INDEPENDENT HUMAN RIGHTS ACT REVIEW

A RESPONSE FROM MY DEATH, MY DECISION.

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About us

My Death, My Decision is a grassroots not-for-profit campaign group, which advocates for a change in the law to allow those who are terminally ill or incurably suffering the option of a legal, safe, and compassionate assisted death.

We were founded to represent the interests of those facing constant and unbearable suffering, at a time when no other right to die organisation would, and to advocate on their behalf to secure a lasting change in the law. We have quickly become one of the leading assisted dying organisations in England and Wales. We are advised by an expert medical group, are a founding member of the UK Assisted Dying Coalition, and at the forefront of social change: nearly 90% of the public now favours a change in the law to allow assisted dying for those who are incurably suffering or terminally ill.[1]

Our Response

This submission relates to the Review's second theme: the relationship between the courts, Government, and Parliament as engendered by the Human Rights Act 1998. It focuses on one particular human rights case: R(Nicklinson) v Ministry of Justice.[2] This is because a key suggestion arising from this questionnaire is whether declarations of incompatibility should become more routine remedies, in lieu of attempts to reinterpret legislation in a human rights compatible manner. Nicklinson underscores the dangers of adopting such an approach. In sum, we advise against amending the Act to make declarations of incompatibility a more customary remedy, and especially advise against it if this amendment were to come at the expense of the courts' current powers under section 3.

General View on the Human Rights Act 1998

Since its inception two decades ago, the Human Rights Act 1998 has proven itself to be a remarkably successful instrument for the protection of fundamental rights. It has enabled ordinary citizens to access freedoms that were once inaccessible,[3] articulate grievances that might otherwise become marginalised, and provided an important lens through which the exercise of public power has become imbued with a respect for human dignity, even in everyday situations far removed from courtrooms.

In the context of end-of-life decisions, the Act has been pivotal in enabling those who are terminally ill or incurably suffering, and who wish to end their life but are physically incapable of doing so without assistance – including Diane Pretty,[4] Debbie Purdy,[5] Tony Nicklinson,[6] the claimant known as Martin,[7] the claimant known as Omid T,[8] Phil Newby,[9] and Paul Lamb[10] –

1 My Death, My Decision, 'New research finds up to 93% of people consider assisted dying acceptable in at least some situations, even if rarely.' (2019). Accessible at: 'https://www.mydeath-mydecision.org.uk/wp-content/uploads/2019/03/Briefing-on-NatCen-assisted-dying-poll.pdf'
2 *R(Nicklinson) v Ministry of Justice UKSC 38*
3 *See Malone v Metropolitan Police Commissioner [1979] CH 344 as but one example relating to the right to privacy.*
4 *R(Pretty) v DPP [2001] UKHL 61; Pretty v United Kingdom (2002) 35 EHRR 1*
5 *R (Purdy) v DPP [2009] UKHL 45*
6 *Ibid no.2*
7 *Ibid*
8 *R (on the Application of T) v Ministry of Justice [2018] EWHC 2615*
9 *R(Newby) v Secretary of State for Justice[2019] EWHC 3118 (Admin)*
10 *R(Lamb) v Secretary of State for Justice [2019] 3606 (Admin)*

to challenge the legality of the UK's prohibition on assisted dying. It has also been central to the protection of basic freedoms, including the freedom to refuse life-sustaining treatment.[11] It has engendered public authorities, including the police, with an appreciation for rights that has enabled those considering an assisted death to be treated with respect, compassion, and dignity.[12] As well as bringing about a seismic change in the way our laws are enforced, by triggering the creation of clear and prospective prosecution guidelines on assisted dying.[13]

Although we believe it is a deplorable abuse of human rights that our current law prevents adults of sound mind, who are either terminally ill or incurably suffering, from being allowed to die with dignity on their own terms, we are confident these individuals would be left in a more precarious state without the protection of the Human Rights Act 1998.

We have a real concern that the technical focus of this review could pave the way for a wider erosion of the basic freedoms guaranteed by the Act. Therefore, we urge the Panel to ensure that the results of this review are squarely based upon upholding the Act's effectiveness, and guaranteeing the conditions necessary to protect people's basic rights.

Theme Two: Should any change be made to the framework established by sections 3 and 4 of the HRA?

We believe that the framework established by sections 3 and 4 of the Act strikes a practical balance between preserving parliamentary sovereignty, respecting the rule of law, and enabling the courts to provide an effective remedy for human rights abuses. We caution against proposals to increase the use of declarations of incompatibility, especially in situations where the courts would ordinarily seek to reinterpret legislation in a human rights compatible manner, since it risks leaving victims of punitive human rights violations without an effective remedy. A relevant case demonstrating such a risk is Nicklinson.

Nicklinson concerned a challenge against the UK's prohibition on assisted dying for violating Article 8 of the European Convention on Human Rights (ECHR) – the right to respect for a private life. The claim was brought by Tony Nicklinson (latterly Paul Lamb, after Tony starved himself to death and died of pneumonia), who suffered from locked-in syndrome and described his life as 'dull, miserable, demeaning, undignified and intolerable'.[14] He sought a declaration that the 1961 Suicide Act was incompatible with his human rights.

In the Supreme Court, there was a near-unanimous agreement that the ability to control the manner of one's own death engaged Article 8 of the ECHR and the Human Rights Act 1998.[15] However, there was a dramatic divergence of opinion on whether it would have been institutionally appropriate to issue a declaration of incompatibility, and whether such a declaration was appropriate in these circumstances. A minority of four judges – Lord Sumption, Lord Hughes, Lord Reed and Lord Clarke – held that issuing a declaration of incompatibility would not have been appropriate since it would have involved trespassing upon Parliament's exclusive domain. Whereas, a majority of five – Lord Neuberger, Lord Mance, Lord Wilson, Lady Hale, and Lord Kerr – determined that it was appropriate for the court to adjudicate upon the issue; splitting further into a three-judge majority – Lord Neuberger, Lord Mance, and Lord Wilson – who held back from issuing a declaration of incompatibility to 'accord Parliament the opportunity of considering whether to amend the legislation', and a two-judge minority – Lady Hale and Lord Kerr – who would have made a declaration of incompatibility at that point in time.

This was a lamentable decision by the court. After all, declarations of incompatibility do not affect the continuing validity of legislation, but rather mark up potential inconsistencies for Parliament (or the Government) to resolve if they so wish. In other words, a declaration of incompatibility is precisely designed to accord Parliament an opportunity to consider amending legislation, so refraining from doing so for that very reason is inherently contradictory. More worrying still, even without this questionnaire's proposed reform, Nicklinson appears to have become authority for the proposition that declarations of incompatibility can be withheld even where punitive human rights findings are made.[16]

11 P Havers et al, 'Impact of the European Convention on Human Rights on medical law' British Medical Journal (2002). Available at: https://pmj.bmj.com/content/78/924/573; Notably, the Human Rights Act 1998 also provided a framework which could have potentially developed medical end-of-life rights, see Burke v GMC [2004] EWHC 1879 (Admin).

12 See principle 2 of 'Investigation: Investigative interviewing', College of Policing. Available at: https://www.app.college.police.uk/app-content/investigations/investigative-interviewing/

13 R (Purdy) v DPP [2009] UKHL 45
Although we have not focused our submission on the relationship between the UK's domestic courts and the European Court of Human Rights (ECtHR), it may be of interest for the review to note that the ECtHR's jurisprudence from Pretty was directly responsible for this advancement. Thus, the obligation to 'take into account' the European court's jurisprudence, as per Section 2(1) of the Human Rights Act, can sometimes produce stronger rights protections under the UK's domestic law.

14 *Ibid no. 2, [3]*

15 *Notably with regard to theme 1 of the review's questionnaire, whilst the European Court of Human Rights had long established assisted dying was within the 'margin of appreciation', the UK Supreme Court ruled that this was not in and of itself the last word on the matter domestically. Lord Neuberger [70], Lord Mance [162 - 163], Lord Sumption [230], Lord Hughes [267], and Lord Reed [295] all considered that the margin of appreciation was not a barrier to domestically interpreting a 'right to die'.*

16 *In the matter of an application by Sarah Jane Ewart for Judicial Review [2019] NIQB 88*

For the avoidance of doubt, we believe a declaration of incompatibility remains the most appropriate remedy for legal cases challenging the legality of assisted dying. However, if declarations became used to flag potential issues of incompatibility earlier within legal proceedings, without the courts also making determinative rulings – which we know many others have taken to be the meaning of this review's proposed reform – Nicklinson provides a glimpse into the sort of problems claimants would experience.

This is because claimants would be left in the unenviable position of having their potential human rights violation acknowledged, but no remedy provided. Thus, their only recourse to redress would become the costly and time consuming route of appealing to the European Court of Human Rights: a problem which the Act was specifically designed to overcome. Equally, in the absence of a declaration of incompatibility, claimants that seek certainty by bringing further cases could be left in worse positions, since there would be nothing to prevent the courts from reassessing a judgment and showing even further deference to our Legislature. Indeed, this has been precisely the experience of those challenging the laws on assisted dying, since in the most recent legal case, brought by Paul Lamb, it was ruled assisted dying had become 'pre-eminently a matter for Parliament' and effectively turning the issue into a non-justiciable matter.[17]

Nevertheless, if the above attempt at dialogue had prompted action from Parliament it is arguable that the worst effects of the Nicklinson ruling could have been mollified. However, this was evidently not the case. In 2014, when the House of Lords revisited the issue of assisted dying, the type of legislation it submitted for consideration expressly excluded those in Tony Nicklinson's and Paul Lamb's situation, and instead solely focused on those with six months left to live.[18] This being in spite of the fact that during Nicklinson the then President of the Supreme Court had said 'there seems to me to be significantly more justification in assisting people to die if they have the prospect of living for many years a life that they regarded as valueless, miserable and often painful, than if they have only a few months left to live'.[19] Second, despite Lord Wilson's [20] and Lady Hale's[21] judgments exploring in – for the strict purposes of their judgements – unnecessary depth, the sort of criteria Parliament would have been wise to include in prospective legislation, no mention of this advice was included. Indeed, one year later when the House of Commons considered substantially similar legislation, only three speakers acknowledged the Supreme Court's judgment.[22] In other words, despite the Supreme Court restraining itself to foster a dialogue with Parliament, no such dialogue has occurred.

It is unclear from this review's questionnaire how the panel envisages declarations of incompatibility would be transformed from a remedy of 'last resort'. If, as suggested above, it would involve the courts making provisional findings of incompatibility we strongly advise against amending the Act.

After all, if our Parliament already ignores the substance of the courts' warnings when declarations of incompatibility are only sought in the most serious of situations, there is obviously a risk that they will take lesser note still when such declarations become a more banal feature of our legal system. Let alone, when they become only provisional. And at any rate, even if this were not the case, shifting more human rights violations to Parliament and the Government for resolution might overburden our Executive and Legislature leading to significant delays in obtaining justice. Indeed, in the context of end-of-life issues this is especially important given that people who are terminally ill can already not afford to wait for Parliament's average 25 months to respond to declarations of incompatibility.[23]

Moreover, if one of the principal drivers for reform is the perceived politicisation of the Act, then it stands to reason that instructing the courts to highlight more issues for Parliament's attention will not resolve but exacerbate the alleged problem, drawing the courts further into contentious areas and political debates.

Overall, we strongly urge the review not to amend sections 3 and 4 as they already strike a sensible balance between providing Parliament with a role in deciding how to address any incompatibility and ensuring claimants are provided with an effective remedy; to reiterate, we believe a declaration of incompatibility remains the most appropriate remedy for challenging the legality of assisted dying.

17 My Death, My Decision 'Court of Appeal refuses Paul Lamb the opportunity to challenge the law on assisted dying' (2020). Available at: https://www.mydeath-mydecision.org.uk/court-of-appeal-refuses-paul-lamb-the-opportunity-to-challenge-the-law-on-assisted-dying/

18 Parliament, 'Assisted Dying Bill (HL Bill 6)' (2014). Available at: https://publications.parliament.uk/pa/bills/lbill/2014-2015/0006/lbill_2014-20150006_en_1.htm

19 *Ibid no.2*, [122]

20 *Ibid no.2*, [205-206]

21 *Ibid no.2*, [314]

22 Parliament, 'Assisted Dying (No.2) Bill', (2015). Available at: https://publications.parliament.uk/pa/cm201516/cmhansrd/cm150911/debtext/150911-0001.htm#15091126000003

23 Jeff King, 'Parliament's Role Following Declarations of Incompatibility under the Human Rights Act', UCL (2015). Available at: https://discovery.ucl.ac.uk/id/eprint/10072227/