

Assisted Dying for Terminally Ill Adults (Scotland) Bill

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Introduction and previous submission

In 2014, the Commission responded to the consultation on the Assisted Suicide (Scotland) Bill 2013, outlining the human rights considerations for state regulation of assisted dying. The submission, which we attach, set out the framework within which determinations on whether to adopt legislation permitting assisted death may be made. The human rights standards outlined therein remain pertinent and this response should be read alongside our previous submission.

In summary:

- Assisted dying has been considered in relation to the following rights from the European Convention on Human Rights (ECHR):
 - The right to life (Article 2);
 - The right to freedom from degrading treatment (Article 3);
 - The right to respect for private and family life (Article 8);
 - The right to freedom of thought, conscience and religion (Article 9)¹ and;
 - The right to freedom from discrimination (Article 14).

We address the right to life and the right to respect for private and family life in more detail below, in response to the consultation questions.

- The European Court of Human Rights (ECtHR) has not taken the view that the ECHR requires either the prohibition or the permission of assisted dying. The approach of the ECtHR is to recognise that domestic authorities are better placed than the Court to decide on nationally sensitive issues (this is known as the “margin of appreciation”).
- The ECtHR has consistently found that the right to private and family life encompasses the right to decide how and when to die, and in particular the right to avoid a distressing and undignified end to life (provided that the decision is made freely). However, it continues to recognise the margin of appreciation allowed to states to determine whether assisted dying should be permitted. We

address the assessment of that margin of appreciation in more detail below.

- If a State does criminalise assisted dying, it has an obligation to ensure that related offences are clearly defined in law, and a clear policy as to when it would, and would not, be appropriate to prosecute individuals who help others to die is indispensable.
- The principle of legality under the ECHR calls for the law to be foreseeable. In the Commission's view there is a strong case for increased clarity in the law of Scotland on the criminalisation of assisted suicide in Scotland, following the decision of the House of Lords in *Purdy v DPP*, as discussed in our 2014 submission².

In this submission, we will address developments in human rights standards and apply the human rights framework to the present proposals.

Developments in human rights standards for disabled people

Since 2014, the understanding of disabled people's rights in terms of the Convention on the Rights of Persons with Disabilities (CRPD) has evolved and continues to do so. Scotland (via the UK) is party to CRPD, a Convention grounded in the social model of disability which requires respect for difference and acceptance of disabled people as part of human diversity and humanity, and recognition and removal of the barriers which serve to disable people.

Right to life

As the proposals acknowledge, there are significant fears among some members of the disability community about the impact assisted dying could have on the protection of their right to life. It is important to acknowledge that these fears may be heightened following experiences of the pandemic, which raised queries around the provision of life-saving treatment to disabled people and concerns about quality of life judgments³.

A report by the UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas-Aguilar, in December 2019, examines the concerns of disabled people within the framework of the Convention on the Rights of Persons with Disabilities⁴. She sets out a series of recommendations for states considering legalising any form of assisted dying. Firstly, states should conduct extensive discussions with the active participation of organisations representing persons with disabilities. If assisted dying is to be permitted, it must be accompanied by strong measures to protect the right to life of persons with disabilities:

- Access to assisted dying should be restricted to those who are at the end of life; having an impairment should never be a reason for assisted dying to be permitted.
- The free and informed consent of persons with disabilities must be secured on all matters relating to assisted dying and all forms of pressure and undue influence prevented.
- Access to appropriate palliative care, rights-based support, home care and other social measures must be guaranteed.
- Accurate information about the prognosis and availability of peer-support counselling must be provided.
- Accountability regulations must be established requiring collection and reporting of detailed information about each request and intervention for assistance in dying.

We wish to highlight the importance of ensuring that adequate support for the full range of human rights for disabled people is a fundamental component to reducing risks to their right to life, without which the risk that they may be placed in a position where they feel they are a burden on society or loved ones may persist.

Right to equal recognition before the law

Article 12 CRPD provides the right to equal recognition before the law. The elaboration of this right by the Committee on the Rights of Persons with Disabilities (which oversees CRPD) states that perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity. Rather, it requires that support be provided in the exercise of legal capacity⁵. This must be carefully considered in relation

to the proposals to restrict access to assisted dying to “competent adults” as determined by the test of mental capacity set out in the Adults with Incapacity (Scotland) Act 2000.

The CRPD Committee points out

“The concept of mental capacity is highly controversial in and of itself. It is not, as it is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.”⁶

However, the drive to ensure equal recognition of legal capacity must also ensure that sufficient safeguards are provided to ensure that consent is informed and free from undue influence. Both the ECHR⁷ and CRPD⁸ emphasise the State’s obligation to put in place a procedure capable of ensuring that a person’s decision to end his/her life does in fact reflect his/her free will. This presents a challenging conundrum – to what extent should a policy of assisted dying attempt to maximise legal capacity while also ensuring that it adequately protects people who require support with decision-making?

The procedure set out in the proposals relies heavily on the assessment of doctors on mental capacity. The assessment of capacity and its use as a determining factor in incapacity legislation is currently under review by the Scottish Mental Health Law Review⁹, in recognition of the fact that it may no longer offer appropriate protection for the full range of human rights. The outcome of that Review remains to be determined, however, changes to the Adults with Incapacity (Scotland) Act 2000 are likely and any proposed Bill should take steps to align with their proposals on capacity and supported decision-making.

Response to consultation questions

- 1. Which of the following best expresses your view of the proposed Bill?**

Our previous submission highlighted the need for legal certainty, in both criminal prosecutions and the operation of procedures for assisted dying. The proposals offer an opportunity to provide such clarity. However, the Commission believes that, first and foremost, disabled people's organisations must be brought into the discussions and their concerns addressed.

The definition of terminal illness in the proposals (diagnosed as having a progressive disease which can reasonably be expected to cause their death and from which they are unable to recover) should, in particular, be discussed with disabled people's organisations to ensure it could not be taken to apply to people with conditions who have many years of life ahead of them. We recognise that the definition was discussed in the context of social security, however, that was for enabling purposes, to provide access to entitlements, whereas this is a situation where stringent protective safeguards are required. This may require a narrower definition. It is also worth considering whether an explicit prohibition on assisted dying for reason of disability/impairment is required.

While we remain neutral on the policy of assisted dying as a whole, we believe the following elements of the human rights framework outlined in this and our previous submission require careful consideration and balancing.

While Article 2 ECHR does not provide a right to die¹⁰, it equally does not explicitly prohibit states from legislating for assisted dying. Article 2 does oblige the national authorities to prevent an individual from ending their life if the decision was not made freely in full knowledge of the facts¹¹. It must also, however, be read as a whole, together with Article 8 ECHR, whereby the ECtHR considers that 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 life¹².

A blanket ban on assisted dying (or what amounts to a blanket ban in the absence of recognition of exceptions which would permit assisted dying) therefore represents an interference with Article 8 which requires to be duly justified by reference to the following criteria:

- i. for a legitimate aim which is important enough to justify interfering with a fundamental right: the aim of protecting those who feel that they are a burden or are vulnerable to pressure (in terms of the ECHR, protecting “the rights of others” or “the protection of health”) is one such aim which has been advanced in recent cases¹³;
- ii. rationally connected to achieving that aim;
- iii. no more than reasonably necessary to achieve it (in other words, proportionate to the aim); and
- iv. in the light of this, striking a fair balance between the rights of the individual and the interests of the community¹⁴

The Supreme Court considered justification for interferences of this nature in England and Wales in detail in *R (on the application of Nicklinson) v Ministry of Justice*.¹⁵ Given the wide margin of appreciation allowed to the State to determine its assisted dying laws, the views of national authorities such as the Supreme Court will be crucial in assessing the compatibility of any proposed laws. As such, the Supreme Court’s assessment in *Nicklinson* is particularly instructive.

While, ultimately, the Supreme Court concluded that it would be institutionally appropriate for Parliament, rather than the Court, to consider the matter, they flagged concerns that the proportionality of a ban was uncertain:

“The interference with Applicants’ article 8 rights is grave, the arguments in favour of the current law are by no means overwhelming, the present official attitude to assisted suicide seems in practice to come close to tolerating it in certain situations [and] the rational connection between the aim and effect of [the legislation banning assisted suicide] is fairly weak.”¹⁶

In particular, a majority of Justices made clear that, if Parliament did not address the situation satisfactorily, there was a “real prospect that a further, and successful, application for a declaration of incompatibility may be made.”¹⁷

The proposals therefore provide the opportunity for the Scottish Parliament to carry out the necessary assessment of whether the current situation remains a necessary and proportionate interference with the right to private and family life.

In order to assess the human rights compatibility of the proposals, it is necessary to consider their purpose. The proposed law seeks to address the lack of clarity over the legal situation of people who provide physical assistance for a person who chooses to die. The proposed form of assistance is the prescription and provision of medication which must be administered by the individual themselves. This purpose advances the 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. It does not, however, address the situation of people who, because of their physical illness, would be unable to act on their decision and would require the physical assistance of others. While the ECtHR has not found this to be discriminatory¹⁸, there should be explicit consideration of the objective and reasonable justification for maintaining this distinction.

4. Which of the following best expresses your views of the safeguards proposed in section 1.1. of the consultation document?

The Supreme Court in *Nicklinson* considered, as an alternative to a universal ban, systems whereby a judge or independent assessor would make a determination as to the voluntary, clear, settled and informed wish to die, as a robust means of reducing concerns about its inappropriate use¹⁹.

Such a system would offer a higher degree of scrutiny and, accordingly, stronger safeguards for the right to life. It might also allow for appropriate

tests to be designed to recognise the legal capacity of disabled people in a manner respecting Article 12 CRPD. Judicial determination would, however, provide a lesser degree of autonomy for the individual. The Commission believes that a system of judicial or independent assessment ought to be more closely considered.

5. Which of the following best expresses your view of the body being responsible for reporting and collecting data?

The reporting and collection of data is essential to ensure each individual use of assisted dying is appropriate and upholds human rights. The Committee on the Rights of Persons with Disabilities has highlighted the importance of regulations for monitoring medical assistance in dying, data to assess compliance with the procedural safeguards regarding such assistance, and sufficient support to facilitate civil society engagement with and monitoring of this practice²⁰. They recommend:

- i. Establishing regulations pursuant to the law requiring collection and reporting of detailed information about each request and intervention for medical assistance in dying;
- ii. Developing a national data standard and an effective and independent mechanism to ensure that compliance with the law and regulations is strictly enforced and that no person with disability is subjected to external pressure.

¹ The ECtHR has not found that a belief in the value of assisted suicide is sufficient to require those assisting to be absolved of otherwise criminal conduct *Pretty v. United Kingdom* [2002] 35 EHRR 1

² *R (on the application of Purdy) v the Director of Public Prosecutions* [2009] UKHL 44. See discussion of this case at p.5 of our previous submission

³ 'Covid 19 and the rights of disabled people – statement supported by disabled people's organisations and allies' [Covid 19 and the rights of disabled people | Disability Rights UK](#)

⁴ [OHCHR | Report on the impact of ableism in medical and scientific practice](#)

⁵ General Comment No.1 (2014) of the Committee on the Rights of Persons with Disabilities, Article 12: Equal recognition before the law, available at [Treaty bodies Download \(ohchr.org\)](#)

⁶ *Ibid* at para 14

⁷ *Haas v Switzerland* (2011) 53 EHRR 33: where the applicant complained that the criteria were too stringent and thus denied him a right to die, The Court considered that the requirement of a prescription, issued on the basis of a thorough psychiatric assessment, was a means of satisfying the obligation on States to put in place a procedure capable of ensuring that a person's decision to end his/her life did in fact reflect his/her free will.

⁸ General Comment No. 1, para 22

⁹ [Terms-of-Reference-1.pdf \(mentalhealthlawreview.scot\)](#)

¹⁰ *Pretty v. United Kingdom*

¹¹ *Haas v Switzerland* at para 54

¹² *Ibid* at para 51

¹³ *R (on the application of Nicklinson) v Ministry of Justice* [2014] UKSC 38

¹⁴ *Nicklinson* at para 310

¹⁵ *Ibid*

¹⁶ *Ibid* at para 111

¹⁷ *Ibid* at para 118

¹⁸ *Pretty v United Kingdom*

¹⁹ *Nicklinson* at para 108 and paras 314-319

²⁰ Concluding Observations on the Initial Report of Canada in 2017