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## Legalizing Assisted Dying: Cross Purposes and Unintended Consequences

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Emily Jackson\*

## Legalizing Assisted Dying: Cross Purposes and Unintended Consequences

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*In the UK, assisted dying continues to be unlawful, and pro-legalization campaigners have made use of human rights based applications for judicial review and Private Members Bills in order to try to change the law. Interestingly, however, the proposed statute would not offer an assisted death to many of the litigants who have sought to force Parliament's hand. This article considers whether this a one-off peculiarity, or whether there might be other mismatches between what the law can achieve and what matters most to people who are seeking an assisted death for themselves. It also explores what seems to be a common feature of debates over assisted dying, namely the tendency for one problem to be solved, while another is created.*

*Au Royaume-Uni, la mort assistée demeure illégale et les militants en faveur de sa légalisation ont eu recours à des demandes de révision judiciaire fondées sur les droits de l'homme et à des projets de loi d'initiative parlementaire pour tenter de modifier la loi. Il est toutefois intéressant de noter que la loi proposée n'offrirait pas une mort assistée à bon nombre des plaideurs qui ont tenté de forcer la main au Parlement. Cet article examine si cette particularité est unique ou s'il peut y avoir d'autres inadéquations entre ce que la loi peut accomplir et ce qui compte le plus pour les personnes qui cherchent à obtenir une mort assistée pour elles-mêmes. Il explore également ce qui semble être une caractéristique commune des débats sur la mort assistée, à savoir la tendance à résoudre un problème et à en créer un autre.*

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### *Introduction*

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### *Introduction*

Over the past few decades, there has been a steady increase in the number of countries and states in which assisted suicide and/or euthanasia have been decriminalized. This has usually involved legislative change,<sup>1</sup> but there have been examples of judicial “law-making.” For example in Montana, the Netherlands and Canada, court judgments laid the foundations for statutory reform.<sup>2</sup>

In the UK, assisted suicide and euthanasia continue to be illegal, but there has been significant activity, in the courts and in parliament, directed towards a change in the law. Since Dianne Pretty’s unsuccessful attempt to secure immunity from prosecution for her husband in 2002, the courts have moved some considerable distance towards acknowledging that the blanket ban on assisted suicide at the very least engages, and perhaps also has the potential to interfere with, claimants’ human rights. At the same time, an assisted dying bill, with slight modifications, has been debated in parliament several times without progressing further, and in 2015, it was defeated decisively in the House of Commons.

While the judicial review claims pursued by Debbie Purdy and Tony Nicklinson, and most recently by Noel Conway and Omid T, were intended

1. For example, *Death with Dignity Act 1994*, ORS § 127.800-.995 (Oregon); *Loi relative à l’euthanasie (Act Concerning Euthanasia)*, 28 May 2002 *Moniteur Belge*, 22 June 2002, 28515; *Death with Dignity Act 2008* 2008 RCW § 70.245 (Washington); *Patient Choice and Control at End of Life Act 2013* 2013, 18 VSA § 113 (Vermont); *Voluntary Assisted Dying Act 2017* No 61, s 93 (Victoria, Australia).

2. *Montana v Baxter*, 354 Mont 234 (SC 2009); District Court of Leeuwarden, 21 February 1973, *Nederlandse Jurisprudentie*, 1973 No 183; *Carter v Canada*, 2015 SCCS, [2015] 1 SCR 331.

to pursue their rights as individuals, they were also directed towards changing the law in order to benefit others in the future. By the time Tony Nicklinson's case reached the Court of Appeal, he had died, and his widow continued his case after his death in order that others would have an option that had been unavailable to her late husband. Some litigants have even been supported formally by the campaigning organisation Dignity in Dying.

What is, however, peculiar about this twin track strategy of litigation and parliamentary reform is that the draft bill, if passed, would not give the option of an assisted death to many of those who have sought to force parliament's hand by seeking a declaration of incompatibility in the courts. Not only is it noteworthy that the draft Bill would specifically exclude those individuals whose cases have been considered especially compelling, but also the practical result would be that even if parliament were to change its mind and pass the assisted dying bill in its current form, litigation challenging its eligibility criteria would be likely to continue.

There is then something interesting about the way in which the litigation and statutory reform agendas of those pursuing legalization in the UK have been talking past each other. Of course, there may be reasons for this specific to the UK, and I explore those in more detail in the next section. But it is also worth considering whether this might not just be a jurisdiction-specific oddity, but a feature more generally of debates about the legalization of assisted dying. Are there contradictions or inconsistencies in other jurisdictions' pursuit of legalized assisted dying? Do the eligibility criteria for assisted dying always dovetail neatly with the reasons why people seek assisted dying, or are there commonly discrepancies between the two?

My purpose in this paper is not to advocate a particular model of law reform. Instead I want to highlight several ways in which there may be a mismatch between what law can achieve and what matters to those people who might want an assisted death for themselves, now or in the future. I also want to explore what seems to be a common feature of debates over assisted dying, namely the tendency for one problem to be solved, while another is created. Although I start with the curious and presumably unsustainable status quo in the UK, I also draw on evidence from Western European countries which have legalized assisted dying.<sup>3</sup>

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3. No countries in Eastern Europe have legalized assisted dying, and indeed there appears to be an East–West split within Europe. See further Ezekiel J Emanuel et al, "Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe" (2016) 316:1 JAMA 79; Joachim Cohen et al, "Public Acceptance of Euthanasia in Europe: a Survey Study in 47 countries" (2014) 59:1 Intl J Public Health 143.

### I. *Law reform in the UK*

This section will begin with a brief and necessarily incomplete history of litigation directed towards a change in the law in the UK, starting with Dianne Pretty's case in 2002. I will set out the shifts not only in the outcomes of these cases, but also in the terms in which the judges discuss the interests of those who wish to have the option of an assisted death, and the prospect of legalization. Next I will provide a brief history of the failed assisted dying bills, and their eligibility criteria, which would specifically exclude those individuals towards whom there has been considerable judicial sympathy.

#### 1. *From Pretty to Conway, via Purdy and Nicklinson*

It was unsurprising that the courts rejected Dianne Pretty's application for judicial review of the Director of Public Prosecutions' refusal to grant her husband prospective immunity from prosecution if he were to help her to commit suicide.<sup>4</sup> More noteworthy, given subsequent Strasbourg jurisprudence,<sup>5</sup> was the House of Lords' unanimous view that Mrs Pretty's desire to end her life, in order to bring to an end her suffering from motor neurone disease, did not engage *any* of her human rights. When Mrs Pretty took her case to the European Court of Human Rights (ECtHR), it was prepared to admit that Mrs Pretty's Article 8 rights were engaged,<sup>6</sup> but it nevertheless rejected Mrs Pretty's claim on the grounds that a complete prohibition of assisted suicide was not a disproportionate response to the state's concern to protect vulnerable members of society.<sup>7</sup>

Six years later, Debbie Purdy mounted a more modest claim against the Director of Public Prosecutions (DPP). Ms Purdy was also concerned about the future prosecution of her husband, if he were to accompany her to Dignitas in Switzerland. But, rather than seek an assurance that Omar Puente would not be prosecuted if he were to do so, Ms Purdy instead sought greater clarity as to the factors that the DPP would take into account

4. *R (on the application of Pretty) v Director of Public Prosecutions*, [2001] UKHL 61, [2002] 1 All ER [Pretty]; see also Michael Freeman, "Denying Death its Dominion: Thoughts on the Dianne Pretty Case" (2002) 10:3 Medical L Rev 245.

5. See, for example, *Haas v Switzerland* (2011), 53 EHRR 33.

6. Article 8 of the European Convention on Human Rights provides that:

1. Everyone has the right to respect for his private and family life, his home and his correspondence.

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being 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.

7. *Pretty*, *supra* note 4.

when deciding whether to prosecute him. Although the lower courts were bound by the House of Lords' decision in *Pretty*, that none of Ms Purdy's human rights were engaged, the House of Lords disagreed. In *R (on the application of Purdy) v Director of Public Prosecutions*,<sup>8</sup> it decided that Ms Purdy's Article 8 rights had been breached by the DPP's failure to set out in advance "a custom-built policy statement indicating the various factors for and against prosecution."<sup>9</sup>

The House of Lords' sympathy and concern for Ms Purdy's predicament was striking, especially since she was challenging guidance that was intended not to help individuals decide whether to break the law, but rather to assist prosecutors in the exercise of their discretion. As Kate Greasley has pointed out, as "an instrument designed to give prosecutors some direction in the exercise of their discretion, ...there is accordingly no reason to think it subject to the same standards of precision and clarity as criminal law defences."<sup>10</sup> In addition, even if the Code for Crown Prosecutors might look vague to Ms Purdy, there had, in fact, been consistency in the practice of non-prosecution by the DPP. Hence it would be impossible to argue that citizens had been adversely affected by capricious and inconsistent decision-making as a result of the failure to provide "custom built" guidance to prosecutors.

Despite the fact that Ms Purdy was not the target audience of the Code, Lord Neuberger was of the view that "a sensible and clear policy document" might offer "some moral and emotional comfort, to Ms Purdy and others in a similar tragic situation."<sup>11</sup> And Lord Brown described a hypothetical scenario in which helping "a loved one, in desperate and deteriorating circumstances" to end their life might be commended as altruistic.<sup>12</sup> This clear expression of sympathy for Ms Purdy's plight did not appear to be confined to the narrow question of the precision, or otherwise, of the Code for Crown Prosecutors, rather it appeared to go to the much broader question of whether, in certain circumstances, there should be exceptions to the blanket ban on assisted suicide.

Five years later, Tony Nicklinson's judicial review action, pursued after his death by his widow Jane, and joined with that of Paul Lamb, reached the Supreme Court. Tony Nicklinson and Paul Lamb sought to challenge directly the compatibility of the prohibition of assisted suicide

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8. [2009] UKHL 45, [2009] 4 All ER 1147.

9. Per Lord Brown, *ibid* at para 86.

10. Kate Greasley, "*R(Purdy) v DPP and the Case for Wilful Blindness*" (2010) 30:2 Oxford J Leg Stud 301.

11. *Purdy*, *supra* note 8 at para 101.

12. *Ibid* at para 83.

in section 2(1) of the *Suicide Act 1961*, and in particular its failure to provide for any exceptions, with their Article 8 rights. In *R (Nicklinson and Another) v Ministry of Justice*,<sup>13</sup> their action failed. But although there was a clear majority in the Supreme Court against issuing a declaration of incompatibility, a majority suggested that the courts might be prepared to intervene in the future.

Two justices were in favour of making a declaration of incompatibility immediately (Lady Hale and Lord Kerr), on the grounds that section 2(1) “fails to admit of any exceptions.”<sup>14</sup> At the other end of the spectrum, two justices (Lords Sumption and Hughes) were of the view that maintaining a blanket ban on assisted suicide lay within the UK’s margin of appreciation.<sup>15</sup> Not only had Parliament decided that there should be no exceptions to section 2(1) when it passed the *Suicide Act* in 1961, but it had also decided to keep the blanket ban when an amendment was debated in 2009.

In between these two settled views, there were a range of positions.<sup>16</sup> Lords Neuberger and Wilson suggested that if Parliament failed satisfactorily to address this issue, there was a real prospect that a further application might be successful.<sup>17</sup> While Lord Mance was of the view that “Parliament is certainly the preferable forum in which any decision should be made,”<sup>18</sup> he would “not rule out the future possibility of a further application.”<sup>19</sup> Lords Reed and Clarke largely shared the view of Lords Sumption and Hughes that this was a matter for Parliament, but Lord Clarke nevertheless agreed with Lord Neuberger that “If Parliament chooses not to debate these issues, I would expect the court to intervene.”<sup>20</sup>

Two other features of the judgments are worth mentioning. First, several of the justices went to considerable lengths to discuss how assisted dying might be legalized. In Lord Neuberger’s opinion, a system of prior approval might provide more robust protection for the vulnerable than the status quo. Lady Hale discussed what sort of eligibility criteria might be appropriate if assisted suicide were to be legalized,<sup>21</sup> and Lord Wilson went so far as to set out the 18 factors which a High Court judge might take into account in order to be “satisfied that a person’s wish to commit

13. [2014] UKSC 38, [2014] 3 All ER 843.

14. *Per* Lady Hale, *ibid* at para 301.

15. See, for example, Lord Sumption, *ibid* at para 218.

16. *R (on the application of Conway) v Secretary of State for Justice*, [2017] EWHC 640 Admin at para 9 (Burnett LJ).

17. *Nicklinson*, *supra* note 13 at paras 118 and 202.

18. *Ibid* at para 190.

19. *Ibid*.

20. *Ibid* at para 293.

21. *Ibid* at paras 314 and 205, respectively.

suicide was...voluntary, clear, settled and informed.”<sup>22</sup> These discussions about how assisted suicide might be legalized, and the potential benefits of legalization were, needless to say, hypothetical, but it is hard to avoid the conclusion that there is some sympathy among a significant minority of the justices of the Supreme Court for the proposition that a system to allow assisted suicide for people in Tony Nicklinson’s situation, while providing safeguards to protect the vulnerable, should not be “beyond the wit of a legal system.”<sup>23</sup>

Secondly, while the Supreme Court judgments set out the familiar arguments as to why the question of legalization should be for the democratically elected legislature, considering the issue in the round, rather than for unelected judges, concerned only to decide an individual’s claim, Lord Neuberger’s judgment contained an interesting and insightful twist on this point:

there is force in the point that difficult or unpopular decisions which need to be taken, are on some occasions more easily grasped by judges than by the legislature. Although judges are not directly accountable to the electorate, there are occasions when their relative freedom from pressures of the moment enables them to take a more detached view.<sup>24</sup>

In acknowledging that emotive issues like assisted dying might be more difficult for MPs, concerned about re-election, than they are for judges, Lord Neuberger offers an explanation for the apparently puzzling divergence between overwhelming public support for the legalization of assisted dying and the decisive majority against legalization in the most recent vote in the House of Commons. MPs concerned about their parliamentary majorities are aware that campaigners against legalization are well-organized and well-resourced, as Evan Harris found out when he was traduced as “doctor death” in the tabloid press and by his evangelical Conservative opponent.<sup>25</sup>

Jonathan Herring has identified a further reason why the courts may be better equipped than the legislature to find a solution to the problem of assisted dying. Devising a generalized response, that could anticipate and accommodate all of the difficult scenarios which might arise in the future may be more challenging than exercising compassion in an individual

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22. *Ibid* at para 205.

23. *Per* Lady Hale, *ibid* at para 314.

24. *Ibid* at para 101.

25. See, for example, Leo McKinstry, “Meet Dr Death, the Lib Dem MP Evan Harris who backs embryo experiments, euthanasia and freer abortions,” *Daily Mail* (31 October 2007), online: <[www.dailymail.co.uk/article-490815/Meet-Dc-Death-Lib-Dem-MP-Evan-Harris-backs-embryo-experiments-euthanasia-freer-abortions.html](http://www.dailymail.co.uk/article-490815/Meet-Dc-Death-Lib-Dem-MP-Evan-Harris-backs-embryo-experiments-euthanasia-freer-abortions.html)>.



case.<sup>26</sup> As Herring explains, by “permitting an exceptional use of necessity, the courts would not be legislating, but acknowledging that in a particular case the criminal law should not apply.”<sup>27</sup> According to Herring, this would certainly not be an isolated instance of the criminal law finding a way to ensure that a general rule is not, in fact, applied where to do so would produce “an unacceptable result.”<sup>28</sup>

In the most recent English case, *R (Conway) v Secretary of State for Justice*,<sup>29</sup> Noel Conway, who has motor neurone disease and is terminally ill, argued once again that the blanket ban in section 2 was incompatible with his Article 8 rights. He also proposed “an alternative statutory scheme” which would “sufficiently protect the weak and vulnerable” and, as a result, “demonstrate that the blanket prohibition in section 2(1) is an unnecessary and disproportionate interference with his Article 8(1) rights.”<sup>30</sup> The Divisional Court had briskly rejected his claim, citing “a rational between the prohibition in section 2 and the protection of the weak and vulnerable.”<sup>31</sup> On appeal, the Court of Appeal rejected the argument that the court was better placed than Parliament to “to form a view about the adequacy of Mr Conway’s proposed scheme,”<sup>32</sup> asserting instead that:

There can be no doubt that Parliament is a far better body for determining the difficult policy issue in relation to assisted suicide in view of the conflicting, and highly contested, views within our society on the ethical and moral issues and the risks and potential consequences of a change in the law and the implementation of a scheme such as that proposed by Mr Conway.<sup>33</sup>

At the time of writing, it is not known whether Mr Conway will be granted permission to appeal to the Supreme Court. And in the case of Omid T, a 54 year old man suffering from multiple system atrophy, whose claim is similarly that the blanket ban breaches his Article 8 rights, judgment is pending following his first hearing in the High Court.

## 2. *The assisted dying bills*

Over roughly the same 15 year period from Dianne Pretty’s case to those of Noel Conway and Omid T, there have been multiple unsuccessful

26. Jonathan Herring, “Escaping the Shackles of Law at the End of Life: *R(Nicklinson) v Ministry of Justice*” (2013) 21 Med L Rev 487.

27. *Ibid.*

28. *Ibid.*

29. [2018] EWCA Civ 1431, [2018] WLR 925 [*Conway*].

30. *Ibid* at para 51.

31. [2017] EWHC 2447 (Admin) at para 96, [2017] Med LR 507.

32. *Supra* note 29 at para 85.

33. *Ibid* at para 186.

attempts in parliament to legalize assisted dying. In 2003, the House of Lords voted against Lord Joffe's first Assisted Dying for the Terminally Ill Bill. If passed, this would have enabled competent adult patients, who were terminally ill and experiencing unbearable suffering, to request either euthanasia or assisted suicide.

Following a further unsuccessful attempt to introduce it, Lord Joffe's Bill was scrutinized by the House of Lords Select Committee on Assisted Dying, which found that there had been several important developments since the previous Select Committee report on assisted dying in the early 1990s, in particular that legislation had been enacted in the Netherlands and in Oregon.<sup>34</sup> The Select Committee had found the evidence from Oregon particularly striking, and recommended that any new Bill should distinguish between euthanasia and assisted suicide, in order that they could be debated separately. It also recommended that consideration should be given to a requirement for psychiatric assessment of applicants.

In 2012, the Commission on Assisted Dying, which had been chaired by Lord Falconer, published a report that concluded that the current legal status of assisted suicide was inadequate and incoherent.<sup>35</sup> With one dissenting voice, the commission was of the view that it would be possible to devise a legal framework to protect vulnerable people. Because it had received funding and support from organisations which support legalization, questions were raised about the commission's independence.<sup>36</sup> The commission's report led to the first version of the most recent Assisted Dying Bill, which would legalize only assisted suicide. This was introduced into the House of Lords by Lord Falconer in 2014, but its progress was halted by the 2015 general election. It was then reintroduced into the Commons by Rob Marris MP in 2015, and after a long debate, the Bill was rejected by 330 votes to 116.<sup>37</sup> In 2016, Lord Hayward introduced an Assisted Dying Bill in the House of Lords, but parliament was dissolved before it received its second reading.

There have been differences between the various Bills: for example, the most recent version introduces a requirement for "the consent of the High Court (Family Division)," in addition to declarations from two

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34. UK, House of Lords Assisted Dying for the Terminally Ill Committee, *Assisted Dying for the Terminally Ill Bill First Report*, Session 2004-5 (London: The Stationary Office Ltd, 2005) [HL Bill].

35. Commission on Assisted Dying, *The Current Legal Status of Assisted Dying is Inadequate and Incoherent ...* (Demos: London, 2011).

36. See, for example, UK, Parliament, Early Day Motion 2030, "The British Medical Association Motion on the Commission on Assisted Dying and the BBC," Primary Sponsor Jim Dobbin MP (4 July 2011).

37. UK, Hansard, Vol 599 No 42 (11 September 2015) [Marris].

registered medical practitioners that the person's circumstances satisfy the statutory criteria. The basic eligibility criteria have remained relatively constant, however. They are that the person is normally resident in the UK, and:

- (a) is terminally ill, and expected to die within six months, and
- (b) has the capacity to make the decision to end their own life; and
- (c) has a clear and settled intention to end their own life which has been reached voluntarily, on an informed basis and without coercion or duress.

The most puzzling of these restrictions is the first one. If the purpose of legalizing assisted dying is the relief of suffering, then restricting access to people who are expected to die within six months leaves those individuals whose unbearable suffering is not likely to come to end soon suffering for an indeterminately long period of time.<sup>38</sup> The "terminal illness" requirement is the only criterion directed towards the condition of the patient, so it is curious that it does not specify that the person's suffering must be unbearable and unrelievable, merely that they must be likely to die soon. Applied literally then, a terminally ill patient who is not suffering, or whose suffering could be alleviated, would be eligible under this criterion, whereas another patient whose unbearable suffering cannot be relieved, would not.

Doctors' predictions of life expectancy are also notoriously unreliable,<sup>39</sup> which makes "likely to die within six months" an inevitably imprecise and haphazard criterion. And since the person who dies an assisted death as a result of satisfying the "six months to live" criterion will die sooner than this, there is no way to evaluate the accuracy of the diagnosis in the individual case.

There is, I would suggest, only one plausible reason for making "death within six months" a necessary condition for access to assisted dying, namely political pragmatism.<sup>40</sup> There is evidence that public support for the legalization of assisted dying is greatest for those who are terminally

38. Jukka Varelius, "Active and Passive Physician-Assisted Dying and the Terminal Disease Requirement" (2016) 30:9 *Bioethics* 663.

39. Nicholas A Christakis et al, "Extent and determinants of error in doctors' prognoses in terminally ill patients: A prospective cohort study" (2000) 320:7233 *Brit Med J* 469.

40. See further Elizabeth Peel & Rosie Harding, "A right to 'dying well' with dementia? Capacity, 'choice' and relationality" (2015) 25:1 *Feminism & Psychology* 137.

ill.<sup>41</sup> It is, perhaps, noteworthy that the public appears sympathetic *in the abstract* to assisted dying only if it is confined to the terminally ill, while also being sympathetic *in individual cases* to assisted dying for people like Debbie Purdy and Tony Nicklinson, who were not terminally ill when their cases were reported. This suggests either that people may not have been aware that Debbie Purdy and Tony Nicklinson were not terminally ill, or it may point to the wider problem highlighted by Jonathan Herring, namely that devising a generalisable rule, capable of operating effectively in all future cases, is significantly more challenging than identifying an individual whose desire for an assisted death merits a compassionate response.

It is also clear that the “terminal illness” requirement is used by pro-legalization campaigners in order to counter the disability lobby’s claim that the Bill sends a message that their lives are not worth living. Pointing to the terminal illness requirement, it is argued that there would be no danger of a slippery slope, because disability and chronic illness are specifically excluded. In addition, when death is hastened for someone who is already at the end of her life, it might look as though less is lost by intervening in the dying process.<sup>42</sup> Those seeking reform might therefore reason that any qualms parliamentarians have about patients dying earlier deaths as a result of legalized assisted dying might be allayed in part because patients would not be dying *very much sooner*, and legalization would therefore not be making much difference in practice.

### 3. *Explaining the mismatch between litigation and the draft bill*

It is, at first sight, peculiar that some of the individuals who have pursued actions in the courts in order to try to bring the legalization of assisted dying closer would not qualify for an assisted death under the draft legislation pursued simultaneously in Parliament. One possible explanation is purely practical. Litigation is time-consuming and there may be considerable

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41. Elizabeth Clery, Sheila McLean & Miranda Phillips, “Quickening Death: The Euthanasia Debate” in Alison Park et al, eds, *British Social Attitudes: The 23rd Report* (Sage: London, 2007); Erwin Stolz et al, “Attitudes towards end-of-life decisions in case of long-term care dependency: a survey among the older population in Austria” (2017) 43:6 J Medical Ethics 413; Maggie Hendry et al, “Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying” (2012) 27:1 Palliative Medicine 13; Ruaidhri McCormack, Margaret Clifford & Marian Conroy, “Attitudes of UK doctors towards euthanasia and physician-assisted suicide: A systematic literature review” (2011) 26:1 Palliative Medicine 23 [McCormack]; Catherine S Shaffer, Alana N Cook & Deborah A Connolly, “A conceptual framework for thinking about physician-assisted death for persons with a mental disorder” (2016) 22:2 Psychol Pub Pol’y & L 141 [Shaffer].

42. Jukka Varelius, “Active and Passive Physician-Assisted Dying and the Terminal Disease Requirement” (2016) 30:9 Bioethics 663-671.

delays before appeals are heard.<sup>43</sup> Until a case reaches the Supreme Court, there is little chance of a fresh claim developing the law. If someone's death is imminent, embarking on a series of hearings and appeals may not be sensible or in her best interests. Individuals who are not likely to die within the next few weeks or months are therefore better placed to pursue potentially protracted litigation.

At the same time, Parliamentary opposition to assisted dying has been fairly constant and emphatic, and those seeking to introduce reform may understandably try to draw the exception to the ban on assisted suicide as narrowly as possible. If a "terminal illness" requirement might help to facilitate the passage of an assisted dying bill, it may be thought better to include it, despite its incoherence and practical implications. It might be simpler to contemplate the future amendment of an overly restrictive assisted dying act, in order to accommodate the needs of patients in the same predicament as Debbie Purdy or Tony Nicklinson, than to achieve an initial Parliamentary majority for a more widely-drawn assisted dying bill.

There are dangers to approaching legalization in this way, however. The terminal illness requirement might, as Samantha Halliday puts it, be "merely a device intended to make the Bill appear more restrictive and thus more palatable,"<sup>44</sup> but if "robust safeguards" become "ritualized practices of verification,"<sup>45</sup> Halliday suggests that compliance "is reduced to ticking items off a checklist." Indeed, there is evidence of this from the Netherlands, where the question for the regional review committees is not "did this patient die a good death?," but rather, "were the due care criteria met?"<sup>46</sup> What legitimates an assisted death is not then the quality of the patient's experience of the dying process, but the fulfilment of the statutory eligibility criteria.<sup>47</sup> Of course, if the statutory eligibility criteria in fact embody the ingredients of a "good death," this may not matter. But since "having six months left to life" is not a necessary feature of dying well, ticking that box does not ensure that the patient died peacefully and with dignity.

43. Delays as long as 19 months have been reported in the Court of Appeal. See further, Owen Bowcott, "Cases taking 19 months to get to appeal court owing to backlogs," *The Guardian* (7 March 2016), online: <[www.theguardian.com/law/2016/mar/07/court-cases-19-months-appeal-court-backlogs](http://www.theguardian.com/law/2016/mar/07/court-cases-19-months-appeal-court-backlogs)>.

44. Samantha Halliday, "Comparative reflections upon the Assisted Dying Bill 2013: A plea for a more European approach" (2013) 13:2 *Medical L Intl* 135.

45. Michael Power, *The Audit Society: Rituals of Verification* (New York: Oxford University Press, 1999).

46. Ton Vink, "Self-Euthanasia, the Dutch Experience: In Search for the Meaning of a Good Death or *Eu Thanatos*" (2016) 30:9 *Bioethics* 681 [Vink].

47. *Ibid.*

4. *Incoherence as a broader theme of legalization debates*

While it might be possible to explain the inclusion of an illogical terminal illness criterion, despite its foreseeable albeit unintended consequences, I want to suggest that this is not an isolated example of pragmatically-tolerated inconsistency. For example, the assisted dying bill's "contemporaneous capacity" requirement might look uncontroversial, but it too might have unintended and undesirable consequences. By ruling out advance requests for assisted dying, to be carried out after a person has lost capacity, it creates a dilemma for someone suffering from a degenerative condition, which is likely to result in her losing capacity in the future. If a person concerned about the death that lies ahead of her is also worried that she will lose the option of assisted dying when she loses capacity, she might seek an assisted death overseas, or commit suicide while she is still able to do so.<sup>48</sup> The need for prior judicial approval might have the same effect, if people worry that by the time their condition becomes unbearable, they might be too weak to face an application to the court, or that the court process might take too long.<sup>49</sup>

As a result, the capacity requirement, and perhaps also the need for the approval of a High Court judge, might reproduce the problem that exists now in the UK in relation to people who wish to have an assisted death at Dignitas in Switzerland. The need to take advantage of Dignitas's services while a person is still fit enough to travel abroad is likely to mean that she dies sooner than she would have done if she could have been reassured that a lawful assisted death would be available to her at home, once her condition became unbearable. Indeed, it is likely that many of those who have travelled to Dignitas would have died naturally, if they had known that "a hypothetical exit plan" was available to them in the UK.<sup>50</sup>

If the draft bill were to become law, it would provide the option of assisted dying for some people, while at the same time placing fresh obstacles in the way of other individuals whose suffering might be unbearable, now or in the future, but who do not meet its restrictive eligibility criteria.<sup>51</sup> And this seems to be a recurrent theme in debates over the legalization of assisted dying: one problem is solved, while another

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48. See further the special edition of *Feminism & Psychology* (2015) volume 25 issue 1, in memory of Sandra Bem, a psychologist who committed suicide four years after having been diagnosed with Alzheimer's disease.

49. Penney Lewis, "Should Assisted Dying Require the Consent of a High Court Judge" (Paper presented at Law Reform and End of Life Workshop, Halifax, Canada, September 2017).

50. Rinat Nissim, Lucia Gagliese & Gary Rodin, "The desire for hastened death in individuals with advanced cancer: a longitudinal qualitative study" (2009) 69:2 *Social Science & Medicine* 165.

51. Samantha Halliday, "Comparative reflections upon the Assisted Dying Bill 2013: A plea for a more European approach" (2013) 13 *Medical L Intl* 135.

is created. For example, medicalizing assisted dying may help secure legitimacy for it, while at the same time, giving doctors considerable autonomy over the process may restrict patient choice. Medicalizing the justifications for assisted dying may also fail to capture the real reasons why some people find the dying process so frightening. Legalization is often shaped by concern for the interests of vulnerable people, whereas all of the evidence suggests that assisted dying is of interest to people who are accustomed to being able to exercise considerable control over their lives.<sup>52</sup> Finally, formalizing the process of assisted dying, whether through a ban, or through restrictions upon access, may mean that conversations about wanting to hasten death are channelled through the relevant legal framework, even though there are multiple reasons why people might want to talk about a desire for death, only one of which is that they want to seek an assisted death now. If the law related to assisted dying serves to shut down conversations about dying, it may be actively working against a key component of a good death.<sup>53</sup>

## II. *To medicalize or not medicalize assisted dying?*

Most of the countries that have legalized assisted dying have made the involvement of the medical profession mandatory, while individual doctors' participation is optional. That is, doctors have to be involved to confirm that the person who wishes to die meets the medicalized eligibility criteria: for example, that the patient's condition is incurable; that her suffering cannot be relieved; that she is not suffering from a psychiatric disorder; and that her request is made voluntarily. The involvement of the medical profession is also required in order to prescribe the fatal dose, and in countries like Belgium, the Netherlands and Luxembourg, where euthanasia as well as assisted suicide is lawful, doctors are expected to administer the drugs.

In the Netherlands, the Dutch Supreme Court decided in the *Sutorius/Brongersma* case in 2002 that "a doctor who assists in suicide in a case in which the patient's suffering is not predominantly due to a 'medically classified disease or disorder,' but stems from the fact that life has become meaningless for him, acts outside the scope of his professional competence."<sup>54</sup> This case played a prominent role in debates over legalization later the same year, with ministers stressing that non-

52. See below, section 4.

53. General Medical Council, *When a patient seeks advice or information about assistance to die* (London, UK: GMC, 2015) at paras 5 and 6 [GMC].

54. *Nederlandse Jurisprudentie* 2003, no 167.

medicalized suffering lay outside the scope of the legislation.<sup>55</sup> In its advice to doctors, the Royal Dutch Medical Association (KNMG) is clear that unbearable suffering without a medical basis “falls outside the scope of current Dutch legislation and is always a criminal offence.”<sup>56</sup>

At the same time as mandating medical involvement, most countries make it optional for individual doctors to participate by recognizing the right of individual doctors conscientiously to object to participation in assisted dying. Legalization then depends upon there being sufficient members of the medical profession who do not conscientiously object in order to fulfil the roles that only registered medical practitioners are permitted to play.

There are clearly good reasons for involving doctors in the practice of legalized assisted dying. First, and most obviously, doctors have the necessary knowledge and skill to end lives quickly and painlessly. Unlike suicide, which can be violent, brutal, and go badly wrong, a medicalized assisted suicide can be achieved efficiently and effectively, or as John Paris puts it “in an antiseptically acceptable fashion.”<sup>57</sup> Many patients have the option of bringing their life to an end, without medical involvement, by stopping eating and drinking. Indeed, this is what Tony Nicklinson did after the High Court had decided his case, with his death from pneumonia following six days later. Voluntarily stopping eating and drinking (VSED) *can* be a relatively peaceful way to die, especially in the presence of an underlying condition, but it can also be torturous and challenging, for the patient and her loved ones.<sup>58</sup> Patients might additionally have the wherewithal to end their own lives by overdosing on medicines which they have been prescribed legitimately. Again, while this might lead to a peaceful death, there are also dangers that the patient might misjudge the dose, and be left worse off than she was before.<sup>59</sup>

Secondly, doctors are well placed to diagnose and confirm the existence of clinical eligibility criteria, such as the presence of an incurable disease

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55. Suzanne Ost & Alexandra Mullock, “Pushing the boundaries of lawful assisted dying in the Netherlands? Existential suffering and lay assistance” (2011) 18:2 Eur J Health L 163.

56. Dutch Medical Association (KNMG), *Position Paper: The Role of the Physician in the Voluntary Termination of Life* (Utrecht, Netherlands: 2011).

57. John J Paris, “Why Involve Physicians in Assisted Suicide?” (2009) 9:3 American J Bioethics 32.

58. Ranjani Varadarajan, Robert A Freeman & Jayesh R Parmar, “Aid-in-dying practice in Europe and the United States: Legal and ethical perspectives for pharmacy” (2016) 12:6 Research in Social and Administrative Pharmacy 1016.

59. Patients contemplating overdosing in this way also express concern about being interrupted, and the anguish this sort of death might cause for the person finding the body. See further Naomi Richards, “Assisted suicide as a remedy for suffering? The end-of-life preferences of British ‘suicide tourists’” (2017) 36:4 Medical Anthropology 348-362.



or the absence of treatable depression.<sup>60</sup> Where the criteria for assisted dying are medicalized, medical practitioners inevitably become their gatekeepers. Thirdly, the experience of legalization in Belgium provides powerful evidence that the integration of assisted dying and palliative care can be beneficial for patients, ensuring continuity of care and a holistic approach to patient suffering.<sup>61</sup> There is certainly no evidence from Belgium that access to high quality palliative care suffers when assisted dying is also an option.<sup>62</sup> Fourth, medicalising the process of assisted dying serves a broader purpose of legitimization; that is, the medical profession tends to be held in high regard, and so making the process a medical one is likely to reassure individual patients, and the public more generally, that rigorous safeguards will be applied.<sup>63</sup>

Certainly there is evidence that insofar as the public is in favour of the legalization of assisted dying, this is dependent upon medical involvement, and there would be hardly any support for the legalization of non-physician assisted suicide.<sup>64</sup> In her interviews with British patients seeking assisted suicides in Switzerland, Naomi Richards found that a medicalized assisted death matched their preference for a “good death”: not only would it be “orderly and controlled,” and have a “guaranteed outcome,” it would also have “some social legitimacy because it involved a medical professional.”<sup>65</sup> Indeed, some of her interviewees valued physician involvement because it offered professional validation of their suffering, and so “that the responsibility for making the decision to die would be shared, making it feel less like a suicide.”<sup>66</sup> Medicalization may also make an assisted death easier for the relatives of the person who has died, whose ability to cope

60. Thomas P Duffy, “Physician Assistance in Dying: A Subtler Slippery Slope” (2014) 44:2 *Hastings Center Report* doi:10.1002/hast.290.

61. Jan L Bernheim & Kasper Raus, “Euthanasia embedded in palliative care. Responses to essentialistic criticisms of the Belgian model of integral end-of-life care” (2017) 43:8 *J Medical Ethics* 489.

62. S Moreels et al, “Trends in palliative care at the end of life in Belgium, 2005–2014” (2016) 26: Supplement 1 *European J Public Health*.

63. A parallel might be drawn with the medicalisation of abortion in the UK, which many have argued has served to depoliticize the issue. See further Sally Sheldon, “The Abortion Act 1967: a Critical Perspective” in Ellie Lee, ed, *Abortion Law and Politics Today* (Palgrave Macmillan, 1998) 43 and Sheelagh McGuinness & Michael Thomson, “Medicine and abortion law: complicating the reforming profession” (2015) 23 *Medical L Rev* 177.

64. Merel Kristi Schoonman et al, “Non-physician-assisted suicide in The Netherlands: a cross-sectional survey among the general public” (2014) 40 *Journal of Medical Ethics* 842.

65. Naomi Richards, “Assisted suicide as a remedy for suffering? The end-of-life preferences of British ‘suicide tourists’” (2017) 36 *Medical Anthropology* 348.

66. *Ibid.*

might be “complicated by the feeling that society will disapprove of the decision.”<sup>67</sup>

There are also powerful arguments against the medicalization of assisted dying, however. First, there is considerable evidence that involvement in assisted dying is not easy for doctors.<sup>68</sup> Given that people enter the medical profession in order to save and prolong lives, it is unsurprising that the prospect of ending patients’ lives might be experienced as difficult and challenging. Opinion surveys consistently find that levels of support for assisted dying are higher among the general public than they are among medical practitioners,<sup>69</sup> and a 2011 survey of Dutch doctors found that 86 per cent “dread” the “emotional burden of performing euthanasia.”<sup>70</sup>

Furthermore, there is evidence from the Netherlands and Belgium that doctors find involvement in assisted dying more difficult when the patient’s reason for wanting to die is the result of either mental or psychosocial suffering.<sup>71</sup> Assisted dying in cases of mental disorder is lawful in both Belgium and the Netherlands, but, while the numbers have increased in recent years,<sup>72</sup> it continues to be comparatively rare.<sup>73</sup> It is, in practice, difficult for doctors to determine whether the patient’s mental suffering is objectively intolerable, and physicians may be wary of relying upon the patient’s self-reporting.<sup>74</sup> While Dutch guidelines exist to help doctors respond to requests in cases of psychiatric disorders,<sup>75</sup> Bolt et al found that a minority of Dutch physicians thought it conceivable that they would grant a euthanasia request in the case of a psychiatric disorder (34 per cent) or early-stage dementia (40 per cent), compared with 85 per cent for patients with cancer.<sup>76</sup>

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67. Birgit Wagner et al, “Social acknowledgement as a predictor of post-traumatic stress and complicated grief after witnessing assisted suicide” (2012) 58 *Intl J Social Psychiatry* 381.

68. Emanuel, *supra* note 3.

69. *Ibid*; McCormack, *supra* note 42; Emily Tomlinson & Joshua Stott, “Assisted dying in dementia: a systematic review of the international literature on the attitudes of health professionals, patients, carers and the public, and the factors associated with these” (2015) 30 *Int J Geriatric Psychiatry* 310 [Tomlinson].

70. ALJ Van der Heide et al, *Second Evaluation of the Euthanasia Law* (Den Haag: ZonMw, 2012), quoted in Emanuel, *supra* note 3 at 87.

71. Judith AC Rietjens et al, “Judgement of suffering in the case of a euthanasia request in The Netherlands” (2009) 35 *J Medical Ethics* 502.

72. Sigrid Dierickx et al, “Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases” (2017) 17 *BMC Psychiatry* 203.

73. Shaffer et al (2016), *supra* note 42.

74. *Ibid*.

75. A Tholen et al, *Guideline dealing with the request for assisted suicide by patients with a psychiatric disorder* [Richtlijn omgaan met het verzoek om hulp bij zelfdoding door patiënten met een psychiatrische stoornis] (Utrecht: Dutch Psychiatric Association; 2009).

76. Eva Elizabeth Bolt et al, “Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living?” (2015) 41 *J Medical Ethics* 592 [Bolt].

In the same study of Dutch physicians, and unsurprisingly given its doubtful legality, 27 per cent thought it conceivable that they would grant a request for someone who was simply “tired of life.”<sup>77</sup> In addition, Kouwenhoven et al found that whether a doctor was willing to perform euthanasia, as opposed to assisting someone’s suicide, depended upon the reason for the patient’s request. Euthanasia was most common in cases of cancer, but, as a result of its “psychological burden,” doctors were unwilling to carry out euthanasia in cases in which the patient’s suffering was harder to judge objectively, and had a preference in such cases for assisted suicide, in which the patient takes responsibility for the final act.<sup>78</sup>

Also difficult, from the perspective of the medical profession, are advance requests for euthanasia.<sup>79</sup> In the Netherlands, while a majority of the public and the nursing profession support euthanasia in cases of advanced dementia, this is true for only a minority of physicians.<sup>80</sup> Ending the life of a patient who is unable to say unambiguously that this is definitely what she wants, on the grounds that she indicated some time ago that this was the point at which she would wish her life to be ended, is understandably challenging.<sup>81</sup> However carefully it was drafted, the passage of time between the writing of an advance decision and putting it into effect creates room for doubt at the moment when the lethal injection is given as to whether this is still what the patient wants.<sup>82</sup>

While advance decisions might be present in some assisted deaths in the Netherlands and Belgium, in the vast majority of cases, the patient has also been able to confirm her request orally. In the Netherlands, for example, even when an advance decision for euthanasia (ADE) is present, there is generally also a contemporaneous request from a competent patient.<sup>83</sup> Penney Lewis and Isra Black point out that there has been “at

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77. *Ibid.*

78. Pauline SC Kouwenhoven et al, “Euthanasia or physician-assisted suicide? A survey from the Netherlands” (2014) 20 *European J General Practice* 25. See also Tomlinson, *supra* note 70.

79. Marike E de Boer et al, “Advance directives for euthanasia in dementia: Do law-based opportunities lead to more euthanasia?” (2010) 98 *Health Policy* 9256; Shaffer, *supra* note 47.

80. Bolt, *supra* note 77. Pauline SC Kouwenhoven et al, “Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach” (2012) 27 *Palliative Medicine* 273.

81. Kathy Davis, “Dying, self-determination, and the (im)possibilities of a ‘good death’” (2015) 25 *Feminism & Psychology* 143 [Davis].

82. Government of the Netherlands, *Guide to Written Euthanasia Requests* (2015), online: <[www.rijksoverheid.nl/documenten/brochures/2015/12/17/handreiking-schriftelijk-euthanasieverzoek-publieksversie](http://www.rijksoverheid.nl/documenten/brochures/2015/12/17/handreiking-schriftelijk-euthanasieverzoek-publieksversie)>; Regional Review Committees *Annual Report 2016* (RTE, 2017).

83. Mette L Runup et al, “The first five years of euthanasia legislation in Belgium and the Netherlands: Description and comparison of cases” (2011) 26 *Palliative Medicine* 43.

least one recent dementia case where an ADE was the effective request.”<sup>84</sup> But given that the KNMG has advised Dutch doctors that they should not perform euthanasia when they cannot communicate with the patient, such cases will continue to be unusual. At first, the evidence that 2.1 per cent of reported cases in Belgium were based upon an advance directive might look rather different, but these are not cases of advanced dementia. Rather, advance decisions for euthanasia in Belgium are possible only for patients who have irreversibly lost consciousness.<sup>85</sup>

Assisted dying may be most straightforward, from the point of view of the medical profession, for patients in the final stages of cancer, when a doctor can be confident in her diagnosis and prognosis, and when the patient is able to confirm both that her suffering is unbearable and that she wishes to die now. In both the Netherlands and in Belgium, although the proportion has fallen in recent years, cancer continues to be the most common reason for requests for euthanasia (68 per cent in both jurisdictions).<sup>86</sup> Interestingly, in Switzerland, where assisted suicide is less medicalized, fewer than half (46 per cent) of those who die assisted deaths were suffering from cancer.<sup>87</sup> Steck et al found that in 16 per cent of death certificates following assisted suicides in Switzerland, no underlying cause of death was recorded, and that Exit Duetsche Schweiz and Dignitas have reported that as many as 25 per cent “involved no fatal illness,” with “weariness of life” an increasingly common reason for choosing assisted suicide.<sup>88</sup> In Gauthier et al’s study of “suicide tourists” to Switzerland, 47 per cent were suffering from neurological disease, and only 37 per cent from cancer.<sup>89</sup>

While patients with cancer make up a non-negligible proportion of those who might want to seek an assisted death, the desire for assisted death is certainly not limited to patients with cancer. And the reasons patients commonly give for wishing to hasten their deaths are, unlike cancer,

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84. Penney Lewis & 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 *JL Med & Ethics* 885.

85. Lukas Radbruch et al on behalf of the board members of the EAPC, “Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care” (2015) 30 *Palliative Medicine* 104 [Radbruch].

86. Regional Review Committees *Annual Report 2016* (RTE, 2017); Commission fédérale de Contrôle et d’Évaluation de l’Euthanasie *Septième rapport aux Chambres législatives années 2014–2015* (2016).

87. Emanuel, *supra* note 4.

88. Nicole Steck et al & Swiss National Cohort, “Suicide assisted by right-to-die associations: a population based cohort study” (2014) 43 *Intl J Epidemiology* 614 [Steck].

89. Saskia Gauthier et al, “Suicide tourism: a pilot study on the Swiss phenomenon” (2015) 41 *J Medical Ethics* 611.

difficult for doctors to diagnose and verify: namely, a loss of meaning, a loss of connectedness, a loss of control, or the simple feeling that their life is now “completed,” and no longer worth living.<sup>90</sup> Van Wijnngaarden et al’s study of people who have developed a wish to die explain that this is often a result of multiple losses, ranging from physical decline and its associated loss of privacy, to the diminution of their social circle through successive bereavements.<sup>91</sup> Moreover, it is often fear of an intolerable future, rather than intolerable present suffering, which prompts interest in assisted dying.<sup>92</sup> While doctors may be able to provide some reassurance about the future management of pain, there is little that they can do to take away people’s fear of a loss of control over their bodies.

For many patients, the fear of physical decline and an unpleasant death is not necessarily simply an abstract concern, resulting from fear of the unknown. Rather, it is not uncommon for people’s interest in hastening their own death to be grounded in the experience of having watched a close friend or relative suffer.<sup>93</sup> People who live with recent and disturbing images of a loved one’s suffering are unsurprisingly sceptical about reassurances that their future distress can be managed effectively.

Patients who are fearful about what lies ahead for them might find the option of an advance decision for euthanasia reassuring,<sup>94</sup> but this is reassurance that few doctors in the Netherlands and Belgium are able to provide, because their use in practice is so rare. If legalized assisted dying depends upon the patient experiencing objectively unbearable suffering at the time when the lethal injection is given, or if the reality is that doctors are unwilling to perform euthanasia unless this is the case, it is impossible to give patients the comfort of knowing that their wish not to continue living once their life has lost meaning to them will be respected. As a result, even in countries where assisted dying has been legalized, patients face the unintended consequence that they may be prompted to “take

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90. Els van Wijnngaarden, Carlo J Leget & Anne Goossensen, “Experiences and Motivations Underlying Wishes to Die in Older People Who Are Tired of Living: A Research Area in its Infancy” (2014) 69 *OMEGA – J Death and Dying* 191.

91. *Ibid.*

92. Mark D Sullivan, “The desire for death arises from an intolerable future rather than an intolerable present” (2005) 27 *General Hospital Psychiatry* 256; Martina Pestinger et al, “The desire to hasten death: Using Grounded Theory for a better understanding ‘When perception of time tends to be a slippery slope’” (2015) 29 *Palliative Medicine* 711 [Pestinger].

93. Kara B Dassel et al, “The Influence of Hypothetical Death Scenarios on Multidimensional End-of-Life Care Preferences” (2018) 1 *American J Hospice & Palliative Medicine* 52; Hadi Karsoho et al, “Suffering and medicalization at the end of life: The case of physician-assisted dying” (2016) 170 *Social Science & Medicine* 188.

94. Eva E Bolt et al, “From Advance Euthanasia Directive to Euthanasia: Stable Preference in Older People?” (2016) 64 *J American Geriatrics Society* 1628.

matters into their own hands” while they still have the capacity to do so, and hence die earlier deaths, and perhaps “give up what may be some good years of life in order to ensure than one can die with dignity.”<sup>95</sup>

In short, then, there may be a mismatch between the reasons why some patients wish to end their lives prematurely and medicalized assisted dying. As a result, while medicalized assisted dying in the Netherlands and Belgium undoubtedly provides reassurance to some patients, there is evidence that it does not help everyone. First, the number of patients in the Netherlands who choose to end their lives through voluntarily stopping eating and drinking (VSED) is much higher than one might expect. Studies indicate that this is the primary cause of death in between 0.4 and 2.1 per cent of all deaths. Bolt et al found that nearly half (46 per cent) of all primary care physicians “had cared for a patient who had hastened death by VSED.”<sup>96</sup> This seems odd in a country in which both euthanasia and assisted suicide have been lawful for more than four decades. Bolt et al found that about a fifth of those who had died following VSED had previously requested an assisted death, but most had not. Some opted for VSED in order not to have to rely upon their physician, and 77 per cent had “existential” motives for hastening death. Most were older than patients requesting an assisted death (median age 84), and a minority (27 per cent) suffered from cancer.

Secondly, in recent years campaigners in the Netherlands have attempted to assert greater autonomy over assisted dying through the “Of Free Will” (Uit Vrije Wil) movement. Although it was ultimately unsuccessful, in 2010 the “Of Free Will” movement managed to put before the Dutch parliament a bill which would have enabled anyone over the age of 70 to have access to assisted suicide, regardless of whether they had any medical problems at all. Another development has been the setting up of the End of Life Clinic (levenseindekliniek), whose 50 teams offer the option of euthanasia for individuals whose requests have been turned down by their treating physicians. Although the numbers are relatively small, demand has increased significantly between 2013 and 2017, from 134 to more than 500 cases.<sup>97</sup>

As Kathy Davis explains, euthanasia in the Netherlands “is not nearly as common as one might imagine,” and “is not at all easy to get.”<sup>98</sup> Doctors,

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95. Davis, *supra* note 82.

96. Eva E Bolt et al, “Primary care patients hastening death by voluntarily stopping eating and drinking” (2015) 13 *Annals Family Medicine* 421.

97. Janene Pieters, “Euthanasia clinic needs 50 more doctor [sic] to keep up with demand,” *NL Times* (27 October 2017).

98. Davis, *supra* note 82.

Davis points out, turn down “two-thirds of the requests for euthanasia” that they receive.<sup>99</sup> Assisted dying is not available as of right, but is a matter of medical discretion. As Ton Vink points out, “the physician’s autonomy is decisive,” not the patient’s.<sup>100</sup> Indeed, the first cases which carved out limited access to euthanasia in the Netherlands were grounded in the fact that a *doctor* might be faced with two irreconcilable duties,<sup>101</sup> not that the patient might have a right to choose to bring her life to an end. There is an obvious parallel here with the decriminalisation of abortion in the UK through the Abortion Act 1967, which did not give women a right to access abortion, even if their circumstances clearly satisfied what might be described as the 1967 Act’s version of “due care” criteria; rather what matters is the doctors’ *opinion* as to whether the woman’s circumstances satisfy one of the four statutory grounds for abortion.<sup>102</sup>

Thirdly, it appears that doctors in both the Netherlands and Belgium are increasingly confronted with requests for assisted dying that do not fit the standard medicalized model. The KNMG, for example, has reported a growth in requests from people with “an accumulation of non-life-threatening geriatric afflictions, including loss of physical function and mental vitality, loneliness and loss of autonomy.”<sup>103</sup> Snijdewind et al.’s interviews with physicians in the Netherlands found that the majority believed that requests for EAS “where there was no medical condition underlying the request,” have become more frequent in recent years, and most found these requests problematic:

Most physicians expressed the view that these requests based on non-medical reasons stemmed from loneliness and that this was not a medical problem but a societal one, not something for which EAS was the right solution. Most physicians also mentioned not feeling competent to make a decision about EAS in these cases where suffering was mostly existential, not motivated by a medical condition; they felt it did not belong to the domain of medical professionals.<sup>104</sup>

It is possible that there are more requests for assisted dying in the absence of a medical condition because people in the Netherlands and Belgium are

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99. *Ibid.*

100. Vink, *supra* note 47.

101. Claudia Grosse & Alexandra Grosse, “Assisted suicide: models of legal regulation in selected European countries and the case law of the European Court of Human Rights” (2015) 55 *Med Sci Law* 246 [Grosse].

102. See further Sally Sheldon, *Beyond control: Medical power and abortion law* (London: Pluto Press, 1997).

103. Grosse, *supra* note 101.

104. Marianne C Snijdewind et al., “Developments in the practice of physician-assisted dying: perceptions of physicians who had experience with complex cases” (2016) *J Medical Ethics*.

more familiar with the availability of assisted dying.<sup>105</sup> It is also possible that as the “baby-boomer” generation starts to face the multiple losses associated with old age, it does so in a more assertive and demanding way than previous generations.

Lawful assisted suicide in Switzerland is undoubtedly less medicalized than it is in the Netherlands and Belgium. Since 1942, the criminal code has prohibited selfishly-motivated assisted suicide. There is no requirement that the assister must be a doctor,<sup>106</sup> nor does the request for assistance have to be the result of a medical condition.<sup>107</sup> Doctors are seldom present during assisted suicides, and the patient will normally be assisted instead by a volunteer, acting on behalf of one of the “right to die” associations. It is also very unusual for patients to receive assistance with suicide in a hospital,<sup>108</sup> and assisted suicides generally take place in apartments rented for the purpose by right to die associations.

In practice, however, there are a number of medical eligibility criteria imposed *de facto*. For an individual’s act to count as suicide, the individual who seeks help must have “decisional capacity.” More significantly, because only medical practitioners can issue prescriptions for sodium pentobarbital, doctors retain the ability to veto an assisted suicide.<sup>109</sup> For the prescription of lethal medication to be within the limits of accepted medical practice, courts have established that the doctor must personally examine the individual.<sup>110</sup>

As part of its medical-ethical guideline on end of life care, the Swiss Academy of Medical Sciences (SAMS) has issued guidance to its members on their involvement in assisted suicide. These guidelines, first issued in 2004 and updated in 2013, express reservations about doctors’ participation in assisted suicides: “the task of the physician is to alleviate symptoms and to support the patient. It is not his task to directly offer assistance in suicide, he rather is obliged to alleviate any suffering underlying the patient’s wish to commit suicide.”<sup>111</sup> Nevertheless, the

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105. Sigrid Dierickx et al, “Comparison of the Expression and Granting of Requests for Euthanasia in Belgium in 2007 vs 2013” (2015) 175 JAMA Intern Med 1703.

106. Samia A Hurst & Alex Mauron, “Assisted Suicide in Switzerland: Clarifying Liberties and Claims” (2017) 31 Bioethics 199 [Hurst].

107. Grosse, *supra* note 101.

108. Sandra Burkhardt & Romano La Harpe, “Debates about assisted suicide in Switzerland” (2012) 33 American J Forensic Medicine & Pathology 410.

109. Hurst, *supra* note 106.

110. Zurich Case, Entscheid der 3 Kammer VB Nr 99.00145 (1999) (Verwaltungsgericht des Kantons Zürich [Zurich Administrative Court]); Aargau Case Entscheid BE 2003.00354-K3 (2005) (Verwaltungsgericht des Kantons Aargau [Aargau Administrative Court]).

111. Swiss Academy of Medical Sciences, *Medical Ethical Guide-lines: End-of-Life Care* (Basel, Switzerland: SAMS, 2013) at para 4.1.



SAMS guidance also acknowledges that “consideration of the patient’s wishes is fundamental for the physician-patient relationship. This dilemma requires a personal decision of conscience on the part of the physician. The decision to provide assistance in suicide must be respected as such.”

If a doctor does decide to assist a patient by issuing a prescription for lethal medication, the SAMS guideline specifies that she should ensure that a number of criteria are satisfied:

- The patient’s disease justifies the assumption that he is approaching the end of life.
- Alternative possibilities for providing assistance have been discussed and, if desired, have been implemented.
- The patient is capable of making the decision, his wish has been well thought out, without external pressure, and he persists in this wish. This has been checked by a third person, who is not necessarily a physician.
- The final action in the process leading to death must always be taken by the patient himself.<sup>112</sup>

These guidelines do not have the force of law, but they are effectively binding on registered medical practitioners, and since only doctors can lawfully prescribe sodium pentobarbital, they are *de facto* binding on the right to die associations as well.

Seven years ago, the Swiss government considered amending Article 115 of the Penal Code, but decided against it, in part because specific measures might legitimize the right to die organisations, and would be likely to face resistance from the medical profession.<sup>113</sup> Just three years later, in *Gross v Switzerland*,<sup>114</sup> the ECtHR, by a majority, found that ‘the absence of clear and comprehensive legal guidelines’ violated the Article 8 rights of a 76-year-old woman who was not terminally ill, but who had wanted to end her life for many years, because she was “becoming more and more frail as time passes and is unwilling to continue suffering the decline of her physical and mental faculties.”<sup>115</sup> A majority in the ECtHR considered that this lack of clarity would be “likely to have a chilling effect on doctors who would otherwise be inclined to provide someone such as the applicant with the requested medical prescription,”<sup>116</sup> and that the Swiss failure to “provide sufficient guidelines ensuring clarity” as to

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112. *Ibid.*

113. Grosse, *supra* note 101.

114. [2013] ECHR 429.

115. *Ibid* at para 7.

116. *Ibid* at para 65.

the extent of the right to obtain a lethal dose of sodium pentobarbital on medical prescription, violated Mrs Gross's Article 8 rights.<sup>117</sup>

In contrast, the three dissenting judges considered that "the applicant in the instant case did not fulfil the conditions laid down in the medical ethics guidelines on the care of patients at the end of life adopted by the Swiss Academy of Medical Sciences which have, in our opinion, been correctly applied and clearly interpreted in the jurisprudence of the Federal Supreme Court."<sup>118</sup> And although the majority specifically declined to express a view as to what the substantive content of clearer Swiss guidelines should be,<sup>119</sup> suggesting that a clearer but more restrictive regime might be compatible with Alda Gross's human rights, Stephen Brown claims that the majority judgment in *Gross* suggests that "the ECtHR has changed gears regarding assisted suicide."<sup>120</sup>

### III. *Vulnerable or not vulnerable?*

The most commonly cited reason not to legalize assisted dying, or to impose rigorous safeguards when doing so, is concern for the vulnerable. Indeed, it seems so obvious as to barely need stating that people who are dying are a potentially vulnerable group: all of them are ill, and many of them will be elderly. The House of Lords Select Committee on Assisted Dying, for example, was "concerned that vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death."<sup>121</sup> In *Purdy*, Lord Neuberger explained that the Code for prosecutors was "simply inadequate" for the unusual crime created by section 2(1) because "it is the victim whose article 8 rights are engaged, and he or she will almost always be unusually vulnerable and sensitive."<sup>122</sup> In introducing the Assisted Dying Bill to the House of Commons, Rob Marris MP said that "coercion of the vulnerable is the most difficult issue, for me and many people in the House and outside."<sup>123</sup> Opponents of his Bill repeatedly mentioned concern for the vulnerable. For example, Lyn Brown MP voted against the Bill on the grounds that it might "fundamentally change the way that our society thinks about and deals with the terminally ill, severely disabled people and the vulnerable,

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117. *Ibid* at para 67.

118. *Ibid* at para 2.

119. *Ibid* at para 69.

120. Stephen Brown, "*Gross v. Switzerland* and Right to Die Jurisprudence in the European Court of Human Rights" (2014) 14 *Chicago-Kent J Intl L* 5.

121. HL Bill, *supra* note 34 at para 239.

122. *Ibid* at para 102.

123. Marris, *supra* note 37 at col 661.

troubled and elderly.”<sup>124</sup> In *Nicklinson*, Lady Hale suggested that protection of the vulnerable was the only legitimate justification for section 2(1) of the Suicide Act’s interference with Tony Nicklinson’s Article 8 rights:

The only legitimate aim which has been advanced for this interference is the protection of vulnerable people, those who feel that their lives are worthless or that they are a burden to others and therefore that they ought to end their own lives even though they do not really want to.<sup>125</sup>

And in *R v Conway*, the Court of Appeal considered “that it is impossible to say that the Divisional Court did not have material on which properly to come to their conclusions on the inadequacy of the proposed scheme to protect the weak and vulnerable.”<sup>126</sup>

But despite this apparent consensus that legalized assisted dying might pose a threat to the vulnerable, and that this represents either a reason not to legalize at all, or a reason to proceed with caution, the evidence that we now have about patients who request legalized assisted dying suggests that they have something in common other than their vulnerability. In the Netherlands and Belgium, typical patients who request assisted death are “older, white and well-educated.”<sup>127</sup> In Switzerland, they are more likely to live alone, to have no religious affiliation, to be well-educated, and to live in urban rather than rural areas and in more affluent neighbourhoods.<sup>128</sup>

Systematic reviews of attitudes towards assisted dying have consistently found support is strongest among the irreligious,<sup>129</sup> the middle classes,<sup>130</sup> and the “highly educated,”<sup>131</sup> and lowest among people with strong religious or spiritual beliefs.<sup>132</sup> Interest in assisted dying comes from those patients who wish to exert control over the dying process.<sup>133</sup> As Raijmakers et al put it, “a shared theme seems to be that those who

124. *Ibid* at col 669.

125. *Nicklinson*, *supra* note 13 at para 311.

126. *Conway*, *supra* note 29 at para 204.

127. Emanuel, *supra* note 4.

128. Steck, *supra* note 90.

129. Kathryn A Smith et al, “Predictors of pursuit of physician-assisted death” (2015) 49 J Pain & Symptom Management 555 [Smith].

130. Sandy Macleod, “Assisted dying in liberalized jurisdictions and the role of psychiatry: A clinician’s view” (2012) 46 Australian & New Zealand J Psychiatry 936 [Macleod].

131. Maggie Hendry et al, “Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying” (2012) 27 Palliative Medicine 13.

132. Macleod, *supra* note 130; McCormack, *supra* note 42.

133. Natasja J H Raijmakers et al, “Assistance in dying for older people without a serious medical condition who have a wish to die: a national cross-sectional survey” (2015) 41 J Medical Ethics 145 [Raijmakers].

support assistance in dying value control.”<sup>134</sup> They are “not prepared to accept paternalistic attitudes on the part of health staff,” and see access to assisted dying “as a way of rising above one’s circumstances.”<sup>135</sup> Smith et al also found that requesters of assisted dying had what they describe as “dismissive styles of attachment,” that is they prioritize “self-reliance, autonomy and independence,” and are interested in assisted dying in order to “maintain an ultimate sense of control and autonomy within a process that allows very little opportunity for either.”<sup>136</sup> Predictably, these differences are reproduced among those who are in favour of assisted dying for older people who are “tired of life,” whom Raijmakers et al again found “were more likely than opponents to be highly educated, to be non-religious, to have little trust in physicians, and to prefer to make their own healthcare decisions.”<sup>137</sup>

Interest in assisted dying therefore appears to be associated with patients who might be described as hyper-autonomous, who have become accustomed to exercising choice and control over their lives and who wish to continue to do so over their deaths. For such patients, an assisted death represents “liberation from a situation that [is] perceived as an affront.”<sup>138</sup>

What is also significant about this growing body of evidence is that it is the patient’s beliefs, characteristics and priorities, rather than their illness or symptoms, which are the principal predictor of the desire to access an assisted death. Patients’ interest in assisted dying stems not from objectively inadequate symptom control, which might be alleviated through access to better palliative care, but from their *subjective* perception of what makes a good death. Smith et al explain that, for some patients, “the anticipated dependency of terminal illness...may have been more unbearable than the physical symptoms themselves.”<sup>139</sup> According to al-Awamer, “these are rational capable patients who are not depressed and who want to die early based on their personal values and views of suffering and life. These wishes are not driven by a failure of palliative care but by a desire to live ‘on their own terms.’”<sup>140</sup>

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134. *Ibid.*

135. *Ibid.*

136. Smith, *supra* note 129.

137. Raijmakers, *supra* note 133.

138. Kathrin Ohnsorge, Heike Gudat & Christoph Rehmann-Sutter, “What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care” (2014) 13 BMC Palliative Care 38 [Ohnsorge].

139. Smith, *supra* note 129.

140. Ahmed al-Awamer, “Physician-assisted suicide is not a failure of palliative care” (2015) 61 Canadian Family Physician 1039.

Opponents of assisted dying often argue that high quality palliative care can eliminate the desire for assisted dying,<sup>141</sup> but if it is the intrinsic internal characteristics of the individual—her lack of spirituality and her desire for control and independence—that drive the desire for an assisted death, it is not clear that palliative care can, or should, be able to eliminate these. In keeping with these findings, interviews with British patients who have started the process of seeking an assisted death with Dignitas in Switzerland have found that “getting the green light” from Dignitas becomes “a different object towards which they could direct their hope.”<sup>142</sup> It became a goal to aim for, and “a hedging strategy for maximising control.”<sup>143</sup>

Needless to say, I do not mean to suggest that concern for the vulnerable is entirely misplaced. On the contrary, it is clearly important that any law which permits assisted dying contains a mechanism capable of weeding out requests that are prompted not by someone’s desire to die, but by unscrupulous others exerting pressure upon them. My point is instead that if assisted dying legislation is designed only to protect the vulnerable, it will not do anything to address the needs of those whose desire for an assisted death comes instead from this need for control.

If people could be reassured about their capacity to exercise control in the future, perhaps through being able to execute a binding advance decision for euthanasia, this might provide the comfort that these people need in order to face the dying process without being overwhelmed by the fear of what might lie ahead. In short, designing an assisted dying law to prevent the abuse of the vulnerable misses the opportunity to address the needs of the autonomous patient, who instead needs reassurance about her future options to exert control and meaning over the process of dying.

#### IV. *Talking about assisted dying as an end in itself*

There are multiple reasons why someone might express an interest in hastening death, only one of which is that they would like to access an assisted death now.<sup>144</sup> Some people engage in conversations about seeking an early death as a way of asking for reassurance,<sup>145</sup> or as a “cry

141. YY Mak, G Elwyn & IG Finlay, “Patients’ voices are needed in debates on euthanasia” (2003) 327 *British Medical Journal* 213.

142. Naomi Richards & Rebecca Rotter, “Desperately seeking certainty? The case of asylum applicants and people planning an assisted suicide in Switzerland” (2013) 18 *Sociological Research Online* 26.

143. *Ibid.*

144. Radbruch, *supra* note 86.

145. *Ibid.*

for help.”<sup>146</sup> At other times, “wish to die” statements can be positively manipulative, in order to gain attention, or to provoke or test the reaction of others.<sup>147</sup> For some patients, expressing a desire to hasten death may be “an extreme coping strategy for intrusive emotional and cognitive experiences, often related to anticipated images of agony and suffering in the dying process.”<sup>148</sup> Alternatively, it might represent simply “a dawning recognition of what lies ahead rather than a request for hastened death.”<sup>149</sup> A request for hastened death can be a way to express a wish to live, but not in the current way.<sup>150</sup> Sometimes, a patient might simply mean that she is looking forward to dying, or hoping that it happens more quickly. Expressing a wish to die might also be a “manifestation of letting go,” and a way for the dying patient to let her loved ones know that she has accepted that she is dying. At other times, or at the same time, it might be “an expression of despair,”<sup>151</sup> and a device through which a patient can “vent her fear” and “regain agency.”<sup>152</sup>

There is now considerable evidence that the wish to die is “dynamic and interactive,” and that patients expressing an interest in dying may be experiencing “several thoughts and wishes concomitantly.”<sup>153</sup> Importantly, as Ohnsorge et al explain, “wish to die” statements are “a vehicle” to enable the patient “to speak about dying.”<sup>154</sup> Indeed, the desire to talk about hastening death appears to be common among dying patients.<sup>155</sup> There are studies that indicate that suicidal thoughts occur in nearly half of all terminally ill patients,<sup>156</sup> and in as many as a third of all residents in long-term care facilities.<sup>157</sup> Most of the time, this is not because these

146. Ohnsorge, *supra* note 138.

147. Kathrin Ohnsorge, Heike Gudat & Christoph Rehmann-Sutter, “Intentions in wishes to die: analysis and a typology—A report of 30 qualitative case studies of terminally ill cancer patients in palliative care” (2014) 23 *Psycho-Oncology* 1021 [Ohnsorge B].

148. Pestinger, *supra* note 92.

149. Romyne Gallagher, “Doctor, can we get this over with?” (2016) 58 *British Columbia Medical J* 30.

150. Cristina Monforte-Royo et al, “What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients” (2012) 7 *PLoS One* 2012, 7:e37117.

151. Ohnsorge B, *supra* note 147.

152. *Ibid.*

153. *Ibid.* See also Albert Balaguer et al, “An international consensus definition of the wish to hasten death and its related factors” (2016) 11 *PloS One* e0146184.

154. Ohnsorge, *supra* note 147.

155. Stephen Claxton-Oldfield & Kathryn Miller, “A Study of Canadian Hospice Palliative Care Volunteers’ Attitudes Toward Physician-Assisted Suicide” (2015) 32 *American J Hospice & Palliative Medicine* 305 [Claxton-Oldfield].

156. SD Bloch, “Assessing and managing depression in the terminally ill patient” (2000) 132 *Annals of Internal Medicine* 209.

157. Briana Mezuk et al, “Suicide risk in long-term care facilities: a systematic review” (2014) 29 *Intl J Geriatric Psychiatry* 1198.

patients have a concrete desire to access an assisted death, but this does not mean that their wish to hasten death should be ignored. On the contrary, Romaine Gallagher suggests that by “exploring what a patient means by such statements and providing information and guidance to the patient, physicians can help make the individual feel heard and supported.”<sup>158</sup> Patients therefore want to have their wish to hasten death listened to and treated with respect, but this is not the same thing as treating it as if it were a command to be acted upon.<sup>159</sup>

One of the unintended consequences of the legal status of assisted dying—whether it is unlawful or lawful only if certain criteria are met—is that it will shape the way in which healthcare professionals and others respond to a dying person’s wish to talk about wanting to die. Where assisted dying is illegal, if a person expresses an interest in hastening death, a common response is: “I can’t help you with that.”<sup>160</sup> In their study of patients who had expressed a desire to hasten death in Germany, Pestinger et al explain that they were “deeply impressed that all patients claimed that both health and family caregivers tended to ignore or deny their desire to die.”<sup>161</sup> The conversation is shut down because opening it up would be uncomfortable for the healthcare professional,<sup>162</sup> as well as legally risky. In the UK, the General Medical Council advises doctors that if patients raise the issue of assisting suicide, while they should “be prepared to listen and to discuss the reasons for the patient’s request,” they should “limit any advice or information in response, to an explanation that it is a criminal offence for anyone to encourage or assist a person to commit or attempt suicide.”<sup>163</sup>

Where assisted dying is legal, but only in certain circumstances, once again, the response to a patient’s interest in an earlier death might be to say that she does not qualify, or to point her in the direction of someone who can assist in determining whether she fulfils the eligibility criteria. As a result of the limits to its legality, there will be restrictions upon what can be discussed openly and legitimately.

As a result, yet another mismatch in debates over whether to legalize assisted dying is that we focus upon the question of whether eligibility criteria can be sufficiently robust and watertight in order to protect the vulnerable, while missing the fact that we may be inadvertently adding to

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158. *Supra* note 149.

159. Pestinger, *supra* note 92.

160. *Ibid.*

161. Pestinger, *supra* note 92.

162. Claxton-Oldfield, *supra* note 155.

163. GMC, *supra* note 54.

the tendency to shut people up when they want to talk in an open-ended way about wanting to die. This matters because there is evidence that simply talking about end of life wishes, and in particular, about the desire for euthanasia, “can bring peace of mind to a patient and that having the conversation sometimes makes the subject less pressing.”<sup>164</sup> Indeed, as Monforte-Royo et al explain, if the wish to hasten death is best understood as a response to multidimensional suffering’, what the patient may need is more personalised care, rather than a response grounded in seeing their wish to die as a request for assistance in dying.<sup>165</sup>

But while we might try to solve this problem by encouraging healthcare professionals to engage in conversations about hastening death, this is not without risks of its own, and where assisted dying is lawful, creates a further dilemma. It is easy to see why it would be problematic for healthcare professionals to raise the option of assisted death with their patients. If a patient’s doctor were to offer the option of an assisted death now, or as a possibility for the future, this might look like endorsement or even encouragement to consider assisted dying.<sup>166</sup> A patient who otherwise would not have contemplated an assisted death might be influenced by their doctor’s mere mention of assisted dying, which might be interpreted as “a loss of hope or abandonment.”<sup>167</sup> It is also possible that a patient might prefer not to know that she meets the eligibility criteria for assisted dying.<sup>168</sup> If, however, assisted dying conversations are never initiated by doctors, then it will be open only to those patients who are well informed and confident enough to raise it with their doctors, and, as a result, it will be an option only for the more privileged sections of society.<sup>169</sup>

This intractable problem is reproduced in relation to organ donation following assisted dying, which is an option in Belgium,<sup>170</sup> and in the Netherlands,<sup>171</sup> for patients who do not suffer from malignancy or other contraindications to donation. If a doctor were to mention the possibility that as a result of dying an assisted death, the patient could donate her organs

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164. Suzanne J Booij et al, “A plea for end-of-life discussions with patients suffering from Huntington’s disease: the role of the physician” (2013) 39 J Medical Ethics 621.

165. Cristina Monforte-Royo, Josep Porta Sales & Albert Balaguer, “The wish to hasten death: Reflections from practice and research” (2016) 23 Nursing Ethics 587.

166. Of course, this may also be an issue when doctors mention the option of refusing other life-prolonging treatments, like dialysis or cardio-pulmonary resuscitation.

167. Mara Buchbinder, “Aid-in-dying laws and the physician’s duty to inform” (2017) J Medical Ethics DOI: <10.1136/medethics-2016-103936.

168. *Ibid.*

169. *Ibid.*

170. Radbruch, *supra* note 86.

171. Jan Bollen et al, “Legal and ethical aspects of organ donation after euthanasia in Belgium and the Netherlands” (2016) J Medical Ethics online first.



and thereby save others' lives, this might look like a strongly persuasive endorsement of an assisted death. Swarte et al are also concerned that the patient might "get the impression that the physician is only willing to perform euthanasia *because* the patient will donate organs" (emphasis in original).<sup>172</sup> Yet at the same time, if doctors do not mention the possibility of organ donation, out of concern that this might influence the patient's choice, someone who would have benefitted from the knowledge that her organs might be able to help others after her death will not be able to do so, unless she has acquired this information independently, which once again is likely to be the case only for the relatively privileged.

There is not an obvious solution to the problem of whether to be open or not with patients about the options of assisted dying and organ donation. But what is clear is that openness to talking about dying in general, and about the desire for death, is associated with better outcomes, for patients and for the relatives and friends that they leave behind.<sup>173</sup> Any legal provisions which make open conversations about death more difficult, and hence less likely to happen, are working against the interests of dying patients.

#### V. *Improving care at the end of life*

Jonathan Herring has persuasively argued that there is a further mismatch between the volume of academic scholarship devoted to the question of assisted dying, which, even when it is lawful, is relevant to a relatively small number of people, and the comparative lack of interest in a numerically much more pressing issue, namely the inadequate social care available to vulnerable and elderly patients:

While we debate the rights and wrongs of assisted dying, older people are dying in poverty, freezing temperatures, and desperate hunger. So many are neglected by their communities, abandoned by their families, living isolated, socially excluded lives. For many, their last months or, if they unlucky, years are spent in care homes marked by abuse, neglect, and over-medication.<sup>174</sup>

In addition to being intrinsically worthwhile, improving the standard of care available to older people might also help to address the fear of the dying process which prompts some requests for assisted dying. Given

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172. *Ibid.*

173. Nikkie B Swarte et al, "Effects of euthanasia on the bereaved family and friends: a cross sectional study" (2003) 327 *British Medical J* 189.

174. Jonathan Herring, "Escaping the Shackles of Law at the End of Life: *R(Nicklinson) v Ministry of Justice*" (2013) 21 *Medical L Rev* 487.

media reports of inadequate care and neglect,<sup>175</sup> and many people's personal experiences of watching someone they love die on a general ward in hospital, or in a joyless nursing home, it is not surprising that a common reaction to a devastating diagnosis is profound and debilitating fear of what lies ahead.

The UK's review of the Liverpool Care Pathway, which had been a laudable attempt to ensure that patients dying in hospital were able to benefit from best practice in palliative care found not, as the *Daily Mail* and the *Daily Telegraph* had suggested, that the Liverpool Care Pathway (LCP) was being used to euthanase vulnerable patients.<sup>176</sup> Rather, although there had been instances of straightforwardly poor care, more commonly families were upset at the way in which their loved ones had died, often because there had been inadequate communication about their imminent deaths, and what to expect.<sup>177</sup> In one acute trust, "new doctors had an induction into the LCP that lasted only an hour. This involved no practical training and it was easy to miss. Nor was it compulsory."<sup>178</sup>

I do not mean to suggest that we should give up on attempts to devise a safe and publicly acceptable scheme for the legalization of assisted dying, just because legalization might carry the risk of unintended consequences. On the contrary, the unintended consequences of illegality, such as the increased incidence of suicide among those with new and frightening diagnoses, are more alarming than the series of mismatches I have described above. Rather, my point is that the legalization agenda should be pursued at the same time as a drive towards better and more dignified care for patients towards the end of their lives,<sup>179</sup> which might in turn assuage some of the fears people have about what will happen to them before they die. We should also make sure that a primary goal of any legal regime is that it facilitates the open discussion of death and dying, including enabling those who are nearing the end of their lives to be able to talk frankly about their desire to hasten death.

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175. Haroon Siddique, "Shocking neglect uncovered at two care homes in Cornwall" *The Guardian* (20 November 2016); Sonia Sodha, "Underfunded and overstretched—the crisis in care for the elderly" *The Observer* (10 December 2016).

176. Julia Neuberger et al, *More Care, Less Pathway: A Review of the Liverpool Care Pathway* (London: Department of Health, 2013) [Neuberger].

177. Emily Jackson, "The Liverpool Care Pathway Review" (2013) 3 *Elder LJ* 402.

178. Neuberger, *supra* note 176 at para 244.

179. Emily Tomlinson et al, "Euthanasia and physician-assisted suicide in dementia: A qualitative study of the views of former dementia carers" (2015) 29 *Palliative Medicine* 720.

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