

Autonomy and the Circumstances of a Good Death



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We all have clear ideas about ways we would prefer or prefer not to end our lives. We would prefer not to be in serious pain, would like to be surrounded by loved ones, we want to die in a humane environment, and so on. What is less clear is how to pull these desires together into a general account which would allow us to make compassionate and rational decisions about how to support individuals and families who are facing death.

I think the idea of *autonomy* can help. Individual autonomy is a concept which crops up repeatedly in medical ethics, as a way of framing our views about patients' rights and their relations to medical professionals. Its origins and importance are much wider than that, though. Autonomy is part of a rich tradition of ways to think about how to live well. Here, I show how one particular way of understanding autonomy can help us to think about how to die well.

An autonomous life is one where the individual decides for herself what is valuable and lives her life in accordance with that decision. Her life goes better, on this view, the more she is able to shape her life as a whole through decisions reflecting her individual values and ambitions. To borrow a phrase from the distinguished philosopher Joseph Raz, it is an ideal of *self-authorship*.

One of the most important elements of a self-authored life is that it is shaped through voluntary decisions that genuinely reflect how we want our lives to go. Making non-voluntary choices, by contrast, means not being in control of how our lives go: acting non-voluntarily means acting as we do because there are no acceptable alternatives. Even though this might be the most sensible thing to do in unpleasant circumstances, there's something about those circumstances which alienates our actions from us. We choose as we do only to avoid something even worse. And that means we're not actively authoring our lives, but merely reacting to a hostile context.

One reason this can happen is because other people try to coerce us, like (for instance) the highwayman who says 'Your money or your life!' When you hand over your money, you act non-voluntarily. It's important to notice that the highwayman doesn't physically compel you to hand over your money. In this sense he doesn't remove your free choice. Rather he *subverts* it. He manipulates you by making sure that none of your options are acceptable, except for the one he wants you to take. Choosing to hand over the money is the only way to avoid his violence. The fact that you still choose, in some minimal sense, doesn't stop it being a situation in which control of your life is taken away from you.

The highwayman example might seem a bit far-fetched. It's rare that someone intentionally puts us in a situation where we must choose non-voluntarily. But we can end up in similar situations without someone deliberately putting us there. Illness or other bad luck can leave us facing a range of options where we must choose non-voluntarily, to avoid alternatives which are unacceptable.

The sad thing – and the reason why this is not a far-fetched line of thought – is that many people find themselves in exactly this sort of situation at the ends of their lives. The point is made most starkly when people report reasons why they seek assisted suicide: it is almost always because death seems the only way to avoid appalling alternatives like unrelieved physical pain, chronic dependency, and psychological trauma for themselves, their friends, and their families. Even setting aside such extreme cases, the same ugly scenarios arise in many of the difficult decisions we must make as we approach death: whether and when to move out of our own homes, whether to continue painful treatment with uncertain outcomes, and so on. It is all too easy for people to find themselves boxed in by unacceptable alternatives, so that these choices are non-voluntary, and controlled by circumstance. That seems like a tragedy to me. If it matters that people are the authors of their own lives, it matters all the more that they exercise their autonomy as their lives come to an end.

I said above that nobody deliberately shapes our end of life circumstances so that they have this malign character. That's true, but of course we as a society *do* make choices which inadvertently have these profound effects. The legal framework (for example governing assisted suicide), how we choose to distribute healthcare resources, how we involve the ill or elderly in decisions about their support: these are all factors which currently undermine people's autonomy at the end of their lives. The fact that we're not *literally* highwaymen doesn't mean that, as a society, we're not responsible for the situation I describe.

However, with responsibility comes opportunity. Once we see that these factors are partly under our control, we can ask: how, with compassion and reason, might we reshape them so that we secure for more people the circumstances of a good death?

One thing we must do is protect people's ability to choose what happens to them. But it's not enough to give people options to choose between. We must also make sure that people can shape their lives by making voluntary choices between those options.

That means attending to the nature of the options: to the circumstances in which people choose, not merely whether they are choosing or not. We need to eliminate or ameliorate the factors which make alternatives unacceptable for someone as they approach the end of their life.

To start with, that means we need a better regime of palliative care. We must ensure that people have relief from pain, as far as is medically possible. And when it isn't, we must help people manage their pain so that it doesn't have such a crushing effect on their lives. There are limits to what is possible, of course. But pain management is a key part of making sure that people don't make end of life decisions which are non-voluntary through the fear of unacceptable suffering.

We must also find ways of dealing with end-of-life care which don't lead to people feeling dependent and disempowered. That doesn't mean withdrawing support, but it does mean giving people more control over the way that support is delivered for them. It means making reasonable adjustments to make sure that people can still participate in social and civic life if they wish. Again, these things won't solve all problems. But they will help to alleviate the systematic feeling of helplessness and disempowerment that is sadly part of many people's experience of terminal illness or old age. And, once again, it will secure people's capacity for autonomy, by making sure that they don't have to make non-voluntary decisions to avoid these unacceptable states of affairs.

Both points explain why a doula can play such an important role in supporting individuals and families at the end of life. A doula can help individuals understand the (often overwhelming) barrage of information they receive, and identify pain management strategies. They can advocate with medical institutions for solutions that will work best for the individual concerned. And (again because of the individual relationship involved) they can help to empower individuals in continuing to live as rich and self-directed a life as possible.

The need for reform doesn't stop here, of course. With an aging population, it's clear that ambitious changes to the legal and medical framework are needed. Still, those things take time. The work of *Living Well Dying Well*, and the revival of the role of an end of life doula, can fulfil an urgent need for many of us. And they give an encouraging indication of what is needed more widely. If we want the circumstances of a good death for everyone, we won't find it by further medicalisation, but through relationships which inform, support and empower individuals in being the author of their lives right up to the end.

Further Reading

My article 'Autonomy and End of Life Decisions: A Paradox', available via my website (below), is the main source for the ideas I explore here. To find out more about the underlying theory of autonomy, my book *Autonomy and Liberalism* (New York: Routledge 2010, pbk. edition 2013) is the place to go. You might also be interested in Serena Olsaretti's book *Liberty, Desert and the Market* (Cambridge: Cambridge University Press, 2004), which develops the concept of voluntariness I use here, and in Jenny Morris's pamphlet *Rethinking Disability Policy* (Joseph Rowntree Foundation, London 2011), which starts the business of thinking seriously about how to shape caring policies which are genuinely empowering for the individuals who need to make use of them.