

Written comment by the Hungarian Civil Liberties Union as a third party intervening in the case Karsai v. Hungary (App. No. 32312/23)

Dear ECtHR,

On behalf of the Hungarian Civil Liberties Union (HCLU, Társaság a Szabadságjogokért), we have the honour of transmitting to you our third-party intervention as authorised by the decision notified on 15 January 2024.

Please allow us to submit our written comments to you herewith, which relate to the theoretical, legal and practical context of end-of-life decisions in Hungary.

I. Theoretical implications

1. The Court had previously acknowledged, as evident in the cases of *Pretty v. the United Kingdom* [2346/02, 29 April 2002] and subsequently affirmed in *Haas v. Switzerland* [31322/07, 20 January 2011] and *Gross v Switzerland* [67810/10, 14 May 2013], that an individual's entitlement to determine the manner and timing of their own death, provided they were capable of independently forming judgments and acting accordingly, constituted a facet of the right to respect for private life under Article 8. The Hungarian Constitutional Court (HCC) similarly adopted a comparable stance, asserting that the right of self-determination (i.e. private autonomy) of an incurable patient encompasses the right to decide between life and death and to select the timing of one's demise. In its Decision 22/2003. (28. 04.) the HCC declared that the decision of an incurable and suffering patient not to endure the remainder of their life is an integral aspect of their right to self-determination. The right to decide on one's own death belongs to everyone, whether healthy or sick and if sick, whether or not the illness can be cured according to medical science. [Para. IV. 6. 1.] The dispute between the parties is not even about whether the choice to terminate one's life is safeguarded by the right to the respect of private life. The current disagreement pertains to whether, in the event the Applicant is incapable of independently concluding his life, he may solicit the aid of others through assisted suicide or euthanasia.

2. HCLU maintains the belief that patients possess the right to die with dignity, even when they are unable to attain it through the refusal of treatment. In such situations, we advocate for the possibility of doctors assisting patients in swiftly and painlessly ending their lives by administering a lethal agent under control with adequate safeguards. We endorse legislation that permits doctors to make such drugs available to patients and offer information on their proper use. This is guaranteed by three constitutional rights for the terminally ill:

- *Right to human dignity* is applicable when a doctor aids a patient in liberating themselves from unbearable physical and mental suffering.
- *Right to self-determination* is exercised when a capable patient requests a doctor's assistance and then exercises their own right to decide to end their life.

- *Right to life* encompasses the right to bring life to an end. A patient retains control over their life and cannot be compelled to endure if they perceive no meaningful continuation of their existence.

3. In the case of an incurable patient who, after careful consideration, determines that the remaining days of their life would not be worth living, they have the right to seek assistance for suicide. This includes the right to request medical assistance to facilitate the act of suicide.

4. We firmly believe that it is crucial for the law to incorporate safeguards against potential abuse. Only a patient with decision-making capacity should be eligible to request assistance, and such requests should be diligently documented. Doctors must ascertain that the patient has made an informed and voluntary request after careful consideration. The patient should be furnished with comprehensive information. Importantly, recognising the right to freedom of conscience, no doctor should be compelled to participate if such cooperation contradicts their personal convictions.

On the outline of personal autonomy

5. The Hungarian Government's observations challenge the Court to provide a compelling explanation, with particular regard to the fact that the vast majority of European States consider otherwise; why one's claim for securing the right (or obligation?) for others to be involved in the termination of one's life is considered an element of one's "private life" deserving respect (or facilitation). Additionally, the Government asks how a decision requiring action (let alone criminal conduct) by others and not oneself can be regarded as within one's personal autonomy.

6. The response to this question lies in the possibility that there may be situations—and in the imminent future, the Applicant will inevitably find himself in such circumstances—where the individual lacks the capability to terminate his own life through his own actions (similar to his inability to sustain his life through his own actions). If, during that period, the option to end life is not available to him, every moment of his life after that becomes inevitably reliant on others. Consequently, the core substance of his privacy and personal autonomy is virtually obliterated, constituting an infringement of rights contrary to the Convention.

7. Moreover, when the effective exercise of a right—in this instance, individual autonomy—is contingent upon a third party, that fundamental right must also be safeguarded against restrictions imposed on third parties that would hinder them from supporting the fundamental right within the scope of their own freedom. The involvement of the third party in the exercise of the right becomes an indispensable condition for the realisation of the right. Authentic acknowledgement of a "right" becomes difficult to substantiate without it.

8. It is imperative for the Court to unequivocally dismiss the Government's ambiguous reference to the "obligation" of providing aid to assisted suicide or euthanasia. The voluntary and altruistic nature of a third party assisting in exercising rights must be distinguished from the notion that someone may be compelled to do

so. It is worth emphasising that, to preclude any form of such obligation, it is advisable to permit the operation of organisations that provide end-of-life support as a professional service, be it in the form of assisted suicide or euthanasia.

9. The Government also raises the question of whether an action (suicide assistance) destroying a personal autonomy (a life) can be regarded as the protection of that personal autonomy (private life).

10. The German Federal Constitutional Court has addressed and sufficiently answered this question in its 2020 decision [BVerfG, 26.02.2020]. According to this, autonomy, which ensures an individual life of self-determination, does not negate the choice of a person capable of freely determining and taking personal responsibility for ending their own life. On the contrary, the self-determined termination of one's own life is a direct manifestation of the concept of autonomous personal development; it represents, albeit the final act, an expression thereof. An individual who, acting with free will, decides to end their life is making a subjective choice in favour of their own death. They relinquish their life as a person in a self-determined manner and according to their own objectives. Consequently, personal autonomy does not restrict a person's self-determination; instead, it serves as the rationale for it. A person is only acknowledged as a self-responsible personality, as a subject, and their claim to value and respect is only maintained if they can shape their existence according to their own self-imposed standards.

On standards of national scrutiny

11. The Government's argument stating that national authorities are in a better position to evaluate their population's collective moral and social values and to protect the vulnerable from overt or covert pressure to kill themselves invites two observations in the context of any government and society.

12. Firstly, governments must assess whether it is necessary to impose restrictions on human rights to protect the vulnerable or if less restrictive means exist to achieve this goal. In doing so, they should acquire objective knowledge and conduct an objective evaluation of various aspects, including the attitudes of their societies towards the terminally ill and the experiences of states that have implemented assisted suicide or euthanasia. To our knowledge, comprehensive surveys and analyses of this nature are not available in Hungary.

13. Secondly, it is crucial to emphasise that governments cannot evade their positive obligations to society by attempting to shield individuals from risks by suspending individual autonomy. Therefore, it remains a guiding principle for national governments across states that they cannot offset deficiencies in the health and social care system or malpractices in the health sector – factors that may influence individual discretion toward suicidal choices – by imposing restrictions on individual autonomy. Limiting rights cannot address neglect or non-compliance with state obligations; instead, the state must seek alternative measures.

On existential choices vs ableism

14. The Government, in its observation and during the oral hearing, raised concerns about the potential discriminatory impact and pressure on terminally ill or disabled individuals if assisted suicide or euthanasia were to be introduced, even mentioning that the Applicant's case touched upon the issue of ableism.

15. In this context, research tends to emphasise that end-of-life decisions, such as opting for assisted suicide or euthanasia, cannot be tied to a specific general standard, a particular stage of an incurable disease, or a specific type of disability. These personal wishes and decisions do not conform to scientific descriptions or definitions of disease or disability; instead, they are viewed as individual existential choices influenced by one's relationship to death, autonomy, a sense of meaningfulness in life, or contemplation about relationships. Notably, research on ALS patients indicates that younger, more educated, and more aware patients more frequently choose euthanasia, regardless of their satisfaction with end-of-life care. Their decisions are driven by personal losses, such as the loss of dignity, dependence on others instead of autonomy, and a lack of prospects for recovery.¹

16. A Hungarian constitutional judge articulates a similar perspective in a dissenting opinion in the HCC's Decision on euthanasia. He argues, "No objective line can be drawn between life worthy of human dignity and life unworthy of human dignity. The individual, as a concrete, individual subject, decides through his or her own evaluative activity which life he or she still considers worthy for himself or herself and which life he or she no longer considers unworthy. This decision is based on the subjective and absolute discretion of the individual, who alone can decide which form, kind, content, or degree of suffering, helplessness, self-sufficiency, inability to provide for oneself, etc., is no longer worthy but unworthy of the human life which he or she no longer wishes to live" [Decision 22/2003. (28. 04.) dissenting opinion of Judge Mihály Bihari].

17. In alignment with these perspectives, the Court's opinion, as articulated in *Pretty*, acknowledges the importance of Article 8, recognising notions of the quality of life. While upholding the principle of the sanctity of life protected under the Convention, the Court underscored the significance of Article 8 in addressing concerns related to the quality of life. It acknowledged that, in an era of advancing medical capabilities and longer life expectancies, individuals may have concerns about being compelled to endure old age or states of advanced physical or mental decline that conflict with their firmly held ideas of self and personal identity [*Pretty v. The United Kingdom*, Para. 65].

18. This reference to changes in attitudes towards enduring physical or mental decline is supported by the findings of the most recent nationally representative survey,² indicating that 79% of Hungarians deem euthanasia acceptable. Within this

¹ van Eenennaam RM et al. Frequency of euthanasia, factors associated with end-of-life practices, and quality of end-of-life care in patients with amyotrophic lateral sclerosis in the Netherlands: a population-based cohort study. Lancet Neurol. 2023 Jul;22(7):591-601.

² <https://www.statista.com/statistics/1430308/hungary-support-for-euthanasia/>, visited on 25.01.2024

percentage, 20% of the respondents express complete support for the right to self-determination, while 59% endorse it in specific circumstances.

II. A practical framework of end-of-life decisions

19. According to the Hungarian Health Act, end-of-life decisions solely mean refusing medical treatment. Refusal of treatment may occur “on-site” during the treatment or in an “advance directive”, also known as “living will”. Those suffering from a condition which does not lead to death closely in a natural way are not in a position to bring the time of their decease any closer.

20. Advance directives can only be made in the form of an *authentic instrument*. Such a document can only be issued before a notary, which raises a high bar for citizens as it is a complicated and costly process.

21. Should the patient be in a situation in which they cannot express their will and their condition leads to death and is incurable—even with appropriate medical support—the court can substitute the refusal of the medical treatment. This legal instrument is barely applied in Hungary—according to our knowledge, only two such decisions were made during the last two decades.

22. The consolidation of the current Hungarian legislation was significantly influenced by the HCC’s Decision 22/2003. (28. 04.), which affirmed the constitutionality of the preceding legal framework. However, it is noteworthy that the HCC rendered this decision without acquiring information on whether incurable patients can exercise the rights stipulated in the Health Act. The decision also does not indicate that the judges evaluated the standard of care for the dying in Hungary, including aspects such as the availability of hospice-palliative care units, the state of pain relief, and the adequacy of financial resources for maintaining a professionally acceptable level of care. Nevertheless, the HCC also articulated that the demarcation between what is constitutional and what is unconstitutional is not always predetermined; the level of knowledge, the state of institutions, and various other considerations may impact the evaluation of the constitutionality of this matter. [Para VI. 1.] This declaration conveys the perspective of the HCC that regulations should be periodically reassessed and, if required, adjusted based on evolving circumstances. The present case offers an opportunity to undertake such a reassessment.

23. Similar to the HCC, the Government did not conduct a comprehensive assessment of the typical fate of an average ALS patient within the Hungarian healthcare system prior to formulating its observations. It is essential to recognise that listing treatments and outlining good practices does not automatically ensure their widespread availability or integration into the treatment options accessible to the average patient. We aim to draw attention to how the Hungarian healthcare system currently fails its patients in real-life situations.

End-of-life decisions

24. The number of end-of-life decisions in Hungary is very small—according to the Chamber of Notaries, they hardly make up a dozen in the last few years.³ The exact number, however, is uncertain; HCLU attempted to acquire information on the number of advance directives a few years ago, but our request was rejected by the Chamber, claiming that the information was not available because of the absence of a specific registry for such documents.

25. With such a low number of advance directives, it is fair to state that it is basically a non-existent category in Hungary. Practical details suggest that even if someone holds a notary-issued document, there is a meagre chance that it will be considered during a medical process. The document itself is an A4 format piece of paper that not everyone can carry at all times; also, medical personnel are not authorised to search a patient's belongings in order to find out if such document is held by them. As there is no registry of advance directives, and neither does the Hungarian electronic healthcare database include any information about advance directives, the only way healthcare workers can be informed about the existence of an end-of-life decision is if the patient (or a family member) presents it. Although the official electronic healthcare system would technically allow advance directives to be made there, it is legally not possible.

26. However, the fact that advance directives as formal papers held by citizens are basically non-existent in Hungary does not mean that end-of-life decisions are not made. The best case scenario is the patient is able to, in some form, declare their will during a hospital stay. From the right to self-determination perspective, a worse but still possible way is for a family member to suggest the patient's intentions. In the lack of written documentation, however, there is no guarantee that such a declaration will be respected.

27. As early as 2010, HCLU submitted a petition to the Hungarian Ombudsman to address these and other difficulties. Although the Ombudsman has not responded to the petition in almost 14 years, an investigation has been launched into the case, and experts of the Ombudsman's staff published their findings in 2019.⁴ According to this, the Ombudsman inquired about six of the most prominent Hungarian clinical centres, asking how many times they ceased life-saving or life-sustaining treatment based on on-site refusal or an advance directive since 2010. It was proven that hospitals and the National Ambulance Service do not keep records of care refusals, regardless of whether they were declared on-site or in an advance directive. However, none of the healthcare providers could mention a single case in which an advance directive would have been presented. On-site refusals were also scarce. The clinical centre in Pécs reported only a few cases of on-site rejections per year, while the

³ <https://web.archive.org/web/20170502180501/http://www.vg.hu/kozelet/tarsadalom/alig-irunk-elo-vegrendeletet-398082>, visited on 24.01.2024

⁴ dr. Kussinszky Anikó, dr. Stánicz Péter: Ki dönt az élet végén? II. – Egy életem, egy halálom..., Arboni, 07.08.2019. <https://arsboni.hu/ki-dont-az-elet-vegen-ii/>, visited on 24.01.2024

Semmelweis University Clinical Center in Budapest reported around 51 cases yearly. The others did not report any of them.

28. Several examples suggest that the medical staff is the one to ultimately make end-of-life decisions, often even without informing the patient and/or the family. This conduct constitutes “indirect euthanasia”,⁵ a practice where the medical professional uses the means to relieve suffering with the secondary effect of shortening the life of the patient. From an ethical point of view, this practice can be distinguished from homicide since the doctor’s intention is primarily to relieve pain, and they merely acquiesce in the possible consequence of causing death. Results-oriented criminal law thinking, however, does not accept the above distinction and examines whether the doctor’s actions were causally related to the death of the patient. Since causation can usually be established—i.e., the patient’s death is directly caused by an overdose of painkillers—this may result in the doctor being held criminally liable for manslaughter.⁶

Hospice-palliative care

29. Although hospice-palliative care is an existing category in Hungary, legal, financial and practical obstacles make it difficult for patients to participate. A legal difficulty is that not all possible forms of hospice-palliative care are regulated—Daytime hospice care and Active palliative care within hospitals are not legally existing categories. A hospice-palliative mobile team within hospitals is a legally existing but financially not supported category, but even financially supported forms of hospice-palliative care are underfinanced, so not all patients can be taken care of. An additional problem is that the medical staff is underinformed, so they do not direct patients (at the appropriate time) to hospice-palliative care, and the number of skilled health workers is critically low.⁷

Professional home care and hospice-palliative care

30. It is important to consider the availability of professional *home care* and *hospice-palliative care* in Hungary. A complex care system which involves several areas of healthcare would be required for incurable patients who deserve to live their last period of life with dignity. ALS patients need respiratory support, physiotherapy, occupational therapy, speech and language therapy, nutritional, psychological, psychiatric, and social support, and well-developed hospice services in the last stages of life. These therapies and services could help slow down the deterioration of the condition and improve the quality of life for the patients. Whilst the Government’s observations draw up a list of possible treatments, for ALS patients, this list of

⁵ Filó Mihály: Fájdalomcsillapítás és életvédelem. Az “indirekt eutanázia” büntetőjogi kérdései. In Filó Mihály (szerk.): Autonómia, életvédelem, jogbiztonság. Az életvégi döntések szabályozása. Budapest 2022, 145-153. o.

⁶ For further elaboration on the topic, see Márkus Attila: Szándékos morfiumtúladagolás Magyarországon. *Lege Artis Medicinae*, 21. (2011) 4., pages 306–308

⁷ https://hospice.hu/docu/Osszefoglalas_a_2022_evi_hospice_betegellatasrol.pdf, visited: 24.01.2024

therapies and services does not reflect the actual access, regional, and qualitative service differences. There are significant variations in services across regions; often, patients can only access services they know of or pay for privately.

31. In Hungary, patients are entitled to receive home care and hospice care through social security. Nevertheless, both home care and palliative care face challenges stemming from inadequate funding and significant understaffing. Consequently, disparities in access to services emerge, and the quality of care is compromised. The complexity or impossibility of achieving effective teamwork further exacerbates these issues.

32. According to data from the National Health Insurance Fund, the number of home care service providers has steadily declined over the past decade. In 2014,⁸ there were 316 service providers, but by 2020,⁹ this figure had decreased to 253, with an uneven distribution of providers across different regions, ranging from 5 to 33. The reduction in the number of providers has been accompanied by a significant drop in the number of patients served and visits made. According to data from the Central Statistical Office, home care services catered to 12,000 fewer patients and 156,000 fewer visits in 2022 than in 2014¹⁰.

33. Palliative care in Hungary is mainly provided through hospice services. However, the number of hospice palliative care providers has experienced a consistent decline in recent years, and their distribution is once again uneven across the country¹¹. Despite a notable increase in the number of institutional beds, it still falls just above half of the WHO's recommended minimum of 50 beds per million population¹². Data from the Central Statistical Office reveals a significant decrease in the number of days of care in the last decade.¹³ In the realm of home hospice activities, nursing dominates at 65%, while medical activities—such as long-term pain relief and medication—account for 26%. Mental health, social, or dietary care comprises only a small percentage, ranging from 0.1% to 2.6%. These proportions indicate that true multidisciplinary teamwork is not feasible in the current situation.¹⁴

34. It is also important to acknowledge the limitations of social security in providing help for home care and home hospice care¹⁵. In home care, free care is accessible for one visit per day, lasting up to three hours. Additional care is limited to

⁸ Majerné Horváth Anita: Otthoni Szakápolás helyzete Magyarországon. Mi a jelenlegi helyzet? Települési Önkormányzatok Országos Szövetsége Idősügyi Hálózatának ülése, 2020. december 15.

⁹ medicalonline.hu/gyogyitas/cikk/az_ottonapolas_helyzeterol_magyarorszag, visited: 24.01.2024

¹⁰ https://www.ksh.hu/stadat_files/ege/hu/ege0010.html, visited on 24.01.2024

¹¹ Dr. Hegedűs K, Farkas A, Lukács M: Hospice betegellátás 2020 a NEAK és a Magyar Hospice-Palliatív Egyesület adatai alapján.. Kharón Thanatológiai Szemle 2022/2, 45-54.

¹² https://hospice.hu/docu/Osszefoglalas_a_2022_evi_hospice_betegellatasrol.pdf, visited:24.01.2024

¹³ https://www.ksh.hu/stadat_files/ege/hu/ege0011.html, visited on 24.01.2024

¹⁴ Dr. Hegedűs K, Farkas A, Lukács M: Hospice betegellátás 2020 a Nemzeti Egészségbiztosítási Adatkezelő (NEAK) és a Magyar Hospice-Palliatív Egyesület adatai alapján (Hospice annual report 2020). Kharón Thanatológiai Szemle 2022/2, 45-54.

¹⁵ https://www.neak.gov.hu/felso_menu/lakossagnak/ellatas_magyarorszagon/egeszsegugyi_ellatasok/ottoni_szakapolas_hospice, visited on 24.01.2024

a maximum of 56 visits, subject to authorisation and availability. Home hospice care is available for up to 150 days, but home visits are restricted to a few hours per day. Although home hospice care is available around the clock, it is limited to phone services.

35. These limitations clearly show that the statutory provision of care for the terminally ill is hindered, providers are facing severe resource and staffing shortages, regional disparities are causing unequal access to care throughout the country, and complex therapy and care are almost unfeasible.

36. Shortcomings in the Hungarian Healthcare system might motivate people to want to end their lives sooner. Instead of providing adequate resources, the Hungarian Government is opting to restrict human rights—and individual autonomy—to fulfil its obligations to protect life. This has to be categorically rejected; the state cannot transfer the burden of its own failings to its citizens (see para. 13.) In order to protect life, the state must establish adequate care systems while leaving the individual's freedom to the manner and timing of their own death untouched.

HCLU's own experience

37. Finally, we kindly request the Court's permission to substantiate our above opinion with three cases in which the HCLU has provided legal representation and other legal assistance to the individuals involved.

38. The case concerns a family from Kistarcsa (Central Hungary), where a man has lost his partner in life, and two young children have been deprived of their mother in undignified circumstances. The mother had been battling cancer for years when her condition suddenly took a turn for the worse. In the last few months of her life, she was hospitalised six times, with each admission held in the hope that her quality of life could be improved. The family held onto the hope of a full recovery, as the patient was never informed that her disease was in the terminal phase. Without proper information, the patient was unaware that she had not been receiving curative treatment for a long time. As a result, she was unable to apply for hospice-palliative care, prepare for her end of life and enjoy quality time with her family in her final months. By the time her true life prospects were discovered, the patient was no longer able to benefit from the hospice-palliative care that had been offered at that time, as she was only a few weeks away from death. In contrast, the ideal time for hospice care is several months. The unworthy circumstances of the mother at the end of her life caused great shock and long-lasting trauma to the whole family.

39. The second case is about an elderly gentleman from Gyula (a town in the south-eastern part of Hungary) whose hospital care during the coronavirus outbreak was halted as, according to a ministerial order, at least 60% of the total bed capacity should have been prepared for possible COVID-19-infected patients. Although hospital treatment improved the patient's condition, who suffered from prostate cancer, dementia and malnutrition—conditions that would have necessitated chronic inpatient, nursing ward, or hospice care for the remainder of his life—he was discharged and sent home. The family had not even been informed that, based on the

patient's condition and social status, he would have been eligible for home care or hospice care. Consequently, the family did not apply for this care despite being incapable of managing the challenges of home care. This undignifying period eventually concluded when the patient, in his terminal stage, was admitted to the hospital again, where he died a few days later.

40. The third case features a 59-year-old woman from Debrecen (eastern part of Hungary) who was diagnosed with cancer in February 2021. She died very quickly, within three months, during which time she received neither curative nor hospice-palliative care. The main complaint of the family of the deceased is that they were not given any information about the actual condition of the patient and possible treatments or end-of-life care at the hospital. The patient was in terrible pain for three months from diagnosis to death, and although she went to hospital several times during this period, she was never given any treatment or at least pain relief; only further tests were carried out each time.

III. Summary

41. End-of-life decisions have very narrow possibilities in Hungary. The restrictive legal framework, the legislation that is barely applicable in practice, and the financial and physical deficiencies all indicate that citizens cannot properly exercise their right to self-determination, which leads to serious harm to dignity.

42. Limiting rights cannot address neglect or non-compliance with state obligations; instead, the state must seek alternative measures. In order to protect life, the Hungarian Government should establish adequate care systems while leaving the individual's freedom to the manner and timing of their own death untouched.

We appreciate the opportunity to submit these comments to the Court and hope they prove useful.

Yours sincerely,

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