



# Article Fodder for Despair, Masquerading as Hope: Diagnosing the Postures of Hope(lessness) at the End of Life

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**Abstract:** Hope is needed for persons confronting the limits of human life, antagonised by the threats of death. It is needed also for those health and medical professionals constrained by the institution of medicine, determined by market metaphors and instrumental reasoning. Yet, despair can masquerade as hope for such persons when functional hoping for particular outcomes or aims proves futile and aimless. The following will examine such masquerades, while giving attention to particular expressions of autonomy, which persist as fodder for despair in our late modern milieu. The late classical account of Hercules and his death, as well as contemporary reasons for soliciting medical assistance in dying, will focus on the diagnostics of despair, while a Christian account practicing presence, and of hope as a concrete posture enfleshed by habits of patience, among other virtues, will point toward counter-narratives that might sustain persons in times of crisis and enable persons' flourishing as human beings, even unto death.

**Keywords:** despair; hopelessness; medical assistance in dying (MAiD); autonomy; Hercules; postures of hope; virtues; patience

# 1. Introduction

As in previous times, we find ourselves in a state of unrest. Hope is needed. Whether considering the dangerous and unrelenting journey of refugees in flight from and towards uncertainty, or the proliferation of violence as a first response, whether expressed by 'pre-emptive' military aggression towards nations or by paramilitary powers of police that target neighbours presumed guilty by race, or the warping of language and truth to suit the techniques of propaganda and the theatre of political office, to list only a few, hope is needed. Hope is also needed in our corporate–technological age, where we have learned to follow the utility of market processes (McDowell 2019) and our imaginations have been constrained by the images of efficient instrumentality (Bishop 2011) and the spirit of the machine (Berdyaev 1935), while the whirring of data streams promise to determine our decision-making (Harari 2011). Hope is needed where the depredations of aging reveal the finitude and frailty of the human condition (Amery 1994). Accordingly, hope is needed not only for those confronting the limits of human life, antagonised by the forerunners of death, whether through disease or decay, but also for those constrained by the institution of medicine, determined by market metaphors and instrumental reasoning.

Hope is needed. Yet, not all hopes can sustain us in times of calamity and crisis. Some hopes offer concrete aims that are fodder for despair, risking life's end (Cioran 2018). Other hopes torment, engendering a sort of longsuffering that never finds respite (Nietzsche 1910). One must learn, therefore, to discern such risks, so as not to be perturbed by such hopes that are as the other evils contained in

Pandora's pithos (jar). One must learn to discern fodder for despair, which masquerades as hope. Such fodder veiled as hope comes in the form of objective aims, values, or optimisms, which the self-sufficient and solitary individual is supposed to procure for a meaning-filled existence. Despair emerges as these objects of one's hoping, of one's pursuit of meaning, which proves to be unattainable or are imminently at risk of being lost. It is important, then, to consider a diagnostic for discerning such fodder. Only then might those persons confronting the threats incumbent to dark times and vulnerable to the gravity of despair be(come) opened to the possibility of hope, which might become as a good enfleshed, habituated through practices of presence and sustained by patient performance. Only then might those persons learn not to wish for a different world, but to be transfigured to say and see the world differently, including those worlds perturbed by dark times (McDowell 2019).

The following will thus attempt to discern such risks accordingly. That is, the following will consider the hope concealing despair for those hurtling toward death, caught up in the throes of terminal diagnoses and futile medical interventions. The argument will demonstrate that our late-modern anthropology, cultivated by images of Herculean self-sufficiency and self-determination, leaves persons vulnerable to despair but without the hope that can hasten the patience necessary to flourish as human beings while experiencing the depths of despair. Instead, that same anthropology entraps both persons and the medical institution, including the professionals it forms, in a reciprocal chasing of individual, institutional, or professional agency in flight from despair. The purpose of the following, therefore, is twofold: first, to demonstrate how modern autonomy, i.e., self-determining agency, leaves persons at risk of despair and death. That same agency also determines not only negative dispositions concerning human limitations and functional losses (such limitations and losses are opposed to the ideal of the modern subject) but also decisions for (voluntary or assisted) death. In fact, the risk of despair is occluded by the logic of functioning hoping and goaded by instrumental reasoning that makes voluntary death essential for the modern subject. The second purpose is to offer an invitation for readers to think again about the significance of Christian hope, and the pedagogy necessary for the cultivation of such a virtue. Hope, thus conceived, not only offers a challenge to modern commitments to absolute agency but also a discipline that can shape moral communities that might sustain persons in times of crisis, while liberating these same persons from the tyranny of autonomy and instrumental rationality.

Put differently, the following will accomplish these purposes (a) by illuminating the way 'hope' functions for many persons confronting death. It will be shown that functional hoping is a hope said to be conferred by autonomy. The following will then (b) interrogate such hope, revealing it is nothing but despair in disguise. Finally, the following will (c) offer a challenge to the incumbent *apologia* for the modern turn toward medical assistance in dying and invite its readers to ask questions of the hospitality of medicine and the performance of hope for those confronting the threat of death and the darkness of personal catastrophe and calamity.

Now, before reading further, it must be stated at the outset that the following essay is not a mere exercise of objective, viz. scientific and dispassionate, theological and philosophical reflection on hope in dark times—the theme of this special issue. It is not merely a parsing and organization of relevant text and argument so that a reader might walk away with further epistemic resources to be used or discarded, as though knowledge stands in reserve. Instead, dark times demand both persuasive opinion and moral conviction. Accordingly, the essay will offer up not only reasoned argument but also passionate tone, given the urgency of the matter in contemporary life.

### 2. The Triumph of Autonomy, Conferring Hope

It might be that medical assistance in dying (MAiD) offers hope for the hopeless—those persons whose diagnoses are irremediable and whose sufferings are unremitting. Some might suggest, for example, that MAiD, whether by physician assistance or active euthanasia, offers hope for a good death, which is delimited by *freedoms* to elect the timing and conditions by which one might die. That freedom is often thought essential for the modern subject, and it is the prognoses of disease that demands the exercise of such liberty. Such freedom, delimited by unencumbered choice, confers hope,

so it is thought. The following will examine such hope by agency, and suggest that it might be 'hope', but of a very particular and, ultimately, corrupt kind.

MAiD is argued by advocates and apologists to be both a "triumph of autonomy", and consistent with the "traditional commitment" of the physician toward the patient (Beauchamp 2006, pp. 644, 651). By autonomy, triumph refers to the liberty of patients to determine their lives, and deaths, by the administration of one's rational agency that is free from coercive influence. Traditional commitment refers to the competent clinical practice and rational care for those confronting pain, suffering, and the threat of death. Now, one should note, this 'traditional' commitment is arguably quite novel, emerging with the seventeenth century revolution, where physicians and surgeons, referred to with elevated status as 'doctors', convinced the ill, infirm, and dying that they had increased choice to elect rational care of, perhaps over, their lives-enabling individuals to take responsibility for themselves (Mortimer 2005, pp. 97–116). They were not merely cornered by fate or determined by fearful patience for divine action. Rather, the medicine of the day, and the determinative attention to disease provided by the doctors, offered the option of control over the 'landscape of disease', wherein such medical practice and prescription bolstered a medical individualism, or agency, that continues, arguably triumphs, in the current milieu. Such control over disease is, in fact, regarded as "a very special thing", when applied to "a self-willed ending", as Bert Keizer, a physician and member of the Levenseindekliniek (End of Life Clinic) in the Netherlands, recently reflected in *The Guardian* (as reported by de Bellaigue 2019). Thus, as such a triumph of autonomy, MAiD signals for many a significant achievement of self-sufficient and solitary individuals—masters of fate, electing for death.

It makes sense, then, that Christopher Braider suggested Hercules at the crossroads, as imagined artfully in Annibale Carracci's *The Choice of Hercules* (oil on canvas, 1596), is a suitable modern archetype (Braider 2004; Braider 2016). After all, Hercules is the self-sufficient and solitary individual par excellence. Hercules at the crossroads of choice is an image that reflects the modern subject and what Western society has learned to value as the ideal human being: the muscular archetype of concrete, powerful, self-conscious agency. Such a heroic sovereign, with his bow and arrows, is thought to be at the helm of fate, in control over life; he is a *strong man* poised to wrestle against the gods and death.

The Herculean individual is seen as one imbued with the reason and will to do-against-death and control his destiny. Perhaps this is why *health* is argued to be a prototypical value, for, by health, biomedically understood as one's physical, mental, and social competence, an individual is viewed by self and others as capable of guaranteeing her self-actualization, achieving what is essential and meaningful to her (Goldstein 1959; Bruhn and Henderson 1991). Both hospice and medical assistance in dying draw upon such a familiar script, suggesting the modern agent ought to be free to enter death on her own terms, thus preserving the essential self and making way for a good death (Banner 2016). Thus, whether sustaining the pursuit of self for as long as possible, until biological death takes hold, or bringing death to the foreground in order to avoid the risk of losing one's self prematurely (as in cases of dementia, for example), the Herculean image is apropos.

Yet the mechanics of modern medicine aim toward similar ends—toward such self-actualization—to the extent that reason and will could be regarded as chief values of the medical institution and the professionals it forms in our late-modern Western society. It is by way of health, by the administration of will and reason in our physical, mental, and social lives, that medicine, and its providers, can serve its constituents. After all, as the 1946 World Health Organization (WHO) congress gave assent, "Health is no longer an optional matter, but the golden key to the relief of human misery. We must be well" (Callahan 1973, pp. 82–83). That is to say, we must exercise absolute agency in matters of life and death. The heroic archetype, who is poised to exercise agency-as-might, must also exercise justice as he sets out "in search of monsters to slay, crimes to avenge, [and] deep-seated wrongs to right" (Braider 2004, p. 89). As the politics of MAiD seem to contend, there are few greater wrongs to right than irremediable disease and unrelenting agony.

Accordingly, Vivian Sleight would argue thus: "To have the option to choose voluntary euthanasia confers hope—the hope of a good death" (Sleight 2004, p. 354). For Sleight, such hope is conditioned

by the ideation that a good death can be secured by the administration of choice (informed consent) and the respect of medical professionals, and legal authorities to abide to such a choice (respect for autonomy). Such hope functions as a sort of optimism, where we not only imagine our future but also recognize our past, aiming to secure those values or ideals thought essential. For the patient, MAiD confers "hope of control, resurgence of identity, and personal dignity" (Sleight 2004, p. 354). For the physician, MAiD secures their intention to practice the traditional commitments of medical practice, and "to relieve suffering" (Sleight 2004, p. 354).

However, such a hope might be thought as a functional hoping. That is to say, such hope might be categorized as an objective hope caught up in a technological rationality, which aims to secure, by the administration of procedure, policy, or programme, the delimited values one desires. Such hope is to be given or received by the administration of one's agency, and the cooperative agency of others intending to respect autonomy, in pursuit of such aims. This type of hoping might be exemplified by the phrase that "I hope that [*fill in the blank*] will happen". For Sleight, one might fill in the blank with, "I hope that *a good death* will happen". Reciprocally, then, the good death pursued by modern agency is thought only to be secured by the actualization of such agency. Linking the logic of patient-directed refusals of treatment when such treatments are futile with the petition for assisted dying, Sleight offers up a narrative that champions the sort of thinking which autonomy has proffered in contemporary late-modern bioethics, while suggesting such thinking procures the hope. The kind of hope Sleight has in mind is bolstered further by claims and legislations that secure the individual's right for such a commodity. However, as I will demonstrate, such hoping is but a masquerade. The logic of such hoping is but fodder for despair. It is hope corrupted. Functional hoping, as described, might therefore fail to be hope at all. One need only raise the following questions to begin the interrogation of such hopes:

What happens when our values go unfulfilled? What happens when such aims prove aimless, and the mechanics of will and reason show their frailty and their limitations? What happens when health cannot be achieved? What happens when the individual places her trust in the institution of medicine, (only) to discover that it cannot secure on her behalf either freedom or happiness against the limits of physical, mental, and social disease? What happens when Hercules is taken by "a strange disease [that he] ... cannot withstand by courage, weapons, or strength" (Ovid 2000).

These questions are relevant to the contemporary turn toward MAiD. The concrete experiences of both patients at the end of life and their physicians, among others, serve as the ground from which the questions above arise—questions that require further reflection. Accordingly, let us turn toward such experiences to furnish a better sense of the rationality the compels persons to elect for, and to support the administration of, MAiD.

# 3. The Triumph of Autonomy, Occluding Despair

As was illumined above, autonomy has become a principal doctrine that delimits and defines the human subject in our late-modern period. Self-determination is anthropological orthodoxy. For medicine, this has meant an increased role of patient self-determination and the subsequent attention given by medical professionals aims not only to respect patient autonomy but also to facilitate the *free* choices of patients. That free choice has extended to petitions for increased control over the timing and circumstances of one's dying, in order to achieve the good, viz., self-willed and controlled, death. Yet the conclusion raised questions about such functional hoping—the way 'hope' functions for many persons confronting death. In fact, the conclusion suggested that such hopes are corrupt; mere *fodder for despair*. The following will show this to be the case. That is, the following will how the triumph of autonomy in modern bioethics, and the pre-eminence of an incumbent Herculean anthropology, not only risks, but also occludes, despair, while allowing persons, so it is argued, to escape their present or pending experiences of life amidst death. However, such escape is not due to an exercise of free rational agency, due to the triumph of autonomy, but by way of the fear and anxiety, i.e., the despair, that persists. The reasons given for persons who pursue MAiD are numerous, often including pain and the cost of treatment as primary. However, Oregon's *Death with Dignity Act* relative statistics (2018 [and total, since 1998]) reveal poor pain control (25.6% [25.7%]) and prohibitive costs of treatment (5.4% [3.9%]) are considered less significant reasons than other concerns. Loss of autonomy and control over bodily functions (91.7% and 36.9% [90.6% and 44.3%], respectively), reduced participation in activities of daily living (90.5% [89.1%]), perceived or threatened loss of dignity (66.7% [74.4%]), and sensitivity of becoming a burden for others (54.2% [44.8]%) are assessed as the principal reasons for soliciting MAiD (Oregon Death with Dignity Act Data Summary 2018, p. 12). Similarly, the *Washington State Death with Dignity Act Report* suggests loss of autonomy (90%) and bodily control (46%), diminished activities of daily life (87%), loss of dignity (73%), and risk of being a burden (56%) persist as principal concerns that motivate decisions to elect for MAiD (Washington State Department of Health 2017 Death with Dignity Act Report 2018, p. 8). Hence, whether one can observe these losses immediately or at some future state of impairment, such reasons do yield sufficient cause for patients to die, as they might say, on their own terms, with dignity intact.

The relevant literature that has surveyed patients requesting MAiD, along with carers and others offering support for MAiD, corroborates and clarifies such reasons. For example, several studies have shown desire for control over the circumstances of death for patients seeking MAiD is considered important by proxies, including both medical and nursing professionals as well as ancillary service providers (i.e., hospice chaplains and social workers) (Ganzini et al. 2008, pp. 154–57; 2003, pp. 381–90; 2000, pp. 557–63; Carlson et al. 2005, pp. 1160–66; Ganzini et al. 2002, pp. 582–88). Moreover, those persons soliciting MAiD have also included as principal reasons the loss of independence, a desire to control the time and manner of death, the risk of becoming a burden, and the prospect of worsening pain or quality of life (Ganzini et al. 2009, pp. 489–93).

Robert Pearlman and his colleagues have also observed that persons are motivated to pursue MAiD due to a range of fears and losses, including but not limited to, pain (Pearlman et al. 2005, pp. 234–39). Diminished sense of self, yearnings to regain control, and fear concerning possible future states of being, or simply death, alongside functional losses and persistent fatigue, contributed significantly to the rationale to pursue MAiD. Put differently, the failure to maintain or to secure the characteristics of autonomy have contributed significantly not only to the ideation, but also the solicitation of, medically mediated death.

These reasons are corroborated further by Maggie Hendry and her fellow researcher's systematic review of the literature that asked the following: "Why do we want the right to die?". The study revealed the following in response to this question: factors such as feeling a burden, loss of interest or pleasure, loneliness, and diminished quality of life and control contributed significantly to the reasons for wanting the right to die (Hendry et al. 2012, pp. 13–26). Although not associated with pain per se, in a biomedical sense, these reasons were tied to patient experiences and expressions of "unbearable suffering" and reflect psycho-emotional, socio-environmental, and existential vulnerabilities to despair. They reflect a succumbing to hopelessness, which additional findings echo.

For example, Marianne Dees and her colleagues observed "all patients [interviewed] considered hopelessness to be a main factor in the perception of unbearableness" (Dees et al. 2011, p. 732). Dees and her colleagues listened to patients, who related statements as follows: an eighty-year-old male declared, "I can't do anything anymore, I used to play music, participated in various clubs, all so very companionable, I had to say farewell to all of it. It feels so awful just waiting to become bedridden and then waiting to die". A fifty-year-old female lamented, "You lie on a bed and none of the normal functions come back. They will never come back, and it will only get worse". Concomitantly, Martina Pestinger and her collaborators recorded similar sentiments concerning the theme of failed self-determination in the ideation to hasten death (collated statements from Pestinger et al. 2015, p. 714):

[Participant 11] They [relatives and caregivers] do not feel the agonies, but I do. Now it has come so far, that I am only lying here. You think. You think and think and you bring

many things to mind and passing in revue I have come to a decision, yes, well ... I am lying waiting for death.

[Participant 7] Activities with friends are not possible—and indeed activities outside or with the faculty, I would say, meanwhile completely pass away.

[Participant 2] This is a bit of a vicious circle. When my wife sees that I am doing badly then that makes her suffer. Then I see that my wife is suffering severely and then I—because I know that basically it is my fault. If you can talk about a fault.

[Participant 8] I am not used to somebody helping me. This I feel is tantalizing, this is no life.

Similarly, in the 2017 *Jaarverslag* [Annual Report] by the *Regionale Toetsingscommissies Euthanasie* [Regional Euthanasia Review Committees] in the Netherlands, case studies reiterate, in one way or another, the statistically collated reasons offered above, as well as the reported patient statements (Jaarverslag 2018; Annual Report 2018). For example, in describing the nature of patient suffering that goads clinical euthanasia consultation, it was reported (Case 2018-68) that a 70-year-old male, with a metastatic cancer is both his lungs and brain, had been suffering from a deteriorating physical condition that threatened his autonomy, quality of life, and independence. Moreover, the possibility of remediating his suffering was determined futile. In fact, the case report put it this way:

"Het lijden van patiënt bestond uit verwardheid, slaperigheid en incontinentie voor urine en feces. Ook had hij last van het toenemend onvermogen te kunnen communiceren. Patiënt was tot niets meer in staat, kon nauwelijks meer zelfstandig lopen, was bedlegerig geraakt en was volledig afhankelijk van de zorg van anderen geworden.... Patiënt ervoer zijn lijden als ondraaglijk" (Jaarverslag 2018, pp. 28–29).

"[The patient's suffering consisted of confusion, drowsiness and urinary and faecal incontinence. He was also suffering from an increasing inability to communicate. There was nothing he was capable of doing: he could hardly walk by himself, had become bedridden and was completely dependent on others for his personal care. ... The patient experienced his suffering as unbearable]" (Annual Report 2018, pp. 26–27).

Another case report (Case 2017-86) identified a woman in her fifties suffering the effects of chronic obstructive pulmonary disease (COPD), who reflected on her irremediable condition:

"Het lijden van de vrouw bestond uit toenemende verslechtering van haar situatie. Er was sprake van ernstige uitval van functies. Eten lukte niet meer en zij kon niet meer goed communiceren. De vrouw, die altijd onafhankelijk, actief en communicatief ingesteld was geweest, was volledig afhankelijk van anderen en tot bijna niets meer in staat. Zij wist dat er geen verbetering van haar situatie mogelijk was en er alleen verslechtering in het verschiet lag. Zij ervoer haar lijden als ondraaglijk" (Jaarverslag 2018, p. 32).

"[The patient's suffering consisted of the increasing deterioration in her situation. She was experiencing severe loss of function. She could no longer eat, nor could she communicate clearly. The patient, who had always been independent, active and communicative, was entirely dependent on others and hardly able to do anything for herself. She knew there was no prospect of improvement in her situation and that the only prognosis was deterioration. She experienced her suffering as unbearable]" (Annual Report 2018, p. 29)

Comparable case narratives are found in the recent 2018 *Jaarverslag*, which correlates disease prognoses, futility of interventions, diminishing patient competencies, and increasing dependence upon caregivers with experiences or expressions of *uitzichtloosheid* [hopelessness] (Jaarverslage 2019). For example, for a woman in her nineties, as it is recorded in (Case 2018-120), "[She] *leed onder* 

*de zorgafhankelijkheid en de uitzichtloosheid van haar situatie* [suffered from care dependency and the hopelessness of her situation]" (43). In Case 2018-121, it is reported that, due to the disease effects and the futility of intervention, a man in his fifties "*lag de hele dag op bed en was tot niets meer in staat*. *Hij was altijd een zeer actieve man geweest en leed onder de ontluistering en uitzichtloosheid van zijn situatie*. *Hij wilde op deze manier niet meer verder leven* [was bedridden and unable to do anything anymore. He has always been an active person and suffered from the shock and hopelessness of his situation. Thus, he no longer wanted to live in this way]" (Jaarverslage 2019, p. 46, translation is mine).

As one can read above, patients express the desire to recover such competencies, capacities, and companions, in their lives, and they dread the eventual or imminent loss of these goods. Yet, so often such aims prove unattainable, while the dread is realized. Albeit an unintentional revelation, in asking the question "What is most important for you to achieve?" Timothy Quill helps us to see the genesis of despair. In response to this question, Quill identified four principal categories of diminishing significance, which were reflected in patient responses; the four categories include (1) improving quality and meaning, (2) achieving relief or comfort, (3) altering the trajectory of illness, and (4) preparing for dying (Quill et al. 2006). Looking only at the first category, improving quality and meaning (52% of responses fit to this category), while also reiterating what we have already shown to be common to such findings, patients expressed a desire to return home, to regain function, and to support significant others or not be a burden upon others (Quill et al. 2006, p. 384). Yet, when unable to achieve these aims, they prove aimless; the commodities (or abstractions) of such common functional hoping, when unrealized and unachieved, prove to form a sort of despair, and the world in which these persons live becomes unbearable. Marianne Dees and her colleagues, therefore, hypothesize the following:

While suffering is rooted in the symptoms of illness or ageing, the existential and psycho-emotional themes determine how much hope there is and whether the patient is able to bear the suffering. Unbearable suffering can only be understood in the continuum of the patient's perspectives on the past, the present, and expectations of the future. Without hopelessness, there is no perception of unbearable suffering (Dees et al. 2011, p. 733).

Conversely, where such a perception exists and persists, it does seem such persons are confronted and confounded by a particular form of hopelessness. Let me explain further, while offering up a brief diagnostic of despair.

It has been argued that life is meaningful in relation to those values or ideals that one pursues. In our contemporary Western society, we value, certainly among other values, will, reason, and technique. We value the exercise of individual autonomy to determine and to control the experiences and expressions of our lives. We value the concomitant technological rationality which organizes our knowing and our doing, so that we might resolve particular problems and pursue practical aims, such that we might secure the artefacts essential to achieving mastery over nature and the commodities of our desires. Yet such meaning-by-values leaves one vulnerable when such problems prove irresolvable or such aims prove unreachable.

Such vulnerability risks feelings of meaninglessness. Such meaninglessness can be realized when the values for which we struggle are not there: one aims, but "aims at *nothing* and achieves *nothing*" (Nietzsche 1968, p. 12). Despair thus emerges. That is to say, delimiting a diagnostic, despair can emerge with failed aims and unattained values.

In medicine, the diagnostic might apply as such: autonomy and technique are values for which both physician and patient struggle. Yet in the face of irremediable diagnoses, unrelenting prognoses, and futile interventions where modern agencies are thwarted by the realities of frailty and finitude, the movement from a meaningful life to its repudiation is quick. If one cannot exercise her capacity for self-determination, or the institution of medicine cannot wield its power to control the mechanics of living, then our ideals have not been grasped, and life made meaningful in relation to such ideals is dissolved of its value.

Despair, then, is the pessimistic apprehension that one's aims have proven illusory. It is a persistent response; a comportment that anticipates subsequent behaviour. It is observation that

provokes pessimism (Reginster 2006, pp. 29–30; Marasco 2015, p. 4). Pessimism in this instance means more than a simple *turn for the worse*, but that "the world does not have the value that [one] once thought it had. . . . It seems worthless" (Nietzsche 1968, p. 22). To be clear, the situation begins with the possibility of realizing that which we value, and concludes that we cannot realize it, casting one into the throngs of despair (Nietzsche 2006, p. 228). Despair is the "passion that *persists*" (Marasco 2015, p. 9). It is a passion that persists by both "fear and anxiety" (Cioran 1992, p. 19). That is to say, comparable with the diagnostic offered above, despair grasps hold of persons caught by the unstable dialectic between desire and fear; between things not yet possessed and things possessed at risk of being lost (Marcel 1951, p. 78). Put differently, "the accumulation of possessions and the fear of losing them anew is what causes anguish and eventually despair" (O'Callaghan 1989, p. 218).

Yet such despair is occluded by the promise of alleviating pain and suffering. It is occluded by the late-modern narratives that insist one is free, and, therefore, one's authentic self, when administering will and reason, as though a Hercules confronting the crossroads of choice. Despair is occluded by the masquerade of hope at the crossroads, promising to deliver the 'good death' by repeating, with the assent of legal and medical opinion in a growing number of jurisdictions, the meaning-by-values that has made not only patients, but also physicians, nurses, and the like, susceptible to despair, all the while thinking it can be avoided by both reason (autonomy) and will (technique). Fittingly, then, in the persistent chase of meaning-by-MAiD, perhaps E. M. Cioran's reflections *on death* are apropos: "they expect everything from the end instead of trying to grasp the meaning of a slow revelatory agony. The end will reveal too little, and they will die as ignorant as they have lived" (Cioran 1992, p. 27). They will die chasing meaning, which only escapes them (Ecclesiastes 2), while experiencing neither the depths nor heights of despair (Cioran 1992, pp. 37–38).

#### 4. Postures of Hopelessness: Escaping Death by Death

We have previously argued the orthodoxy of autonomy and instrumental reasoning in late modernity has not only elevated the risk of persons succumbing to despair, but also serves to nourish such despair. The literature that explored the reasons for soliciting MAiD demonstrate the significance of self-determination and control in the valuation of one's life—when persons experience threats to, or the loss of, these characteristics (aims or values) of autonomy and control, a persistent experience of despair emerges. Hopelessness becomes an unwelcomed existential weight as the aims that render meaning prove unachievable or illusory, while tempting people toward MAiD, and back toward the orthodoxy of autonomy and instrumental reasoning. The previous two sections have therefore laboured to interrogate 'hope' for those persons confronting the limits of human finitude and the threats of frailty and death, while revealing such 'hope' as despair in disguise. The following will continue to illuminate the veiling of despair and the postures of hopelessness that persist.

Despair antagonizes human existence in such ways. It tempts relentlessly, while drawing human existence towards its annihilation: "One [thus] cannot separate the thought of [hopeless struggle] from that of weariness and death" (Cioran 1992, p. 16). Put differently, those ideals most important for us risk becoming fodder for a despair which consumes us, anticipating death. It tempts us to hug death (Marcel 1949, p. 104; 1951, pp. 37–38).

Such a hugging of death is exemplified in the modern turn toward MAiD. Such a posture is one wherein both patients and physicians, among others including family, caregivers, and professionals, come to embrace death, voluntarily. That is, death by will is thought of as that which offers hope. Paradoxically, the embrace of death functions as an escape from both despair and death. That is to say, the posture of hugging death is grounded in a pessimism nurtured by the modern desire for, and fear of, losing control, both individually and institutionally. MAiD affords the rational assent and clinical technique to escape the death that one does not want—the death that does not fit the narrative arc of a Herculean subject.

It makes sense, then, that Guernsey's state Deputy Rhian Tooley's conjecture concerning her mother's health was presented as justification in favour of assisted dying legislation: "She does not cling

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to life, it has snagged her. It is not death which is undignified, but living after what you love in life is stripped away" (Morris 2018). That is to say, so long as despair is cultivated within the surgical theatres, doctors' offices, and patient's bedsides in our contemporary medical milieu, suffering, loss, and pain will continually render life as visibly unattractive and meaningless—as unbearable (Dees et al. 2011). However, MAiD will be presented as the 'ace up one's sleeve' to cling to the withering strength of a heroic will to self-determine (Monforte-Royo et al. 2012). Thus, it seems appropriate to return to the imagery of Hercules, as late Classical accounts disclose, when he is poised to exercise heroic will even in his death. In such accounts, he has been poisoned by deceit<sup>1</sup> and left alone to build a funeral pyre, to drag *himself* to its pinnacle, only to command the final aid to relieve his suffering by setting the pyre ablaze (Ovid 2000, pp. 211–72).

We can see that patients are vulnerable to such despair, as proposed above. Yet they are conditioned also by the Herculean will to power, habituated by narratives of self-determination and technological rationalities that are retold by professionals, policies, and legislation. The withering patient, inundated by despair, imagines the clinical administration of death as the only remaining act of control (Monforte-Royo et al. 2012). It determines a response: death is the right thing *to do*.

So now, in many jurisdictions, for the individual hugging her own death, medical services are offered to aid her despair, affirming her judgement while also reinforcing illusions of self-control. This is done whilst safeguarding the illusion of meaning and control for the physician and the physicians' guild, because of their capacity to bring forth death by will. Or, as Philoctetes willed to set the funeral pyre ablaze, relieving Hercules of his torment, the physician and the physician's guild emerge, readied to slay the anxieties and intolerabilities of life in the midst of death. Another hero, thus, ascends ready to hug the death of the other—all the while arguing he does so according to his traditional commitment to the patient, thus on behalf of and in service to, the triumph of autonomy.

But all might not be as heroic. There are those, after all, who might wield Death as a power (Stringfellow 2004, pp. 67–94), not only affirming the judgement of those in the depths of despair, but condemning others, whose state is incompatible with contemporary ideals constrained by technological rationalities and expressions of autonomy. Consider, for example, the inflammatory words of the late British philosopher Baroness Mary Warnock, as reported in *The Times*, regarding those persons suffering dementia: "you're wasting people's lives—your family's lives—and you're wasting the resources of the National Health Service" (as quoted by Beckford 2008). Warnock went on to argue that such persons have a "duty to die" (as quoted by Beckford 2008). An unnamed physician, now in possession of the poisoned arrows of Hercules, was culpable, to ensure such a duty (described as a previous self-expression of will) was fulfilled in the Netherlands, as one might have read in both The Guardian and The Telegraph (Boffey 2018; Boztas 2018). Her defence relies heavily upon the apparatus of autonomy at work in biomedical ethics: as conveyed by Christopher de Bellaigue in The Guardian, "she was fulfilling her patient's request and that, since the patient was incompetent, her protests before her death were irrelevant" (de Bellaigue 2019). Steven Pleiter, the director of the Levenseindekliniek, implicitly supports the actions of the unnamed physician, hoping "the most complex varieties of euthanasia, like psychiatric illnesses and dementia" will be found acceptable (as quoted by de Bellaigue 2019). After all, drawing upon a technological imperative, Pleiter continued: "If the situation is unbearable and there is no prospect of improvement, and euthanasia is an option, it would be almost unethical [of a doctor] not to *help* that person" (as quote by de Bellaigue 2019. Emphasis is mine).

<sup>&</sup>lt;sup>1</sup> Poisoned by the blood of the deceptive centaur Nessus. Nessus was killed by Hercules' poisoned arrows after assaulting his wife, Deianira. Nessus, while dying gave Deianira his blood, saying it was a potent love potion. So, when Hercules brought home as a concubine the beautiful Iole, the young daughter of his archery master, whom he killed in revenge for not giving of his daughter earlier, Deianira thought of the blood as a guarantee. By its application, Hercules' love for her would remain steadfast. Thus, the blood was smeared upon a cloak, which Deianira placed upon Hercules' shoulders. Unable to remove the cloak, the poisonous blood, like an acid through metal, consumed his flesh (Ovid 2000, pp. 89–210).

Some might suggest that such help is heroic. Perhaps not. Perhaps the present milieu of MAiD is, as discussed, cultivated from despair. If so, it is woefully dreadful. After all, if suffering, loss, and pain encumbers the modern subject *and* thus renders life as unsightly and morose, as having no worth, such rejection of existence, and inescapable despair, is not only a valuation of the self (or another) as being worth less, but also a judgment that I am (or Thou is) worth less for others. It is akin to stating that life is wholly disposable and utterly unworthy of existence in a particular present state because of its functional, often rational, encumbrances or impediments.

Thus, the potent allure of the modern subject and the corresponding promises of technological rationalities incumbent to our late modern milieu does seem to hazard derision and a determinative logic wrought from despair. The logic might be as thus: bereft of choices, bereft of a particular understanding of being and of freedom, we would, it is argued, prefer to exercise by medical means a final will to self-determine, our 'right', or our duty, to die. Others therefore argue, that we have been so formed by the late-modern society, where persons often cannot get out from under the imperative for autonomy and the corresponding technological rationality. Some go so far as to suggest that such persons are paradoxically enslaved by its appeal. Carol Stoneking is one such person, offering the provocative assessment:

Our society is so captive to the notion of control that we imagine we ought to control our own deaths; thus physician-assisted suicide is nothing if not cooperation born of the desire to secure the 'best outcome'. Belief in human autonomy, rather than belief in God, is the background belief that makes a positive description of suicide or euthanasia possible. Autonomy has become an imperative; that which we cannot control, our belief in autonomy teaches us to hate. Thus we learn to hate our aging bodies; and we learn to hate those others who are sick and dying. We even learn to hate those we would define as 'permanently dependent', exactly because they will always need our care (Stoneking 2006, p. 382).

So, although the conjecture of a moral philosopher and maleficence of a Dutch physician might seem an outlier, and Stoneking's logic of 'hate' might sound hyperbolic, the bioethical literature does point toward increasing support for MAiD. Moreover, it points toward an increasing endorsement of MAiD not only for those persons who command their death, as Hercules commands Philoctetes, but also for persons suffering various grades of dementia and unable to utter such a command, due to restrictions of competence and capacity. Some, like Steven Pleiter, *hope*, that "acceptance ... grows and grows over the years" (as quote by de Bellaigue 2019).

In 1998, for example, an American study surveyed the general public (N = 447, aged  $\geq 65$ years) and revealed that approximately 11% accepted medically assisted dying for persons with mild dementia (Cicirelli 1998, pp. 186–203). In a 1999 Australian survey of registered nurses (N = 1220), 39% supported the legislation of euthanasia for patients with mild dementia (Kitchener and Jorm 1999, pp. 25–30). Two different studies from the Netherlands in 1998 and 2013 revealed significant support for medical assistance in dving for persons suffering dementia. (Van Holsteyn and Trappenburg 1998, pp. 63–73) surveyed the public (N = 911), revealing 48% supported euthanasia for severe dementia, if requested whilst a person was capable. (Kouwenhoven et al. 2013, pp. 273-80), using mixed methodologies, showed variable opinions, depending on the grade of dementia: among the general public (N = 1960), 24% supported physician assistance and 77% supported euthanasia for persons with mild and advanced dementia, respectively; among health professionals (N = 1243, nurses; N = 793, physicians), 28% of physicians and 31% of nurses supported physician assistance in dying, while 33% of physicians and 58% of nurses supported euthanasia for those with mild and advanced dementia, respectively. Finally, a 2006 study in the Netherlands revealed that 74% of carers (N = 36) agreed that euthanasia is permissible for patients suffering late-stage dementia when accompanied by advanced directive, while a 2007 study in the UK revealed that approximately 44% to 60% of persons surveyed from the general public (N = 725) would support medical assistance in dying for themselves or their partners with mild to severe dementia (Rurup et al. 2006, pp. 372-80; Williams et al. 2007, pp. 1229-34). What, then, does one make of such data in light of the argument thus far? One might turn again to the ways the modern subject and the ideals of our technological society have coerced a particular disposition. But such repetition is not necessary here.

Perhaps it better to think of physicians, and nurses and carers, as we might consider Deianira: deceived by a story of potions and powers, she had a blood-smeared cloak placed upon her husband Hercules. While intending to secure fidelity, Deianira unwittingly adorned him with anguish and hastened his death. Of course, this might stretch the comparison too far. For now, we will move to conclude.

### 5. The Postures of Practicing Presence and the Call for Hope in Dark Times

As has been argued thus far, the pre-eminence of a Herculean autonomy has persisted, cultivating a commitment to control and self-determination, which both risks despair and resources decision-making in favour of electing for MAiD. The desire for control is further emphasised by instrumental rationalities that aim to organize knowledge and practice in order to accomplish practical aims and pursuits, i.e., to secure further control. Accordingly, the anthropology that has nurtured both patients and medical professionals has contributed to the despair that torments the medical milieu. Such torment has deeply impacted the way persons think not only of themselves when encumbered by disease and dysfunction, but also others, whose (especially, but not only, rational) capacities are limited. This anthropology thus requires both dissent and a constructive response in order to challenge the incumbent *apologia* for the modern turn toward MAiD.

By way of dissent, it seems appropriate to draw from the words of Swiss theologian Karl Barth to protest the self-sufficiency and solitude of the Herculean archetype, the modern individual freed *from* all others: *"si quis dixerit hominem esse solitarium anathema sit* [if someone says that a human is a solitary being, let that one be anathema]" (Barth 2009b). By way of dissent, or denouncement, one might repeat, therefore, as Barth reminds his reader, the judgement upon us—the Divine 'No'!—which stands to oppose such a posture of being that, by principle (i.e., late modern autonomy), isolates the individual from her fellows, both Divine and human, and erects as essential the self-determinism that, in the end, cultivates despair masquerading as hope. One might also denounce those ethics, policies, and practices that call persons to adjudicate the moral milieu where life is lived in the midst of death, but without due attention to those fellows who gather, and claim us for mutual recognition and cooperation, at the nexus of crises. Such claims are as the divine claim that secures the freedom, the permissions, to become who we are (human beings), in communion with our fellows, both near and distant. Yet, such claims are clothed in the "garment of another", who stands before us as the one to, with, and for whom life is to be lived (Barth 2009a).

We must listen, therefore, to these claims and respond accordingly. Yet such listening must be performed amidst (even against) the whirring of instrumental reasoning and the crescendo of individualist autonomy, which tend toward the bodies of the ill and infirmed as objects to control (Moyse 2019). Such listening must be performed with a readiness to adjudicate and to advocate good medicine, which might be described as the "due care for those who cannot provide care for themselves ... [and] ever-vigilant to concentrate upon [each] *demanding* body" (Moyse 2019, p. 26). With "gratitude and responsibility, we must ... take seriously the historicity and particularity of embodied human beings struggling *together* amidst the ambiguities of present crises and toward the flourishing of human life even unto death" (26).

Such struggle, for the Christian, however, is to be disciplined, viz., educated, by "a teleological vision of hope for future transformation in ways that depart from mechanistic aims at controlling nature" (Ridenour 2019, p. 189). As Autumn Alcott Ridenour reminds her reader, a Christian theological hermeneutic will give a description of nature, of human life amidst death, which accounts both "for suffering, change, decay, and death resulting from evil", and "for anticipating transformative renewal" (190). The account of suffering, change, decay, and death resulting renewal is eschatological. It might too be considered as apocalyptic—meaning, while remaining

realistic, the Christian account anticipates something better after resurrection (eschatology), but also with the possibility of the inbreaking of the divine world into human history (apocalyptic), which "transfigures the world [actually, paradoxically, and existentially] for the eyes of faith" (Congdon 2015, p. 177, 179). Transformation and transfiguration, for the person inundated by the existential weight and depredations of illness, must be actual (paradoxical and existential), although without necessitating the clinging to life as though to an idol or ultimate end (Moyse 2015; Barth 2009c). Moreover, the realistic, eschatological, and apocalyptic narratives of the Christian traditions remind us that "followers of Christ are called to remain present to one another through life and death . . . practicing presence to one another over time" (Ridenour 2019, p. 191).

Regarding this practice of presence, Ridenour continued, drawing upon the words of Stanley Hauerwas, who has challenged his reader, "Only a community that is pledged not to fear the stranger—and illness always makes us a stranger to ourselves and others—can welcome the continued presence of the ill in our midst. The hospital is, after all, first and foremost a house of hospitality along the way of our journey with finitude. It is our sign that we will not abandon whose who have become ill simply because they currently are suffering the sign of that finitude" (Hauerwas 1985, pp. 81–82). She explains, saying, "In other words, the practice of medicine ought to be a sign that the human community *will not* abandon those who are suffering and dying … [but will] comfort the suffering through compassionate presence" (Ridenour 2019, pp. 191–92). Emphasis is mine. While such compassionate presence is said to be the discipline of hospitable medicine, it is not what the practice of MAiD demonstrates or cultivates.

To be sure, the contemporary turn to control dying in such circumstances as described above, therefore, is not to be accepted or rejected without critical acumen. Yet critical perspicuity ought not to focus on the means and modalities used to palliate pain and to mediate the experiences and expressions of dying, per se. Neither ought it to contend with the patients' ideation of hastened death during times of personal calamity and evolving malady. Rather, the problem with MAiD, and its failure to maintain a house of hospitality for those struggling for life and toward death, is the rejection of existence, corresponding with the vulnerability to despair. The problem is the rejection that stems from a hermeneutic that interprets the patient's feelings of functional loss, reduced sense of self and agency, and fear concerning future burdens, discomfort and the like, as well as the actualities incumbent to disease and disorder, without any teleological vision-market metaphors, instrumental reasoning, and atomized desires forestall time and history (McDowell 2019), while resourcing despair. Connected with such despair is the institution's, and its physicians', metastasising endorsement of such feelings, coupled with their own vulnerabilities to despair as the inability to relieve suffering and proffer a cure emerges. Such rejection becomes codified in principle and practice, narrating life as wholly disposable and utterly unworthy of existence in particular present states. MAiD, then, is the act of denying being. It is the act of forbidding the potential of becoming, of being a human, of being a subject claiming others for mutual recognition and cooperation, regardless of the state of health or sickness one might be in.

It is that question of becoming human within a community, within a community *practicing presence to one another over time*, as quoted above, that will take us to towards the conclusion, and champion a call for hope—although hope differentiated from the functional hoping that risks despair. It is such a call for hope during times of tragedy and personal catastrophe that has provoked us to challenge the rhetoric presented as normative because of the legal protections and conventional ethical parameters of MAiD. It has excited critical reflection and has goaded us to raise questions of despair and hope in the institution of medicine and the practices of MAiD, such that one might not die in flight from despair and, thus, captive to it.

Ought we to want such a death? Ought we to want such a death even if the illusions of dignity, of control, and of benefit are presented with the full supports of clinical best-practice and legal precedence? Ought we to want the narratives that train such postures that risk despair, and its masquerades, without learning to live (and die with Christ) through despair, even without answers for it (Hauerwas 1997)?

This paper is arguing that we that we ought not to want such things. Yet we ought not to want to frustrate continued progress in clinical measures and competent care when people are confronted with the limits and frailty of human life, either. Rather, we ought to be thinking discerningly about a response *for* medicine, and to reflect further, perhaps, on the following questions: should we not be diligent to think again and again about what it means to flourish as a human being, even unto death by medical means and the provision of care executed by the helping professions? Should we not to think again about how one might die in hope rather than by despair?

It is the position of this paper that we should. Yet, we should not be thinking about hopes that are but vain optimisms or fodder for despair in disguise. Rather, we should both narrate and perform hope with and for our fellows, creatively enabling ways for persons to flourish as human beings—even while perturbed by despair and living unto death. Hope, as such, might become enlivened as we learn to cultivate a gathering of persons, a communion of fellows practicing presence (learning to participate in the life and passion, and thus glory, of Christ (Hauerwas 1997)). Such communion, such practicing presence, is not to be delimited by a mere enduring together but by longsuffering education, a paideutic training, by which one might not resource answers to human suffering but learn to flourish as human beings *together* in living and in dying. It has been argued that (Christian) hope emerges by such performance, as persons learn to live through despair, confronting it rather than escaping from it.

As Gabriel Marcel has argued, "The truth is that there can strictly speaking be no hope except when the temptation of despair exists. Hope is the act by which this temptation is actively or victoriously overcome" (Marcel 1951, p. 36; c.f. Marcel 1949, p. 93). It is victoriously overcome, however, not by an exercise of individual will, or a power wrought from knowing and choosing (as argued above). Epistemology and self-determining agency offer no reprieve. Rather, as Marcel's writings on hope have argued, despair is overcome when "human societies [become] enduring spiritual communities from whom individuals could, and indeed must, derive not only their elementary human formation but also a kind of interior strength powerful enough to sustain them in periods of personal disintegration and catastrophe" (MacKinnon 2011, p. 182). We must, therefore, learn to participate in the well-being of our fellows, performing hope as a material and social practice that cultivates patience *for* dark times, such as those times that compel persons to hug death. Such hope, a habit of patience where we are enabled to grow and to develop, where we are freed to become human, Marcel maintained, can sustain us even during times of prolonged darkness. As such, it is by enduring communities, forged through such learning, that persons might be sustained in times of personal catastrophe and calamity, and enabled to confront crises of life and in death.

The condition here is that hope is not a commodity or an abstraction that risks despair while offering illusions of flight from it—as though one has a choice to make. Rather, the condition is that hope is practiced as a virtue, caught up by a pedagogy that forges a readiness to confront despair and death—a pedagogy that recovers a strength to be, in living and in dying. Hope is habituated and enfleshed as persons labour to listen and to hear "the stories of forbearers who learned how to go on when it wasn't clear there was a way to go on" (Hauerwas 2018, p. 97). Such listening and hearing can become the foundation of hopeful communities that learn to endure together—who learn to participate in the cultivation of hope, in the possibility of its virtue, as offered through the performance of mutual recognition and commitment (Hernandez 2011). Such hope precludes the sort of narratives that seek to evade death and escape despair. Such hope precludes narratives that elevate the efficient decision of the solitary and self-sufficient hero, and acknowledges that one "cannot hope alone" (Hauerwas 2018, p. 97). Such hope precludes narratives of stereotyped agency and technological rationalities that persist in our modern milieu, and "faces difficulty in a creative way by learning to improvise" (97). Such improvisation might also cultivate or correspond to the courage, for example, which not only "names" that for which we are determined (those aims or commitments illumined in those stories that form us) but also enables us "to see them through"—albeit, perhaps, and quite importantly, *differently* than imagined in the first instance (113). Such hope learns from those stories of the Christian scriptures and traditions, from "stories of Israel and the Jews [that teach us] ... to live in

a world in which we aren't in control" (97). Such stories, which we are invited to give our attention to and to follow, not only elaborate but also epitomize the way of hope in and through dark times. Hope, as with the virtues in their totality, enfleshed in the lives of those whose habituations make them concrete, can confront such times decisively—making decisions not at a crossroads, but because of who such persons have become; because "they could have done nothing other than what they have done" (187).

The problem with hope as so considered and practiced, as with any virtue, however, is that it takes a long time to internalize. Patience, therefore, is critical. Perhaps patience and hope are tautological. To be storied in the way of hope requires a perennial discipline, a patience for hope-saying, so that one might become hope-seeing—especially in times of crisis and calamity; especially when dark times and the threat of death, in all of its forms, persists. One must prepare accordingly, patiently practicing hope, whether dark times persist or not.

What is being suggested through these gestures of dissent and response, is that a different narrative is required for persons caught up by pernicious darkness and unrelenting despair. Familiar modern narratives about human being and human agency, about values and meaning, have left persons at risk of despair without the resources to endure to its heights and depths. But a theologically informed narrative regarding hope in dark times, which is to be recited and practiced, will not construct a different world before our eyes (like those worlds where suffering does not exist), but will transfigure the world before us, enabling our own eyes, together with the many eyes of our fellows, to see the world differently. That is to suggest, such training to say and to see hope as such might afford the prudence necessary to see the familiar narrative of hope-as-commodity as a profane doctrine, which torments, rendering despair as it promises respite. Such training to say and to see hope as such might discipline our being and ready each one of us for the long struggle amidst present ambiguities and trials, while seeking creative ways to endure and practice a patience that is hope-enabling. It might discipline learning such that we might be enabled to participate in the well-being of our fellows, performing hope as a material and social practice that cultivates patience for dark times. Such a hope, a habit where we are enabled to grow and to develop, where we are freed to become human in the triumphs and tragedies, if not also the calamities and comedies of our finite and frail existence, might sustain us even during times of prolonged darkness and imminent death. Yet it must be a freedom, which does not determine such sustain as though an idol. Rather, it must become a freedom that can open one to the world, liberating one to pursue human being, to become what one is, to become who one is, in living and dying.

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