

# **Finitude, Choice and the Right to Die: Age and the completed life.**

## **Introduction**

In recent years, the idea of the completed life and the right of people to seek assistance in determining the length of their later life has gained traction both in Europe and North America. The aim of this paper is not to support or reject this idea as a moral position but to consider it and the movements advocating it as critical issues for ageing and later life. Irrespective of whether a person experiences serious illness, suffers unbearably or undergoes progressive infirmity in old age, the idea of the completed life implies that the sheer quantum of years can be judged 'enough'; and that no more need be borne (Beekman, 2011; van Wijngaarden, Leget and Goossensen, 2015). In addressing this concept, the paper revisits issues concerning 'setting limits', the 'right to die' social movement and the valorisation of extending the 'third age values' of choice autonomy and self-determination at every point in later life. It concludes by considering the extent to which the self-determination of the length of life expresses less the consequence of an oppressive ageism than the inexorable expansion of 'third ageism'.

## **Setting limits**

Towards the end of his life, the life span developmental psychologist Paul Baltes turned from his long standing interest in the plasticity of adult development to consider what he termed the fourth age, when "hope wears a mourning band" (Baltes, 2006: 38). After reaching 80 years or so, the good news of the third age was exhausted. The remaining task, as he saw it, was maintaining dignity within the limits of life. "[E]ven if there is no maximum biological limit to life", he wrote, "such a limit can still become a part of our decision making as self-directed individuals" (Baltes, 2006: 39). Baltes was returning to a theme articulated two decades earlier in Daniel Callahan's book "*Setting Limits*" (Callahan, 1995). Callahan

argued that society should actively set limits to its investment in late old age and “alter our perception of death as an enemy ...to its being a condition of life to be accepted” (Callahan, 1995: 223). Setting limits was for Callahan a societal decision not to invest resources into prolonging life but not, as he later made clear, to enshrine a human right to death (Callahan, 1992).

When Callahan wrote his book on *Setting Limits*, increasing life expectancies were seen to be increasing costs as if health was a good worth any price at any age. Not so, argued the advocates of setting limits, the returns are not equal. Every dollar spent does not yield an equivalent increase in health or longevity. Age itself sets limits on the rate of return. Given the finite nature of public resources, universal systems of care and welfare should target those offering the best returns to the society. Calls for ‘care with dignity’, of course, accompanied such position statements, and Callahan himself remained opposed to voluntary euthanasia (Callahan, 1992). Still his implicit message was that society should acknowledge limits to human possibility and not seek actively to prolong old age.

At the same time, household expenditure amongst the older population was rising. From the 1980s onwards, retired people were spending increasing amounts of money on non-essential goods and services, including anti-ageing products and services designed to stave off if not age, at least the appearance of agedness. Such individualised consumerism has been (and is still) condemned by some, on both the left and right, as deluded, self-indulgent, and vain. The neo-liberal regimes that emerged during the 1980s encouraged personal responsibility for health maintenance, rather than supporting rising public expenditure. The combination of human rights and Foucauldian principles of ‘care of the self’, whose linkages have been mapped out (Lefebvre, 2018) can be seen ‘paradoxically’ as legitimating rather than challenging such regimes (Zamora, 2016: 4). As the consumerism of the third age established itself, ageing without limits became a widely promoted goal, even as limits were

being set around public expenditure on health and social care for frail older people. The division between the possibilities of later life attached to this new age of ageing and the increasing disablement among recipients of publicly funded care grows wider. The nursing home has become not so much the symbolic end of the road, but the outcome of an unsuccessfully negotiated later life, of failing faithfully to follow the path of self-care and self-determination, and not quitting at the right time (Heilbrun, 1997: 7).

Setting limits became shorthand for pulling back on social spending, a policy that was made more unjust by the austerity imposed after the financial crisis of 2007/8. What was needed were not limits, but the elimination of inequalities – in the length of life, in health and in well-being. Policies that set limits denied those with the least cultural financial and social resources the right to a long and healthy life. With the decline in religious belief, where goodness rather than resourcefulness guaranteed life without limits (after death) the importance of living long and well on this earth became a paramount good. This right to equal health and longevity was compromised by those advocating setting limits. Life without limits, however, may not be what most people want. One of Paul Baltes' last empirical researches concerned people's expectations and desires for longevity (Lang, Baltes and Wagner, 2007). Surveying nearly two thousand people aged 20 to 90 they asked them what age they expect to live until, what age they would like to reach and whether or not they wanted to determine when and how to die (op.cit. p. 270). Irrespective of setting, age and gender, a strong clustering was observed for a desired length of life of around 80-84 years, with smaller groups of respondents preferring to live either into their nineties or not wishing to live beyond 75 years of age. Most of those surveyed expressed a clear desire to control their own death and dying. Baltes' own view that as self-directed individuals we should limit and control the length of our life seemed vindicated. His research suggested there may be an

amount of life that exceeds the desire for life. The right to life, liberty and longevity may need matching by another right – to an ending, to limits.

### **The right to life and to end life**

‘Right to die’ movements emerged in the context of the broader civil rights movements (Beauchamp, 2006). The human rights movement arose as part of the 18<sup>th</sup> century Enlightenment, epitomised in the French Republic’s “*Declaration of the Rights of Man*” (National Assembly of France, 1789). Though the declaration guaranteed the principle of individual liberty it did not declare any right to life. Individual freedoms were not unlimited. For actions deemed hurtful to the new republic, there was no right to life. Instead there was the guillotine, for killing those citizens whose actions were judged ‘hurtful’ to the new republic. In the wake of the Second World War, a new sensibility arose. The *Universal Declaration of Human Rights* stated forthrightly that: “Everyone has the right to life, liberty and security of person” (United Nations Assembly, 1948). The ending of life *by others* including the state became a violation of human rights. This ‘right to life’ was meant to delegitimise measures to end life. No one should be condemned to the death penalty; all should enjoy the freedom to perform any act that is not damaging to others’ freedom or contrary to ‘the just requirements of morality, public order and the general welfare’ of society (Article 29, UN, 1948)<sup>i</sup>. This of course left open judgements of what might be considered to exceed ‘the just requirements’ of society. The decriminalization of suicide, for example, did not follow from this declaration, but took place later, during the 1960s and even then by no means in all of the UN’s signatory countries (Mishara and Weisstub, 2016).

Developments in the right to die have taken place rather more sporadically. As with most new social movements, the focus has been on changing legislation within the setting of national case law. Each ‘right to die’ movement has charted its own pathway in determining

what can and cannot be permitted in the disposing of a life (Fox, Kamakahi and Capek, 1999). Attempts to draw upon generic ‘human rights’ legislation such as the European Charter of Human Rights (European Union, 2012) have proved unsuccessful, as in the recent case of a UK citizen<sup>ii</sup> claiming that denying her ‘right’ to assisted suicide constituted an infringement of her human rights. The European Court of Human Rights “held that the right to life could not be interpreted to include the opposite right, namely the right to die” (Niemenin, 2018: 417).

Legislating for the right to die has not focused upon suicide (already decriminalized in all those states where such movements have emerged) but on physician assisted suicide. Progress has been uneven. While several states in Australia and in the USA and several European countries have passed legislation authorizing physicians to help patients die, a much larger number of states have opposed such legislation. Even those states that have passed physician assisted suicide (PAS) have not in effect passed a law giving people the right to call upon medicine to help them end their life. When cases for and against PAS have been taken to the US Supreme Court, for example, no ‘constitutional right to die’ has been affirmed (Fox, Kamakahi and Čapek, 1999:107). In effect nearly all the debates have concerned the legality of professionals helping terminally ill people die, and the acceptability of such forms of assistance.

While the ‘right to die’ is related to the right to put limits around life, the main reason for wanting to legitimate PAS has been the wish to put an end not to life, but to intense or unbearable suffering – no life at all. Absent illness, absent pain and suffering, absent the body’s agonies, the idea that people have the right simply to ‘put a limit’ to the length of life has only recently been placed on the political agenda. These new proposals for legitimating assistance in limiting life raise anew questions concerning the validity of distinguishing between the ‘suffering’ of someone with a terminal illness and suffering arising from other

considerations, including the pain of sheer longevity (Hale, 2003: 147). This widening debate first concerned the inclusion of psychiatric illness alongside physical illness as conditions justifying people applying for PAS, a position that was later legitimated in Belgium, Luxembourg and the Netherlands (Kim, De Vries and Peteet, 2016). The more recent form goes beyond any medical condition to include the burden of years. The critical site for this new debate is the Netherlands and the focus of concern, the sheer weight of longevity.

### **Weariness of life: clinical or cultural entity**

The movement termed (in English) *Of Free Will* was set up in the Netherlands by Yvonne van Baarle. Its goal was assisting older people “who consider their life complete” to end it (Beekman, 2011: 12). The group seeks to legitimize those older people (aged 70 years or more) who consider they have reached or are reaching a point when more life is less attractive than death, to act upon their beliefs and embrace death. According to Beekman, around 500 elderly people had requested assistance to end their lives on such grounds, but only 1% of such requests are ever granted (Beekman, 2011: 19). Subsequent surveys indicate that substantial numbers of the Dutch population consider that elderly people should be eligible for help to terminate their life in such circumstances, whether or not they have a terminal illness (Buiting et al., 2012; Cohen et al., 2014; Kouwenhoven et al., 2019; Raijmakers, et al., 2015). Although support for this right remains much less than it is for those who are terminally ill, it seems to be growing and has recently been taken up by a similar organisation in the United States, *The Completed Life Initiative*, (<https://www.completedlife.org>).

Does this expanding right to die movement reflect the deteriorating position of older people in Western society or a rather a ‘culture of narcissism’ and entitlement said to characterize the post-war ‘boomer’ generation (Lasch, 1991)? Support for the latter

interpretation can be found in the idea of ‘boomercide’, advanced by Peter Levitan (Levitan, 2012). He argues for the virtue of people making ‘an objective decision about the benefits of ending one’s life based on an assessment of his or her future’ (Levitan, 2012: 14). Such a considered approach, Levitan argues, reflects true ‘Baby Boomer thinking’ (Levitan, 2012: 15). That life constitutes a kind of hedonic balance which eventually tips over in favour of death is not necessarily the ethos of a particular generation. But for some, it has become culturally embedded within the new social movements, within a political culture valorising ‘self-determination, autonomy and individualism’ (van Wijngaarden, Leget and Goossensen, 2015: 257). While self-determining the limits of one’s life does not necessarily reflect a ‘post-modern’ approach toward death and dying, locating *the individual* as both the context and the site for such agency arguably is. Weariness of life may have a long cultural history, but the implications now being drawn seem to be of an era, at least, if not defining of a cohort.

Many clinicians continue to interpret such feelings as “simply a variant on the older more established field of research known as late life depression” (Morgan, 2013: 324). While there is no doubt a ‘bias’ favouring the dominance of medical-psychiatric discourse concerning suicide and suicidality in later life (Shahtahmasebi, 2013), the wish to put an end to one’s life is not an uncommon feature of depression in later life, affecting perhaps as many as one in five older people presenting in general practice with depression (Vannoy et al., 2007: 1024). The frequency of depression among people aged 65 and over known to have committed suicide has been reported as high as 50% (Pompili et al., 2008). Nevertheless, suicide rates continue to rise through to very late in life, and at a rate much faster than could be accounted for by any age-related variation in depression (Canetto, 2017; Van Orden and Conwell, 2016: 240). Moreover, elevated rates of suicide in later life appear to be

widespread and relatively longstanding phenomena that are common to most countries where data is available (Diekstra, 1993: 12; Värnik, 2012: 765).

Such invariant patterns have led some to view ‘suicidal ideation’ in later life as ‘a natural phenomenon’ of old age, with the “wish to die ... an outcome of a rational assessment of their personal lives” (Van Humbeeck et al., 2019). This ‘naturalness’ of suicide in very old age has been judged “a legitimate exit in the face of unbearable living conditions” (De Leo and Kõlves, 2017: 363-4). But sheer weariness of life, however often expressed, has rarely served as the necessary trigger for suicide, nor indeed for claiming the right to die, at least until recently. While the continuing secularization of society has diminished the power of religious prohibitions against suicide at any age, the growth in individualised attributions of human rights has reinforced the authority of self over society within the institutionalized individualism said to characterise ‘second modernity’ (Beck and Beck-Gernsheim, 2002). While chronic ennui is not itself a novel sensibility, nor is the co-occurrence of such notions with clinical depression, what is novel is the change in the collective consciousness that is leading many to assert the right to place limits around what constitutes a bearable life, including in that notion, the tolerability of life’s sheer length.

## **Reservations**

This paper has considered the limited life as a valid expression of choice – of autonomy – in later life, espoused as part of a ‘third age’ culture. But endorsing the implicit value of autonomy, self-determination of when and how a person should die risks ignoring the social matrix in which later lives are lived. Choosing to end one’s life (and choosing moreover to seek help in doing so) can be seen as a selfish rather than autonomous act,



evidence of the narcissism of the boomer generation, ignoring the hurt such deaths have for society. The fact that many consider one's eighties as the limits of a desirable life does not imply that the majority of people actively wish to end their life at that point: **they do not (van Wijngaarden et al., 2020)**. That life may go beyond what is wanted does not mean that is sufficient cause to end it. One's continued presence in the world may be desirable to others even when not for the individual. Choosing to end it may cause them irredeemable harm.

Research into the impact on friends and family of self-selected death (whether assisted suicide, suicide or euthanasia) has only recently appeared (Gamondi et al., 2019). Physician assisted suicide of people with terminal illness has been associated with less family trauma than that arising from 'natural' deaths (Gamondi et al., 2015: 148; Gamondi et al., 2019). In the context of Switzerland, where assisted suicide typically takes place outside medical settings, such deaths seem to occasion a greater degree of family trauma when the decision is not discussed or takes place outside accepted institutional settings **(Gamondi et al., 2015: 150)**. Studies of 'rational suicide' undertaken without formal healthcare input also suggest a greater degree of family trauma although there is little research directly comparing the impact of 'rational' suicide with suicides associated with mental disorder (Van Orden and Conwell, **2016**). What seems clear is that many older people who choose to end their life live alone and have limited social networks, suggesting that the presence of others does to some degree mitigate acting on the wish to limit one's life (Rurup et al., 2011).

A further reservation articulated by professional groups opposed to the idea of euthanasia and physician assisted suicide is that such elected deaths represent a slippery slope. Accepting 'self-murder' leads to accepting assistance in self-murder, then 'mercy-killing', ending with the legitimization of state mandated murder of those deemed to have too poor a quality of life to warrant their 'undignified' survival. Maintaining a line between killing which can or cannot be legally or morally justified is too difficult and too dangerous

for states to legitimate let alone undertake (Sprung et al., 2018: 198). As the prohibitions on suicide and assisted suicide are lessened, it is argued, old and very old people may feel pressured to request assistance with suicide. Cultural change in society, changing guidelines and practices in healthcare and changing attitudes expressed in the media, it has been argued, may replace “the right to die ... [with] a duty to die” (Sprung et al., 2018: 199; Sprung et al., 2019: 1698).

Opposition also comes from disability rights organisations (Behuniak, 2011: 17). In her review of the group calling themselves “*Not Dead Yet*”, Behuniak outlines three arguments against legalising any right to die. First the group argues that there exists a ‘deadly double standard’ that protects the non-disabled from suicidal behaviour while condoning and enabling it for those with disabilities; secondly that unlike other stigmatised identities that are protected from serving as the basis for differential treatment, people with disabilities are seen as reasonably judged as qualifying for assisted suicide on assumptions of the inferiority or limitations of their life; and finally, that given “the unaccommodating and openly hostile cultural context within which those with disabilities live...fears of disability ...lead to the conclusion that the lives of those with disabilities are inherently bad, unfulfilled ...and lack dignity” (Behuniak, 2011: 27). While Behuniak outlines the case against the right to die in the case of people with disabilities, it is no great stretch to extend the same argument to late old age and its equally ‘disadvantaged’ position. Only if applied to all competent adults could the right to die be afforded any possible legitimacy.

Lastly is the argument that “to legalize assisted dying for older people who are generally healthy but feel that they have led a so-called ‘completed life’” reflects less “a neo-liberal paradigm that strongly focuses on self-determination, autonomy and a drive to satisfy individual choices and interests” than the failure of modern societies to provide sufficient opportunities for social engagement throughout later life (van Wijngaarden et al., 2018: 427).

The sense of purpose in life and the desire for life are less products of individual circumstances than reflections of impoverished conditions in later life. Self-limited life, in such circumstances, does not reflect the limitations of any individual's life and what it can offer, but the limitations of society and what it fails to offer later life. Unless and until dignity, engagement and inclusion are extended across the whole lifespan, however long or short, it is not possible to ensure that legislating for the right to die does not perpetuate a serious injustice.

## **Conclusions**

As old age has become a common expectation, concerns have grown over its increasing longevity. While for some these are framed as questions over the affordability of retirement and the mounting costs of later life health and social care, for others the increasing length of later life is in and of itself problematic. While few do not wish to reach old age, a significant number wish to place limits around its length, not as a matter of normativity but as a matter of individual preference. While right to die movements typically advocate for society to secure medical assistance for people to end their lives with a maximum of comfort and a minimum of risk, a clear division exists between those who wish this for adults who, whatever their age, are experiencing unbearable suffering as a result of a chronic, terminal illness and those advocating the availability of an 'end of life pill' which older people can take to determine the length of their later life (Rurup et al., 2005). Only the latter seek to legitimise the self-determination of a limit to longevity (in contrast to limiting an insufferable illness). A degree of overlap exists in the centrality of psychic pain and suffering as reasons for ending life but there is a clear divergence in the necessity of debilitating life shortening pathology as the source of suffering. For those advocating the completed life, even if weariness of life is accompanied by signs of chronic clinical depression, such judgements can

still legitimately be expressed. A preference for a fixed finitude can be a rational judgement when the likelihood of future life is judged poorer than is tolerable, poorer than death.

Such issues are perhaps incapable of final resolution; nor has it been the aim of this paper to proffer one. The ‘youthful’ desire to exercise autonomy and the freedom to live life in the way one wants now colonises later life. Growing numbers of older people are seeking to place limits around what is an acceptable longevity, avoiding what goes beyond that and risking an unacceptably overlong life. Both the law and professional practice are shifting to accommodate such views<sup>iii</sup>. This is illustrated by the evolving code of practice of the Dutch Euthanasia Review Committee which has now accepted both that suffering can extend to anxiety about future deterioration and that patients can refuse care or treatments without jeopardising their access to PAS (Kuwenhoven et al., 2019: 45). While living later life without limits may have a certain ‘third age’ appeal, for an increasing number of people, if there are to be limits, they rather than others, would rather determine them. This wish seems better understood as a reflection of third age culture, a sense less of despair than of entitlement. Research consistently indicates that those approving of and those actively seeking PAS are among the more, not the less advantaged (Dierickx et al., 2015; Domino, 2003; Steck, Junker and Zwahlen, 2018) while the less advantaged show less support for and experience greater difficulty in accessing end-of-life care, be it PAS or palliative care (Parks et al., 2011; Shaw et al., 2019; Sikka, 2019).

Advocates of older people’s right to die and to choose the manner and timing of their own death seem to encapsulate the aspirations of those older people with the assets, capitals and resources that support autonomy choice and self-determination. They reflect a complexity of attitudes toward later life evidenced in the suicide of the literary scholar, feminist and writer of detective fiction, Carolyn Heilbrun. She had expressed the view that it was important to make the most of later life, when at its best, and to know when “to leave at

the height” before “the inevitable decline” (Heilbrun, 1997: 7). Although she anticipated this being 70, in line with the Biblical ‘three score years and ten’, she continued her life until reaching her seventy seventh year. In reasonably good physical and mental health until then, she left as her final note, “*The journey is over. Love to all*”. Rather than leaving it to nature or society – or indeed, to gerontological normativity - to determine the length and breadth and quality of later life, a growing minority of older people, like Heilbrun, are seeking to determine the limits for themselves. Trends evident during the first decades of this century suggest that these islands of agency are beginning to shape and shift professional views too.

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## Notes

<sup>i</sup> Article 29 states that “Everyone shall be subject only to such limitations as are determined by law *solely for the purpose of securing due recognition and respect for the rights and freedoms of others*” (UN, 1948).

<sup>ii</sup> The case is that of Mrs Pretty, who argued that not letting her husband assist with her request to die constituted a violation of her human right, but “the Court held that the right to life could not be interpreted to include the opposite right, namely the right to die, there had been no violation of Article 2, or a violation of Article 3 (Prohibition of inhuman and degrading treatment) or Articles 8, 9 (freedom of conscience) or Article 14 (prohibition of discrimination) of the Convention” (Nieminen, 2018: 417).

<sup>iii</sup> In the Netherlands, the Schnabel commission argued that tiredness with life, anticipated deterioration and multiple health problems form reasonable considerations in existing applications for medically assisted death and hence no further changes in the law are needed (Schnabel et al., 2016: 231). But just before the COVID-19 pandemic, the Dutch News reported that “the Liberal Democratic Party is drawing up its own legislation which would make it possible for the elderly who consider their life is at an end to be helped to die” (Dutch News, accessed via: (<https://www.dutchnews.nl/news/2019/09/d66-to-press-ahead-with-bill-to-support-assisted-suicide-for-completed-lives/>)).