Refusing Life-Prolonging Medical Treatment and the ECHR

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**Abstract**

This paper considers the content of the right to refuse life-prolonging medical treatment under the European Convention on Human Rights, as well as the European Court of Human Rights’ supervision of domestic legal regimes for refusing life-prolonging treatment. I argue, employing doctrinal and philosophical analyses, that developments in the Convention jurisprudence with regard to the protection of private life under article 8 ECHR imply a substantively extensive right to refuse life-prolonging treatment, both contemporaneously and in advance. Moreover, I suggest that there is sufficient consensus among Council of Europe Member States on the right to refuse life-prolonging treatment to engage ECtHR supervision of States’ legal frameworks for such refusals. In addition, or in the alternative, I advance that the Strasbourg court may scrutinise Member States’ legal arrangements for refusals of life-prolonging treatment in virtue of the positive obligations to secure respect for private life that inhere in article 8 ECHR.

**Keywords**

human rights; European Convention on Human Rights; refusal of treatment; medical law; ethics; legal philosophy

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# Introduction

In this paper, I consider the content of the right to refuse life-prolonging medical treatment under the European Convention on Human Rights (henceforth ECHR), as well as the European Court of Human Rights’ (henceforth ECtHR) supervision of domestic legal regimes for refusing life-prolonging treatment.[[1]](#footnote-1) I argue, employing a combination of doctrinal and philosophical analysis, that developments in the ECtHR jurisprudence with regard to the protection of private life under article 8 ECHR (§2) imply a substantively extensive right to refuse life-prolonging treatment, both contemporaneously and in advance (§3). Moreover, I suggest that there is sufficient consensus among Council of Europe Member States on the right to refuse life-prolonging treatment to engage ECtHR supervision of States’ legal frameworks for such refusals (§4). In addition, or in the alternative, I advance that the Strasbourg court may scrutinise Member States’ legal arrangements for refusals of life-prolonging treatment in virtue of the positive obligations to secure respect for private life that inhere in article 8 ECHR (§5).

Why it is worth writing about the right to refuse life-prolonging under ECHR law? First, Elizabeth Wicks’ substantive treatment of this issue predates the developments in the article 8 ECHR jurisprudence discussed in §2.[[2]](#footnote-2) This is the first detailed consideration of refusals of medical treatment under ECHR law since Wicks. Second, while a substantively extensive legal right to refuse *any* medical treatment exists in England and Wales,[[3]](#footnote-3) elsewhere within the Council of Europe it may be that no right to refuse exists, that right is substantively qualified, or does not extend to advance refusals.[[4]](#footnote-4) Were the ECtHR to identify a Convention right to refuse life-prolonging treatment, this might provide impetus for permissive legal change across Member States, as well as ground for evaluation of permissive regimes. This paper develops an account of such a right’s content, and assesses the prospects for its recognition and enforcement by the ECtHR.

By way of preliminaries, I should clarify that my aim is to provide an account of the right to refuse life-prolonging treatment under article 8 ECHR at a general level. The right I defend is substantively extensive, but not unlimited. Therefore, further work is necessary to specify the class of individuals who may possess the right to refuse life-prolonging treatment, and when members of that class possess said right.

# *Right D*: the Right to Decide How and When to Die

In litigation challenging State regulation of assisted suicide, the ECtHR has found *the right to decide how and when to die* (henceforth *right D*) to be an aspect of the right to private life protected by article 8 ECHR.[[5]](#footnote-5) The genesis of this right is *Pretty v United Kingdom*, in which the Court held:

[T]he Court considers that the notion of personal autonomy is an important principle underlying the interpretation of [Article 8 of the Convention].

The applicant in this case is prevented by law from exercising her choice to avoid what she considers will be an undignified and distressing end to her life. The Court is not prepared to exclude that this constitutes an interference with her right to respect for private life as guaranteed under Article 8(1) of the Convention.[[6]](#footnote-6)

More explicitly, in *Haas v Switzerland*, the ECtHR ruled that:

the right of an individual to decide how and when to end his life, provided that said individual is in a position to make up his own mind in that respect and to take the appropriate action, is one aspect of the right to respect for private life within the meaning of art.8 of the Convention.[[7]](#footnote-7)

While the *Pretty* and *Haas* cases relate to suicide assistance, the ECtHR frames *right D* as a subset of the right to individual autonomy. This is significant insofar as it admits the possibility of *right D*’s multifarious expression, that is, the reach of article 8 ECHR at the end of life is not confined to the regulation of suicide assistance. Indeed, *right D* claims might plausibly manifest in a variety of end of life situations, including instances in which an individual seeks to participate in clinical decision-making,[[8]](#footnote-8) in which she seeks an assisted death,[[9]](#footnote-9) and in which she refuses life-prolonging treatment (henceforth LPT). Moreover, the underlying facets of *right D* invoked in such cases—claims to participation, assistance, and non-interference—are not mutually exclusive; appeals to *right D* in individual cases may rely on more than one of these aspects.[[10]](#footnote-10)

There may consequently be ample opportunities for State (and potentially third party) conduct to interfere with an individual’s right to decide the manner and moment of her own death. This interference might consist in overt restriction on the exercise of *right D*.[[11]](#footnote-11) Alternatively, it may arise more subtly in virtue of the substantive or procedural features of legal regimes that ostensibly permit the exercise of individual autonomy,[[12]](#footnote-12) or factors such as implementation failure.

However, not every interference with *right D* necessarily makes out a violation of the Convention. Article 8 ECHR is a ‘qualified right’; interference with *right D* will be permissible according to the terms of article 8(2) ECHR just when it is:

… in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

It follows that talk of a ‘right’ to decide the manner and moment of one’s death is somewhat loose. For if an interference with *right D* is permissible under article 8(2) ECHR, individuals do not in fact possess a right in respect of the matter under consideration. Until it is established that interference amounts to a violation of the Convention, *right D* is a merely prima facie right. However, since the entitlements that typically characterise rights do not attach to prima facie rights (or attach only embryonically), speaking of them as rights is question-begging.[[13]](#footnote-13) It is more accurate, then, to speak of interference with an individual’s *fundamental freedom to decide the manner and moment of her own death* (henceforth *freedom D*), which will only amount to a violation of *right D* if the requirements of article 8(2) ECHR are not met. This distinction between *freedom D* and *right D* will be helpful in the next section, in which we develop an account of the content of *right D* as it applies to refusals of life-prolonging treatment.[[14]](#footnote-14)

# The Content of *Right DR:* the Right to Refuse Life-Prolonging Treatment

In the previous section, I note that interference with an individual’s freedom to decide the manner and moment of death need not amount to a violation of *right D*. Thus, in order to ascertain the content of *right D* as it applies to refusals of LPT (henceforth *right DR*), we need an account of when State regulation of *freedom D* as it applies to refusals of LPT is impermissible.

Article 8 ECHR provides the scaffold for an account of the content *right DR*: if an individual (henceforth ‘*P*’)exercises *freedom D* when she refuses LPT such as to engage article 8(1) ECHR*, P* possesses a *right DR* just when any regulation inconsistent with *P*’s exercise of *freedom D* cannot be justified in terms of the article 8(2) ECHR limitation clause. Thus whether an individual possesses *right DR* depends on the following questions:

(1) Does the interference relate to *P*’s exercise of freedom D?

(2) Does the interference pursue a legitimate aim?

(3a) Is the interference in accordance with the law?

(3b) Is the interference necessary in a democratic society [proportionate]?

In respect of (1), if the interference does not relate to *P*’s exercise of *freedom D*, *right DR* is not in play; article 8(1) ECHR is ‘not engaged’. The analysis only progresses when article 8(1) is engaged.[[15]](#footnote-15) On (2), *P* possesses *right DR* in respect of the regulated activity if the interference with *freedom D* does not pursue a legitimate aim. If the interference is legitimate in its purpose, *P* possesses *right DR* in the event of a negative answer to any one of (3a-b). In the next sections, I consider questions 1, 2, and 3b. I assume that any measure regulating refusals of LPT is prescribed by law and adheres to the Convention principle of legality,[[16]](#footnote-16) since this criterion pertains to the means, rather than the substance, of interference with *right DR*.

## Engagement

Not all refusals of LPT express *freedom D*. This is because *freedom D* is tied to, and derives its value from, individual autonomy. It follows that non-autonomous refusals of LPT do not express *freedom D*, and thus do not engage article 8(1) ECHR.[[17]](#footnote-17) This argument is implicit in the ECtHR’s judgment in *Pretty v United Kingdom*, in which the Court also gave a clear indication that refusals of LPT fall within the scope of article 8(1) ECHR:

[I]n the sphere of medical treatment, the refusal to accept a particular treatment might, inevitably, lead to a fatal outcome, yet 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) ECHR].[[18]](#footnote-18)

According to the ECtHR, therefore, interference with the exercise of *freedom D* by overriding a refusal of LPT engages article 8(1) ECHR,[[19]](#footnote-19) subject to the requirement that *P* is an adult with decision-making capacity.[[20]](#footnote-20) However, an individual’s autonomy may be undermined by factors other than mental incapacity, such as coercion or undue influence. Thus the Court’s dictum in *Pretty* gives a somewhat incomplete picture. Rather, competence and voluntariness are individually necessary and jointly sufficient conditions for the exercise of *freedom D*, and consequently the engagement of article 8(1) ECHR. This broader view of what constitutes a *valid* autonomous decision is perhaps reflected in *Haas v Switzerland*:

the Court considers that the right of an individual to decide how and when to end his life, *provided that said individual is in a position to make up his own mind* in that respect… is one aspect of the right to respect for private life within the meaning of art.8 of the Convention.[[21]](#footnote-21)

Does the argument that article 8(1) ECHR is engaged when *P* makes a valid refusal of LPT apply to both contemporaneous and advance refusals? It might be argued that since *P* lacks capacity at the time an intervention is offered, she is not autonomous for the purposes of the exercise of *freedom D*, and therefore article 8(1) ECHR is not engaged. This argument seems uncompelling, however. An advance refusal shifts the temporal location of *P*’sdecision in respect of a medical intervention away from the time that same decision takes effect. The object of an advance refusal, therefore, is to displace the material time from its usual location (when medical treatment is offered) to an earlier moment (when *P* possesses decision-making capacity and contemplates future medical treatment). I advance that the temporal displacement does not make a relevant difference for the purposes of the exercise of *freedom D*. This is because, all else being equal, if a valid advance refusal of LPT is applicable, that is, if its subject matter relates to relevant facts about *P* and the proffered intervention, it is identical to a valid contemporaneous refusal in the following way: both types of refusal constitute an attempt by *P* to decide how and when she shan’t live. I argue, therefore, that article 8(1) ECHR is engaged when *P* makes a valid refusal of LPT, contemporaneous or advance.[[22]](#footnote-22)

## Legitimate aim

Any of the aims listed in article 8(2) ECHR may in principle serve as a legitimate ground for interfering with *freedom D*. Nevertheless, some of the purposes contained in the limitation clause are more plausible objects for State intervention in this domain than others.

Perhaps the most obvious ground for regulation of refusals of LPT is the ‘protection of health or morals’. The ECtHR has held that this heading includes measures designed to promote individual welfare,[[23]](#footnote-23) as well as population health.[[24]](#footnote-24) It is also clear from the Court’s jurisprudence that State interference in defence of morals is a legitimate aim even if ‘morality’ is merely a reflection of the prevailing views of the community (as opposed to a more considered ethical outlook).[[25]](#footnote-25) Thus legal regimes that license frankly paternalistic interventions, or that restrictively regulate refusal of LPT in response because it is thought immoral, may pursue a legitimate aim for the purposes of article 8(2) ECHR.[[26]](#footnote-26)

The ‘protection of the rights and freedoms of others’ and the ‘prevention of crime’ may be legitimate aims for the purposes of regulating refusals of LPT. These grounds may closely linked, to the extent that the protection of third party rights provides the justification for criminal law offences against the person. Hence the State may permissibly aim at discharging, *inter alia*, its positive obligation under article 2 ECHR to safeguard individuals whose lives are endangered by the conduct of others.[[27]](#footnote-27) In *Pretty v United Kingdom*, the ECtHRheld that this obligation constituted a legitimate aim for the purposes of criminal law measures restricting access to suicide assistance:

The law in issue in this case, section 2 of the 1961 Act, was designed to safeguard life by protecting the weak and vulnerable and especially those who are not in a condition to take informed decisions against acts intended to end life or to assist in ending life.[[28]](#footnote-28)

In addition, the ECtHR has noted on a number of occasions that the ‘Convention should be read as a whole’.[[29]](#footnote-29) This interpretive tool allows the Court to take into account in its assessment any other rights an individual possesses under the Convention. Thus in *Haas v Switzerland*, the Court referred to the State’s positive obligation in respect of suicide prevention:

Reference should therefore be made, in the context of the examination of any violation of art.8, to art.2 of the Convention, which imposes upon the authorities the duty to protect vulnerable persons, even against actions by which they threaten their own lives.[[30]](#footnote-30)

To the extent that the exercise of *freedom D* has implications in respect the State’s positive obligations under article 2 ECHR, therefore, measures regulating refusals of LPT may have a legitimate aim for the purposes of article 8(2) ECHR.[[31]](#footnote-31) Of course, interference with *freedom D* in pursuit of a legitimate aim must also be justified as ‘necessary in a democratic society’.

## Proportionality

When is state interference with a refusal of LPT justifiable in virtue of its *necessity* in a democratic society? The ECtHR employs a two-limb test to assess whether interference with a fundamental freedom in pursuit of a legitimate aim is lawful.[[32]](#footnote-32) The first limb, ‘necessity’ *stricto sensu*, does very little work in the Court’s jurisprudence.[[33]](#footnote-33)

George Letsas observes that the second limb, proportionality, is ‘by far the most important and demanding criterion for whether the limitation of a right was permissible under the Convention’.[[34]](#footnote-34) Unfortunately, however, the ECtHR has been inexplicit in enumerating the elements of its proportionality analysis.[[35]](#footnote-35) Drawing on the work of Robert Alexy,[[36]](#footnote-36) Letsas argues that the ‘orthodox’ view of proportionality, that is, the conception employed, *inter alios*, by the ECtHR, consists in two principal claims:

(1) Proportionality *stricto sensu* (‘balancing’) is a test that speaks to the limitation, rather than the content of rights…

(2) Rights may justifiably be limited if the overall societal benefits of limiting them exceeds the cost of the harm done to the person whose right it is…[[37]](#footnote-37)

Letsas notes that proportionality so framed ‘has made it very unpopular amongst scholars who reject utilitarianism and defend rights as resistant to utilitarian calculations’.[[38]](#footnote-38) However, Letsas’ own criticism of the proportionality orthodoxy centres on its status as a ‘misleadingly vacuous metaphor’:[[39]](#footnote-39)

All that [the orthodoxy] really says, charitably interpreted, is that courts should consider the effect of an impugned measure on the interests of others, as well as on the interests of the applicant. This is not a moral principle, nor is it an account of what moral rights we have and when they can be overridden…[[40]](#footnote-40)

Thus it is misguided to attack the orthodox view of proportionality in virtue of its commitment to some form of utilitarianism, insofar as this implies ‘two unwarranted equations’:

first to equate balancing with utilitarian reasoning. And second, to equate judicial tests courts use to decide cases (which is an *epistemic* or heuristic task), with a theory of what human rights we have (which is a *constitutive* moral question).[[41]](#footnote-41)

On Letsas’ view, ‘[j]udicial tests employed by human rights courts are [merely] diagnostic institutional tools that help the courts reach outcomes’.[[42]](#footnote-42) It follows that mechanically working our way through a doctrinal test of proportionality is unlikely in and of itself to yield a plausible account of the content of *right DR.* What then are we to do? Letsas argues that for the purposes of retrospective analysis of the outcomes in human rights cases, ‘[a]ny attempt to reconstruct what courts do under the heading of proportionality should… begin with normative arguments about the nature of human rights as moral rights made independently of legal practice’.[[43]](#footnote-43) Thus theories of rights can help explain and evaluate judicial decisions about whether interference with a Convention freedom is justified.

I advance that Letsas’ explanatory account of proportionality is also applicable *ex ante* to the question of what domestic courts or the ECtHR *ought* to do when asked to decide cases that bear on the content of Convention rights. Thus proportionate interference with *P*’s *freedom D* should track the content of *P*’s *right DR* according to the distribution of rights yielded by the most attractive moral theory. Of course, there is disagreement about the nature of rights.[[44]](#footnote-44) In the next sections, therefore, I consider *right DR* in light of two rival theories of human rights, the *interest* view and the *reason-blocking* view.[[45]](#footnote-45) Since both theories yield a substantively identical right to refuse LPT, it is not necessary to consider which of these theories is most plausible,[[46]](#footnote-46) or which theory best explains the jurisprudence of the ECtHR.[[47]](#footnote-47)

### The interest theory

According to the interest theory of rights, ‘[r]ights protect objective interests of individual well-being that are important enough to impose duties on others’.[[48]](#footnote-48) As Letsas notes, the possession of an interest is a necessary, but not sufficient condition for *P*’s possession of a right to φ.[[49]](#footnote-49) Rather, the ‘conditions for when an interest generates a right depends on factors such as the nature of the interest and how demanding it is to impose a duty on others to respect or promote it’.[[50]](#footnote-50) As such, the interest view requires the ‘balancing’ of *P*’s interests with those of others. Letsas argues that this balancing exercise is non-utilitarian in nature:

[A] type of cost–benefit analysis would be part and parcel of what courts would have to do to discover what human rights we have… According to the [interest theory], costs and benefits are moralized notions, viewed from the objective standpoint of the importance of different interests for our well-being and without being committed to the need to maximize the serving of those interests.[[51]](#footnote-51)

On the interest theory therefore, *P* possesses *right DR* iff her interest in refusing LPT is sufficient to impose a duty to uphold it on the State. Thus we require an account of the interests engaged in *P*’s refusal of LPT, and an assessment of the costs of respecting *P*’s refusal. Since our discussion relates to the proportionality of interference with *P*’s freedom to decide how and when to die, *P*’s interest in autonomy should be our starting point.

#### Autonomy

It seems an uncontroversial observation that many individuals value the exercise of autonomy, attach priority to it over other valuable goods, such as pleasurable experience,[[52]](#footnote-52) and consequently believe that interference with autonomous choices requires compelling justification. Of course, this is not sufficient to establish autonomy’s axiological or normative significance.

It is possible to explain the value of autonomy both in instrumental and intrinsic terms. On the instrumental view, autonomy has value to the extent that it helps achieve better outcomes, such as increases in prudential or aggregate welfare.[[53]](#footnote-53) Thus the weight of an individual’s interest in autonomy, and consequently whether she possesses an autonomy-derived right such as *right DR*, depends on the relation between self-determination and what else matters. In what follows, I assume that autonomy derives instrumental value from its contribution to welfare.[[54]](#footnote-54)

Many philosophers argue that autonomy (also) has intrinsic value.[[55]](#footnote-55) Thomas Hurka explains of autonomy’s intrinsic value in terms of agency:

There is intrinsic value in the autonomous choice of important goals… And the value of these choices can be captured under the heading of agency. Someone who chooses, in the fullest sense, among forms of life determines not only that she lives in one way, but that she does not live in others. Her autonomy makes her responsible, not just for the positive fact that her life has one shape, but for the negative facts that it does not have various other shapes… to be autonomous, to choose among life-options, is to determine more of what is true than if one is constrained.[[56]](#footnote-56)

Hurka ascribes relatively weak intrinsic value to autonomy. The claim that ‘free choice… is no isolated good, but follows with other goods from more fundamental values’ implies that ‘[a]utonomy is just one value among others, with no special weight and no special [normative] standing’.[[57]](#footnote-57) Hurka’s conception of autonomy thus provides a useful basis for discussion of the content of *right DR*. For if a relatively weak conception of autonomy gives rise to *right DR* on the interest theory, conceptions that assign autonomy more value or more moral weight will also imply *right DR*.

Hurka writes that ‘[i]f autonomy is intrinsically good, any restriction of choice has some morally undesirable effects’.[[58]](#footnote-58) Therefore, interference with *P*’s autonomous refusal of LPT entails moral cost for the agent (henceforth *Q*) who treats *P*; *P*’s autonomy is intrinsically valuable, and its violation makes out a pro tanto moral wrong. Thus all else being equal, *P’s* autonomy provides a reason in favour of imposing a duty on *Q* to respect *P*’s refusal of LPT, such that *P* possesses *right DR*. The interest theory, together with the view that autonomy has intrinsic value, implies that restricting *P*’s freedom to refuse of LPT in the absence of other morally relevant considerations is disproportionate.

The next stage in our proportionality exercise requires ‘balancing’ autonomy against the relevant article 8(2) ECHR ‘legitimate aims’ identified earlier—welfare, morals, and the interests of others.[[59]](#footnote-59)

#### Welfare

Unless we commit to a theory of prudential value according to which being alive always equates to faring well, paternalistic considerations cannot support the argument that *P* never possesses *right DR*. All else being equal, if *P* is reasonably expected to experience surplus suffering, welfare considerations do not count against the existence of *right DR*. However, the paternalist might concede that *P* possesses *right DR* *unless* *P* is expected to fare well on balance in the future, in which case *P*’s interest in welfare permits *Q* not to respect *P*’s autonomous refusal of LPT. The claim is therefore that *P* possesses a substantively qualified *right DR* because *Q*’s reasons to promote *P*’s welfare are stronger than those to respect her autonomy.

If the value of autonomy merely derives from its instrumental contribution to welfare, it may seem to follow that when respecting *P*’s autonomy fails to promote her welfare, autonomy has no value. Therefore, in circumstances when respect for a refusal of LPT is inconsistent with *P*’s welfare, there can be no *right DR*. However, this conclusion is somewhat hasty. We might nevertheless be required to respect *P*’s autonomy all the time for certain situation-types, notwithstanding that respecting autonomy would not promote *P*’s welfare in certain situation-tokens. Thus *right DR* may extend to all refusals of LPT, notwithstanding that some such refusals would be inconsistent with *P*’s welfare.

The justification for this approach to *right DR* is twofold. First, there may be epistemic uncertainty as to whether overriding *P*’s autonomous refusal will in fact promote her welfare. This uncertainty has two facets: it may be difficult to predict the impact of interference with autonomy on any one individual’s welfare, given variations between individuals in the experiential effects of such interference or in their preferences thereabout, and uncertainty about the benefits of treatment; welfare-promoting forced medical treatment may also negatively affect *P*’s welfare, insofar as it at minimum requires physical or psychological interference, and potentially physical restraint and deprivation of liberty. It is not implausible, therefore, that we would lack epistemic access to the answer whether intervention to override a refusal of LPT would make any one *P* fare better or worse, prudentially speaking. Faced with this uncertainty, we might therefore adopt a decision rule that denies that interference with a refusal of LPT promotes welfare. Second, were we to second-guess individuals’ autonomous decisions, this might undermine autonomy’s contribution to prudential good in general. There may be welfare-relevant instrumental value in allowing individuals to decide for themselves, notwithstanding that a particular decision may (or will) fail to exert a positive influence on an individual’s welfare, or cause the total loss of capacity for welfare—death. Thus considerations of prudential good may not provide ground for substantive limitation of *right DR*, even if autonomy is valuable only as a contributor to welfare.

If autonomy has intrinsic value in addition to instrumental value,[[60]](#footnote-60) the wrong that results from violating *P*’s autonomy adds moral cost to non-respect for a refusal of LPT. Whether the violation of autonomy operates to trump *P*’s interest in welfare—and thereby defeat any welfare-driven limitation of *right DR*—will depend on the relative intrinsic value of autonomy (and values such as agency)[[61]](#footnote-61) and welfare. However, following John Stuart Mill one might also argue that autonomy (or ‘individuality’) is ‘one of the elements of well-being’.[[62]](#footnote-62) Accordingly, every violation of autonomy results in a pro tanto diminishment of welfare. Such diminishments need not be uncompensable; as Richard Kraut argues, ‘[s][omething valuable is lost when independence of mind is not developed or exercised; but certainly not everything’.[[63]](#footnote-63) However, the absence of bright line between *P*’s autonomous wishes and her prudential good, together with the claim that depriving *P* of the choice of how and when to die entails a significant violation of autonomy favours the conclusion that overriding a refusal of LPT entails substantial moral cost on balance. Thus if autonomy has intrinsic value, this fact likely supports the argument that *P*’s interest in welfare does not limit *right DR*.

Suppose the paternalist concedes that the balance falls in favour of autonomy in respect of contemporaneous refusals of LPT. She might nevertheless argue that this does not hold for advance refusals since *P* is not contemporaneously autonomous, and thus it is less clear that respecting *P*’s advance decision respects her autonomy. This argument encounters familiar difficulties. First, few individuals who lack decision-making capacity are mere automata with no conception of their own past; some may be all too conscious that their advance refusal is not respected.[[64]](#footnote-64) And individuals who lack capacity may possess preferences that are consistent with their autonomous selves.[[65]](#footnote-65) It is not certain that an individual with an advance refusal whose preferences or values are stable pre- and post-incapacity will comply with medical treatment. Therefore, forced treatment, with its attendant welfare costs, may be required.[[66]](#footnote-66) These factors raise the epistemic problem of identifying individuals whose welfare will be promoted through non-respect for an advance refusal. Second, it seems plausible that non-respect for advance refusals would undermine the general instrumental contribution of autonomy to prudential good in a similar fashion to non-respect for contemporaneous refusals. Third, if autonomy has intrinsic value, its violation is intrinsically wrong, and does not depend on facts about *P*’s knowledge of that state of affairs. Finally, for desire-theorists about prudential value,[[67]](#footnote-67) non-respect for an advance refusal may negatively impact on *P*’s welfare, notwithstanding that the frustration of *P*’s autonomous desire to refuse LPT is remote relative to *P*’s holding of the same desire.[[68]](#footnote-68)

With the preceding observations in mind, I advance that *P*’s interest in welfare is of insufficient strength to limit the scope of *right DR* to circumstances in which she autonomously wishes to refuse LPT *and* this wish aligns with prudential good. This is the case for both contemporaneous and advance refusals of LPT.

#### Morals

Recall that the interest theory yields rights just when ‘objective interests of individual well-being… are important enough to impose duties on others’.[[69]](#footnote-69) Might it be that *P*’s interest in autonomy is secondary to her duty to behave morally, such that the former cannot give rise to *right DR*?

This claim has some plausibility. However, *P*’sduty to adhere to moral standards is usually explainable in terms of rights others possess in virtue of the interest theory. For example, individuals have a defeasible interest in life that is of sufficient weight to underpin an extensive right not to be involuntarily killed.[[70]](#footnote-70)Therefore, reference to *P*’s duty to behave morally is ‘repetitive’ or superfluous.[[71]](#footnote-71) In other circumstances, however, the argument that *P* has a duty to lead a moral life does not clearly track other-regarding moral considerations. Rather, the claim may be that *P* has a duty not to live in a way that others regard as immoral, offensive, or disapproval-worthy, potentially because so to behave undermines ‘social cohesion’.[[72]](#footnote-72)

Refusal of LPT is thought impermissible on several moral views. For example, *vitalism* ‘requires human life to be preserved at all costs’;[[73]](#footnote-73) refusal of LPT curtails life, and is therefore impermissible. More moderately, on John Keown’s *inviolability* account, refusals of LPT are morally impermissible just when *P*’s refusal has suicidal intent.[[74]](#footnote-74) Either view may support a moralistic argument that substantively limits *P*’s freedom to decide how and when to die, either wholly such that *right DR* not exist (*vitalism*), or in part such that *right DR* does not extend to suicidal refusals (*inviolability*).

Refusal of LPT, however, is not clearly immoral. *Vitalism* is not a plausible moral theory; attempting to preserve life at all costs would likely cause great suffering, and potentially be self-defeating in its intense use of resources. *Inviolability* disallows only suicidal refusals of LPT, whose impermissibility relies on the existence of basic human goods (one of which is life) and the principle that intentional behaviour inconsistent with a basic good is an absolute moral wrong.[[75]](#footnote-75)

Suppose the *inviolability* view is true, and suicidal refusals of LPT are morally impermissible. Alternatively, suppose that *inviolability* is false, but suicidal refusals of LPT are nevertheless generative of widespread opprobrium.[[76]](#footnote-76) The balancing of *P*’s autonomy interests and the ‘protection’ of morals might nevertheless require that individuals possess a blanket *right DR*, because of the risk of false positives, that is, permissible conduct that is wrongly identified as impermissible, in virtue of the harms attendant on forcing treatment on individuals mistakenly thought to intend suicide while refusing treatment. John Keown concedes as much:

in order to avoid the injustice of doctors forcing treatment on patients who are wrongly suspected of refusing treatment with intent to kill themselves, the law could properly require doctors to respect all competent refusals of treatment, without in any way endorsing those which are suicidal.[[77]](#footnote-77)

Therefore, even if we concede that morals might constitute a relevant counterweight to *P*’s autonomy, we might doubt whether the former provides ground for the substantive limitation of *right DR*.

#### The interests of others

To what extent might other-regarding considerations outweigh an individual’s autonomy interests such as to deny or limit her right to refuse LPT? Let us first consider two arguments from welfare, before moving on to arguments from the right to life and population health.

The moralist might advance the following argument from welfare: *P*’s immoral conduct of her own life, in our case, the refusal of LPT, is so outrageous that it has an impact on another welfare subject (henceforth *R*), and *R*’s welfare interest is sufficiently important to defeat *P*’s right to refuse LPT. This argument seems wildly implausible.[[78]](#footnote-78) We might reasonably think that the negatives associated with violating *P*’s autonomy and forcing treatment would always outweigh any negative impact of *P*’s ‘immorality’ on *R*’s welfare, such that *R*’s moralistic welfare interest could never defeat *P*’s interest in autonomy. However, it might be counter-argued that while any one *R*’s welfare is not significantly affected by *P*’s refusal of LPT, if many individuals share the same moralistic states of mind or a few individuals experience particularly intense and persistent moralistic outrage, the aggregate negative effect on welfare may be very significant, and sufficient to outweigh the aggregate negatives for any number of individuals whose refusal of LPT is overridden*.*

Recall, however, that the interest theory’s cost-benefit analysis is ‘moralised’, that is, it need not commit to the promotion of interests that apparently maximise the net aggregate welfare of a particular population;[[79]](#footnote-79) we may discount interests if there are plausible moral reasons for so doing. Robert Goodin argues that, *inter alia*, individuals’ *implicit preferences for preferences* may justify the *laundering* of preferences such that ‘certain classes of desires and preferences [do not count] when aggregating individual utilities’.[[80]](#footnote-80) Implicit preferences for preferences are the ‘logical relations among those preferences that people *do* acknowledge which imply certain other preferences that they may fail to acknowledge’.[[81]](#footnote-81) To the extent that these implicit second-order preferences possess greater moral importance than individuals’ expressed first-order preferences,[[82]](#footnote-82) it may be permissible to launder moralistic welfare interests that might otherwise defeat *P*’s possession of *right DR*. For beneath the explicit preference not to have one’s welfare negatively impacted by the immoral behaviour of others appears to lie a preference that speaks to the freedom to live one’s life according to beliefs of one’s own choosing, in this instance, a particular moral code. Yet it seems difficult to deny the universalizability of this preference, that is, the extension of its benefit to other individuals. Yet so universalised, the second-order preference appears to require the discounting of the first; the freedom to follow one’s *conception of the good life* requires giving up any claim to restrain others in their pursuit of the same. This is not to diminish the negative impact that an individual’s ‘immoral’ refusal of LPT may have the moralist’s welfare. It is merely to deny that preferences to avoid such impacts count in the balance when establishing what rights individuals possess.[[83]](#footnote-83)

Perhaps more promising arguments for restricting refusal of LPT arise when *P*’s refusal impacts on the welfare or autonomy of others in a direct sense, that is, unmediated by moralism. One such argument stems from the welfare interests of loved ones.[[84]](#footnote-84) Here it is advanced that we should disallow *P*’srefusal of LPT just when it causes her close personal relations to suffer emotionally or materially. On a straightforward balancing exercise, we might again suggest that in any one case the negative consequences of *P*’s refusal of LPT are perhaps unlikely to be outweigh the moral costs associated with overriding *P*’s refusal of LPT. In addition, it seems plausible that negative consequences for loved ones do not always accompany refusals of LPT.[[85]](#footnote-85) Thus we might advance that the aggregate welfare implications of refusal of LPT may not be particularly significant. However, since these are empirical matters, it is possible to counterargue that the negative consequences that result from refusal of LPT would at least sometimes be substantial. This raises anew the issue of balancing in the presence of epistemic uncertainty. Should we limit *right DR* to circumstances in which we know that others will not suffer substantially? Again, I would argue no. If we are uncertain as to whether close personal relations will be substantially worse off in individual cases of refusal of LPT, we ought not to qualify *right DR* because of the moral costs that attach to mistakenly overriding a refusal of LPT when that refusal would not in fact make loved ones worse off. There is a further reason why we ought not to limit *right DR* out of concern for the welfare of loved ones. To limit *right DR* on this ground implies not only that we ought to take into account the interests of loved ones in our decision-making but also that we ought to do what would be best for those others, if the pairwise comparison of our own and their interests favoured the latter. This seems a highly unintuitive characterisation of the obligations that attach to close personal relationships, at least when important decisions about how (not) to live are in play.

A second other-regarding argument is what we might call the *vulnerability* argument. This argument rests on an empirical premise: permitting individuals to decide how and when to die opens the door to coercion, undue influence, and manipulation, which in turn may result in externally-induced invalid refusals. On the basis of this empirical premise, the proponent of the *vulnerability* argument might advance that the autonomy interests of individuals who wish to exercise *freedom D* require balancing against the autonomy and welfare interests of individuals susceptible to make externally-induced invalid refusals. In addition, a *vulnerability* argument proponent might claim that it is worse for any number of individuals to refuse LPT involuntarily than it is to compel individuals who would otherwise refuse LPT voluntarily to stay alive.

It would be cavalier to dismiss the *vulnerability* argument out of hand. However, it is difficult to know how much weight to attach to it. There are both normative and empirical factors to consider. In respect of the normative, the weight we attach to the *vulnerability* argument will in part depend on our views about interpersonal aggregation.[[86]](#footnote-86) While it is perhaps plausible that, all else being equal, it is worse to kill one individual involuntarily than it is to force treatment (and life) on another, the involuntary killing of a few is not obviously worse than the forced treatment of many. In respect of the empirical, we must consider the extent to which permitting refusals of LPT will cause the risk of involuntary killing to materialise, whether the incidence of risk is within acceptable limits given our theory of aggregation, and whether anything short of universal prohibition on refusal of LPT might acceptably mitigate the risk.

If it is legitimate to draw a parallel between refusals of LPT and assisted death, it is noteworthy that the *vulnerability* argument is very frequently invoked by opponents of assisted death in both academic and public fora.[[87]](#footnote-87) This is notwithstanding that the evidence base for the risk materialising is weak.[[88]](#footnote-88) Contrariwise, the claim that individuals will be coerced or unduly influenced to refuse LPT does not feature in academic commentary on treatment refusal. And if the experience of England and Wales is any guide to public debate, the *vulnerability* argument was seldom fielded during parliamentary discussions that led to the placement of advance refusals on a statutory footing.[[89]](#footnote-89) This is notwithstanding that in respect of advance refusals, the individual required to respect *P*’s wishes is usually not present when the refusal is made, and as such does not have first-hand knowledge as to *P*’s voluntariness (or indeed capacity) at the time the decision was executed.[[90]](#footnote-90) Perhaps the empirical premise on which the *vulnerability* argument rests is not thought in play in the context of refusals of treatment? Alternatively, it may be that the *vulnerability* argument is not deployed in the debate over the content of *right DR* because concerns about *P*’s voluntariness (or capacity) can be assuaged through procedural requirements designed to evince that *P*’s (contemporaneous or advance) refusal is autonomous.[[91]](#footnote-91) To disallow refusals of LPT would tip the scales too much; the protection of the vulnerable, at least in respect of refusals of LPT, need not come at the expense of the autonomy interests of individuals who wish to avail themselves of *freedom D*. For this reason, the *vulnerability* argument ought not to provide a foundation for constraining *right DR*.[[92]](#footnote-92)

Considerations of population health may, however, serve as a plausible substantive restriction on any right to refuse medical treatment, including LPT. Frances Kamm writes that the ‘right [to refuse treatment] is, to be sure, not absolute and can sometimes be overridden by considerations of public safety’.[[93]](#footnote-93) Thus if *P* refuses treatment for, for example, an infectious disease, and the health or lives of *R*(s)are endangered as a consequence, *R*’s interests in welfare/autonomy might plausibly outweigh *P*’s interest in autonomy. However, given the rarity of infectious disease outbreaks, any population health limitation on *right DR* would probably be relatively limited in scope.[[94]](#footnote-94)

#### Conclusion on the interest theory

I argue that the interest theory yields a right to refuse LPT that is substantively extensive. I advance that *P*’s prudential interests, moralistic considerations, the welfare interests of loved ones, and the *vulnerability* argument are of insufficient weight to defeat *P*’s possession of *right DR* derived from her interest in autonomy*.* However, it is plausible that *right DR* reaches its limit when *P*’s refusal poses a threat to population health. This seems to be a modest exception to the right to refuse LPT. As we have seen, however, the interest view balancing exercise is complex, and other distributions of *right DR* may be possible in light of our views about prudential value and interpersonal aggregation.

### The reason-blocking theory

The reason-blocking theory starts from a denial that ‘the point of rights is to protect interests of individual well-being’.[[95]](#footnote-95) Rather, the view attaches primacy to the individual’s right to be treated with equal respect and concern by the State.[[96]](#footnote-96) It is from this fundamental right to equality that other rights derive.

On the *reason-blocking theory*, the specification of rights takes place by way of an assessment of the compatibility of State conduct with the right to equal respect and concern. By the same token, ‘the judicial test of proportionality [involves] an inquiry into whether the government offended the status of the applicant as an equal member of his political community’.[[97]](#footnote-97) This enquiry has exclusive and inclusive facets. The exclusive element of specification excludes ‘considerations that are normally irrelevant to what equal respect and concern requires’,[[98]](#footnote-98) that is, it discounts ‘empirical facts [that] are not normative reasons for action in virtue of the value of equal respect and concern’ from forming part of the basis for denying (or indeed granting) an individual a right.[[99]](#footnote-99) These excluded considerations, Letsas argues, include an individual’s ‘religion… political and philosophical beliefs… conception of the good life… lifestyle choices… genetic or biological condition… and many others’.[[100]](#footnote-100) The inclusive element of specification requires attention to whether the State has ‘employed a blanket or indiscriminate measure that prevents it from taking into account morally relevant considerations’ that would justify individuals receiving different treatment in virtue of differing circumstances.[[101]](#footnote-101)

In contrast to the interest theory, the specification of *right DR* on the reason-blocking theory is a relatively uncomplicated affair. What right to refuse LPT does the reason-blocking theory yield, taking into account the relation between equal respect and concern and *P*’s autonomy, and arguments from *P*’s welfare, the protection of morals, other-regarding considerations?

Let us treat considerations of *P*’s welfare and the protection of morals together, since similar reasoning applies to both grounds. In either case, we should deny that paternalistic or moralistic considerations are relevant to the determination of the contours of *right DR*. Recall that when *P* exercises her autonomy, she, as Hurka puts it, ‘determines not only that she lives in one way, but that she does not live in others’.[[102]](#footnote-102) To the extent that valid refusals of treatment are manifestations of *P*’s autonomy, therefore, we might argue that *P*, by her refusal, follows her own conception of the good life.[[103]](#footnote-103) If so, *P*’s refusal of LPT ‘trumps’ paternalistic or moralistic considerations, because to hold otherwise would be inconsistent with *P*’s right to equal respect and concern. To fail to respect *P*’s refusal of LPT on grounds that it is not prudentially good, or immoral, is to hold her autonomous choices in lesser esteem than those of others who choose differently. It may be better prudentially or morally better for *P* not to refuse LPT, but equal respect and concern includes, to adopt the language of the ECtHR, ‘the opportunity to pursue [self-regarding] activities perceived to be of a physically or morally harmful or dangerous nature’.[[104]](#footnote-104) The alternative, ‘[m]aking someone die in a way that others approve’, Ronald Dworkin argued, ‘is a devastating, odious form of tyranny’.[[105]](#footnote-105)

Turning to other-regarding considerations, the above argument applies *mutatis mutandis* to the argument from the welfare of loved ones, and the moralistic argument from welfare; the right to equal respect and concern blocks these facts from supplying reasons to limit *right DR*. However, the *vulnerability* argument and public health considerations appear prima facie to be factors that warrant inclusion in the specification of *right DR*, and as such deserve closer attention.

As we saw above, according to the *vulnerability* argument permitting individuals to decide how and when to die gives rise to voluntariness concerns, whose consequence is, for our purposes, that individuals refuse treatment to which they would consent, absent autonomy-undermining influence. Framed in terms of the reason-blocking theory, a proponent of the vulnerability argument might say that allowing refusals of LPT violates the right to equal respect and concern of individuals exposed in consequence to pressure to end their own lives, insofar as the State ranks the liberty of the vulnerable lower than those individuals who would avail themselves of *right DR*.

The *vulnerability* argument appears to point to a shortcoming in the reason-blocking theory, for it identifies a scenario that requires choosing between *Policy*1 {allowing refusals of LPT} and *Policy*2 {disallowing refusals of LPT} in which pursuing *Policy*1 violates the right to equal respect and concern of some population A, whereas pursuing *Policy*2 violates the right to equal respect and concern of some population B. In such circumstances, the reason-blocking theory apparently fails to yield a determinate answer as to the (existence or) content of *right DR*, since there is no option consistent with equal respect and concern for all community members.[[106]](#footnote-106)

We need not choose, however, between *Policy*1 and *Policy*2. It is plausible that a measure mandating respect for *all* refusals of LPT without reference to the autonomous quality of the decision would violate the right to equal respect and concern of some individuals. However, since the reason-blocking theory requires *P* to be autonomous in order to possess *right DR*, it can accommodate the *vulnerability* argument. Thus provided we enshrine *right DR* within a procedural framework that evinces that *P*’s (contemporaneous or advance) refusal is autonomous, we need not to pit the equality of individuals who would refuse LPT against that of individuals vulnerable to improper external influence.

In respect of the argument from population health considerations, the situation in which *P* endangers *R* directly by refusing treatment, for example, for an infectious disease, provides a plausible ground for circumscribing *right DR.* Arguably, for *P* to behave in such a fashion exhibits a lack of respect and concern for others in a way that risks seriously impairing *R’*s pursuit of the good life. It seems plausible that on the reason-blocking view *P* has no right so to behave,[[107]](#footnote-107) and contrariwise by respecting *P*’s refusal in such circumstances the State would violate its obligation to promote the public health of individuals within its jurisdiction.[[108]](#footnote-108)

Identical to the interest theory of rights, therefore, the reason-blocking theory yields a right to the right to refuse LPT that is substantively extensive. However, when *P*’s refusal threatens population health, limitation of the right to refuse is likely to be proportionate.[[109]](#footnote-109)

# The structural margin of appreciation

I have argued that *right DR*, properly specified, affords individuals a substantively extensive right to refuse LPT. Interference with *right DR* is likely to be proportionate only in situations in which respect for *P*’s autonomy requires setting aside her advance refusal, on the rare occasion that *P*’s refusal threatens population health, and to the extent that procedural requirements are necessary to ensure *P*’s refusal of LPT is in fact a manifestation of *freedom D*. State interference with refusals of LPT that deviates from *right DR* so conceived, therefore, will be inconsistent with article 8 ECHR.

Article 1 ECHR enjoins Council of Europe Member States to secure the Convention rights and freedoms to all individuals within their jurisdiction. An individual who claims that the State has behaved in a way that is incompatible with her ECHR rights may be able to invoke the Convention in proceedings against the relevant public authority,[[110]](#footnote-110) and national courts may have an obligation to read and give effect to legislation in a way that is consistent with the ECHR rights.[[111]](#footnote-111) As such, a State that fails to make, or makes only limited, provision for contemporaneous or advance refusals of LPT risks litigation whose aim is to (re)align domestic law with *right DR*.

Of course, there is no guarantee that national courts will accept the argument that there exists a substantively extensive right to refuse LPT, and that this right extends to contemporaneous and advance refusals in almost equal measure. An individual who has exhausted all domestic remedies might consequently apply to the ECtHR for judgment as to whether the State has violated her Convention rights, which would in principle require the Court to consider the content of *right DR*.[[112]](#footnote-112)

As Letsas notes, however, the ECtHR employs a *structural* concept of the margin of appreciation ‘to express the degree to which the Court will rely on an earlier decision of the national authorities and refrain from second-guessing whether, in its own view, the right has been violated’.[[113]](#footnote-113) Thus the ECtHR may decline to examine the merits of a case, *inter alia*, in virtue of the state of *consensus* among Member States on the existence and extent of the relevant right.[[114]](#footnote-114) As the Court held in *Evans v United Kingdom*, the less consensus, the *wider* the margin of appreciation, and, consequently, the more latitude accorded to the State.

Where… there is no consensus… either as to the relative importance of the interest at stake or as to the best means of protecting it, particularly where the case raises sensitive moral or ethical issues, the margin will be wider.[[115]](#footnote-115)

A detailed examination of the state of consensus within the Council of Europe in respect of refusals of LPT warrants (and would require) a paper of its own. I will, however, sketch an argument that there is sufficient consensus for the ECtHR to consider the content of *right DR*. My contention may seem unpromising in light of the Court’s observations on the margin of appreciation in its assisted suicide jurisprudence. In *Haas v Switzerland*, the Court held that ‘Member States are far from having reached a consensus as regards the right of an individual to choose how and when to end his life… states have a wide margin of appreciation in that respect’.[[116]](#footnote-116) If this appraisal refers to the totality of *right D*, ECtHR consideration of the content of *right DR* seems unlikely. However, I think we should read the Court’s dictum restrictively; we should take it to concern only the structural margin of appreciation with regard to physician-assisted death.

As a general interpretive matter, we should be cautious to infer a determination on any issue broader than the matter under consideration.[[117]](#footnote-117) More practically, the state of consensus among Member States with regard to physician-assisted death is significantly different to that in respect of refusals of LPT. As the ECtHR noted in *Koch v Germany*, ‘[o]nly four [Member States allow] medical practitioners to prescribe a lethal drug in order to enable a patient to end his or her life’.[[118]](#footnote-118) By contrast, there is substantial evidence of permissive consensus on contemporaneous refusals of LPT in law,[[119]](#footnote-119) and evidence of an emerging consensus in the same direction for advance refusals of LPT.[[120]](#footnote-120) Moreover, we should note that the ECtHR does not require a plurality, majority, or greater amount of agreement among Member States to find consensus on an issue. As the Court noted in *Goodwin v United Kingdom*, a numerical approach may set the bar too low:

[S]ince the Convention is first and foremost a system for the protection of human rights, the Court must have regard to the changing conditions within the respondent State and within Contracting States generally and respond, for example, to any evolving convergence as to the standards to be achieved… A failure by the Court to maintain a dynamic and evolutive approach would indeed risk rendering it a bar to reform or improvement.[[121]](#footnote-121)

Thus it may be that the ECtHR will find consensus on the basis of (at best) a modest convergence in Member State practice, which I have demonstrated in respect of both contemporaneous and advance refusals of LPT. Furthermore, the absence of consensus among Member States with regard to an issue need not determine that its regulation lies within the State’s margin of appreciation. In *Goodwin*, the ECtHR abandoned its finding in *Sheffield and Horsham v United Kingdom* that the absence of ‘common European approach to the problems created by the recognition in law of post-operative gender status’ precluded an examination of the substantive decision of the national authorities.[[122]](#footnote-122) However, the basis for departure was not greater agreement among Member States—little had changed in this regard—but rather ‘clear and uncontested evidence of a continuing international trend’ toward convergence among States outside the Council of Europe.[[123]](#footnote-123)

Tentatively, I argue that there is numerically sufficient consensus on both advance and contemporaneous refusals of LPT for the ECtHR to determine the content of *right DR*. Alternatively, if am wrong on the numerical issue, the ECtHR might nevertheless choose, consistent with *Goodwin*, to consider what set of arrangements for refusals of LPT are consistent with article 8 ECHR.

# Positive obligations in respect of *right DR*

Suppose that I am correct insofar as there exists an article 8 ECHR norm applicable to contemporaneous and advance refusals of LPT that Council of Europe Members States must adopt. Alternatively, suppose I am wrong, and that no such norm exists at present in virtue of the absence of Member State consensus; regulation of refusals of LPT thus falls within the margin of appreciation. Suppose also that, following my initial stipulation, a State aligns its legal regime with *right DR* as I frame it, or following my alternative stipulation, a State adopts a legal regime for refusals of LPT that is more permissive than a blanket ban. Suppose finally that in both scenarios individuals encounter difficulty refusing treatment in practice.[[124]](#footnote-124) Under these conditions, regardless of whether the content of *right DR* is subject to ECtHR supervision, the discrepancy between law and practice may lead to a violation of the Convention.

Rosamund Scott observes that ‘once a state has established a particular legal regime, the margin of appreciation *narrows* because the state can be held to account for not fulfilling its obligations within that regime’.[[125]](#footnote-125) This ground of accountability arises in virtue of positive obligations whose purpose is to guarantee that the Convention rights are ‘practical and effective’ as opposed to ‘theoretical and illusory’.[[126]](#footnote-126) The ECtHR has held that such obligations inhere in the right to private life protected by article 8 ECHR, including that to ‘secure… effective respect for [individuals’] physical and psychological integrity… even in the sphere of relations between individuals’.[[127]](#footnote-127) This may variously require the State’s:[[128]](#footnote-128)

provision of a regulatory framework of adjudicatory and enforcement machinery protecting individuals’ rights, and the implementation, where appropriate, of specific measures.[[129]](#footnote-129)

Commenting on the ECtHR’s abortion jurisprudence, Daniel Fenwick notes that once a permissive legal regime is in place, ‘the state’s margin of appreciation does *not* extend to the *manner* in which [abortion] is made available’.[[130]](#footnote-130) That is, the ECtHR will scrutinise the state’s discharge of its positive obligations under article 8 ECHR.[[131]](#footnote-131) In particular, the Court will consider: whether the state has ‘structure[d] its legal framework in a way which would limit real possibilities [for the exercise of the permitted activity]’; whether there exists ‘a procedural framework enabling [an individual] to effectively exercise her right of access to lawful [activities]’; and whether ‘the relevant decision-making process is fair and such as to afford due respect for the interests safeguarded by it’.[[132]](#footnote-132)

The principles set out in the ECtHR abortion jurisprudence have clear implications for refusals of LPT. If a State enshrines contemporaneous or advance refusals in law, it must provide a legal framework that enables individuals who meet the legal criteria to refuse treatment in practice. This plausibly entails, *inter alia*, effective mechanisms for determining whether *P*’s refusal of LPT is valid, and the ability to challenge medical decision-making,[[133]](#footnote-133) ideally prior to the administration of LPT, and certainly before the meaningful exercise of *right DR* is moot.[[134]](#footnote-134) As the ECtHR observed in *Tysiac v Poland*, retrospective measures alone may fail to provide adequate protection for private life, even assuming robust implementation of such regimes.[[135]](#footnote-135) Thus the possibility of civil, criminal, and regulatory sanctions on medical behaviour that fails to respect refusals of LPT may not suffice. Moreover, a Convention-compliant legal regime should not incentivise non-respect for refusals of LPT. Such incentives might take the form of more rigorous assessment of medical conduct respectful of a refusal of LPT than that which disregards the same,[[136]](#footnote-136) or a lack of adequate guidance in respect of the substantive conditions for the exercise of the right,[[137]](#footnote-137) against a backdrop of serious sanctions in the case of erroneous respect for refusal. As the ECtHR observed in *A, B, C v Ireland*, asymmetries in the respective costs of erroneously allowing or restricting the exercise of the relevant right, and uncertainty in the application of the law are liable to ‘constitute a significant chilling factor’ for individuals and physicians contemplating a legally permitted course of action.[[138]](#footnote-138) This is irrespective of the whether conduct falling outside the permitted scope of the legal regime will in fact incur sanction.

The ECtHR’s positive obligations regime, therefore, presents clear risks for States that pay lip service to refusals of LPT, or that fail effectively to implement the law.[[139]](#footnote-139)

# Conclusion

I have argued that there exists a substantively extensive right to refuse LPT, which I called, *right DR*, that is derivable from the *freedom to decide how and when to die* that the ECtHR recognises as part of the protection of private life under article 8 ECHR.

An individual’s freedom to decide how and when to die engages article 8(1) ECHR when she autonomously refuses LPT, whether contemporaneously or in advance. Since article 8 ECHR is a qualified right, interference with an autonomous refusal of LPT may be permissible. I considered whether interference with a refusal of LPT whose aim is to safeguard welfare, morals, or the rights and freedoms of others would satisfy the Convention requirement of *proportionality*. Drawing on Letsas’ work, I advanced that philosophical investigation permits us to determine the content of *right DR* *ex ante*, that is, in the absence of any ECtHR decision on the issue. I appealed to two rival theories of human rights: the interest theory and the reason-blocking theory. My analysis of *right DR* under these views yields a right to refuse LPT (both contemporaneous and advance) tempered only by considerations of population health. If my conclusions on the content of *right DR* are persuasive, there are significant implications for those Council of Europe jurisdictions whose legal regimes for refusal of LPT are inconsistent with *right DR* so framed.

A failure to enshrine *right DR* (as I conceive) it in domestic law in principle violates the Convention. However, the ECtHR might nevertheless decline to examine the content of *right DR* by invoking an absence of consensus among Member States on its existence and extent. I attempted, *inter alia*, to demonstrate that there is sufficient consensus among Council of Europe Member States on refusals of life-prolonging treatment to justify ECtHR supervision of domestic law. However, my survey of Member States’ legal regimes for contemporaneous and advance refusals is not comprehensive, and further research to assess the state of consensus on refusals of life-prolonging treatment is necessary. That said, we should not forget that the ECtHR has exercised its supervisory jurisdiction in cases where consensus among Member States with regard to the relevant right has been quite lacking.

Finally, I argued that States that take a permissive stance toward refusals of life-prolonging treatment may violate the positive obligations that the ECtHR has found to inhere in article 8 ECHR, in the event that individuals cannot exercise their legal right to refuse LPT in a practical and effective manner. It is not sufficient for States merely to permit refusals in law. Moreover, there apparently exists widespread professional reluctance to respect valid refusals of treatment. As such, it is perhaps on the terrain of positive obligations that we are most likely to see ECtHR intervention on the right to refuse life-prolonging treatment.

1. My argument is likely to apply *mutatis mutandis* to any refusal of medical treatment. However, because I draw the right to refuse life-prolonging treatment under ECHR law out of cases relating to assisted death, I prefer not to beg the question of any wider right to refuse treatment. [↑](#footnote-ref-1)
2. Elizabeth Wicks, ‘The right to refuse medical treatment under the European Convention on Human Rights’ (2001) 9(1) Med Law Rev 17. [↑](#footnote-ref-2)
3. See eg *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam). [↑](#footnote-ref-3)
4. See footnote text at nn 119-120. [↑](#footnote-ref-4)
5. European Convention on Human Rights www.echr.coe.int/Documents/Convention\_ENG.pdf accessed 17/01/01: Right to respect for private and family life

   1. Everyone has the right to respect for his private and family life, his home and his correspondence. [↑](#footnote-ref-5)
6. *Pretty v United Kingdom* (2002) 35 EHRR 1 (ECtHR) [61], [65], [67]. [↑](#footnote-ref-6)
7. *Haas v Switzerland* (2011) 53 EHRR 33 (ECtHR) [51]. [↑](#footnote-ref-7)
8. *See Glass v United Kingdom* [2004] 1 FCR 553; Application no 61827/00 (ECtHR (Fourth Section)); *R (oao Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors* [2014] EWCA Civ 822; *Winspear v City Hospitals Sunderland NHS Foundation Trust* [2015] EWHC 3250 (QB). [↑](#footnote-ref-8)
9. See *Sanles v Spain* 48335/99 (Unreported, 26 October 2000) (ECtHR); *Pretty* (n 6); *Haas* (n 7); *Koch v Germany* (2013) 56 EHRR 6 (ECtHR); *Gross v Switzerland* (2014) 58 EHRR 7 (ECtHR); *Gross v Switzerland* (2015) 60 EHRR 18 (ECtHR); *Nickinson v United Kingdom (Admissibility)* (2015) 61 EHRR SE7 (ECtHR). [↑](#footnote-ref-9)
10. eg In respect of assisted death, an individual might assert a right to non-interference against the State in respect of legislation that punishes (and thereby discourages) assistors, and a right to third party assistance to die. [↑](#footnote-ref-10)
11. eg Suicide Act 1961, s 2(1). [↑](#footnote-ref-11)
12. eg The exercise of *right D* may be in tension with a general or specific right to conscientious objection afforded to health professionals; or individuals wishing to exercise *right D* may require, as a matter of course, official ‘sanction’ from a court or other body. [↑](#footnote-ref-12)
13. See Leif Wenar, ‘The Nature of Rights’ (2005) 33(3) Phil Pub Affairs 223. [↑](#footnote-ref-13)
14. The freedom/rights distinction is attributable to: George Letsas, *A theory of interpretation of the European Convention on Human Rights* (OUP 2007) 84. [↑](#footnote-ref-14)
15. See *R (oao Pretty) v DPP* [2001] UKHL 61. [↑](#footnote-ref-15)
16. *Hasan v Bulgaria* (2002) 34 EHRR 55 (ECtHR); See *R (oao Purdy) v DPP* [2009] UKHL 45 for discussion of the Convention principle of legality in the context of assisted death. [↑](#footnote-ref-16)
17. At least, not for this reason. Insofar as article 8(1) ECHR covers the ‘physical and moral integrity of the person (*Haas* (n 7)[50]), its protection might be engaged in respect of non-autonomous individuals for some reason other than *freedom D*. See *X v Netherlands* (1985) 8 EHRR 235 (ECtHR); *Glass* (n 8); *P v Poland* [2013] 1 FCR 476 (ECtHR). [↑](#footnote-ref-17)
18. *Pretty* (n 6)[63]. [↑](#footnote-ref-18)
19. I submit that the difference between the ECtHR’s formulation ‘capable of engaging…’ and my formulation ‘engages article 8(1) ECHR’ is not meaningful. First, the Court’s circuitous language may be attributable to refusals of LPT not being the litigated issue in *Pretty*. Second, ‘capable of engaging…’ may reflect a *ceteris paribus* qualification: see text at n 20. Third, in *X v Finland* [2012] ECHR 1371 (ECtHR) [212]-[223]the ECtHR affirmed that involuntary medical treatment administered under mental health legislation engages article 8(1) ECHR. Therefore, the Court’s ‘capable of engaging’ formulation in *Pretty* does not support the interpretation that article 8(1) ECHR is not engaged in circumstances in which an individual makes a valid refusal of treatment but is subject to involuntary mental health treatment. Rather, in such cases, article 8(1) ECHR is engaged, and the treatment requires justification under article 8(2) ECHR. [↑](#footnote-ref-19)
20. Presumably, interference with the refusal of a competent minor would also engage article 8(1) ECHR: Jane Fortin, ‘Accommodating Children's Rights in a Post Human Rights Act Era’ (2006) 69(3) MLR 299. [↑](#footnote-ref-20)
21. *Haas* (n 7) [51] (emphasis added). [↑](#footnote-ref-21)
22. There are two further arguments that potentially tell against article 8(1) ECHR’s engagement in respect of advance refusals. Detailed consideration of either is unfortunately beyond the scope of the present paper. First, according to what is variously termed the *slavery*, *identity* or *someone else* argument, while an advance refusal may constitute an attempt by *P* to exercise freedom *D*, at the time the decision falls to be executed the subject of the refusal is not *P*, but some other incapacitated person *S* who has not made an advance refusal: see eg Rebecca Dresser, ‘Dworkin on Dementia: Elegant Theory, Questionable Policy’ (1995) 25(6) Hastings Cent Rep 32; cf Ronald Dworkin, *Life's dominion: an argument about abortion, euthanasia, and individual freedom* (1st edn, Knopf 1993). The *slavery* argument relies on the loss of personal identity between *P* at t1 and t2 in virtue of an absence of psychological continuity: Derek Parfit, *Reasons and Persons* (Clarendon Press 1984) Part III. Since *P* and *S* are not identical, there is no subject to whom *P*’s advance refusal applies, and thus there is no relevant exercise of autonomy in respect of the manner and moment of death. One possible response to the *slavery argument* is to adopt the view—*animalism*—according to which personal identity consists in being numerically identical to an animal (or more restrictively, to a human animal): Eric T Olson, *The human animal: personal identity without psychology* (Oxford University Press 1997); David DeGrazia, ‘Advance directives, dementia, and 'the someone else problem'’ (1999) 13(5) Bioethics 373. Thus provided *P*’s animal exists at *t*1 and *t*2, the advance refusal is an autonomous decision taken by *P* at *t*1, for *P* at *t*2. Alternatively, we might accept the psychological continuity account of personal identity, but deny that this is a general problem for article 8(1) ECHR’s engagement when *P* makes an advance refusal. For the loss of personal identity is the exception (eg severe dementia), rather than the rule. In most cases, it seems plausible that sufficient psychological continuity exists between autonomous *P* at *t*1 and non-autonomous *P* at *t*2. Second, and somewhat trickier, according to the *self-knowledge* argument, *P*’s lack of knowledge about the values and beliefs she will hold when she lacks capacity makes it the case that any advance refusal is non-autonomous. Hence, article 8(1) ECHR would not be engaged. In respect of this *epistemic* concern about advance refusals, we might consider our present acts of self-interpretation to determine the values and beliefs that our incapacitated selves possess. As Christopher Buford argues, ‘[p]erhaps I know what my future self will want or value in virtue of expressing such attitudes now. That is, since I am now a person, capable of forming the higher-order desires needed to express such attitudes, and my future-self will not be in a position to express or form these attitudes, my expression of certain values makes it the case that my future self has these values as well’: Christopher Buford, ‘Advance directives and knowledge of future selves’ (2017) 3 Palgrave Communications 17077. [↑](#footnote-ref-22)
23. eg *Scozzari v Italy* (2002) 35 EHRR 12 (ECtHR) [143]. [↑](#footnote-ref-23)
24. eg *Acmanne v Belgium* (1984) 10435/83 (ECmHR). [↑](#footnote-ref-24)
25. See Christopher J Nowlin, ‘The Protection of Morals Under the European Convention for the Protection of Human Rights and Fundamental Freedoms’ (2002) 24(1) Human Rights Quarterly 264; *Handyside v United Kingdom* (1979-80) 1 EHRR 737 (ECtHR); Letsas (n 14) 120-123. [↑](#footnote-ref-25)
26. ‘Paternalism is the interference of a state or an individual with another person, against their will, and defended or motivated by a claim that the person interfered with will be better off or protected from harm’: Gerald Dworkin, ‘Paternalism’ [2016](Winter) Stanford Encyclopedia of Philosophy; Sarah Conly, *Against autonomy: justifying coercive paternalism* (CUP 2013) 17, text at n 3. [↑](#footnote-ref-26)
27. *Osman v United Kingdom* (2000) 29 EHRR 245 (ECtHR). [↑](#footnote-ref-27)
28. *Pretty* (n 6)[74], [69]. [↑](#footnote-ref-28)
29. eg *Haas* (n 7)[54]. [↑](#footnote-ref-29)
30. ibid, citing *Keenan v United Kingdom* (2001) 35 EHRR 38 (ECtHR) [91]; this has been recognised (in certain circumstances) in English Law: *Rabone v Pennine Care NHS Foundation Trust* [2012] UKSC 2. [↑](#footnote-ref-30)
31. It is implicit in the foregoing that the State’s positive obligation to take appropriate steps to safeguard the lives of individuals within its jurisdiction is non-absolute. The ECtHR Grand Chamber has held that while ‘Article 2 ranks as one of the most fundamental provisions in the Convention… 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 latter have a certain margin of appreciation… [in] striking a balance between the protection of patients’ right to life and the protection of their right to respect for their private life and their personal autonomy’: *Lambert v France* (2016) 62 EHRR 2 (ECtHR) [144], [148]. Indeed, it is the apparent non-absoluteness of the State’s positive obligations under article 2 ECHR that allows space for *right D* under article 8; *Lambert* ibid [142]: ‘reference should be made, in examining a possible violation of Article 2, to Article 8 of the Convention and to the right to respect for private life and the notion of personal autonomy which it encompasses’. Thanks to an anonymous reviewer for pressing me to explicate this point. [↑](#footnote-ref-31)
32. eg *P v Poland* (n 17) [94]: ‘According to the court’s settled case law, the notion of necessity implies that the interference corresponds to a *pressing social need* and, in particular, that it is *proportionate* to one of the legitimate aims pursued by the authorities (emphasis added)’. [↑](#footnote-ref-32)
33. The ECtHR has explained that ‘necessary’ for the purposes of the article 8(2) limitation clause ‘does not have the flexibility of such expressions as “useful”, “reasonable”, or “desirable, but implies a “pressing social need”’ for the interference in question, whose existence turns on the risks that attach to allowing the unimpinged exercise of the freedom in question: *Dudgeon v United Kingdom* (1982) 4 EHRR 149 (ECtHR) [52], [60]. [↑](#footnote-ref-33)
34. Letsas (n 14) 86. [↑](#footnote-ref-34)
35. eg In *Pretty* (n 6) [72]-[77], the discussion of the proportionality of State interference with the applicant’s *freedom D* takes place without reference to a standard of review. [↑](#footnote-ref-35)
36. See Robert Alexy, *A theory of constitutional rights* (Oxford University Press 2002). [↑](#footnote-ref-36)
37. George Letsas, ‘Rescuing Proportionality’ in Rowan Cruft, S. Matthew Liao and Massimo Renzo (eds), *Philosophical foundations of human rights* (1st edn, Oxford University Press 2015) 323. [↑](#footnote-ref-37)
38. ibid 324; See Guglielmo Verdirame, ‘Rescuing Human Rights from Proportionality’ in Rowan Cruft, S. Matthew Liao and Massimo Renzo (eds), *Philosophical foundations of human rights* (1st edn, Oxford University Press 2015). [↑](#footnote-ref-38)
39. See Letsas ibid 325-327 for the development of this argument. [↑](#footnote-ref-39)
40. ibid 327. [↑](#footnote-ref-40)
41. ibid 324-325 (original emphasis). [↑](#footnote-ref-41)
42. ibid 327. [↑](#footnote-ref-42)
43. ibid 328. [↑](#footnote-ref-43)
44. Wenar (n 13). [↑](#footnote-ref-44)
45. Again, I borrow the terminology from Letsas (n 14) 101. [↑](#footnote-ref-45)
46. See Wenar (n 13). [↑](#footnote-ref-46)
47. See Letsas (n 37) 330-339. [↑](#footnote-ref-47)
48. ibid 328; See Joseph Raz, *The morality of freedom* (Clarendon Press 1986) Chapter 7. [↑](#footnote-ref-48)
49. Letsas ibid 329. [↑](#footnote-ref-49)
50. ibid; See Raz (n 48) 181-182. [↑](#footnote-ref-50)
51. Letsas ibid; It is not obvious how far this view takes us from rule-utilitarian accounts of rights (see eg RB Brandt, ‘Utilitarianism and Moral Rights’ (1984) 14(1) CJPhil 1), but we need not dwell on this issue here. [↑](#footnote-ref-51)
52. Jonathan Glover, *Causing Death and Saving Lives: The Moral Problems of Abortion, Infanticide, Suicide, Euthanasia, Capital Punishment, War and Other Life-or-death Choices* (New ed edn, Penguin 1990) §5.4: ‘Suppose people’s marriage partners and jobs were chosen by experts, and that studies showed a far higher level of satisfaction among those whose marriages and jobs were so chosen than among people who made their own arrangements. Even so, many of us would prefer not to delegate such important decisions, for if we did so we would lose the sense of living our own lives, and we prefer to forgo a great deal of happiness, or risk a fair amount of disaster, to losing control of our lives in this way … perhaps for some of us there is no degree of additional pleasure for which we would surrender control of the central decisions of our lives.’ [↑](#footnote-ref-52)
53. See eg Jeremy Bentham, *An introduction to the principles of morals and legislation* (T Payne & Son 1789). [↑](#footnote-ref-53)
54. Of course, I leave open the possibility that autonomy is instrumentally valuable because of its relation to other goods, such as diversity. [↑](#footnote-ref-54)
55. eg Glover (n 52); Robert Young, ‘The Value of Autonomy’ (1982) [31](126) PhQ 35. [↑](#footnote-ref-55)
56. Thomas Hurka, ‘Why Value Autonomy?’ (1987) 13(3) Soc Theor Pract 361, 375-376. [↑](#footnote-ref-56)
57. ibid 379. [↑](#footnote-ref-57)
58. ibid 380. [↑](#footnote-ref-58)
59. We should note, however, the limitations that inhere in *right DR* in virtue of its derivation from *P*’s interest in autonomy. First, the possibility of disallowing refusals of LPT when *P* is not autonomous is left open, and requires a distinct balancing exercise. Second, I assume that the outcome of any such balancing exercise fails to yield an unlimited right to respect for a non-autonomous refusal of LPT. This assumption may be contentious in light of some interpretations of the Convention on the Rights of Persons with Disabilities, art 12; cf Matthew Burch, ‘Autonomy, Respect, and the Rights of Persons with Disabilities in Crisis’ (2017) 34(3) J Applied Phil 389-402. But if it holds, *appropriate* procedural requirements designed to establish that *p* is autonomous at the time she refuses LPT (whether contemporaneously or in advance) will be required, for autonomy is a precondition for the enjoyment of *right DR* derived from an interest in *deciding* how and when to die. (I say *appropriate* in virtue of the positive obligations that inhere in article 8 ECHR: see §5.) Third, if *P* makes an advance refusal and subsequently behaves inconsistently with its provisions while still autonomous, there is reason to believe that the advance refusal no longer reflects her autonomous wishes. Thus we might anticipate a limitation on *right DR* that invalidates *P*’s advance refusal in the event of inconsistent autonomous conduct, eg Mental Capacity Act 2005 (MCA 2005), s 25(2); see *Re QQ* [2016] EWCOP 22. Similarly, it may be permissible for *D* to disapply an advance refusal in the event of an unanticipated change of circumstances (perhaps the classic example is a novel cure) that may well have had a material influence on *P*’s decision, eg MCA 2005, s 25(3). Here the argument is that *P* would not have chosen to make an advance refusal had she factored the unanticipated circumstance into her decision-making. [↑](#footnote-ref-59)
60. I take it that no philosophers who believe that autonomy has intrinsic value deny that it also has instrumental value. See eg Allen Buchanan and Dan W Brock, ‘Deciding for Others’ (1986) 64(S2) The Milbank Quarterly 17-94, 51-52. [↑](#footnote-ref-60)
61. Hurka (n 56). [↑](#footnote-ref-61)
62. John Stuart Mill, *Utilitarianism and On Liberty: including Mill's Essay on Bentham' and selections from the writings of Jeremy Bentham and John Austin* (2nd edn, Blackwell Pub 2003) 131-146; See Valerie Tiberius, ‘Prudential Value’ in Iwao Hirose and Jonas Olson (eds), *The Oxford handbook of value theory* (OUP 2015) §9.2. [↑](#footnote-ref-62)
63. Richard Kraut, *What is good and why: the ethics of well-being* (Harvard University Press 2007) 201. [↑](#footnote-ref-63)
64. See eg *A Local Authority v E* [2012] EWHC 1639 (COP); For commentary: John Coggon, ‘Anorexia nervosa, best interests, and the patient's human right to ‘a wholesale overwhelming of her autonomy’: *A Local Authority v E* [2012] EWHC 1639 (COP)’ (2014) 22(1) Med Law Rev 119. [↑](#footnote-ref-64)
65. See eg *Sheffield Teaching Hospitals NHS Foundation Trust v TH* [2014] EWCOP 4; *Wye Valley NHS Trust v B* [2015] EWCOP 60. These were not advance refusal cases. [↑](#footnote-ref-65)
66. See eg *A Local Authority v E* (n 64), in which the court declared that force-feeding, and if necessary sedation or physician restraint, was in the best interests of an individual with anorexia nervosa. The duration of this treatment was predicted to last not less than one year. [↑](#footnote-ref-66)
67. Tiberius (n 62) §9.4. [↑](#footnote-ref-67)
68. Of course, the idea that the satisfaction/frustration of remote desires affects *P*’s welfare is often seen as an unintuitive implication of desire theories: ibid 166. [↑](#footnote-ref-68)
69. Letsas (n 37) 328. [↑](#footnote-ref-69)
70. See Glover (n 52) chapters 3 and 5. [↑](#footnote-ref-70)
71. Nowlin (n 25) 265. [↑](#footnote-ref-71)
72. See Patrick Devlin, *The enforcement of morals* (Liberty Fund 2009); cf H L A Hart, ‘Social Solidarity and the Enforcement of Morality’ (1967) 35(1) U Chicago Law Review 1; Ronald Dworkin, ‘Lord Devlin and the Enforcement of Morals’ (1966) 75(6) Yale Law J 986. [↑](#footnote-ref-72)
73. John Keown, *Euthanasia, ethics, and public policy: an argument against legislation* (CUP 2002) 39 (original emphasis). [↑](#footnote-ref-73)
74. ibid 66-68. [↑](#footnote-ref-74)
75. ibid 41; John Finnis, ‘A philosophical case against euthanasia’ in John Keown (ed), *Euthanasia examined: ethical, clinical, and legal perspectives* (CUP 1995). [↑](#footnote-ref-75)
76. It is not necessary here to discuss *inviolability* in detail, but perhaps it is not unfair to say that the account requires the acceptance of considerable normative machinery, and entails the unattractive conclusion that suicide is always wrong. [↑](#footnote-ref-76)
77. Keown (n 73) 67. [↑](#footnote-ref-77)
78. cf Judge Zekia (dissenting) in *Dudgeon* (n 33). Judge Zekia seems to make a moralistic welfare argument, in addition to the straightforwardly moralistic argument discussed in the previous section. [↑](#footnote-ref-78)
79. Letsas (n 37) 329. [↑](#footnote-ref-79)
80. Robert E Goodin, *Utilitarianism as a public philosophy* (Cambridge University press 1995) 134, 139-140. [↑](#footnote-ref-80)
81. ibid 139 (original emphasis). [↑](#footnote-ref-81)
82. Harry Frankfurt, ‘Freedom of the will and the concept of a person’ (1971) 68(1) J Phil 5. [↑](#footnote-ref-82)
83. Alternatively, we might launder individual utilities prior to their aggregation, for example, by appeal to *desert*: see eg Fred Feldman, *Pleasure and the Good Life: Concerning the Nature, Varieties, and Plausibility of Hedonism* (New Ed edn, Clarendon Press 2006) Chapter 5. If *R*’s faring poorly (or less well) depends on outrage about *P*’s purportedly immoral conduct, we might say that her outrage is an appropriate object ofill-being. In such circumstances, *R* *deserves* to fare poorly in virtue of her moralistic beliefs, and therefore her moralistic welfare interest need not have weight in the balancing exercise. Of course, an appeal to desert (or any other means of discounting individual utilities) would require philosophical justification, notwithstanding that it is intuitively compelling to think that moralistic states of mind are not prudentially valuable. [↑](#footnote-ref-83)
84. A similar argument might also be advanced by treating clinicians; see *Ms B* (n 3). [↑](#footnote-ref-84)
85. eg in *Re E* (n 64), *E*’s refusal of LPT had the support of her parents. [↑](#footnote-ref-85)
86. See Alastair Norcross, ‘Comparing Harms: Headaches and Human Lives’ (1997) 26(2) Phil Pub Affairs 135. [↑](#footnote-ref-86)
87. eg Keown (n 73); I G Finlay and R George, ‘Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups--another perspective on Oregon's data’ (2011) 37(3) J Med Ethics 171; J Pereira, ‘Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls’ (2011) 18(2) Curr Oncol e38-45 See Isra Black, ‘Better off dead? Best interests assisted death’ (PhD thesis, King's College London 2015) for discussion of the *vulnerability* argument in UK parliamentary debate on assisted death between 1936 and 2009. [↑](#footnote-ref-87)
88. Penney Lewis and Isra Black, ‘Reporting and scrutiny of reported cases in four jurisdictions where assisted dying is lawful: A review of the evidence in the Netherlands, Belgium, Oregon and Switzerland’ (2013) 4 MLI 221; Penney Lewis and Isra Black, ‘Adherence to the request criterion in jurisdictions where assisted dying is lawful? A review of the criteria and evidence in the Netherlands, Belgium, Oregon, and Switzerland’ (2013) 41(4) J Law Med Ethics 885; Margaret Pabst Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal and Bregje D Onwuteaka-Philipsen, ‘Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups’ (2007) 33(10) J Med Ethics 591; Stephen W Smith, ‘Evidence for the Practical Slippery Slope in the Debate on Physician-Assisted Suicide and Euthanasia’ (2005) 13(1) Med Law Rev 17. [↑](#footnote-ref-88)
89. eg In the Second Reading debate, only Lord Clarke (cols 55-57) and Baroness Masham (cols 65-67) raised the vulnerability argument with regard to advance decisions, while Baroness Finlay, a notable proponent of the *vulnerability* argument in the context of assisted death spoke in favour of the Bill’s advance refusal clauses (cols 87-90): HL Deb, ‘Mental Capacity Bill (Second Reading)’ 2005/01/10, vol 668 cols 11-26, 42-126 http://hansard.millbanksystems.com/lords/2005/jan/10/mental-capacity-bill; http://hansard.millbanksystems.com/lords/2005/jan/10/mental-capacity-bill-1 accessed 2016/08/01; rather, concern for the ‘vulnerable’ focused on best interests decision-making introducing ‘euthanasia by the back door’; see John Coggon, ‘Ignoring the moral and intellectual shape of the law after Bland: the unintended side-effect of a sorry compromise’ (2007) 27(1) LS 110 on MCA 2005, s 4(5). [↑](#footnote-ref-89)
90. The MCA 2005, s 25(6) contains a requirement that advance refusals of LPT are witnessed. However, the witnessing provision only establishes that the advance refusal is attributable to *P*: Department for Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (TSO 2007) 9.20-9.21. It does not establish that *P*’s made her advance decision voluntarily, or as Rob Heywood observes, that she had capacity: Rob Heywood, ‘Revisiting advance decision-making under the Mental Capacity Act 2005: A tale of mixed messages’ (2015) 23(1) Med Law Rev 81, 92. In England and Wales, therefore, the task of protecting individuals who refuse treatment in advance falls primarily to the Court of Protection, which has the power in virtue of MCA 2005, s 26(4) to make declarations as to the existence, validity, and applicability of an advance decision. It is somewhat uncertain whether the presumption of capacity set out in MCA 2005, s 1(2) of the Act applies to advance decisions: see *A Local Authority v E* (n 64). [↑](#footnote-ref-90)
91. Of course, it is a bone of some contention whether procedural safeguards can protect the ‘vulnerable’: see Lewis and Black, ‘Adherence to the request criterion…’ (n 88) and Penney J Lewis and Isra Black, *‘The effectiveness of legal safeguards in jurisdictions that allow assisted dying’, Briefing Paper for the Commission on Assisted Dying* (Demos, 2012) http://philpapers.org/rec/LEWTEO-8 accessed 2017/11/01 for an evidence-based appraisal of this issue in the context of assisted death. [↑](#footnote-ref-91)
92. However, such measures may be justifiable if the outlook in respect of coercion and undue influence in a particular jurisdiction is very poor or the procedural framework is not robust. [↑](#footnote-ref-92)
93. FM Kamm, *Bioethical prescriptions: to create, end, choose, and improve lives* (OUP 2013) 47; See also Buchanan and Brock (n 60) 53. [↑](#footnote-ref-93)
94. Of course, it may be possible to promote public safety by some other means, for example, quarantine, in which case it is unlikely to be justifiable also to restrict *P*’s refusal of treatment. [↑](#footnote-ref-94)
95. Letsas (n 37) 329. [↑](#footnote-ref-95)
96. Ronald Dworkin, *Taking rights seriously* (Harvard University Press 1977). [↑](#footnote-ref-96)
97. Letsas (n 37) 329. [↑](#footnote-ref-97)
98. ibid 330. [↑](#footnote-ref-98)
99. ibid 329; These excluded empirical facts might be described as ‘irrelevant utilities’: F M Kamm, ‘The Choice Between People: 'Common Sense' Morality, and Doctors’ (1987) 1(3) Bioethics 255. [↑](#footnote-ref-99)
100. Letsas (n 37) 330. [↑](#footnote-ref-100)
101. ibid 330, 332. [↑](#footnote-ref-101)
102. Hurka (n 56) 375. This claim is true regardless of whether autonomy has instrumental or intrinsic value. [↑](#footnote-ref-102)
103. This may, but need not be, underpinned by a comprehensive scheme of moral beliefs: John Rawls, *Political liberalism* (expanded edn, Columbia University Press 2005) 13. [↑](#footnote-ref-103)
104. *Pretty v UK* (n 6) [62]. [↑](#footnote-ref-104)
105. Dworkin (n 22) 217. [↑](#footnote-ref-105)
106. I take it that the reason-blocking theory implies that any one individual’s equality is incommensurable with any other individual’s equality such that we may not choose either *Policy*1 or *Policy*2 on grounds that both options have equal value. Likewise, the equality of any number of individuals in population A is incommensurable with that of any greater or lesser number of individuals in population B, such that we may not choose between *Policy*1 and *Policy*2 by selecting the option that produces an adequate or maximal sum of equality. [↑](#footnote-ref-106)
107. ibid 334. Dworkin (n 96) chapter 12. [↑](#footnote-ref-107)
108. See James Wilson, ‘The right to public health’ 42(6) J Med Ethics 367-375. [↑](#footnote-ref-108)
109. As I note above, population health objectives might be achieved by other means, in which case it may not be justifiable to limit *right DR*. [↑](#footnote-ref-109)
110. eg Human Rights Act 1998, ss 6(1), 7(1). [↑](#footnote-ref-110)
111. eg ibid s 3(1). [↑](#footnote-ref-111)
112. ECHR, arts 34-35. [↑](#footnote-ref-112)
113. Letsas (n 14) 90. [↑](#footnote-ref-113)
114. ibid 91. [↑](#footnote-ref-114)
115. *Evans v United Kingdom* (2008) 46 EHRR 34 (ECtHR) [77]; See also *A, B, and C v Ireland* (2011) 53 EHRR 13 (ECtHR) [233]-[234]. [↑](#footnote-ref-115)
116. *Haas* (n 7) [55]. [↑](#footnote-ref-116)
117. This point potentially draws support from the ECtHR’s more guarded comments on the margin of appreciation in respect of the related issue of withdrawal of treatment in *Lambert* (n 31) [148]: ‘States must be afforded a margin of appreciation… as to whether or not to permit the withdrawal of artificial life-sustaining treatment… However, this margin of appreciation is not unlimited…’. I say related rather than analogous, since the relation between refusal of LPT and withdrawal of treatment is one of possibility, rather than necessity. [↑](#footnote-ref-117)
118. *Koch* (n 9) [70]. Those jurisdictions are: Belgium *Loi relative à l'euthanasie du 28 mai 2002* [Law on euthanasia of 28 may 2002] (Euthanasia Law (BE) 2002), Luxembourg *Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide* [Law of 16 mars 2009 on euthanasia and assisted suicide] (Euthanasia Law (Lux) 2009), the Netherlands *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding* [Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002] (Euthanasia Act (NL) 2002), and Switzerland Code pénal suisse du 21 décembre 1937 [Swiss penal code of 21 December 1937], art 115; *Loi fédérale sur les stupéfiants et les substances psychotropes du 3 octobre 1951* [Federal law on narcotics and psychotropic substances of 3 October 1951] (LStup); *Loi fédérale sur les médicaments et les dispositifs médicaux du 15 décembre 2000* [Federal law on medicines and medical devices of 15 December 2000] (LPTh). [↑](#footnote-ref-118)
119. eg The Convention on Human Rights and Biomedicine (Ovideo Convention), article 5, provides that ‘an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it’. Article 5 is qualified only by articles 7 (mentally disordered individuals whose health would be seriously jeopardised without treatment), 8 (emergencies), and 26 (restrictions ‘prescribed by law and … necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others). Thus the Oviedo Convention appears not to license overriding a refusal of treatment in service of *P*’s welfare, or the protection of morals. To the extent that the Convention has been signed and ratified by 29 Council of Europe Member States, it is indicative of consensus that a contemporaneous right to refuse LPT exists, although it is an open question whether each State has enshrined such a right in law. Moreover, of the Member States who have not signed the Oviedo Convention, or who have signed but not ratified the instrument, several make provision for refusals of LPT in domestic law: Belgium, *Loi relative aux droits du patient du 22 août 2002* [Law on patient rights of 22 August 2002]; Germany, *Bürgerliches Gesetzbuch* [German Civil Code] (BGB), §630(d) Einwilligung [Consent]; Ireland, *Fitzpatrick & Ryan v FK & Attorney General* [2008] IEHC 104; United Kingdom, *Airedale NHS Trust v Bland* [1993] 1 AC 789 (HL); *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67; *Montgomery v Lanarkshire Health Board* [2015] UKSC 11; Luxembourg, *Loi du 24 juillet 2014 relative aux droits et obligations du patient* [Law of 24 July 2014 on patient rights and obligations], art 8§4; Italy, *Costituzione della Repubblica Italiana del 22 dicembre 1947* [Constitution of the Italian Republic of 22 December 1947] art 32, Sofia Moratti, ‘Italy’ in John Griffiths, Heleen Weyers and Maurice Adams (eds), *Euthanasia and law in Europe* (Hart 2008) 13.3.1); the Netherlands, *Wet op de geneeskundige behandeIingsovereenkomst* [Law on Contracts for Medical Care 1995], art 450(1); Sweden, *Patientlag* [Patient law] (2014:821), 4 kap, §1, 2. [↑](#footnote-ref-119)
120. The Oviedo Convention, art 9 leaves the possibility of a right to refuse LPT in advance open, but does not provide authority for it: ‘The previously expresses wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account’. As the Council of Europe Committee of Ministers, *Reply to Recommendation 1418 (1999): Protection of the human rights and dignity of the terminally ill and the dying* (2000) notes, the ‘wording [of article 9] reflects the maximum convergence of views among states which took part in drawing up the convention as regards reconciling patient self determination and medical responsibility’. The degree of consensus appears to have shifted considerably since 1997, insofar as advance refusals of LPT are in principle binding in an increasing number of Council of Europe jurisdictions, including (not an exhaustive survey): Austria, *BGBI I Nr 55/2006: Patientenverfügungs-Gesetz* [Federal law on advance directives]; England and Wales *Re AK (Medical Treatment: Consent)* [2001] 2 FCR 35 (Fam) (at common law); MCA 2005; France, *Code de la santé publique* [*Public health code*], art L1111-11, 12 Germany, BGB, §1901a; Assisted Decision-Making (Capacity) Act 2015; Portugal, *Lei nº 25/2012 de 16 de julho Regula as diretivas antecipadas de vontade...* [Law no 25/2012 of 16 July on advance directives]; the Netherlands, Law on Contracts for Medical Care (NL), art 450(3); Slovenia (refusal permitted only in circumstances of terminal illness and qualitative futility), *Zakon o pacientovih pravicah (Uradni list RS, št. 15/08)* [Patient Rights Act (Official Gazette RS, no 15/08] http://www.nkt-z.si/wps/portal/nktz/home/healthcare/rights%26obligations/rights/ accessed 2016/09/01; Switzerland *Code civil suisse du 10 décembre 1907* [Swiss civil code of 10 december 1907], arts 370-373. [↑](#footnote-ref-120)
121. *Goodwin v United Kingdom* (2002) 35 EHRR 18 (ECtHR) [74]. [↑](#footnote-ref-121)
122. *Sheffield and Horsham v United Kingdom* (1999) 27 EHRR 163 (ECtHR) [57]-[58]. [↑](#footnote-ref-122)
123. *Goodwin* (n 121) ibid [84]-[85]. [↑](#footnote-ref-123)
124. eg Physicians treat over a valid and applicable refusal in violation of the law, and the relevant professional/legal authorities fail to sanction this behaviour. [↑](#footnote-ref-124)
125. Rosamund Scott, ‘Risks, reasons and rights: The European Convention on Human Rights and English abortion law’ (2016) 24(1) Med Law Rev 1, 8 (original emphasis). [↑](#footnote-ref-125)
126. See eg *P v Poland* (n 17) [99]; *Tysiac v Poland (2007)* 45 EHRR 42 (ECtHR) [115]. [↑](#footnote-ref-126)
127. *P v Poland* ibid [95], citing *Glass v United Kingdom*:[74]-[83]; also *Tysiac* ibid [112]. [↑](#footnote-ref-127)
128. ‘Variously’ is the appropriate modifier, insofar as the ECtHR has held that what ‘respect for private life’ requires ‘will vary considerably from cases to case’: *Tysiac* ibid. [↑](#footnote-ref-128)
129. *P v Poland* (n 17) [95]. [↑](#footnote-ref-129)
130. Daniel Fenwick, ‘The modern abortion jurisprudence under Article 8 of the European Convention on Human Rights’ (2012) 12(3-4) MLI 249, 261 (original emphasis). [↑](#footnote-ref-130)
131. Daniel Fenwick, ‘'Abortion jurisprudence' at Strasbourg: deferential, avoidant and normatively neutral?’ (2014) 34(2) LS 214, 227; Scott (n 125) 8. [↑](#footnote-ref-131)
132. *P v Poland* (n 17) [95]. [↑](#footnote-ref-132)
133. See *A, B, and C v Ireland* (n 115) [252]-[255]. [↑](#footnote-ref-133)
134. See *Ms B v An NHS Hospital Trust*, in which the NHS Trust failed to initiate proceedings to determine *P*’s capacity to refuse treatment, with the consequence *P*’sclinicians committed battery for a substantial period of time; for an example of good practice, see *King's College NHS Foundation Trust v C* [2015] EWCOP 80. [↑](#footnote-ref-134)
135. *Tysiac* (n 126) [127]-[129]. [↑](#footnote-ref-135)
136. eg The liability scheme for non-respect/respect for advance refusals under the MCA 2005, s 26 may be incompatible with art 8 ECHR for this reason. MCA 2005, s 26(2) provides: ‘A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment’; MCA 2005, s 26(3) provides: ‘A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment’. As Emily Jackson observes, ‘There is a significant difference between the test for avoiding liability depending on whether the doctor has wrongly treated despite the existence of a valid AD. or not treated because he was relying on an invalid AD’: Emily Jackson, *Medical law: text, cases, and materials* (4th edn, OUP 2016) 280-281. If a physician disregards a valid and applicable advance refusal, the test is subjective—satisfaction; if a physician respects and invalid/inapplicable advance refusal, the test is objective—reasonableness. The upshot of this, as Jackson notes is that a physician will usually be able to ignore an AD with ‘impunity’: ibid. [↑](#footnote-ref-136)
137. See, *mutatis mutandis*, *A, B, and C v Ireland* (n 115) [253]*.* [↑](#footnote-ref-137)
138. ibid [254]. [↑](#footnote-ref-138)
139. eg Post-legislative scrutiny of the MCA 2005 has given rise to significant worries in respect of the implementation of the Act, particularly as regards its Core principles (including the presumption of capacity, and unwise decisions not indicating, in and of themselves, incapacity), and as regards the regime for advance decisions to refuse treatment: House of Lords, *Select Committee on the Mental Capacity Act 2005, Mental Capacity Act 2005: post-legislative scrutiny* (2014) http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf accessed 2016/10/01. The prospects for effective implementation of legal regimes for refusals of LPT may be better or worse, according to the extent to which physicians in a particular jurisdiction value patient autonomy: See Ruth Horn, ‘“I don’t need my patients’ opinion to withdraw treatment”: patient preferences at the end-of-life and physician attitudes towards advance directives in England and France’ (2014) 17(3) Medicine Health Care Phil 425. [↑](#footnote-ref-139)