Terminally Ill Adults (End of Life) Second Reading Briefing

The differences between treatment refusal and assisted death: synopsis and summary of case law

Introduction

This briefing is prepared by Professor Gareth Owen, Professor Alex Ruck Keene KC (Hon) and Professor Katherine Sleeman, all members of the Complex Life and Death Decisions Group (CLADD). CLADD is a King's College London based group with expertise in psychiatry, palliative care, bioethics, public policy and law. We are neutral as to whether assisted dying / assisted suicide should be made law. We are committed to the principle that it is for Parliament to decide. We are equally committed, however, to the principle that any law that is passed must function as a workable framework which protects the interests of patients, professionals and wider society.

In our broader briefing, we set out why the Terminally Ill Adults (End of Life) Bill ('the TIA Bill') as it stands is not good law. We have prepared a version of the Bill which remedies the key problems that we identify in that briefing.

This briefing looks in more detail at the issue of treatment refusal (in particular refusal of life sustaining treatment), and explains why, from a clinical and legal perspective, withdrawal or withholding such treatment following a refusal is different to the provision of assistance under the Bill.

Treatment refusal vs assisted dying: the clinical perspective

The treatment framework starts with the doctor considering what treatment(s) are clinically appropriate to address the patient's condition. It moves on to the doctor proposing the treatment(s) to the person, highlighting the risks and benefits of those treatment(s) by reference to the person's own condition and situation. It then concludes with the patient deciding whether to have any of those treatments – or none.[1]

There are factual and experiential matters to talk about regarding both having treatment and not having treatment. The patient may have had experience of the treatment(s) in question but also of not having it and be able to compare and contrast. The doctor will be able to give information about the treatment and not having the treatment including the reasonably foreseeable consequences of death. Here there should be no question of the doctor intending death.

In the TIA Bill the context is not one of treatment as conventionally understood: the administration of lethal substances is not treatment for terminal illness (see further our briefing here). Rather, it is best understood as a new context altogether: of a societally legitimated response to a particular conception of patient autonomy.

Within this very different context, the decision for the patient is a very different one. It is not whether or not to accept treatment proposed by the doctor, but rather a decision by the patient about ending their own life and, in turn, seeking assistance from others in doing so.

Notwithstanding information about the procedures of assisted dying, the relevant information for this decision concerns living compared to not living and is *essentially* existential. The patient and the doctor can exchange relevant facts and experiences about living but neither of them are able to exchange facts (at least not uncontroversial ones) about not living. This is because not living, unlike refusing treatment,

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[1] The steps are summarised in *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 and *McCulloch v Forth Valley Health Board* [2023] UKSC 26.

is not an event in life. They will be able to have a conversation about ending life but this would have to be a different kind of conversation to a conversation about treatment (including refusing treatment).

If a treatment refusal results in death, the death arises 'naturally' from biological/disease processes (or, in other words, from *non-interference* with them). In contrast, a death arising as a result of provision of assistance under the Bill is 'non-natural', as a result of self-administration of lethal substances (i.e., from *interference* with biological/disease processes).

Treatment refusal vs assisted dying: the legal perspective

The courts have laid down a series of important propositions regarding treatment refusal, including its relationship to assisted dying / assisted suicide. The key propositions can be summarised as follows:

1. The law respects a person's bodily integrity by requiring consent to treatment. It is that consent which transforms an assault into a lawful act. Absent special circumstances, refusal therefore stands as an absolute bar to treatment, i.e. a shield against violation of bodily sovereignty.

2. A doctor has to consider whether a person's refusal of life-sustaining treatment is capacitous, informed and free. If it is, the doctor is required to follow that refusal. That might require actions that result in death (for instance turning off a ventilator) but in legal terms, they are respecting a refusal of treatment, as opposed to taking active steps with the intention of bringing about the person's death.

3. A request to a doctor to deploy an intervention to be used with the intention of causing death (as envisaged by the TIA Bill) could not be lawfully followed by a doctor in English law, as the doctor would be committing an offence under s.2(1) Suicide Act 1961. That position is one that the courts have consistently held to be compatible with the European Convention on Human Rights.

4. The fact that a person reliant on life-sustaining treatment may appear to be able to exercise a 'right to die' – by refusing such treatment – more effectively than a person who is not currently reliant on such treatment is justified, as the two categories of people are in different positions.

5. Whilst the European Convention on Human Rights enshrines a right for a capacitous person to choose the time and manner of one's death (whether by taking one's own life or by refusing treatment) it does not enshrine a right to be provided with assistance to die by a third party.

6. For the avoidance of doubt (as the TIA Bill is only relevant for those with capacity), even for those who lack capacity to make decisions about life-sustaining treatment, the law maintains a distinction between acting upon a known desire to refuse treatment, and authorising the administration of a lethal substance. The former is lawful; the latter unlawful, even if it is understood that the person would have wished it.

In the appendix to this document, we set out the caselaw supporting each of these propositions. Some of the cases may well be well known to Peers; others, especially the ECtHR caselaw from last year, may not.

Against this backdrop, legal and clinical perspectives in England and Wales currently align: withdrawal of life-sustaining treatment is permissible because it is the underlying condition from which the person is suffering which causes death, rather than the withdrawal itself. But acceding to a request for provision or administration of a lethal substance is both clinically and legally impermissible as doctors cannot, themselves, cause death.

The TIA Bill would therefore require a fundamental change to legal as well as clinical perspectives – in other words a paradigm shift.

Whether the paradigm should be shifted is a matter for Parliament - the purpose of this briefing is simply to make clear that paradigm shift is what is under consideration.

Further information

For more detail about any of the matters set out above, please contact alexander.ruck_keene@kcl.ac.uk.

More information about CLADD can be found here.

Alex Ruck Keene maintains a resources page on the TIA Bill here.

Appendix: relevant caselaw

This appendix sets out the extracts from the relevant domestic caselaw and that of the European Court of Human Rights (ECtHR). The cases all concern adults, rather than children, as the Bill under consideration by Parliament only relates to adults.

Proposition 1: The law respects a person's bodily integrity by requiring consent to treatment. It is that consent which transforms an assault into a lawful act. Absent special circumstances,[2] refusal therefore stands as a bar to treatment – a shield against violation of bodily sovereignty.

Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 (Baroness Hale):

> *19.* […] *Generally it is the patient's consent which makes invasive medical treatment lawful. It is not lawful to treat a patient who has capacity and refuses that treatment.*

Kings College Hospital NHS Foundation Trust v C & Anor [2015] EWCOP 80 (Macdonald J):

> 1. *A capacitous individual is entitled to decide whether or not to accept medical treatment. The right to refuse treatment extends to declining treatment that would, if administered, save the life of the patient. In Re T (Adult: Refusal of Treatment) [1993] Fam 95 at 102 Lord Donaldson observed that:*
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> > *"An adult patient who…suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered… This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent."*
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> 2. *This position reflects the value that society places on personal autonomy in matters of medical treatment and the very long established right of the patient to choose to accept or refuse medical treatment from his or her doctor (voluntas aegroti suprema lex). Over his or her own body and mind, the individual is sovereign (John Stuart Mill, On Liberty, 1859).*

At the European Court of Human Rights level, see the Grand Chamber decision in *Pindo Mulla v Spain* [2024] ECHR 753, a recent decision in which the Strasbourg court looked in detail at the (potentially) competing obligations of States to secure life under Article 2 ECHR, and to respect personal autonomy under Article 8 ECHR:

> *138. In the sphere of health care, respect for personal autonomy is a general and fundamental principle. It is safeguarded notably by the universally recognised rule of free and informed consent. The legally competent patient who has been duly informed about his or her health condition and the available treatments, as well as the implications if no treatment is accepted, has the right to freely decide whether to give consent to treatment or to withhold it (see Article 5 of the Oviedo Convention and paragraphs 34-35 of its explanatory report, Article 3 of*

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[2] Most obviously where a person is detained under the Mental Health Act 1983, when Part 4 Mental Health Act 1983 provides authority to provide medical treatment for mental disorder even in the face of the person's capacitous refusal.

> *the Charter of Fundamental Rights of the European Union, and Article 6 of the Universal Declaration on Bioethics and Human rights, all quoted above).* […]
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> *139. As for the refusal of treatment, in Pretty the Court stated that while this might lead to a fatal outcome, the imposition of medical treatment without the consent of a mentally competent adult patient would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Article 8 § 1 of the Convention (at § 63; see also Lambert and Others, cited above, § 180).*

Proposition 2. A doctor has to consider whether a person's refusal of life-sustaining treatment is capacitous, informed and free. If it is, the doctor is required to follow that refusal. That might require actions that result in death (for instance turning off a ventilator) but in legal terms, they are respecting a refusal of treatment, as opposed to taking active steps with the intention of bringing about the person's death.

The Grand Chamber decision of the European Court of Human Rights has recently reaffirmed the importance of identifying that the refusal of life-sustaining treatment is informed and capacitous; see *Pindo Mulla v Spain* [2024] ECHR 753:

> *143. The Court has also adverted to the importance of establishing that the patient still has the capacity to take such a decision, if there are circumstances that may give rise to doubt in this regard. The case of Arskaya v. Ukraine (no. 45076/05, 5 December 2013) involved a complaint under Article 2 about the failure to protect the life of the applicant's adult son, who died following his persistent refusal of the necessary treatment for a serious respiratory illness. At the time, the deceased had shown signs of mental disorder, but his refusals had nevertheless been taken at face value by the doctors treating him. The Court considered that, from the standpoint of Article 2, a clear stance should have been taken by the medical staff regarding the validity of the deceased's refusal of life-saving treatment so as to remove the risk that that decision was made without a full understanding of its implications. It pointed to the need for sufficient guarantees in this respect, and for a regulatory framework which adequately ensures that, where necessary, a patient's decision-making capacity can be promptly and objectively established via a fair and proper procedure (see Arskaya, cited above, § 88).*

On the refusal being free, see *Re T (Adult: Refusal of Treatment)* [1992] EWCA Civ 18 (Lord Donaldson MR):[3]

> *In some cases doctors will not only have to consider the capacity of the patient to refuse treatment, but also whether the refusal has been vitiated because it resulted not from the patient's will, but from the will of others. It matters not that those others sought, however strongly, to persuade the patient to refuse, so long is in the end the refusal represented the patient's independent decision. If, however, his will was overborne, the refusal will not have represented a true decision. In this context the relationship of the persuader to the patient - for example, spouse, parents or*

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[3] The case also emphasised, at a domestic level, the importance of the refusal being capacitous, as did *Re B*, set out below.

> *religious adviser - will be important, because some relationships more readily lend themselves to overbearing the patient's independent will than do others.*

On doctors then being required to give effect to the patient's wishes if these criteria are met, see *In re B (Consent to Treatment – Capacity)* [2002] 1 FLR 1090:

> *if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so.*

See also, more recently, the *Kings College Hospital NHS Foundation Trust v C & Anor* [2015] EWCOP 80 noted above.

On how this step is then characterised, see Lord Goff in *Airedale NHS Trust v Bland* [1993] UKHL 17:

> *I agree that the doctor's conduct in discontinuing life support can properly be categorised as an omission. It is true that it may be difficult to describe what the doctor actually does as an omission, for example where he takes some positive step to bring the life support to an end. But discontinuation of life support is, for present purposes, no different from not initiating life support in the first place. In each case, the doctor is simply allowing his patient to die in the sense that he is desisting from taking a step which might, in certain circumstances, prevent his patient from dying as a result of his pre-existing condition; and as a matter of general principle an omission such as this will not be unlawful unless it constitutes a breach of duty to the patient.*

[Note: the *Bland* case concerned the situation where the person could not, themselves, make the request for life-sustaining treatment to be stopped because they lacked the capacity to do so (nor, indeed, was there any evidence as to what Anthony Bland's wishes might have been), but the analysis of the legal effect of 'not treating' applies equally to the position where a doctor is acting on the capacitous wish of a patient to have their life-sustaining treatment stopped].

Proposition 3: A request to a doctor to deploy an intervention to be used with the intention of causing death (as envisaged by the TIA Bill) could not be lawfully followed by a doctor in English law, as the doctor would be committing an offence under s.2(1) Suicide Act 1961. That position is one that the domestic courts have consistently held to be compatible with the European Convention on Human Rights.

Challenges to the ban on the provision of assistance with suicide contained s.2(1) Suicide Act 1961 have all failed in the English courts, the most recent substantive challenge failing in 2018 when the Supreme Court refused permission to Noel Conway to appeal the decision of the Court of Appeal in *R (Conway) v The Secretary of State for Justice & Ors* [2018] EWCA Civ 1431. Refusing permission,[4] Lady Hale, Lord Reed and Lord Kerr identified that the issues raised were of "*transcendent importance*" and involved "*arguable points of law*," but that Mr Conway's likelihood of securing a declaration that s.2(1) Suicide Act 1961 was incompatible with the European Convention on Human Rights was insufficient to warrant granting permission to appeal. The panel noted in evaluating the prospects of success:

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[4] The Supreme Court has recently updated its website, and the permission to appeal decision can no longer be found on it; this link, however, contains the relevant wording.

- *The long-standing common-law distinction between allowing death to occur and actively assisting death;*
- *The multiple policy reasons underpinning the current criminal prohibition, including protection of the vulnerable and maintenance of public ethics;*
- *The European Court of Human Rights' confirmation that national authorities have a wide margin of appreciation in the area.*

Proposition 4: The fact that a person reliant on life-sustaining treatment may appear to be able to exercise a 'right to die' – by refusing such treatment – more effectively than a person who is not currently reliant on such treatment is justified, as the two categories of people are in different positions.

An argument was run in *Karsai v Hungary* [2024] ECHR 516[5] that there was discrimination contrary to Article 8 ECHR read together with Article 14 ECHR inherent in a legal system which (as in England & Wales) accepted refusal of life-sustaining treatment but did not accept requests for assistance in dying. The Strasbourg court rejected this argument, the key passages being the following:

> *175. The Court notes that the right to refuse or request discontinuation of unwanted medical treatment is inherently connected to the right to free and informed consent to medical intervention, which is widely recognised and endorsed by the medical profession, and is also laid down in the Oviedo Convention (see paragraphs 35, 36, 41 and 56 above; see also Mayboroda v. Ukraine, no. 14709/07, § 52, 13 April 2023, and Reyes Jimenez v. Spain, no. 57020/18, §§ 29 and 30, 8 March 2022). This point has also been consistently reiterated by the Court with regard to situations where the refusal to accept a particular treatment might lead to a fatal outcome (see Pretty, cited above, § 63; V.C. v. Slovakia, no. 18968/07, § 105, ECHR 2011; and Jehovah's Witnesses of Moscow and Others v. Russia, no. 302/02, § 135, 10 June 2010). It must be acknowledged that the refusal or withdrawal of treatment in end-of-life situations is the subject of particular consideration or regulation because of the need to safeguard, inter alia, the right to life (see paragraphs 37, 38, 130 and 171 above); however, such refusal or withdrawal is intrinsically linked to the right to free and informed consent, rather than to a right to be assisted in dying.*
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> *176. The Court further notes that it has found it justified for Hungary to maintain an absolute ban on assisted suicide, on account, among other aspects, of: the risks of abuse involved in the provision of PAD* [physician assisted dying], *which may extend beyond those involved in RWI* [refusal or withdrawal of life-sustaining interventions] *(see paragraph 150 above); the potential broader social implications of PAD (see paragraph 149 above); the policy choices involved in its provision (see paragraphs 151, 157 and 161 above); and the considerable margin of appreciation afforded to the States in this respect (see paragraph 144 above). Similar cogent reasons exist under Article 14 for justifying the allegedly different treatment of those terminally ill patients who are dependent on life-sustaining treatment and those patients who are not, and who in consequence cannot hasten*

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[5] This is the most recent Strasbourg case on assisted dying, and includes both a review of the position in different European jurisdictions together with (unusually) evidence from two experts – one on palliative care, and one on ethics.

> *their death by refusing such treatment. The Court would note in this connection that, in contrast to the situation with regard to PAD, the majority of the member States allow RWI (see paragraph 59 above). Furthermore, as mentioned above, the right to refuse or withdraw consent to interventions in the health field is also recognised in the Oviedo Convention, which, in contrast, does not safeguard any interests with regard to PAD (see paragraphs 35 and 36 above). The Court therefore considers that the alleged difference in treatment of the above-mentioned two groups of terminally ill patients is objectively and reasonably justified.*

Proposition 5: Whilst the European Convention on Human Rights enshrines a right for a capacitous person to choose the time and manner of one's death (whether by taking one's own life or by refusing treatment) it does not enshrine a right to be provided with assistance to die by a third party.

In *Haas v Switzerland* [2011] ECHR 2422, the European Court of Human Rights held that:

> *51.* […] *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 within the meaning of Article 8 of the Convention.*

That the Convention does not go further to enshrine a 'right to die' was confirmed most recently by the European Court of Human Rights in *Mortier v Belgium* [2022] ECHR 764.

> *119. In particular, the Court has found that no right to die, whether at the hands of a third person or with the assistance of a public authority, can be derived from Article 2 (see Pretty v. the United Kingdom, no. 2346/02, § 40, ECHR 2002-III, and Lings v. Denmark, no. 15136/20, § 52, 12 April 2022).*

For completeness, we note that the court went on to say that:

> *138.* […] *the Court considers that, while it is not possible to derive a right to die from Article 2 of the Convention (see paragraph 119 above), the right to life enshrined in that provision cannot be interpreted as per se prohibiting the conditional decriminalisation of euthanasia.*

The court emphasised, however, that:

> *139. In order to be compatible with Article 2 of the Convention, 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.* […]

Proposition 6: For the avoidance of doubt (as the TIA Bill is only relevant for those with capacity), even for those who lack capacity to make decisions about life-sustaining treatment, the law maintains a distinction between acting upon a known desire to refuse treatment, and authorising the administration of a lethal substance. The former is lawful; the latter unlawful, even if it is understood that the person would have wished it.

The general position in relation to decision-making in respect of those lacking capacity to make their own decisions in relation to medical treatment in England & Wales is set down in *Aintree v James* by Baroness Hale thus:

> *22. […] the focus is on whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty towards the patient if they withhold or withdraw it.*
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> *45. Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.*

For an example of a detailed analysis of the application of *Aintree* to determine: (1) whether there was an identified desire on the part of the incapacitated person to refuse treatment; and (2) the consequences of such a desire, see *Briggs v Briggs* [2016] EWCOP 53. For more detail on decision-making in this context, and the weight placed on the person's identified wishes and feelings, see Alex Ruck Keene and Annabel Lee, Withdrawing life-sustaining treatment: a stock-take of the legal and ethical position' *Journal of Medical Ethics* 2019;45:794-799.

In *The Public Guardian v DA & Ors* [2018] EWCOP 26, Lord Justice Baker confirmed that an attorney under a Lasting Power of Attorney cannot be granted the power to ask for assistance in dying on behalf of a person lacking capacity to make decisions about health and welfare:

> *27. I agree with the combined view of the Public Guardian and the Official Solicitor that an instruction or preference in an LPA directing or expressing a wish that an attorney takes steps to bring about the donor's death is instructing or encouraging someone to commit an unlawful act and therefore ineffective.*

Baker LJ also emphasised (at paragraph 22) that this issue was different to the giving of authority to continue or refuse life-sustaining treatment, provided for under the Mental Capacity Act 2005; reflecting the distinction between stopping life-sustaining treatment and providing assistance in dying set out in propositions 2 and 3 above.

In *NHS North West London Integrated Care Board v Z & Anor* [2024] EWCOP 35 (T1), the argument was advanced that the incapacitated adult reliant on clinically assisted nutrition and hydration ('CANH') would wish "*a quick painless passing*," which could not be achieved by the withdrawal of

CANH alone.[6] Theis J, the Vice-President of the Court of Protection made clear at paragraph 71(7) that enabling Z to die swiftly (i.e. by endorsement of the provision of medication designed to bring about death) "*is not an option open to the court*." The court was therefore limited to considering whether the continuation of CANH was in Z's best interests.

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[6] The medical evidence being recorded at paragraph 71(6) thus: "[i]*f CANH is discontinued Z is likely to die within 1 - 3 weeks. Dr H considers it more likely to be a week. Dr Barry cautions that whilst these are the averages it can (unusually) be longer.to die within 1 - 3 weeks. Dr H considers it more likely to be a week. Dr Barry cautions that whilst these are the averages it can (unusually) be longer*."