# Autonomy and End of Life Decisions: A Paradox

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### <u>Introduction</u>

Suppose that we think it important that people have the chance to enjoy autonomous lives. An obvious corollary of this thought is that people should, if they want it, have control over the time and manner of their deaths, either ending their own lives, or by securing the help of others in doing so. So, generally, and even if we overall think that the practice should not be legalized on other grounds, it looks like common sense to think that considerations of autonomy tell at least somewhat in favour of legalizing at least some acts of suicide and voluntary euthanasia.<sup>2</sup>

In this paper, I argue for the opposite, paradoxical, conclusion. In fact, when we scrutinize the reasons for most end of life decisions, it turns out that they are seriously problematic from the point of view of autonomy. Full autonomy requires that we are responsible for the consequences of our decisions, and responsibility is precluded by non-voluntariness, which is to say decisions made because there are no acceptable alternatives. Since most end of life decisions are made for precisely this reason, it looks as though most such decisions are non-voluntary, and therefore undermine our autonomy: a discomforting and paradoxical claim. I argue that we should respond by taking the paradox to illuminate the context required by an autonomy-respecting framework for legalizing assisted suicide and euthanasia. People should have a legal right to a reasonable choice about when and how to die. However, this must go hand in hand with institutions that ensure, as far as possible, that such choices are made against a background which ensures, as far as possible, that people choose death clear-sightedly and not because nothing else is acceptable.

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<sup>&</sup>lt;sup>1</sup> For example, see Dan A. Brock's influential essay 'Voluntary Active Euthanasia', *The Hastings Centre Report* 22 (1992): 10-22, at 11-12.

<sup>&</sup>lt;sup>2</sup> But see e.g. R. Horton 'Euthanasia and assisted suicide: what does the Dutch vote mean?', *The Lancet* 357 (2001): 1221-1222, and J. Keown *Euthanasia, Ethics and Public Policy* (New York: Cambridge University Press, 2002); unusually for opponents of voluntary euthanasia most of whom argue that some non-autonomy based consideration tells decisively against legalization, both Horton and Keown specifically deny that considerations of autonomy tell in favour of legalizing voluntary euthanasia.

### 1. The conditions of autonomy

Autonomy, on the view that I am defending, is a global ideal, predicated of an entire life, which consists in deciding for oneself what is valuable and living one's life in accordance with that decision.<sup>3</sup> To be autonomous, on this view, means satisfying three conditions.

First, one must have the right sort of relation to one's ends and actions: that is, a disposition to *endorse* them. This might mean going through the actual process of reflecting on what one might want to do or be, and coming to a conscious decision about it; or it might mean the sort of wholehearted and unreflective pursuit of some goals or projects which makes it clear that one *would* consciously endorse them if the question arose. In respect of the end of life, this requires that the agent concerned either consciously decides to die – and so either commits suicide herself or requests assisted suicide – or possesses a disposition such that she would choose that if asked.<sup>4</sup>

Second, those endorsements must be *independent*: the ambitions and preferences that shape one's life must be one's own, if their pursuit is to contribute to the living of an autonomous life. My view is that independence consists in a property of the explanation of our decisions about what is valuable.<sup>5</sup> In particular, those explanations must not be covert, which is to say (qua true explanation) necessarily hidden from the agent concerned. That might be because it is being kept hidden by some other agent: *you* say that the reason you endorse giving all your money away to a cult is because you've been touched by divine revelation, but we can see that the real explanation is that you were hypnotised by the cult leader, who has successfully kept the hypnotism secret from you. Or, it might be because the explanation is such that, if you were to become aware of it, you would cease to endorse the decision or action concerned. If the cult leader isn't as competent at covering her tracks as she had supposed, for example, you might find out about it – learning that *that* (rather than the greatness of Zeus) is the explanation for your

<sup>&</sup>lt;sup>3</sup> See my *Autonomy and Liberalism* (New York: Routledge, 2010: chapter 2 for a more extensive statement and defence of this way of construing autonomy. This conception of autonomy is similar to that defended by Joseph Raz in *The Morality of Freedom* (Oxford: Clarendon, 1986), and the ideal of individuality described by John Stuart Mill in *On Liberty* (in S. Collini ed. *J.S. Mill: On Liberty and Other Writings*, Cambridge: Cambridge University Press, 1989).

<sup>&</sup>lt;sup>4</sup> The difficulty of determining when an individual has such a disposition, if she doesn't actively exercise it, suggests that a prudent legal framework for end of life decisions would require an active expression of intent on the part of the individual concerned. Nevertheless, the underlying endorsing disposition is what does the normative work in such cases; active expressions of consent just give us evidence about that disposition's existence. This is important because it allows for the permissibility (morally, and perhaps legally) of non-voluntary euthanasia in the case of individuals who are unable explicitly to consent but of whom we have good reason to believe that their disposition under such circumstances would be to die.

<sup>&</sup>lt;sup>5</sup> This is an analysis of independence developed in 'Autonomy and Adaptive Preferences', *Utilitas* 23 (2011): 52-71; and in 'Authenticity', forthcoming in a collection entitled *Autonomy, Authenticity, Culture* ed. Geoff Levey.

decision to give away your money would very likely cause you to repudiate that decision. The crucial feature of such cases is that our decisions about what is valuable depend on something being withheld from us. Our decisions are independent only when this is not the case. In respect of end of life decisions, this requires that someone's decision to die must not be explained covertly, by some influence or cause which would cause her to decide otherwise if she knew about it.

These first two conditions of endorsement and independence elucidate what it means to decide for oneself what is valuable. For a life to be fully autonomous, on my conception, the individual concerned must also successfully pursue those ambitions, decisions and goals; or, at any rate, failure to satisfy an ambition diminishes one's autonomy to some extent. That means, at least, that one's life goes in accordance with what one values. If someone wants to be a musician, and she is frustrated in that ambition, her life lacks autonomy for that reason. But one's life merely following the valued pattern won't be sufficient, because that could happen purely by chance, or because of benevolent external management. To capture the additional requirement that one *makes* ones life go in accordance with what is valuable, I incorporate a responsibility condition. Assuming that she endorses her decisions with independence, someone's life is autonomous to the extent that her life goes in accordance with those decisions, and she is responsible for the fact.

For full autonomy, she must be responsible in two ways. First, she must bear *explanatory* responsibility for how her life goes. Her decisions must play a crucial causal role in what happens to her, and the shape of her life must be attributable to her agency. Second, she must be evaluatively responsible. This is a normative concept, which picks out a relation between an individual and a state of affairs which grounds some normative upshot, by which I mean some normative claims about what that individual must, may, or may not do or demand, which are true because the relation obtains, and all else equal wouldn't be true if it didn't. Evaluative responsibility is an important part of autonomy because living one's life is a matter not just of causing it to go a certain way, but also – to use Joseph Raz's phrase – of being author of it. Authority over one's life consists in standing in a normative relation to it which makes it

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<sup>&</sup>lt;sup>6</sup> In this I side with Joseph Raz's comments that 'the autonomous person is one who makes his own life' (Raz 1986: p. 375), and against e.g. Gerald Dworkin, on whose view autonomy consists just in ones desires being structured a certain way, regardless of whether they are satisfied. See *The Theory and Practice of Autonomy* (Cambridge: CUP, 1988): chapters 1 & 2.

<sup>&</sup>lt;sup>7</sup> For more on this distinction between explanatory and evaluative responsibility, see my 'In Defence of Comprehensive Liberalism', *Philosophy and Public Issues* 2 (2012): 17-29. My distinction echoes those drawn by Thomas Scanlon between attributive and substantive responsibility, and by Ronald Dworkin between causal and consequential responsibility. To some extent, my theory is an attempt to improve on those important but somewhat ill-drawn distinctions. See T. Scanlon *What We Owe to Each Other* (Cambridge, Mass.: Harvard University Press, 1998) chapter 6, and R. Dworkin *Sovereign Virtue* (Cambridge, Mass.: Harvard University Press 2000) pp. 278-8.

<sup>&</sup>lt;sup>8</sup> Raz The Morality of Freedom: p. 369.

appropriate to give one praise, blame, punishment, liability, reward and so on. One is not the author of a life shaped by one's will being subverted in such a way that one cannot claim authorship of the consequences of one's actions. So, full autonomy requires both explanatory responsibility *and* evaluative responsibility in the sense which grounds such consequences.

In respect of end of life decisions, the condition of explanatory responsibility requires just that the individual's death is appropriately causally related to her decision to die, and that she is not prevented from choosing otherwise. Following Serena Olsaretti, I claim that the condition of evaluative responsibility requires, further, that her decision is *voluntary*. According to Olsaretti's theory, an act is voluntary so long as it isn't non-voluntary, and actions are non-voluntary when they are chosen because there are no acceptable alternatives. This involves both objective and subjective conditions being met. The standard of acceptability is here construed objectively and non-comparatively: an alternative is unacceptable if it involves falling below a certain absolute level. But it also matters what are the motivational reasons that explain one's action: one acts non-voluntarily if the *reason* one acts is to avoid unacceptable alternatives, so long as that is judged on an appropriate standard of acceptability. Leave the condition of explanatory responsibility requires is unacceptable alternatives, so long as that is judged on an appropriate standard of acceptability.

Non-voluntariness vitiates evaluative responsibility because it involves the agent's will being subverted, either by circumstances or by the will of another. The consequences of those

<sup>9</sup> David Owens has recently argued that certain duties and obligations are valuable *for us*, because being obliged is sometimes constitutive of relations we bear to others which are valuable; hence, there's even something valuable about being in a position where our receiving blame, guilt (and, we may add, punishment, though Owens doesn't) might be appropriate. My idea is similar: the value of autonomy consists in us having a certain type of relation not to other people but to the states of affairs that make up our lives. For Owens' proposal, see his *Shaping the Normative Landscape* (Oxford: Oxford University Press, 2012).

<sup>&</sup>lt;sup>10</sup> Serena Olsaretti *Liberty, Desert, and the Market* (Cambridge: Cambridge University Press, 2004): pp. 139-141, and 159-161.

Olsaretti *Liberty, Desert, and the Market*: p. 154. Olsaretti, when fleshing out what standard she has in mind, says that an option is unacceptable 'if pursuing or choosing it threatens some basic need'. One might worry that positing an objective standard for what counts as unacceptable here runs counter to the underlying motivations behind a theory of autonomy, and that the combination of objective and subjective criteria mentioned here is therefore unstable. I tend to think not, because I think that it is possible to generate a standard by measuring unacceptable losses in autonomy; such a standard would pay heed to an individual's own perspective on her options, but need not treat an individual's judging an option to be unacceptable as either necessary or sufficient for the purposes of voluntariness. My thanks to Jason Park for pointing out the problem.

<sup>&</sup>lt;sup>12</sup> There is further discussion of this conception of voluntariness, and of its connection with responsibility, in B. Colburn 'The Concept of Voluntariness' and S. Olsaretti 'The Concept of Voluntariness – A Reply', *Journal of Political Philosophy* 16 (2008): 101-111 and 112-121 respectively.

actions are alienated from the actor, and this alienation precludes the sort of relationship between her and those consequences which would make it appropriate to insist that she bears those consequences without compensation or aid. To illustrate, consider cases of coerced action. The problem with coercion is not that it eliminates free choice, strictly speaking. The highwayman's threat - "Your money or your life!" - does not prevent me from refusing to hand over the money, if I so choose. Indeed, far from precluding choice, its intelligibility and effectiveness presuppose my ability to choose. The point is that my choice is subverted by altering the character of my options: the highwayman arranges circumstances so that every practical alternative to surrendering my wallet, while remaining an option that I may choose, leads to a messy death. It is this that explains why my choice to hand over my money isn't sufficient to justify the exchange; or, to put it another way, leave me evaluatively responsible for my impoverishment in the sense that I have no claim against the highwayman for my money's return. One may not think that voluntariness is sufficient for evaluative responsibility; one might, for example, think that even some voluntary choices take place against such an unfair background that they vitiate responsibility. Still, so long as one thinks that there's something wrong with making people bear the consequences of choices which they perform as a result of the sort of force exemplified by coercion, one should think that voluntariness is necessary for evaluative responsibility.

To conclude, then, the theory of autonomy elaborated here suggests the following tests that we should apply to end of life decisions, to see whether they are compatible with the independence and responsibility components of individual autonomy. Both have to do with the explanation for an individual's decision to die. Those decisions lack independence to the extent that their explanations are covert; and they lack responsibility to the extent that those explanations hinge on the agent acting as they do because the alternatives are all unacceptable.

# 2. Decisions to die

The preceding section concluded with some necessary conditions for autonomy which have to do with the explanation for why an agent chooses as she does: the explanation must not be covert, and it must not be that all alternative actions are unacceptable.

The first condition, of independence, will be failed in end of life decisions when those decisions fall short of the threshold of self-transparency required for independence. This happens, most notably, in cases of adaptation. Adaptive preference formation consists, in general, in the unconscious altering of our preferences in light of the range of options that we have available. In the context of end of life decisions, this is plainly a danger, given that such decisions are made at times of duress and stress. The danger is twofold. First, we might think there's a particular danger of individuals deciding to die by dint of adapting their preferences to a perceived lack of alternatives; and second, the fact these decisions end in death makes it impossible subsequently to check the grounds of these decisions and to correct misapprehensions.

Despite this danger, and despite the high stakes, I think that adaptive preferences pose no peculiar problems here. There is no reason to believe that end of life decisions are generally adaptive in character: though some such decisions may lack independence, there is little reason to think that someone will wish to end her life only if she is deceived about the real explanation for her decision. Moreover, with a view to legislation, it will be comparatively easy to ensure that people's end of life decisions *are* independent, by making sure that they know about and reflect upon the reasons for their decision as far as possible, though (as Dudley Knowles points out) it is important to recognise the human costs of insisting upon people demonstrating their informed consent in situations which involve, as almost all end of life decisions will, significant emotional duress.<sup>13</sup> Still, in general, it seems to me that the problem of non-independence in end of life decisions is neither systemic nor difficult to address.

Nevertheless, there is a serious problem in the vicinity. This has to do with the second condition, of responsibility. As with adaptive preferences, the crucial determinant of responsibility is the explanation for an individual's decision. As the following argument shows, there is much more reason to think that these explanations will be malign in a way that affects responsibility, rather than independence.

- 1. A decision is non-voluntary if it is made because there are no acceptable alternatives.
- 2. If a decision is non-voluntary, the decider's evaluative responsibility (for the consequences of that decision) is undermined.
- 3. Anything that undermines evaluative responsibility undermines autonomy.
- 4. At present, most decisions to die are made because there are no acceptable alternatives.
- 5. (From 1 and 4) At present, most decisions to die are non-voluntary.
- 6. (From 2 and 5) At present, most decisions to die undermine the decider's evaluative responsibility.
- 7. Conclusion (From 3 and 6) At present, most decisions to die undermine the decider's autonomy.

The argument is valid. Moreover, we have good reason to accept each of the premises. Premise 1 is just a definition. Premises 2 and 3 follow from the theory of autonomy, responsibility and voluntariness defended in the preceding section. Premise 4 is borne out by studies of the reasons people seek to die: such decisions are almost always made in order to avoid alternatives correctly judged to be unacceptable. The usual reasons cited are the prospect of physical pain without prospect of relief; chronic dependency and loss of autonomy; and psychological trauma for the individual, friends, and family. Those who act on these reasons aren't using an inappropriate standard for what counts as unacceptable: I have said little about what is necessary for an option

<sup>&</sup>lt;sup>13</sup> I'm grateful to Dudley Knowles for this point; and see, for an illuminating discussion of the costs of demanding informed consent in an analogous situation, his 'Parents' consent to the post-mortem removal and retention of organs', *Journal of Applied Philosophy* 18 (2001): 215-227.

<sup>&</sup>lt;sup>14</sup> For empirical data concerning the reasons people seek assisted suicide or euthanasia, see e.g. C. Seale & J. Addington-Hall 'Euthanasia: why people want to die earlier', *Social Science and Medicine* 39 (1994): 647-654; E. Emanuel, D. Fairclough, E. Daniels & B. Clarridge 'Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public', *Lancet* 347 (1996): 1805-10; Y.Y.W. Mak, G. Elwyn & I.G. Finlay 'Patients' voices are needed in debates on euthanasia', *BMJ* 327 (2003): 213-215; and A. Chapple, S. Ziebland, A. McPherson & A. Herxheimer 'What people close to death say about euthanasia and assisted suicide: a qualitative study', *Journal of Medical Ethics* 2006 (32): 706-710.

to count as objectively unacceptable, but I take it that almost any account will have to judge that many of these paradigm factors do indeed count as such. So, Premise 4 is true, and the argument as a whole looks sound. This presents us with a paradox: far from expressing or supporting our autonomy, as common sense suggests, most end of life decisions in fact undermine the decider's autonomy.

There are two ways we might respond to this paradoxical conclusion. One possibility would be to treat it as a *reductio ad absurdum*. If the theory of autonomy set out above implies that almost all decisions to die diminish autonomy – including those made by competent individuals in full possession of all the relevant facts – then so much the worse for this theory of autonomy, or at least one of its elements. Our choice would then be to reject or revise either Premise 2 or Premise 3; that is, either the necessity of voluntariness for evaluative responsibility, or the importance of evaluative responsibility for autonomy. <sup>15</sup> As I indicated above, however, there are significant theoretical costs associated with rejecting either premise. <sup>16</sup> Taking this course also relies entirely on the uncritical acceptance of the intuition that there is indeed nothing troubling about most contemporary decisions to die. So, I conclude by showing what options we have if we retain both premises intact, and therefore accept the paradoxical conclusion.

# 3. The circumstances of a good death

If the above argument is correct, it implies that as things stand most people's decisions to die detract from their autonomy, rather than (as common sense might suggest) either expressing or supporting it.

One point worth clarifying is that this does not imply that we should prohibit either suicide or voluntary euthanasia. Even if there is a loss of autonomy involved in end of life decisions when those are made to avoid unacceptable alternatives, this would give us a reason to prevent people making and acting on such decisions only if that didn't involve a similar loss. Clearly, it would: someone prevented from acting in this way would be unable to shape the end of her life in accordance with what she judged to be valuable and appropriate, and her

15 My thanks to Robert Cowan for pushing this point particularly vigorously.

<sup>&</sup>lt;sup>16</sup> For example, a critic might argue that, since the presence of dependency and pain are not intentionally caused by others, their being the factors that make alternatives unacceptable or unpalatable isn't enough to make these choices non-voluntary; the autonomous agent should be able to face these facts and come to terms with them. I think this criticism mistaken for two reasons. The first is that the painfulness and disempowerment of the alternatives to death clearly *are* caused by other humans, insofar as we have some (not unlimited, but considerable) means to relieve them through palliative medicine and social care, as I indicate below. The second, which I cannot really substantiate here, is that I anyway see no reason to distinguish between human-caused and non-human-caused reasons for unacceptability here: the crucial feature for voluntary choice is the nature of the chooser's options and the character of the choice she makes in light of them, not facts about the history of how those options come to have that nature. My thanks to Jukka Varelius for the objection.

responsibility – both explanatory and evaluative – would be seriously compromised. This lose-lose situation is part of the paradox, I take it. Either we prevent people acting on their considered decisions, in which case they lose autonomy because their explanatory responsibility for their lives is undermined; or we don't, in which case their autonomy is undermined indirectly by dint of those decisions' non-voluntary character and the consequent effect on their evaluative responsibility.

We can break this deadlock by recognising two important points. The first is that it is not necessary that the reasons for most end of life decisions make them non-voluntary. People can, as a matter of fact, decide to die for reasons other than the unacceptability of their alternatives. If we can ensure that most people's end of life decisions are like that, then we escape the tragic situation posited by my earlier argument, by changing things so that Premise 4 is no longer true.

Sadly, looked at from the standpoint of institutional design, it is no easy matter to see how to use this insight. As I have shown, the status vis-à-vis autonomy of a given decision to die is a matter of the reasons on which the agent chooses or seeks to end her life. It is hard to design institutions and rules which detect and respond appropriately to such elusive internal features. One reason is the epistemic cost of doing so. Radically different motivations can issue in externally indistinguishable actions. Did the elderly parent who asked for an overdose of sedatives do so because she wanted to be out of pain, or because she was satisfied that her projects were done, or because she wanted her children not to see her in pain any more, or because she felt covert pressure from them to get herself out of the way? Designing a legal apparatus which reliable detects these differences is a formidable task. Moreover, even if these epistemic difficulties could be met, there would be more principled problems that might make us baulk, as I indicated in my earlier discussion of adaptive preferences: costs in terms of individuals' privacy, for example, or the psychological costs of demanding that people bare their motivations and reasons at a painful time.

So, direct interference or scrutiny of individual end of life decisions looks neither practical nor desirable as a way to guarantee their voluntariness. The second step in breaking the tragic deadlock is therefore to identify another important tactic that social and legal institutions can deploy. All decisions take place against a background at least partly formed by such institutions. Merely by shaping that background in a certain way, those institutions can have an effect upon whether decisions are voluntary or not, in a way that requires no direct interference with or scrutiny of those particular decisions.

To illustrate, consider the example (adapted from G.A Cohen) of someone who undertakes hazardous employment – let's say military service – because all alternatives involve

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<sup>&</sup>lt;sup>17</sup> For arguments that privacy is important to individual autonomy, see e.g. L. Henkin 'Privacy and Autonomy', *Columbia Law Review* 74 (1974): 1410-1433; J. Reiman 'Privacy, Intimacy, and Personhood', *Philosophy & Public Affairs* 6 (1976): 26-44; J. Kupfer 'Privacy, Autonomy and Self-Concept', *American Philosophical Quarterly* 24 (1987): 81-89; and J. Cohen *Regulating Intimacy: A New Legal Paradigm* (Princeton: Princeton University Press, 2002).

<sup>&</sup>lt;sup>18</sup> Knowles 'Parents' consent to the post-mortem removal and retention of organs'.

starvation and penury for them and their family. This individual acts non-voluntarily, as things stand. Now suppose, however, that this decision (whether or not to undertake military service) takes place against the background of a state guaranteed minimal income for all citizens. That background changes the nature of our individual's options, such that the alternatives to military service are no longer unacceptable, for they no longer involve destitution. He or she may still choose to enter military service. However, given the background, we can now be confident that her motivation will be something else – the desire to see the world, a sense of justice or patriotism, sheer adrenaline-seeking bloodlust, or something like that – which preserves, rather than vitiates, the voluntariness of her decision.

Given this, I think the problematic reasons for most current end of life decisions gives us reasons to shape the context of these choices in an analogous way. We should shape the context of those decisions so that the explanations for people's decisions to die are, as little as possible, the unavailability of acceptable alternatives. In practice, this means two policies, each implemented with a view to neutralizing one of the two most important features which make the alternatives to death unacceptable: avoidance of pain, and avoidance of disempowerment and dependency.

The former implies an adequate regime of palliative care to ensure, as far as is medically possible, that individuals can enjoy surcease from pain even if they don't choose to die. This will ensure that avoiding unacceptable pain will not be the explanation for people's decisions to die in any but the most severe cases. It is striking that this argument reveals a deep and principled connection between legalizing euthanasia with the provision of palliative care and social support. In general, it is often assumed by opponents of legalized euthanasia that adequate palliative care is an alternative to legalized euthanasia: in particular, the possibility of the former undermines the argument for the latter. My argument shows that this is not the case. Improvements in our ability to provide palliative care strengthen, rather than weaken, arguments to legalize euthanasia.

The latter is more complex. Institutional action to reduce such dependency might seem to be self-defeating, if it simply replaces one form of dependency and disempowerment with

<sup>19</sup> G. A. Cohen 'Are Disadvantaged Workers who taker Hazardous Jobs Forced to take Hazardous Jobs?' in his *History, Labour and Freedom* (Oxford: Clarendon, 1988): pp. 239-254.

<sup>&</sup>lt;sup>20</sup> I have in mind here something substantial, like the basic guaranteed income argued for by Philippe van Parijs in *Arguing for Basic Income: Philosophical Arguments for a Radical Reform* (London: Verso, 1992) and *Real Freedom for All* (New York: Oxford University Press, 1995).

<sup>&</sup>lt;sup>21</sup> E.g. J.F. Childress 'Religious Viewpoints' in L.L. Emanuel ed. Regulating How We Die: The ethical, medical and legal issues surrounding physician-assisted suicide (Cambridge MA: Harvard University Press, 1998): pp. 120-147; H. Matthews 'Better palliative care could cut euthanasia', BMJ 1998 (317): 1613; R. Hamel 'A better approach to care of the dying. Catholic healthcare and the Catholic community can present an alternative to physician-assisted suicide.' Health Progress 79 (1998): 54-9; the exchange between John Finnis and John Keown in J. Keown ed. Euthanasia Examined (Cambridge: Cambridge University Press, 1997), chapters 1-6; and L.J. Matersveldt et al 'Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force', Palliative Medicine 17 (2003): 97-101.

another. Recent research on the experience of adults with disabilities suggests that different mechanisms for external support result in wildly different experiences of dependency.<sup>22</sup> Identifying the features in virtue of which this difference obtains will allow us to ensure that the alternatives to deciding to die are not unacceptably disempowering. We should, for example, extend the principles of reasonable adjustment to allow the very elderly to participate in social and civic life if they so wish, and ensure that the forms of support are shaped and agreed with by the individuals affected.<sup>23</sup>

Much more work is required on the details of both these proposals, and it is important to recognise that their effect will only ever be mitigative: it will be impossible to eliminate all factors which made some individuals' decisions to die non-voluntary. However, they offer a model for how we might provide institutional support which allows us to deal with the uncomfortable conclusion of Section 2: even if we accept the conclusion that (as things stand) many decisions to die diminish our autonomy, it is open to us to deploy our social and legal institutions to eliminate, as far as possible, the toxic background that makes those decisions non-voluntary. Under such circumstances, we can be much more confident that when people *do* nevertheless decide to die, they are doing so voluntarily, and hence in a way that expresses, rather than diminishes, their autonomy.

### Conclusion

I have argued that end of life decisions pose a serious problem for autonomy. Whether or not a decision contributes to your autonomy depends on whether it is voluntary, and – at least as things currently stand – there is good reason to believe that most end of life decisions are non-voluntary, because they are made to avoid alternatives correctly perceived as unacceptable. If the reader thinks that this conclusion is absurd – because there plainly is no autonomy-based problem with the majority of contemporary decisions to die – then they will take this argument to be a *reductio* of the theory of autonomy defended at the start of this paper. I suggest a different interpretation. This argument genuinely reveals a troubling problem for many current end of life decisions. To solve it, we must change the circumstances of those decisions so that, as far as possible, the individuals concerned always have acceptable alternatives. People are indeed deeply vulnerable when they are contemplating decisions to die, because their chances of autonomously

<sup>&</sup>lt;sup>22</sup> For useful summaries of such research, see A. Macfarlane 'Ageing and Disability' in L. Laurie ed. *Building Our Lives: Housing, Independent Living and Disabled People* (London: Shelter, 1991); G. Zarb & M. Oliver *Ageing With A Disability: What Do They Expect After All These Years?* (London: University of Greenwich, 1993); M. Oliver & C. Barnes 'Disabling or Enabling Welfare: What Next for Disabled People' in M. Oliver ed. *Understanding Disability* 2<sup>nd</sup> edition (Tavistock: Palgrave, 2009): 119-133; and J. Morris Rethinking Disability Policy (London: Joseph Rowntree Foundation, 2011).

<sup>&</sup>lt;sup>23</sup> Jenny Morris (in *Rethinking Disability Policy*: pp. 16-17) identifies these as two of the key factors which disabled adults regard as making the difference between support which empowers and enables, and support which disempowers and creates dependency.

navigating the final most important event in their lives are at risk. The measures above indicate a way in which we can mitigate that vulnerability, and offer people the best possible chance of an autonomous death.<sup>24</sup>

<sup>&</sup>lt;sup>24</sup> Thanks to Jukka Varelius and Juha Räikkä for their helpful comments on a draft of this paper. Thanks also to Robert Cowan, Jennifer Corns, Derek Brown, Adam Rieger, Emily Askham, Dudley Knowles, Gareth Young, Jason Park, and Harriet Morse, for discussion of the arguments it contains; and to Daniel Elstein, Hallvard Lillehammer, Serena Olsaretti and Jonathan Quong for discussions of different elements of the underlying theory.