

Locating a Right to a 'Good Death' within the Human Rights Lexicon

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conflicts of interest

- Nothing to disclose

'Martin'

- Martin is 50, and lives in England. In August 2008 he suffered a brain stem stroke, leaving him virtually unable to move.
- He cannot speak. He communicates through small movements of his head and eyes and, very slowly, by using computer technology which detects where on a screen he is looking.
- He is totally dependent on others for every aspect of his life. He can swallow, and is fed by carers putting food in his mouth, so could take lethal medication by mouth but would need assistance.
- He is unlikely to die of natural causes in the near future. Since at least 2011, Martin has had a strong, settled and reasoned wish to end his life, which he finds undignified, distressing and intolerable.
- The General Medical Council may take disciplinary action against any physician who writes a report to Dignitas on his medical condition, a precondition to his accessing assisted dying there [*R (AM) v General Medical Council* [2015] EWHC 2096 (Admin) under appeal].

The obstacle to access to PAD

England (Pretty, Purdy, Nicklinson, Lamb, 'Martin')

Canada (Rodriguez, Carter & Taylor)

Ireland (Fleming)

→ the criminal offence of assisting suicide

Does a competent person have a right to commit suicide?

Savage v S Essex NHS (HL, 2008) per Lord Scott:
with the exception of

- Children, or
 - adults who are mentally ill, or
 - in police custody or in prison,
- the State has no general obligation at common law or under Article 2(1) to place obstacles in the way of persons desirous of taking their own life; the prevention of suicide is not amongst the allowable proportionate limitations on the right to personal autonomy [11] (also Lord Rodger [25])
- Reiterated by Lady Hale in *Rabone v Pennine Care NHS* (UKSC 2012) [100]
- And by Lord Sumption in *Nicklinson v Ministry of Justice* (UKSC 2014) [255].
- However controversial, this is clearly the law in a medical context.

The common law's approach to voluntary death in a medical context

A person considered to have *mental capacity*:

- (1) has the absolute right to personal autonomy and bodily integrity in determining whether to accept or refuse beneficial medical treatment, regardless of whether the physician considers such treatment to be vital to the continuation of life, and however irrational that decision may appear to others.
[confirmed by ECtHR in *Pretty v UK* [63] under Art 8(1)]
 - (2) is entitled to assess for herself the quality of her life, and if she determines that she wishes to die, can require the cessation of
 - all life-sustaining medical treatment
 - nutrition or hydrationuntil she dies.
- * NO slippery slope consequentialist arguments are ever advanced against this right.

Common law: voluntary death in a medical context

(3) who is capable of taking the necessary steps herself to end her life is entitled to do so.

(4) who, having assessed for herself the quality of her life, but

→ is not on life support which can be disconnected, or

→ is physically incapable of taking the necessary steps to end it quickly, has only one recourse: to refuse nourishment and hydration until death ensues, and to instruct that palliative care only be provided; [*again no slippery slope consequentialist arguments are advanced here]

(5) apparently is entitled to exercise her right to travel to a jurisdiction where assisted dying is not criminalised, [*Purdy, Pretty*]

→ but anyone in the jurisdiction who knowingly assists her in so doing is subject to police investigation, and the possibility of a criminal prosecution.

How can exercise of a human right be subject to discretion of a public official?

Human rights pathways for Martin

- (1) The right to **life** (usually absolute)
- (2) Protection from **degrading and inhuman** treatment (usually absolute) → **indignity**
- (2) Entitlement to interlocking **personal integrity** rights (usually qualified)
 - ❖ **Security** of the person (a.k.a. **dignity**)
 - ❖ **Self-determination** (a.k.a. **autonomy**)
 - ❖ **Privacy** (broadly, personal flourishing)
 - ❖ **Equality** rights → equality in medical law with self-determination accorded to patients who are
 - (a) able to direct cessation of life support; or
 - (b) physically capable of acting on their decision to die.

Human rights pathways

- * Many intersections within these pathways
- * Rights coupled and decoupled in different human rights instruments, eg
 - In Canadian Charter rights to “life, liberty and security of the person” all compendiously in s. 7, and all found engaged in *Carter v Canada*
 - In ECHR “life” is in Art 2, “liberty and security of the person” in Art 5, the latter being narrowly construed as applying only in cases of deprivation of liberty
- * Some rights are express, some (e.g. dignity and self-determination) may be implicit in one or more express guarantees.
- * Limitations have different content, usually based on rights of others or societal interests.

The orthodox judicial view:

Death is inherently incompatible with the right to life because it extinguishes life

ECHR Art 2: *Pretty v UK* (ECtHR, 2002)

[39] Art 2 “*is unconcerned with issues to do with the quality of living or what a person chooses to do with his or her life....*”

*Article 2 cannot, without a distortion of language, be interpreted as conferring the **diametrically opposite right**, namely **a right to die**; nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life.”*

The alternative view: *Dying is part of living*

Joseph Raz:

*“The right to life protects people from the time and manner of their death being determined by others... Those who reflect, plan and decide on the manner of the dying make **the dying part of their life**. And if they do so well then by integrating their dying into their life they enrich their life.”*

Ronald Dworkin:

*“It is a platitude that we live our whole lives in the shadow of death; it is also true that we die in the shadow of our whole lives... Death has dominion because it is not only the start of nothing but the end of everything, and how we think and talk about dying – the emphasis we put on dying with “dignity” – shows how important it is that life ends appropriately, **that death keeps faith with the way we want to have lived.**” (i.e. our “critical interests”)*

The alternative view:

Dying is part of living

Rodriguez v AG of Canada (1993, Supreme Court of Canada)
per Cory J (dissenting):

Dying is an integral part of living and, as a part of life, is entitled to the protection of s. 7 [protecting the right to life, liberty and security of the person]. It follows that the right to die with dignity should be as well protected as is any other aspect of the right to life.

3 human rights fallacies in the orthodox view

#1 Martin's right to life is transmogrified into a **duty to live**

→ Regardless of the personal cost to Martin

(noted in *Carter* [63], observing that this calls into question the legality of refusal or withdrawal of consent to treatment)

#2 That duty is imposed **for the sake of others** due to (inchoate) fears regarding other right-holders, requiring Martin to become the **conscripted instrument** of protecting them

→ Contradicts Kant's categorical imperative not to use a person as a means to another's ends → fundamental to the concept of inalienable rights held by every human being.

→ No human rights instrument expressly qualifies the right to life in this way

3 human rights fallacies in the orthodox view

#3 The right would necessarily set up a **claim-right**, ie the right to compel others to lend active assistance to fulfil that right.

“A right which extends to the termination of life must ... necessarily extend to a right to have terminated by a third party in a case of total incapacity.” [Fleming v Ireland (Sup Ct of Ireland)]

➔ BUT Martin is not asserting a claim-right enforceable against reluctant others, just a right of non-interference by the state with exercise of his right to die with voluntary assistance. [fallacy noted in dissent *Nicklinson* (UKSC) by Lord Kerr, Lady Hale]

One pathway through the Right to Life

The spectre of premature suicide before P becomes totally incapacitated:

Fleming v Ireland (Sup. Ct of Ireland)

[134] ... *What prevents [Fleming] from committing suicide is, on her own evidence, her own disability. The appellant was able to avail herself of s. 2(1) [to commit suicide] for some time: when she lost that ability it was not through any operation of law before which she is required to be unequal, but the fact of her condition.*

One pathway through the Right to Life

Rebuttal tactics: transform mere assertion into actual evidence tested in the adversarial trial

Carter v Canada (SCC 2014)

- the right to life is engaged whenever **the state imposes an increased risk of death on a person**, as here.
- prohibition had the effect of forcing some individuals to take their own lives prematurely for fear that they would not be able to die at the point where suffering became intolerable.

Inhuman & degrading treatment → indignity

- As yet untested, although ECtHR in *Pretty* rejected Art 3 argument formulated on her dying by suffocation as that was not caused by “treatment” by the state but by her disease
- Alternative formulation: the State forces competent totally incapacitated patients to take what they regard as an inhuman or degrading route to death, self-starvation and dehydration
- They may find that to be unachievable, distressing or demeaning, or may have already failed in attempting that escape route (as Martin, Purdy discovered).

Dignity and Indignity

- Dignity is a much-criticised concept – invoked by both sides of the debate [objective → inherent in humanity, or subjective → expression of autonomy]
- But beyond doubt, dignity is viewed as directly in issue by patients giving evidence to assert their right to assisted dying in the courts
- Loss of control over their own destiny exercisable by able-bodied persons is the most intolerable loss, which they wish to reclaim.

(3) The personal integrity rights

- ❖ **Security** of the person (a.k.a. **dignity**)
- ❖ **Self-determination** (a.k.a. **autonomy**)
- ❖ **Privacy**
- ❖ **Equality** rights

- ➔ Arguably the most viable remaining niche for PAD
- ➔ BUT the rights are usually qualified, allowing extraneous and/or unvalidated counter-assertions about third party interests to intercept their exercise.
- Device: extraditing the applicant from the ranks of the disabled ➔ stereotyping all disabled people as incapable of exercising their autonomy.

Carter v Canada (SCC)

- Charter s. 7 encompasses life, liberty and security of the person → applies to the passage to death ([63])
- “**Liberty**” = the right to make fundamental personal choices here, about their bodily integrity and medical care
- “**Security of the person**” = personal autonomy involving control over one’s bodily integrity, free of state interference
- engaged by state compelling individuals to endure intolerable physical or psychological suffering due to a grievous and irremediable medical condition ([64])
- Distinct concepts but both engaged here due to deprivation of the right to “decide one’s fate” by making decisions about one’s own bodily integrity

ECHR Art 8 rejected by the UK courts: *Pretty v DPP*

Lord Bingham:

*“Article 8 is expressed in terms directed to protection of personal autonomy while individuals are living their lives, and there is **nothing to suggest that the Article has reference to the choice to live no longer.**”*

The ECtHR: Politics over Principle?

- Parked right to avoid “an undignified and distressing end to her life” in the elastic Art 8(1) right to privacy [*Pretty*, confirmed in *Haas*, *Gross*]
- Art 8(2) conveniently heavily qualifies the right and is subject to a wide margin of appreciation [*Haas*, *Lambert v France* ([145])
 - ❖ primarily for States to assess the “clear risks of abuse” of others in a vulnerable class against the countervailing principle of personal autonomy
- thereby allowing C of E States to continue diametrically opposed positions on assisted dying (permissive vs criminalisation) in purported fulfilment of the same Art 8(1) ‘right’.

❌ **A right without enforceable content**

Nicklinson, Lamb and 'Martin' v Ministry of Justice (UKSC 2014)

- Ruled 7:2 that it would be inappropriate for the UKSC to rule that the assisted suicide offence was incompatible with ECHR article 8 (right to privacy, self-fulfilment) *at that time* given that Lord Falconer's private member's Bill was before Parliament
 - BUT majority (5:4): **the interference with Art. 8 rights was "particularly grave" and that legislative judgment [if the Bill was defeated] would not be determinative of the issue**
 - Minority would have made a declaration of incompatibility to guide Parliament
 - Assisted Dying (No 2) Bill defeated in Parliament. in Sept 2015
- ? return to the UKSC? BUT Parliament can ignore the Court's ruling under the Human Rights Act 1998 (unlike Canada)**

Discrimination on basis of disability

Fleming v Ireland (Supreme Court of Ireland)

]133]... It is difficult to succeed in an equality challenge to a law that applies to everyone without distinction, and which is based on the fundamental equal value of each human life. It is often the case that neutral laws will affect individuals in different ways: in the absence of impact on a fundamental right that does not normally give rise to any unconstitutionality.”

BUT: Indirect discrimination = a facially neutral law or measure which has disproportionate impact on an identified group on a prohibited ground

→ Court's assertion: the assister, not disabled person, is penalised → State is preventing a disabled person from accessing assistance required to perform a legal act.

Human rights strategies

*The argument from disability discrimination law as located in existing medical law governing patient rights remains largely untested on its merits.

➔ Indirect discrimination to attack a facially neutral criminal offence

➔ discriminatory to deem all disabled people as *ipso facto* too vulnerable to exercise their right to self-determination

*Call *viva voce* evidence to test the ethical claims and empirical studies in an adversarial trial.

* Keep the focus on the discrepancy with existing patient rights to control their destiny within medical law (cf. *Carter* at [66] using discrepancy in liberty analysis)

* Keep the Court focussed on real people, not abstract argument