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Death, debility and disability

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The question of assisted dying with respect to people with disabilities is a hugely controversial area. Public opinion in western Europe is broadly in favour of decriminalisation - as is already the case in Belgium, Switzerland, Luxembourg and the Netherlands. But on the part of disabled people there seems to be an overwhelming rejection of any proposals that loosen current laws¹. It is not difficult to understand the special anxieties that any form of euthanasia evokes but that is not to say that the issue should be closed off from discussion. We should ask whether there are significant misconceptions at stake; are there good reasons why a specific group should reject what the majority now see as a fundamental right; and most importantly, are there alternative ways of understanding the issue? I will answer the latter affirmatively by rethinking the parameters of life.

My own position, outlined in a paper entitled 'Deciding on death' (Shildrick 2008), is that *if* we value autonomy, then everyone, regardless of their form of embodiment, should be entitled to make an individual choice regarding whether to live or to die. Knowing anecdotally – for the literature is non-existent – that many disabled people in private conversation feel isolated and angry that their wish for death is not only legally disallowed,

but if voiced is likely to attract opprobrium from the disability community, I wanted to open up the debate to more critical scrutiny. Whilst strongly supporting the very proper demand of disability activists and theorists that all end of life decisions should be scrutinised for signs of a socio-cultural desire to violently limit the incidence of disability, my concern is that such a demand has segued into something damagingly restrictive. What begins as an ethically and politically necessary analysis of potential wrongs swiftly solidifies into an uncritical condemnation of all practices – whether externally or self-operationalised – that shorten the lives of disabled people in apparent suffering or distress. The fear of disabled people is that they are excluded from the categories of lives that matter. On a lay level, there is indeed a persistent belief that it is better to be dead than disabled (see Schaller, 2008 for a discussion of the notion) and in law and bioethics, adequate protection falls short for those whose embodiment does not approximate to normative standards (Koch 2004). In consequence, anyone with severe physical or cognitive restrictions is seen as especially vulnerable to unequal treatment. And of course no-one forgets the so-called euthanasia program, conducted during the years of Nazi ascendancy in Germany, in the course of which many thousands of disabled people – mainly children - were killed (Mostert 2002). I do not suggest that such fears are ill-founded – we don't know what other atrocities so-called democracies will deliver in the future – so it is incumbent on those without such anxieties to make a more responsive and sensitive case for assisted dying .

The new approach I call for may sound initially like a classic argument for the extension of rights – that alongside a right to life, each should have the right to control the time of death whenever that is possible. I am not, however, concerned with that aspect of the problematic and would strongly argue that the whole nexus of personal autonomy and freedom to choose as one wishes is far too precarious to ground definitive rights. Most of us may believe that we are free-choosing agents but in reality the overwhelming

decontextualisation of the conditions of choice obscures the extent to which any individual is compelled to follow in certain directions and not others. It is not that rights are irrelevant but that the prevailing socio-political moment may persuade many of us to choose what is apparently not in our own interests. The well-rehearsed arguments that elderly people, those with disabilities, or those in chronic ill-health are likely to be targets rather than the autonomous users of any new legislation springs in part from this intuition. The counter argument that I outlined in the past (Shildrick 2008) is that if adequate safeguards were set and used, then the much-feared abuse of a more liberal system would become unlikely. I have, however, rethought the parameters of my argument and am now less certain than previously.

One major factor that makes a difference is the full-scale pursuit of neoliberalism by the governing powers in the global north, a pursuit that has significance for populations worldwide. The neoliberal mantra of self-responsibilization is well-suited to promoting death as just another experience around which to exercise our capacities for personal development. We are already familiar with how health care more widely has become the site of active entrepreneurship, in the sense of external corporations offering pharmaceuticals and biotechnologies to the individuals who utilise them as a matter of good self-management. There is nothing peculiar to disabled people in this state of affairs, and indeed Lauren Berlant has coined the resonant phrase ‘slow death’ to describe the overwhelming existential condition of debility that characterises most populations under neoliberalism. Unlike previous usage, which relates precisely to those in ill-health or who are disabled, debility here must be understood as the universal and inherent condition of worn-out bodies in late capitalist society. At the very same time ‘cruel optimism’, another phrase of Berlant’s (2011), describes and explains why those enduring slow death are compelled to keep going. It speaks to a state in which each individual is carried along in the face of adversity by the seductive promise of

something better that justifies living on. The promise is of course unsustainable but nonetheless buttresses positive expectation on the part of those who hope. I mention this analysis precisely because it helps explain why in the aftermath of the 2008 economic crisis, disabled people may well face new dangers. The cruel optimism of the majority relies on identifying scapegoats – immigrants, unproductive older people, those with disabilities, the unemployed – who are all cast as a drain on society's resources. In politics and the popular media there is strikingly little sympathy for others less fortunate than the mainstream but rather a feeling that we would all be better off without them (The Black Triangle Campaign 2010, Penny, 2010 and Shakespeare, 2012). Our democratic ideals, nonetheless, may obscure the bluntness of that self-interest and what becomes ubiquitous in preserving a semblance of communal concern is the notion that we are acting for the other's own good.

The time of austerity and neoliberalism, then, is almost certainly not the time for those with disabilities or their allies to make claims for the 'right' of assisted dying. If the value of a body is heavily related to its utility then those who unable or unwilling to exemplify societal norms will attract negative comment at best and material violence at worse (Briant, Watson & Philo 2013). In many western democracies, such actions are already entrenched, and the neoliberal psycho-political imaginary is fully engaged in identifying the inherent debility of the moment with conditions of disability. I fully agree with Kateřina Kolářová when she suggests that our time 'is a period of anxious recognition on the part of the global North of its own biological vulnerability and precariousness' (2015 forthcoming). The principle of exercising an ultimate control over our bodies – inviting death – may serve as a reassurance of self-sovereignty as things fall apart, but matters are rarely that simple. The cruel optimism of 'not now, not yet' pushes the performance on to others, those whom we tell ourselves have nothing left to live for. In dying through the apparent exercise of a right, those others fulfil the need for unambiguous signs that choice is still an option. It matters little that

some of those who die may be incapable of resisting the choice of others; what counts is the illusion of certainty. What is at stake, I would claim, is a form of abjection, a subconscious refusal to acknowledge the commonality of vulnerability. In short the climate of neoliberalism does indeed appear to support anxieties that people with disabilities will be targeted for death.

Reflection must not stop there, however. Whilst I have no wish to devalue passionately held personal views, a better discussion of assisted dying might shift away from the focus on opposing individual choices. Much feminist thinking, in particular, contests the emphasis on the individual subject and demonstrates instead the relationality of human lives. The bioethicist Anne Donchin (2000), for example, has directly addressed assisted suicide as an event with *many* mutually interested participants. Such views begin to challenge the belief that the importance of life resides primarily in its individual manifestation, that the death of any one is an insult to life as such. But could we radically reconfigure what is meant by life and push the debate onto ground whose very unfamiliarity may provoke new movement? Could we rethink the parameters of life as a *non-personal* vitalist force that exceeds the unique interests of any individual (Braidotti 2006)? In Deleuzian philosophy, the ‘being’ of any subject is always dynamically engaged in multiple webs of connections that constitute becoming. The relatively unchanging modernist subject as the lifetime holder of rights fades into insignificance, and life is no longer seen as having finite duration bookended by birth and death. In exploring the proliferation of life in ever-new and multiple forms, Deleuze (2001) decisively breaks with the notion of an autonomous subject, and signals a state in which the will to live is a pre-personal power that goes beyond any individual lived experience. If life for Deleuze is a continuing project marked by connection and transformation, how are we to understand death and assisted dying?

The radical starting point is to recognise that although life is continually materialised in the individual body that represents personal value, and is marked by discrete events, in another sense, it is also unstructured and has no anchorage in time. The death of a human being, then, marks both the final dissolution of a singular being, *and* the point at which the individual actualisation of life resolves into *impersonality*. As Deleuze notes: 'It's organisms that die, not life' (1995: 143). Without doubt, *my* death signals the cessation of my self, but nonetheless the event of dying is a further opening, another moment of becoming. In that sense, the individual instance of dying celebrates the flux and flow of becoming, and death itself is negated. For Deleuze and Braidotti alike what matters is the capacity to affirm life, to enhance personal and communal potentials through pleasure and suffering alike. There is here no easy invitation to give up in the face of pain or discomfort, but a disposition to embrace all that occurs. The good life is one that sustains and transforms itself in the face of adversity, exceeding expectations and always opening up new possibilities of becoming other. The corollary of that approach, nonetheless, is that *life* may also be affirmed through the self-suppression of an individual existence that blocks the expression of joyous endurance. To accept that the event of death may recompose life under new relations of sustainability means assisted dying need no longer be an ethical problem.

To dismantle the equation between life:good and death:bad goes against deeply entrenched western values, but if we think with Deleuze and Braidotti, then some intriguing and productive modes of living *and* dying begin to emerge, including those related to disabled people. In rejecting the unproblematised mantra that *all* personal life is worthwhile, and valuing not individual autonomy, but the productive possibilities of interconnections, assisted dying – for disabled people as others - would not be a wrong. In short, there is nothing about disability *per se* that would make life not worth living, but that is not an absolute prohibition on desiring death if the condition blocked the potential to affirm life in

the wider impersonal sense. The task is to both challenge any system that pushes disabled people towards death – and here I include neoliberalism - whilst recognising that for some, disability may be a condition that sustains the move into alternative forms of affirmative becoming. The Deleuzian approach makes no claim to provide final answers, and certainly does not exempt everyday ethics from the task of adequately protecting the interests of all equally. But if we want to rise above the current impasse, then it offers the hope, and risk, of thinking differently.

Note

¹ See Hendry et al (2013) for a systematic review of opinion in the global north. They found that while over 60% of people with terminal illness or dementia and their relatives supported assisted dying, only 33% of the disabled people were in favour of legislative change.

Interestingly the UK disability group SCOPE found that while 75% disabled people supported change in principle, over 70% of the same respondents feared coercion (<http://www.scope.org.uk/media/scope-against-legalising-assisted-suicide>). Clery et al (2007) report public opinion running at 80% for assisted dying to be legalised. See also the special issue journal edited by Lillie and Werth (2005) for a sense of the powerful hostility to assisted dying expressed in academic disability studies as well the activist websites *Care not Killing* (<http://www.carenotkilling.org.uk>) and *Not Dead Yet* (<http://www.notdeadyetuk.org>).

References

- Berlant, L. (2007). Slow Death (Sovereignty, Obesity, Lateral Agency). *Critical Inquiry*, 33, 754-80.
- Berlant, L. (2011). *Cruel Optimism*. Durham, NC: Duke University Press.

- Black Triangle Campaign (2010). *End Demonisation of Disabled Claimants/Unemployed, etc.* Retrieved from <http://www.urban75.net/forums/threads/the-black-triangle-campaign-end-demonisation-of-disabled-claimants-unemployed-etc.255475/>
- Braidotti, R. (2006). *Transpositions: On nomadic ethics*. Cambridge, UK: Polity.
- Briant, E., Watson, N., & Philo, G. (2013). Reporting disability in the age of austerity: The changing face of media representation of disability and disabled people in the United Kingdom and the creation of new ‘folk devils’, *Disability & Society*, 28, 847-889.
- Clery E., McLean S. & Phillips, M. (2007). Quickening death: the euthanasia debate. In A. Parks, J. Curtice, K. Thomson, M. Phillips & M. Johnson (eEds.) *British Social Attitudes: the 23rd report – perspectives on a changing society* (pp 35-54). London: Sage.
- Deleuze, G. (1995). *Negotiations*. New York: Columbia University Press.
- Deleuze, G. (2001). *Pure immanence: Essays on a life*. New York: Zone Books.
- Donchin, A. (2000). Autonomy, interdependence, and assisted suicide: Respecting boundaries/crossing lines. *Bioethics*, 14, 187-204.
- Hendry, M., Pasterfield, D., Lewis, R., Carter, B., Hodgson, D., & Wilkinson, C. (2013). Why do we want the right to die? A systematic review of the international literature, *Palliative Medicine*, 27, 13–26.
- Koch, T. (2004). The difference that difference makes: Bioethics and the challenge of ‘disability’, *Journal of Medicine and Philosophy*, 29, 697-716.
- Kolářová, K. (2015 forthcoming). Death by choice, life by privilege: Bio-political circuits of vitality and debility in the times of empire. In S. Tremain (Ed.) *Foucault and the Government of Disability* (2nd edition). Ann Arbor: University of Michigan Press.
- Lillie, T. H. & Werth J. L. Jr (2005). (Eds). *Journal of Disability Policy Studies*.16. 1. Special Issue on *End of Life Issues and Persons with Disabilities*

- Mostert, M.P. (2002). Useless eaters: Disability as genocidal marker in Nazi Germany. *Journal of Special Education* 36, 157–170.
- Penny, L. (2010). How the disabled were dehumanised. *New Statesman*, 16 December 2010. Retrieved from: <http://www.newstatesman.com/blogs/laurie-penny/2010/12/real-disabled-jody-mcintyre>
- Schaller, J. (2008). Reconfiguring dis/ability: Multiple and narrative constructions of self, *Pastoral Psychology*, 57, 89-99.
- Shakespeare, T. (2012). Blaming the victim: Disability hate crime, *The Lancet*, 380, 9845-878.
- Shildrick, M. (2008). Deciding on death: Conventions and contestations in the context of disability, *Journal of Bioethical Inquiry*, 5, 209-219.

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