BIHR Briefing: Human Rights Law and Assisted Dying/Suicide

18th November 2024
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>
> – European Court of Human Rights: Lambert & Others v France

ABOUT THE BRITISH INSTITUTE OF HUMAN RIGHTS

The British Institute of Human Rights (BIHR) is a charity working in communities across the UK to enable positive change through the practical use of human rights law. We work with people to provide the information they need to benefit from their rights; with community groups to advocate for social justice using human rights standards; and with staff across local and national public bodies and services to equip them to make rights-respecting decisions. This enables us to provide policy analysis which is based both on human rights law, and people's experiences of their human rights.

A significant amount of BIHR's work is in the health, care and social work sectors. We support several thousand people each year, who both receive and provide services, including frontline doctors, nurses and healthcare professionals, senior managers, leaders, commissioners and regulators. One issue we have extensive experience of, supporting both healthcare staff and people in need of care and treatment, is how the right to life in human rights law works and interacts with other human rights focused on dignity, autonomy, and non-discrimination.

ABOUT THIS BRIEFING

This briefing has been prepared in advance of the second reading of the Terminally Ill Adults (End of Life) Bill in the House of Commons in November 2024. There is

currently a significant amount of discussion about the law surrounding the issues raised in this Bill, including the practical application and reach of human rights laws and duties. Rather than setting out recommendations about the Bill, this briefing is intended to provide parliamentarians (and the public) with an overview of existing UK human rights law related to the issue of assisted dying/suicide.*

We would usually provide a summary of key points, but it is important to recognise the law here is nuanced, and full considerations of the human rights implications are needed. Therefore below we set out:

1) The Human Rights Act and European Convention on Human Rights
2) Key human rights: the rights and legal duties associated with these, including reach of positive or negative obligations to act or not intervene, and balancing competing rights:
    a. Absolute and non-absolute human rights and balancing
    b. Absolute right: The right to life
    c. Absolute right: The right to be free from inhuman or degrading treatment
    d. Reconciling absolute rights
    e. Non-absolute right: The right to private life, including autonomy
    f. Conjunctive right: The right to be free from discrimination
3) Relevant case law:
    a. Assisted suicide in the UK: Diane's story (Pretty v UK)
    b. Assisted suicide in UK courts: Noel's story (Conway v Secretary of State for Justice)
    c. Physician-assisted dying: G.T.'s story (Mortier v Belgium)
    d. Differential ability to end own life: Daniel's story (Daniel Karsai v Hungary)
4) Human rights accountability in law-making

* We note that there are a range of different terms used on this space, often with contested meanings. We use the term assisted dying/suicide throughout this briefing. When discussing legal cases, we use the terminology used by the court.

1) THE HUMAN RIGHTS ACT & EUROPEAN CONVENTION ON HUMAN RIGHTS

The Human Rights Act (HRA) brings 16 rights from the Convention (ECHR) into UK law. The HRA sets out domestic duties for how the State (including national and local government, the courts and public services such as the NHS) must respect,

protect and fulfil people's human rights. Below we set out four of the key human rights relevant to assisted dying/suicide and how far the legal duties reach.*

As a party to the ECHR, the UK is subject to the European Court of Human Rights (ECtHR). The ECtHR has placed great emphasis on the margin of appreciation on the issue of assisted dying/suicide, recognising that different countries have different understandings on certain issues and so have scope to make decisions about how rights apply on those matters in their country. This summer, in the case of Daniel Karsai v. Hungary (2024), the ECtHR discussed the variation of approaches of Member States of the Council of Europe. Whilst some States permit physician-assisted dying, the majority do not permit assisted dying/suicide, with criminal law penalties for such actions.

Under Article 46, ECHR Member States have an international legal obligation to implement judgments of the ECtHR involving their country. One of the key cases on assisted dying/suicide involved the UK: Pretty v UK (2346/02), which we set out below. This made it clear that whilst a range of human rights may be engaged where assisted dying/suicide is not part of a country's legal system, the positive obligations to protect these rights do not reach so far as to require a country to implement such a system.

However, the ECtHR has been clear in cases involving countries that do have a system of assisted dying/suicide, human rights law will be relevant to its implementation: "in order to be compatible with [the human right to life], the decriminalisation of euthanasia has to be accompanied by the provision of appropriate and adequate safeguards to prevent abuse and thus ensure respect for the right to life." (Mortier v Belgium (78017/17)) Therefore, should the UK Parliament decide to implement a system of assisted dying/suicide, it would be subject to the legal duties to implement it in a way that supported human rights, and open to challenge in the same way as other law.

* Other human rights may also be engaged; find more information about all 16 human rights in the UK's Human Rights Act on the BIHR website.

2) KEY HUMAN RIGHTS

a) Absolute and non-absolute human rights and balancing

When making decisions that impact human rights, it is important to understand how they work, including whether and how they can be restricted.

Human rights belong to each person all of the time. Some can be restricted in specified circumstances; these are known as "non-absolute" rights. Human rights that can never be restricted are known as "absolute" rights.

This means that while a non-absolute right might be restricted if necessary to uphold an absolute right, the same is not true in reverse; an absolute right cannot be restricted to uphold a non-absolute right. For example:

- the State can restrict the right to private life, including autonomy and choice (non-absolute) to uphold the right to life (absolute right).
- the State cannot restrict the right to life (absolute right) to uphold the right to private life (non-absolute).

b) Absolute right: The right to life (Article 2)

This is an **absolute** right[1], meaning everyone's life must be protected in law and through the actions and decisions of the State, including national and local public authorities.

Public authorities have a duty to:

- **Respect** this right: i.e. not to intentionally take away life. This is known as the negative duty.
- **Protect** this right: i.e. to take proactive steps to protect life. This is known as the positive duty. This is about both:
    a) having the legal framework to protect against threats to life from both the State/public officials and private individuals* and
    b) protecting an individual's life when the State knows (or ought to know) they know their life is at real and immediate risk.
- **Fulfil** this right: i.e. investigate when public officials may have been involved in a death or failed to act. This is known as the procedural duty.

The ECtHR has been clear that the right to life does not include a right to die (see Diane's story below). In fact, States have a duty to protect people from taking their own lives **if** the decision is not made freely and with full understanding. However, the ECtHR has also said the right to life "cannot be interpreted as per se prohibiting the conditional decriminalisation of euthanasia."

[1] There are 4 situations where a state actor's actions resulting in death will not be considered a deprivation of the right to life. These are strictly limited and focus on police and armed forces, not health and social care situations.

*This could include where another private person assists someone to take their life, and here states will need to be mindful of consent and choice, as covered by the right to respect for private life in Article 8 (see below).

Assisted dying / suicide compared to ceasing life-sustaining treatments

UK courts have differentiated between "external violation" of life (i.e. causing death) and "the duty to provide humane care and assistance" (i.e. preventing death e.g. by providing life-sustaining treatment).

UK courts have been clear that "a mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death". This means that if an adult patient has capacity to make decisions about their treatment and refuses to consent to life-support treatment, doctors must respect this; "to this extent, the principle of the sanctity of human life must yield to the principle of self-determination".

Where a patient doesn't have capacity to make decisions about their care, including life-support treatment, the decision about whether to continue treatment must be made in their best interests. UK courts have confirmed that "the duty to provide care — for example, to provide medical treatment — ceases when such treatment can serve no humane purpose. In cases when further treatment can prolong the life of the patient only for a short period and at the cost of great pain and suffering, the doctor is under no obligation to continue."

In a recent case concerning Hungary, the ECtHR said it was not necessary to decide if people with terminal illnesses who can end their lives by refusing treatment are in a substantively different position to those who can only hasten their death through assisted dying. In any event, the State can objectively and reasonably justify treating them differently because the right to refuse medical treatment is "intrinsically linked to the right to free and informed consent, rather than to a right to be assisted in dying."

Similarly, UK courts have differentiated between medication that is given to reduce pain, which may have the side effect of hastening death, and medication given for the primary purpose of hastening death, saying that under current law, while the former will often be justified, the latter can never be.

c) Absolute right: The right to be free from inhuman or degrading treatment (Article 3)

This is an **absolute** right, meaning the State cannot restrict this right for any reason, whether by their direct actions or failures to act.

Public authorities have a duty to:

- **Respect** this right: i.e. not to treat someone in an inhuman or degrading way. This is known as the negative duty.
- **Protect** this right: i.e. to take proactive steps to prevent someone being treated an inhuman or degrading way. This is known as the positive duty. The ECtHR has been clear that this does not include an obligation to "sanction actions intended to terminate life." (Pretty v UK, below)
- **Fulfil** this right: i.e. investigate if someone has been treated in an inhuman or degrading way and take steps to stop it happening again. This is known as the procedural duty.

There is no list of what constitutes "inhuman and degrading treatment" because the law recognises that different treatment will impact different people differently. To determine if treatment is inhuman and degrading, decision-makers must consider:

- **Objective element:** does it reach a minimum level of serious ill treatment? This involves looking at the duration of the treatment; the mental and physical effects on a person; the impact given a person's sex, age and their physical and mental health; and whether harm was caused on purpose.

- **Subjective element:** what is the purpose or motivation of the treatment (though intent to cause harm is not necessary; it is the impact/result that is the focus)? What is the context it takes place in, including atmospheres of heightened tensions and emotions? Is the person in a vulnerable situation?

In broad terms, inhuman and degrading treatment is treatment which:
makes someone very frightened or worried;

- causes them a lot of pain; and/or
- makes them feel worthless or hopeless.

This can include:

- "suffering which flows from naturally occurring illness" **if** it is or could be exacerbated by actions of public authorities, for example through a failure to provide palliative care. As noted, this does not mean there is a legal duty to provide for assisted dying under human rights law.
- treatment caused by non-public authorities, such as abuse from a family member, which the authorities have failed to protect the person from.

d) Reconciling absolute rights

The right to life and the right to be free from inhuman or degrading treatment are both absolute human rights. This means that neither of them can lawfully be interfered with by the State and it' public authorities. However, sometimes circumstances will arise when these two rights seem to conflict or compete.

The ECtHR has said that cases with a conflict between the right to life and the right to be free from inhuman or degrading treatment are "not solved by the Convention itself". To find a solution, it has to look at the laws in the country and consider whether the public body acted "solely in the best interests" of the person they were supporting. The ECtHR has said that:

> **"in the context of the State's positive obligations, when addressing complex scientific, legal and ethical issues concerning in particular the beginning or the end of life, and in the absence of consensus among the member States, the Court has recognised that the latter have a certain margin of appreciation [flexibility to decide how best to protect human rights in their own laws]... However, this margin of appreciation is not unlimited".**
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> – European Court of Human Rights: Lambert & Others v France

In the past, UK courts have differentiated between "external violation" of life (i.e. causing death) and "the duty to provide humane care and assistance" (i.e. preventing death e.g. by providing life-sustaining treatment). In a 1993 case, the House of Lords (then the highest court in the UK), acknowledged that "at the moment, English law [gives] priority to the [prohibition on causing death]" but said it was not the time or place to debate whether another position could be taken instead because that case was not about euthanasia. This means that, as the law stands, the right to life will not always be breached in cases where life-sustaining treatment is withdrawn – particularly where it is stopped to prevent someone experience inhuman or degrading treatment.

On the other hand, courts have also said "as a general rule, a measure which is [in a patient's best interests on the basis of] therapeutic necessity cannot be regarded as inhuman or degrading." This means that treatment that is in the best interests of a person and medically necessary will not breach the right to be free from inhuman or degrading treatment.

e) Non-absolute human rights: The right to private life, including autonomy (Article 8)

This is a **non-absolute** right. Any interference must meet the three-stage test that shows it is: (1) lawful (permitted by the law); (2) for a legitimate aim (set out in the right itself e.g. to protect the person or wider community); and (3) a proportionate means to achieve the legitimate aim (the least restrictive option to do this).

This right protects each person's autonomy, wellbeing and ability to be involved in decisions that impact our lives. The application of this right to people's lives will be specific to their circumstances. It clearly applies to involvement in decision-making about healthcare and treatment.

In relation to ending one's own life, the ECtHR has said "an individual's 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, is one of the aspects of the right to respect for private life".

Public authorities have a duty to:

- **Respect** this right: i.e. not interfere with someone's private life unless it is lawful, legitimate and proportionate to do so. This is known as the negative duty.
- **Protect** this right: i.e. to take reasonable steps prevent interference with someone's private life that is not lawful, legitimate and proportionate. This is known as the positive duty.
- **Fulfil:** i.e. investigate when someone has had their private life interfered with in a way that is not lawful, legitimate and proportionate, and take steps to stop it happening again. This is known as the procedural duty.

There is a strong presumption in favour of upholding people's wishes; consent and mental capacity to make decisions are both relevant to this right. However, this is not an absolute right, and so if the three-stage test noted above can be met by the State/public authority, then autonomy and choice may be restricted.

As noted above, when a non-absolute right such as this competes with an absolute right, such as the right to life, the absolute right takes precedence.

e) Conjunctive right: The right to be free from discrimination (Article 14)

This right protects equal enjoyment of other human rights. It is often referred to as a "piggy-back right" (or conjunctive) because it can only be raised in connection with another human right, like Articles 2, 3 or 8. The other right does not have to be breached, just engaged, in order to raise an Article 14 discrimination point.

Article 14 provides both a list of grounds for which discrimination is prohibited and ends with "or any other status". Clarification about which statuses are covered has been carefully developed through legal cases, enabling human rights protections to develop in line with societal development. This is known as the living instrument principle. **Characteristics such as health status, disability, and age have been established as protected statuses under Article 14.**

A difference in treatment will not be discriminatory, and therefore not prohibited by Article 14, if it can be reasonably and objectively justified by the State/public authority. This means it can be shown to have a legitimate aim, there is a link between the measure being taken and the aim, and the measure is proportionate, i.e. it is the least restrictive option which strikes a fair balance between the aim pursued and the rights of people impacted. Consideration of which rights are involved, whether they are absolute or non-absolute, and the balancing between competing rights will be important factors.

3) KEY HUMAN RIGHTS LEGAL CASES:

a) Assisted suicide in the UK at the ECtHR: Diane's story

In 1999, Diane Pretty was diagnosed with Motor Neurone Disease – a condition for which there is no cure, and which gets worse over time. By 2002, she was paralysed from the neck down and doctors said they expected she would only live for a few more months. Diane had full capacity to make decisions about her care and wanted her husband to help her end her own life.

UK authorities refused to confirm they would not prosecute her husband for doing so. Diane took a case first to UK courts and then to the European Court of Human Rights (ECtHR), saying this breached her human rights to life (Article 2); to be free

from inhuman or degrading treatment (Article 3); to private life (Article 8); to freedom of thought (Article 9); and to be free from discrimination (Article 14).

However, the ECtHR said that the right to life does not include a right to die and that the duty on states to protect people from inhuman or degrading treatment doesn't go as far as to include an obligation to allow actions intended to end their life. The ECtHR acknowledged that Diane's right to private life was interfered with, but said this was justified as a way of safeguarding life, particularly for people in vulnerable positions. It also said that Diane's beliefs about assisted suicide were better protected by the right to private life than the right to freedom of belief. Finally, the ECtHR said that the refusal to treat Diane differently to those able to end their lives on their own by allowing her husband to help her did not amount to discrimination because it was justifiable given the safeguarding risks.

The ECtHR ultimately decided that there was no violation of Diane's human rights. Diane passed away in a hospice the following month.

ECtHR: Pretty v UK (2346/02)

b) Assisted suicide in UK courts: Noel's story

Noel had Motor Neurone Disease and required non-invasive ventilation (where a machine is used to help someone breathe) for 23 hours a day. Doctors expected he would live for six months or less.

Noel wanted a doctor to prescribe him medication which he could take to end his life. He said he did not believe other, unsupervised methods of suicide were "humane or acceptable" and said they would be more distressing for his loved ones. Noel acknowledged that he could choose to refuse non-invasive ventilation, which would bring about his death, but said this would not be dignified and he did not know how long it would take or how it would feel. He wanted a doctor's assistance to die "in a way that is swift and dignified".

The UK's Suicide Act 1961 says it is a criminal offence for anyone, including a doctor, to assist someone to carry out or attempt suicide. Noel asked UK courts to declare the law incompatible with human rights as he said the blanket ban on assisted suicide was a disproportionate interference with his Article 8 right to private life. A declaration of incompatibility under Section 4 of the HRA is a statement that a court does not believe a piece of law can possibly be interpreted in a way that respects human rights; it does not change the law as only Parliament can do this. However, UK courts said the law had three legitimate aims which were enough to justify the interference with Noel's right to private life: protection of "the weak and

vulnerable"; protecting the sanctity of life as a moral principle; and promotion of trust and confidence between doctor and patient. The courts also did not agree with Noel's suggestion that there was a less restrictive way of meeting these aims, for example through an alternative process where the High Court has to authorise assisted suicide in individual cases. The courts were not convinced this would be a complete safeguard to protect people who felt pressured to end their lives.
The courts did reject arguments from the UK Government that they had to make the same decision as the courts in Pretty v UK (Diane's story, explored above). They said they had to consider the facts in the individual case. As part of this consideration, the courts recognised the importance of respecting Parliament's views on assisted suicide, demonstrated by the laws it had chosen to pass or not. This was an important factor in assessing whether the ban on assisted suicide was proportionate. Ultimately, the UK Court of Appeal said the Suicide Act is not incompatible with human rights. It also said,

> "**there is a great deal of conflicting evidence as to the consequences of legalising assisted dying about which reasonable people clearly do reasonably disagree** and which the court, by contrast with Parliament, is not well placed to assess".

It noted that the court could not carry out public consultations or engage with its own experts. Noel asked for permission to appeal to the Supreme Court, but the Supreme Court said there was not a high enough likelihood of him winning his case to justify it. Noel passed away in 2021 after deciding with his family to remove his ventilator.

UK Supreme Court: Conway v Secretary of State for Justice [2018] EWCA Civ 1431

c) Physician-assisted dying: G.T's story

G.T. had been diagnosed with chronic depression for around 40 years. She was being seen by a psychiatrist but said she had "lost faith in psychiatry" and wanted to undergo euthanasia to end her "intense suffering". The Belgian Euthanasia Act says it will not be a criminal offence for a doctor to perform euthanasia if certain criteria are met. In G.T.'s case, these criteria were considered to be met and, in 2012, G.T. underwent euthanasia in a public hospital.

G.T.'s son later brought a case to the European Court of Human Rights, arguing that her right to life had been breached. He said that the law in Belgium did not adequately protect people in a vulnerable position.

The ECtHR said that G.T.'s case concerned the positive obligation of the state to protect life (rather than the negative obligation not to take it) and the state's duty to have and comply with an adequate legal framework. This is because the law said that a doctor is not committing a crime by performing euthanasia in accordance with the specified requirements. It stopped the state from stepping in with criminal sanctions.

The ECtHR decided that there was no breach of the positive obligation as there were adequate safeguards in the Belgian law (and considered it particularly important that there were additional safeguards in cases concerning mental suffering and where death will not otherwise occur in the short term).

ECtHR: Mortier v Belgium (78017/17)

d) Differential ability to end own life: Daniel's story

Daniel Karsai had advanced amyotrophic lateral sclerosis (a type of Motor Neurone Disease with no known cure). He wanted to be able to decide when and how to die before his illness reached a stage he found unbearable. He said he would need assistance, but under Hungarian law (similarly to UK law), anyone who assisted him would risk prosecution – including if they helped him to travel to a country which allowed physician-assisted dying. Daniel said this meant that once he reached a point where his mobility was so reduced that he could not end his own life unassisted, he would have to wait until he required life-sustaining treatment and then refuse it in order to die.

Daniel and organisations that intervened in the case raised similar claims to Diane in the case above. This was that he would not be able to exercise his Article 8 rights to autonomy in the same way as others (either those who could travel abroad to receive physician-assisted dying or those reliant on life-sustaining treatment who could refuse it), and this was discriminatory under Article 14.

The ECtHR found neither human right was breached in this situation. It did note the need for "a fundamentally humane approach by the authorities to the management of these situations, an approach which must necessarily include palliative care that is guided by compassion and high medical standards." On the wider issue of assisted dying / suicide the ECtHR said,

> **"the wider social implications and the risks of abuse and error entailed in the provision of [physician assisted dying] weigh heavily in the balance when assessing if and how to accommodate the interests of those who**

> **wish to be assisted in dying … States enjoy a considerable margin of appreciation in deciding how that balance should be struck."**

Daniel passed away in 2024.

ECtHR: Daniel Karsai v. Hungary (2024)

4) HUMAN RIGHTS ACCOUNTABILITY IN LAW-MAKING

The HRA contains important accountability mechanisms for law-making. Section 19(1) of the HRA requires a Government Minister, before second reading, to make a statement about its compatibility with the human rights in the Act (drawn from the ECHR).

Parliament's Joint Committee on Human Rights has previously noted the importance of this statement and process behind it, calling it "a vital tool in understanding the Government's intention and in assisting Parliament's scrutiny of Bills for human rights compatibility, as well as improving transparency." The JCHR further noted this Section 19 statement comes alongside a written assessment from the Minister on human rights compatibility of bills, either within the Explanatory Notes accompanying the Bill, or in a separate ECHR Memorandum. This is published on the Parliamentary website alongside other information about the Bill.

The section 19 statement and accompanying detailed human rights memorandum is key part of the process to enable parliamentarians to scrutinise any proposed laws from the Government. This process helps ensure the human rights implications and mitigated any risks; and highlight where this has not been done so law makers can scrutinise how these gaps will be addressed.

However, this process and the vital human rights scrutiny tools it provides parliamentarians do not exist with Private Members' Bills, even when such bills may have significant implications for people's human rights, and the ability of the state and its public bodies and services to secure those rights.

Additionally, we note that Parliament's Joint Committee on Human Rights, which has an important role to play in parliamentary scrutiny, is not yet fully reconstituted following the General Election (at the time of writing).

This briefing is for information purposes only. It is not intended be used as, legal advice or guidance. The law referred to in this briefing is up to date at the point of publication in November 2024.

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