanasia on the basis of a psychiatric illness. Being physically healthy, her motive was that she struggled with mental illnesses such as depression, autism, and personality disorder.⁷ After 3 years of waiting Zoraya got the final approval and died on the 16th of May at the age of 29.⁸

The case of Alfie Evans from the UK may also sound familiar, Alfie was a young boy struggling with a progressive neurological degenerative condition.⁹ He was treated in the hospital for over a year and was held on artificial ventilation, however, his condition didn’t improve, and his illness was terminal.¹⁰ His parents’ wish was to transfer Alfie to Rome, where he was promised to have further ventilator support and operations that could help him breathe in the Bambino Gesù Hospital. The medical team did not agree and argued that his brain tissues were severely damaged and further medical treatment would be futile and inhumane.¹¹ After a long legal debate between the parents and the hospital, his life support was removed and 5 days later Alfie Evans died.¹²

All these three cases pose quite controversial questions relating to decision-making in end-of-life setting. Does a person possess the right to decide on his or her death? What happens if

³ Ibid.

⁴ Dániel Karsai v Hungary App. no 32312/23 (ECtHR [Chamber], 13 June 2024).

⁵ Ibid.

⁶ The Netherlands, Termination of Life on Request and Assisted Suicide Act (2002) Article 2.

⁷ Sherwood Harriet, The Guardian. Dutch woman, 29, granted euthanasia approval on grounds of mental suffering Viewed: 30/09/2024 Available at: <https://www.theguardian.com/society/article/2024/may/16/dutch-woman-euthanasia-approval-grounds-of-mental-suffering>.

⁸ Rupa Subramanya, The Free Press, She Was 29. And Doctors Helped Her Die Viewed: 30/09/2024 Available at: <https://www.thefp.com/p/zoraya-ter-beek-dead-assisted-suicide>.

⁹ Wilkinson, D., Savulescu, J., Alfie Evans and Charlie Gard-should the law change?. *BMJ (Clinical research ed.)*, 361, k1891. (2018) <https://doi.org/10.1136/bmj.k1891>.

¹⁰ Jonas, M., Ryan, S., (2021) The Discourse of Dignity in the Charlie Gard, Alfie Evans and Isaiah Haastrup Cases, *Medical Law Review*, 29(1) 24–47, <https://doi.org/10.1093/medlaw/fwaa038>.

¹¹ Ibid.

¹² Ibid.

someone decides to voluntarily ‘give up her right to life’? Do patients have a ‘right to die’? What happens if a patient’s relative does not want to give it up, and wants to pursue further treatment, even though treatment proved to be futile? Euthanasia is an ancient Greek term adapted as "good death" in English,¹³ meaning that instead of a painful, and undignified death, through euthanasia patients can experience a relatively “good death.”¹⁴ Besides euthanasia, which tends to be the most well-known term, there are other end-of-life decisions relating to palliative care that can pose legal and ethical questions. The laws governing assisted dying practices vary from nation to nation because there is no comprehensive regulation about end-of-life decisions within the framework of international law.¹⁵ Nevertheless, the issue’s pertinence from a human rights perspective is undeniable.¹⁶ My aim in this paper is to explore how palliative care and different types of assisted dying: physician-assisted suicide and euthanasia can be attached to one’s basic human rights. I would like to investigate how countries in Europe legislate these acts domestically and to what extent these legislations differ from each other. Exploring the exact national regulation on end-of-life decisions in four countries, namely: Belgium, Switzerland, the United Kingdom, and Hungary will outline an extensive spectrum of types of end-of-life legislation. Additionally, I aim to explore how assisted dying is viewed by the European Court of Human Rights, by researching five cases and elaborating on how the ECtHR assesses them, and what kind of similarities and differences can be seen between the cases. I wish to draw a conclusion on its jurisprudence and answer three research questions. First, to which human right is the question of end-of-life decisions most closely related? My hypothesis is that in this regard the most relevant right under the ECHR is the right to respect for private and family life. Secondly, have the ECtHR’s decisions had an impact on Member States’ domestic legislation on end-of-life decisions? My hypothesis for this research question is that these decisions are not that influential on the State’s legislation because the ECtHR grants a margin of appreciation to countries in issues regarding end-of-life. However, it could generate the start of a public discussion on end-of-life decisions, which eventually could lead to changes in domestic legislation. Despite this negative hypothesis, thirdly I asked, whether there is an

¹³ Honderich T., (2005) *The Oxford Companion to Philosophy* (2 ed.) Euthanasia
<https://doi.org/10.1093/acref/9780199264797.001.0001>.

¹⁴ Guenter, L., *Assisted Death in Europe and America: Four Regimes and Their Lessons* (2010; online edn, Oxford Academic, 1 Jan. 2011), <https://doi.org/10.1093/acprof:oso/9780199746415.001.0001>.

¹⁵ Zaman, S., Inbadas, H., Whitelaw, A., & Clark, D. Common or multiple futures for end of life care around the world? Ideas from the 'waiting room of history'. *Social science & medicine* (1982), 2017, 172, 72–79.
<https://doi.org/10.1016/j.socscimed.2016.11.012>.

¹⁶ Frank, B., Gwyther, L., 'Human rights issues', in Cherny, N., and others (eds), *Oxford Textbook of Palliative Medicine*, 5 edn, Oxford Textbook (Oxford, 2015; online edn, Oxford Academic, 1 Apr), 323-334
<https://doi.org/10.1093/med/9780199656097.003.0101>.

evolution in the European Court of Human Rights' jurisprudence regarding the issue. To which the answer is affirmative, ECtHR is developing in assessing the issue of end-of-life decisions more precisely.

2. Methodology

During my research, I pursue a comparative approach and compare the legislation of assisted dying in different countries. I identify the similarities and differences between them and outline a wide range of models on end-of-life decisions. I also compare the ECHR's relevant articles and the different cases before the ECtHR regarding end-of-life decisions. Mostly using sources in English, I researched academic papers, the most relevant laws and criminal codes of the chosen countries, the cases before the European Court of Human Rights and the European Convention on Human Rights. Additionally, I used qualitative deep-interview analysis, based on the interviews I conducted with three Hungarian experts: Dr Anikó Kussinszky (Senior Legal Advisor at Office of the Commissioner for Fundamental Rights), Dr. Katalin Hegedűs (Chairman for the For Dignity Foundation [*Méltóságért Alapítvány*]), and Dr. Péter Stánicz (human rights lawyer represented Mr. Karsai before the ECtHR). In the first part of my paper, I will evaluate all the relevant definitions connecting to the issue. The reader will gain an insight into the theoretical framework of end-of-life decisions. In the second part, I will give a detailed overview of each country's (Belgium, Switzerland, the United Kingdom, and Hungary) national legislation on end-of-life decisions. Lastly, I look into the link between human rights and end-of-life decisions by investigating the decisions of the European Court of Human Rights.

3. Specific remarks on end-of-life decisions

Since the beginning of medicine, the doctor's main responsibility has been to help their patients and refrain from harming.¹⁷ However, controversy regarding this concept is definitely not a new one as medical futility emerged in the early periods of medicine as well, with Hippocrates teaching his students *“to refuse to treat those who are overmastered by their diseases, realizing*

¹⁷ Ko, Danielle N., and Craig D. Blinderman, 'Withholding and withdrawing life-sustaining treatment (including artificial nutrition and hydration)', in Nathan Cherny, and others (eds), *Oxford Textbook of Palliative Medicine*, 5 edn, Oxford Textbook (Oxford, 2015; online edn, Oxford Academic, 1 Apr. 2015), 323-334
<https://doi.org/10.1093/med/9780199656097.003.0108>.

that in such cases medicine is powerless.”¹⁸ People now have a different medical profile, they have more comorbidities – meaning that different medical conditions are present simultaneously in the patient – and a longer life expectancy as well.¹⁹ This advancement in the healthcare industry and society made decision-making complex at the end of life. "Doing everything medically possible" and "ensuring the patient does not suffer" must be balanced.²⁰ It also made the establishment of an adequate system necessary, capable of providing comfort and care to people with terminal illnesses, which are hospice care and palliative care. While both approaches are used when dealing with a fatal illness at the end of life, there are differences between them. Palliative care's main objective is to maintain the terminally ill patient's life quality and the patient's care partners through managing the patient's symptoms effectively and providing spiritual, social, and psychological support.²¹ Palliative care must be personalized starting as early as a person's diagnosis and can happen alongside curative treatments for the disease.²² Hospice care is provided during the final months of a patient's life,²³ placing a big emphasis on supporting and comforting the family of the patient. It may may happen at a nursing home, at home of the patient, a hospice, or a hospital.²⁴

3.1. Withholding/withdrawing life-sustaining treatment

Today, the main essence of the withholding or withdrawing life-supporting treatment is to cease the pursuit of further therapeutic options for the given problem of the patient.²⁵ It can include the medical treatments being withheld or withdrawn, or a decision not to transfer the patient to the hospital.²⁶ Another important aspect that must be highlighted is that withholding or withdrawing treatment is not a form of abandonment, because it should include a plan that

¹⁸ Scannell, K., & Henry, S. C. (2002) Medical Futility. *The Permanente journal*, 6(1), 52–54.
<https://doi.org/10.7812/TPP/02.989>.

¹⁹ Hamidi, M., & Joseph, B. (2019) Changing Epidemiology of the American Population. *Clinics in geriatric medicine*, 35(1), 1–12. <https://doi.org/10.1016/j.cger.2018.08.001>.

²⁰ van Beinum, A., (2023) Challenging the logic of lifesaving in the intensive care unit. *Social science & medicine* 321, 115769. <https://doi.org/10.1016/j.socscimed.2023.115769>.

²¹ Max Watson, and others (eds), 'Introduction', in *Oxford Handbook of Palliative Care*, 3 edn, Oxford Medical Handbooks (Oxford, 2019; online edn, Oxford Academic, 1 July 2019),
<https://doi.org/10.1093/med/9780198745655.002.0012>.

²² Mount, B., Hanks, G., McGoldrick, L., (2006) The principles of palliative care, *ABC of Palliative Care* (Second edition).

²³ National Institute on Aging, What Are Palliative Care and Hospice Care? Viewed: 17 September 2024, Available at: <https://www.nia.nih.gov/health/hospice-and-palliative-care/what-are-palliative-care-and-hospice-care>.

²⁴ Ibid.

²⁵ Chambaere, K., Bernheim, J. (2018) End-of-Life Decisions. In: MacLeod, R., Van den Block, L. (eds) Textbook of Palliative Care. Springer, Cham. https://doi.org/10.1007/978-3-319-31738-0_91-1.

²⁶ Ibid.

provides further care or symptom management for the patient.²⁷ A wide range of procedures are commonly withdrawn or withheld at the last stage of life, for example: “cardio-pulmonary resuscitation, intubation, mechanical ventilation, artificial nutrition and hydration, kidney dialysis, surgery, and antibiotics treatment.”²⁸ According to the Islamic, Orthodox Jewish, and Catholic authorities artificial nutrition and hydration differ from other medical treatments and must be assessed in another way, for example, the Catholic church believes it to be a humane care.²⁹ However, in the countries’ jurisprudence, artificial nutrition and hydration are treated the same as other medical treatments.³⁰ Whether to differentiate between withholding or withdrawing is a subject of discussion. On one side a moral distinction could be made as withholding is an act by omission, and withdrawing is an act by commission. On the other side according to the Western bioethical perspective, there is no need to morally distinguish one from the other.³¹ The developed countries’ jurisprudence seems to favor the second approach and leans toward accepting moral equivalency between the two.³² It is also worth mentioning that while there is no legal or ethical distinction, the two acts can have different moral or psychological effects on the physician, the patient, or the family members.³³ While in developed countries (examples) it tends to be legal most of the countries have a different approach to withdrawing or withholding treatment.³⁴ On the contrary in developing countries (examples) it is illegal or doesn’t have a certain legal status.³⁵

²⁷ Ko, Danielle N., and Craig D. Blinderman, 'Withholding and withdrawing life-sustaining treatment (including artificial nutrition and hydration)', in Nathan Cherny, and others (eds), *Oxford Textbook of Palliative Medicine*, 5 edn, Oxford Textbook (Oxford, 2015; online edn, Oxford Academic, 1 Apr. 2015), 323-334
<https://doi.org/10.1093/med/9780199656097.003.0108>.

²⁸ Ibid.

²⁹ May, W.E. (2008) Caring for Persons in the “Persistent Vegetative State” and Pope John Paul II’s March 20 2004 Address “On Life-Sustaining Treatments and the Vegetative State”. In: Tollefsen, C. (eds) *Artificial Nutrition and Hydration. Philosophy and Medicine*, vol 93. Springer, 2008. https://doi.org/10.1007/978-1-4020-6207-0_3.

³⁰ Ibid.

³¹ United States (1982). President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *United States code annotated. United States, Title 42 Sect. 300v as added 1978*.

³² Chambaere, K., Bernheim, J. (2018) End-of-Life Decisions. In: MacLeod, R., Van den Block, L. (eds) *Textbook of Palliative Care*. Springer, Cham. https://doi.org/10.1007/978-3-319-31738-0_91-1.

³³ Ibid.

³⁴ Mendelson, D., & Jost, T. S. (2003). A Comparative Study of the Law of Palliative Care and End-of-Life Treatment. *Journal of Law, Medicine & Ethics*, 31(1), 130–143. <https://doi.org/10.1111/j.1748-720X.2003.tb00063.x>.

³⁵ Blank, R.H. (2011). End-of-life decision making across cultures. *Journal of Law, Medicine & Ethics*, 39, 201–214 <https://doi.org/10.1111/j.1748-720X.2011.00589.x>.

3.2. Alleviation of pain or other symptoms

Managing pain and symptoms during the final stages is a key element in palliative care, usually by administering progressively higher dosages of morphine or sedatives.³⁶ Regarding symptoms besides pain, other four intensify near death: lack of appetite, drowsiness, dyspnoea,³⁷ and fatigue.³⁸ What seems to be problematic with this decision, and may arouse fear is that if the physician provides the opioids in a higher dose, it may have different side effects, or it hastens the death of the patient.³⁹ Actively and intentionally hastening the death of a patient without their consent is considered illegal around the world.⁴⁰ Nevertheless, relieving the pain is an essential part of both palliative and hospice care, and has a significant role during the process of withdrawing life-prolonging therapies. Another term, which must be discussed is palliative sedation, which means the usage of drugs to achieve various states of unconsciousness, in patients who are close to death to relieve their unbearable and refractory symptoms.⁴¹ On the one hand, it can be light sedation, during which the patient can communicate, and on the other hand, it can be deep sedation, which means that the patient can't do that. Ethical concerns could be raised especially with deep sedation as it could have life-shortening side effects.⁴² For this reason, all types of sedation should be proportionate for the intended purpose of relieving suffering and deep sedation can only be applied in the patient's last phase of life, meaning the last days.⁴³ Sedation that is continued until the last moment is continuous deep sedation, and it is often the subject of controversy as some fear that it results in a potential grey area between euthanasia and intensified symptom treatment.⁴⁴ The fear stems from the fact that physicians do not need explicit permission from the patient to apply continuous deep sedation, therefore it provides more space for abuse than euthanasia, for which

³⁶ Chambaere, K., Bernheim, J. (2018) End-of-Life Decisions. In: MacLeod, R., Van den Block, L. (eds) *Textbook of Palliative Care*. Springer, Cham. https://doi.org/10.1007/978-3-319-31738-0_91-1.

³⁷ Difficulty with breathing. (Oxford Reference, Dyspnoea, Viewed: 20/10/2024 Available at: <https://www.oxfordreference.com/display/10.1093/oi/authority.20110803095738703>).

³⁸ Cheung, W. Y., Barmala, N., Zarinehbab, S., Rodin, G., Le, L. W., & Zimmermann, C. (2009). The association of physical and psychological symptom burden with time to death among palliative cancer outpatients. *Journal of Pain & Symptom Management*, 37(3), 297e304. <http://dx.doi.org/10.1016/j.jpainsymman.2008.03.008>.

³⁹ Chambaere, K., Bernheim, J. (2018) End-of-Life Decisions. In: MacLeod, R., Van den Block, L. (eds) *Textbook of Palliative Care*. Springer, Cham. https://doi.org/10.1007/978-3-319-31738-0_91-1.

⁴⁰ Ibid.

⁴¹ Bookbinder, M., & McHugh, M. E. (2010). Symptom management in palliative care and end of life care. *The Nursing clinics of North America*, 45(3), 271–327. <https://doi.org/10.1016/j.cnur.2010.04.002>.

⁴² Hasselaar, J. (2019). Palliative Sedation: A Medical-Ethical Exploration. In: MacLeod, R., Van den Block, L. (eds) *Textbook of Palliative Care*. Springer, Cham. https://doi.org/10.1007/978-3-319-77740-5_92.

⁴³ Ibid.

⁴⁴ Ibid.

consent is a requirement.⁴⁵ However, the distinction can be made because, during palliative sedation, the death is attributed to the illness and not to the act of the physician and the sedatives' dosages are different as well.⁴⁶

3.3. Assisted dying: Euthanasia, physician-assisted suicide, and assisted suicide

Euthanasia is the most well-known term regarding end-of-life decisions, however, what exactly falls under is not precisely known. An obsolete categorization of euthanasia based on morality divided it into passive and active forms, meaning passive euthanasia = “letting die” and active euthanasia = “killing”.⁴⁷ An opposing argument by James Rachels written in 1975 became highly publicized, stating that no moral distinction could be made between the two, because “letting die”⁴⁸ also requires an act, the act not to do anything, and in fact, it is often slower and more painful.⁴⁹ Based on nowadays perception the categorization of euthanasia into passive and active forms is an outdated classification.⁵⁰ The Netherlands's definition describes euthanasia well, stating that it means: ‘the administering of lethal drugs by a physician with the explicit intention to end a patient's life on the patient's explicit request.’⁵¹ According to this approach, the act specifically entails injecting the patient with two different kinds of drugs: first, barbiturates, which put them into a coma, and then, neuromuscular blockers, which paralyze the respiratory muscles.⁵² Another important distinguishment should be made on the basis of consent of the patient: voluntary euthanasia, involuntary euthanasia, and nonvoluntary

⁴⁵ Quill TE, Lo B, Brock DW. (1997). Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA*. 278(23): 2099–2104. <https://doi.org/10.1001/jama.278.23.2099>.

⁴⁶ Broeckaert B. (2011) Palliative sedation, physician-assisted suicide, and euthanasia: “same, same but different”. *The American journal of bioethics: AJOB* ;11(6):62–64. <https://doi.org/10.1080/15265161.2011.577518>.

⁴⁷ Brassington I. (2020). What passive euthanasia is. *BMC Med Ethics* 21(1), 41. <https://doi.org/10.1186/s12910-020-00481-7>.

⁴⁸ Rachels J. (1975). Active and passive euthanasia. *The New England journal of medicine*, 292(2), 78–80. <https://doi.org/10.1056/NEJM197501092920206>.

⁴⁹ Ibid.

⁵⁰ Anikó Kussinszky in discussion with the author, 17th October 2024, Katalin Hegedűs in discussion with the author 7th October 2024, Péter Stánicz in discussion with the author, 8th October 2024.

⁵¹ Onwuteaka-Philipsen, B. D., Brinkman-Stoppelenburg, A., Penning, C., de Jong-Krul, G. J., van Delden, J. J., & van der Heide, A. (2012). Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet*, 380(9845), 908–915. [https://doi.org/10.1016/S0140-6736\(12\)61034-4](https://doi.org/10.1016/S0140-6736(12)61034-4).

⁵² Materstvedt, L. J., Bosshard, G. (2015). Euthanasia and palliative care. In: Cherny, N; Fallon, M; Kaasa, S; Portenoy, R; Currow, D. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 314-322. <https://doi.org/10.1093/med/9780199656097.003.0107>.

euthanasia.⁵³ According to the legislation of States legalizing euthanasia, it can only happen upon the request of the patient, therefore it can only be voluntary euthanasia.⁵⁴ The involuntary nature means that the patient is capable of making a decision, but did not request euthanasia, while the nonvoluntary nature means that the patient is not capable of voluntarily requesting euthanasia, because he is not mentally competent to make a decision.⁵⁵ In most European countries these terms are not even called euthanasia and are regarded as “*the termination of life without the patient’s explicit request*”, which is illegal in all jurisdictions around the world.⁵⁶

How the two other concepts of assisted dying (PAS and assisted suicide) differ from euthanasia is based on the execution of the acts. While during euthanasia the physician is the final actor, during PAS and assisted suicide the patient is.⁵⁷ Physician-assisted suicide means that the patient voluntarily self-administer the lethal medication, which was provided to him by the physician.⁵⁸ On the contrary, during assisted suicide, the lethal drug is handled to the patient by a layperson and not a medical professional.⁵⁹ While PAS is legal in a number of countries (the Benelux countries, Germany, Austria, Spain, and some States in the USA), assisted suicide is considered to be illegal in most jurisdictions, with an exemption in Switzerland.⁶⁰ A common thread in the different forms of assisted dying is that all of them can only happen if the patient voluntarily requests it.⁶¹

⁵³ Goligher, E. C., Ely, E. W., Sulmasy, D. P., Bakker, J., Raphael, J., Volandes, A. E., Patel, B. M., Payne, K., Hosie, A., Churchill, L., White, D. B., & Downar, J. (2017). Physician-Assisted Suicide and Euthanasia in the ICU: A Dialogue on Core Ethical Issues. *Critical care medicine*, 45(2), 149–155.

<https://doi.org/10.1097/CCM.0000000000001818>.

⁵⁴ Emanuel, E. J., Onwuteaka-Philipsen, B. D., Urwin, J. W., & Cohen, J. (2016). Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe. *JAMA*, 316(1), 79–90.

<https://doi.org/10.1001/jama.2016.8499>.

⁵⁵ Ibid.

⁵⁶ Ibid.

⁵⁷ Chambaere, K., Bernheim, J. End-of-Life Decisions. In: MacLeod, R., Van den Block, L. (eds) *Textbook of Palliative Care*. Springer, Cham. 2018 https://doi.org/10.1007/978-3-319-31738-0_91-1.

⁵⁸ Materstvedt, L. J., Bosshard, G. (2015). Euthanasia and palliative care. In: Cherny, N; Fallon, M; Kaasa, S; Portenoy, R; Currow, D. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 314-322. <https://doi.org/10.1093/med/9780199656097.003.0107>.

⁵⁹ Ibid.

⁶⁰ Bosshard, G. (2008). Switzerland. In J. Griffiths, H. Weyers, and M. Adams (eds.) *Euthanasia and Law in Europe*, 463–482. Oxford: Hart Publishing.

⁶¹ Materstvedt, L. J., Bosshard, G. (2015). Euthanasia and palliative care. In: Cherny, N; Fallon, M; Kaasa, S; Portenoy, R; Currow, D. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 314-322. <https://doi.org/10.1093/med/9780199656097.003.0107>.

4. National legislation on end-of-life decisions

4.1. Belgium

Belgium is considered to follow a liberal approach in assessing end-of-life decisions in contrast to other European countries, as they legalized physician-assisted suicide and euthanasia with the Euthanasia Act, which came into force in September 2002.⁶² According to the Belgian model assisted dying and palliative care exist side by side, but rather than being opponents of each other, assisted dying becomes part of palliative care, when the latter proves to be futile.⁶³ This is a unique approach compared to the other countries I will elaborate on. In fact, the legalization of euthanasia is seen to have contributed to the advancement of palliative care.⁶⁴ Nothing proves this better than the fact, that a law concerning palliative care was also adopted in the same year.⁶⁵ The law ensures that each and every citizen is entitled to be informed about his condition and to receive adequate palliative care, including that it is accessible to the patients.⁶⁶ A notable development is that by the precise legislation of active aid in dying and palliative care the amount of life-ending procedures performed without the consent of the patient has declined.⁶⁷

Regarding the exact decisions in the sphere of end-of-life, the Belgian law is wide-ranging, from which I will only deal with the most relevant sources according to the subject of my research. The first one that should be mentioned is the Law on Patients' Rights, Article 8 of it ensures that grants patients can refuse or withdraw their consent for a 'medical intervention'.⁶⁸ This right also ensures an 'advance refusal', which means that the patient can make a written statement refusing a given medical intervention prior, while he is able to do so.⁶⁹ The physicians

⁶² Belgium, Act on Euthanasia of May 28th, 2002.

⁶³ Bernheim JL, Distelmans W, Mullie A, Ashby A. (2014). Questions and answers on the Belgian model of integral end-of life care: experiment? Prototype?: "Eu-euthanasia": the close historical, and evidently synergistic, relationship between palliative care and euthanasia in Belgium: an interview with a doctor involved in the early development of both and two of his successors. *Journal of bioethical inquiry*, 11(4), 507–529. <https://doi.org/10.1007/s11673-014-9554-z>.

⁶⁴ Gerson, S. M., Koksvik, G. H., Richards, N., Materstvedt, L. J., & Clark, D. (2020). The Relationship of Palliative Care With Assisted Dying Where Assisted Dying is Lawful: A Systematic Scoping Review of the Literature. *Journal of pain and symptom management*, 59(6), 1287–1303. <https://doi.org/10.1016/j.jpainsymman.2019.12.361>.

⁶⁵ Belgium, the Law on Palliative Care of 14th June 2002.

⁶⁶ Bernheim JL, Deschepper R, Distelmans W, et al. (2008) Development of palliative care and legalisation of euthanasia: antagonism or synergy?. *BMJ (Clinical research ed.)*, 336(7649), 864–867. <https://doi.org/10.1136/bmj.39497.397257.AD>.

⁶⁷ Pardon, K., Chambaere, K., Pasma, H. R. W., Deschepper, R., Rietjens, J., and Deliens, L. (2013). Trends in end-of-life decision making in patients with and without cancer. *Journal of Clinical Oncology*, 31(11), 1450–1457 <https://doi.org/10.1200/JCO.2012.44.5916>.

⁶⁸ Belgium, the Law on Patients' Rights of 22nd August 2002, Article 8.

⁶⁹ Ibid.

should avoid continuing a treatment that has proved to be futile, therefore withholding or withdrawing treatment can also be performed out without the patient's explicit request.⁷⁰ Going further, Article 11 of the Law on Patients' Rights states that a physician must provide assistance to a patient experiencing pain near death and to sufficiently relieve their suffering.⁷¹ Palliative sedation or terminal sedation is not explicitly mentioned in the legislation, however, some related principles are covered in the Law on Patients' Rights.⁷²

Moving on to the regulation of assisted dying, the most significant source of law is the Euthanasia Act, providing a detailed description of the procedure of legal euthanasia. First Chapter I Section 2 of the Act starts with a definition and defines euthanasia as the following: "For the purposes of this Act, euthanasia is defined as intentionally terminating life by someone other than the person concerned, at the latter's request."⁷³ Chapter II. Section 3. describes the condition which has to be met by the patient to be able to request the ending of his life, and the physician's duties. It requires that while making the request the patient is conscious, its request is voluntary and made in writing, free from any external pressure, and that "*the patient is in a medically futile condition of constant and unbearable physical or mental suffering that can not be alleviated, resulting from a serious and incurable disorder caused by illness or accident;*".⁷⁴ Regarding the duties of the physician, he must provide every detail to the patient about his life expectancy, health condition, any potential treatment options, and what their outcome would be.⁷⁵ The physician must also be sure of the permanent character of the physical or mental suffering of the patient, along with that the request made on their behalf is entirely voluntary, through several conversations over a "*reasonable period of time*".⁷⁶ Additionally, another physician needs to be consulted to discuss the terminal nature of the disorder and the consulted physician "*must be certain of the constant and unbearable physical or mental suffering that cannot be alleviated*" of the patient by analyzing its medical record and examining the patient.⁷⁷ If the patient is "*clearly not expected to die in the near future*",⁷⁸ as the cause of his suffering is a mental disorder, consultation is required with a second independent physician, it can be a specialist in the disease in question or a psychiatrist.⁷⁹ This consulted physician should also be

⁷⁰ Herman, Nys., (2019) Medical Law in Belgium. *Wolters Kluwer*; 5th edition.

⁷¹ Belgium, the Law on Patients' Rights of 22nd August 2002, Article 11.

⁷² Belgium, the Law on Patients' Rights of 22nd August 2002, Article 5-7, 8, 9.

⁷³ Belgium, Act on Euthanasia of May 28th, 2002, Chapter I. Section 2.

⁷⁴ Belgium, Act on Euthanasia of May 28th, 2002, Chapter II. Section 3. §1.

⁷⁵ Belgium, Act on Euthanasia of May 28th, 2002, Chapter II. Section 3. §2.

⁷⁶ Ibid.

⁷⁷ Ibid.

⁷⁸ Belgium, Act on Euthanasia of May 28th, 2002, Chapter II. Section 3. §3.

⁷⁹ Ibid

sure that every procedural requirement is met. Another criterion in this case is that the time between the written request and the euthanasia must be at least one month.⁸⁰ Further, Chapter III. Section 4. makes a crucial distinction and details how euthanasia could be performed on an advance written request. The patient may prepare an advance directive for the time when he is unable to articulate his wishes.⁸¹ In this case, other criteria for euthanasia include that the situation of the patient is irreversible and he has lost consciousness.⁸² Apart from this, the procedure of euthanasia in this instance is essentially similar to the current written request, implying that another physician must also be consulted about the condition of the patient focusing on its irreversibility.⁸³ For euthanasia to be legal the physician is required to register it with Federal Control and Evaluation Commission.⁸⁴

A debated aspect of this law is its amendment, which abolished the biological age requirement for euthanasia and many consider it to be the proof of a ‘slippery slope’.⁸⁵ It made possible that euthanasia can be performed on a patient who is a minor, who is judged to have a “*capacity of discernment*” and voluntarily request euthanasia, regardless of their biological age.⁸⁶ In these cases, the physician is required to consult with a child psychologist or psychiatrist, and the legal representative of the minor must also consent to the procedure.⁸⁷ A distinction is made from adult patients, as minors can only request euthanasia “*for constant and unbearable physical suffering that cannot be alleviated and that will result in death in the short term*”.⁸⁸ Besides this difference – that they cannot request euthanasia for mental suffering – minor patients have to comply with all other criteria set in the Act.⁸⁹ The argument supporting this view was that minors with terminal illnesses mature more rapidly.⁹⁰

Physician-assisted suicide has an ambiguous legal status because it is neither specifically prohibited by the Euthanasia Act nor criminalized under the Belgian Criminal Code, however,

⁸⁰ Ibid.

⁸¹ Belgium, Act on Euthanasia of May 28th, 2002, Chapter III. Section 4. §1.

⁸² Ibid.

⁸³ Belgium, Act on Euthanasia of May 28th, 2002, Chapter III. Section 4. §2.

⁸⁴ Belgium, Act on Euthanasia of May 28th, 2002, Chapter IV. Section 5.

⁸⁵ Raus, K., Deliens, L., & Chambaere, K. (2021). The extension of the Belgian euthanasia law to minors in 2014. In B. P. White & L. Willmott (Eds.), *International perspectives on end-of-life law reform : politics, persuasion and persistence* (40–62). <https://doi.org/10.1017/9781108779364.006>.

⁸⁶ Belgium, Act amending the Act of 28 May 2002 on euthanasia, sanctioning euthanasia for minors, 2014.

⁸⁷ Ibid, Article 2(d).

⁸⁸ Ibid, Article 2(c).

⁸⁹ Raus K. (2016). The Extension of Belgium's Euthanasia Law to Include Competent Minors. *Journal of bioethical inquiry*, 13(2), 305–315. <https://doi.org/10.1007/s11673-016-9705-5>.

⁹⁰ Mroz, S., Deliens, L., Cohen, J., & Chambaere, K. (2022). Developments Under Assisted Dying Legislation: The Experience in Belgium and Other Countries. *Deutsches Ärzteblatt International*, 119(48), 829–835. <https://doi.org/10.3238/arztebl.m2022.0378>.

it is legal if it is performed according to certain criteria.⁹¹ The latest amendment of the Belgian Criminal Code makes incitement to suicide a crime in Belgium. Article 109 states that incitement means a deliberate performance of an act likely to cause a person to commit suicide.⁹² Despite this new legislation, physician-assisted suicide remains legal in Belgium, and it was reaffirmed that assisted suicide is distinguished from incitement in suicide.⁹³ Regarding its relation to euthanasia, during the drafting of the Euthanasia Act, it was intentionally left out, arguing that in principle physician-assisted suicide is the same as euthanasia. It was suggested by the Council of State to regulate assisted suicide according to the Euthanasia Act, which was later confirmed by the Order of Physicians, highlighting how assisted suicide is analogous to euthanasia if the provisions of the Euthanasia Act are followed.⁹⁴

4.2. Switzerland

At first glance, thinking of Switzerland's approach to end-of-life the first thing that can come into one's mind is "death tourism". The legislation of assisted dying and palliative care in Switzerland may seem futuristic and unusual, contradicting the previously discussed Belgian model in some aspects, and is even further away from the legislation of the United Kingdom and Hungary. Compared to Belgium the most prominent distinction is that the Swiss law does not recognize the concept of euthanasia. Further, palliative care and assisted dying are not in close collaboration with each other.⁹⁵ In Switzerland, they refer to assisted dying as 'Sterbehilfe', which covers all medical behavior regarding the termination of life, or potentially shortening life.⁹⁶ Under the concept of 'Sterbehilfe', there are four distinct categories: active, passive, indirect, and assisted suicide.⁹⁷ Each category refers to different medical acts or omissions and is regulated differently. Under passive 'Sterbehilfe', they refer to withdrawing or withholding a life-sustaining treatment, which is legal and there is slightly any distinction

⁹¹ Nys, H. (2022). The ambiguous legal status of physician assisted suicide in Belgium. *Journal Für Medizin- Und Gesundheitsrecht (JMG)*, 7(3), 191–194. <https://doi.org/10.33196/jmg202203019101>.

⁹² Belgium, Book II of the Criminal Code, 2024, Article 109

⁹³ European Institute of Bioethics, Criminalisation of incitement to suicide: the Belgian legislator excludes assisted suicide and euthanasia Viewed: 20/09/2024 Available at: <https://www.ieb-eib.org/en/news/end-of-life/euthanasia-and-assisted-suicide/criminalisation-of-incitement-to-suicide-the-belgian-legislator-excludes-assisted-suicide-and-euthanasia-2247.html>.

⁹⁴ Nys, H. (2022). The ambiguous legal status of physician assisted suicide in Belgium. *Journal Für Medizin- Und Gesundheitsrecht (JMG)*, 7(3), 191–194. <https://doi.org/10.33196/jmg202203019101>.

⁹⁵ Preisig, E. (2013). Médecine palliative et assistance au décès. *Primary Care*, 13, 397–398.

⁹⁶ Bosshard, G. (2008). Switzerland. In J. Griffiths, H. Weyers, and M. Adams (eds.) *Euthanasia and Law in Europe*, 463–482. Oxford: Hart Publishing.

⁹⁷ Ibid.

made between competent or incompetent patients.⁹⁸ One intriguing feature is that competent patients have the freedom to decline therapy at any point during their illness, not only in end-of-life circumstances.⁹⁹ Indirect ‘*Sterbehilfe*’ refers to alleviating or managing the pain or other symptoms of the terminally ill patient including terminal sedation.¹⁰⁰ Active ‘*Sterbehilfe*’ means ending the life of a terminally patient to relieve his suffering on purpose.¹⁰¹ Unlike the previous ones active ‘*Sterbehilfe*’ is illegal under Article 113 and 114 of the Federal Penal Code. Article 113 criminalizes non-voluntary active ‘*Sterbehilfe*’, which is taking the patient's life against his will as manslaughter.¹⁰² Article 114 criminalizes voluntary active ‘*Sterbehilfe*’: euthanasia, as “*Homicide at the request of the victim*”,¹⁰³ which is less serious than murder committed without the consent of the victim.¹⁰⁴ The next provision article 115 legalizes the last category of ‘*Sterbehilfe*’: assisted suicide, and states that inciting or assisting someone in suicide is a crime if it was out of selfishness.¹⁰⁵ It logically follows that a person who provides assistance to someone in committing suicide cannot be prosecuted under Article 115 if his motives are not selfish.¹⁰⁶ Suicide of sick people is recognized as a freedom for which support may be considered, however, an absolute right to assisted suicide is not recognized.¹⁰⁷ The law makes the operation of five right-to-die organizations – providing assistance in suicide for people seeking to terminate their life over medical reasons – legal.¹⁰⁸ The criterion for their legal operation is that they cannot be profit-making ventures, to comply with Article 115 and must ensure that the patient asking for assistance understands the implications of their request and is competent.¹⁰⁹ An argument that is often raised against this legislation is that there is no

⁹⁸ Ibid.

⁹⁹ Riklin F. (1999) Die strafrechtliche Regelung der Sterbehilfe. Zum Stand der Reformdiskussion in der Schweiz, in: A. Holderegger (Hrsg.), *Das medizinisch assistierte Sterben, Zur Sterbehilfe aus medizinischer, ethischer, juristischer und theologischer Sicht*, S. 328-350.

¹⁰⁰ Bosshard, G. (2008). Switzerland. In J. Griffiths, H. Weyers, and M. Adams (eds.) *Euthanasia and Law in Europe*, 463–482. Oxford: Hart Publishing.

¹⁰¹ Ibid.

¹⁰² The Federal Assembly the Swiss Confederation, Swiss Criminal Code of 21 December 1937, Article 113.

¹⁰³ The Federal Assembly the Swiss Confederation, Swiss Criminal Code of 21 December 1937, Article 114.

¹⁰⁴ Ibid.

¹⁰⁵ The Federal Assembly the Swiss Confederation, Swiss Criminal Code of 21 December 1937, Article 115.

¹⁰⁶ Ibid.

¹⁰⁷ Burkhardt, S., & La Harpe, R. (2012). Debates about assisted suicide in Switzerland. *The American journal of forensic medicine and pathology*, 33(4), 410–413. <https://doi.org/10.1097/PAF.0b013e318273b83f>.

¹⁰⁸ Mauron, A., (2015) 'Acting on a wish to die at the end of life: the Swiss situation', in Rehmann-Sutter, C., Gudat, H., and Ohnsorge, K.,(eds), *The Patient's Wish to Die: Research, Ethics, and Palliative Care*, Oxford Academic, <https://doi.org/10.1093/acprof:oso/9780198713982.003.0009>.

¹⁰⁹ Guilloid, O., & Schmidt, A. (2005). Assisted suicide under Swiss law. *European journal of health law*, 12(1), 25–38. <https://doi.org/10.1163/1571809054663140>.

comprehensive regulation on the profile of patients who can request assisted suicide.¹¹⁰ The organizations are allowed to use their own criteria in accordance with their best judgment, as long as they comply with the law.¹¹¹ For instance, Exit—German Switzerland provides assistance only to members. To become a member, one must be at least 18 years old, have Swiss citizenship, or foreigners should have a second residency within the country.¹¹² As for the request, it must be made in person and must be accompanied by proof that the person has a terminal illness, or some kind of serious disability that results intolerable pain without prospect of relief.¹¹³ While Dignitas got a lot of attention worldwide because it offers assistance in suicide to foreigners, and because the organization's non-profit nature is questionable, as it requires a substantial fee for assistance in suicide.¹¹⁴ What makes the Swiss model unique besides the operation of these organizations compared to other parts of the world, is that the suicide is not assisted by a physician but rather by a volunteer, who is usually a layperson. Because of this rather liberal approach and slim legal framework, what determines the incidence of aid in dying in the country is not the legality of assisted suicide but the work of these organizations.¹¹⁵

4.3. United Kingdom

The United Kingdom's end-of-life decisions regulations are entirely different from those the two countries previously discussed. To begin with, the legal framework is different as a common law system operates, meaning that creating precedents through legal rulings is just as important as the passing of legislation.¹¹⁶ This approach could greatly speed up the legislation process, if the judges were to take an activist role, however so far they have declined to do so.¹¹⁷ Under

¹¹⁰ Hamarat, N., Pillonel, A., Berthod, M. A., Castelli Dransart, D. A., & Lebeer, G. (2022). Exploring contemporary forms of aid in dying: An ethnography of euthanasia in Belgium and assisted suicide in Switzerland. *Death studies*, 46(7), 1593–1607. <https://doi.org/10.1080/07481187.2021.1926635>.

¹¹¹ Ibid.

¹¹² Baezner-Sailer, E.M. (2008). Physician-Assisted Suicide in Switzerland: A Personal Report. In: Birnbacher, D., Dahl, E. (eds) Giving Death a Helping Hand. *International Library of Ethics, Law, and the New Medicine*, vol 38. Springer. https://doi.org/10.1007/978-1-4020-6496-8_12.

¹¹³ Ibid.

¹¹⁴ Bartsch, C., Landolt, K., Ristic, A., Reisch, T., & Ajdacic-Gross, V. (2019). Assisted Suicide in Switzerland: An Analysis of Death Records From Swiss Institutes of Forensic Medicine. *Deutsches Arzteblatt international*, 116(33-34), 545–552. <https://doi.org/10.3238/arztebl.2019.0545>.

¹¹⁵ Ibid.

¹¹⁶ Bankowski, Z., McCormick, D. & Marshall, G. (2016). Precedent in the United Kingdom, Interpreting Precedents 315-354 <https://doi.org/10.4324/9781315251905-10>.

¹¹⁷ Pridgeon, J. (2006). Euthanasia Legislation in the European Union: is a Universal Law Possible? *European Law* 2(1) 45-60 Viewed: 07/10/2024 Available at: https://www.researchgate.net/publication/239538605_Euthanasia_Legislation_in_the_European_Union_is_a_Universal_Law_Possible.

this legislation assisted dying, both euthanasia and any form of assisted suicide is illegal. The ‘Suicide Act 1961’ regulates assisted suicide, while suicide became legal under Section 1 of this Act, any assistance or incitement in suicide remained illegal under Section 2.¹¹⁸ The act qualifies as an offense – for which the sentence can be 14 years – if it is “*capable of encouraging or assisting the suicide or attempted suicide of another*”, with the explicit intention of doing it.¹¹⁹ In practice conviction under this section rarely happens.¹²⁰ It is visible that euthanasia is not included in this Act, however, it is criminalized and subject to criminal penalties under murder.¹²¹ There is no distinct category for euthanasia under murder; neither the fact that the patient is terminally ill¹²² nor the consent of the patient,¹²³ is a mitigating factor in relation to the offender’s innocence or guilt.¹²⁴ What can be used as partial defense and can reduce the offense from murder to manslaughter in these cases are the following: “*loss of control, diminished responsibility, or suicide pact.*”¹²⁵ Over time, some efforts have been undertaken to make a distinct offense as “mercy-killing”, however, these proved to be unsuccessful.¹²⁶ Going even further, many attempts have also been made to legalize assisted dying, which all failed so far.¹²⁷ However, a change could come in the legislation, as a new bill on the legislation of assisted dying was formally introduced to the parliament recently, and the parliament is debating on it just now. The Bill suggests that terminally ill people who are expected to die within six months could choose to end their lives with assistance.¹²⁸ As assisted dying in these forms is illegal, assisted dying is separated from palliative care in any way. Regarding other end-of-life decisions, the regulation is more indulgent. In the event of a refusal of life-prolonging treatments, there is made distinction on the patient’s competence. Competent patients can refuse life-prolonging treatments, as these can only happen with their explicit

¹¹⁸ United Kingdom, The Suicide Act 1961, 1961.

¹¹⁹ Ibid.

¹²⁰ Lipscombe, S., Dawson, J., Rough, E., (2024): The law on assisted suicide, *House of Commons Library* Viewed: 07/10/2024 Available at:

<https://researchbriefings.files.parliament.uk/documents/SN04857/SN04857.pdf>.

¹²¹ Andrew Grubb (2001). Euthanasia in England – A Law Lacking Compassion? *European Journal of Health Law*, 8(2), 89–93. <http://www.jstor.org/stable/45442487>.

¹²² United Kingdom, R v Cox (1992) Crown Court 12 BMLR 38.

¹²³ United Kingdom, HM Advocate v Rutherford (1947) High Court of Justiciary.

¹²⁴ Otlowski, M., (2000) Voluntary Euthanasia and the Common Law *Oxford, online edn*,

<https://doi.org/10.1093/acprof:oso/9780198298687.001.0001>.

¹²⁵ Grubb, A., (2001). Euthanasia in England – A Law Lacking Compassion? *European Journal of Health Law*, 8(2), 89–93. <http://www.jstor.org/stable/45442487>.

¹²⁶ Ost S., (2009) Euthanasia and the Law in Europe, *Medical Law Review*, 17(1) Spring 118–126, <https://doi.org/10.1093/medlaw/fwn027>.

¹²⁷ Ibid.

¹²⁸ United Kingdom, Assisted Dying for Terminally Ill Adults Bill, Private Members' Bill (Starting in the House of Lords), 26 July 2024.

consent.¹²⁹ However, the patient cannot challenge the professional judgment of the physician, meaning that the treatment will not be continued if it does not serve the best interests of the sick.¹³⁰ According to the Mental Capacity Act 2005 Section 24, competent patients can make an “advance decision to refuse treatment” prior to the occasion when they are incapable of making such decisions.¹³¹ This should include the treatments that the patient is refusing and the situation when it should be applicable.¹³² In the case of an incompetent patient without any advance refusals, a proxy or surrogate may make decisions on whether to refuse treatment.¹³³ Regardless of whether the proxy was chosen by the patient when he was competent or was judicially appointed, he must make his decision according to the detailed provisions of Section 4 of the Mental Capacity Act 2005.¹³⁴ In addition to the patient's best interests, the decision-maker must take into account the patient's beliefs as well as any feelings or desires they may have had in the past or present.¹³⁵ As has been repeatedly highlighted, the treatment can only be continued if it serves the patient's best interest. Therefore, withdrawing or withholding treatment is legal if the treatment proves to be futile as was decided in the case of Anthony Bland by the House of Lords.¹³⁶ Another feature that is unique in this legislation is the principle of ‘Medical Exception’. The concept means that some acts done by medical expertise would constitute a crime if it was done by someone else, a layperson.¹³⁷ Moving forward, managing pain and other symptoms is also common practice, as it is considered that the aim of the physician is to minimize the suffering of the patient.¹³⁸ The legal framework does not address palliative sedation specifically, however, the relevant legal requirements like consent, the best interest, and the mental capacity of the patient are applicable.¹³⁹

¹²⁹ Re T (adult: refusal of medical treatment) (1992) 4 All ER 649 Court of Appeal, Civil Division.

¹³⁰ R (on the application of Oliver Leslie Burke) v the General Medical Council, (2004) EWHC 1879 (Admin) Royal Courts of Justice.

¹³¹ United Kingdom, Mental Capacity Act 2005 Section 24-26.

¹³² Ibid.

¹³³ United Kingdom, Mental Capacity Act 2005 Section 4.

¹³⁴ Ibid.

¹³⁵ Ibid.

¹³⁶ Airedale NHS Trust v Bland (1993) 1 All ER 821, Court of Appeal, Civil division.

¹³⁷ R v Brown (1993) 2 All ER 75, House of Lords.

¹³⁸ Ost S., (2009) Euthanasia and the Law in Europe, *Medical Law Review*, 17(1) Spring 118–126, <https://doi.org/10.1093/medlaw/fwn027>.

¹³⁹ Garralda, E., Busa, C., Pozsgai, É., Osztromok-Lukacs, V., Csikós, A., Radbruch, L., Hasselaar, J., Menten, J., Payne, S., Adile, C., Hurducas, F., & Centeno, C. (2023). Regulations on palliative sedation: an international survey across eight European countries. *European journal of public health*, 33(1), 35–41. <https://doi.org/10.1093/eurpub/ckac153>.

4.4. Hungary

Hungarian legislation on end-of-life decisions is considered conservative compared to Belgium's and Switzerland's. Under this legislation, Act C of 2012 on the Criminal Code criminalizes assisted suicide and euthanasia.¹⁴⁰ Euthanasia is criminalized under Section 161 as "*Voluntary manslaughter*", for which the sentence is lighter compared to murder.¹⁴¹ Assisted suicide is criminalized under the next section, Section 162, as "*Aiding and Abetting Suicide*", If the persuaded individual is older than eighteen, the sentence is lighter; if he is younger than eighteen, the sentence is heavier.¹⁴² A new aspect, compared to the criminal ban in the United Kingdom, is that the Criminal Code has extraterritorial jurisdiction.¹⁴³ Therefore, helping a Hungarian terminally ill patient, who would like to end his suffering to go to Switzerland constitutes a crime, and the legislation accepts no excuses, even in the sphere of non-Hungarian citizens. Therefore, the patient's autonomy to decide on his death can only be exercised through the right to decide on whether to refuse treatments. This right was introduced into the Hungarian legal system with Article 20-23 of the Act CLIV of 1997 on Health, which details under what conditions can this right be exercised and by whom.¹⁴⁴ Regarding the majority of issues relating to treatment, the patient is free to make decisions and communicate his wishes, including that in the event of refusal later he is free to change his mind at any moment, even without reasoning.¹⁴⁵ As to what treatments can be refused, Article 20 (3) prescribes that life-sustaining or life-saving interventions can only be refused "*if the patient suffers from a serious illness which, according to the current state of medical science, will lead to death within a short period of time even with adequate healthcare, and is incurable*".¹⁴⁶ This section of the Act has come in for a lot of criticism because it uses vague terms, like "*short period of time*" or "*adequate healthcare*" whose meaning is difficult to define. Additionally, the procedure for the practice of the right is inefficient, as it is quite circumstantial. Article 20 (4) prescribes that the refusal should be done through "*a public deed or in a private deed with full probative value*", which can only come into effect after a committee of three physicians has made sure that the "*patient took his or her decision in full cognizance of its consequences*" and after which three days later the patient confirmed his or her wish to refuse treatment.¹⁴⁷ In practice, this construction is quite

¹⁴⁰ Hungary, Criminal Code, Act C of 2012, 2012 .

¹⁴¹ Ibid, Section 161.

¹⁴² Ibid, Section 162.

¹⁴³ Ibid, §3(2[b]).

¹⁴⁴ Hungary, Act CLIV of 1997 on Health, 1997.

¹⁴⁵ Ibid.

¹⁴⁶ Ibid §20(3).

¹⁴⁷ Ibid §20(4).

unrealistic, because if the patient is in the condition to go through the procedure, he probably does not want to die, and if he wishes to die, he is no longer in a condition to participate in the procedure. Therefore, there is another option the ‘living will’, meaning that a person chooses to make the refusal in advance: “*a person with full disposing capacity may refuse in a public deed, for the event of his eventual subsequent incapacity*”.¹⁴⁸ According to Péter Stánicz, the ‘living will’ has the biggest potential in ensuring that the patients can decide on their deaths, as it makes it possible for people to make considered decisions.¹⁴⁹ This law is also relevant in the question of alleviating symptoms and pain of terminally ill patients, as Article 99 regulates how care for people with terminal diseases at the end of life should be conducted.¹⁵⁰ It prescribes that “*the patient shall be entitled to palliative care to mitigate pain, alleviate physical symptoms and emotional suffering, and to have family members and other significant persons at his or her side*”,¹⁵¹ aiming to ensure the highest possible quality of living and preserve his dignity.¹⁵² According to Katalin Hegedűs, a developed hospice and palliative care could be the alternative to assisted dying, what is the difficulty is that in Hungary these are not that developed.¹⁵³

5. End-of-life decisions under international human rights law

5.1. End-of-life decisions under the European human rights protection system

It is visible that withdrawing or withholding treatment, pain and symptom management, palliative sedation, and refusing treatment are less controversial end-of-life decisions. Regarding assisted dying, there is no consensus between the states, in fact, their approaches and attitudes in the domestic legislation towards the issue differ significantly.¹⁵⁴ The legal framework of universal international human rights law barely mentions end-of-life decisions, therefore I will elaborate on how end-of-life decisions are reflected in the European Convention on Human Rights (ECHR), and in the jurisprudence of the European Court of Human Rights (ECtHR). The ECHR, the most significant human rights instrument in Europe, was drafted after

¹⁴⁸ Ibid §22(1).

¹⁴⁹ Péter Stánicz in discussion with the author, 8th October 2024.

¹⁵⁰ Hungary, Act CLIV of 1997 on Health, 1997 §90.

¹⁵¹ Ibid §90(2).

¹⁵² Ibid §90(1).

¹⁵³ Katalin Hegedűs in discussion with the author 7th October 2024.

¹⁵⁴ Schabas, William A, (2015) The European Convention on Human Rights: A Commentary, Oxford Commentaries on International Law (online edn, Oxford Academic) <https://doi.org/10.1093/law/9780199594061.001.0001>.

World War II and finally came into force in 1953 under the auspice of the Council of Europe.¹⁵⁵ The articles of the treaty include positive and negative obligations imposed on the States.¹⁵⁶ Positive obligations compel countries to take action in order to achieve the intended result, whereas negative ones demands them to abstain from a particular kind of behavior.¹⁵⁷ The role of the European Court of Human Rights is to ensure that States respect the specific rights outlined in the Convention.¹⁵⁸ The Court describes the Convention as a '*living instrument*', which means that "*the rights enshrined in the Convention have to be interpreted in the light of present-day conditions so as to be practical and effective.*"¹⁵⁹ This also implies that the Court formally is not bound by its recent jurisprudence and can depart from it if it has "*cogent reason*" to do so.¹⁶⁰ Exploring how the Court works, according to Article 34 of the ECHR people have the right to submit a complaint to the ECtHR when the State has infringed upon their rights.¹⁶¹ Applicants have to be direct victims of the violation and must meet the criteria of admissibility set in Article 35, which means that they exhausted the domestic remedies, and complied with the time limit of the Court, which is four months.¹⁶² Each case first has to be determined to be admissible by the court, which then moves on to consider its merits. Examining end-of-life decisions in this case law, the doctrine of the margin of appreciation cannot be overlooked. Through this doctrine, the Court grants a space for maneuvering in how they safeguard the different rights enshrined in the ECHR.¹⁶³ The doctrine seeks to protect human rights at the domestic level because those authorities are thought to be better equipped to evaluate local needs than international courts.¹⁶⁴ Whether the Court grants a wider or narrower appreciation to the States varies based on each case's unique circumstances and what kind of right in question. The margin tends to be wider when a consensus is missing on behalf of the States on how a certain right should be ensured, and when assessing specific issues, especially moral and ethical concerns,¹⁶⁵ like end-of-life decisions. Even though the ECHR does not raise the right to decide on one's death in either of its provisions, there are five articles closely relating in

¹⁵⁵ Ibid.

¹⁵⁶ Ibid.

¹⁵⁷ Ibid.

¹⁵⁸ Schabas, William A, (2015) The European Convention on Human Rights: A Commentary, Oxford.

¹⁵⁹ Tyrer v United Kingdom App. no 5856/72 (ECtHR [Chamber], 25 April 1978) §31.

¹⁶⁰ Stafford v United Kingdom App. no 46295/99 (ECtHR [Grand Chamber], 28 May 2002) §68.

¹⁶¹ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950. Article 34.

¹⁶² Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950. Article 35.

¹⁶³ Protocol No. 15 amending the Convention on the Protection of Human Rights and Fundamental Freedoms.

¹⁶⁴ Council of Europe, Protocol No. 15 Amending the Convention on the Protection of Human Rights and Fundamental Freedoms: Explanatory Report (2013) CETS 213, para 9 (Protocol 15).

¹⁶⁵ Evans v the United Kingdom App. no 6339/05 (ECtHR [Chamber], 10 April 2007) §77.

nature to end-of-life decisions. Victims who claimed that their rights had been infringed upon in connection with end-of-life decisions also referred to these articles before the ECtHR.¹⁶⁶

Another source of law worth mentioning, alongside the ECHR safeguards, the human rights biomedicine and healthcare is the Oviedo Convention, formally Convention on Human Rights and Biomedicine, which came into force in 1999,¹⁶⁷ and only 29 States ratified it.¹⁶⁸ The most relevant sections of the Oviedo Convention for this paper's objective are Article 5 and 6 about consent in general and in the event of incompetent patients.¹⁶⁹ Article 5 prescribes that "*an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it*".¹⁷⁰ Article 6 prescribes specific measures on how medical decisions should be taken in the event of, for example, minors, who are not able to give consent or adults with mental disability.¹⁷¹ Assessing the legal weight of the Oviedo Convention, it must be noted that it is much less than the ECHR's as it can only be enforced by the States' domestic legislation.¹⁷² The Oviedo Convention's provisions cannot be enforced by the European Court of Human Rights, or by any other designated international judicial forum.¹⁷³ Consequently, I will move on by addressing the articles of the ECHR alongside the European Court of Human Rights's relevant case law.

5.1.1. ECHR Article 2 on the right to life

Article 2 on the right to life states:

1. *"Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.*
2. *Deprivation of life shall not be regarded as inflicted in contravention of this Article when it results from the use of force which is no more than absolutely necessary:*

¹⁶⁶ Pretty v the United Kingdom App no 2346/02 (ECtHR [Chamber], 29 April 2002) §3.

¹⁶⁷ Council of Europe, Oviedo Convention and its Protocols, Viewed: 20/10/2024 Available at: <https://www.coe.int/en/web/bioethics/oviedo-convention>.

¹⁶⁸ Council of Europe, Treaty Office Chart of signatures and ratifications on Treaty 164 Viewed: 20/10/2024 Available at: <https://www.coe.int/en/web/conventions/full-list?module=signatures-by-treaty&treaty=164>.

¹⁶⁹ Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, 4 April 1997

¹⁷⁰ Ibid Article 5.

¹⁷¹ Ibid Article 6.

¹⁷² Ibid Article 1.

¹⁷³ Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine: Explanatory report (1997) CETS 164 §165.

- a. *in defence of any person from unlawful violence;*
- b. *in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;*
- c. *in action lawfully taken for the purpose of quelling a riot or insurrection.*¹⁷⁴

The right to life is “*one of the most fundamental provisions in the Convention*”, as the Court described it.¹⁷⁵ It includes both types of obligations on behalf of the States. Firstly, States must protect the individual’s life by abstaining from unlawfully or intentionally taking it away, but also safeguarding the people’s life within its jurisdiction.¹⁷⁶ They are also obliged to ensure an adequate legal framework to guarantee protection, by applying preventive measures and there is also a procedural obligation, meaning that they must have the capacity to carry out an investigation effectively when these rights are violated.¹⁷⁷ The Court provides a comprehensive list of numerous contexts in which these obligations are applicable.¹⁷⁸ However, the second part of the Article suggests that this right is not absolute.¹⁷⁹ Additionally, Article 15 highlights that derogation is possible from Article 2 in lawful acts of war.¹⁸⁰ As to assisted dying the Court ruled that there is no ‘right to die’, on the contrary, the Court highlighted that Article 2 makes the protection of the individual’s life a duty of the State.¹⁸¹ On the other hand, this obligation does not mean that it would prohibit the decriminalization of euthanasia, subject to conditions to prevent abuse of the act.¹⁸² Besides assisted suicide and euthanasia, the margin of appreciation is also granted to states assessing withdrawing or withholding treatment.¹⁸³ In this context despite differences regarding the exact procedures, it is mostly allowed in the Council of Europe’s Member States, unlike euthanasia and assisted suicide.¹⁸⁴

¹⁷⁴ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950. Article 2.

¹⁷⁵ Giuliani and Gaggio v. Italy App. no 23458/02 (ECtHR [Grand Chamber], 24 March 2011).

¹⁷⁶ L.C.B. v. the United Kingdom App. no 23413/94 (ECtHR [Chamber], 9 June 1998) § 36.

¹⁷⁷ Centre for Legal Resources on behalf of Valentin Câmpeanu v. Romania App. no 47848/08 (ECtHR [Grand Chamber] 17 July 2014).

¹⁷⁸ Ibid.

¹⁷⁹ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950. Article 2.

¹⁸⁰ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950, Article 15.

¹⁸¹ Pretty v the United Kingdom App no 2346/02 (ECtHR [Chamber], 29 April 2002) §39, Mortier v Belgium App. no 78017/17 (ECtHR [Chamber], 4 Oktober 2022) §119.

¹⁸² Mortier v Belgium App. no 78017/17 (ECtHR [Chamber], 4 October 2022) §138-139.

¹⁸³ Lambert and Others v. France App. no 46043/14 (ECtHR [Chamber] 5 June 2015) §148.

¹⁸⁴ Ibid §72.

5.1.2. ECHR Article 3 on the prohibition of torture, inhumane and degrading treatment

Article 3 on the prohibition of torture, inhumane and degrading treatment states:

*“No one shall be subjected to torture or to inhuman or degrading treatment or punishment.”*¹⁸⁵

This article's relevance from the perspective of assisted dying stems from the claim that depriving someone of the ability to choose how to end suffering, which is unbearable, could add up to inhumane or degrading treatment.¹⁸⁶ However, there is no case law that would support this argument, if there were, then the prohibition of assisted dying could not be justified. This is because the prohibition under Article 3 is an absolute prohibition from which derogation is not allowed under Article 15 under any circumstances.¹⁸⁷ Besides, States' negative obligation to avoid interfering with their rights, a positive obligation arises to protect individuals in three aspects. These are the following: *“an obligation to put in place a legislative and regulatory framework of protection; an obligation to take operational measures to protect specific individuals against a risk of treatment contrary to that provision; and thirdly, an obligation to carry out an effective investigation into arguable claims of infliction of such treatment.”*¹⁸⁸ For a case of unbearable suffering of a patient to amount to a breach of Article 3 it must reach a *“minimum level of severity”* set by the ECtHR to be able to fall within the scope of Article 3.¹⁸⁹ In general, it is not easy to determine whether this factor has been reached, because the assessment level for it can be relative, details of the case, such as how long the act lasted or whether the victim was affected physically and psychologically.¹⁹⁰ Moving forward, the motivation for the act should also be reviewed.¹⁹¹ Regarding the types of acts, it can be torture, inhumane treatment or punishment, and degrading treatment or punishment. The difference between them originates from the intensity of the suffering which they cause.¹⁹² The most severe form of this act is torture, which is an *ius cogens* norm in international law.¹⁹³ The difference between degrading and inhumane treatment is that the latter is intended to be

¹⁸⁵ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950. Article 3.

¹⁸⁶ Ziebertz, H-G. (ed.), Zaccaria F., (ed.), (2019) *Euthanasia, Abortion, Death Penalty and Religion - The Right to Life and its Limitations: International Empirical Research*, 1st edn, Springer, Cham, 10.1007/978-3-319-98773-6.

¹⁸⁷ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950 Article 3, 15.

¹⁸⁸ *X and Others v. Bulgaria* App. no 22457/16 (ECtHR [Grand Chamber], 2 February 2021) §178.

¹⁸⁹ *Muršić v. Croatia* App. no 7334/13 (ECtHR [Grand Chamber], 20 October 2016) §97.

¹⁹⁰ *Ibid.*

¹⁹¹ *Khlaifia and Others v. Italy* App. no 16583/12 (ECtHR [Grand Chamber], 15 December 2016) §160.

¹⁹² *Ireland v. the United Kingdom* App. no 5310/71 (ECtHR [Court, Plenary], 20 March 2018) §167.

¹⁹³ Advisory opinion on the applicability of statutes of limitation to prosecution, conviction and punishment in respect of an offence constituting, in substance, an act of torture (ECtHR, 26 April 2022).

humiliating or to diminish one's dignity.¹⁹⁴ According to these criteria, it is unlikely that the ECtHR will ever rule that the criminal prohibition on assisted dying amounts to either of these acts.

5.1.3. ECHR Article 8 on the right to respect for private and family life

Article 8 on the right to respect for private and family life states:

1. *"Everyone has the right to respect for his private and family life, his home and his correspondence."*
2. *"There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."*¹⁹⁵

For end-of-life decisions the most relevant provision of the ECHR is the right to private life because the principle of autonomy offers that individuals might possess a right to end their lives.¹⁹⁶ As to what is in the scope of this right, in addition to the exact provision, which includes *"his private and family life, his home and his correspondence,"* the Court has defined the concept broadly.¹⁹⁷ According to the case law, *"private life includes a person's physical and psychological integrity,"*¹⁹⁸ as well as one's health.¹⁹⁹ Moreover, in the first end-of-life related case *Pretty v. the United Kingdom* the Court decided that *"applicant's choice to avoid what she considered an undignified and distressing end to her life fell within the scope article 8"*.²⁰⁰ More specifically it even decided that this right also encompasses *"the right to decide by what means and at what point his or her life will end"* in the *Haas v. Switzerland* judgment.²⁰¹ However, a margin of appreciation is granted to domestic legislations regarding end-of-life issues, and how they fulfill their positive and negative obligations under this right. Primarily, States have a negative obligation with respect to this right to protect against arbitrary

¹⁹⁴ *Gäfgen v. Germany* App. no 22978/05 (ECtHR [Grand Chamber], 1 June 2010) §89.

¹⁹⁵ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950.

¹⁹⁶ Wicks E. Challenging some myths about the right to life at the end of life. 1: Not an absolute right. *Clinical Ethics*. 2011;6(4):167-171. <https://doi.org/10.1258/ce.2011.011042>.

¹⁹⁷ *Jehovah's Witnesses of Moscow and Others v. Russia*, App no. 302/02, (ECtHR [Chamber], 10 June 2010) §117.

¹⁹⁸ *Tysiąc v Poland*, App. no 5410/03 (ECtHR [Chamber], 20 March 2007) §107.

¹⁹⁹ *Nada v Switzerland* App. no 10593/08 (ECtHR [Chamber], 12 September 2012) §151.

²⁰⁰ *Pretty v the United Kingdom* App no 2346/02 (ECtHR [Chamber], 29 April 2002) §67.

²⁰¹ *Haas v Switzerland* App no 31322/07 (ECtHR [Chamber], 20 January 2011) §51.

interferences with it.²⁰² The positive obligations arise as States also have to guarantee that the right is respected between private parties, by providing measures that secure respect for private life.²⁰³ States have a certain margin of appreciation in how they implement their obligations under Article 8, the margin will be narrower when a “*particularly important facet of an individual’s existence or identity is at stake*”,²⁰⁴ however, it is wider when a consensus is missing between the Member States.²⁰⁵ Another aspect, which will be important is that the nature of the right is not absolute and interference by the State is allowed if it pursues a legitimate aim, necessary and lawful.²⁰⁶

5.1.4. ECHR Article 14 on the prohibition of discrimination

Article 14 on the prohibition of discrimination states:

*“The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.”*²⁰⁷

From the case law of the ECtHR, it is visible that regarding end-of-life decisions, the prohibition of discrimination is usually linked to assisted suicide.²⁰⁸ The ban on assisted suicide is argued to create inequalities between people who can commit suicide and those are not able to because of physical constraints.²⁰⁹ A different argument that was used by Mr. Karsai concerned discrimination regarding withholding or withdrawing life-prolonging treatments. The applicant argued that the Hungarian law resulted in a difference in treatment, for those patients suffering from a terminal illness who can refuse life-sustaining treatment and who cannot refuse such treatment because of the nature of their illness, as they do not need life-prolonging treatment. Regarding discrimination, the first aspect which should be explored is that on which ground it is based. The article, besides providing a detailed list also includes ‘other status’, which leaves

²⁰² *Libert v France* App. no 588/13 (ECtHR [Chamber], 22 February 2018) §40-42.

²⁰³ *Bărbulescu v. Romania* App. no 61496/08 (ECtHR [Grand Chamber], 5 September 2017) §108-111.

²⁰⁴ *A.D.T. v the United Kingdom* App. no 35765/97 (ECtHR [Chamber], 31 July 2000) §37.

²⁰⁵ *Frette v France* App. no 36515/97 (ECtHR [Chamber], 26 February 2002) §41.

²⁰⁶ *Lozovyye v Russia* App. no 4587/09 (ECtHR [Chamber], 24 April 2012) §36.

²⁰⁷ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950.

²⁰⁸ *Pretty v the United Kingdom* App no 2346/02 (ECtHR [Chamber], 29 April 2002), *Dániel Karsai v Hungary* App. no 32312/23 (ECtHR [Chamber] 13 June 2024).

²⁰⁹ Bertrand, Mathieu, (2006) *The Right to Life in European Constitutional and International case-law*, Strasbourg, Council of Europe Publishing, p. 77.

space for a broader interpretation.²¹⁰ What falls under the scope of other status is not clear, the case law provides both a narrow interpretation that uses only personal characteristics as a benchmark and a more comprehensive perspective that takes into account any situation.²¹¹ Supporting the latter, the ECtHR stated that the listed grounds are illustrative rather than exhaustive.²¹² An important distinction that must be drawn between Article 14 and other articles is that it cannot be invoked alone, therefore any claim has to be in conjunction with a right stipulated in the ECHR.²¹³ Discrimination can either be direct constituting a “*difference in the treatment of persons in analogous, or relevantly similar, situations*”,²¹⁴ or indirect meaning that a “*difference in treatment may take the form of disproportionately prejudicial effects of a general policy or measure which, though couched in neutral terms, discriminates against a group*”.²¹⁵ However, treating people in different situations the same also constitutes discrimination, as under certain circumstances treating those people differently who, are in different situations to correct “*factual inequalities*” is justified and failure to do so breaches Article 14.²¹⁶ To make the assessment of these cases reasonable the Court developed the ‘*proportionality test*’, which firstly weighs whether the aim of the difference in treatment was legitimate. Secondly, it examines proportionality and if the means employed were appropriate for reaching the desired aim.²¹⁷

5.2. End-of-life decisions and the United Nations

Palliative care makes up a good amount of the World Health Organization’s work,²¹⁸ but other than that the legal framework of universal human rights does not deal with medical decisions such as assisted dying. The two most prominent universal treaties, namely, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic Social and Cultural Rights (ICESCR), both safeguard the same rights as the ECHR, the right to

²¹⁰ Bernadette, R., Wicks, Elizabeth, Ovey, Clare, Jacobs, White, and Ovey (2017) *The European Convention on Human Rights*, 7th edn, Oxford University Press.

²¹¹ *Ibid.*

²¹² *Engel and Others v. the Netherlands* App. no 5370/72 (ECtHR [Chamber], 8 June 1976, § 72.

²¹³ Gerards, J., (2013). ‘The Discrimination Grounds of article 14 of the European Convention on Human Rights’, *Human Rights Law Review*, 13(1) 99–124 <https://doi.org/10.1093/hrlr/ngs044>.

²¹⁴ *Carson and Others v the United Kingdom* App. no 42184/05 (ECtHR [Grand Chamber], 16 March 2010) §61, *Biao v Denmark* App. no 3859/10 (ECtHR [Grand Chamber], 24 May 2016) §89.

²¹⁵ *D.H. and Others v the Czech Republic* App. no 57325/00 (ECtHR [Grand Chamber], 13 November 2007). §184, *Sampanis and Others v. Greece* App. no 32526/05 (ECtHR [Chamber], 5 May 2008) §67.

²¹⁶ *Thlimmenos v Greece* App. no 34369/97 (ECtHR [Grand Chamber], 6 April 2000).

²¹⁷ *Molla Sali v Greece* App. no 20452/14 (ECtHR [Grand Chamber], 19 December 2018) §135, *D.H. and Others v the Czech Republic* App. no 57325/00 (ECtHR [Grand Chamber], 13 November 2007) §196.

²¹⁸ Connor, S., (2020). *Global Atlas of Palliative Care 2nd Edition. Worldwide Hospice Palliative Care.*

life,²¹⁹ the right to private life,²²⁰ the prohibition of torture²²¹ and the prohibition of discrimination,²²² from which the latter is included in both Covenants. As an universal human rights judicial forum does not exist, where the provisions of these treaties could be implemented, the European human rights protection system seems to be more significant from the perspective of end-of-life decisions. Nevertheless, a subsidiary piece of law on the issue, which could be mentioned is General Comment No. 36 on Article 6 of the ICCPR on the right to life.²²³ The most relevant part is paragraph 10, which outlines the controversy that, States should take adequate measures to “*prevent suicides, especially among individuals in particularly vulnerable situations*”, but should allow adults who are “*mortally wounded or terminally ill.*” to end their lives.²²⁴ The General Comment seeks to resolve the dichotomy by specifying that the latter can only take place within a State where “*robust legal and institutional safeguards*” exist.²²⁵

6. Jurisprudence of the European Court of Human Rights in end-of-life decisions

6.1. Pretty v. United Kingdom

The ECtHR’s first case relating to end-of-life decisions was the case of *Pretty v. United Kingdom*. Mrs. Pretty suffered from a motor neuron condition, which is an incurable degenerative disease affecting the muscles.²²⁶ Her wish was to control her death before reaching the final stage of her disease, which is undignified.²²⁷ She wanted to end her life, but she could not, as she was physically unable to do so. His husband was willing to help but under Section 2 of the 1961 Suicide Act, he could have been prosecuted for assisting.²²⁸ Mrs. Pretty argued that her rights were violated under several Articles of the Convention, namely Article 2, 3, 8, 9, and 14.²²⁹ Regarding Article 2 she argued that protecting “*the right to life and not life itself*”,

²¹⁹ UN General Assembly, International Covenant on Civil and Political Rights, United Nations, Treaty Series, vol. 999, p. 171, 16 December 1966, Article 6.

²²⁰ *Ibid*, Article 17.

²²¹ *Ibid*, Article 7.

²²² *Ibid*, Article 2.

²²³ Human Rights Committee, General Comment No. 36: Article 6 (Right to Life) 124th Sess., 3 September 2019

²²⁴ *Ibid* §10.

²²⁵ *Ibid*.

²²⁶ *Pretty v the United Kingdom* App no 2346/02 (ECtHR [Chamber], 29 April 2002) §7.

²²⁷ *Ibid* §8.

²²⁸ *Ibid* §9.

²²⁹ *Ibid* §3.

should include the “*right to choose whether or not to go on living*”.²³⁰ The Court held that the right to life “*cannot without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die*”.²³¹ As to the alleged violation under Article 3, the Court stated that it is “*beyond dispute that the respondent State has not, itself, inflicted any ill-treatment on the applicant*”.²³² From the assessment of the Court, it is visible that the issue of deciding on one’s death most likely falls under the purview of the right to privacy. The Court acknowledged that the desire for assistance in suicide is a part of “private life,” but it came to the conclusion that, under the second part of the Article, interfering with this “choice” can be justified as “necessary in a democratic society,” since it protects the right of others.²³³ As to the freedom of thought, conscience, and religion, Article 9 the Court found no violation and held that Mrs. Pretty is free to have her belief, however, it holds no relevance in the issue.²³⁴ The claim of the applicant on the alleged discrimination was dismissed as well, holding that there is no ‘right to suicide’.²³⁵

6.2. Haas v. Switzerland

Mr. Haas applied to the ECtHR because he had been experiencing severe bipolar affective disorder for more than two decades.²³⁶ His illness was a burden for him and made him unable to live in a dignified manner, he had suicide attempts and was treated in psychiatric hospitals several times.²³⁷ Therefore, he joined Dignitas and asked for assistance in suicide, which ambition proved to be unsuccessful as well, as he could not find a psychiatrist who would prescribe him the lethal medication.²³⁸ After exhausting the domestic remedies, the Applicant filed his claim to the Court complaining of a violation of his “*right to choose the time and manner of his death*”.²³⁹ The ECtHR noted that what Article 8 encompasses is the “*right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence*”.²⁴⁰ However, the question in this exact case was the existence of the positive obligation of domestic legislation

²³⁰ Ibid §35.

²³¹ Ibid §39.

²³² Ibid §53.

²³³ Ibid §78.

²³⁴ Ibid §31.

²³⁵ Ibid §89.

²³⁶ Haas v Switzerland App no 31322/07 (ECtHR [Chamber], 20 January 2011) §7.

²³⁷ Ibid.

²³⁸ Ibid.

²³⁹ Ibid §32.

²⁴⁰ Ibid §51.

to provide someone the means to end his life in dignity. As unlike Mrs. Pretty, Mr. Haas did not have an incurable illness which made him infirm, consequently, he was able to commit suicide.²⁴¹ The answer as to whether the right of the applicant in this case has been violated lies in the margin of appreciation.²⁴² The Court highlighted that the criteria set to acquire a lethal drug “*on the basis of a full psychiatric assessment*”²⁴³ is consistent with the State’s responsibility and, therefore found no violation. The judgment also states that the positive obligation lies under Article 2, and not under Article 8.²⁴⁴

6.3. Gross v. Switzerland

The second case filed against Switzerland in 2013 discussing end-of-life decisions concerned Mrs. Gross an old woman, wishing to terminate her life to escape the misery resulting from the gradual degradation of her mental and physical abilities.²⁴⁵ She did not have a terminal illness therefore she could not get a prescription for lethal drugs that she could end his life with.²⁴⁶ As her requests for an exemption had been denied in Switzerland, she filed a case before the Court, where she claimed that her “*right to decide by what means and at what point her life would end*” had been violated.²⁴⁷ First, the Court determined that Mrs. Gross's desire to acquire the fatal medication is an aspect of Article 8, the right to respect for her private life.²⁴⁸ Further, the Court examined that States’ positive duty regarding Article 8 contain the implementation of strategies to ensure that private life is respected between individuals “*including both the provision of a regulatory framework of adjudicatory and enforcement machinery protecting individuals*”.²⁴⁹ Regarding the exact situation the Court held that “*sufficient guidelines ensuring clarity*”²⁵⁰ are missing from the Swiss law as the situation of people like Mrs. Gross was not regulated, therefore found that the applicant’s right was violated.²⁵¹ The lack of clear legal regulation in the matter “*is likely to have a chilling effect on doctors*”,²⁵² meaning that otherwise, they might prescribe the lethal medication to someone in a similar situation such as

²⁴¹ Ibid §52.

²⁴² Ibid §55.

²⁴³ Ibid §58.

²⁴⁴ Ibid §61.

²⁴⁵ Gross v Switzerland App no 67810/10 (ECtHR [Chamber], 14 May 2013) §7.

²⁴⁶ Ibid §11.

²⁴⁷ Ibid §38.

²⁴⁸ Ibid §60.

²⁴⁹ Ibid §62.

²⁵⁰ Ibid §67.

²⁵¹ Ibid.

²⁵² Ibid §65.

Mrs. Gross.²⁵³ However, a year later the case took an unexpected turn, and the judgment was overruled by the Grand Chamber as it turned out that Mrs Gross had obtained the lethal medication meanwhile and died,²⁵⁴ without her representative informing the Court.²⁵⁵ Therefore, the Grand Chamber ruled nine votes by eight to declare this decision inadmissible as it does not comply with the admissibility criteria and abused the right of individual application.²⁵⁶

6.4. Mortier v. Belgium

The case of Mortier v. Belgium is significant because its subject matter was whether the procedure of euthanasia complied with the provisions of the ECHR. A patient's son applied to the Court, who did not know that his mother had started euthanasia proceedings.²⁵⁷ As euthanasia is legal in Belgium, this case did not concern whether the State should provide euthanasia to a patient, but whether the procedure complied with the Convention. The applicant argued that as the act was not performed accordingly and a thorough and efficient investigation into the issue was missing, the State did not fulfill its positive obligations under Article 2, to save the life of his mother.²⁵⁸ He also argued that due to this failure, his right to private life under Article 8 was also violated.²⁵⁹ The Court found the legislative framework in Belgium on euthanasia to comply with Article 2 of the Convention as it provided safeguards, further, how the euthanasia was performed in this exact case also did not violate Article 2.²⁶⁰ Nevertheless, the Court found a violation of Article 2 on how the post-euthanasia review was carried out, assessing that it did not afford all the safeguards required by the Convention.²⁶¹ Specifically, because the Federal Board for the Review and Assessment of Euthanasia is not independent.²⁶² As to Article 8, the Court found that the responsible physician had complied with the law following the patient's desire not to contact her children, therefore it found no violation.²⁶³ As was previously detailed, the margin of appreciation grants freedom to the States concerning how they fulfill their responsibilities under Article 8., but in this case, the Court's judgment was

²⁵³ Ibid.

²⁵⁴ Gross v Switzerland App no 67810/10 (ECtHR [Grand Chamber], 30 September 2014) §17.

²⁵⁵ Ibid §31.

²⁵⁶ Ibid §37.

²⁵⁷ Mortier v Belgium App. no 78017/17 (ECtHR [Chamber], 4 October 2022) §7.

²⁵⁸ Ibid §8.

²⁵⁹ Ibid §186.

²⁶⁰ Ibid §149.

²⁶¹ Ibid §177.

²⁶² Ibid §184.

²⁶³ Ibid §207.

crucial to establish that no reading of the right to life could prohibit the conditional decriminalization of euthanasia.²⁶⁴

6.5. Dániel Karsai v. Hungary

In its recent ruling on end-of-life matters, the European Court of Human Rights addressed assisted suicide. The applicant was a 47-year-old terminally ill Hungarian lawyer, Mr. Dániel Karsai, who was in the advanced stage of amyotrophic lateral sclerosis (ALS).²⁶⁵ ALS is a progressive neurodegenerative disease with the final outcome that the patient losing voluntary control of his muscles, hence the patient becomes completely paralyzed in the end stage, while his intellectual functions and consciousness are not affected.²⁶⁶ Mr. Karsai stated that soon he will be “*imprisoned in his own body without any prospect of release apart from death*” making his existence consist only of pain and suffering.²⁶⁷ His aim was to shorten this phase through physician-assisted dying, but both forms of that are illegal in Hungary.²⁶⁸ He applied to the Court complaining about the fact that he cannot end his life with assistance, and that is a violation of his right to private life under Article 8.²⁶⁹ Additionally, he complained of a violation of Article 14 in conjunction with Article 8 articulating that he is discriminated as the law did not offer an alternative for him to “*hasten his death*” like for people who were dependent on life-sustaining treatment, which they have the right to refuse.²⁷⁰ The Court concluded that having access to physician-assisted dying concerns the core aspects of his right enshrined in Article 8, as it is in close connection with respect for his autonomy, and physical and mental integrity.²⁷¹ The Court conducted the proportionality test between the applicant’s desire to end his suffering through PAD with dignity and the obligation of States to safeguard the lives of people through the criminal prohibition on assisted dying.²⁷² Examining this the ECtHR refers to the margin of appreciation that States enjoys in finding a compromise between these conflicting interests and concluded that as Hungary remained within their margin it did not violate Article 8.²⁷³ As to the applicant’s claim of a violation under Article 14, the Court’s

²⁶⁴ Ibid §138.

²⁶⁵ Dániel Karsai v Hungary App. no 32312/23 (ECtHR [Chamber], 13 June 2024) §12.

²⁶⁶ Ibid.

²⁶⁷ Ibid §14.

²⁶⁸ Ibid.

²⁶⁹ Ibid §81.

²⁷⁰ Ibid §168.

²⁷¹ Ibid §85.

²⁷² Ibid §147.

²⁷³ Ibid §166.

assessment was not that detailed. The ECtHR agrees with the government's submission that physician-assisted suicide and RWI are different acts,²⁷⁴ and concludes that *"the alleged difference in treatment of the aforementioned two groups of terminally ill patients is objectively and reasonably justified."*²⁷⁵ In addition to the margin of appreciation States enjoy in relation to physician-assisted suicide, the Court also acknowledges that a *"certain trend is currently emerging towards the decriminalization of medically assisted suicide"*.²⁷⁶ The shift in the legislation of some European countries (Austria, Italy, Germany, Portugal, and Spain) grants access to certain forms of physician-assisted death, in order to respect the people's right to self-determination.²⁷⁷ Compared to the previous jurisprudence of the Court this judgment is significant because the Court elaborates on the terms and uses a transparent terminology: physician-assisted dying covering both voluntary euthanasia and physician-assisted suicide.²⁷⁸

6.6. Comparison of the case law

State	Case	Date	Violation	Judgement
United Kingdom	Pretty v. the United Kingdom	19/04/2002	Article 2, 3, 8, 9, 14	No violation [Chamber]
Switzerland	Haas v. Switzerland	20/01/2011	Article 8	No violation [Chamber]
Switzerland	Gross v. Switzerland	(14/05/2013) 30/09/2014	Article 8	(Violation of Article 8 [Chamber]) Inadmissible [Grand Chamber]
Belgium	Mortier v. Belgium	04/10/2022	Article 2, 8	Violation of Article 2 [Chamber]
Hungary	Dániel Karsai v. Hungary	13/06/2024	Article 8, 14	No violation [Chamber]

1. Table: Summary of cases²⁷⁹

One of the most important observations is that the Court dealt with a wide range of end-of-life decisions and situations. The cited cases illustrate the range of situations that could arise starting with Mrs. Pretty who suffered from a terminal physical illness, making her unable to commit suicide. A quite big difference between the case of Pretty v the United Kingdom and the other cases is that Mrs. Pretty relied on five different articles, while the others mostly relied on Article

²⁷⁴ Ibid §174.

²⁷⁵ Ibid §176.

²⁷⁶ Ibid §143.

²⁷⁷ Ibid §142.

²⁷⁸ Ibid §82.

²⁷⁹ Table made by the author on 23/10/2024.

8, Article 2, or Article 14. Mr. Haas had a mental illness, and multiple Swiss physicians refused to prescribe him the lethal drug, while Mrs. Gross desired assistance in suicide because of her growing old, and eventually found a physician in Switzerland who wrote the prescription for her. In the case against Belgium, the applicant tested whether his mother's euthanasia proceeding was conducted properly, which is an entirely new perspective in the ECtHR's case law, not just because it is the first case dealing with euthanasia and not assisted suicide, but because it was submitted by the son of the patient. Mr. Karsai's situation could easily be compared to Mrs. Pretty's because of the similar nature of their illness, but there are two major differences. Firstly, the criminal ban on assisted suicide has an extraterritorial effect in Hungary. Secondly, 22 years have passed during which the perception of assisted dying changed in Europe increasing the number of countries decriminalizing some forms of assisted dying from zero to nine (the Netherlands, Belgium, Luxemburg, Switzerland, Austria, Italy, Germany, Spain, and Portugal). On the other hand, this is still not enough to result in a consensus within Europe, and the issue will not be resolved until then as it is visible from the decisions of ECtHR. The Court will not take part in the debate on whether assisted dying should be legalized or criminalized. It highlights this position in the Pretty case by the statement that "*the vast majority of member States seem to attach more weight to the protection of the individual's life than to his or her right to terminate it*".²⁸⁰ Maybe the Court's cautious approach did not change over the 22 years, but the approach of some States definitely did. A great achievement is that the Court takes note of this development in the case of Mr. Karsai by mentioning that there is a trend among countries to decriminalize assisted suicide.²⁸¹ Besides this, the Court only deals with the technical and procedural aspects of the cases, it does not produce guidelines on how States should act. It strictly does not consider the emotional elements of the cases, and assesses all cases from a technical perspective. Additionally, the Court is also very mindful about viewing the Convention as a whole, meaning that it interprets the articles in connection with each other, not individually.

7. Conclusion

The paper's objective was to elaborate on the jurisprudence of the European Court of Human Rights on the issue of end-of-life decisions and to show how assisted dying is regulated within the national legislation of four countries (Belgium, Switzerland, the United Kingdom, and Hungary), whose legislation greatly differ from each other. Besides these different approaches,

²⁸⁰ Haas v Switzerland App no 31322/07 (ECtHR [Chamber], 20 January 2011) §55.

²⁸¹ Péter Stánicz in discussion with the author, 8th October 2024.

there is one crucial common point regarding these countries, which is that their legislation on end-of-life decisions has been tried before the ECtHR. Researching these cases, it is visible that the ECtHR acknowledges the right to decide on one's death as an aspect of human rights falling under the provision of Article 8, the right to private life. As for the other articles cited by Mrs. Pretty and Mr. Karsai, the Court did not recognize their relevance. It is visible that Article 2 does not have an opposite right as the 'right to die', therefore it is a false allegation. Still, the right to life has a crucial role but from a different perspective, as it can be read from the case law the reason why a person's right to decide on his death could be limited is because of the positive obligation of States under Article 2 to protect the individuals' life. It implies that my hypothesis in this respect has been proven meaning that the most relevant article of the European Convention on Human Rights on end-of-life decisions is "*the right to respect for private and family life.*"²⁸²

Moving forward to the next hypothesis, the ECtHR's decisions were not influential on the States' national legislation. In the case of Belgium, the law on euthanasia came into force in 2002 and the ECtHR ruled in 2022 in the *Mortier v Belgium* case, therefore because of their timing it is impossible to have a link between them. On the other hand, it should be highlighted that the Court in that case found that Belgium's post-euthanasia procedure infringed on the right to private and family life of the applicant. The cases against Switzerland also demonstrate how little weight the Court's rulings have in national legislation. First, in the *Haas v. Switzerland* case in 2011, the ECtHR concluded that the criteria set in the Swiss law, that a full psychiatric assessment is needed to acquire a lethal drug is a necessary safeguard and was in line with the provisions of the ECHR. However, in the *Gross v. Switzerland* case two years later the Court first, condemned Switzerland for not having a clear legal framework on who could get the prescription for the drug. Then it overruled this decision because of the death of the applicant during the proceedings, which can be considered a step backward on behalf of the Court. The case of *Pretty* did not bring a change in the national legislation as well, whether this time the parliament will change its mind one can only take a guess, as this is not the first time that such a bill is presented to parliament. As for Hungary, the case of Mr. Karsai led to a social discussion which is a good starting point, but for the time being it appears that the criminal ban on assisted suicide will remain in force. Lastly, the doctrine of margin of appreciation is highlighted in each

²⁸² Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, ETS 5, 4 November 1950.

of these cases, which implies that it does not wish to take part in the debate on whether to legalize assisted dying.

Turning to my last hypothesis on the evolution of the jurisprudence of the European Court of Human Rights, it must be recognized that development is not as conspicuous as many would expect it to be. In the case of Mr. Karsai, there was great expectation that the Court would take a concrete position on the issue, which did not happen. What counted as a step forward is the fact that it used defined terminology as to what physician-assisted dying is, covering assisted suicide and voluntary euthanasia. It also distinguished the refusal or withdrawal of life-sustaining or life-saving treatments from physician-assisted dying and did not refer to passive or active forms of euthanasia, which is an outdated allocation. The use of clear definitions is significant and leads to a common understanding between States, despite having no consensus. Further, the Court acknowledged the increasing tendency to legalize some forms of assisted dying among states, which is also a great improvement, meaning that there is a change in the judgment on the issue. Despite not actively forming the discussion on assisted dying, the Court's work is essential as it sets a common standard for European states in human rights issues. Still, it is visible that regarding the legislation of end-of-life decisions States are the main actors, and the Court is not likely to take a more assertive role in shaping the assessment of the issue. How the debate will continue is up to the States, only the future will tell whether more states decide to take a more liberal stance and recognize the right to decide on death as a human right or not.

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