The Right To Die Like The Trees: Standing

Dániel Karsai

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My name is dr. Dániel András Karsai. I am a human rights attorney. I am also terminally ill.

In August 2022, I was diagnosed with ALS. ALS – the legendary physicist Stephen Hawking suffered from the same disease – is a so-called motor neurone disease. For reasons unknown to medical science, this disease causes nerve cells that move the muscles to deteriorate, leading to muscle atrophy and ultimately complete paralysis. At the end of the disease, respiratory functions also cease, resulting in death by asphyxiation. However, the mental faculties are not affected, forcing one to experience this with a fully lucid mind.

ALS leads to an extremely humiliating life situation, increasingly depriving you of independence. The final stage of the disease is virtually a vegetative existence, without any possibility of conscious activity or communication. For me, this form of existence is devoid of all meaning and dignity. In this situation, I firmly believe in the arguable claim to demand the right to end my life with dignity instead of enduring meaningless suffering.

In Hungary, patients in a situation like mine, suffering from an incurable disease, do not have this option. What is more, they do not even have the opportunity to go abroad for this purpose and end their lives there with dignity. The reason is that, under the Criminal Code in force, Hungary has extraterritorial jurisdiction, it can prosecute those who assist them in dying with dignity, i.e. family members, friends and doctors – even if this occurs abroad.

In my personal and professional opinion, the total ban on end-of-life decisions in Hungary violates my fundamental human rights, in particular the right to self-determination based on human dignity, the prohibition of inhuman and degrading treatment, and the right to freedom of choice of ideological belief. As there is no legal remedy for this violation in Hungary, I lodged an application with the European Court of Human Rights in Strasbourg.

I want to emphasize from the beginning that my application is not a general plea for a complete legalization on a European level of all forms of end-of-life decisions for all types of individuals concerned. The question this application raises is the following: what is the scope of the right to freedom of choice for individuals in a position like mine – that is, those with full mental capacity – regarding end-of-life decisions?

My aim is to use my unfortunate situation to initiate a meaningful and respectful public conversation on the subject of the right to make end-of-life decisions. In the following blog post, I will briefly summarize my personal and legal arguments submitted to the Court. Since the aim of the present blog post is to start a public conversation, I am not addressing all the possible arguments and counter-arguments. I am neither quoting nor analysing the Court's related previous case law – but I am very aware of it.

Introducing myself

Each person brings an individual case to Strasbourg. Since context is everything, I'll begin with a brief introduction of myself.

I am a 46-year-old former staff member of the Registry. I worked at the Court between 2005 and 2009. Since 2009, I have been working as an attorney at law specialising in human rights litigation. I have represented more than a thousand clients before the Constitutional Court of Hungary and the European Court of Human Rights, including four Grand Chamber cases.

I see myself as a spiritual, emotional and intellectual person. My worldview rests on three pillars: belief in God, belief in human rights, and belief in following the path of the Japanese martial art ju-jitsu Kelemen Ryu, a school officially registered in Japan.

I believe that a higher entity – God – created the Universe. I also believe that God gave everybody a certain lifeline, including tasks and hardships (predestination), along with the free will to decide how to navigate them. I have dedicated my life to protecting the rule of law and human rights on a secular basis, on the assumption that the essence and fundamental principle of human rights is equal dignity and the right to self-determination. As a martial artist, I completely endorse the spirituality of my jiujitsu school which can be summarised by the famous aphorism of its founding master, Soke István Kelemen: "We practice ju-jitsu for being able to die like the trees: standing.

Dignity

My case is about dignity. The word "dignity" appears in many international and regional texts and instruments. Although the Convention does not mention that concept, the Court has emphasised that respect for human dignity forms part of the very essence of the Convention.

For me, the final state of ALS described above does not constitute real life but merely a simple existence stripped of all dignity. A dignified life is one where an individual can set and pursue meaningful goals. This capability will be seriously curtailed and, finally, extinguished. However, an existence containing overwhelmingly or even exclusively pain and suffering, leaving no room for any other meritorious activity, is a life without purpose. Enduring suffering may serve a higher purpose – such as saving a beloved person or standing for high ideas. This is a meaningful choice of conscience and faith.

However, suffering merely for the sake of pain and existing solely for this purpose has no meaning at all in my belief. A dignified life shall mean more than just suffering, and it must at least entail the possibility to decide freely whether to accept it or not.

I do not wish to live a life that is reduced to observing and enduring my own physical and mental deterioration, along with the resulting suffering. If I had a choice, I would end or at least curtail this phase of my existence. Such a choice is not available to me under Hungarian law. However, I wish to follow my religious and secular beliefs and to die standing.

Right to self-determination

The Court already stated that an individual's right to decide when and how their life should end, provided they are in a position to freely form their own judgment and act accordingly, is one of the aspects of the right to respect private life within the meaning of Article 8 of the Convention. Consequently, the subject matter of the present application falls within the ambit of Article 8.

Regarding end-of-life decisions, there is a clear trend among Member States towards securing this right. Therefore, a complete ban with extraterritorial effects on end-of-life decisions for people suffering from lethal and incurable illnesses who possess full mental and decision-making capacity cannot be justified under Article 8 of the Convention. It is, in fact, the creation of a „negative obligation". It is not merely a Hungarian prohibition but a universal persecution order.

At this juncture, the prohibition of discrimination shall be raised. Hungarian law only allows treatment-related end-of-life decisions. This means that only persons whose health status requires lifesaving or life-sustaining treatment are allowed to refuse the treatment and thus shorten or terminate their lives.

Consequently, those – like myself– who "only" suffer from a dying process resulting in an undignified and inhuman situation causing enormous mental stress and psychological suffering without needing life-saving or sustaining treatment are denied the right to make end-of-life decisions. This is a form of indirect discrimination since the seemingly neutral legal framework puts me in a grossly disadvantageous situation compared to other individuals in similar or at least analogous dire health situations. The above-mentioned difference in treatment lacks objective and reasonable justification.

The right to decide at what point my life should end should not be made conditional solely on the basis of an individual's medical condition. It is not the illness but the individual who enjoys the protection of

the Convention. A life entirely confined to observing one's own mere existence and suffering without any possibility for meaningful activity is inhumanly undignified. This inhuman situation inflicts enormous mental and physical hardship. One has the right to decide to live through this pain. However, no one should be obligated to do so as it starkly contradicts the right to dignity and self-determination enshrined in Article 8 of the Convention. Consequently, the Member States have the obligation to provide individuals with the option to end their suffering by ending their lives with dignity.

As Hungarian law excludes certain categories of persons with incurable diseases, myself included, from making end-of-life decisions, the Member State fails to provide an adequate level of protection of my Article 8 rights, both independently and read in conjunction with Article 14 of the Convention.

Degrading treatment

The complete paralysation of my body puts me into a state of vulnerability and indignity, causing enormous mental suffering, including feelings of fear, anguish, and a sense of inferiority, not just in the eyes of others, but particularly from my own perspective. This situation reaches the threshold of the minimum level of severity.

I am fully aware that the development of my illness and its lethal consequences cannot be attributed to the Member State. However, any action I wish to take to free myself from the suffering and indignities of my condition can only be legally executed within the confines of the Hungarian legal framework. Consequently, by prohibiting end-of-life decisions, Hungary actively causes my suffering and bears Conventional responsibility for it.

By analogy, it may be argued that the Hungarian state imposes a de facto life sentence on me – imprisoned in my own body – without the prospect of release. In this profoundly dark phase of life, a glimmer of hope would be the allowance to decide the time and manner in which my life should end. The mere possibility of ending one's suffering should not be underestimated for its spirit-lifting power, which may provide the otherwise absent strength needed to endure the unspeakable hardships in question.

The complete denial of any end-of-life decisions, while simultaneously allowing other terminally ill patients to refuse life-saving and life-sustaining treatments, constitutes a violation of Article 14 of the Convention, read in conjunction with Article 3 for the same reasons addressed under Article 8 in detail.

Choosing freely my religious and secular beliefs

Ending my life with dignity for me is the manifestation of the core element both of my religious and secular worldview and belief. As I wrote in the introduction, I firmly believe that God has given each individual a certain lifeline, complete with tasks, challenges, and the free will to decide how to navigate them. As a lawyer, I have dedicated my life to protecting various facets of self-determination flowing from the principle of equal dignity. As a martial artist, I am devoted to fighting for noble causes in a dignified manner. Therefore, the complete ban on end-of-life decisions falls under the ambit of and constitutes an interference with my Article 9 rights.

Even assuming that the restriction in question follows the legitimate aim of the protection of the health or rights of others, it is not proportionate to these allegedly legitimate aims. Granting me the freedom to end my life with dignity would not infringe upon the rights of other individuals, in particular, the freedom of religion and conscience. The reason is simple: the freedom to make end-of-life decisions by no means imposes an obligation on anybody.

Moreover, other individuals' rights under Articles 2 and 3 are not endangered either. It is clear that robust safeguards must be established in this regard. However, this is a feasible task for lawmakers. The Court has examined the compatibility of such legal frameworks with the Convention on numerous occasions and found the safeguards to be sufficient.

In light of the above considerations, it cannot be stated that Hungary has chosen the least restrictive measures, and no other means exist capable of achieving the same end. This results in the violation of my rights under Article 9.

Moreover, denying me even the possibility of refusing life-saving and life-sustaining treatments, while providing this possibility to other terminally ill patients, constitutes a breach of Article 14 of the Convention read in conjunction with Article 9. This is for the same reasons addressed under Article 8.

Seneca

I would like to conclude with the thoughts of the ancient Roman philosopher Seneca, in the hope of starting a meaningful and serious public debate on this subject:

"Only a weak and idle man chooses death on account of pain, but only a fool lives for the sake of suffering."

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The Court, granting my request for priority, will hold a public hearing on 28 November 2023. A press release from the Court can be accessed here.

On 17 October, the government submitted its observations. The observations can be found here.

ABOUT THE AUTHOR

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