

ECHR 151 (2024) 13.06.2024

No right to physician-assisted death for Hungarian with motor neurone disease

In today's **Chamber** judgment¹ in the case of <u>Daniel Karsai v. Hungary</u> (application no. 32312/23) the European Court of Human Rights held, by 6 votes to 1, that there had been:

- no violation of Article 8 (right to respect for private and family life) of the European Convention on Human Rights; and
- no violation of Article 14 (prohibition of discrimination) in conjunction with Article 8.

The case concerned the question of the asserted right to self-determined death of the applicant, who is a Hungarian national and has advanced amyotrophic lateral sclerosis (ALS) — a type of motor neurone disease with no known cure. He would like to be able to decide when and how to die before his illness reaches a stage that he finds intolerable. He would need assistance, but anyone assisting him would risk prosecution, even if he died in a country which allowed physician-assisted dying. He complained of not being able to end his life with the help of others and of discrimination compared to terminally ill patients on life-sustaining treatment who are able to ask for their treatment to be withdrawn.

The Court observed that there were potentially broad social implications and risks of error and abuse involved in the provision of physician-assisted dying. Despite a growing trend towards its legalisation, the majority of the member States of the Council of Europe continue to prohibit both medically assisted suicide and euthanasia. The State thus had wide discretion in this respect, and the Court found that the Hungarian authorities had not failed to strike a fair balance between the competing interests at stake and had not overstepped that discretion.

Nevertheless, the Convention had to be interpreted and applied in the light of the present day. The need for appropriate legal measures should therefore be kept under review, taking into account the developments in European societies and in the international standards on medical ethics in this domain.

The Court considered that high-quality palliative care, including access to effective pain management, was essential to ensuring a dignified end of life. According to the expert evidence heard by the Court, the available options in palliative care, guided by the European Association of Palliative Care's revised recommendations, including the use of palliative sedation, were generally able to provide relief to patients in the applicant's situation and allow them to die peacefully. Mr Karsai had not alleged that such care would be unavailable to him.

As regards the alleged discrimination, the Court found that the refusal or withdrawal of treatment in end-of-life situations was intrinsically linked to the right to free and informed consent, rather than to a right to be helped to die, and was widely recognised and endorsed by the medical profession, and also laid down in the Council of Europe's Oviedo Convention. Furthermore, refusal or withdrawal of life-support was allowed by the majority of the member States. The Court therefore considered that the alleged difference in treatment of the two categories was objectively and reasonably justified.

A legal summary of this case will be available in the Court's database HUDOC (link).

Once a judgment becomes final, it is transmitted to the Committee of Ministers of the Council of Europe for supervision of its execution. Further information about the execution process can be found here: www.coe.int/t/dghl/monitoring/execution.



^{1.} Under Articles 43 and 44 of the Convention, this Chamber judgment is not final. During the three-month period following its delivery, any party may request that the case be referred to the Grand Chamber of the Court. If such a request is made, a panel of five judges considers whether the case deserves further examination. In that event, the Grand Chamber will hear the case and deliver a final judgment. If the referral request is refused, the Chamber judgment will become final on that day.

The terms used for assisted dying practices varies from country to country. For the purposes of this judgment, physician-assisted dying (PAD) refers to assisted suicide and voluntary euthanasia, when performed in a regulated and medically supported setting. Refusal (by the patient) or withdrawal (at the patient's request) of life-sustaining or life-saving interventions, such as respiratory support, ultimately leading to death is referred to as "RWI".

Principal facts

The applicant, Dániel András Karsai, is a Hungarian national who was born in 1977 and lives in Budapest. He is a prominent human-rights lawyer in Hungary.

Mr Karsai has advanced amyotrophic lateral sclerosis (ALS) - a type of motor neurone disease with no known cure. It consists in the gradual loss of motor neurone function, and hence of the voluntary control of muscles. Patients generally maintain their intellectual functions and consciousness throughout the progression of the disease. Typically, death due to respiratory paralysis occurs within three to five years.

Mr Karsai would like to be allowed to have help in ending his life before that and before his suffering becomes too much to bear. He would like that to happen in Hungary or, if that is not possible, abroad. However, it is a criminal offence in Hungary to help somebody to end his or her own life, and anyone assisting the applicant at home or abroad could face criminal prosecution by the Hungarian authorities.

Complaints, procedure and composition of the Court

Relying on Article 8 (right to respect for private and family life) of the Convention, Mr Karsai complained that it was not possible for him, under Hungarian law, to be helped to die despite being terminally ill and suffering. Relying on Article 14 (prohibition of discrimination) in conjunction with Article 8, he complained that he was discriminated against because there was no legal way for him to end his life whereas terminally ill patients who were dependent on life-sustaining treatment could ask for the treatment to be stopped. He complained that not having access to physician-assisted dying (PAD) meant that he would eventually "become locked inside his body while being fully conscious over a prolonged period, thus awaiting death without any meaningful existence", contrary to Article 3 (prohibition of inhuman or degrading treatment). He further alleged under Article 9 (freedom of thought, conscience and religion) that he was not going to be able to die with dignity, which was a core element of his religious and philosophical beliefs. In his view, the national legal framework needed changing, especially in light of the evolving legislation in other member States and the increasing general acceptance of physician-assisted dying.

The application was lodged with the European Court of Human Rights on 10 August 2023. The case was given priority, and on 26 September 2023 the Hungarian Government was given notice² of the application, with questions from the Court.

The following were granted leave to intervene in the written proceedings as third parties: the Italian Government; the European Centre for Law and Justice (ECLJ); the Alliance Defending Freedom (ADF) International and Care Not Killing (CNK) Alliance; the Hungarian Civil Liberties Union (HCLU); and Dignitas.

On 27 November 2023 the Chamber, of its own motion, held a fact-finding hearing, in camera, and heard evidence from two experts, namely Professor Régis Aubry and Professor Judit Sándor, in the

^{2.} In accordance with Rule 54 of the Rules of Court, a Chamber of seven judges may decide to bring to the attention of a Convention State's Government that an application against that State is pending before the Court (the so-called "communications procedure"). Further information about the procedure after a case is communicated to a Government can be found in the Rules of Court.

presence of the parties' representatives. A public <u>hearing</u> was held in the Human Rights Building, Strasbourg, on 28 November 2023.

Judgment was given by a Chamber of seven judges, composed as follows:

Alena Poláčková (Slovakia), President, Marko Bošnjak (Slovenia), Krzysztof Wojtyczek (Poland), Gilberto Felici (San Marino), Ivana Jelić (Montenegro), Erik Wennerström (Sweden), Raffaele Sabato (Italy),

and also Liv Tigerstedt, Deputy Section Registrar.

Decision of the Court

Article 8

A blanket ban, under criminal law, on assisting suicide had been at the centre of a similar case before the Court, *Pretty v. the United Kingdom* (no. 2346/02) of 2002. Mr Karsai had submitted that his case differed from that one because (i) it also concerned the extraterritorial effect of the Hungarian ban on assisting suicide; (ii) prosecution of the offence of assistance in suicide was mandatory; and (iii) the legal and social context in Europe had changed since the Court had adopted that judgment, with a growing trend towards legalisation of physician-assisted dying. He referred to other judgments, such as *Haas v. Switzerland* (no. 31322/07) and *Mortier v. Belgium* (no. 78017/17), to illustrate that the case-law of the Court had evolved, as had the legislation in many member States, which increasingly recognised a right to make end-of-life decisions.

The Court had already found that Article 2 (right to life) did not prevent national authorities from allowing or providing physician-assisted dying (PAD), so long as appropriate and sufficient safeguards were in place to prevent abuse. It was primarily for the national authorities to assess whether PAD could be provided within their jurisdiction in compliance with this requirement.

The Court noted that assistance in suicide and euthanasia were both punishable under the 2012 Hungarian Criminal Code and that anyone who helped Mr Karsai to commit suicide, including helping him to travel or to make arrangements for physician-assisted dying to be carried out abroad, could indeed be prosecuted in Hungary.

The Court observed that Mr Karsai's request involved intertwining duties, in other words, both "negative and positive obligations" under Article 8 since, as he himself had submitted, the decriminalisation of certain forms of assisted suicide required strict regulation and appropriate safeguards, which would amount to a "positive obligation" for the State, including provision of access to medical intervention, such as access to life-ending drugs.

The Court found that the matters in the case raised sensitive moral, ethical and policy issues in respect of which the national authorities were better placed to assess priorities, use of resources and social needs. At the same time, the Court acknowledged that there was a growing trend towards decriminalisation of medically assisted suicide, especially with regard to patients with incurable diseases. Over the last few years, there had been important legal developments in favour of granting some form of access to PAD in certain European countries, such as Austria, Italy, Germany, Spain and Portugal. Nevertheless, the majority of member States continued to prohibit and prosecute assisted suicide, including PAD. Moreover, relevant international instruments and reports, including the Council of Europe's Oviedo Convention, provided no basis for concluding that the member States were advised, let alone required, to provide access to PAD. The Court found that in view of the

above, Hungary should be granted considerable discretion in deciding whether to allow PAD in Hungary.

The question for the Court was whether Hungary, by preventing Mr Karsai from having recourse to any form of PAD, was overstepping that discretion and whether a fair balance had been struck between Mr Karsai's desire to end his life through PAD, and the legitimate aims behind the legislation in question, also taking into account the duties that would fall upon the State if PAD were to be decriminalised.

The Court observed that the wider social implications and the risks of abuse and error entailed in the provision of PAD weighed heavily in the balance when assessing if and how to accommodate the interests of those who wished to be helped to die. Both of the experts heard by the Court had referred to the challenges in ensuring that a patient's decision to use PAD was genuine, free from any external influence and was not underpinned by concerns which should be effectively addressed by other means. Furthermore, the possibility that the patient might change his or her mind as the disease progressed should be taken into account. The Court understood from the expert evidence that effective communication with a patient required special skills, time and significant commitment on the part of medical and other professionals, as did the provision of adequate palliative care. It found that the assessment and allocation of such resources was, in principle, a matter which fell within the national authorities' discretion.

The Court considered that high-quality palliative care, including access to effective pain management, was essential to ensuring a dignified end of life. According to the expert evidence heard by the Court, the available options in palliative care, guided by the European Association of Palliative Care's revised recommendations, including the use of palliative sedation, were generally able to provide relief to patients in the applicant's situation and allow them to die peacefully.

It observed that Mr Karsai had not contested the adequacy of the palliative care available to him, nor had he argued that he would be unable to refuse breathing assistance when the time came. He had maintained, however, that that course of action would only become available to him after he had been "locked inside his body" for a prolonged period of time and exposed to unbearable "existential suffering" while fully conscious. He had also argued that if he accepted medical sedation, he would lose what was left of his autonomy. Noting that this was a legitimate personal choice, the Court considered that a personal preference to forego otherwise appropriate and available procedures could not in itself require the authorities to provide alternative solutions, let alone to legalise PAD.

The Court observed that the existential suffering could not necessarily lend itself to an objective assessment and noted that it was not for it to determine the acceptable level of risk involved in PAD in such circumstances. However, such a heightened state of vulnerability warranted a fundamentally humane approach to the management of the situation, an approach which absolutely had to include palliative care guided by compassion and high medical standards. Mr Karsai had not alleged that such care would be unavailable to him, and the national authorities could not therefore be regarded as falling foul of any positive obligation that might arise from Article 8 of the Convention in this regard.

The Court further found that the criminal prohibition on assisted suicide was intended to deter life-endangering acts and to protect interests arising from considerations of a moral and ethical nature. There was nothing unusual or excessive in the fact that the State's prohibition applied also to suicides carried out abroad. Ensuring that Mr Karsai's wish to use PAD abroad was not penalised in Hungary would in effect require the creation of an exception in the operation of its criminal law. The Court considered that issues relating to the coherency of the national-law system and the collective moral and ethical considerations underpinning the prohibition of assisted suicide, which had been raised by the Hungarian Government, provided reasonable grounds for the Hungarian authorities' reluctance to introduce the type of exception sought by the applicant.

It also noted that the Government had asserted that mitigating factors could be taken into account and that, where justified, the sentence imposed could be lower than the statutory minimum.

Taking into account these factors and the State's wide discretion in this domain, the Court did not find that the criminal ban on assisted suicide, including its application to any person assisting the applicant to have recourse to PAD abroad, was disproportionate. Moreover, it did not find that the Hungarian authorities had overstepped the discretion afforded to them in the striking of the balance between the competing interests. Therefore, there had been no violation of Article 8 of the Convention.

Nevertheless, the Convention had to be interpreted and applied in the light of the present day. The need for appropriate legal measures should therefore be kept under review, regarding the developments in European societies and in the international standards on medical ethics in this sensitive domain.

Article 14 in conjunction with Article 8

The Court noted that the right to refuse or request discontinuation of medical treatment in end-of-life situations was inherently connected to the right to free and informed consent to medical intervention, which was widely recognised and endorsed by the medical profession, and also laid down in the Oviedo Convention, whereas PAD was not. Furthermore, the majority of the member States allowed RWI.

The Court therefore considered that the alleged difference in treatment of the two groups was objectively and reasonably justified. Therefore, there had been no violation of Article 14 taken in conjunction with Article 8 of the Convention.

Articles 3 and 9, taken alone and in conjunction with Article 14

These complaints were unanimously rejected as manifestly ill-founded.

Separate opinion

Judge Wojtyczek expressed a partly concurring, partly dissenting opinion. Judge Felici expressed a dissenting opinion. These opinions are annexed to the judgment.

The judgment is available only in English.

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The European Court of Human Rights was set up in Strasbourg by the Council of Europe member States in 1959 to deal with alleged violations of the 1950 European Convention on Human Rights.